

4.10.2013, 7200 words

[This is the first draft I sent to Ilena, with her first series of instructions in track changes]

If Margaret Pabst Battin hadn't had a cold that November afternoon in 2008, she would have gone bike riding with her husband, Brooke Hopkins, a newly-retired professor from the University of Utah. Instead Peggy (as just about everybody calls her) went to two lectures at the U, where she teaches philosophy with a specialty in end-of-life bioethics. So she wasn't with him in City Creek Canyon in Salt Lake City the instant [both their lives](#) changed.

Brooke was on his way back down the hill when he collided with an oncoming bicycle around a blind curve, catapulting from his bike onto the mountain path. Peggy still keeps [his helmet, which is](#) cracked just above the left temple, meaning Brooke fell directly on his head. His body followed in a grotesque somersault, breaking his neck at the top of the spine. Brooke stopped breathing, turned gray, and probably would have died on that path if a flight rescue nurse hadn't happened to jog by. The jogger resuscitated and stabilized him, and someone raced to the bottom of the canyon to call 911.

Had Peggy been there, she might have urged the rescuers not to [intervene](#). Brooke had signed a living will the previous year, specifying that if he should suffer a grievous illness or injury, he wanted no procedures done that "would serve only to unnaturally prolong the moment of my death and to unnaturally postpone or prolong the dying process." But Peggy wasn't there, and Brooke wasn't [carrying ID](#), much less his "Do Not Resuscitate" orders. The EMTs kept him breathing through a hand-pumped airbag all the

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way to University Hospital, three miles away, and as soon as he got there he was attached to a ventilator.

By the time Peggy arrived a few hours later and saw her husband tethered to the invasive machinery he'd always hoped to avoid, decisions about intervention already had been made. She didn't know yet that Brooke would end up a quadriplegic, and that he would look much like the people she had always said, during a long career defending physician-assisted suicide, should be allowed to die.

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As Brooke lay immobile in the ICU, Peggy kept thinking about the title character in Tolstoy's *The Death of Ivan Ilych*, as he gradually realized that he was dying and started to wonder, "What if my whole life has been wrong?"

As a scholar, she had spent 30 years championing people's right to die on their own schedule and on their own terms. Since the mid-1980s she'd written or edited 17 books on bioethics, often emphasizing the moral constructs of autonomy and mercy.

MUCH MORE DETAIL THROUGH HERE. THIS SECOND SECTION SHOULD BE AN INTELLECTUAL BIOGRPAHY OF PEGGY'S THINKING. She occasionally was asked to testify on behalf of individuals seeking permission to end their lives legally with a doctor's help. She published a few provocative short stories on similar themes (she has an MFA in fiction), like one about an elderly couple planning a so-called rational suicide to make way for the younger generation.

COULD CUT THIS GRAPH. RATHER HEAR MORE DEEPLY ABOUT ABOUT HER IDEAS. Peggy was "engaging, erudite, and often funny," wrote Diane

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If any pair was well-positioned to survive
If any pair was well-positioned to survive this kind of ordeal, it was Peggy and Brooke. Because of her academic work, they already knew each other's thinking about choosing death, conversations most people avoid as ghoulish and depressing. They had vast resources: financial security, a wide circle of friends, a close and loving marriage, and ways to intellectualize the meaning of life and death -- she as a philosopher, he as a literary scholar and a dabbler in Buddhism. So it makes sense to expect that a close look at how they worked through his end-of-life choices would shed light on this murky and diff ... [1]

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Comment [1]: "The Irony of Supporting Physician-Assisted Suicide: A Personal Account," *Medicine, Health Care and Philosophy* 2010 Nov. 13(4):403-11.

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Meier, a leading geriatrician, in a *New England Journal of Medicine* review of Peggy's book *Ending Life: Ethics and the Way We Die*. Praising its "clarity and passion," she said the book would help "religious leaders, policymakers, health professionals, the sick, and the worried well . . . extract meaning and morals from modern life and its variety of deaths."

But in the days after Brooke's accident, [Peggy](#) worried that if she looked now at *Ending Life* and the "wheelbarrows full" of other things she'd written about dying, she'd want to tear them all up.

"It is not just about terminally ill people in general in a kind of abstract way now," she wrote; "it's also about my husband, Brooke. I still love him, that's a simple fact.

