2016-2017 Georgia State University Law Review Symposium: Exploring the Right To Die In The U.S.

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Recommended Citation
Available at: https://readingroom.law.gsu.edu/gsulr/vol33/iss4/4

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MB: Thanks for listening. That’s my personal introduction to these end-of-life issues and actually as you see from this I’ve been thinking about these things for a long time beforehand. . . . And so I’m happy to answer questions about this. Anything you’d like to ask is just fine. I think you all see that legal point that it makes. Namely, this is just as far as you can go. It’s right on the edge of what’s legally permissible in most still most of this country. And it also makes the case for something stronger. Namely, legal aid in dying. So now, about one in five people in this country is covered by laws that statutes that permit direct aid in dying and I think you can see from this account . . . actually you can’t see the clinical aspects of it very much in this account, but that might have been easier, given this person’s choice. So I’m going to talk about something else, but before that are there any questions that need answering right away about this? Is there a question over here?

Audience: You showed a picture you said was taken immediately after [inaudible] with a physician who said he would in fact assist. How long between that conversation and when he chose to pass?

MB: Well there’s a, there’s a little more story this was required by TedMed to be collapsed into fifteen minutes. We got an extra five out of it but, uh, so the actual full story is that he had written a letter, uh, a year in advance. So he lived almost five years, uh, after the accident. And about a year before his actual death, he had written a letter, uh, in which he, um, that was addressed to, um, anybody, saying, uh, “I wish to make this choice to have my ventilator
discontinued. I don’t want any rescue efforts.” Uh, he had it signed by, by then he was living at home. He had a staff of—count them—twelve home care folks. The, uh, the legal intention was to protect any of those people if [he] should happen to die on their watch. He also had it to sign... signed by every single family member, including the physician family member and also his spinal cord physician. And they all signed this. They all recognized a year in advance that he was, um, thinking about, reflecting on, this choice. Then, when it got to the point where he said to himself, “it really is time,” he made an appointment with his regular spinal cord physician, who had been treating him for four-and-a-half years by then. More than four, almost five years. He went to see him. This doctor spent almost three hours with him—in an era of fifteen-minute clinic visits, almost three hours—to make sure that that was some of the time together with the rest of, the whole rest of the family, the children, myself, some of his care givers, we all went together. He spent time alone with Brooke, the physician did, and also with the family to make sure that the choice was genuine. Of course he’d signed this letter a year before, so he knew that this wasn’t a sudden thing. And then he said, after the three hours, he said, “Let me think about it. I’ll let you know in the morning.” Because this was now a formal request to have his ventilator removed. So I don’t know what—and in the morning he said, “I will refer you to hospice.” So I don’t know what went on between the time we left the clinic visit and the next morning. Did he consult with the ethics committee? Did he call up hospital risk management? Did he call the vice president? Because Brooke was a pretty conspicuous person around campus, he was a well-known and much-beloved professor there, and this had been widely reported in papers and in the New York Times and stuff like that, and so wasn’t just any old person in the view of anybody who was concerned about publicity. So, I don’t know what went on during that period, but in the morning he said, “I will refer you to hospice.” That hospice, um, doctor came and, it was actually the next morning, there was, um, papers signing the night before, and the

