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THE CHOICE

Under a new
right-to-die law,
Lesley McAllister '91
confronts a most
difficult decision

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**Lesley McAllister '91
with her husband,
Andrew, and son
at home.**



LESLEY'S STORY

An alumna facing terminal cancer considers her end-of-life options

BY MARK F. BERNSTEIN '83



Anne Chadwick Williams/AP Images

“Y

ou may be interested in my story,” the email read, “and if so, I could be interested in sharing it.”

PAW hears from a lot of readers, but this message, received on the first morning of Reunions last May, jumped off the screen. Like hundreds of her classmates, Lesley McAllister '91 was

returning to celebrate her 25th. Unlike them, she knew that the visit would likely be her last.

As she explained in her message, the 46-year-old mother of two and law professor at the University of California, Davis, is fighting metastatic cancer, a fight she is certain to lose. Radiation treatments over the summer have robbed her of her hair, which had grown back since her first round of chemotherapy two and a half years ago, shortly before an operation to remove her cancerous right lung. Surgery to remove lesions on her adrenal gland, liver, and pancreas left her with debilitating pancreatitis and a wound that has not fully healed. Once an avid hiker, she now moves slowly and speaks in little more than a whisper until her pain medications kick in.

McAllister's days are numbered, but the uncertainty surrounding that certainty is part of cancer's cruelty. In his posthumously published memoir, *When Breath Becomes Air*, Stanford University neurosurgical resident Paul Kalanithi wrote, “Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely.” That is where McAllister sits now.

With that acute knowledge come more existential thoughts, which are sharpest as she lies awake in the small hours of the night. If she begins hospice care, sedatives could keep her comfortable, but would she linger for weeks in a narcotic haze? Would her children's final memory of her be of a long, agonizing decline? “Victory” in McAllister's case might mean delaying cancer's inexorable advance for a few months. How much is that time worth to her family — and how much is she willing to endure for it?

As she explained in her email to PAW, McAllister is contemplating whether to take advantage of California's End of Life Option Act, which permits those with terminal illnesses to obtain a lethal dose of sedatives and so end their own lives. At the time this story is being written, McAllister has not chosen

her course. She does not prescribe for others. But clear-eyed and reflective, she wants to tell her story.

The late writer Christopher Hitchens described his cancer diagnosis as “a very gentle and firm deportation, taking me from the country of the well across the stark frontier that marks off the land of malady.” McAllister remembers her own transfer vividly.

A petite woman, now wan and slowed by pain, she sits in her living room in Davis and pulls an afghan around her for warmth on a hot June morning. The randomness of fate still hits her. She had no family history of cancer, had never smoked, had sailed through two pregnancies, had always been in perfect health. “I've had incredible luck in my life,” she says. “And I remember when I was diagnosed, one of my first thoughts was, oh, my luck just ran out.”

She received that diagnosis on the Sunday after Thanksgiving in 2013, driving home after a week with her family in the Mendocino redwoods. X-rays for a persistent dry cough had come back negative, but she was X-rayed again when the cough continued and she began to feel discomfort in her chest. When the phone rang that morning, with her husband, Andrew, and two young children in the car, the family pulled over to the side of the road and the doctor broke the bad news: McAllister had a 5-centimeter tumor in her right lung that had metastasized to her lymph nodes. Although the family had been bracing for the report, Andrew likens that phone call to “getting hit by a truck.”

Cancer descended on a woman whose life seemingly had moved from one peak to another: a degree in civil engineering with a certificate from the Woodrow Wilson School; the Peace Corps in Costa Rica; a law degree from Stanford; a Ph.D. from the University of California, Berkeley. After clerking for a federal judge, she was hired at the University of San Diego School of Law, where she wrote two books and numerous journal articles, earning a reputation as an expert on U.S. and Latin American environmental law. She also nurtured a fledgling student law journal and spent six months in Spain on a Fulbright research scholarship. When Andrew was appointed to the state energy commission in Sacramento, she moved with tenure to UC Davis. McAllister arrived at her new job in August 2013, just three months before her diagnosis.

“I had spent all of my life in learning mode,” she says. “And I was just at the point where I felt I had really made the shift to teacher and mentor. And I realized that I wasn't going to have a chance to develop that as I had expected.”

Doctors said that her cancer was inoperable, recommending chemotherapy and radiation instead. McAllister began searching for a surgeon nonetheless, accepting the chemo but refusing radiation because it would damage the tissue and preclude surgery. While undergoing chemo, she scoured medical journals for everything she could find about her cancer, a rare type called atypical carcinoid of the lung or intermediate-grade neuroendocrine cancer, and wrote to some of the authors directly. After visiting cancer centers around the country, she found a surgeon at Massachusetts General Hospital who removed her right lung in April 2014.