What if he wanted to die? Can I imagine standing by while his ventilator was switched off?"

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[A](#) the time of his bike crash [Brook was active](#), six-foot-five with a brilliant smile and a wild mop of steely gray hair. As a neighbor put it recently, "At parties he was the one who ate the most, drank the most, talked the loudest, danced the longest." He had scores of friends, [BETTER WAY TO SAY](#) and loved adventure travel; he went on treks and backpacking expeditions to South America, the inner Himalayas, China. At age 66, he skied, rode his bike, or hiked in the mountains around Salt Lake whenever he could.

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Comment [2]: n engl j med 353:25
www.nejm.org december 22, 2005

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Comment [3]: "The Irony of Supporting Physician-Assisted Suicide: A Personal Account," *Medicine, Health Care and Philosophy* 2010 Nov. 13(4):403-11.

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"There was always an incredible powerful life force that emanated from Brooke," said Sheila Steiner, his friend since he arrived at the U in the mid-1970s. "His size, his eyes, his smile. There was intense attraction that many people had to him."

He had a bachelor's degree and a doctorate from Harvard, and had been a hugely popular English professor at Utah for 33 years. When he finally emerged from his post-crash spinal surgery in the ICU, his first thought was of one of his favorite poets. As his stepson explained the extent of his injuries, Brooke immediately thought of Keats:

The feel of not to feel it,

When there is none to heal it

Nor numbed sense to steel it,

"Those words, the feel of not to feel it, suddenly meant something to me in ways that they never had before," Brooke wrote later on a blog his stepdaughter started to keep people apprised of his progress. "The feel of not to feel it -- that was what I felt at that moment. My suffering was going to be a drop in the bucket compared to all the human suffering experienced by people throughout human history, but still, it was going to be a suffering nevertheless."

He took solace, too, in Buddhism, which he had begun exploring in his forties. When he was still in the ICU he was startled to see the local Buddhist lama sweep over to his bedside. "The body is nothing, it is ephemeral; the mind is everything," the lama announced. At the time it was a great comfort to Brooke to think that all that mattered was his mind, which meant he could still be the same man he always was. But as much as he yearned to believe it, his experience with paralysis and all that accompanied it — serious infections including several bouts of pneumonia, urinary tract infections, infected

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[abscesses in his groin and buttocks](#) —

has shown him that "the mind is everything" is an oversimplification. A mind tethered to a useless body can never truly be separated from that body's incessant neediness.

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On a gray morning last February, Brooke was rolled in his \$47,000 motorized wheelchair into the living room of his house on M Street, in a funky Salt Lake neighborhood called The Avenues. One month shy of 71, he had a still-handsome face enlivened by intense, shiny brown eyes, deep-set and shadowed by a bristly awning of eyebrow.

He was [wearing](#) a pullover, polyester pants that snap open all the way down each leg, and green Crocs. A friend was reading on a couch nearby, a caregiver was doing her schoolwork in the kitchen — [there are 12, most of them young, who work in shifts so there's always at least one on duty](#) — and Peggy was upstairs in her office amid towers of papers, books, and magazines, [WAS SHE WORKING ON ANYTHING IN](#)

[PARTICULAR THAT WAS RELEVANT TO BROOKE'S SITUATION?](#)

Scattered around the living room were counter-height chairs that Peggy picks up at yard sales. She urges visitors to pull them up to Brooke's wheelchair, since he's tall and the chairs [bring most people to Brooke's eye level](#). [Buying new chairs was one of the many](#) adjustments she made to the house [before Brooke came home in](#) late 2010 after two years [of living in](#) institutions, first [at](#) University Hospital and then in a rehab center 20 minutes north of town. She [renovated](#) the first floor [to tk and outfitted](#) the master bedroom suite, now a suite for Brooke alone, with a system of ceiling tracks and pulleys

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so any caregiver could single-handedly hoist Brooke from bed to wheelchair to shower to bed and back again.

MAYBE START SECTION WITH THESE GRAPHS. DON'T THINK YOU REALLY NEED GRAPHS THAT PRECEED THIS IN THIS SECTION. Brooke has good days and bad days – DIFFERENT FIRST SENTENCE ABOUT THE GENERAL STATE OF BROOK'S HEATH. When friends are around playing blues harmonica or reading aloud to him, that's a good day. On a good day, he feels even more creative than he was in his able-bodied life — he teaches continuing education literature classes to students who come to his home and he's working on an autobiography. He sometimes feels that his relationships with Peggy, his stepchildren, and his friends are richer and more intimate than before. Every so often he'll turn to Peggy and announce, "I love my life."

