

Unspeakable Conversations

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Should I Have Been Killed at Birth?

He insists he doesn't want to kill me. He simply thinks it would have been better, all things considered, to have given my parents the option of killing the baby I once was, and to let other parents kill similar babies as they come along and thereby avoid the suffering that comes with lives like mine and satisfy the reasonable preferences of parents for a different kind of child. It has nothing to do with me. I should not feel threatened.

Whenever I try to wrap my head around his tight string of syllogisms, my brain gets so fried it's . . . almost fun. Mercy! It's like "Alice in Wonderland."

It is a chilly Monday in late March, just less than a year ago. I am at Princeton University. My host is Prof. Peter Singer, often called -- and not just by his book publicist -- the most influential philosopher of our time. He is the man who wants me dead. No, that's not at all fair. He wants to legalize the killing of certain babies who might come to be like me if allowed to live. He also says he believes that it should be lawful under some circumstances to kill, at any age, individuals with cognitive impairments so severe that he doesn't consider them "persons." What does it take to be a person? Awareness of your own existence in time. The capacity to harbor preferences as to the future, including the preference for continuing to live.

At this stage of my life, he says, I am a person. However, as an infant, I wasn't. I, like all humans, was born without self-awareness. And eventually, assuming my brain finally gets so fried that I fall into that wonderland where self and other and present and past and future blur into one boundless, formless all or nothing, then I'll lose my personhood and therefore my right to life. Then, he says, my family and doctors might put me out of my misery, or out of my bliss or oblivion, and no one count it murder.

I have agreed to two speaking engagements. In the morning, I talk to 150 undergraduates on selective infanticide. In the evening, it is a convivial discussion, over dinner, of assisted suicide. I am the token cripple with an opposing view.

I had several reasons for accepting Singer's invitation, some grounded in my involvement in the disability rights movement, others entirely personal. For the movement, it seemed an unusual opportunity to experiment with modes of discourse that might work with very tough audiences and bridge the divide between our perceptions and theirs. I didn't expect to straighten out Singer's head, but maybe I could reach a student or two. Among the personal reasons: I was sure it would make a great story, first for telling and then for writing down.

By now I've told it to family and friends and colleagues, over lunches and dinners, on long car trips, in scads of e-mail messages and a couple of formal speeches. But it seems to be a story that just won't settle down. After all these tellings, it still lacks a coherent structure; I'm miles away from a rational argument. I keep getting interrupted by questions -- like these:

Q: Was he totally grossed out by your physical appearance?

A: He gave no sign of it. None whatsoever.

Q: How did he handle having to interact with someone like you?

A: He behaved in every way appropriately, treated me as a respected professional acquaintance and was a gracious and accommodating host.

Q: Was it emotionally difficult for you to take part in a public discussion of whether your life should have happened?

A: It was very difficult. And horribly easy.

Q: Did he get that job at Princeton because they like his ideas on killing disabled babies?

A: It apparently didn't hurt, but he's most famous for animal rights. He's the author of "Animal Liberation."

Q: How can he put so much value on animal life and so little value on human life?

That last question is the only one I avoid. I used to say I don't know; it doesn't make sense. But now I've read some of Singer's writing, and I admit it does make sense -- within the conceptual world of Peter Singer. But I don't want to go there. Or at least not for long.

So I will start from those other questions and see where the story goes this time.

That first question, about my physical appearance, needs some explaining.

It's not that I'm ugly. It's more that most people don't know how to look at me. The sight of me is routinely discomfiting. The power wheelchair is enough to inspire gawking, but that's the least of it. Much more impressive is the impact on my body of more than four decades of a muscle-wasting disease. At this stage of my life, I'm Karen Carpenter thin, flesh mostly vanished, a jumble of bones in a floppy bag of skin. When, in childhood, my muscles got too weak to hold up my spine, I tried a brace for a while, but fortunately a skittish anesthesiologist said no to fusion, plates and pins -- all the apparatus that might have kept me straight. At 15, I threw away the back brace and let my spine reshape itself into a deep twisty S-curve. Now my right side is two deep canyons. To keep myself upright, I lean forward, rest my rib cage on my lap, plant my elbows beside my knees. Since my backbone found its own natural shape, I've been entirely comfortable in my skin.

I am in the first generation to survive to such decrepitude. Because antibiotics were available, we didn't die from the childhood pneumonias that often come with weakened respiratory systems. I guess it is natural enough that most people don't know what to make of us.

