

[Draft 7 was 8600 words on 3/15, and Ilena told me she couldn't send around something that long -- it was still before my due date of early April, but I was talking to her about what I had. So I hacked it down to 6900. This shows the deletions in track changes. It's not the draft I ultimately sent to her on April 10.]

Margaret Pabst Battin was tired of suicide. On this afternoon in late 2008, she'd just finished yet another article about physician-assisted suicide, and felt as if she'd been cutting and pasting the same thoughts into the same articles for years. Was there anything new to say about defending people's right to die with dignity, on their own schedule and on their own terms? She was pleased with a few turns of phrase in this newest article -- "bottom dredging for lurid detail" was a nice one -- but it had all become a bit too predictable for her.

Peggy (as just about everybody calls her) had been writing since the early eighties about autonomy and mercy, the two moral constructs at the heart of her argument in favor of physician-assisted suicide. A philosophy professor at the University of Utah, she had written or edited five books on the subject, and 12 books on other topics in bioethics; she'd also put her fiction MFA to use publishing short stories on similar themes, like one about an elderly couple planning a so-called "rational suicide" to make way for the younger generation. Much of her writing had been in defense of the right to choose how and when to die. "It is ultimately a personal issue: that is, right-to-die issues are issues about our own *personal futures*," she wrote in *The Least Worst Death*. "As we discover this, public ferment over right-to-die issues is likely to increase and to involve disagreement at a deeper level."

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**Comment [1]:** p. 9?

The deeper-level disagreements often involved the "slippery slope" argument, the belief that helping the terminally ill end their lives today will lead eventually to undue pressure on vulnerable people -- the elderly, the poor, the chronically disabled -- to end their lives just to ease the burden on the rest of us. To Peggy the slippery slope argument was undermined by, a study she'd helped conduct the previous year that found that in Oregon and the Netherlands, where physician-assisted dying was legal, the vulnerable groups everyone was worried about were actually *less* likely to die this way.

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On this afternoon in late 2008, though, this expert on physician-assisted dying was about to find out how little she really understood about the end of life. And the discovery would revitalize her scholarly interest in the right to die --at the same time making it much more personal, and infinitely more fraught.

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Within days of Peggy handing in her journal article, her husband, a newly-retired English professor who embodied the word "gusto," was in a bicycle accident that paralyzed him from the shoulders down. He would look to outsiders much like the people whom Peggy had long argued should be allowed to die with dignity. But Peggy's husband will want desperately to live. And her experience with this man, who even today cherishes what some would think an intolerable life, will demonstrate to her, as she puts it now, "how complex and how delicate individual choice really is."

[ ]

If Peggy hadn't had a cold that November afternoon in 2008, she would have gone bike riding with her husband, Brooke Hopkins, who had retired from the University of Utah the previous spring. Instead, she went to two lectures on campus, both of which were dull. So she wasn't in City Creek Canyon in Salt Lake City when Brooke had his

collision with an oncoming bicycle around a blind curve, catapulting him from his bike onto the mountain path. His helmet, which Peggy still keeps, cracked just above the left temple, meaning Brooke fell directly on his head. The rest of his body followed in a grotesque somersault, breaking his neck at the very top of the spine. Brooke stopped breathing, turned gray, and would probably have died on that path if a passing jogger had not happened to be a flight nurse. 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 jogger not to bother reviving Brooke. He had signed a living will a year and a half prior to the accident, which specified that if he should suffer a grievous injury or illness, he wanted doctors to withhold or withdraw medical procedures 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 even carrying his driver's license, much less his "Do Not Resuscitate" orders. The EMTs kept him breathing through a hand-held pump all the way to University Hospital, three miles away, and as soon as he got there he was intubated.

By the time Peggy arrived a few hours later and saw her husband tethered to all the invasive machinery he'd always hoped to avoid, many of the decisions about intervention had already been made.

Until the accident, Brooke had been a larger-than-life physical specimen: six-foot-five with a brilliant smile and a wild mop of steely gray hair. As one friend 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, and loved adventure travel; we went on

Robin Marantz Henig 3/14/13 4:21 PM

**Comment [2]:** five or six hours, she says on Utah Conversations, <http://www.podcast.tv/video-episodes/peggy-battin-13586691.html>

treks and expeditions to the inner Himalayas, Argentina and Chile, western China, Venezuela. At age 66, he skied, rode his bike, or hiked in the mountains around Salt Lake whenever he could. He had a larger-than-life intellect, too; he'd earned a bachelor's degree and a doctorate from Harvard, and for 33 years had been a hugely popular English professor at Utah. He taught literature courses that featured a range of British and American authors, and had a special fondness for the Romantic poets.

