

Confronting Death

Who Chooses, Who Controls?

A Dialogue between Dax Cowart and Robert Burt

On 21 November 1996, Dax Cowart and Robert Burt jointly delivered the Heather Koller Memorial Lecture at Pacific Lutheran University. This was the first time that they spoke together in a public forum. Dax Cowart now lives and practices law in Corpus Christi, Texas. In the summer of 1973, he was critically injured in a propane gas explosion that took his father's life and very deeply burned more than two-thirds of his own body. He was left blind and without the use of his hands. For more than a year Dax underwent extraordinarily painful treatments in the acute burn ward of two hospitals. Throughout his ordeal he demanded to die by refusing consent to his disinfectant treatments. Despite repeated declarations of competence by his psychiatrist, all his pleas were rejected. In 1974, while still hospitalized, he helped make the famous "Please Let Me Die" video, and in 1984 a second video, "Dax's Case." In 1986 Dax Cowart received a law degree from Texas Tech University.

Burt and Cowart have corresponded over the course of several years on the subject of Dax's case and related issues. They met for the first time during their trip to Tacoma, Washington for the Koller Memorial Lecture. The following is an edited transcript of their public remarks.

Robert Burt: Let me start at a place where I think we agree. Before 1974, the dominant attitude of physicians toward patients was by and large intensely disrespectful of patients' autonomy. The basic posture was paternalistic. Physicians knew what was best for patients, and the patient's job was just to go along. Dax himself has been a critically important actor and symbol in identifying the wrongdoing in that attitude, and raising into high social visibility the proposition that autonomy is a vitally important value; patients are the central actors here and physicians must attend to them in a respectful and careful way. On that point we agree.

The place at which I get troubled or confused is what exactly follows if we embrace this important norm of autonomy. Start with a simple version of two alternatives, perhaps extreme alternatives, to try and sharpen what the issues are. One version of autonomy says: well, it's the physician's job, like it's anybody's job who needs to respect autonomy, to say to a patient, "What do you want?"; the patient says "I want A, B, C," or "I don't want A, B, and C," and then it's just the physician's job to implement that. That is a possible interpretation of the law and way of proceeding.

I find that interpretation of the law, however, to be quite unsatisfactory. It is not only permissible, but important—I would even say essential—that a somewhat different step be taken by a physician (or anyone dealing with a patient). "What do you want?" Dax says, "I don't want treatment." At that point I think it is

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not only permissible but imperative that whoever hears that respond not with “OK, great, let’s go ahead,” but instead with, “Well, why exactly do you want that? Why have you come to that conclusion? I want to explore that with you.” Now imagine the next step. Dax says, “None of your business.” I think it is then both permissible and essential for the doctor to say, “No, no, it is my business, and not because I’m a doctor but because I am another human being who is necessarily involved in your life. We define one another in important kinds of ways, and while, of course, I can’t define you, we have to negotiate together what our shared meanings are about, what it is that you want me to do or not to do.” It is correct not only for me to say, “Why do you want to do that?” but also permissible for me to argue with you if I disagree, and to argue strenuously with you on a variety of grounds.

Now come the end of the day, yes, it’s your life, it’s not my life. But the question is, When have we reached the end of the day? When may we terminate this conversation so that I believe that the choice that you’re making is as considerate a choice as I think it is morally obligatory for you to make? I know that this can become a kind of trick, and it shouldn’t be that; this is only the first step in a conversation.

Why do I think it’s not just important but imperative that anybody hearing such a request on Dax’s part explore it with him and even quarrel with him? I think we define one another for one another. We are not isolated creatures, popped into this world, who chart ourselves only by what’s in our head. We are intensely social creatures. Dax himself has become more than just an individual, he has become a symbol and independent force that shapes our way of thinking about ourselves when we imagine ourselves to be patients. We are mutually shaped by our expectation in lots of ways.