Two or three times in my life -- I recall particularly one largely crip, largely lesbian cookout halfway across the continent -- I have been looked at as a rare kind of beauty. There is also the bizarre fact that where I live, Charleston, S.C., some people call me Good Luck Lady: they consider it propitious to cross my path when a hurricane is coming and to kiss my head just before voting day. But most often the reactions are decidedly negative. Strangers on the street are moved to comment:

I admire you for being out; most people would give up.

God bless you! I'll pray for you.

You don't let the pain hold you back, do you?

If I had to live like you, I think I'd kill myself.

I used to try to explain that in fact I enjoy my life, that it's a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people. But

it gets tedious. God didn't put me on this street to provide disability awareness training to the likes of them. In fact, no god put anyone anywhere for any reason, if you want to know.

But they don't want to know. They think they know everything there is to know, just by looking at me.

That's how stereotypes work. They don't know that they're confused, that they're really expressing the discombobulation that comes in my wake.

So. What stands out when I recall first meeting Peter Singer in the spring of 2001 is his apparent immunity to my looks, his apparent lack of discombobulation, his immediate ability to deal with me as a person with a particular point of view.

Then, 2001. Singer has been invited to the College of Charleston, not two blocks from my house. He is to lecture on "Rethinking Life and Death." I have been dispatched by Not Dead Yet, the national organization leading the disability-rights opposition to legalized assisted suicide and disability-based killing. I am to put out a leaflet and do something during the Q. and A.

On arriving almost an hour early to reconnoiter, I find the scene almost entirely peaceful; even the boisterous display of South Carolina spring is muted by gray wisps of Spanish moss and mottled oak bark.

I roll around the corner of the building and am confronted with the unnerving sight of two people I know sitting on a park bench eating veggie pitas with Singer. Sharon is a veteran activist for human rights. Herb is South Carolina's most famous atheist. Good people, I've always thought -- now sharing veggie pitas and conversation with a proponent of genocide. I try to beat a retreat, but Herb and Sharon have seen me. Sharon tosses her trash and comes over. After we exchange the usual courtesies, she asks, "Would you like to meet Professor Singer?"

She doesn't have a clue. She probably likes his book on animal rights. "I'll just talk to him in the Q. and A."

But Herb, with Singer at his side, is fast approaching. They are looking at me, and Herb is talking, no doubt saying nice things about me. He'll be saying that I'm a disability rights lawyer and that I gave a talk against assisted suicide at his secular humanist group a while back. He didn't agree with everything I said, he'll say, but I was brilliant. Singer appears interested, engaged. I sit where I'm parked. Herb makes an introduction. Singer extends his hand.

I hesitate. I shouldn't shake hands with the Evil One. But he is Herb's guest, and I simply can't snub Herb's guest at the college where Herb teaches. Hereabouts, the rule is that if you're not prepared to shoot on sight, you have to be prepared to shake hands. I give Singer the three fingers on my right hand that still work. "Good afternoon, Mr. Singer. I'm here for Not Dead Yet."

I want to think he flinches just a little. Not Dead Yet did everything possible to disrupt his first week at Princeton. I sent a check to the fund for the 14 arrestees, who included comrades in power chairs. But if Singer flinches, he instantly recovers. He answers my questions about the lecture format. When he says he looks forward to an interesting exchange, he seems entirely sincere.

It is an interesting exchange. In the lecture hall that afternoon, Singer lays it all out. The "illogic" of allowing abortion but not infanticide, of allowing withdrawal of life support but not active killing. Applying the basic assumptions of preference utilitarianism, he spins out his bone-chilling argument for letting parents kill disabled babies and replace them with nondisabled babies who have a greater chance at happiness. It is all about allowing as many individuals as possible to fulfill as many of their preferences as possible.

As soon as he's done, I get the microphone and say I'd like to discuss selective infanticide. As a lawyer, I disagree with his jurisprudential assumptions. Logical inconsistency is not a sufficient reason to change the law. As an atheist, I object to his using religious terms ("the doctrine of the sanctity of human life")

to characterize his critics. Singer takes a note pad out of his pocket and jots down my points, apparently eager to take them on, and I proceed to the heart of my argument: that the presence or absence of a disability doesn't predict quality of life. I question his replacement-baby theory, with its assumption of "other things equal," arguing that people are not fungible. I draw out a comparison of myself and my nondisabled brother Mac (the next-born after me), each of us with a combination of gifts and flaws so peculiar that we can't be measured on the same scale.