All that explosive life force hung on tenuously in the ICU after the accident as Brooke drifted in and out of consciousness. When he finally awoke, a ventilator tube was stuffed in his mouth and he couldn't move his arms or legs. It fell on his stepson to explain the full extent of his injury, and Brooke remembered thinking immediately of lines from 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 family blog his stepdaughter had started to keep people apprised of his progress -- a blog that soon turned into a lifeline for Brooke, a way to turn his experience into something grander. "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."

His good friend Dave Mikelson, another retired English professor at the U, was also at the bedside. He could see that Brooke wanted to say something, but Brooke

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**Comment [3]:** March 27, 2009 blog entry -- line from Keats on p. 9 p. 24 <http://englishhistory.net/keats/poetry/inadream ighteddecember.html>

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couldn't speak because of the ventilator. So Dave patiently recited the whole alphabet, one letter at a time, over and over, until Brooke spelled out what it was that he wanted his friend to know: *I love you*.

"How extraordinary under the circumstances," says Dave's wife Liz Kuhlman, remembering that moment recently. Brooke was someone who rarely spoke about emotions, she says; he was a man's man, everybody's buddy, and the bond he tended to have with his male friends -- Dave included -- came from doing stuff together. But now, Liz says, "despite the horrific physical diminishment he was just *there*, in a way that was less accessible when he was more fully embodied." To Liz, a soft-spoken woman with a straight gray bob, "the shock of waking up and not being dead . . . shocked out of him a new level of availability and presence and attention."

On Day Ten Brooke had a cardiac arrest, and no one thought about his previous DNR order; the "crash team" at the hospital went right to work. Later, with Brooke's consent, surgeons implanted a pacemaker to keep his heart from stopping again.

In early December, with a breathing tube permanently inserted through a tracheostomy hole in his throat and a new speaking valve on the tube, Brooke finally could utter some thoughts aloud for Peggy to post on the blog. "I'm not afraid, I'm not angry," he dictated; "I'm looking forward to a new life. . . ." But the effort of timing his vocalizations with his exhalations was exhausting, and three sentences were all he could muster.

These difficult early weeks turned out to be the easy part.

In the first month or so after a catastrophic injury like Brooke's there's a period doctors call the "spinal storm," when most sensation and movement are knocked out by

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**Comment [4]:** dec. 9, 2008

the body's inflammatory response. During this stretch, patients usually can't feel much of anything, and doctors can't really tell whether any motor control will return.

As Brooke's spinal storm ended in January 2009, he got back a little movement in his left hand. That was the good news. But the bad news was really bad. Several times a day, Brooke's long legs would flail in horrific spasms, and he experienced waves of brutal pain.

But what was "remarkable," Peggy pointed out on the blog, was that Brooke "never said, even in his darkest moments and even when he was realizing the full extent of his injuries, that he didn't want to live; even when the intrusiveness of lung suctioning and every-six-hour catheterizing and spasms that wrack his whole body are worst, he still has this drive to keep going. It isn't fake; it's clearly real, and deep; and even when he speaks of the hell he's going through, he keeps **going**."

This drive to keep going has generally persisted ever since. At every decision point -- whether to treat an infection, whether to implant a diaphragmatic pacemaker, whether to treat another infection, and another -- Brooke has chosen life, even his incredibly diminished, dependent life. Partly this is just a matter of dumb biology; [as he put it when I visited him recently in Salt Lake](#), "Everyone has a will to live." Partly it's related to something he was told in the first weeks after the accident, when a local Buddhist leader, Lama Thupten Dorje Gyaltzen, swept into Brooke's hospital room like a fever dream. "The body is nothing; it is ephemeral," Lama Thupten told Brooke, gesturing dismissively at his own body under its flowing maroon-and-saffron robe. "The mind is everything." **Brooke**, who has identified as a Buddhist since date tk, took solace in this idea, and repeated it often in the first few years of his recovery. It's still an

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**Comment [5]:** jan. 13, 2009

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**Comment [6]:** may 19, 2009

important concept to him, but he's learned that it isn't exactly accurate; a mind tethered to a useless body, he's found, can't really be separated from the body's incessant neediness.