1. Referring to her husband
hospice doctor said, “I will help you,” that’s when our daughter snapped that photograph and she interviewed him also at considerable length and in private, so, um, and then she said, um, “would you like to set a date?” And he said “today.” Which was, in a way, devastating. As I—as I confess I was the main foot-dragger, this is pretty common in families, isn’t it? It was amazing for somebody who advocated, um, greater attention to aid in dying, to find yourself in the role of the one whose—but anyway, that’s what—she said “very well,” she went, um, she said “well, in that case we need to get some more medication,” so it was about noon then, she said “we’ll be back”—she and the hospice nurse, the doctor and the nurse, said “we’ll be back around three o’clock, um, we have to go out and get more medication.” And he said, we’d had this—dis—we’d done everything over all this time. We’d made wills, we’d bought a—we’d bought cemetery plots that he picked out himself, we lived right close to the cemetery, he could go around in his motorized wheelchair, and “shop around,” so to speak, and um, he’d picked out a location, we’d taken care of that long before and he said, “you know there’s one thing we haven’t done, we never picked a headstone.” So he had—this is he had chosen burial and all that stuff. Now, it so happens we live about a block and a half from a little tiny monument company that’s right near this—um, it’s right in the middle of Salt Lake, but there it is—so he sails out the door, in his motorized wheelchair, right, together with his family members, who were all around, friends, right, uh, a couple of his respiratory therapists, because we had to have respiratory therapy on—or trained respiratory care on deck all the time, sails out down the street to this place, goes shopping for a headstone. Alright, this later got dubbed the uh “Hopkins Liberation March.” But, um, ‘course he was completely paralyzed so he couldn’t point, but he’d say, “uh well there’s one right there that,” he’d say, “that one, the third one over in the second row,” and so, I went inside to the little house to, you know make the arrangements, and I got this message from Alison, saying, “come out here. He sees one he likes better.” So I came out, and sure enough it was better. Fourth one over to the right, he was completely alert,
right, completely confident, but nonfunctional from here down. Or virtually nonfunctional. And by the time we got back up the hill, right, the, uh, hospice physician and the hospice nurse had returned, they, um, started an IV, they—she confirmed again that that was his wish, and again that he wanted this now, and um, you heard the rest of the story. So this is not easy, but just the same you have to recognize how earnestly you have to take someone’s well-considered wish.

Audience: You mentioned that, you yourself in this situation were the foot-dragger. Contrary to—(inaudible).

MB: Turns out I’m a human being, and not just (laughter)

Audience: I perfectly understandable, I just, um, has the whole situation affected your long-term views on this topic? Has it developed them in a way that you wouldn’t have expected they would be? Or, have you pretty much stayed consistent to how you felt before?

MB: That’s a great question, because I had been, um, a defender of aid-in dying legalization and social acceptance, and I’d spent my entire academic career working on this issue and others as well, but always I’d spent long periods in the, um—or many trips to the Netherlands to see what was going on there. I’d written wheelbarrows full of stuff about end of life stuff. Did it change my view? It got, actually, it got recorded by some people because I wrote a little piece called the, um, *The Irony of Supporting Aid-in Dying*. Some uh (inaudible) but what it did was not change my view, but make me realize how complicated, how extremely difficult, how, um, complex and multi-textured and enormously hard a decision like this is. It’s often portrayed as something that “oh well we have to have a lot of protections because somebody might decide on the spot that, you know, this . . . ” But, that isn’t the picture at all, at least not in
this case. So it didn’t change my view, but it made it, I think more, um, alert to the, um, complexities, of this case. Anybody else?

Audience: (inaudible) [I]n terms of the path that he took. That he had to have a long consultation with the spinal doctor, and he thought it over before making a referral to the hospice. And, um I know you’re not inside the spinal doctor’s head . . .

MB: Well, we knew the spinal doctor pretty well by then.

Audience: . . . But um, but I’m just sort of wondering why, why, um Brooke couldn’t just say I want to shift to hospice care and somebody moves him to hospice care. I, I don’t understand why there had to be . . .

MB: We, we

Audience: All that contemplation worrying about the referral to hospice.

MB: Well he, the, the spinal, so the spinal cord doc was his official doc of record. Uh, and you have to be referred to hospice right, you can’t just sort of come in the door to hospice and say, “here I am, I’d, I’d like, you know, help dying.”

Audience: But why not?