He responds to each point with clear and lucid counterarguments. He proceeds with the assumption that I am one of the people who might rightly have been killed at birth. He sticks to his guns, conceding just enough to show himself open-minded and flexible. We go back and forth for 10 long minutes. Even as I am horrified by what he says, and by the fact that I have been sucked into a civil discussion of whether I ought to exist, I can't help being dazzled by his verbal facility. He is so respectful, so free of condescension, so focused on the argument, that by the time the show is over, I'm not exactly angry with him. Yes, I am shaking, furious, enraged -- but it's for the big room, 200 of my fellow Charlestonians who have listened with polite interest, when in decency they should have run him out of town on a rail.

My encounter with Peter Singer merits a mention in my annual canned letter that December. I decide to send Singer a copy. In response, he sends me the nicest possible e-mail message. Dear Harriet (if he may) . . . Just back from Australia, where he's from. Agrees with my comments on the world situation. Supports my work against institutionalization. And then some pointed questions to clarify my views on selective infanticide.

I reply. Fine, call me Harriet, and I'll reciprocate in the interest of equality, though I'm accustomed to more formality. Skipping agreeable preambles, I answer his questions on disability-based infanticide and pose some of my own. Answers and more questions come back. Back and forth over several weeks it proceeds, an engaging discussion of baby killing, disability prejudice and related points of law and philosophy. Dear Harriet. Dear Peter.

Singer seems curious to learn how someone who is as good an atheist as he is could disagree with his entirely reasonable views. At the same time, I am trying to plumb his theories. What has him so convinced it would be best to allow parents to kill babies with severe disabilities, and not other kinds of babies, if no infant is a "person" with a right to life? I learn it is partly that both biological and adoptive parents prefer healthy babies. But I have trouble with basing life-and-death decisions on market considerations when the market is structured by prejudice. I offer a hypothetical comparison: "What about mixed-race babies, especially when the combination is entirely nonwhite, who I believe are just about as unadoptable as babies with disabilities?" Wouldn't a law allowing the killing of these undervalued babies validate race prejudice? Singer agrees there is a problem. "It would be horrible," he says, "to see mixed-race babies being killed because they can't be adopted, whereas white ones could be." What's the difference? Preferences based on race are unreasonable. Preferences based on ability are not. Why? To Singer, it's pretty simple: disability makes a person "worse off."

Are we "worse off"? I don't think so. Not in any meaningful sense. There are too many variables. For those of us with congenital conditions, disability shapes all we are. Those disabled later in life adapt. We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own. We have something the world needs.

Pressing me to admit a negative correlation between disability and happiness, Singer presents a situation: imagine a disabled child on the beach, watching the other children play.

It's right out of the telethon. I expected something more sophisticated from a professional thinker. I respond: "As a little girl playing on the beach, I was already aware that some people felt sorry for me, that I wasn't frolicking with the same level of frenzy as other children. This annoyed me, and still does." I take the time to write a detailed description of how I, in fact, had fun playing on the beach, without the need of standing, walking or running. But, really, I've had enough. I suggest to Singer that we have exhausted our topic, and I'll be back in touch when I get around to writing about him.

He responds by inviting me to Princeton. I fire off an immediate maybe.

Of course I'm flattered. Mama will be impressed.

But there are things to consider. Not Dead Yet says -- and I completely agree -- that we should not legitimate Singer's views by giving them a forum. We should not make disabled lives subject to debate. Moreover, any spokesman chosen by the opposition is by definition a token. But even if I'm a token, I won't have to act like one. And anyway, I'm kind of stuck. If I decline, Singer can make some hay: "I offered them a platform, but they refuse rational discussion." It's an old trick, and I've laid myself wide open.

My invitation is to have an exchange of views with Singer during his undergraduate course. He also proposes a second "exchange," open to the whole university, later in the day. This sounds a lot like debating my life -- and on my opponent's turf, with my opponent moderating, to boot. I offer a counterproposal, to which Singer proves amenable. I will open the class with some comments on infanticide and related issues and then let Singer grill me as hard as he likes before we open it up for the students. Later in the day, I might take part in a discussion of some other disability issue in a neutral forum. Singer suggests a faculty-student discussion group sponsored by his department but with cross-departmental membership. The topic I select is "Assisted Suicide, Disability Discrimination and the Illusion of Choice: A Disability Rights Perspective." I inform a few movement colleagues of this turn of events, and advice starts rolling in. I decide to go with the advisers who counsel me to do the gig, lie low and get out of Dodge.