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Who can say precisely when suffering becomes unbearable? Each of us no doubt has a different breaking point. For Tony Nicklinson, a British civil engineer who had a stroke in 2005 at age 51 that left him completely paralyzed except for the ability to blink and breathe, the agony and isolation of "locked-in syndrome" made him yearn for death.

Last August, he lost his case at the British High Court requesting the right to die with a doctor's help. The video of Nicklinson's helpless weeping after the verdict is agony to watch.

But for Jean-Dominique Bauby, a 43-year-old magazine editor from Paris who also suffered from locked-in syndrome after a stroke in 1996, that point of desperation never came. Using a tedious system of eye blinks to signify letters, much like what Brooke used with his friend Dave, Bauby dictated a memoir that was a paean to the value of life even in his externally 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."

Would an intensely physical man like Brooke -- whose athletic prowess was so much a part of his self-image -- also be able to live his life almost totally in the mind? The experience of Christopher Reeve, Hollywood's original Superman, comes to mind. Like Brooke, Christopher Reeve was outsized and handsome, fond of testing his physical

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<http://www.guardian.co.uk/society/video/2012/aug/16/tony-nicklinson-right-to-die-video>

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limits through sailing, skiing, scuba-diving, and competitive steeplechase, which is what led to his spinal cord injury when he was thrown from his horse at age 43. And like Brooke, he chose life over death, seeing the challenge of recovery as a spur to work harder. He lived as a quadriplegic for nine years after his 1995 injury, returning to acting and directing, writing two memoirs, testifying before Congress dozens of times to promote research into stem cell therapy. Maybe Brooke could do it, too.

And what about Peggy? How did she visualize the years ahead, living with a physically diminished and utterly dependent husband? Did she, as one friend asked, wish they lived in Oregon, where it would have been legal for her to help him to die? And would she find herself re-thinking her lifelong commitment to choice at the end of life? "I keep thinking about [Tolstoy's character] Ivan Ilych," she wrote shortly after the accident, "confronting the gnawing realization that he had what we would now identify as a fatal cancer, asking 'What if my whole life has been wrong?'"

[ ]

Brooke's salvation has been his continued ability to teach. Every semester since the fall of 2010, not quite two years after his injury, he has taught a University of Utah adult ed class in literature: Thoreau's *Walden*, Shakespeare's "The Winter's Tale," *The Iliad*, *The Odyssey*, Dante's *Inferno*, Chaucer's *Canterbury Tales*. The chief concession to his quadriplegia is that the classes are taught not on campus but at Brooke's house on M Street, in a funky Salt Lake City neighborhood known as The Avenues.

On a Monday afternoon in February, I'm at the M Street house as about two dozen students, all over age 60, cram into the living room to discuss *Moby-Dick*. They sit on the couch, on low leather chairs, on stools and counter-height chairs that Peggy picks up

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



from yard sales. She loves counter-height chairs; she urges visitors to pull them up to Brooke's wheelchair, since Brooke is tall and the chairs get them right up to eye level. This is one of the many adjustments she made to the house in preparation for Brooke's homecoming after two years in institutions, first at University Hospital and then in a rehabilitation facility twenty minutes north of town. Among the others: moving and widening the front door, removing furniture, re-grading the garden, configuring a walk-in shower, [assembling a team of 12 caregivers to work in shifts around the clock](#), and installing a system of ceiling tracks along which a hoist and sling contraption can be moved so any caregiver can single-handedly get Brooke from bed to wheelchair and back again.

[The class conversation turns to the mind-body problem.](#) "Melville is making fun here of Descartes, as though you could exist as a mind without a body," says Howard Horwitz, a former colleague of Brooke's from the English department who, along with retired English professor Mike Rudick, is helping co-teach this class. To Ishmael, he points out, "your sense of yourself is deeply linked to your sense of your body." With Brooke sitting in the middle of the group, impassive in his huge \$47,000 motorized wheelchair, this observation is particularly poignant.

