

The irony of supporting physician-assisted suicide: a personal account

Margaret Pabst Battin

Published online: 14 August 2010
© Springer Science+Business Media B.V. 2010

Abstract Under other circumstances, I would have written an academic paper rehearsing the arguments for and against legalization of physician-assisted suicide: autonomy and the avoidance of pain and suffering on the pro side, the wrongness of killing, the integrity of the medical profession, and the risk of abuse, the “slippery slope,” on the con side. I’ve always supported the pro side. What this paper is, however, is a highly personal account of the challenges to my thinking about right-to-die issues. In November 2008, my husband suffered a C2/C3 spinal cord injury in a bicycle collision, leaving him ventilator-dependent, almost completely paralyzed, and in the hospital—but fully alert and profoundly self-reflective. What if he wanted to die? This paper draws from two multimedia presentations—file:///Users/margaretbattin/Documents/BROOKE’S%20ACCIDENT/The%20Salt%20Lake%20Tribune%20%7C%20Multimedia:%20Metamorphosis.webarchive and file:///Users/margaretbattin/Documents/BROOKE’S%20ACCIDENT/The%20Salt%20Lake%20Tribune%20%7C%20Multimedia:%20Learning%20to%20live%20again.webarchive—and personal material concerning quality of life (he’d rank at the bottom on the SF-36 and similar scales) and concerning autonomy (his own accounts, verbatim). This is a detailed portrait of a man whose life involves extraordinary suffering but also luminous experience some of the time. It only makes the question harder: *What if he wanted to die?*

Keywords Autonomy · Paralysis · Physician-assisted suicide · Quadriplegia · Quality of life · Right to die · Spinal cord injury · Suffering · Ventilator dependency · Wanting to die

Under other circumstances, I would have written an academic paper for the themed section on physician-assisted suicide in this journal, *Medicine, Health Care and Philosophy*. It would have started off like any conventional academic paper: first, it would have set up the problem—theoretical and political tension over issues of physician-assisted suicide; then it would have made conceptual clarifications—exactly what is meant by “physician-assisted suicide” and what nomenclature is replacing it? (“aid in dying”), and how do conceptual issues differ from one language to another? Then it would have moved on to the more general argument about the ethics and other concerns over social acceptance and/or legalization of PAS. And finally, it would have set up the problem by exhibiting the major tensions as involving two groups of arguments, those on the “pro” side favoring social acceptance and legalization—primarily the arguments from autonomy and from “mercy” or compassion for the relief of pain and suffering—and those on the “con” side, the arguments concerning the intrinsic wrongness of killing, compromises to the integrity of the medical profession, and the risks of abuse.

This would have been a pretty easy article to write. After all, I could crib from my own work over the past 30 years, in which I’ve explored many facets of this overall argument, especially issues about autonomy and rationality, refusal of treatment and the “least worst death,” euthanasia and assisted suicide in international perspective, and empirical evidence concerning the risks of abuse. I’d even

M. P. Battin (✉)
Department of Philosophy and Division of Medical Ethics and Humanities, University of Utah, CTIHB, 215 S. Central Campus Drive, Fourth Floor, Salt Lake City, UT 84103, USA
e-mail: battin@utah.edu

Table 1 The debate over physician-assisted suicide

<i>The Debate Over Physician-Assisted Suicide</i>	
PRO	CON
<p><i>*The argument from autonomy, self-determination</i></p> <p><i>*The argument from mercy, or avoidance of pain and suffering</i></p>	<p><i>*The argument from the intrinsic wrongness of killing</i></p> <p><i>*The argument concerning the integrity of the medical profession</i></p> <p><i>*The argument concerning abuse: The risk of the "slippery slope"</i></p>

be able to use the schematic diagram that has appeared in various versions in several of my previous articles: (Table 1).

And I'd be able to reiterate my unwavering support for legalization, even though I've spent much of my career trying to understand the arguments made by those on the opposing side. Despite objections concerning the moral status of killing, the erosion of physician integrity, and the dreaded slippery slope, all of which are to be taken seriously, I would have argued: *A person should be accorded the right to live his or her life as they see fit (provided, of course, that this does not significantly harm others), and that includes the very end of their life.* That's just the way I see it, and pretty much always have.