MB: Why not? Well it’s a, I don’t know the full details of why not, but I assume that one of them is that the, um, spinal cord physician’s privileges are in-patient. I mean, that’s where he would, where he would be referred to. So, if he wanted, um, to discontinue a ventilator, right, the, and, and in fact that’s where it’s mostly done. The, um, hospice physician, by this time he was at home, right, uh the hospice physician who actually did assist him, did do the removal, um, said, “I’ve never done this in a home setting before. I
do it all the time in an in-patient setting, but”—and it was actually quite difficult for her because of course you don’t have all that extra equipment, and, um, there were some uh, somewhat difficult surprises. She had prepared for it pretty thoroughly, but there’s still things you can’t anticipate, even though there’s one hospice physician, one hospice nurse, and two respiratory therapists, all on duty for this. He wanted to die at home. He didn’t want to be in a hospital. Being in a hospital was enormously difficult, and probably doubly-difficult because of course he was incapable of movement, of self-movement, right, um, and things always happen on somebody else’s schedule. He wanted to be at home with his family, right? With his friends. So that required, um, technical referral to hospice which could do this at home. That’s why.

Audience: I recognize that the nurse who, who happened to be behind him on a bicycle accident, wouldn’t have known whether or not he had any wishes in place or any other advanced directive, corrective or otherwise, but did this go with his preference or against them?

MB: This is a great question, the answer is it went against them. So, he had no identification on him, just had his, you know, biking clothes, and we went biking all the time—nobody ever thought at all about this sort of thing. Um, she, she had the kind of training that could tell her immediately what his injury was. He wasn’t breathing. When, but she, this is a very heavily-visited recreational canyon, it’s right in the middle of, um, Salt Lake City. Uh, and there are lots of, and it’s near all these hospitals, and so there are lots of medical personnel as well as everybody else jogging, biking, and walking. And it was just coincidence, um, so she knew what was in store for him, you can’t be sure, because with a spinal cord, there often is a, uh, period called spinal, spinal storm. With spinal cord injury there’s a spinal storm period in which you can’t be sure that, um, how severe the damage is, but she was pretty sure, and of course right. She, um, when she, it took us about four months to figure out who she was.
Because I wasn’t there, and incidentally, I would have been the decision maker had I been there. We had advance directives and living will and the whole package. That said, “no tubes, no machines, no this and that.” Um, would I have said, “don’t do anything?” Because that was her question. She, she was wearing jogging clothes, she wasn’t on duty, she could have kept right on going and nobody would have known the difference. Alright. When we finally met her four months later, she was so relieved to discover that he was glad he’d been rescued. Because, that had been on her mind a lot. It took us four months to find her. Um, Later, you know, we had lots of contact with her later on. There developed quite a bond between them, it was nice. But, if there’s nothing else, we might think about a couple of other issues. So, this is a transition from the personal to the speculative. You might say. So I have a few slides to show you about, as we said as we talked before, um this is I think constitutes an argument in favor of more direct aid in dying so you don’t need the charade of discontinuing the ventilator. Ah, and indeed, the actual medical procedure involving the very heavy doses of drugs for controlling stuff, the deliberate discontinuation of the ventilator, the uh, of all the other stuff, right? The turning off of the, by then he had a uh, a uh respiratory pacer, um, that had to be turned off too, right, and, uh, then the ventilator dialed down. But that all looks pretty deliberate. That looks pretty direct. That doesn’t look, it doesn’t feel like, allowing to die. It feels like, even though legally it isn’t, it feels like causing to die. And that’s a dilemma for many patients who make these end of life decisions of all sorts. And, they feel as if they’ve caused the death, even though that’s not the legal construction.

Audience: It’s very common and actually (inaudible) Is healthcare providers . . . as sort of . . . and logic it out. (inaudible)

MB: I know that this, uh, hospice physician asked if we wanted the chaplain, the hospice chaplain, to come in, and Brooke had declined that and so we said, “no.” It turned out that she had called the
chaplain herself, contrary to our consent, but for herself, and not for the patient, and when I left, after he died, I, what can you do? Right then there’s . . . I went swimming, just as a way of, where as I drove out of the driveway I saw her sitting on the curb outside with the chaplain. She was crying. This is not easy. Even though, she, I had, lots of contact with her later on, she was convinced that this was the right thing to do, but not easy. So um. Yeah?