"He's never looked this bad," Peggy whispers during the break, [seeing that he's hardly spoken a word](#). She rushes over to Brooke and gives him a big smile. "Are you okay?" she asks softly.

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

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I'll soon learn that this is a regular exchange: Peggy leaning in to ask Brooke if he's okay, Brooke urging her not to worry, assuring her that everything's fine. The subtext, of course, is often much more profound.

Peggy, 72, has yellow-white hair, bright blue eyes, and a pretty freckled face with skin that's surprisingly smooth. She has a youthful manner, wears jeans and running shoes, takes Pilates, and seems to have endless energy. But when she stands up you can see that she's bent over at the waist, a sign that her life-long scoliosis is getting progressively worse. Watching her stooped gait makes me wonder if she wishes she could retire from teaching, which of course she can't because the university's excellent health insurance -- which covers Brooke's in-patient care and some out-patient services as well -- lasts only while he's the spouse of a full-time employee.

Brooke, who turned 72 in March, still has a dramatic face dominated by his intense, shiny brown eyes, deep-set and shadowed by a bristly awning of eyebrow. He had flashed Peggy one of his huge white smiles when he saw her arrive -- she was late, since there'd been a meeting on campus -- and then watched her position herself near the scarred old baby grand that hugs a corner of the living room, a memento from Brooke's mother's house back in Baltimore. Above the piano is a huge painting Peggy retrieved from the sidewalk one trash collection day. It looks to be 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.

After class Peggy and I sit on stools at the high table next to the always-unlocked front door. Amir Nazari, one of Brooke's caregivers, has brought over a Persian meat dish his father made. Amir lives across the street in one of two small houses Peggy bought in

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2010 in preparation for Brooke's homecoming. She thought it would be wise to have at least a few of Brooke's caregivers living nearby; it takes a village, or at least a mini-compound on M Street, to raise a quad. (Amir's roommate, Mazi Arnourian, is another of Brooke's caregivers, as is the caregiver on duty tonight, Jaycee Carter, who lives in the second house with her two little girls.)

As Peggy and I have our dinner, Jaycee wheels Brooke into the dining area so he can chat with us. He doesn't eat anymore; last August he had a feeding tube inserted, in hopes of reducing the risk of aspiration pneumonia that had sent him to the hospital twice in the previous six months. If he doesn't chew, drink, or swallow, he minimizes the chance of having food or fluid end up in his lungs.

Brooke has no chat in him tonight; he keeps nodding off. Peggy insists on having him stay up until 9 o'clock, when his normal 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 four cans of Replete Fiber (inexplicably labeled "vanilla-flavored") that will slowly drip into his feeding tube during the night -- usually begins. He barely makes it.

The following day starts for Brooke, as they all do, at about 7 o'clock, when it's time for bowel care and a shower. Two caregivers are on duty for the morning routine. Together they arrange Brooke, lying flat on his back in bed, onto a blue waterproof sling, and attach it to the overhead hoist, lifting him about six inches above the mattress. The sling has an opening at the buttocks.

This is the stuff of quad care that's missing in movies like "The Intouchables" and "The Sea Inside." As Brooke hangs naked in the sling, one of the caregivers sticks a

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finger in his rectum to digitally stimulate the feces. Soon Brooke's stool drops out into a plastic-lined bedpan, and the caregiver doing bowel care - the morning I watch, it's Amir -- reaches into his rectum again to make sure everything has been evacuated. Then Amir hoists Brooke higher, propels him along a track in the ceiling toward the bathroom door, and, with help from the other caregiver, negotiates an exchange of hoists, detaching and re-attaching straps to move Brooke's sling from one ceiling apparatus to another and into the bathroom. They lower Brooke onto an ordinary lawn chaise, the kind you buy at Lowe's, that's been fitted with wheels, and Amir gets barefoot to roll Brooke into the shower stall.

After the shower, Brooke gets back in bed, and the caregivers change all his pads at the openings in his skin: under the tracheotomy tube at his throat, at the leads for the diaphragmatic pacer on the right, at the feeding tube into the stomach on the left. Then Peggy -- still in her nightgown, since she usually stays up working long past midnight and has barely gotten out of her own bed upstairs-- approaches with a flashlight to take a close look at the two sores on Brooke's buttocks. She decides that one of them looks better than it did yesterday, and the other looks no worse.