I ask Singer to refer me to the person who arranges travel at Princeton. I imagine some capable and unflappable woman like my sister, Beth, whose varied job description at a North Carolina university includes handling visiting artists. Singer refers me to his own assistant, who certainly seems capable and unflappable enough. However, almost immediately Singer jumps back in via e-mail. It seems the nearest hotel has only one wheelchair-accessible suite, available with two rooms for \$600 per night. What to do? I know I shouldn't be so accommodating, but I say I can make do with an inaccessible room if it has certain features. Other logistical issues come up. We go back and forth. Questions and answers. Do I really need a lift-equipped vehicle at the airport? Can't my assistant assist me into a conventional car? How wide is my wheelchair?

By the time we're done, Singer knows that I am 28 inches wide. I have trouble controlling my wheelchair if my hand gets cold. I am accustomed to driving on rough, irregular surfaces, but I get nervous turning on steep slopes. Even one step is too many. I can swallow purees, soft bread and grapes. I use a bedpan, not a toilet. None of this is a secret; none of it cause for angst. But I do wonder whether Singer is jotting down my specs in his little note pad as evidence of how "bad off" people like me really are.

I realize I must put one more issue on the table: etiquette. I was criticized within the movement when I confessed to shaking Singer's hand in Charleston, and some are appalled that I have agreed to break bread with him in Princeton. I think they have a very good point, but, again, I'm stuck. I'm engaged for a day of discussion, not a picket line. It is not in my power to marginalize Singer at Princeton; nothing would be accomplished by displays of personal disrespect.

However, chumminess is clearly inappropriate. I tell Singer that in the lecture hall it can't be Harriet and Peter; it must be Ms. Johnson and Mr. Singer.

He seems genuinely nettled. Shouldn't it be Ms. Johnson and Professor Singer, if I want to be formal? To counter, I invoke the ceremonial low-country usage, Attorney Johnson and Professor Singer, but point out that Mr./Ms. is the custom in American political debates and might seem more normal in New Jersey. All right, he says. Ms./Mr. it will be.

I describe this awkward social situation to the lawyer in my office who has served as my default lunch partner for the past 14 years. He gives forth a full-body shudder.

"That poor, sorry son of a bitch! He has no idea what he's in for."

Being a disability rights lawyer lecturing at Princeton does confer some cachet at the Newark airport. I

need all the cachet I can get. Delta Airlines has torn up my power chair. It is a fairly frequent occurrence for any air traveler on wheels.

When they inform me of the damage in Atlanta, I throw a monumental fit and tell them to have a repair person meet me in Newark with new batteries to replace the ones inexplicably destroyed. Then I am told no new batteries can be had until the morning. It's Sunday night. On arrival in Newark, I'm told of a plan to put me up there for the night and get me repaired and driven to Princeton by 10 a.m.

"That won't work. I'm lecturing at 10. I need to get there tonight, go to sleep and be in my right mind tomorrow."

"What? You're lecturing? They told us it was a conference. We need to get you fixed tonight!"

Carla, the gate agent, relieves me of the need to throw any further fits by undertaking on my behalf the fit of all fits.

Carmen, the personal assistant with whom I'm traveling, pushes me in my disabled chair around the airport in search of a place to use the bedpan.

However, instead of diaper-changing tables, which are functional though far from private, we find a flip-down plastic shelf that doesn't look like it would hold my 70 pounds of body weight. It's no big deal; I've restricted my fluids. But Carmen is a little freaked. It is her first adventure in power-chair air travel. I thought I prepared her for the trip, but I guess I neglected to warn her about the probability of wheelchair destruction. I keep forgetting that even people who know me well don't know much about my world.

We reach the hotel at 10:15 p.m., four hours late.

I wake up tired. I slept better than I would have slept in Newark with an unrepaired chair, but any hotel bed is a near guarantee of morning crankiness. I tell Carmen to leave the TV off. I don't want to hear the temperature.

I do the morning stretch. Medical people call it passive movement, but it's not really passive. Carmen's hands move my limbs, following my precise instructions, her strength giving effect to my will. Carmen knows the routine, so it is in near silence that we begin easing slowly into the day. I let myself be propped up to eat oatmeal and drink tea. Then there's the bedpan and then bathing and dressing, still in bed. As the caffeine kicks in, silence gives way to conversation about practical things. Carmen lifts me into my chair and straps a rolled towel under my ribs for comfort and stability. She tugs at my clothes to remove wrinkles that could cause pressure sores. She switches on my motors and gives me the means of moving without anyone's help. They don't call it a power chair for nothing.

