

Lawyers Alan Meisel and Mark Nordenberg, former Pitt chancellor, c. 1994

GOOD ENDINGS:

LEGAL SCHOLAR ALAN MEISEL ON OUR LAST DAYS

BY ROBYN K. COGGINS

lan Meisel, a JD, has spent a career engrossed in a topic people typically shy away from—death. The professor emeritus of law and psychiatry at the University of Pittsburgh retired this June. He is a national authority on the case law that outlines physician responsibility and patient rights involved in choosing to end one's life.

Appropriately, he's also one of the founders of Pitt's multidisciplinary Center for Bioethics and Health Law, which began as the Center for Medical Ethics in 1984.

"The area was so active that [when] you picked up The New York Times every morning, there would be an article on the front page about some ethical issue in medicine," he says of that time.

For decades, Meisel and Ken Schaffner (a PhD philosopher who went back to get his MD with Pitt Med's Class of '86 and is now Distinguished University Professor Emeritus of History and Philosophy of Science), codirected the center. Since 2016, the center has been directed by Lisa Parker, professor of human genetics, who's a philosopher (and a Pitt PhD graduate, A&S '90) known for her work on ethical issues surrounding informed consent and genetic research.

Meisel's rise as a young scholar accelerated Here, Me in 1982, when he was invited to join the staff of probin of the President's Commission for the Study of decisions.

Ethical Problems in Medicine and Biomedical and Behavioral Research—a group charged with reporting on current ethical subjects. That led to Meisel working on the commission's report, Deciding to Forego Life-Sustaining Treatment, in 1982.

His subsequent legal tome, The Right to Die: The Law of End-of-Life Decisionmaking, was first published in 1989 and is still updated twice a year by his coauthors, Kathy Cerminara (LAW '87) and Thaddeus Pope, to reflect the ever-changing legal analyses for these thorny issues. At nearly 1,500 pages, it is considered the authoritative source for legal precedents relevant to end-of-life decisions.

Can, and should, doctors actively help their patients die?

Today, six states and the District of Columbia allow physician aid in dying, with bills in the legislature or court decisions pending in several others. (Bills in Pennsylvania have failed to come to a vote.) There have been many court cases over the last few decades that grapple with this difficult issue: Can, and should, doctors actively help their patients die?

Such challenging questions are common fodder for debates within Pitt's bioethics center. Here, Meisel shared some insights from 50 years of probing tough questions about end-of-life decisions

Why is law such an important part of medicine and medical ethics?

It's very difficult to analyze bioethics issues in the United States in the last 30 years without paying attention to legal aspects of the same issues. So, they really are overlapping, complementary disciplines.

One of the subjects you study has been in the news a lot recently, so let's start with that: What is death with dignity?

[First of all,] I don't like the term "death with dignity," because I don't think it conveys very much at all. I talk about "actively aiding patients in dying." Many physicians still

have a very, very hard time accepting the idea of actively aiding

patients to die—so-called death with dignity. Although, I do think that there is increasing acceptance of it.

[End-of-life approaches such as] palliative care have been, of course, a tremendous development. It's helped so many people. But, it's also proved to be a major barrier to the acceptance of physicians of aid in dying.

How so?

Because [some] palliative care docs think that everybody can die painlessly—that they can medicate the pain away. And that's not always true. In addition, pain is not even the major concern of most people at the end of life: If you look at the surveys in Oregon and Washington

where [physician aid in dying is legal and] the state department of health does a report on this every year, you find that the major reason that people seek medication to end their

life is not pain, but loss of

Meisel independence, loss of abil-

ity to control their lives and do the things they want to do that they find meaningful.

And I think that doctors like to say they're afraid of the slippery slope—that if we legalize aid in dying, we will eventually get to involuntary euthanasia. My feeling is, there isn't anything we do that doesn't have some risk of being taken to the extreme. But, we've been pretty good at drawing lines that would allow people to engage in certain practices and not go any further.

Bring [the practice of aid in dying] out in the open and regulate it.

Do you get a sense physicians generally feel like these laws for revoking care or making end-of-life decisions are clear now?

Clearer, yeah. The current generation of physicians grew up with these practices. Whereas, when they were first being estab-

lished between '75 and '90, you had a generation or two of doctors for whom this was all new, it was changing.

What are some of the newest ethical concerns in end-of-life care?

[In addition to] the adoption of death with dignity laws, another area has been so-called futile treatment.

Whereas the whole right-to-die movement was kicked off by patients or their families wishing to refuse treatment, the futility cases involve patients and families *demanding* treatment from doctors who believe that it's futile to provide it. That had a fair amount of momentum for a while, but there's not been a lot of litigation in that area in recent years. It may be because they get settled at the bedside level or the hospital level, and they just never make it into the legal annals.

What would you say to physicians who feel uneasy about the aid-in-dying movement?

My position is, doctors have been aiding patients in dying in the United States legally since the Karen Quinlan case in 1976. [That was a landmark suit in which Quinlan's parents petitioned to remove comatose Karen from artificial respiration after a devastating accident; doctors refused, and the Quinlans took their case to the New Jersey Supreme Court and won.]

They've been doing it by withholding treatment, by withdrawing treatment at the patient's request—or at the request of a family member who has the legal authority to speak for the patient who can no longer speak for himself.