Audience: So in one sense, this is a very big imposition on the medical personnel who take these actions that end with the persons death, on the other hand, you know, from a policy perspective as a society we seem to value agency, personal agency, autonomy, and at this point your husband is incapable physically of doing anything for himself, so the only way . . .

MB: As he’d been for five years.

Audience: . . . the only way any of his will can be exercised is through other people acting for him, and I just think that’s so tough, there is not a real clean answer.

MB: I hope everybody heard this cause this is a genuinely important point, the fact that he had, sometimes it’s just causally said, “we don’t need that aid in dying,” or “just go jump off a building,” or, you know, “everyone has guns, just go get one of those.” But, the fact of complete physical incapacity, to have any decision of his effectuated he had to get somebody else to do it. Right? Everything. Feeding, eating, cleaning, toileting, everything. So, um, not that people weren’t perfectly willing to help him and dedicated to helping him, but . . .

Audience: Helping with this last thing is the hardest.

MB: Helping with this last thing. Well the hospice physician of course had um, removed, or discontinued ventilators for many people. She had been a hospice director for, I think over a decade.
So, that part wasn’t, uh, difficult, but it was, um, almost always people, um, already no longer competent. Um, Identified as futile care, all that. And of course this is a different case. This is, um, still completely competent and alert, and uh, human being, who could live presumably for a longer time. So, shall we see these slides for a minute. This is just, yeah, ok, so this is just to change direction here a little bit. So. We’ve tried to make, and jointly we’ve made the case a little bit for, um, aid in dying, at least that’s the part of the case that I think is made here, and as you see, I think it is, at least adds . . . I think the picture looks as though this will creep across the country. Already legal in um, as I said, at least one in five, for at least one in five people in this country, for all of Canada, for a good handful of countries in Europe, and an issue everywhere in the developed world. Because we’re the ones with the long downhill slopes. So it seems to me we ought to look at the enemies. The announced enemies. Alright, and I think there are three of them that we can take a look at: the disabilities rights movement, the suicide prevention folks, and some religious groups. Uh, you saw this picture earlier, this is the same picture, the same famous slide from Joanne Lynn, about the ways we die. Um, these are the downhill trajectories, but the point is this is, these are the ways almost all of us will die. A few of us will be hit by buses and die instantaneously and without warning, but this is the much more common picture. So, with all these three groups, we ought to take a look at what it is, why they are objecting to active aid-in dying, uh, and whether they could actually contribute anything to this movement, even if they certainly don’t have that in mind. So, take the disability rights group, this is Not Dead Yet, the most vocal of them. Uh, and here is the thing that they are, I think are, trading on in a way. This is the concern for the slippery slope and possibility of abuse. This is, the um, all of the medical societies, the American Medical Association, the Canadian Medical Association, the British Medical Association, the New York State Task Force on Life, Death and the Law, and virtually all other professional organizations that spoke to this issue. Issued statements like this, and the claim was, “if we allow active aid in dying this will focus, the impact will be worst
on, um, on people in various groups of vulnerability. So the sick, the elderly, the poor, ethnic minorities, right, the disabled, the incompetent, uh, and the list was a little different for all of them, but this was what they are concerned with. And the notion that disabled lives are less worth living. Right? That is the thing that is there. That perceptions of people who are, have disabilities, are that are painful, that they are burdensome to others, they’re expensive, right? And certainly these perceptions are realistic, right? There is inadequate access to healthcare for many people with disabilities. Um, inadequate access and enormous difficulties, in terms of mobility, and things like transportation, to getting inadequate social and income supports, environmental limits and constraints, all of that is real. And even if we have made some progress thanks to the ADA and improving these circumstances, it is still real. And now there’s no evidence in the U.S., Canada, or Europe of increased rates of impact of legal aid in dying on people with disabilities, but that doesn’t change the perception. The fear is, if we make this generally legal, this is what we’ll get. Rather, I sort of like to trace this back to something that was expressed. I’ve tried hard to find the original expression of this, this is, um, a phrase from early feminist literature: “It’s hard to fight an enemy who has outposts in your head.” It’s hard to fight an enemy who has outposts in your head. And so