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Defying Patients' End-of-Life Wishes Can Be Costly

By Paula Span



When Elaine Greenberg's husband, Gerald, was diagnosed with early-onset Alzheimer's, his specific advance directive — comfort measures only — went unheeded at the hospital where he was treated.

Gerald and Elaine Greenberg married in 1976, as dental students. They practiced on Long Island and in Manhattan and raised two sons. Then in 2010, she noticed that her husband, the math whiz, was having trouble calculating tips in restaurants. "He just didn't seem as sharp," she said.

The devastating diagnosis from a neurologist: early-onset Alzheimer's disease.

"We knew what could be ahead for him," Elaine Greenberg said. "He didn't want to lie there with tubes and diapers. That's not how he wanted to end his life."

Together, they called a lawyer and drew up advance directives in 2011. “We gave it a lot of thought,” she said. His directive was very specific: If he became terminally ill, permanently unconscious or seriously and irreversibly brain damaged, he wanted comfort measures only. No cardiac resuscitation or mechanical respiration. No tube feeding. No antibiotics.



Dr. Greenberg with Gerald Greenberg and their first grandchild in 2016.

Gerald Greenberg died in 2016 — and a recent lawsuit brought by his widow charges that when he was unresponsive and near death from sepsis at Montefiore New Rochelle Hospital in Westchester County, the hospital and an attending physician there failed to follow his directive.

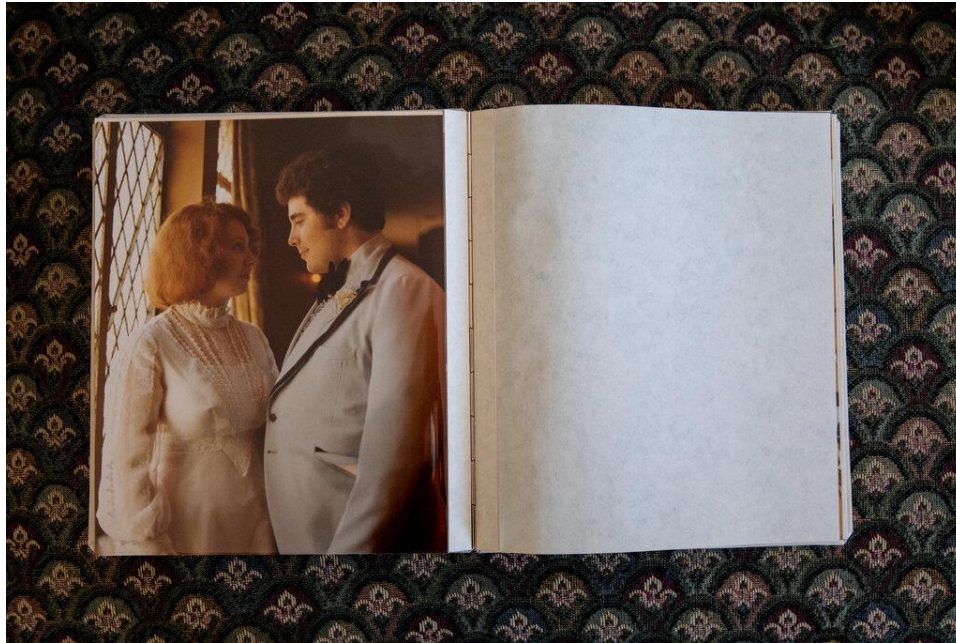
The suit alleges that they also disregarded a New York State MOLST — medical orders for life-sustaining treatment — form and his spouse’s explicit instructions to a doctor who called to seek her guidance.

Medical records show that her husband received antibiotics and other unwanted treatments and tests. The suit charges that he survived for about a month in the unresponsive state that he had sought to avoid. (A Montefiore spokesman said the hospital could not comment, given ongoing litigation.)

“They made the end of his life horrible and painful and humiliating,” Dr. Greenberg said.

“What’s the sense of having a living will if it’s not honored?”

Lawsuits charging negligence or malpractice by hospitals and doctors typically claim that they have failed to save patients' lives. More recently, though, some families have sued if providers failed to heed patients' documented wishes and prevented death from occurring.



The Greenbergs on their wedding day in 1976.

“In the past, people have said, ‘How have we harmed you if we kept you alive?’” said Thaddeus Pope, a professor at the Mitchell Hamline School of Law in St. Paul, Minn., who follows end-of-life legal cases. “Now, courts have said this is a compensable injury.”

The campaign to persuade people to document end-of-life instructions goes back decades, but it remains an uphill battle. A 2017 analysis of 150 studies, involving nearly 800,000 Americans, found that among those over 65, only 45.6 percent had completed an advance directive, including barely half of nursing home residents.

But recent evidence suggests that those proportions have climbed during the coronavirus pandemic. The crisis has made such questions less abstract and the need to honor documents more urgent.