There is one way I want to particularize that in Dax’s case. All of us, as members of a society, have attitudes toward people with disabilities. Those of us who are able-bodied or, as they say correctly among disability advocates, those of us who are temporarily able-bodied, often spend an enormous amount of energy denying the fact that our able-bodied status is, in fact, temporary. It is for many, many of us an unattractive, if not to say frightening, possibility to think of ourselves as significantly disabled. Many people in this society, for lots of different reasons, have stereotypical views of disabled people and what their possibilities are. You correct me if I misstep here, Dax, but just on the face of the matter, it seems to me that until your accident you were a member of the able-bodied

community, and a very able-bodied member at that, for whom your physical prowess was a matter of great importance and pride to you. Suddenly and deeply beyond your control, in a way that can happen frighteningly to any of us, you found yourself pushed over this divide between the able-bodied and the not-able-bodied. But you inevitably brought with you attitudes that were shaped at a time when you were comfortably, happily, proudly a member of the able-bodied community.

Now it seems to me that having been pushed over that divide in physical terms, there still was a question, at least, about your attitudinal concerns, your attitudinal shift.

Let me read one passage from this initial conversation that Dax had with Dr. White.¹ Dr. White said to Dax, “From the very beginning, according to what you’ve told me, and what’s been written in your hospital record, you had very strong feelings that you didn’t want the doctors to go on with your treatment, that you wanted them to leave you alone and not attempt to sustain your life. How do you feel about that at this point?” Dax said in response, “At this point I feel much the same way. If I felt that I could be rehabilitated to where I could walk and do other things normally, I might have a different feeling about it. I don’t know. But being blind itself is one big factor that influences my thinking on the matter. I know that there’s no way that I want to go on as a blind and a cripple.”

Now human communication is a chancy and somewhat crude thing. I only have your words. Dr. White only had Dax’s words. Reading those words and putting myself imaginatively in the shoes of your physician, or your lawyer asked to represent you, I have a whole series of questions. How realistic was your perception at that point, just a few months after your accident? How realistic was it of the full range of capacities that could be held out to you, even if you were permanently blind, and even if you were permanently unable to walk (which it turns out, of course, you were not)? How much contact had you had with people with significant disabilities of these sorts? How much were you devaluing your own capacity, thinking that in fact you would be able to do nothing more than your mother’s observation in the subsequent videotape interview. She said that you said at one point, “You know, all I’m going to be able to do is to sit on a street corner and sell pencils.” Well, of course we see today that you are very active and don’t sell pencils. But this is a very common fear of able-bodied people

who have had no substantial contact with people with disabilities.

So I would ask myself first of all, how realistic is someone like Dax's sense of the real possibilities open for him? But then second of all, how can I as a helper, someone who wants to be useful and helpful to him, communicate in a way that is fully understandable and believable what the real range of options are to him, disabled, that he, formerly able-bodied and now still able-bodied in his image of himself, is not able to see. What do you do? There are many possibilities. You bring people to talk, you discuss, you challenge. All this takes time. It's not something that you can just say to Dax, "Well, how realistic are you? Let's have a brief discussion." In the kind of immensely difficult, immensely traumatic situation in which he found himself, in the midst of his treatment and with the physical pain that he was feeling, and with the psychological pain of his losses including the loss of his father in the same accident, this is not a conversation that can take place in ten minutes or one day. Over how much time and with what kind of constraints?

Dax Cowart: Now I know how it feels to be killed with kindness. It makes it more difficult to take the opposing position, but being the good lawyer that I am I will do my best (audience laughter).

The right to control your own body is a right you're born with, not something that you have to ask anyone else for, not the government, not your treating physician, not your next-of-kin. No one has the right to amputate your arms or your legs without your consent. No one has the right to remove your internal organs without your consent. No one has the right to force other kinds of medical treatment upon you without your consent. There is no legitimate law, there is no legitimate authority, there is no legitimate power anywhere on the face of this earth that can take the right away from a mentally competent human being and give it to a state, to a federal government, or to any other person.

A number of quotations constitute a brief overview of what others have said throughout history and also give insight into my own feelings. In *A Connecticut Yankee in King Arthur's Court*, the leading character and one of his companions come across a whole family which has almost died of smallpox. The mother appears to be the only one still alive. Later on they discover she has a fifteen-year-old daughter up in a sleeping loft who is in a near-comatose state and almost dead. So they rushed the young girl down and began

administering aid to her. I'll pick up the quotation there. "I snatched my liquor flask from my knapsack, but the woman forbade me and said: 'No, she does not suffer; it is better so. It might bring her back to life. None that be so good and kind as ye are would do her that cruel hurt. Thou go on thy way, and be merciful friends that will not hinder.'"