I drive to the mirror. I do my hair in one long braid. Even this primal hairdo requires, at this stage of my life, joint effort. I undo yesterday's braid, fix the part and comb the hair in front. Carmen combs where I can't reach. I divide the mass into three long hanks and start the braid just behind my left ear. Section by section, I hand it over to her, and her unimpaired young fingers pull tight, crisscross, until the braid is fully formed.

A big polyester scarf completes my costume. Carmen lays it over my back. I tie it the way I want it, but Carmen starts fussing with it, trying to tuck it down in the back. I tell her that it's fine, and she stops.

On top of the scarf, she wraps the two big shawls that I hope will substitute for an overcoat. I don't own any real winter clothes. I just stay out of the cold, such cold as we get in Charleston.

We review her instructions for the day. Keep me in view and earshot. Be instantly available but not intrusive. Be polite, but don't answer any questions about me. I am glad that she has agreed to come. She's strong, smart, adaptable and very loyal. But now she is digging under the shawls, fussing with that scarf again.

"Carmen. What are you doing?"

"I thought I could hide this furry thing you sit on."

"Leave it. Singer knows lots of people eat meat. Now he'll know some crips sit on sheepskin."

The walk is cold but mercifully short. The hotel is just across the street from Princeton's wrought-iron gate and a few short blocks from the building where Singer's assistant shows us to the elevator. The elevator doubles as the janitor's closet -- the cart with the big trash can and all the accouterments is rolled aside so I can get in. Evidently there aren't a lot of wheelchair people using this building.

We ride the broom closet down to the basement and are led down a long passageway to a big lecture hall. As the students drift in, I engage in light badinage with the sound technician. He is squeamish about touching me, but I insist that the cordless lavalier is my mike of choice. I invite him to clip it to the big polyester scarf.

The students enter from the rear door, way up at ground level, and walk down stairs to their seats. I feel like an animal in the zoo. I hadn't reckoned on the architecture, those tiers of steps that separate me from a human wall of apparent physical and mental perfection, that keep me confined down here in my pit.

It is 5 before 10. Singer is loping down the stairs. I feel like signaling to Carmen to open the door, summon the broom closet and get me out of here. But Singer greets me pleasantly and hands me Princeton's check for \$500, the fee he offered with apologies for its inadequacy.

So. On with the show.

My talk to the students is pretty Southern. I've decided to pound them with heart, hammer them with narrative and say "y'all" and "folks." I play with the emotional tone, giving them little peaks and valleys, modulating three times in one 45-second patch. I talk about justice. Even beauty and love. I figure they haven't been getting much of that from Singer.

Of course, I give them some argument too. I mean to honor my contractual obligations. I lead with the hypothetical about mixed-race, nonwhite babies and build the ending around the question of who should have the burden of proof as to the quality of disabled lives. And woven throughout the talk is the presentation of myself as a representative of a minority group that has been rendered invisible by prejudice and oppression, a participant in a discussion that would not occur in a just world.

I let it go a little longer than I should. Their faces show they're going where I'm leading, and I don't look forward to letting them go. But the clock on the wall reminds me of promises I mean to keep, and I stop talking and submit myself to examination and inquiry.

Singer's response is surprisingly soft. Maybe after hearing that this discussion is insulting and painful to me, he doesn't want to exacerbate my discomfort. His reframing of the issues is almost pro forma, abstract, entirely impersonal. Likewise, the students' inquiries are abstract and fairly predictable: anencephaly, permanent unconsciousness, eugenic abortion. I respond to some of them with stories, but mostly I give answers I could have e-mailed in.

I call on a young man near the top of the room.

"Do you eat meat?"

"Yes, I do."

"Then how do you justify--"

"I haven't made any study of animal rights, so anything I could say on the subject wouldn't be worth everyone's time."

The next student wants to work the comparison of disability and race, and Singer joins the discussion until he elicits a comment from me that he can characterize as racist. He scores a point, but that's all right. I've never claimed to be free of prejudice, just struggling with it.

Singer proposes taking me on a walk around campus, unless I think it would be too cold. What the hell? "It's probably warmed up some. Let's go out and see how I do."

He doesn't know how to get out of the building without using the stairs, so this time it is my assistant leading the way. Carmen has learned of another elevator, which arrives empty. When we get out of the building, she falls behind a couple of paces, like a respectful chaperone.