the, um, conclusion drawn from this, the assumption is that people with disabilities will be more easily lead into seeking assisted dying because they have internalized these perceptions of lesser worth, um greater burdensomeness, um, um, and so forth. So I think they are actually right about the enemy having outposts in your head, but what we ordinarily call this is social programming. We are all subject to social programming all the time and outposts in your head is a, but here’s what we need to recognize–patients who are dying are already subject to social programming. Until very recently, this social programming has been to continue on as long as possible, right, to the very end of your disease, this is what we say, “keep on fighting,” “you’re such a hero,” right, “do it for us,” right, and here’s what you get, right, you see this slide, this . . . this, this is fuzzed out, the face
here, for, um HIPPA reasons, but actually I take it to be a way of visualizing the optundation, the um compromise of um cognitive function that goes with heavy medication. That’s what’s in store for us, not in every case, not always, but not uh as I think has been pointed out, not infrequently. So we’re socially programmed this way but, um. Now take suicide prevention. So, uh, there’s a little disclosure here, I’ve been a member of the Association, of, um the American Association of Suicidology for my entire academic career. Uh these are the suicide prevention people, alright, uh, and uh I think it’s correct that suicide prevention is in a sense everyone’s business. There’s an issue about what counts as suicide, but I think there are other more complex issues. So here is a little map that the, this Association and other organizations like it do some very um important work in tracking suicide rates ah, for instance, uh and in providing um suicide prevention practices and there, there are many, many different schools of suicide prevention therapy umm uh but they all have the same core. The, the, umm belief that, view uh, that suicide is a tragedy. And that it is a tragedy not only for the person, but for the family for whom the effects of the suicide can be long-lasting and be lifelong, alright, and indeed for the society as a whole. It’s a tragedy. This is the goal. This is the official goal uh the name of an organization specifically about certain department of healthcare but I think it is the underlying goal for virtually everybody who works in suicide prevention. So we can think about ways of trying to prevent suicide. One school of um suicide prevention works this way: It assumes that there is a sort of basic level of wish-to-die, this in a way harks back to Freud a little bit, uh wish to die that is more or less constant for different individuals. In some people it is a little higher, in some people it’s lower, umm, but it’s, in the view of this school it’s pretty steady, but what fluctuates is the desire to live, alright. It fluctuates over the top of that and sometimes it dips, dips down, well if it dips down below and the person has access to lethal means like guns, uh that’s when suicide occurs. So the way you treat, you do suicide prevention, is to try to reinforce the upswings in the desire to live. Uh as I say, there are many other schools of suicide
prevention but that is a major one. And here’s where it disagrees, it agrees I think, with uh supporters of aid in dying, that choices to die can be misguided. After all, even where it is legal, many, we have um, uh data for this from the Netherlands, also from Oregon, choices to die, requests for aid-in-dying are not honored. They’re uh sometimes not honored on grounds of, uh, mental, umm uh, instability or, uh, illness. Sometimes because the physician doesn’t think the circumstances are appropriate. Sometimes for, um, other reasons. But the view here is just because somebody says they want to die, that’s not good enough reason. We have to be persuaded that this choice is somehow um understandable, um, realistic, um, something to be um honored. Uh, and uh, there’s another consequences sometimes, some places. The, uh, sometimes even expressing the wish to die can, uh, illicit consequences you don’t want. So here’s where I think the overlap between suicide prevention and aid-in-dying. This is what suicide prevention could contribute to aid-in-dying. Its skills in helping somebody think through choices to die. But it has to be without antecedent commitment to preventing such a choice. The suicide prevention is now practiced, not all, but many of its, uh, clinicians are antecedently committed to preventing anything that counts as suicide across the board. And that’s the thing that makes it incompatible and opposed to aid-in-dying where I think the skills that it has to offer could actually be useful in this context. Okay, um, some religious groups. Let’s try this one, haha. (audience laughs) So now, the [Catholic] Church is of course opposed to a lot of social practices: divorce, abortion, contraception, invitro-fertilization, stem cell research, same-sex relationships, and a host of other things. And I should add that some people that I discuss would say “this isn’t the church I know.” Right? But I think that, um, this is the official position of the church on many things. And so it’s really tempting to say well you know aid-in-dying is just another thing it’s used on . . . on euthanasia, aid-in-dying, these are just, you know, part of this, and so we can ignore it just the same way we ignore all the rest of this. Um, now it cannot be pretended that the church is not articulate in opposing this. Uh, here’s what Pope