That's just the way I've seen it—that is, until just over a year ago. It was November 14, 2008, to be exact. Some images stick indelibly in my mind: the policeman standing outside my door when I arrived home from my office late that afternoon—instead of going biking with my husband, I'd gone to a couple of lectures, and though I'd phoned him afterwards, I did not get an answer. The news coverage: *Professor paralyzed in bicycle accident*, with an aerial photo from the news helicopter overhead, showing the paramedics and spectators and the flight nurse who'd saved his life, with just his long legs sticking out from the little crowd as he lay on the pavement. Then there are images still in my mind of the CT scans of his spinal cord—fracture at C2/C3, about as high and devastating an injury as possible. There are innumerable shadowy images of

repeated X-rays of his lungs, as they tried to reverse the atelectasis and conquer the pneumonia that followed. I have an indelible image of his eyes rolled up, as he coded during a transfer from one hospital unit to another: there he was, dying right before my eyes, and while the code team tried to get me out of the room as they worked to resuscitate him, I refused to budge. This was not a man who was terminally ill, as most end-of-life discussion about PAS involves: this was a man who had come within an ace of dying at the time of the accident and several times since. But there he was, after the code, alive—on a ventilator, completely paralyzed from the neck down, but, still, alive. And he had no head injury at all, though the bicycle helmet he'd been wearing at the time of the accident was completely smashed in on the upper left side. He was alert, sentient, and (intensely) self-aware. He could tell us what things were like for him.

Of course, that only made the issue of PAS harder for me. I keep thinking about Dostoevsky's character Ivan Ilych, 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?"

Academic papers and real life

This paper is a first step in trying to answer that question. To begin, here's a 3-min multimedia presentation made by two staff reporters for *The Salt Lake Tribune*: Leah Hogsten, the photographer, and Peggy Fletcher Stack, the writer, that portrays the kind of personal challenge this has meant for me (watch it, please; just paste this address into your web browser): [file:///Users/margaretbattin/Documents/BROOKE'S %20ACCIDENT/The%20Salt%20Lake%20Tribune%207C%20Multimedia:%20Metamorphosis.webarchive](file:///Users/margaretbattin/Documents/BROOKE'S%20ACCIDENT/The%20Salt%20Lake%20Tribune%207C%20Multimedia:%20Metamorphosis.webarchive).

Much of my entire career in writing and thinking about PAS was now on the line. All that academic prose—wheelbarrows full of it, it seems—had come under horrifying challenge from life itself. I said I did not know what I'd do if I reread everything I'd ever written on this topic, but I'm sure that part of me would want to tear it all up.

But what, exactly, would I want to tear up? Not the analyses of the structure of the dispute over PAS; that still seems to me right. Not the discussions of "manipulated" suicide or the ways in which greedy or overstressed family members, overworked or callous physicians, or cost-conscious health care organizations might pressure a dying person into ending life sooner; those things still seem to me important to consider. Not the linguistic explorations of differences between English and German in the terms used for 'suicide,' and not the study of the evidence in Oregon and the Netherlands, where assisted dying is legal, about whether risks are heightened to people in vulnerable

groups. And not the principle that been central to my thinking: *A person should be accorded the right to live his or her life as they see fit (provided, of course, that this does not significantly harm others), and that includes the very end of their life.*

But, obviously, something had dramatically changed, and the issue that seemed so easy has become profoundly hard. It is not just about terminally ill people in general in a kind of abstract way; now, 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, or for that matter watching a physician deliberately euthanize him, since after all, because he is almost fully paralyzed, he could not bring about his own death himself without help? It is often argued that discontinuing ventilator support is not killing, just allowing to die, but even just disconnecting his ventilator is something he could not do himself.

Fortunately, he did not seem to want to die. He was glad to be alive, however hard it was. He was immensely grateful to the flight nurse who'd been jogging on the same road where the bicycle accident occurred and, thanks to her training in CPR and spinal cord injury management, had saved his life; he met with her several times, always in a spirit of utter gratitude. Despite his evident and sometimes intense suffering through the serious lung problems early on and all the other problems associated with high spinal cord injury—neuropathic pain, wide-swing temperature dysregulation, vise-like spasms—he still said he was glad he had survived. He was surrounded by friends, family, and legions of acquaintances, former colleagues, students, and the various hospitals' caregiving staff, almost all of them remarkably kind and indeed caring.