In the classroom there was a question about keeping alive the unconscious. In response, I told a story about a family I knew as a child, which took loving care of a nonresponsive teenage girl, acting out their unconditional commitment to each other, making all the other children, and me as their visitor, feel safe. This doesn't satisfy Singer. "Let's assume we can prove, absolutely, that the individual is totally unconscious and that we can know, absolutely, that the individual will never regain consciousness."

I see no need to state an objection, with no stenographer present to record it; I'll play the game and let him continue.

"Assuming all that," he says, "don't you think continuing to take care of that individual would be a bit -- weird?"

"No. Done right, it could be profoundly beautiful."

"But what about the caregiver, a woman typically, who is forced to provide all this service to a family member, unable to work, unable to have a life of her own?"

"That's not the way it should be. Not the way it has to be. As a society, we should pay workers to provide that care, in the home. In some places, it's been done that way for years. That woman shouldn't be forced to do it, any more than my family should be forced to do my care."

Singer takes me around the architectural smorgasbord that is Princeton University by a route that includes not one step, unramped curb or turn on a slope. Within the strange limits of this strange assignment, it seems Singer is doing all he can to make me comfortable.

He asks what I thought of the students' questions.

"They were fine, about what I expected. I was a little surprised by the question about meat eating."

"I apologize for that. That was out of left field. But -- I think what he wanted to know is how you can have such high respect for human life and so little respect for animal life."

"People have lately been asking me the converse, how you can have so much respect for animal life and so little respect for human life."

"And what do you answer?"

"I say I don't know. It doesn't make a lot of sense to me."

"Well, in my view--"

"Look. I have lived in blissful ignorance all these years, and I'm not prepared to give that up today."

"Fair enough," he says and proceeds to recount bits of Princeton history. He stops. "This will be of particular interest to you, I think. This is where your colleagues with Not Dead Yet set up their blockade." I'm grateful for the reminder. My brothers and sisters were here before me and behaved far more appropriately than I am doing.

A van delivers Carmen and me early for the evening forum. Singer says he hopes I had a pleasant afternoon.

Yes, indeed. I report a pleasant lunch and a very pleasant nap, and I tell him about the Christopher Reeve Suite in the hotel, which has been remodeled to accommodate Reeve, who has family in the area.

"Do you suppose that's the \$600 accessible suite they told me about?"

"Without doubt. And if I'd known it was the Christopher Reeve Suite, I would have held out for it."

"Of course you would have!" Singer laughs. "And we'd have had no choice, would we?"

We talk about the disability rights critique of Reeve and various other topics. Singer is easy to talk to, good company. Too bad he sees lives like mine as avoidable mistakes.

I'm looking forward to the soft vegetarian meal that has been arranged; I'm hungry. Assisted suicide, as difficult as it is, doesn't cause the kind of agony I felt discussing disability-based infanticide. In this one, I understand, and to some degree can sympathize with, the opposing point of view -- misguided though it is.

My opening sticks to the five-minute time limit. I introduce the issue as framed by academic articles Not Dead Yet recommended for my use. Andrew Batavia argues for assisted suicide based on autonomy, a principle generally held high in the disability rights movement. In general, he says, the movement fights for our right to control our own lives; when we need assistance to effect our choices, assistance should be available to us as a matter of right. If the choice is to end our lives, he says, we should have assistance then as well. But Carol Gill says that it is differential treatment -- disability discrimination -- to try to prevent most suicides while facilitating the suicides of ill and disabled people. The social-science literature suggests that the public in general, and physicians in particular, tend to underestimate the quality of life of disabled people, compared with our own assessments of our lives. The case for assisted suicide rests on stereotypes that our lives are inherently so bad that it is entirely rational if we want to die.

I side with Gill. What worries me most about the proposals for legalized assisted suicide is their veneer of beneficence -- the medical determination that, for a given individual, suicide is reasonable or right. It is not about autonomy but about nondisabled people telling us what's good for us.

In the discussion that follows, I argue that choice is illusory in a context of pervasive inequality. Choices are structured by oppression. We shouldn't offer assistance with suicide until we all have the assistance we need to get out of bed in the morning and live a good life. Common causes of suicidality -- dependence, institutional confinement, being a burden -- are entirely curable. Singer, seated on my right, participates in the discussion but doesn't dominate it. During the meal, I occasionally ask him to put things within my reach, and he competently complies.

I feel as if I'm getting to a few of them, when a student asks me a question. The words are all familiar, but they're strung together in a way so meaningless that I can't even retain them -- it's like a long sentence in Tagalog. I can only admit my limitations. "That question's too abstract for me to deal with. Can you rephrase it?" He indicates that it is as clear as he can make it, so I move on.