Eventually Brooke's public day begins. He appears in the living room dressed in a diaper, a boatneck pullover, polyester pants with snaps running down each leg, and green Crocs. It's the second day of my February visit, and my first chance to be alone with Brooke, who is feeling depressed today. He recognizes the symptoms, he says, having dealt with bipolar depression since he was 11 years old.

"It's just too much snow, too many dark, gloomy days," he says. The weather confines him, keeping him from the small pleasures he usually looks forward to. What

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pleasures are those? I ask. "I like to go outside," he says. "I like to take long walks, quote-unquote, in the park; there's a graveyard somewhat lugubriously next to us that I like to go through. I just like to get out." Sometimes, Brooke goes to a movie or to the symphony, an undertaking that involves getting his massive wheelchair into the blue van that hulks in the driveway.

The monotony and grind of paralysis, the inability to do anything spontaneously, are what get to him. "You get infantilized and that's very painful," he tells me. "I used to be very independent. I was a very active person . . . it's very hard to convey how it feels, even to somebody who is very close to me."

Peggy, who'd been working upstairs in her cluttered office, is downstairs now and overhears our conversation. "Depression is not uncommon in winter," she tells Brooke, gently, kissing his forehead. "It's important to think positive thoughts."

"Basically I dislike being dependent, that's all," Brooke says, looking deep into Peggy's eyes. He spits some excess saliva into a cup.

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

He: "One thing I don't like is people speaking for me, though."

She: "And that includes me."

He: "Yes. I don't like that."

This obviously stings. Peggy will bring up this conversation a few more times during my visit; it touches on something she's sensitive about, especially as a philosopher who defends individual autonomy. She makes an effort now not to get defensive. "Well,

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**Deleted:** The monotony and grind of paralysis, the inability to do anything spontaneously, are what get to him. "It takes a long time to get ready for anything, 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," he says. "Day after day, day after day, day after day." [...](#) [6]

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sometimes that has to happen, for me to speak for you," she begins. "But . . . but not always. I try not to."

Brooke seems sorry to have spoken up; he doesn't want to hurt her. "I'm trying to be as frank as possible," he says.

"No, it's good," she assures him, her protective instincts clicking in. "It helps me for you to say that, to tell me what you would have wanted to say instead."

All Brooke can muster right now is a croaky, "Yep."

"The most important thing is to not speak for someone else," Peggy insists.

"Yep," Brooke repeats. "What I want to do most right now is be quiet and read."

So Peggy and I leave him in the living room, where the big-screen monitor is queued up to chapter 46 of *Moby-Dick*. Jackie [Calhoon, the caregiver on duty](#), positions a Bluetooth headset for him, so he can periodically issue the command "page down" as he makes his way through the novel, preparing for next week's class. He's a fast reader.

[ ]

Even though Peggy works ferociously to [preserve Brooke's quality of life](#), she hasn't changed her mind about not wanting to live this way herself. Based on what she knows about the dependence, indignity, and sheer physical travail that are part of a serious spinal cord injury, Peggy says Brooke's decision is not the decision she would make. "Not for me," she tells me more than once.

But her experience with Brooke has [shown her more than how grueling life as a quad can be, of course](#). [It's also shown her that what you think you would want can be vastly different from what you end up being willing to tolerate.](#)

[ ]

Robin Marantz Henig 3/18/13 10:29 AM

**Deleted:** A few days later Peggy re-introduces the subject of others speaking for Brooke, at first launching into a long, soft-voiced monologue that unwittingly demonstrates that very problem. I interrupt her and turn to Brooke. Why is it, I ask him, that Peggy sometimes speaks for you? ... [7]

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**Deleted:** Another thing she's learned is that if she had an injury like Brooke's, she'd forestall any active effort to end her life until after the spinal storm had passed. She'd like to experience what Brooke did in the first few weeks, she says: an outpouring of love from friends and family that can be incredibly affirming, like attending your own funeral. "There's this deluge of stuff from everyone you've ever known; it's amazing," she says. "For Brooke there was something enormously positive about it. We didn't know what was coming after the six weeks, so it's a time when you can be optimistic; you're encouraged to be." ... [8]