But that was in the early months after the injury, when the prospect of significant return of function still seemed real. As the months wore on—still on the ventilator, still in the hospital, still nearly completely paralyzed—the early enthusiasm for his recovery dimmed. The hospital staff, though still wearing the same cheerful smiles, grew ever so slightly more distant. The insurance company grew impatient, since it would not keep someone in this facility who had reached a plateau. No one said “awesome” anymore. Brooke's mood, tempered by reality, grew darker, as did everyone else's. At a particularly difficult moment, he said he wanted to die. This is from an entry I wrote at the time but never dared post on our blog (www.brookeandpeggy.blogspot.com, written for November 7, 2009):

It had been a hard day for Brooke—many secretions, short and unsatisfying trach-mask times in his off-the-vent weaning trials, frustrations with the electric wheelchair, which because it is so complex can go wrong in many different ways. Suddenly there we

were, his sister and I, but with Brooke wagging his head wildly back and forth, banging it backwards again and again against the wheelchair's headrest. “You don't understand what I'm going through,” he'd been saying, “You don't understand.” Now it had become “I want to die, I just want to get this over with.” He was saying it at the top of his voice, through the trach, but loudly enough so that the nursing staff discretely refrained from barging in with the usual parade of vent checks, vitals, routine medications, trach care, and so on.

“I want to die, I just want to get this over with.” A pause, but a brief one. “I'm crazy right now,” he said, accurately enough. “Just give me a pill.” All I could do was smile evenly in a steely controlled way, knowing there was no way to respond to this outburst, and despite the panic I was trying to control I knew the episode would dissipate pretty soon. We'd talk it over quietly after a while, piecing together who said what and how it had been misinterpreted, and eventually say to each other that part of what had always made our relationship so good was that we could work together in figuring out what had gone wrong.

We did. But even things said in episodes of craziness cannot be ignored. Wanting to die is hardly uncommon in quadriplegics and other people with catastrophic, life-altering injuries. The spinal-cord-injury physician caring for Brooke says that 100% of his patients say they want to die. But Brooke? Could Brooke really want to die? Brooke, who has been so fantastically positive, so energetic in his efforts at rehab, so resolute in working on vent-weaning, so deeply engaged with so many people, family, friends, former students and colleagues, nurses and respiratory therapists and even nurses' aides? He's capable of real friendship; he's capable of deep love. And he receives it, in huge measure. So how could he want to die, when he has already suffered so much to get to this point, and when he would leave so much behind?

The implications of a single case

Brooke said he wanted to die. True, he said it at a particularly hard moment, but just the same he said it, and he might after all say it again in the future, more directly, more urgently, in a way more demanding of a response. True, he later said that he had not really meant it, that he just did not want to have to keep going through the physical hell that is often the case, but he has said it several times again since then. Recognizing this possibility as real is what has made the issue of PAS far more difficult for me: *what if he really wanted to die?* Should I change my mind

about PAS, seeing how excruciatingly hard, how impossible, this would be?

This is to be sure not just a personal dilemma but an intellectual one as well, a central threat to the work I've been doing all these years. Of course, it raises methodological issues: after all, responding to Brooke's plea, whether by offering assistance or refusing it, would be to respond in just one case, albeit one very close to home. To try to base medical practice or public policy or law on the chronicle of one man's catastrophe and his preferences about the continuation or termination of his life would be to make one of the most elementary (but frequent) errors in reasoning in bioethics: to generalize from the experience of a single individual and its impact on those around him or her. This does not provide the kind of population-wide data you'd need to make any meaningful general statements; you cannot argue that PAS or any other social policy should or should not be socially accepted or legalized just on the basis of your own immediate experience, no matter how intense, even though it is often explored this way in the literature. This is not to say that personal-experience writing is not important: consider, for example, Eva Kittay's work concerning her severely impaired daughter, Susan Wolf's writings on the death of her father, or for that matter Franz Ingelfinger's famous essay in the *New England Journal of Medicine* on how his own cancer made him understand what it was to have a doctor. These have been important pieces, but whether they form an adequate basis for public policy is quite another question. And consider Brooke's case: could it make a contribution to public policy? To be sure, it might provide an occasion for sobering reflection, but what about a basis for generalization to other cases? The issue before us as a society, or rather one among societies around the globe, is whether PAS should be socially accepted, medically supported, legalized, and indeed recognized as a matter of fundamental human right. "One swallow," I might have quoted Aristotle, "does not a summer make," and one difficult medical case does not make good widely-applicable social policy.