On a good day, Brooke's voice is strong, which lets him keep up with reading and writing. One of his caregivers arranges a Bluetooth microphone on Brooke's head, calls up the right document on the monitor, and sets up the voice recognition software; Brooke can usually take it from there. He races through books on his computer, periodically instructing the Kindle app to "page down," or dictates email or passages from his memoir. If all goes well he needs to stop only occasionally to say "scratch that" if the software guesses wrong.

On a good day, he can also get outside for a while. "I like to take long walks, quote-unquote, in the park," he said. "There's a graveyard somewhat lugubriously next to us that I like to go through," pushed in his wheelchair by a caregiver with Peggy alongside. Sometimes, with lots of prior planning, he and Peggy go to a movie or to the

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symphony in the big blue van that sits in the driveway. The last film he saw was "Lincoln," which he liked so much he's thinking of teaching a course on the president and other authors from the 1850s.

But those are the good days. On bad days the few pleasures of the good days fade, and everything about his current life seems bleak. The day I visited Brooke was feeling tk, "It takes a long time to get ready for anything," he said, lamenting the lack of spontaneity that he said is the worst part of quadriplegia. "To get up in the morning which I kind of hate, to have every day be more or less the same as every other day . . . and then to spend so much time going to bed. Day after day, day after day, day after day. MAYBE PUT STUFF ABOUT HIS BIPOLAR AND HISTORY IN HERE SOMEWHERE,

Peggy sat nearby, half-listening to our conversation. Within a few minutes she walked over. She's 72 with bright blue eyes, a pretty, freckled face. and a youthful manner. Most days, she wears jeans and running shoes and seems to have endless energy. Tk times a week she takes Pilates, to help treat her scoliosis, which she has had all her life but which is getting progressively worse; she walks bent over at the waist.

"Depression is not uncommon in winter," she said to Brooke, gently kissing his forehead. "It's important to think positive thoughts."

"Basically I dislike being dependent, that's all," he said, looking into her eyes. He spit some excess saliva into a cup.

"It's something you never complain about," she said in the soft voice she almost always uses with him. "You're not a big complainer."

"One thing I don't like is people speaking for me, though." Peggy looked a little stung.

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"And that includes me?" she asked.

"Yes," he said, still looking into her eyes. "I don't like that."

SOMETHING LIKE: YOU COULD FEEL BROOKE'S PALPABLE

FRUSTRATION ABOUT THE BIND THAT HE'S IN. Given the extent of his near-complete dependence on Peggy, it's hard to see how she could avoid speaking as though she knows what's on his mind. And it's hard to see how he could do anything but let her.

AND YET CLEARLY HE HASN'T RECONCILED HIMSELF TO A LIFE WITH SO LITTLE AUTOMONY.

THEN MAYBE END SECTION HERE. OR COULD JOIN THIS SECTION WITH THE ONE THAT COMES NEXT WHERE PEGGY MAKES DECISIONS FOR

HIM. ["I don't worry that Peggy puts words in his mouth," said Leslie Francis, a law professor at the U who often collaborates with Peggy (their most recent book together was *The Patient as Victim and Vector: Ethics and Infectious Disease*), when we met for coffee at a place near campus. "Not because I would guess it hasn't happened, but because it's just going to happen. And part of the working it out is dealing with that."

SEEMS BETTER AFTER DIALOGUE ABOVE TO HAVE A CONCRETE SCENE INSTEAD OF THESE LITTLE EXAMPLES. SMALL EXAMPLES IN THIS GRAPH AND NEXT, INSTEAD LET'S PAINT ONE SCENE. In the cautious minuet of the past four years, the "working it out" can get tricky. Usually if Peggy misreads or overrides Brooke's wishes, it's not that big a deal. He wants to go to bed, she thinks he'll be happier if he sits up a bit longer; he wants a Klonopin, she thinks it will make him groggy and tells his caregivers not to give him any.