Physician-assisted suicide is legal, with restrictions, in Oregon and Washington, as well as in Switzerland, Belgium, the Netherlands, and Luxembourg. A "death with dignity" ballot initiative was narrowly defeated in Massachusetts last fall, and state legislators are now considering bills to legalize assisted dying in New Jersey, Vermont, Connecticut, and Montana (where physician-assisted suicide has been *de facto* legal since 2009, when a court ruled that nothing in the law prohibited it). In the past few years lawsuits have been brought in Canada and Europe by terminally-ill patients seeking help with dying, and Peggy has testified at several of them. She went to Vancouver in late 2011 to testify on behalf of a woman with ALS who wanted help ending her life, and presented testimony by Skype in 2012 in the case of a Dublin woman with MS with the same request. The woman in Vancouver won her case but later died of an infection, and the government appealed; the woman in Dublin lost and it's her appeal that's now underway. There's a case in England being heard on appeal now, too, the one originally brought by Tony Nicklinson, who died last year.

In her testimony and academic writing, Peggy often mentions the complexity of teasing out exactly what a dying patient wants. But only in her life with Brooke has she understood, at a gut level, the true nature of that complexity. Brooke generally tells her he does not want to die -- but every now and then he tells her he does. "There can be an underlying stable decision, a wish for control over one's own end," Peggy says, "but there can be surface fluctuations." The trick -- the crucial, no-room-for-errors trick -- is to differentiate the surface from the deep.

Peggy keeps morphine hidden in the house, she says, but she won't tell me where. She doesn't want anyone to know -- not because she's afraid Brooke will find it, since he

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**Comment [14]:** <http://www.commonnews.org/site/site05/story.php?articleno=7135&page=1#.UUG9susjpUs>

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can't get to it on his own anyway, but because she worries that well-meaning friends or family members might misinterpret his melodrama and go looking for it on his behalf.

"Brooke is very expressive when he's in his full self," she says (adding, parenthetically, "imagine what it was like to make love with him -- it was amazing"). She says she knows him well enough to see when his apparent urgency -- "I need the morphine *right now*, I need it *right now*, get it for me *right now*" -- is just a matter of Brooke's natural histrionics: his deep voice, his massive size, his grimaces. She worries that others in his life might not be able to calibrate to what extent those over-the-top pleas are really

heartfelt, and to what extent they're just Brooke being Brooke,

But a few of Brooke's caregivers think Peggy's interpretations might be clouded by wishful thinking. "I've worked with death a lot," says Suzy Quirantes, who has been on the caregiving team since the day Brooke came home. "Last year, right after the feeding tube, he 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.'" But even Suzy sees how readily he vacillates. "He has said, 'I'm done,' and then when we kind of talk more about it, he gets scared," she tells me. "He says, 'What I mean is I'm done doing this stuff in the hospital. But I'm not ready to die yet.'"

For a period last spring and summer, though, even Peggy was convinced that Brooke's thoughts about ending his life were for real. He had suffered through a terrible year, two hospitalizations for drug-resistant pneumonia, two long recoveries, a return to the ventilator after being vent-free, loss of some small improvements in motor control. Worst, he'd suffered for months from intractable pain, and nothing his doctors did -- acupuncture, cortisone shots, pressure-point therapy, a technique called nerve-impulse

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scrambling -- made any difference. "Pain eats away at your soul," he wrote in a document he called "Final Letter" addressed to friends and family:

*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 that I would reach a limit to what I could do. And I have arrived at the limit over the past couple of weeks. . . . You may think that I'm depressed. I am. And I have every reason to be, I think. But that doesn't take away from the fact of what I am currently feeling. Despair. And hopelessness.*

That's when Peggy got busy. As dynamic as she'd always been about trying to ease Brooke's life, she was just as dynamic about trying to ease his death. It's all in a blue folder she labeled "Death and Dying."