A little while later, my right elbow slips out from under me. This is awkward. Normally I get whoever is

on my right to do this sort of thing. Why not now? I gesture to Singer. He leans over, and I whisper, "Grasp this wrist and pull forward one inch, without lifting." He follows my instructions to the letter. He sees that now I can again reach my food with my fork. And he may now understand what I was saying a minute ago, that most of the assistance disabled people need does not demand medical training.

A philosophy professor says, "It appears that your objections to assisted suicide are essentially tactical."

"Excuse me?"

"By that I mean they are grounded in current conditions of political, social and economic inequality. What if we assume that such conditions do not exist?"

"Why would we want to do that?"

"I want to get to the real basis for the position you take."

I feel as if I'm losing caste. It is suddenly very clear that I'm not a philosopher. I'm like one of those old practitioners who used to visit my law school, full of bluster about life in the real world. Such a bore! A once-sharp mind gone muddy! And I'm only 44 -- not all that old.

The forum is ended, and I've been able to eat very little of my pureed food. I ask Carmen to find the caterer and get me a container. Singer jumps up to take care of it. He returns with a box and obligingly packs my food to go.

When I get home, people are clamoring for the story. The lawyers want the blow-by-blow of my forensic triumph over the formidable foe; when I tell them it wasn't like that, they insist that it was. Within the disability rights community, there is less confidence. It is generally assumed that I handled the substantive discussion well, but people worry that my civility may have given Singer a new kind of legitimacy. I hear from Laura, a beloved movement sister. She is appalled that I let Singer provide even minor physical assistance at the dinner. "Where was your assistant?" she wants to know. How could I put myself in a relationship with Singer that made him appear so human, even kind?

I struggle to explain. I didn't feel disempowered; quite the contrary, it seemed a good thing to make him do some useful work. And then, the hard part: I've come to believe that Singer actually is human; even kind in his way. There ensues a discussion of good and evil and personal assistance and power and philosophy and tactics for which I'm profoundly grateful.

I e-mail Laura again. This time I inform her that I've changed my will. She will inherit a book that Singer gave me, a collection of his writings with a weirdly appropriate inscription: "To Harriet Johnson, So that you will have a better answer to questions about animals. And thanks for coming to Princeton. Peter Singer. March 25, 2002." She responds that she is changing her will, too. I'll get the autographed photo of Jerry Lewis she received as an M.D.A. poster child. We joke that each of us has given the other a "reason to live."

I have had a nice e-mail message from Singer, hoping Carmen and I and the chair got home without injury, relaying positive feedback from my audiences -- and taking me to task for a statement that isn't supported by a relevant legal authority, which he looked up. I report that we got home exhausted but unharmed and concede that he has caught me in a generalization that should have been qualified. It's clear that the conversation will continue.

I am soon sucked into the daily demands of law practice, family, community and politics. In the closing days of the state legislative session, I help get a bill passed that I hope will move us one small step toward a world in which killing won't be such an appealing solution to the "problem" of disability. It is good to focus on this kind of work.

But the conversations with and about Singer continue. Unable to muster the appropriate moral

judgments, I ask myself a tough question: am I in fact a silly little lady whose head is easily turned by a man who gives her a kind of attention she enjoys? I hope not, but I confess that I've never been able to sustain righteous anger for more than about 30 minutes at a time. My view of life tends more toward tragedy.

The tragic view comes closest to describing how I now look at Peter Singer. He is a man of unusual gifts, reaching for the heights. He writes that he is trying to create a system of ethics derived from fact and reason, that largely throws off the perspectives of religion, place, family, tribe, community and maybe even species -- to "take the point of view of the universe." His is a grand, heroic undertaking.

But like the protagonist in a classical drama, Singer has his flaw. It is his unexamined assumption that disabled people are inherently "worse off," that we "suffer," that we have lesser "prospects of a happy life." Because of this all-too-common prejudice, and his rare courage in taking it to its logical conclusion, catastrophe looms. Here in the midpoint of the play, I can't look at him without fellow-feeling.

I am regularly confronted by people who tell me that Singer doesn't deserve my human sympathy. I should make him an object of implacable wrath, to be cut off, silenced, destroyed absolutely. And I find myself lacking a logical argument to the contrary.

I am talking to my sister Beth on the phone. "You

kind of like the monster, don't you?" she says.

I find myself unable to evade, certainly unwilling to lie. "Yeah, in a way. And he's not exactly a monster."