McAllister approached the grueling operation with characteristic stoicism and good humor. “However tomorrow

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**The family
enjoys the
backyard.**

unfolds,” she wrote on her blog at CaringBridge, a nonprofit that provides free websites to people facing serious medical conditions, “I want to express how grateful I am for all the love and kindness I have received — so much, from so many. My heart is full.”

She recovered from the six-hour surgery quickly and returned to the classroom the following semester. “I’m enjoying teaching again — and teaching 60 energetic first-year law students really doesn’t leave much time for my usual worrying,” she wrote in September 2014. Doctors said that while the cancer could not be cured, they could keep it at bay for a time. Over the next 18 months, with a few ups and downs and a regimen of oral chemotherapy, her situation appeared to be stable. McAllister continued to teach and even felt strong enough to travel to New Zealand last March.

By April, however, the cancer had become active again, spreading to her adrenal gland, liver, and pancreas. She underwent surgery in Denver to remove the new lesions, but this time the operation did not go as well. Complications put her in intensive care for more than two and a half weeks as doctors tried to manage a painful case of pancreatitis. Even worse, pathology tests on the new tumors led doctors to change McAllister’s diagnosis to large cell neuroendocrine cancer — a more aggressive form of the disease.

Still, she kept a promise to three old friends, Gray Tuttle ’91, Liz White ’91, and Deirdre O’Mara ’93, to return to campus for her 25th reunion. Enduring the heat, she, O’Mara, and Tuttle rode the P-rade route in a golf cart they decorated with Tibetan prayer flags. The pancreatitis, which later would cause unrelenting pain, had subsided temporarily. McAllister even managed to sleep well in her Whitman College dorm room, just a few yards away from the band. As much as she could, she sat in the courtyard, catching up with classmates.

If people asked, she was not reticent about her cancer. But except to a select few, she did not mention the circumstances that had led her to write her email to PAW.

In early 2015, California took up legislation to enable terminally ill patients to end their lives. Though she was undergoing chemotherapy at the time, McAllister advocated for the bill when she could: testifying before the state Assembly, soliciting signatures on a petition, and writing a letter to Gov. Jerry Brown, which her husband, Andrew, hand-delivered.

“I want to have the option to take medication that will allow me a peaceful death at a time of my choosing,” she wrote. “It would probably be hard for me to make the decision to leave the world earlier than I absolutely have to because I don’t want to leave my family. But I would take comfort in knowing that I have the means.”

The End of Life Option Act, which took effect two weeks after Reunions, is modeled on a statute Oregon enacted in 1997. (Washington and Vermont have similar laws.) A state

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resident who is 18 or older and mentally competent, and who has been diagnosed with an illness that will lead to death within six months, may obtain a lethal dose of sedative from a physician. To receive the drug, the patient must make two oral requests, with a 15-day waiting period in between, followed by a written request signed by two witnesses, at least one of whom is not a family member or someone who would benefit from the patient’s estate. The patient also must receive information about other end-of-life options, including pain management and hospice care. Finally, the patient must be able to take the life-ending drugs without assistance.

Physician Peter Lyon ’68, now retired, says he wrote prescriptions for two patients while practicing in Portland: one an older woman with metastatic cancer, the other a younger man in the late stages of ALS, a progressive neurodegenerative disease. Secobarbital, which usually causes death within 30 minutes at the dosage prescribed, is now the drug of choice, Lyon says.

Last year in Oregon, 132 died people from ingesting medications prescribed under the Death With Dignity Act, according to the state health authority, accounting for about 0.39 percent of all Oregon deaths that year. Those who did make use of the law overwhelmingly were white, and about 71 percent had at least some college education — statistics that advocates say refute concerns that medical aid in dying would be used to victimize minorities and the poor. More than 90 percent of these patients died at home (across the country, only about 20 percent do that).

McAllister is adamant that taking drugs to end her life would not be suicide. “In suicide,” she says, “you’re choosing between life and death. With the End of Life Option Act, you’re choosing the time and manner of your death, knowing that it is inevitably coming within a short period of time. The law allows you to have a little bit of control over when, where, and how.” She would rather die at home, with an opportunity to say goodbye to family and friends, than in a hospital.

Advocates of right-to-die laws say control, or at least the sense of it, is important to the terminally ill. What people seem to want is the comfort of knowing that they have a way out if pain becomes unbearable or their condition deteriorates too far.

“For myself, having always been a planner and a Type A person, the idea of having some control appeals to me quite a bit,” McAllister says. “Cancer can deal out a lot of pain and suffering before it actually kills you. I am very concerned about my kids witnessing that.”

Traditionally, there have been deep moral and religious objections to taking one’s own life or assisting another person to do it. The Catholic Church opposes aid in dying, as does the American Medical Association, although it has appointed a committee to review the issue. (The California Medical Association remained neutral on passage of the End of Life Option Act.)