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INSTEAD OF THIS SUMMARY OF TWO MOMENTS. LET'S HAVE A SCENE WITH ONE. But sometimes much more is at stake. Brooke gets wild with frustration as he works to breathe off the ventilator, for instance, and starts begging for an overdose to end the "hell" he's going through; Peggy hears anxiety but not a true death wish, and she sits with him waiting for the anxiety to pass. Or Brooke says he never wants to go to the hospital again, that he hates it so much he'd rather die than go back there; Peggy sees him in distress, unable to breathe and just about delirious, and she calls 911.

. I'D FOLD IN THIS BIOGRAPHICAL INFO ABOUT PEGGY AND BROOKE INTO EARLIER IN THE PIECE INSTEAD OF GIVING IT A SEPARATE PLACE HERE. MOST OF THE STUFF ABOUT BROOK – FRIENDS, COMMITMENT TO TRAVEL – YOU HAVE OR COULD TELL US EARLIER.

As in any couple, Peggy and Brooke bring their separate histories to these conversations. Brooke brings a complicated childhood, a relatively privileged Catholic upbringing in Baltimore with a late-life turn to Buddhism, a love of the outdoors and adventure travel bordering on the obsessive, an intense commitment to a wide circle of friends, a reverence for literature. Peggy brings a happier home life in Washington, D.C., a Quaker background, fewer inner demons, a greater need for solitude, powerful professional ambition, and a fondness for the finer things in life: nice hotels, good books, wine.

What seems most relevant now, as the marriage is stripped to its essence, is their different mind-sets. Brooke was diagnosed with bipolar disorder at age 11, and has wrestled with his moods through psychotherapy, prescription drugs, and

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meditation; he's always been a man of intense highs and intense lows. Peggy is more even-tempered and describes herself, despite her professional interest in death, as an inveterate optimist; she's naturally upbeat, and finding the bright side to any situation seems to come easily to her.

Which means, sometimes, that Peggy might put too positive a spin on what Brooke is trying to say -- especially if the conversation is about whether he wants to go on living.

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One day while I was there I observed one of the adult-ed classes that Brooke teaches with two former colleagues from the English department. SENTENCE HERE ABOUT BROOK NOT FEELING WELL, ETC. On that day, the other two professors had to lead the entire discussion. At one point a student called out that she wanted to hear what Brooke thought of a particular passage. He responded with an oblique, "I'd much rather hear what *you* think." No one asked again, and Brooke barely spoke for the remainder of the class.

He watched Peggy arrive she'd been at a meeting on campus -- and flashed her one of his dazzling white smiles. His eyes stayed on her as she positioned herself near an old baby grand that hugs a corner of the living room, a memento from Brooke's mother's house in Baltimore. Above the piano is a huge painting that Peggy retrieved from the sidewalk one trash collection day, a serial self-portrait of a dark-haired man with a mustache, six full-body images of the same man in various stages of disappearing.

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"He's never looked this bad," Peggy whispered to me during the break as students milled around, a sea of gray hair and scraggly beards. She went to Brooke and kissed his forehead. "Are you okay?" she asked softly.

"I'm fine," he said. "Don't worry."

I'd heard similar conversations before: Peggy leaning in to ask if he's okay, Brooke telling her not to worry, he's fine and then Peggy getting involved anyway. That evening, she asked the caregiver on duty, Jaycee Carter, when Brooke last had his CoughAssist therapy, a method of forcing out mucus that can gunk up his lungs. Three hours ago, said Jaycee. But Brooke didn't want it now MEANING THAT JAYCEE HAD ASKED BROOKE ABOUT IT BEFORE THIS MOMENT AND BROOKE HAD DECLINED?; it's noisy, it takes a long time, and the goop that comes out isn't pretty. Peggy suggested a more discreet alternative: a spritz into his trach tube of albuterol, used in asthma inhalers to relax the airways. He resisted that, too. Peggy insisted. OK, he finally said. THIS SCENE COULD BE CLEARER. IS IT THE 3 OF THEM DISCUSSING THIS? IS IT MOSTLY BETWEEN PEGGY AND BROOKE? ARE THERE STUDENTS AROUND? ARE THEY WHISPERING? DID IT INTERRUPT THE CLASS? ARE THEY IRRITATED WITH EACH OTHER? KIND? BOTH?