I was asking my own physicians to be merciful friends who go on their way and do not hinder. But they would not listen. In the first part of this century, Justice Louis Brandeis wrote in one of his Supreme Court opinions: "The makers of our Constitution sought to protect Americans, and their beliefs, their thoughts, their emotions, and their sensations. They conferred as against the government the right to be left alone, the most comprehensive of rights and the right most valued by civilized man."

Warren Burger, who later became chief justice, referred to Justice Brandeis: "Nothing suggests that Justice Brandeis thought an individual possessed these rights only as to sensible beliefs, valid thoughts, reasonable emotions or well-founded sensations. I suggest that he intended to include a great many foolish, unreasonable and even absurd ideas that do not conform, such as refusing medical treatment even at great risk."

Justice Burger did not want to encourage foolish, unreasonable, or absurd conduct, but he did recognize the importance that the individual has in making his or her own decision. He understood that what some of us might think of as foolish, unreasonable, or absurd can also be something that is very precious and dear to someone else.

The English poet John Keats, almost 200 years ago, wrote simply, "Until we are sick, we understand not." That is so true—until we are the ones who are feeling the pain, until we are the ones who are on the sick bed, we cannot fully appreciate what the other person is going through. And even having been there myself, today I cannot fully appreciate what someone who has been badly burned is going through on the burn ward. Our mind mercifully blocks out much of that pain.

When I was in the second grade, a popular joke concerned a mother who severely reprimanded her young son for coming home late from school. He said, "Mom, now that I'm a Boy Scout, I stopped to do my good deed for the day and helped this little old granny lady cross the street." She said, "Young man, it sure doesn't take an hour to help one little old granny lady cross the street." He said, "Well, it sure did this one, 'cause she didn't want to go." I was like that little old granny lady; I didn't want to go. And even today there

are many patients who are being forced to endure things that they do not wish to endure, while being taken places that they don't even want to go.

John Stuart Mill, the English philosopher, in his essay *On Liberty*, came down on the side of the right to self-determination by dividing acts into those that are self-regarding and those that are other-regarding in nature. Mill concluded that when the act is self-regarding in nature, the individual should be left to make his or her own decisions. That is precisely my view. In a medical context, I am saying that before a physician is allowed to pick up a saw and saw off a patient's fingers or pick up a scalpel and cut out a patient's eyes, we must make sure that the physician has first obtained that patient's informed consent. I always like to stick the word "voluntary" in there—informed and *voluntary* consent—because consent that is obtained through coercion or by telling half-truths or withholding the full measure of risk and benefit is not truly consent. Medical providers need to understand that patients do not lose their constitutional rights simply because they find themselves behind a hospital wall. They have the same constitutional rights that the rest of us have, that we expect and enjoy outside hospital walls.

Fortunately today we have many protections that we did not have when I was in the hospital in 1973 and 1974. We have legally enforceable advance directives such as durable power of attorney and other health care proxies. Studies, though, have shown that even when these advance directives are part of the patient's hospital records, over half the time they are ignored by the patient's physician.

When I was in the hospital there were many reasons I wanted to refuse treatment, but one was overriding—the pain. The pain was so excruciating, it was so far beyond any pain that I ever knew was possible, that I simply could not endure it. I was very naive. I had always thought in that day and age, 1973, that a doctor would not let his or her patient undergo that kind of pain; they would be given whatever was needed to control it. Then I found out that was not true. I found out later that much more could have been done for my pain.

There were other important issues, too. One, though it was a distant second, was what Dr. Burt mentioned, my quality of life. I just did not feel that living my life blind, disfigured, with my fingers amputated and at that time not even able to walk, would be worthwhile. With that quality of life it did not seem that I would ever want to live. I have freely ad-



mitted for many years now that I was wrong about that.

Dax Cowart
in 1972.

I want to clarify this, though. Freedom, true freedom, not only gives us the right to make the correct choices; it also has to give us the right sometimes to make the wrong choices. In my case, however, it was a moot point whether I was wrong as far as my quality of life went, because that was a secondary issue. The immediate issue, the urgent issue, was that my pain was not being taken care of. That was why I wanted to die.