At least, that's what I would have said. A year into this, a year after Brooke's accident and a year of watching him suffer and change, I see more clearly why realistic generalization is impossible. Not only cannot we generalize from single cases, as we always knew, but the ways in which we document attempts at generalization do not succeed in capturing the texture of life adequately. At least with an experience of this intensity, including both the overwhelming horror of it and the sublime transcendence of it some of the time, there is no way to fit this lived experience into the standard assessment measures and hence no basis for contributing to "objective" policy formation.

Consider the paradigmatic argument-scheme about PAS, as in the box at the outset of this paper, the one I've been

using for years in my writing about this issue. There are two mainstay issues in the "pro"-PAS column: the autonomy argument and the one about "mercy" or "compassion" and the relief of pain and suffering. These two arguments jointly provide the foundations of the case for social acceptance and legalization of PAS, at least where both are the case—that is, where a patient wants to die and dying is the only way acceptable to him or her of avoiding pain and suffering. Neither provides an adequate basis for PAS by itself, but jointly they do. Each provides a safeguard against abuse: if PAS is either involuntary or if it is not a response to pain and suffering, the societal provision of PAS cannot be supported. Because this point is so often misunderstood, it is well to say it again: *you need both*.

The mercy argument: avoiding pain and suffering

Here's the second one of these arguments first, the argument from mercy: *No one should have to suffer pain or other forms of intolerable suffering, where that cannot be treated by means acceptable to the patient and is not embraced for other reasons having to do with values important to that person, even if this may mean ending life.*

Pain and suffering are usually understood as central factors that contribute to reduced "quality of life," a standard notion in the medical and bioethics literatures. There are well-developed, well-validated measures for assessing health-related QoL: for example, the well-known Medical Outcomes Study Short Form-36 health survey, or SF-36, originally developed by the Rand Institution and widely used in many contexts (http://www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html). It has eight subscales:

- vitality
- physical functioning
- bodily pain
- general health perceptions
- physical role functioning
- emotional role functioning
- social role functioning
- mental health

But what does it tell us in the single case in question here, that of a professor who sustained a spinal cord injury in a bicycle accident more than a year ago, who is still in a hospital, still on a ventilator, and still nearly completely paralyzed?

The SF-36 asks questions like these:

2. Compared to one year ago, how would you rate your health in general now?
 1. Much better now than one year ago
 2. Somewhat better now than one year ago

3. About the same as one year ago
 4. Somewhat worse now than one year ago
 5. Much worse than one year ago
5. Does your health now limit you in this activity? If so, how much? Lifting or carrying groceries.
1. Yes, limited a lot
 2. Yes, limited a little
 3. No, not limited at all
20. During the past 4 weeks, to what extent has your physical health OR emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
1. Not at all
 2. Slightly
 3. Moderately
 4. Quite a bit
 5. Extremely
26. How much of the time during the past 4 weeks: Have you felt calm and peaceful?
1. All of the time
 2. Most of the time
 3. A good bit of the time
 4. Some of the time
 5. A little of the time
 6. None of the time

Brooke would rank at the bottom on almost all questions on the scale, including #2, #5, and #20, though a little higher some of the time on some, like #26. If a single, unitary score were to be demanded, he'd be scored as having an extremely low "quality of life" overall. He cannot do any physical activities except to move his head and shrug the upper parts of his shoulders; while he has some motion in all four extremities he has no effective function in any part of his body below his neck beyond driving his wheelchair with a joystick; and he can't "lift or carry groceries" (question #5). On the other hand, he's had great social support, both from family and friends; his "social activities with family, friends, neighbors" (question #20) are way beyond "normal," indeed, extraordinarily intensified and meaningful. Where would he rank, exactly, and how would this assignment of rank be scored? Then too are the things the SF-36 does not assess very well, but to understand his situation we'd need to know: is he terminally ill, plateaued, or recovering?—the question itself is simplistic, since he's getting "better" but now has a dramatically shortened life expectancy and is always subject to the risks of potentially fatal infection. Must he worry about financial issues?—that includes not just whether he is insured, but whether the insurance he carries covers

specific elements of his care and therapy, like inpatient rehab and extensive OT and PT therapy. And perhaps most important, is he pessimistic or optimistic, both as a matter of background character trait and in the specific circumstances at the specific moment? Do the scoring; what result do you get? Despite the few sublime peaks, you'd get a composite score that registered at the bottom, as an abysmally low quality of life.