Here in the folder are Peggy's notes from May 8, 2012, a page of typing paper with pencil scrawls from a phone call with a hospice nurse:

*end of life medication:*

*put between cheek & teeth, a few drops*

*they don't use pumps as much as they used to*

*in the kit -- of the doctor --*

*morphine takes care of air hunger*

*lovazepam*

*haldol/haldol -- for delusions, end of life agitation, calms.*

*tylenol suppositories*

*end of life fever, 99-101°*

*anti-emetic*

*atropine, to handle extra secretions*

*tk press because of pulmonary edema, heart "gets tired" and  
doesn't pump*

-----

*with Brooke likely to put him on a pump, for tk control --*

Peggy contacted Brooke's psychiatrist, Dr. K., to see if he'd offer some kind of objective second opinion as to Brooke's state of mind. They spoke on July 11, 2012, and Peggy took notes in pencil on another page she kept in the folder:

*Dr. K. -- whom I'd said might be contacted if Brooke were to request aid-in-dying etc, says he doesn't think he could do this, he couldn't possibly be objective.*

*(Quite understandable)*

Peggy also put some sticky notes in the blue file; she obsessively uses sticky notes to keep things organized, pasting colorful scribbled-on squares all around the house. One includes notes from conversations with a second hospice nurse, who said end-of-life aid via a respiratory route wouldn't work for Brooke. "Duragesic patches (all over)," the nurse, suggested, referring to the potent opium derivative fentanyl used for extreme pain.

And then, after a few more frantic pages of other recommendations, there's this note, dated August 18, 2012:

*10:37 am*

*Brooke says he "wants to soldier on despite difficulties"*

*"My despair had to do with a whole concatenation of difficulties"*

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What changed his mind? Finally getting rid of the pain. During his August hospitalization, a palliative care team suggested treatment with low-dose methadone, 25 mg. at 9 a.m. and 25 mg. at 9 p.m., each and every day. And with that, the pain disappeared, and Brooke rediscovered his will to live.

[ ]

My visit takes place about six months after this episode, and I ask Brooke -- who's still on a strict regimen of low-dose methadone every 12 hours -- what he thinks when he's alone with his thoughts. "How I'm going to teach the next section of the course," he says. Anything else? He considers for a few long moments. "I remember the past neutrally, without any particular emotion," he says at last. "I think about the future without any particular emotion. And I try to stay -- and this is the most difficult, oddly -- squarely in the present moment."

Brooke mentions a mantra from the Vietnamese Zen master Thich Nhat Hanh, which he says he learned when he first started meditation in date tk. It's something he relies on to calm himself when he wakes in the middle of the night, and I occasionally hear him chanting it during the day, too. He closes his eyes now and intones it:

*Breathing in, I calm my body and my mind.*

*Breathing out, I smile to the world.*

*Breathing in, I know I live in the present moment.*

*Breathing out, I know that the present is the only moment.*

If during his able-bodied earlier life he had seen a man who looked like he does now -- paralyzed from the shoulders down, fed by a feeding tube, struggling and generally failing to get off a ventilator, unable to move more than a few fingers and

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**Deleted:** Right before Christmas 2007, almost exactly one year before his bike accident, Brooke went on a ten-day Zen meditation retreat in Shelburne, Mass. It involved long eight-hour sits, silent and nearly-immobile meditation sessions that turned out to be startlingly good practice for the rigors of quadriplegia. ... [9]

gripped often by discomfort and pain -- Brooke tells me that "I would have thought he was weird to want to stay alive."

Is that what people think about you, I ask, that you're weird to want to keep going?

"Yes," he says.

Who thinks that?

"Everybody," he says. "Except Peggy."

Not that he blames them. "If I were somebody else I would feel the same way," he says. "You can't know what it's like to be me as opposed to many other people."

Well, try me, I say. What are we missing about what it's like to be you?

It's a tough question. The first time I ask, while I'm still in Salt Lake, Brooke is too cognitively cloudy to give me a straight answer. I will call him again three weeks later, when his undetected urinary tract infection has cleared up, but he still won't be able to say. His friend Dave will be in the living room with him then, listening in on the speaker phone, and the three of us will leave it as one of life's eternal mysteries: the sheer impossibility of ever getting inside another person's head.

[ ]

Physician-assisted dying, I've long believed, is an option I want available to me.

I'm afraid of death, to be blunt about it. But I'm also afraid of losing control, being a burden, suffering, languishing -- afraid of all the anguish that plaintiffs in assisted suicide lawsuits are so desperate to avoid. My husband says much the same thing. Neither of us wants to be kept alive artificially, tethered to a body that will only become more and more debilitated as the years drag on.