Today I'm happy; in fact I even feel that I'm happier than most people. I'm more active physically than I thought I ever would be. I've taken karate for a couple of years, I've climbed a 50-foot utility pole with the assistance of a belay line on the ropes course. I do other mental things, like write poetry and practice law. That is not to say, though, that the doctors were right. To say that would reflect a mentality that says, all's well that ends well, or the ends justify the means—whatever means necessary to achieve the results are okay to use. That totally ignores the pain that I had to go

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“The time that I was asking for was time to address your problem in the best way a doctor is trained to do. If you insist now that you’re not going to give me that time, it frustrates what I know I can do as a caretaker. Look, a discussion needs to take place; that’s what I want, rather than people talking as if they are in isolation booths.”

—Robert Burt

through. I check myself on this very often, several times a year, since I do speak so much. I ask if the same thing were to happen today under identical circumstances, would I still want the freedom? Knowing what I know now, would I still want the freedom to refuse treatment and die? And the answer is always yes, a resounding yes. If I think about having to go through that kind of pain again, I know that it’s not something I would want. Another individual may well make a different decision. That’s the beauty of freedom; that’s his or her choice to do so.

Burt: You said at the end of your remarks that if you had to, if it happened all over again to you, you would nonetheless come to the same conclusion. If instead of this happening to you, imagine for a minute that there would be somebody in exactly the same situation that you were in, but that today you were called in to talk with this person. This person had also said to his or her physicians, “I don’t want to be treated. Stop now.” What would you say to that person?

Cowart: I would say to that person, just as you suggested earlier, “What are your concerns?” I do not urge, when a physician goes to a patient’s bedside and the patient says, “Doc, I don’t want to be treated, leave me alone,” that the physician say, “It’s your decision” and walk away. The physician has a duty to inform the patient, as well as he or she can, what in all honesty can be done and then solicit the patient’s concerns. I’m not talking about painting some rosy scenario that is really not accurate. So to answer your specific question, were I called to that patient’s bedside, I would want to ask why he or she wanted to refuse treatment. I would expect that one of the answers might be the pain. I would then say, “If that were addressed, would that change things for you?” They may say yes, and they may say no. I would try to give that person the benefit of my own experiences—not just the positive points, but the negative ones, because it took me seven years following the explosion before I even began to get on my feet again and life became really worth living. But I would try to reaffirm the person, let him or her know what I thought was possible, what I thought could help, but I would not skirt the problems. One of the problems we have today, for example, is that once patients are out of the multimillion-dollar hospital facilities and away from all the nurses and doctors there, they don’t often have good support. They have understaffed and underfunded government agencies to rely on in most cases, and often they fall far short of what they should be.

Burt: That’s interesting. I continue to be puzzled about whether we significantly disagree. I completely buy your proposition that there is a right here, a right of autonomous choice. The only point that I keep pushing is your old question of how that is implemented. Let me, if you will, try to push you a bit more just on this point. To me it is the crucial question. This imaginary patient says to you that first of all there’s a pain problem and it’s not being addressed. I take it that given what you now know about the possibilities of pain control, you would then start moving around and see to it that such treatment would be available—the kind that at the time you were in the hospital wasn’t made available to you. Am I right?

Cowart: Yes.

Burt: So you would fight for them. What, though, if they said to you, “Don’t fight for me. Go away. My life isn’t worth living. I don’t care what the possibility of getting on top of this pain is, just go away.” What would you say then?

Cowart: At some point you have to say, “Okay, it’s your decision.”

Burt: Yes, at some point, but that day? The next week? If not right away, are you comfortable in arguing with them?

Cowart: I would feel comfortable in confronting them. I would not say argue, but I would discuss it with them, even confront them.

Burt: What do you mean by confront?

Cowart: Take an opposing position, discuss it, and have a lively debate about it. I have no problem with that.

Burt: I have another question. The observation that you just made, that it took you seven years to get to the point where life seemed fully worthwhile is a very powerful one. Would you say to our imaginary patient, “You know, the seven years time, it was hard time. Looked at from the other side, it now feels to me worth it, and it might feel like that to you, too”?

Cowart: That would be the honest way to do it.