Physician aid in dying [as a movement] is saying, There are certain patients who are near death, [but] who are not being kept alive by any medical treatment that you could withhold or withdraw. All we're doing is providing them with the means to end their life, the same as the patients from whom you could withdraw treatment. They deserve the same humane treatment. (I use treatment in the nonmedical sense there.) And that can be done by providing them, at their request, with medication.

What about in cases where the person can't make that request?

Here, if you want to err on the safe side, let's say the patient has to be competent to do it. Let's see how that works. If we want to expand it later, we can.

I think that probably the laws in the states where it has been legalized have one major flaw, and that is for patients who are going to suffer from dementia. The laws require that you be terminally ill [and] within six months of death. Well, people who are demented, by the time they're six months from death, no longer have the capacity to make these kinds of decisions on their own. So, we need to be able to figure out some way to provide aid in dying for them, as well. And my feeling is you do that through an advance directive. You either specify that when you reach a certain point, you would like to have a lethal dose of medication, or when you reach a certain point, that you authorize your family members to decide whether or not to do that.

It sounds like you and colleagues [in medicine] have some pretty interesting conversations.

Yeah. Sometimes it's like, Okay, we'll have to agree to disagree on this one. . . .

But one of the reasons that I have no desire to leave Pittsburgh, especially as I get older, is because of the great medical care here.

ESQUIRING MINDS

Though Alan Meisel is stepping back from his work at Pitt, he will continue to direct the Master of Studies in Law program, which he says could be a boon to physicians seeking more knowledge of the law. "Part of my portfolio is dreaming up new online legal education programs for nonlawyers," he says. "There are so many people that have jobs that are affected by law in one way or another, who need to know something about law and don't need a law degree." -RKC

TAKE TWO

THE PHYSICIAN'S RESPONSE

ROBERT ARNOLD ON GOOD ENDINGS

nown to collaborate as well as disagree, Alan Meisel and Robert M. Arnold—associate director of the Center for Bioethics and Health Law—have worked together on end-of-life ethics and training at Pitt for years. Arnold, an MD, is a Distinguished Service Professor of Medicine, director of the Section of Palliative Care and Medical Ethics, and director of the Institute for Doctor-Patient Communication at Pitt. He is a recipient of the Patricia Price Browne Award, as well as other honors recognizing his lifetime achievements in palliative care. We asked him to weigh in on debates about death.

What kind of legacy is Alan Meisel leaving behind?

Alan basically started a field. He's a scholar in this space, and his book is the reference for all others. Starting a center for bioethics and running it for 30 years is a humongous accomplishment. In some ways, you could tie the birth of palliative care to the work that Alan did.

How does a lawyer like him approach end-of-life issues differently than a physician like you?

Lawyers are logical and rational. For those of us who are physicians, the degree to which emotions are important, and the degree to which people make decisions [based on them], matters.

Bioethics [—and law—] often is about the worst-case scenarios. In medicine, you work to try to avoid the worst-case scenario.

Meisel suggested that some doctors think they can do more than is realistic to help someone at the end of life—say, relieve all people's pain.

I think that some of the push for physician aid in dying has to do with the fact that you

can't always relieve all of a patient's pain. We should be honest about what we can and what we can't do.

While I think he's right, I still think that's the exception rather than the rule. And so the question is, How much time and energy should we spend on the cases when we can't relieve all of someone's pain, and what are the options then?

I would like us to spend a lot more time training clinicians to promote good quality of life for seriously ill patients and develop

that means.

So rather than get into a debate regarding futility, I find that by communicating better, you can resolve the issue.



Arnold

What's your reaction to the legal actions in California and elsewhere regarding death with dignity?

I think that it's clearly the case that physician aid in dying is going to happen in America. The question, it seems to me as a physician, is, How do we develop good policies? [And] how do we collect data so that we know we are doing as good a job as possible

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public policies that have this focus, rather than letting the conversation be dominated by physician aid in dying.

What about so-called "futile treatment," which is just starting to become a legal issue?

Well it's not really a new controversy [in medicine], but there is this issue: How do you define treatment that's futile? Do doctors have to offer treatment that they think is futile? How do you figure that out? Who gets to decide if things are futile?

It doesn't happen as much as we think it happens, because we always remember the worst cases, right? We should spend at least as much time thinking about what we could do to try to help people not get stuck in that fight.

That is, often, patients will say things like, "We want everything done." My response would be to say, "Oh, tell me what you mean by everything." Because often people say they

want everything done, but they don't have any idea what for dying patients?

It's sad that the medical profession is basically taking a hands-off position to this. Because, when 20 percent of the [country's] population has access to aid in dying, it seems to me you can't take a hands-off position. We need to make sure that we're paying attention to the dying, and we're training doctors so that they can deal with these very difficult issues.

What's on the horizon for end-of-life issues from your perspective?

Changes are going to continue to occur. The issue now is about the use of opiates: How do you come up with good opiate [pain relief] policies for people who have serious life-limiting illnesses, given the rise in opiate abuse? Another example is how to deal with marijuana. As health care delivery changes, we need to think about how social and health care policies affect the care of seriously ill patients.

I see Pitt scholars continuing Alan's legacy for the foreseeable future. —*RKC*

Both conversations have been edited for clarity and length.