Peggy retreated to the piano as the class resumed, her eyes brimming. "This is bad," she murmured. "This is really bad."

At dinner that evening, Jaycee wheeled Brooke over to the dining area so he could sit with Peggy and me. He doesn't eat anymore; last August he had a feeding tube inserted, in hopes of preventing the aspiration pneumonias that kept sending him to the

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hospital. If he doesn't chew, drink, or swallow, the thinking was, there's less chance that food or fluid will end up in his lungs.

Brooke told me that he never imagined himself living with a feeding tube — he loved food too much to consider a life without it. —OR SOME SUCH. When he wrote his living will in 2007, he specifically listed his wish to avoid "administration of sustenance and hydration." But the will has a caveat found in most advance directives, one that has proved critical in negotiating his care over the past four years: "I also reserve the right to give current medical directions as long as I am able, even if they conflict with the living will."

So a man who has always taken great joy in preparing, presenting, sharing, and savoring food decides to give up the final sensuous pleasure remaining to him in order to go on living. He swears he doesn't miss it. "You can get used to anything," he said.

Brooke tried to stay alert after the class I watched, but he had no chat in him and kept nodding off. Peggy gently insisted on keeping him up until 9 o'clock, when his normal hour-long bedtime routine -- hoisting him from wheelchair to bed, changing him into a hospital gown, washing his face, brushing his teeth, hooking him up to the ventilator, setting up the four cans of Replete Fiber that will slowly drip into his feeding tube during the night -- usually begins. Later, when he settled into bed, Peggy climbed in for a while, too. Brooke told me this nightly routine was one of the best things about his current life— OR SOME SUCH. They lay there, side by side, their heads close on the pillow, talking in the low, private rumbles of any intimate marriage.

BREAK

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Shortly after Brooke's accident, a friend asked Peggy whether she felt rage at the universe. She didn't. "I can't find the anger anywhere," she wrote on the family blog. All she felt was "anguish when it seems so difficult for Brooke and when I see his whole big body stretched out motionless on the bed." Her life would be severely constrained by his injury, she knew, but she insisted that she didn't mind; in fact, she wrote, she was "sort of looking forward to a less frenetic, less globe-trotting, quieter home-based life."

She did find herself wondering how their relationship would survive this change from one of vibrant physicality -- hiking together, cooking gourmet meals, traveling, making love -- to one circumscribed by pain and immobility. But she never doubted that it would survive. "If I had been married to somebody else that I liked less" she might have worried more, she said recently. "But I've been amazingly lucky to have a relationship that's close and intimate and fruitful for both of us. I don't think there was any of that guilty ambivalence, the 'I wish this would be over for my sake.'"

But there are times when B is so miserable that he contemplates ending his life and these are particularly difficult moments for Peggy, Suzy Quirantes, a respiratory therapist and member of the caregiving team, who Brooke confides in, told me. "I've seen a lot of death," Quirantes said, explaining that many spouses of very sick people, including Peggy, have a hard time taking in their spouses true wishes because what they hear is obscured by their own wishful thinking. For a while last year, Suzy said, Brooke kept refusing his therapies, and I said, 'If you're really serious, if you're done, I need you to be very clear, and you need to be able to talk to Peggy so she understands.'

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Comment [4]: journal entry dec. 30 2008

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Deleted: For all her acumen as an international expert in the field, Peggy's ability to hear Brooke's end-of-life requests can be incomplete. "I've worked with death a lot," said the senior member of the caregiving team, Suzy Quirantes, who is a trained respiratory therapist and is unusually close to Brooke. And she thinks Peggy's ability to hear her husband's true wishes is sometimes muddled by wishful thinking.

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Peggy knows that Suzy hears his desires differently than she does. She traces it to a phenomenon she first observed back in 1988, when she spent five weeks in the Netherlands studying physician-assisted suicide (which is legal there as well as in Belgium, Luxembourg, and Switzerland). Her research partner was a Catholic nun whose conservative, religious world view was almost the polar opposite of Peggy's. Together they would travel around the country interviewing experts about what it was like to die in Holland, and then would get back on the train and discuss what they'd just heard. Peggy would say she'd heard A, B, and C; her companion would reply that she'd heard D, E, and F, as well as not-A and not-B. [THIS A,B,C FORMULATION IS TOO VAGUE. YOU NEED FOR PEGGY TO GIVE US CONCRETE EXAMPLES SO THAT WE KNOW EXACTLY WHAT SHE'S TALKING ABOUT.](#)