Alternatively, consider the measures of "a life worth living following spinal cord injury" examined in a recent meta-synthesis of qualitative research (Whalley 2007). Key themes included far more sensitive qualitative measures, including "relationships," "responsibility for, and control of one's life," and "self-continuity," but ones that are still difficult to apply. Does he have "a life worth living," as this study calls it? That would be key (if such language weren't tainted by the continuing specter of Nazism) to objective assessment in connection with access to physician-assisted suicide. If you pursued a subjective approach and asked him, sometimes he'd say yes but sometimes no; outside observers, presumably more objective, would do the same depending on their contact with him.

Or consider Bronsteen, Buccafusco, and Masur's account of well-being or quality of life: they reject preference-satisfaction and nature-fulfillment theories but point to "happiness or positive affect—*feeling good*." "A person's well-being is the aggregate of how she feels throughout her life," they argue (Bronsteen et al. 2009, p. 2). So how will this sort of analysis work for Brooke?—he "felt good" most of the time before the accident; now he feels even better some of the time, albeit extremely briefly, but endures astonishing suffering much of the time as well.

Of course, in the real world there are other less formal observational measures of quality of life. A medic, watching from the foot of the bed during one of the frequent respiratory crises that occur while Brooke's inert body is being turned, as it is every 2 h to prevent bedsores, summed up his entire quality-of-life observation in this way: he mouthed, silently and seemingly involuntarily, "the poor fucker."

But now listen to—and see—Brooke himself: would he really answer these questions, including those on the SF-36, the way we've thought? Here's a second 3-min multimedia presentation made by the two reporters, Leah Hogsten and Peggy Fletcher Stack, at *The Salt Lake Tribune*, entitled "Learning to Live Again": <file:///Users/margaretbattin/Documents/BROOKE'S%20ACCIDENT/The%20Salt%20Lake%20Tribune%20%7C%20Multimedia:%20Learning%20to%20live%20again.webarchive>.

Of course, from the apparent fact that one man's case does not fit well into one of the instruments designed to assess quality of life you cannot conclude that other people do not fit this or other assessment instruments, but unless we assume that other people's situations are far more

uniform and measurable, as well as commensurable with those of others, this argument against appealing to QoL judgments in any simplistic way holds. That is to say, external appraisal of what someone's life is like, whether it's better or worse than other people's lives (Wolff and De-Shalit 2007; Chang 1997), and whether it's bad enough to warrant PAS or assistance in dying does not work very well in at least this case, or if it works at all is not generalizable; but without being able to assess cases like this—the hard ones, in which someone might really want to die and have good reason, it might seem, for doing so, we risk losing one of the two principal arguments that are jointly required as a basis for PAS, namely the argument from mercy, and with it, one of the principal safeguards against the abusive use of the “right to die.” Yet this is central to the case for social acceptance, medical assistance, and legalization of PAS.

The autonomy argument

Autonomy, or self-determination, is the other mainstay argument, indeed often taken as the primary one. But what does “autonomy” look like in Brooke's situation? What he wants, or at least says he wants, swings wildly with the moment: when things are good—for example when he is “in the groove” during his vent-free training exercises in breathing, they can be very good: he has what he describes as sublime experiences, and while he's not exactly Buddhist, they are sometimes couched in Buddhist language. Again from our blog (www.brookeandpeggy.blogspot.com, entry for November 25, 2009):

We're looking at the brighter side of a difficult situation: Brooke achieved several milestones over the past twenty-four hours. For one thing, yesterday afternoon, in his second trach mask trial of the day, he reached a tidal volume of 682 cc.—way, way beyond the 100's and 200's he was drawing when he was first here, and even beyond the 300's and 400's of recent days. His tidal volumes have normed somewhere between the higher 400's and 500's. His 682 seems to have impressed even the most hard-boiled of respiratory therapists, especially the ones who once thought he was never going anywhere. Then today, Brooke spent six and a quarter hours altogether off the vent. The afternoon was a particularly sublime experience. After “releasing impure thoughts from his mind” by meditating on what he calls the “Great Sea of Tranquility,” beneath which the kelp of his earlier imagery waves gently in the currents with a single fish gliding through it, sometimes he sees the Buddha in his sitting position,

floating above the Sea of Tranquility, meditating upon it. This image, when it comes into his consciousness, he says, immediately purges impure thoughts.