"You know, Harriet, there were some very pleasant Nazis. They say the SS guards went home and played on the floor with their children every night."

She can tell that I'm chastened; she changes the topic, lets me off the hook. Her harshness has come as a surprise. She isn't inclined to moralizing; in our family, I'm the one who sets people straight.

When I put the phone down, my argumentative nature feels frustrated. In my mind, I replay the conversation, but this time defend my position.

"He's not exactly a monster. He just has some strange ways of looking at things."

"He's advocating genocide."

"That's the thing. In his mind, he isn't. He's only giving parents a choice. He thinks the humans he is talking about aren't people, aren't 'persons.'"

"But that's the way it always works, isn't it? They're always animals or vermin or chattel goods. Objects, not persons. He's repackaging some old ideas. Making them acceptable."

"I think his ideas are new, in a way. It's not old-fashioned hate. It's a twisted, misinformed, warped kind of beneficence. His motive is to do good."

"What do you care about motives?" she asks.

"Doesn't this beneficent killing make disabled brothers and sisters just as dead?"

"But he isn't killing anyone. It's just talk."

"Just talk? It's talk with an agenda, talk aimed at forming policy. Talk that's getting a receptive audience. You of all people know the power of that kind of talk."

"Well, sure, but--"

"If talk didn't matter, would you make it your life's work?"

"But," I say, "his talk won't matter in the end. He won't succeed in reinventing morality. He stirs the pot, brings things out into the open. But ultimately we'll make a world that's fit to live in, a society that has room for all its flawed creatures. History will remember Singer as a curious example of the bizarre things that can happen when paradigms collide."

"What if you're wrong? What if he convinces people that there's no morally significant difference between a fetus and a newborn, and just as disabled fetuses are routinely aborted now, so disabled babies are routinely killed? Might some future generation take it further than Singer wants to go? Might some say there's no morally significant line between a newborn and a 3-year-old?"

"Sure. Singer concedes that a bright line cannot be drawn. But he doesn't propose killing anyone who prefers to live."

"That overarching respect for the individual's preference for life -might some say it's a fiction, a fetish, a quasi-religious belief?"

"Yes," I say. "That's pretty close to what I think. As an atheist, I think all preferences are moot once you kill someone. The injury is entirely to the surviving community."

"So what if that view wins out, but you can't break disability prejudice? What if you wind up in a world where the disabled person's 'irrational' preference to live must yield to society's 'rational' interest in reducing the incidence of disability? Doesn't horror kick in somewhere? Maybe as you watch the door close behind whoever has wheeled you into the gas chamber?"

"That's not going to happen."

"Do you have empirical evidence?" she asks. "A logical argument?"

"Of course not. And I know it's happened before, in what was considered the most progressive medical community in the world. But it won't happen. I have to believe that."

Belief. Is that what it comes down to? Am I a person of faith after all? Or am I clinging to foolish hope that the tragic protagonist, this one time, will shift course before it's too late?

I don't think so. It's less about belief, less about hope, than about a practical need for definitions I can live with.

If I define Singer's kind of disability prejudice as an ultimate evil, and him as a monster, then I must so define all who believe disabled lives are inherently worse off or that a life without a certain kind of consciousness lacks value. That definition would make monsters of many of the people with whom I move on the sidewalks, do business, break bread, swap stories and share the grunt work of local politics. It would reach some of my family and most of my nondisabled friends, people who show me personal kindness and who sometimes manage to love me through their ignorance. I can't live with a definition of ultimate evil that encompasses all of them. I can't refuse the monster-majority basic respect and human sympathy. It's not in my heart to deny every single one of them, categorically, my affection and my love.

The peculiar drama of my life has placed me in a world that by and large thinks it would be better if people like me did not exist. My fight has been for accommodation, the world to me and me to the

world.

As a disability pariah, I must struggle for a place, for kinship, for community, for connection.

Because I am still seeking acceptance of my humanity, Singer's call to get past species seems a luxury way beyond my reach. My goal isn't to shed the perspective that comes from my particular experience, but to give voice to it. I want to be engaged in the tribal fury that rages when opposing perspectives are let loose.

As a shield from the terrible purity of Singer's vision, I'll look to the corruption that comes from interconnectedness. To justify my hopes that Singer's theoretical world -- and its entirely logical extensions -- won't become real, I'll invoke the muck and mess and undeniable reality of disabled lives well lived. That's the best I can do.

Utilitarian Philosophers :: Peter Singer :: 'Unspeakable Conversations', by Harriet McBryde Johnson