Professor Robert George, who has written extensively on philosophy and ethics, argues that statutes such as California’s diminish respect for the sanctity of life. “Opposition to medicalized killing” is “grounded in a recognition of ... the idea that no one has ‘a life unworthy of life,’ or is ‘better off dead’ or a ‘useless eater,’” he writes in an email. “It reflects the belief that nothing should be done that gives credit to or encourages



From left: Gray Tuttle '91, Deirdre O'Mara '93, Liz White '91, McAllister, Duke Guthrie '92, and Louisa (de Roethh) Burdette '91 at Reunions.

the adoption of these beliefs, even by those suffering pain and tempted to despair.” George rebuts those who argue that individuals should be free to determine their own fates, calling medical assistance in dying “a policy question that implicates many aspects of the common good of our civil society and legal order.” Many who end their lives, he says, are driven by fear and depression. He urges that people facing terminal illness be provided with palliative care and counseling to help make their last months comfortable and peaceful.

Matthew Whitaker, the California and Oregon state director for Compassion & Choices, a group that advocated for the End of Life Option Act, says that patients should be fully informed about all alternatives. Whitaker cites a study that found that for every end-of-life prescription written in Oregon, 25 people initiate the process by making at least the first oral request. The reason so few go through with it, he says, “is that oftentimes when a person brings this up to their physician it opens the door for a very transparent and open conversation around end of life, which does not happen very often in medical settings, in part because physicians are afraid to bring it up.”

“People want to live, and so long as their quality of life is satisfactory, they don’t want to die,” adds Ann Jackson, a former director of the Oregon Hospice Association. Most people who choose to die “have been managing their own lives and want to continue to manage their own deaths,” she says. Many people reach a different conclusion: “Once they have a plan for their worst-case scenario, they can get on with living.”

On a warm summer morning, though, the words of philosophers and advocates echo into silence, leaving a weakened woman in a darkened room with an afghan wrapped around her, and perhaps not a lot of time left.

“It will happen to all of us,” Hitchens observed shortly before his death, “that at some point you’ll be tapped on the shoulder and told, not just that the party is over, but slightly worse: The party’s going on — but you have to leave.” McAllister has begun preparing for this, filming legacy videos and buying birthday gifts for her children, now 13 and 9, to last through their 18th birthdays. Each gift will come with a note she has written, to be delivered after she is gone.

Like many in her position, she has sought comfort in spirituality. Though raised Catholic, she has been drawn to Buddhism since college. After her diagnosis, she converted a walk-in closet into a meditation room and has gone on several

multi-day silent meditation retreats. We are all interconnected, Buddhism teaches; everything that is born, dies. She quotes Ram Dass, an American spiritual teacher, who says that “dying is absolutely safe.” Our primary work, McAllister believes, is to put an end to suffering by embracing the conditions of our lives with compassion. As a Buddhist teacher counseled her: “If I were in your situation, I would try to have a really good death.”

“I want to give my children an example of a ‘good death,’” McAllister says, “but it is hard to know how.” Her son and daughter are now old enough that she would want to talk to them beforehand in some detail, to help them understand her decision. Andrew loyally supports her decision to choose her own course. “I think that taking control of your final moments is empowering,” he says. “It’s that comfort of knowing that you can go with whatever happens and be OK. I don’t want her to suffer.”

In bleaker moments, she has contemplated where she might actually end her life, should it come to that, her thoughts a jumble of the personal and practical. There is a cabin in the Eldorado National Forest, high in the Sierras a few hours from Davis. It is primitive, isolated, beautiful — everything she loves in the outdoors. It might be an idyllic place to spend her last hours, yet she can’t escape the thought that someone would have to put her body in the car afterward and drive it back to town.

“Really, ever since my diagnosis, death has been on the radar screen,” she acknowledges, her voice breaking for the first time. “And where I’m at now, the writing is clearly on the wall. When you’re a stage 4 cancer patient and you’re not eating well and you’re losing weight and your head is bald, it looks pretty damned end-stage. You look in the mirror and it’s like, oh my God, this is how this thing goes.”

For now, McAllister is doing everything she can to postpone that day. She is teaching this semester and exploring whether she might be eligible for cutting-edge immunotherapy treatment.

“I don’t know that I have made a decision,” McAllister says about ending her life. “When it seems likely that doctors will readily sign off on the idea that I have six months or less, I’m pretty sure that I will go through the process to get the prescription. And then I could put it in my bedside drawer and wait to see if the right time to use it arises.

“It would comfort me to know that it is there when life’s meaning, especially the capacity to be present with my kids, is overwhelmed by pain and disability.” ♦

Mark Bernstein '83 is PAW's senior writer.