Impure thoughts? Anger, resentment, disillusionment. You don't have to use weird Buddhist language to recognize these things; they're always around. But during this afternoon's trach mask, Brooke says he could visualize and actually feel his own chest wall moving back and forth, in and out, in and out, in and out, as he inhaled air through his nose and expelled it through his mouth. The visualization helps to concentrate the mind, he says, when it wanders away, as in any form of meditation, in random thoughts about the past or the future. He says he can pull his mind back into the immediate experience of feeling his chest wall move back and forth, and sometimes he can visualize his diaphragm ballooning out and then contracting, over and over again. This afternoon he was on the trach mask for two and a quarter hours—after four hours this morning—and didn't want to stop at all. He says this made him think that in some odd way this whole nine months has been leading up to these moments, as day after day, day after day, twice a day on a regular basis, he has tried to push himself to gain strength. The pattern is so predictable: there are periods in which his strength dips, almost inevitably, followed by rest periods in which his mind and body gain strength and then push toward new heights of breathing ability. This is what he asked: “How many people have been given this crazy opportunity to recover breathing, over such a long period?”

When he is trach-masking, Brooke's room takes on the air of a monastic cell. He is confined here, in effect, since he still has to be tethered to the warmed and humidified air supply, even if he is breathing this air on his own. He only rarely gets glimpses of the outside world, especially since he has to remain in bed, not in the wheelchair, as the surgical wound from an abscess heals. Not until 8:30 in the morning, when his morning trach mask begins, does the sun even penetrate his room, and it remains at a low, dim angle all day.

Brooke says he always wanted to go on a year-long Buddhist retreat. Now here I am doing it, he says, and somehow my earlier meditative practices are bearing fruit. They were often painful and frustrating, especially during the early parts of a ten-day sit, but they were of tremendous importance to me as well. Of course they were different from my present breathing trials: for one thing, during those ten-day sits I didn't have Bach cantatas playing in the background, as they are now, or Julian Bream's guitar—you wouldn't find these in a Buddhist monastery. But so what; Bach penetrates the mind on a deep level,

making profound, almost organic meditation possible. My room feels like a monastic cell—larger, perhaps, and more cluttered, and if my eyes were open I would see boxes and paintings and a looming TV set that is almost never on, but it bears sticky notes with love-hearts and cupid’s-arrows and stars. You wouldn’t find these in a monastic cell either, but in spite of the fact that this same room is open to a regular procession of nurses and aides and respiratory therapists, as well as visitors, it can still feel like a monastic cell when I am in my deepest mode of breathing. I like it. I love it.

All this is to look on the bright side of a difficult experience. (We certainly know there’s a darker side, of course, much darker.) Not always, but sometimes, these breathing exercises give me enormous joy as they are occurring, and I now actually look forward to these sessions, instead of anticipating them with the stark terror they once held. I look forward to them in the same sort of way I looked forward to the last several days of meditation during my Vipassana courses—that meant just sitting, and running the mind up and down the body, feeling the sensations. Here, in my trach-masking, the meditation is partly Zen-like in that it especially focuses on breathing, not just physical sensations. How many breaths of my own can I have taken over the past nine months here at South Davis?—who knows, hundreds of thousands, I suppose—and now, all that breathing, all that anxiety, seems to be passing away as the trach trials become something I actually look forward to, especially when the therapists are empathic and respond to what is going on with enthusiasm, and especially with Peggy in the room, grading her papers and sometimes dozing off in the big green reclining chair that is part of the furniture of this room. You wouldn’t find a chair like that in a monastic cell either, or your wife, but I’m glad they’re here.

What can one say if all this stuff about organic meditation and monastic cells sounds curious, or bizarrely religious, or just weird and strange? That’s fine. Life is sometimes extremely curious, and offers gifts when you least expect them and under circumstances that from the outside would appear desperate and impossible.