"We would have these vivid conversations all the way back, even though we'd both been in the same room talking the same language," Peggy recalled. "It all made me much more aware of the selectiveness of perception." [THIS IS ALL INTERESTING BUT WE NEED IT TO BE CONCRETE. WHAT IS GOING ON SPECIFICALLY VIS A VIS SUZY, PEGGY AND BROOKE?](#)

["Even though my academic interest is in the right to die, when I talk to Brooke I hear the 'I want to keep going.' I hear the 'This is a positive.' And I'm aware that other people don't hear the same things." THIS SEEMS LIKE A CRUCIAL MOMENT. WOULD BE GOOD TO GET HER TO THINK OUT LOUD ABOUT THIS MORE. WHAT IS SHE HEARING EXACTLY THAT'S DIFFERENT FROM WHAT SUZY HEARS? DOES PEGGY ACKNOWLEDGE THAT SHE MAY JUST NOT BE READY](#)

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Deleted: Selective perception is probably happening now, she continued, when different people hear Brooke say different things. "It's not intentional. It's just the way we see certain features in a landscape."

TO LET BROOKE GO. TO TRULY HEAR WHAT HE HAS TO SAY ABOUT HIS OWN LIFE?

To complicate matters, Brooke often doesn't seem sure about what he wants to do. "He has said, 'I'm done,'" Suzy told me, "and then when we kind of talk more about it, he gets scared," He says, "What I mean is I'm done doing this stuff in the hospital. But I'm not ready to die yet."

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He's not ready to die yet, he has said, partly because he feels an obligation to go on living for the sake the people who love him. "I feel obligated to keep living, in a way, aside from the will to live," he wrote on the blog two years after the accident on the heels of a particularly tough hospitalization for yet another pneumonia. "I don't honestly believe that that will [to live] would be strong enough to counter the pain" without them.

Ilena Silverman 4/30/13 4:22 PM
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And while he relies on the love and support of his family and friends, there are times he also feels their silent reproach. He told me that "everybody, except Peggy," probably looks at his severely constrained life and thinks he's "weird" to want to keep living it. Not that he blames them; he would have thought the same thing when he was strong and able-bodied, since it's hard to know in prospect how much loss you'd be willing to tolerate.

Robin Marantz Henig 4/10/13 9:30 AM
Comment [5]: march 31, 2011

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He might be wrong about Peggy being an exception; there are times she probably thinks his choice is a little "weird," too. She told me more than once that if she endured a devastating injury like Brooke's, she would want to find a way to die. She watches how hard he works to maintain his strength, his dignity, and his will to live in the face of near-paralysis, and she mutters, "Not for me."

[]

Who can say when suffering becomes unbearable? Each of us, it seems, has a different breaking point. For Tony Nicklinson, a British civil engineer whose stroke in 2005 left him almost completely paralyzed at 51, the agony and isolation of "locked-in syndrome" made him yearn for death. Last August, he lost his request to the British High Court to die with a doctor's help. The video of Nicklinson's helpless weeping after the verdict is agony to watch.

For Jean-Dominique Bauby, a 43-year-old editor from Paris who also suffered locked-in syndrome after a stroke in 1996, the breaking point never came. Using a tedious system of eye blinks, Bauby dictated a memoir that was a paean to the value of life even in his frozen state. With an active mind "there is so much to do," he wrote in *The Diving Bell and the Butterfly*. "You can wander off in space or in time . . . visit the woman you love, slide down beside her and stroke her still sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, realize your childhood dreams and adult ambitions."

Brooke did reach a breaking point last year. In July, he decided to dictate to Peggy for his friends and family and caregivers, what he called his "Final Letter." He had had unremitting pain in his back and legs for months and had had a few long hospitalizations. He tried a variety of pain treatments -- acupuncture, cortisone shots, pressure-point therapy, nerve-impulse scrambling -- but nothing provided relief. "Pain eats away at your soul," he dictated in the letter dated July 28, 2012:

For many years since the accident I have been motivated by a deep will to live and to contribute to the benefit of others in my small way. I think I have done that. And I am proud of it. But, as I have told Peggy over the past few months, I knew

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that I would reach a limit to what I could do. And I have arrived at the limit over the past couple of weeks.