Burt: What if they said, “No, you’re different from me, it just can’t be. I can’t do it, I can’t do it”? Is there anything you would do then?

Cowart: This goes back to your question, When is the end of the day? Is the end of the day at the end of one day, at the end of one week, or at the end of one year? To answer truthfully, I don’t think I can say when it is without knowing more about the circumstances. For me, one hour was an eternity, with the pain I was going through. Certainly no longer than one day under those circumstances. There may be times when we would want to extend that to a week or maybe a month, depending on how severe the pain was. But the problem I see in doing that is that I don’t believe our health care providers would be honest about letting go of a patient earlier than whatever we set up as the maximum time. Our health care providers have been entrenched in paternalism since probably the

beginning of the profession, and until we break out of the paternalistic mode, I can’t see our physicians allowing patients to exercise their free choice unless they’re legally bound to.

Audience Question: Mr. Burt, when is it okay for a doctor to say to a patient who refuses lifesaving treatment, “I agree with you”? The patient’s in a lot of pain, she’s suffering, and has a chronic illness. When is it okay to say, “All right, you can call an end to it”? When is the end of the day? When is it appropriate to acknowledge that to the patient?

Burt: I agree that there must be an end of the day. Otherwise one is disrespectful of the person who is saying “No, no, no—enough.” I also agree that you should make it clear to patients from the beginning that ultimately it’s their choice. But then I would say it’s appropriate to say, “Give me time. Give me an opportunity, at least.” Now once you say that, you’re on the line and you must continue to spend time with this person—respectful time, extensive time. That itself is a very risky thing for you to do. It’s a very considerable commitment, and you can’t go into it lightly. You can’t go into it lightly as a friend, and you can’t go into it lightly as a professional. So you’ve got to be prepared to follow through by saying, in effect, “I’m here with you, I’m going to stay with you.” But also, “I would hope and expect that as we struggle together it will become clearer to the both of us when that end of the day is. But at least right now it’s not clear to me that we’re there.” Then see what the person says. This is not saying something and then vanishing for two weeks, because you’re going on vacation somewhere or have other things to do. The commitment is enormously burdensome for a caretaker to take on in these situations. But that to me is the heart of caretaking. Is that an answer?

Same Questioner: Not really. As Dax said earlier, he had torturous pain. Are you saying that this patient should go through such suffering for this delayed, extended dialogue that you want?

Burt: Well, look, when I say “Give me, time,” I would hope, particularly on these pain issues, that one would also take some action. The provision of adequate pain control in this culture today is a disgrace, but it shouldn’t be. Medical technology that is extraordinarily responsive in lots of ways is available. It’s a great puzzle in a way—part of the sense of isolation and dis-

regard for patients—that we are doing so little to implement what we know about addressing issues of pain. Lots of pain, though, is complicated to deal with. So when I ask for time, I don't mean, give me time because I'm going down to the cafeteria since I'm hungry. What I mean is, give me time to get the resources that I know exist that can address this in some way. If it turns out that there aren't those resources, or I really tried to get them and they did not work, then I come back to the patient and say, "Okay, I failed on that score; now we have to go from here." At that point, it does make sense for me to say, "Okay, this is intolerable for you. That's it, that's enough." So the time that I was asking for, was time to address your problem in the best way a doctor is trained to do. To the patient who said, "What do you mean, give you time?" I'd say, "Give me time to do my job. I acknowledge that we're not meeting your needs right now, but I think we can, though it will take some time for me to do that." If you insist now that you're not going to give me that time, it frustrates what I know I can do as a caretaker. Look, a discussion needs to take place; that's what I want, rather than people talking as if they are in isolation booths.

Cowart: A physician has to establish rapport with his or her patient, treat that patient as a human being, let the patient know that he or she really cares. I don't know whether it's taught or whether it's just picked up or by watching other physicians, but I think there is a professional distance, a real displacement, by physicians that is counterproductive for good medical treatment. I'll give you an example. When I was in the hospital, the director of the burn ward wanted to do surgery on my fingers. He felt I could probably get some use out of my hand, but I wouldn't do it, because the surgery I had had before on my hands was so painful.