There are hundreds of poems and prose works built around the topos of the prison—think of Coleridge’s “This Lime Tree Bower My Prison” or Winnicott’s paper on imprisonment. The paradox of the prison is that it can hold the body in confinement—in my case, not just confinement but paralysis—and yet liberate the spirit. My monastic cell—when it’s not serving as a hospital room or a living room for receiving friends

and family and guests—is like that kind of prison, confining and yet sometimes strangely liberating when I breathe.

Thus, while his body scores at the bottom of virtually every category on the SF-36, to take just one instrument for measuring quality of life, his mind can soar, and so can his moods and lived experience.

But they can plummet, as you’ve seen above. I had continued (entry written for November 7, 2009, but not posted), describing the occasion when he said he wanted to die,

After his sister and I tucked Brooke into bed—put on the boots for preventing foot-drop, the splints for correct positioning of the hands and fingers, brushed his teeth, watched the CoughAssist treatment and the night meds and the last cath before sleep—we drove home, poured a couple of glasses of wine, sat down to talk. One of us defended him, wanted to take his plea to die seriously; the other insisted he didn’t really want to die, even if that’s what he sometimes said. We could imagine scenarios from cheap novels and bad bioethics cases: on one side, greedy family members who want him to die, perhaps to lessen the burden, to speed the inheritance, or to erase the family shame of having someone disabled; on the other side, a panicked wife or a devoted sister who cannot imagine letting go, no matter what, even at his terrible expense. But we talked and talked, and both came to see at least dimly circumstances in which we might have to respect someone’s wish to die—a wish which, in this case, because Brooke is so completely helpless, would have to be aided in order to take effect. It wouldn’t be now, and it might not be ever, but as she pointed out, you can imagine someone saying, I’ve given it a good try, and I’ve been showered with love from every direction. I’ve harvested the best from this awful situation, but it has crested now, and I can’t go on. I’ve had, well, enough. It’s like going to your own funeral, something we ordinarily can’t do, when you discover all the amazing things people have to say about you and how much they really cared. You see them stunned, silent, crying, and you hear their recounting of all the things they remember about you. But the fact that they care doesn’t mean I have to stay, not when things are as hard as this, and if they really, really loved me they would embrace my broken, useless body and look straight into my eyes, and let me—help me—go.

The accounts on our blog are for the most part direct, first-person accounts at the immediate moment. Brooke and I write them together as we lie next to each other in his

hospital bed (he has a wide bariatric bed because he's so tall, but since he's not fat we can both fit into it); he is motionless, but I type on the laptop as we talk. They're as close as you can get, I think, to the real thing—he can tell us what things are like for him. But what does he actually tell us? Could he describe his own quality of life in an adequately informative way? If we can't, can he, even if he is the one closest to it? At least in this case, there's no way to assess quality of life in any way that makes realistic sense, and certainly not by trying to fit it into a prefabricated questionnaire; indeed, the whole notion of "quality of life" may be theoretically problematic, especially if it assumes a scale that can yield a more or less unitary score, one that can be compared among different individuals. And there's no way to identify genuinely autonomous choice—not because he doesn't make choices, but because the situation about which he makes choices, the condition of his own body and how he sees it, fluctuates so widely, so wildly. Furthermore, there's no way for him to realistically imagine what his own future will be like; he could not have imagined exactly this, and he cannot imagine his future or how he will respond to it (Ubel et al, 2005). One could hardly speak of a "stable, persistent choice"—either against or for continuing to live—in this situation; it is too hard and changes too rapidly, though of course any outside assessor would see him at just selected moments, like the medic watching from the foot of the bed during one particularly difficult event. Furthermore, these problems hold not only for external observers, whether standing at the foot of the bed or in a medical office or in an insurance boardroom, but by the patient as well, that person most directly involved but also most vulnerable of all.

The upshot?

So neither argument on the Pro side of the debate over physician-assisted suicide works in practice in this case—not the one about autonomy, and also not the one about mercy, compassion, avoidance of pain and suffering, or quality of life. It's not that these arguments are unsuccessful in theory; it's just that they don't have adequate purchase in this one very complex case. But if they don't have adequate purchase in one complex case, they may not have very good purchase in others; after all, while Brooke's case may be more starkly dramatic than the "ordinary" terminal illness, the experiences and situations of people who are dying may well have much in common with his. These are after all people with distinct personalities, who suffer in a variety of serious ways but also may have experiences of extraordinary luminosity, just as he does. There's nothing "ordinary" about terminal illness, even if it seems that way when viewed from the outside.