Francis has said to, has said about right to die issues. Alright, and, uh, you can see that, uh, and it’s, um, objections or a mix of a number of things, but it has led to many sorts of protests. This is a protest in France where the government was persuaded, although it had announced in advance, um, that it would support a light to die, a right to die, law in France. It then rejected it but approved terminal sedation, right. This is just one of many things that church opposition has fueled. Uh, it has sometimes, um, led to, um, recourse to things that don’t involve direct ending of life. In the same, apparent way like terminal sedation or VSED, right. Although it’s, uh, I don’t know that it has, uh, a view about VSED, uh, yet, um. And it has a positive view about the benefits of spending time with the dying. None of this is precluded by aid-in-dying, a use of terminal sedation, or VSED, or anything else. But the blocking of aid in dying legislation has been, has been a central enterprise of the Catholic Church. It, um, was the biggest money spender in the opposition to Oregon uh it succeeded with a big infusion of money in defeating the Massachusetts initiative couple of years ago, ah, and it—this has been high on its priority list. Well, I think we need to look back a little further in the history of religious thought to think ab-, to try to understand what the core issue here might be and whether, and whether we might see it differently. So this is Extreme Unction you can see the dying person there being anointed with um ah holy oils, ah you can see the attendants, right, and here is one of many prayers for the um uh pr-preparation for death. So there is an introduction, um, but it’s the part in blue that’s relevant to our concerns here. “Grant us the grace of perfect sorrow, sincere contrition, the pardon and remission of our sins, a worthy receiving of the holy Vaticum, and the comfort of the Sacrament of Extreme Unction,” which is, of course, uh been renamed now, “in order that we may appear with greater security before the throne of the just but merciful Judge, our God and our Redeemer.” That’s this is what characterizes um these practices. So where does this agree with contemporary aid in dying? Last moments are important. Communication’s important. Acceptance of oncoming death, that’s what this prayer is about. It is
important, and at least for some spiritual experience, whatever you
would call that, think it is, is also important. But what’s precluded by
the way we now respond to death? So, either intolerable suffering, or
the pain relieving and symptom relieving medications that dull
consciousness interfere with all this stuff. If you’re in severe pain, or
if you’re medicated heavily, self-awareness is lessened, the prospect
for communication with family, friends, is reduced. All that
traditional capacity for bestowing wisdom, saying goodbye, giving
blessings, that’s good and even for the religious the ability to pray is
gone. In medieval Christianity it’s the last moments of life that are
the crucial moments. Maybe there are theologians here who would
like to speak to this, because it in medieval thought is that the
opportunity for repentance and absolution you have to be conscious
to do these things. And of course in medieval catholic theology may
determine the entire course of one’s afterlife. It is the difference
between Hell and um, we do have some contemporary secular, um,
stuff the way we do life closure and you know that often involves um
thinking about what you regret and what you wish and what you hope
for and all of that stuff, but it’s the last moment stuff that’s really um
essential. This is what we get. Not every time, but sometimes, this,
this, this. So what the church I think could contribute if we would let
it, alright, is this sense of this deep importance of the very end of life.
So in sum, of these three enemies, I think they and people who favor
this, uh, aid in dying, all intend to make human life better and all
could help to make human death go better too. So here is what we get
from disability rights. There’s this alertness to social programming
that we’re all affected by. From suicide prevention we could get skill
in helping somebody think through these theories. There’s nobody in
the armamentarium of end of life care whose main competency is
this. Hospice helps. Psych evals might help. Alright. The physician
doesn’t have time to do this, alright, the nurses have even less time to
do this, ah and there is a whole, you know, retinue of people if they
are not committed to prevention. And finally from religious groups,
ah, a sense of the importance of the end of life. I think they’d all
enrich the right-to-die movement. And they we don’t need to think of
them as enemies, alright, even if that’s not what they have in mind.  
Thanks. Thanks. (applause) So, so now I think we have time for, the,  
do we have time—I was told we could keep going for a while, so. Is  
that right, April?