There was a medical student, though, who was assigned to work with me. He'd come by every day. We'd have friendly, heart-to-heart talks, and I liked the guy a lot. He wanted me to have my hands operated on and asked me why I would not allow the doctor to do it. I explained to him about the pain. He said, "Well if I guaranteed you that you would be kept out of pain, would you?" I told him I'd consider it, but I just didn't see how he could guarantee that, especially since he was a medical student. But he continued to talk with me until finally I agreed to talk to the director of the burn ward about it, who then came in and assured me that he would do everything he could to

keep me out of pain. He would give me as much pain medication as he possibly could and not jeopardize my life. It wasn't until then that I agreed to the surgery, and he did keep his word on the pain control. That is more the model of what should take place. But the physician should not have the power to force upon the patient a long, ongoing discussion like that over an extended period of time, whether it be days or weeks.

Audience Question: Mr. Cowart, you have focused a lot on the physicians up to this point. How were you treated by your nurses?

Cowart: Overall, I was very impressed by their good care. Nurses tend to understand, to have a very caring and compassionate side to them that I don't see nearly as often in physicians. Sometimes you can have nurses who are barracudas, though, and a physician who is very loving and compassionate. I don't know how much of the general difference is gender-based, or how much of it is in the training; I suspect it's some of both. Above all, nurses are there with the patients; they're in the trenches working with the patients, seeing what the patient's going through on a minute-to-minute, hour-to-hour basis. They seem to have a much better understanding of and empathy for the patient than I've seen in most physicians.

Audience Question: Mr. Burt, I'm an RN and a hospice nurse. I have two patients right now; both of them have recliners, both of them have TV remotes, both of them have morphine, and both of them have pain. In the last two weeks, one patient said, "I have everything I need. I have my recliner, my remote, my morphine, and I'm fine." The other patient said, "I hate my life. All I have is this stinking recliner and TV and my morphine. This isn't a life." Now in the last week, one of those patients has died because he made a decision to stop all of his medication except his morphine, and he died. I was not ready for him to die, but he was ready to die. If I had argued with him, whose need would be met? It would not be his need, would it?

Burt: I guess I would say that if you had stopped him, that would be inappropriate. But this word "arguing," maybe we get hung up on it. Importuning, offering to explore, not just taking this patient's statement in a way that I'm sure you didn't—that is appropriate to move into.

Same Questioner: I mean, we talked a lot!

Burt: Good—that's right. The root of this is in the particularity of individual interaction. It sounds to me, even in the minute in which I have heard you describe this, that you reached what I would agree is the end of the day. That is, the end of an involved, caring, committed relationship in which it was very clear that you were not going to walk away. That's the most that you can offer. You've got to offer that, and you did. And hospice care generally does. I see the forces of disregard, of speedy resolution, of turning away from patients, of being aversive to death and dying, for example, as so strong generally in the medical profession that by contrast hospice is a wonderful exception.

So, too, is the caregiver who may lovingly challenge a patient's requests. You ask, whose needs are such caregivers meeting? Do they do it only for their patients? Or do they do it for their patients and themselves? There's a mix in these things. Who can draw a strict line and say, "Hey, I know that I'm just doing this for you and not for me?" I would turn the question around. A patient is complaining and saying, "Everything that you do is wrong. You give me the recliner and I don't like it. You give me the morphine and I don't like it. So let me out of here." If you say "Right," what and who would you be doing that for? Many people whom I've talked to involving the care of "difficult" patients, when they are honest with themselves, say it's very hard to make sure that what they're doing is not for themselves but for the patients. Sometimes, in hanging in there, it's a mix—no, it's always a mix. The goal is only that it should be principally for the patient and only secondarily for you. But that's not an easy goal to get to either. You get closest to it by struggle, sweat, honesty, reflection.

Audience Question: Mr. Cowart, I'm trying to understand your thinking. You were in the hospital and kept saying you wanted to die, and then you were released home without much care. You said it took seven years for you to turn your life around, but you did. You didn't kill yourself. At what point did you say, "I want to live"?