What about the arguments on the other side? They have also become more complex, though I can treat them only briefly here. To the first, what's "killing" or "suicide," in a case like this? We tend to think of big, major, readily identifiable actions in terms like these, but there are many, many inconspicuous, minor things that could end in death: the ballard that is the vent connection slips easily from its port at the patient's throat, as it does often enough anyway; what if there is nobody close enough to hear the alarm the vent makes if it is disconnected? What if life-threatening infections are not noticed fast enough or treated effectively? Those are just two among myriad ways in which life could become death. To the second of the principal arguments on the Con side, the concern about the integrity of the medical profession: this question is always framed with reference to physicians, but it's the nurses, the nurses' aides, the respiratory therapists, the physical therapists, the occupational therapists, and even the shower aides who really make the day-to-day difference. Their attitudes, their care or lack of it, and in particular their subliminal messages have extraordinary influence, especially over a patient in such a vulnerable position.

And what about the third of the Con arguments, the slippery slope argument about the possibility of abuse? There are many forms of this argument: the procedural form, the precedential form, the direct-causal form. Some have to do with, for example, bureaucratic assessments like using cost measures (Brooke's year so far of hospital care has, needless to say, been expensive) or simplistic assessments of quality of life in rationing contexts (Brooke would lose out), but the most persuasive and hardest to prevent have to do with pushing or urging or exerting sustained if subtle pressure on someone to choose to end his or her life. In the year since the accident, I've seen just one person—though someone loved and trusted—intimate openly to Brooke that he might be better off dead, and that it would be understandable if he were to choose to die. In contrast, I've seen friends and family and caregivers at every level, from shower aides to surgeons, and former students and erstwhile colleagues and clerics of every stripe praise Brooke for his courage, urge him on, support every part of every wish he has to stay alive. Perhaps this is abuse in its own way, given what he has to suffer, but what they see is the inspired, extraordinary, luminous character of some parts of his life. I do this too.

In short, I do not think the Con arguments have gotten any stronger, just more complex; and they do not take the day.

In the end, although Brooke's injury in all its complexity makes the issue of social acceptance and legalization of physician aid-in-dying much more difficult theoretically and incalculably more difficult as a matter of personal anguish—the irony of this situation is not lost on me—

these things still do not diminish my support for social acceptance and legalization of this practice. It just makes me realize that like any difficult moral issue, it is hard to translate the immensely complex features of any particular case into workable social policy. Of course, we cannot generalize from a single case. But we can learn something that's relevant to virtually all cases, even though rather different from Brooke's. I'm deeply humbled by Brooke's catastrophic experience and the suffering he has endured, and I'm profoundly grateful that he's still alive, but I also have to recognize that he has the right to choose how and whether he wants to continue his life.

It is hard enough to put this into print. Imagine what it would be like if you had to put it into practice.

References

- Bronsteen, J., C. Buccafusco, and J. Masur. 2009. Well-being analysis. <http://ssrn.com/abstract=1397843>, p. 2.
- Chang, R. (ed.). 1997. *Incommensurability, incomparability and practical reason*. Cambridge: Harvard University Press.
- Ubel, P.A., G. Loewenstein, N. Schwarz, D. Smith. 2005. Mismagining the unimaginable: the disability paradox and health care decision making. *Health Psychology* 24(4(Suppl)):S57–S62.
- Whalley, H.K. 2007. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord* 45(2): 124–139. Epub 7 Nov 2006.
- Wolff, J., and A. De-Shalit. 2007. *Disadvantage*. Oxford: Oxford University Press.

Multimedia links

- Metamorphosis*: file:///Users/margaretbattin/Documents/BROOKE'S%20ACCIDENT/The%20Salt%20Lake%20Tribune%20%7C%20Multimedia:%20Metamorphosis.webarchive.
- Learning to Live Again*: file:///Users/margaretbattin/Documents/BROOKE'S%20ACCIDENT/The%20Salt%20Lake%20Tribune%20%7C%20Multimedia:%20Learning%20to%20live%20again.webarchive.