April: A little bit.

MB: A little bit! So if you have questions, ah for any of the um,  
previous 4 speakers who are all here, There’s one, right and, there’s  
um one over there, and there’s one there, and where is the other one?  
Right there, oh right there! So if you have questions for any of us,  
we’re here, we’re happy to um uh respond and we have, I think up to  
15 minutes. Is that right? 7, 7, we have 7 minutes by order of the  
umm uh administration here (chuckles).

Great, so questions for me about this, about the film, about any of  
the things said before about right-to-die stuff? Yes.

Audience: My question is for you, and I guess after listening t o  
your presentation, I guess my question is do you think that aid in  
dying has, should be a right, and if it is a right, is it a right that  
belongs to the die, the dyer, or is it a right that belongs to the  
physician and maybe would you not characterize it . . .

MB: Um, well, no no no. The, different parties may have different  
rights. So the law, the laws that have been passed in this country, and  
in fact as far as I know, everywhere, all give the physician, the aider,  
ah the right to either participate or refuse, decline to do so. So no  
physician is compelled to do this uh in any way, nor any pharmacist,  
right. They all have the right to umm, uh, it, for any aider it must be  
voluntary, alright. So, uh, they can always opt-out. Now of course  
there are problems about supposing you are the only physician on a,  
you know, on the island, and you know stuff like that, you’re the only  
one that could help, that is a different question. But in ordinary  
medical contexts, ah not only the physician can hop, opt-out but a  
whole healthcare system can, as the Catholic hospitals have, for
instance. So there’s the physician’s right to not participate, and of course it is also optional for the patient. No patient can be compelled to make this choice, and, I’m not sure about all these statutes, the one that’s proposed in Utah, um, and currently in committee, uh explicitly states that um persuading, forcing, or in any way pushing a patient to make this choice is a first-degree felony. Right? It’s perfectly straightforward like that, on that basis. So, the idea is this is a voluntary choice, it’s actually made by quite a small number of people, even where it’s legal in the, in um, Oregon, it’s point three percent. In the Netherlands, its three percent of people who are dying. So that means, uhh, in the Netherlands, uhhh, in in all, in the vast majority of cases these are, these are people who are dying of cancer. Alright? The vast majority of people actually dying of cancer don’t die in this way, it’s over ninety percent and it’s in uh, So what that says is this, this is an option, but certainly not a requirement. Yeah?

Audience: I mean, first I would just say I really admire your presentation, both professionally and . . .

MB: I know there’s a “but” coming right?

Audience: (Laughter)

Audience: And also just personally it seems . . . I just admire what you went through

MB: I even wore the same jacket so you’d know it was me.

Audience: And I just, from my point of view . . . situation, I mean it’s a terrible situation but other terrible situations that we encounter we hope that every, that they would remain in the same, the same thoughtfulness and uh, compassion, and deliberation that that was that that seemed to be very obvious to those appearing in this situation. I guess my question, my question, it’s not a criticism, my question to you is do you worry that it would be very busy where,
especially if you are talking about a systemic change, where the laws changed in the state or maybe the entire nation whether there will be many cases where . . .