Cowart: I don't know where or when that point was. When I was in the burn ward and was told I was going to live regardless of whether I had that last skin graft operation or not, I told myself, I'm just going to do whatever I can to make the best of a bad situation. I didn't really live up to that. Subsequently, and within

that seven-year period, I tried to take my own life twice—three times if you count the time I crawled over the hospital bed rails trying to get to the window to jump out of an eight-story window. But in 1980, and all during the entire seven years after I was in the hospital, I was not able to sleep very well at all. I'd stay awake most of the night and then could hardly stay awake during the day. I was trying to go to law school, too, and every time I felt like I was getting something going, I couldn't sleep then and I couldn't function. I felt just slammed right down to the ground again. In 1980 Dr. White was able to help me sleep better. Then I really saw my life turn around.

Audience Question: Mr. Cowart, it seems to me that you are a perfect example of what now seems to be success in spite of any physical disability. Do you now feel at all grateful, thinking back? Are you glad that the doctors fought your request to die?

Cowart: I do not feel grateful to anyone for fighting my request to die. What I do feel grateful to them for is that I believe they honestly felt they were acting in my best interest. But no, I'm not glad they forcibly treated me because the pain that I went through was pure hell. We lose sight of how painful pain can be. Einstein apparently once talked about comparing sitting five minutes on a park bench beside a beautiful girl with sitting five minutes on a hot plate and said, "that's relativity!"

Audience Question: In fighting for your right to choose your fate, were you also fighting physically against the care that was forced upon you? Were you physically trying to refuse treatment?

Cowart: Oh yes! I would have done anything to keep them away from me. I used everything I had at my disposal to try to do that.

Same Questioner: Do you suppose that this fight within you, this struggle, this energy you were putting out, actually made you live?

Cowart: Yes. I think it was, ironically, counterproductive for what I wanted. There was a burn ward nurse I later learned of who left the hospital before I got there. She would not take anything off her patients, no matter how badly they were burned and what their expectation was about living. She also wouldn't take any lip from them, and even the other

“Don Cowart has certainly left a lasting impression with me. No other burn patient has made it so clear what a difficult time they’re having and that they really do desire to die. That lasting impression has carried throughout my entire life. Every burn patient that I take care of or any other patient who is critically ill—when it comes down to whether he lives or dies—I can’t help remembering Don Cowart and in my mind should I stop or should I continue. This is an ongoing battle that we have to individualize.”

—Duane L. Larson, MD
Director of the burn unit,
John Sealy Hospital, University of
Texas Medical Branch, Galveston
from the videotape, “Dax’s Case”

nurses were appalled by how rough and how rude she was to these patients. Her patients were so angry that they would, literally, have killed her on the spot. The other nurses began to notice that some of her patients were living, who would not normally have lived. What may have been at work there—this is only my hunch—is that such passion, even when it’s negative, helps. When people die, it can be just lack of any passion, negative or positive—just the languishing.

Audience Question: Mr. Cowart, at the time that you were fighting against treatment, your mother was fighting for continued treatment. Did you consider getting an attorney at that time?

Cowart: I asked the attorney who was representing me in a personal injury suit against the oil company whose duty it had been to maintain the pipeline properly to help me. He had been a long-time friend of my father’s, and he also knew me. He would not help me get the legal resources. He did go to the doctors, though, and say, “You have got to do more to keep him out of pain. It’s ridiculous that you’re not doing more.” I tried to get family members, relatives, friends to find another attorney for me. I wasn’t able to do that. I asked the hospital staff to take me to a pay phone there on the floor to call one, and they said there weren’t any pay phones. I said, “Take me to the lobby, then.” They said, “Burn patients can’t leave the ward.” I said, “Well let me use the phone at the nurses’ station. I know you have a phone there because I hear it ringing all the time.” They said, “No, patients aren’t allowed to use it. It’s only for staff.” I wrote at least one letter privately with a nurse. I dictated a letter to that nurse, and he apparently addressed it to my uncle. The letter (I don’t know whether it was the original or a copy) ended up in the doctor’s file, without my knowledge. The patient may have a right not to be treated, but without an advocate—someone at the hospital who has the authority and power to act on behalf of the patient—it’s hard to enforce that right. Finally it was Dr. White, the psychiatrist who was brought in to declare me incompetent, who both declared me competent and contacted an attorney for me. The attorney finally came down from Dallas. We talked. He said he’d do what he could, but I never heard back from him.