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But after steeping myself in Brooke's life -- reading his blog posts, [drafts](#) of his autobiography, even the diary he kept in his twenties, neatly typed on yellow legal pads and stacked in the upstairs hall -- I've lost some of my certainty about this issue. Yes, Brooke's days are often filled with tedium and despair; yes, much of what he treasured has been stripped from him; yes, his can be a difficult road. Yet when Brooke talks or writes about his life today, he can still find aspects that delight him. Who can say for sure whether that's how I'd face such challenges, too?

He's more creative than ever, he says; his marriage and his friendships are more intimate now. Every so often he'll turn to Peggy and announce, "I love my life." So when I think about how I'd like to see my own life end, if faced with a series of difficult decisions, I still think I know what I'd do. But I'm also aware of how much can change once you look your own final options square in the face.

[ ]

On my last night in Salt Lake, Peggy and I go downtown to hear the Utah Symphony. We're accompanied by Bonnie Baty, who teaches genetics counseling at the nursing school. Two weeks after Brooke's accident in 2008, Bonnie and her husband, another beloved University of Utah professor, were hiking in Zion National Park when he slipped on something, plunged twenty feet, and died. Bonnie's husband, Craig Forster, was 55.

When Peggy first mentioned Bonnie, she told me they "sometimes go to the symphony together and talk about this stark coincidence, and whether it would be better for our respective husbands to have been killed instantly, as hers was, or damaged so severely, as mine was." Tonight I get to listen in on this ongoing conversation.

Bonnie thinks she is the luckier one. "It seems like Peggy's life is really hard," she says over a pre-concert dinner. "And it seems like Brooke's life is really hard. I'm not sure that's how I would feel if I were in that life, but that's how it looks to me now." Even though Peggy and Brooke still have each other, which is huge, Bonnie thinks that for her the "frustrations" of dealing with his condition might outweigh the consolation of having her husband still alive.

At the concert hall, a change in the program is announced. Tonight's soloist, pianist Nicholas Angelich, has injured his right hand, and rather than cancel his appearance, he's requested a different selection: Concerto for Piano in D Major (Left Hand) by Maurice Ravel. "Ludwig's brother!" Peggy says when she reads that Ravel wrote the piece for the pianist Paul Wittgenstein. Wittgenstein [had](#) lost his right arm in World War I, "a heavy price for a musician to pay," according to the program notes, "the kind that could have broken the spirit of most." But rather than give up his career, he commissioned new music suitable for a one-armed pianist.

Whatever motivated Wittgenstein to alter compositions to suit him, something similar must be what motivates Brooke -- an urge to adapt and transcend rather than despair. Within a few years of drawing up a document that said he didn't want to live through an accident like the one he had, he reconfigured both his own professional life and his self-image, converting his experience with meditation into a focus on getting off the ventilator and breathing on his own; converting his athleticism into a willingness to push himself in physical therapy so hard he sometimes passes out; converting his love of teaching into something that, with modifications, can continue to give him a reason to live.

Peggy is late getting home -- it takes forever to get out of the parking garage, and then she has to drop me at my hotel -- and while we're in the car Brooke calls to say he's waiting up for her. "He's happier when I'm home," Peggy explains. She gets home at about 10:30, and goes straight to Brooke's bed for her favorite time of day. As she does most nights, she takes her old-school BlackBerry out of her pants pocket, slips off her sensible shoes, and climbs with some effort into Brooke's extra-wide hospital bed. She lies cheek-to-cheek with her husband, who wants to know if she had fun, what she ate, what we talked about.

"I told him about the way the evening was constructed, as a way to talk about two parallel cases that have so many things in common that it's eerie," Peggy tells me the next morning. "I told him we discussed whether it would it have been better if he had been killed outright or if what did happen was the better -- and that it had become much clearer to me that despite all the difficulties I was glad to have had it turn out the way it did."

Later that day, Peggy phones me at the airport as I wait for my flight home. She and Brooke, along with his caregiver Amir, are out walking in crisp winter sunshine in City Cemetery, whose entrance is just three blocks from the house. Two funerals are going on: one that they can see right down the hill, another they can only hear in the form of a bagpipe whining in the distance. Peggy and Brooke own adjoining plots in this cemetery. They've always taken walks here, even long before Brooke's injury, she tells me. "It's a constant reminder of how death is a part of life."

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