Peggy immediately threw herself into trying to ease Brook's death. She spoke to a hospice nurse, whose end-of-life cocktail included morphine for "air hunger," Haldol for "delusions, end-of-life agitation," and Tylenol suppositories for "end-of-life fever, 99-101°." She talked to another who thought that instead of morphine Brooke should get "Duragesic patches (all over)" to deliver fentanyl, a potent opium derivative used for pain. She talked to Brooke's psychiatrist about tktttk, and to his cardiologist about whether he would be willing to deactivate the heart pacemaker at Brooke's request. (He was.) She kept pages of notes in a blue folder marked, Death and Dying.

But in early August, Brooke's health worsened. Fluid was accumulating in his chest cavity, and he was having trouble breathing; he was uncomfortable and becoming delirious. Peggy decided that this was not the "generous death" Brooke wanted. He didn't want to die confused and in pain, she reasoned; he wanted a death for which he was alert, present, in control, and surrounded by people he loved. So she ignored the "Final Letter" she had typed up for him just days earlier, and got him to the emergency room instead.

DOES SHE HAVE ANY INSIGHT INTO WHAT'S GOING ON HERE?

This put Brooke back in the hospital, the place he'd told Peggy he wanted to avoid at all costs. He stayed for a week, heavy-duty antibiotics treating yet another pneumonia. It was during his stay, that he decided to get the feeding tube inserted. And he met with the hospital's palliative care expert, who suggested one more pain treatment they hadn't yet tried: low-dose methadone around the clock, 25 mg. at 9 a.m. and 25 mg. at 9 p.m., every day.

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With the methadone, Brooke's pain disappeared. And in the Death and Dying folder is one last penciled note from Peggy dated August 18, 2012:

10:37 am

Brooke says he "wants to soldier on despite difficulties"

In the past few years terminally ill patients in Canada and Europe have gone to court seeking help with dying. Peggy testified at a few of these trials. She went to Vancouver in late 2011 to testify on behalf of Gloria Taylor, a woman with ALS who wanted help ending her life. Peggy presented testimony by Skype in 2012 in the case of Marie Fleming, an Irish woman with multiple sclerosis who was making the same request. The plaintiffs both looked a lot like Brooke, cognitively intact with progressively more useless bodies, with this crucial difference: they were certain they wanted to die.

During Peggy's cross-examination in the Vancouver trial, the government's attorney wanted to talk about how Brooke's choice to keep living weakened Peggy's argument. Isn't it true, the attorney asked, that "this accident presented some pretty profoundly serious challenges to your thinking on the subject?" WE DON'T HAVE A GOOD SENSE OF WHAT HER THINKING ON THE SUBJECT IS.

Yes, Peggy said, but only by provoking the "concerted re-re-rethinking" that any self-respecting philosopher subjects herself to. Even after the re-re-rethinking, WHAT DOES THIS RE RETHINKING LOOK LIKE he said, she remained convinced that physician-assisted dying was justified, as long as the patient's autonomy was respected

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Robin Marantz Henig 4/8/13 10:43 AM

Comment [6]: <http://www.deathwithdignity.org/historyfacts/chronology>

Robin Marantz Henig 4/8/13 10:43 AM

Comment [7]: <http://www.deathwithdignity.org/advocates/national>

Robin Marantz Henig 4/8/13 10:43 AM

Comment [8]: <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2211.page>

<http://www.acponline.org/pressroom/assisted.htm>

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and the goal of mercy was being invoked. "Only where both are operating -- that is, where the patient wants to die and dying is the only acceptable way to the patient to avoid pain and suffering -- is there a basis for physician-assisted dying," she told the court. "Neither principle is sufficient in and of itself and, in tandem, the two principles operate as safeguards against abuse."

Gloria Taylor won her case but later died of an infection, and the case is now being heard on an appeal brought by the government. Marie Fleming lost, and her appeal got underway in Dublin in March. A case in England is also being heard on appeal, the one originally brought by Tony Nicklinson, who died last year.

[]

One morning in April, six weeks after my visit, I phoned the M Street house.

Brooke was getting a treatment and Peggy did most of the talking.

Peggy told me that it turned out that Brooke had had a urinary tract infection when I was there last. It had cleared up and he was finally back to himself. "He's a different person than the one you saw," she said.