Patients themselves may bear some responsibility for mix-ups. Advance directives go astray, get locked in desk drawers, become so outdated that designated decision makers have died. Or they use language like “no heroic measures,” so vague that “it’s hard for doctors to comply with,” Mr. Pope said.

The state MOLST or POLST (portable orders for life-sustaining treatment) forms strive to make the decisions concrete by providing detailed documentation of patients' wishes and functioning as physicians' orders. Studies in Oregon and West Virginia have demonstrated the forms' effectiveness, but as several of these cases show, that is not universal.

Sometimes — nobody has tracked how often — institutions overlook the documents in patients' charts or ignore conversations with health care proxies. Doctors who doubt that a patient actually prefers to die may override the instructions.

"Their attitude is, 'Nobody was hurt,'" said Gerald Grunsfeld, the lawyer representing Dr. Greenberg. "But there was physical hurt, emotional hurt, a lot of hurt."

In an interview four years ago, Mr. Pope noted that nobody at that point had received compensation from any "wrongful life" suit. Since then, several plaintiffs have received hefty payments, and courts have weighed in as well.

In Georgia, Jacqueline Alicea won a \$1 million settlement from Doctors Hospital of Augusta and a surgeon there (from their insurers, more accurately). They had placed her 91-year-old grandmother on a ventilator, disregarding both Ms. Alicea's instructions as her grandmother's health care proxy and her grandmother's advance directive. That meant Ms. Alicea had to eventually order that life support be removed, a wrenching decision.

Settlement amounts often remain confidential, but "we wanted this settlement to be shouted from the mountaintops," her lawyer, Harry Revell, said. "We wanted it to have a deterrent effect on health care providers who think this isn't important."

The Alicea case, already being cited in other lawsuits, may have an impact because after the trial court denied a motion to dismiss it, the state's Court of Appeals and its Supreme Court both ruled that the suit could proceed. The parties settled on the eve of a trial in 2017.

In Montana, a jury delivered what is believed to be the first verdict in a wrongful life case, awarding \$209,000 in medical costs and \$200,000 for "mental and physical pain and suffering" to the estate of Rodney Knoepfle in 2019.

Debilitated by many illnesses, Mr. Knoepfle had a do-not-resuscitate order and a POLST form in his records at St. Peter's Health, Helena's largest hospital. "He'd suffered more pain than anyone should in a lifetime and was comfortable with going, if it was his time to go," said Ben Snipes, one of his lawyers.

But a medical team resuscitated Mr. Knoepfle — twice. Tethered to an oxygen tank, he lived another two years before dying at age 69. “The last few months, he was almost incoherent with pain, living in a hospital bed, getting morphine crushed into his pudding,” Mr. Snipes said.

Beatrice Weisman, 83, had been hospitalized after a stroke in 2013 when doctors at Maryland General Hospital found her turning blue and resuscitated her, an action that her advance directive and MOLST form specifically prohibited.

The Weisman family sued and in 2017 received a “satisfactory” sum through mediation, said Robert Schulte, their lawyer. He could not divulge the amount but said it had helped pay for seven years of round-the-clock care, until Ms. Weisman died last October.

A California case developed differently. Dick Magney had opted for palliative care, and his doctors were complying, until someone reported potential neglect to Humboldt County’s adult protective services agency. The county filed a petition to take over his health care, removing his wife as his decision maker, and ordered that Mr. Magney receive antibiotics he had earlier refused. At one point, the county won temporary conservatorship.

“It just led to him suffering longer,” said Allison Jackson, the lawyer representing Mr. Magney’s wife. Mr. Magney died in 2015.

A state appellate court ruled that the petition to remove Mr. Magney’s wife had been fraudulent. She eventually won more than \$200,000 in reimbursement for lawyers’ fees and pursued a federal civil rights complaint, leading to a \$1 million settlement from the county. Two lawyers representing the county now face disciplinary charges from the California state bar.

Such awards and rulings, and news coverage, have led more families to seek legal remedies and have encouraged lawyers to take such cases, said Mr. Pope, who is a consultant to the Montana lawyers and a testifying expert witness in the upcoming California disciplinary hearings.

Now similar suits are pending in Georgia, Maryland and New Jersey, in addition to two malpractice cases that Mr. Grunsfeld has brought against Montefiore in New York.

Lawyers for Montefiore have moved to dismiss the Greenberg suit; even if the court allows it to go forward, resolution could take years. But Dr. Greenberg and her sons are in it for the long haul, she said.

During the month her husband survived, after his directive would have permitted him to die, he lay unconscious, diapered, in restraints and moaning in pain, she recalled.

“He tried to make choices, and his choices weren’t respected,” Dr. Greenberg said. “I don’t want anyone else to go through what we went through.”