MB: People are pushed or maneuvered you mean?

Audience: I don’t think people will be pushed. I’m not that cynical . . .

MB: There’s some pretty pathological families around. So, right?

Audience: Ok, well I wouldn’t rule it out. I think probably more, there are a lot of people that are depressed or there are people who commit suicide all the time, and I wonder if you get some of those people.

MB: Here are two things that are relevant, in every one of these statutes. Um. If there’s any concern on the part of either of the physicians involved, there has to be an original physician and a consulting, independent physician, uh, to evaluate issues, including terminality. If either one of them suspects that mental illness or depression, including depression, is compromising this choice, uh, then they, uh, there has, there has to be a psych, um psychiatric evaluation. So, will that be perfect? We don’t know. But . . .

Audience: I guess when you only have a few physicians doing this, and you only have a few cases . . . They can be very careful And very deliberative to make sure that they are totally devoted to the subject and probably do a perfect job. But if we’re talking about the situation that is going on throughout the country, when you talked about having, um, you know everyone that goes . . .

MB: So let me see if I can focus on what I think you’re asking, and that is well if this becomes general, won’t there be more casual cases, less um attention to, um, if there’s safeguards. So notice this. Of the
ways in which we die, we just depicted this long picture of long, down-hill courses, cancer, heart, uh, organ and heart and other organ failure, uh, or the dementias. Those are all less well protected than actual aide in dying is. You don’t need two physician opinions, you don’t need two written statements separated by, two oral statements separated by fifteen days plus a written statement. You don’t need um, um, uh, a um witnesses, you don’t need witnesses, you don’t need um, uh, the prospect of a psych eval[uation]. Right? None of that applies for discontinuing treatment, for um stopping um other forms of care for these, especially not for the um very heavy use of opioids in treating pain, which is a main way we have dealt with dying. Just turn up the morphine, put them on a morphine drip. Right? That’s what we always did. Right? Where are the old-timers of medicine here? Is that right?

Audience: Old timers? (Laughter) It’s a slippery slope, I mean it gets to the heart of intent I think, what are you trying to do? There’s the doctrine of double intent. It’s ok push it. It’s ok to push it if the intent is to relieve the suffering, knowing that it is inevitable that you are going to hasten somebody’s death.

MB: Right! And so here’s the here’s the core thing that David Orehlicker wrote about this one. So my doctor says, well, I just upped the morphine. Right? I didn’t intend that death. Right? I just merely meant to ease pain. But the result is the patients dead. Right?

Audience: Right.

MB: Can we really take seriously the claim that this wasn’t intended and if it, if the doctor does something that results in your death and said “Oh, well, I didn’t intend that. I only intended to relieve your pain.” Is this a safeguard? (audible sigh)
Audience: And then you have the patient saying, the, the, the patients family saying why aren’t they dying? Why aren’t they dying soon enough?


Audience: You know and they perceive that they’re uncomfortable in some way that nobody else can perceive it, let’s say. And then, the push is, let’s increase that morphine drip just a little bit more.

MB: Umhm. Umhm. I think we’re caught in, it would be a little strong to call it a web of hypocrisy but maybe it would be safer to call it just a nexus of legal semi-fiction.

Audience: (Laughter)

MB: Will that do? (laughter) Anyway, you see the problem, we are at a crux point. A crux I think in the ways in which we deal with dying. We’ve made dying longer uh and uh more medicalized in a sense. And in the, in the and in doing that have taken away control by the patient. Right? When it’s hard to see why there should be any reason why we’re encouraged in a sort of Libertarian flavored country, that where at least it stresses autonomy and so on, why we should be encouraged to think of ourselves as free and independent and the architects of our own lives during the main part of our lives but when we get to dying we lose that. That’s the issue. I’m sorry did anyone else have any questions or anybody else? No? You wouldn’t dare right? (laughter) Anyway, thank you all.