"I'm cautiously happy about life in general," he added on speakerphone, stopping between phrases to catch his breath. "I'm getting stronger. Working hard. Loving my teaching. My friends and caregivers. My wife."

I asked him about Brooke's Final letter. I was still trying to understand why Peggy had ignored it, just days after he'd dictated it to her, and taken him to the ER to treat his pneumonia. Why didn't she just let pneumonia be the thing that ended his life? Brooke said Peggy had made the right decision, since he wanted his death to be

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"something I'm aware of." In hindsight, he said, "this had a really happy ending." [AGAIN](#)
[WE NEED PEGGY TO HAVE SOME INSIGHT INTO HER OWN MOTIVATIONS.](#)

Soon Brooke's physical therapist arrived and Peggy took the phone upstairs. She and I spoke for another hour or so. We hung up at about 10:30 a.m. Salt Lake City time.

By noon, [I would later learn](#), everything had changed.

Brooke suddenly became agitated and started to yell. "Something bad is happening," he cried. "I'm not going to make it." Peggy and the caregiver on duty, Jaycee, tried to figure out what might have brought it on. He had gone the previous two nights without his usual Klonopin; maybe this was a drug withdrawal reaction. He had listened in my interview with Peggy about his "Final Letter"; maybe [remembering that desperation had upset him](#). He was also getting ready for the first class of the new semester; maybe [he was experiencing](#) anxiety, which had plagued him his whole career.

Deciding that Brooke was having a panic attack, Peggy told Jaycee to give him half a dose of Klonopin. But things got [worse](#). [Brooked tked and tked](#). [Finally, he](#) [announced that he wanted to turn off all the machines](#). Everything. He wanted to be disconnected from all the tubes and hoses that were keeping him alive. He was ready to die.

They did what he asked. They turned off the ventilator and removed the breathing tube, putting a cap on the end of it. They turned off the oxygen. They turned off the battery for the diaphragmatic pacer. They showed Brooke that everything was disconnected.

Brooke sat back in his wheelchair then and closed his eyes. He sat there waiting to die, expecting to die, ready to die, and felt an incredible sense of calm.

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Two minutes passed. Three minutes passed. He opened his eyes and saw Peggy and Jaycee sitting on stools, one on either side, watching him.

"Is this a dream?" he asked.

"No, it's not a dream."

"I didn't die?"

"No, you're alive. Here, let me touch your ear. Can you feel that? That's real."

To Brooke, it was a kind of miracle -- all the machinery had been shut off, just as he'd asked, but he was still alive, and he was glad to be. He felt refreshed, as though he had [made it](#) through some sort of trial. He asked Jaycee to re-attach everything, and three hours later, after he'd had a nap, his students arrived.

But it was no miracle. "I know what his medical condition is," Peggy told me later, out of Brooke's earshot. "The reason he didn't die is he's not at the moment fully vent-dependent anymore. He can go without oxygen for a while, and he can go with the pacer turned off for some time." And Peggy hadn't intended to take any chances; if he had become unconscious, she would have told Jaycee to revive him.

She didn't [say any of this to her husband.](#) "It seems to have been such an epiphany, such a discovery, when he woke up and discovered he was still alive," she said. "I don't really want to puncture that bubble."

He probably didn't really want to die anyway, she said. She thinks what he really wanted was to believe he [had a measure of control, that he could](#) ask for an end to his life and [be heard.](#) "We showed him that we would do what he asked for, and he thought it was real." But it wasn't real, I said. It all sounded like an elaborate end-of-life placebo. Peggy laughed and did not disagree.

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She's not good at keeping secrets from Brooke, though, and by the time I contacted them by Skype later in the week, she'd told him the truth about what had happened. In retrospect, he told me, the whole thing was kind of comical. He mimed it all for me, leaning back with his eyes closed waiting for the end to come, then slowly opening them, raising his eyebrows practically to his hairline, overacting like a silent movie star tied to the tracks who looks to the left and to the right and to the left again as he realizes the distant train never will arrive. He looked good, handsome in his burgundy polo shirt, mugging for the webcam.

As Peggy sat next to him, both of them smiling, ready for the next go-round, the next decision, the next change of heart. Brooke said, "I think it will be a productive summer."

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