Audience Question: Mr. Cowart, when you were first injured, if your intractable pain had been effectively managed, do you think that your attitude would have been different? Do you think you might have had a very different outlook as to prolonging your life? Do you think that the pain was really the main issue that wasn’t being addressed by your physicians and the medical community, and that that interfered with your ability to really look at the future?

Cowart: Your concern is what I hear time after time from many people in the health care professions. Dr. White, the psychiatrist who was called in, expressed that same type of concern. Another concern Dr. White had was whether I had a major issue with control, whether once I showed that I was in control, then I would want to be treated. That just was not the case. It was not the future that I was concerned with; it was the present moment, the pain that I was undergoing. I knew that the physical pain would be gone eventually, but I was not willing to tolerate it for long enough to get beyond it. Even if my



pain had been competently managed, I still don't think that I would want to have been treated, because of my physical condition and what I did see as the future. Possibly without the pain, and possibly with much better professional support, maybe I could have been persuaded to go ahead and accept treatment. But you know, a psychiatrist was not called in to try to help me with these concerns until almost a year into my hospitalization. And then they called the psychiatrist in, not for the purpose of helping me, but to have me declared incompetent. He refused to do it and in fact found me competent, and so did the second psychiatrist, as you know.

Audience Question: Mr. Burt, I get the impression that both the medical profession and the society assume a temporary incompetence in anybody who is in severe pain or in severe emotional grief. Do you take the word of somebody in severe pain as at that moment truly their decision? Is a presumption of temporary incompetence justifiable?

Burt: I don't like the language, "presumption of temporary incompetence." It has a disrespectful and excessive quality to it. I don't think we should operate on such a premise. What I do think is that people in grief or extraordinary pain deserve a response by a whole range of caretakers, personal and professional: "I'm with you and I'll stick with you, and I'll be as helpful as I possibly can in working this through with you. I won't abandon you." Sometimes, in fact maybe even frequently, I think people who are in severe grief or severe pain have trouble, because they feel so hopeless, believing that people are responding to them in this way. So it takes an awful lot of assurance—not just words but being there when it counts, and it's not something that you can just say once and have it sink in to someone in great physical or psychological pain. Now I don't call that incompetence; I call that humanity—our human condition. It's naturally how people respond in times of enormous stress, woe, and trouble. In organizing caretak-

Dax Cowart
in 1996.

ing we should be thinking of ourselves as responding to that—not just in cheap words, and that takes time.

Audience Question: It seems to me that you, Mr. Cowart, actually made a very articulate defense of Mr. Burt's position when you so ably identified the essentials of informed consent, making the very clear point, well respected and recognized in medical-legal law, that informed volitional consent demands a full appraisal and understanding of the risks and benefits of the therapy. The difficulty that I see Mr. Burt focusing on here is that these decisions don't take place instantaneously in time. Even a patient who is not in pain, to make a fully informed decision about the risks versus benefits of treatment, has to be able to appropriate a different set of attitudes and expectations, and the process for that is one of knowledge and dialogue and information. Setting aside the pain issue, which ought to be aggressively manageable, how does your own experience help us understand how to balance respecting the patient's request with confidence that enough time has been given to the patient to allow a truly informed personal assessment of what the risks and benefits are?

Cowart: Assuming that pain is not an issue and that there's not some other issue present analogous to pain as far as the immediacy of the situation goes, I would not be nearly as inclined to favor a very short time pe-

riod. I probably would favor a longer period of time, maybe weeks, maybe even months, but I don't think that I would be in favor of years. As far as physicians being able to work with a patient during that time, I think it would probably be good in instances where you don't have the immediacy that something like severe physical pain requires. The trouble I have is how you go about assessing what is sufficient time from the patient's viewpoint, since we're all different. I just know that for myself I would like to have the right to make my own decisions at zero point in time. At the same time I'm willing to forgo some of my own autonomy in the interest of better decisions being made. What I don't know is how to determine always, as Dr. Burt calls it, when the end of the day has come. If the patient gives away some of that autonomy, I just don't know how you go about protecting the patient so he or she can still say, "Okay, I've heard you out, I've tried what you said, and it's not for me."

Acknowledgments

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References

1. From the transcript made of the initial videotape and published as an appendix to Robert Burt, *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations* (New York: The Free Press, 1979), pp. 174-80.