

Peter Saul: Let's talk about dying

5 Look, I had second thoughts, really, about whether I could talk about this to such a vital and alive audience as you guys. Then I remembered the quote from Gloria Steinem, which goes, "The truth will set you free, but first it will piss you off." (Laughter) So -- (Laughter)

10 So with that in mind, I'm going to set about trying to do those things here, and talk about dying in the 21st century. Now the first thing that will piss you off, undoubtedly, is that all of us are, in fact, going to die in the 21st century. There will be no exceptions to that. There are, apparently, about one in eight of you who think you're immortal, on surveys, but -- (Laughter) Unfortunately, that isn't going to happen.

15 While I give this talk, in the next 10 minutes, a hundred million of my cells will die, and over the course of today, 2,000 of my brain cells will die and never come back, so you could argue that the dying process starts pretty early in the piece.

20 Anyway, the second thing I want to say about dying in the 21st century, apart from it's going to happen to everybody, is it's shaping up to be a bit of a train wreck for most of us, unless we do something to try and reclaim this process from the rather inexorable trajectory that it's currently on.

25 So there you go. That's the truth. No doubt that will piss you off, and now let's see whether we can set you free. I don't promise anything. Now, as you heard in the intro, I work in intensive care, and I think I've kind of lived through the heyday of intensive care. It's been a ride, man. This has been fantastic. We have machines that go ping. There's many of them up there. And we have some wizard technology which I think has worked really well, and over the course of the time I've worked in intensive care, the death rate for males in Australia has halved, and intensive care has had something to do with that. Certainly, a lot of the technologies that we use have got something to do with that.

30 So we have had tremendous success, and we kind of got caught up in our own success quite a bit, and we started using expressions like "lifesaving." I really apologize to everybody for doing that, because obviously, we don't. What we do is prolong people's lives, and delay death, and redirect death, but we can't, strictly speaking, save lives on any sort of permanent basis.

40 And what's really happened over the period of time that I've been working in intensive care is that the people whose lives we started saving back in the '70s, '80s, and '90s, are now coming to die in the 21st century of diseases that we no longer have the answers to in quite the way we did then.

45 So what's happening now is there's been a big shift in the way that people die, and most of what they're dying of now isn't as amenable to what we can do as what it used to be like when I was doing this in the '80s and '90s.

50 So we kind of got a bit caught up with this, and we haven't really squared with you guys about what's really happening now, and it's about time we did. I kind of woke up to this bit in the late '90s when I met this guy. This guy is called Jim, Jim Smith, and he looked like this. I was called down to the ward to see him. His is the little hand. I was called down to the ward to see him by a respiratory physician. He said, "Look, there's a guy down here. He's got pneumonia, and he looks like he needs intensive care. His daughter's here and she wants everything possible to be done." Which is a familiar phrase to us. So I go down to the ward and see Jim, and his skin his translucent like this. You can see his bones through the skin. He's very, very thin, and he is, indeed, very sick with pneumonia, and he's too sick to talk to me, so I talk to his daughter Kathleen, and I say to her, "Did you and Jim ever talk about what you would want done if he ended up in this kind of situation?" And she looked at me and said, "No, of course not!" I thought, "Okay. Take this steady." And I got talking to her, and after a while, she said to me, "You know, we always thought there'd be time."

5 Jim was 94. (Laughter) And I realized that something wasn't happening here. There wasn't this dialogue going on that I imagined was happening. So a group of us started doing survey work, and we looked at four and a half thousand nursing home residents in Newcastle, in the Newcastle area, and discovered that only one in a hundred of them had a plan about what to do when their hearts stopped beating. One in a hundred. And only one in 500 of them had plan about what to do if they became seriously ill. And I realized, of course, this dialogue is definitely not occurring in the public at large.

10 Now, I work in acute care. This is John Hunter Hospital. And I thought, surely, we do better than that. So a colleague of mine from nursing called Lisa Shaw and I went through hundreds and hundreds of sets of notes in the medical records department looking at whether there was any sign at all that anybody had had any conversation about what might happen to them if the treatment they were receiving was unsuccessful to the point that they would die. And we didn't find a single record of any preference about goals, treatments or outcomes from any of the sets of notes initiated by a doctor or by a patient.

15 So we started to realize that we had a problem, and the problem is more serious because of this.

20 What we know is that obviously we are all going to die, but how we die is actually really important, obviously not just to us, but also to how that features in the lives of all the people who live on afterwards. How we die lives on in the minds of everybody who survives us, and the stress created in families by dying is enormous, and in fact you get seven times as much stress by dying in intensive care as by dying just about anywhere else, so dying in intensive care is not your top option if you've got a choice.

25 And, if that wasn't bad enough, of course, all of this is rapidly progressing towards the fact that many of you, in fact, about one in 10 of you at this point, will die in intensive care. In the U.S., it's one in five. In Miami, it's three out of five people die in intensive care. So this is the sort of momentum that we've got at the moment.

30 The reason why this is all happening is due to this, and I do have to take you through what this is about. These are the four ways to go. So one of these will happen to all of us. The ones you may know most about are the ones that are becoming increasingly of historical interest: sudden death. It's quite likely in an audience this size this won't happen to anybody here. Sudden death has become very rare. The death of Little Nell and Cordelia and all that sort of stuff just doesn't happen anymore. The dying process of those with terminal illness that we've just seen occurs to younger people. By the time you've reached 80, this is unlikely to happen to you. Only one in 10 people who are over 80 will die of cancer.

35 The big growth industry are these. What you die of is increasing organ failure, with your respiratory, cardiac, renal, whatever organs packing up. Each of these would be an admission to an acute care hospital, at the end of which, or at some point during which, somebody says, enough is enough, and we stop.

40 And this one's the biggest growth industry of all, and at least six out of 10 of the people in this room will die in this form, which is the dwindling of capacity with increasing frailty, and frailty's an inevitable part of aging, and increasing frailty is in fact the main thing that people die of now, and the last few years, or the last year of your life is spent with a great deal of disability, unfortunately.

45 Enjoying it so far? (Laughs) (Laughter) Sorry, I just feel such a, I feel such a Cassandra here. (Laughter)

50 What can I say that's positive? What's positive is that this is happening at very great age, now. We are all, most of us, living to reach this point. You know, historically, we didn't do that. This is what happens to you when you live to be a great age, and unfortunately, increasing longevity does mean more old age, not more youth. I'm sorry to say that. (Laughter) What we did, anyway, look, what we did, we didn't just take this lying down at John Hunter Hospital and elsewhere. We've started a whole series of projects to try and look about whether we could, in

fact, involve people much more in the way that things happen to them. But we realized, of course, that we are dealing with cultural issues, and this is, I love this Klimt painting, because the more you look at it, the more you kind of get the whole issue that's going on here, which is clearly the separation of death from the living, and the fear — Like, if you actually look, there's one woman there who has her eyes open. She's the one he's looking at, and [she's] the one he's coming for. Can you see that? She looks terrified. It's an amazing picture.

Anyway, we had a major cultural issue. Clearly, people didn't want us to talk about death, or, we thought that. So with loads of funding from the Federal Government and the local Health Service, we introduced a thing at John Hunter called Respecting Patient Choices. We trained hundreds of people to go to the wards and talk to people about the fact that they would die, and what would they prefer under those circumstances. They loved it. The families and the patients, they loved it. Ninety-eight percent of people really thought this just should have been normal practice, and that this is how things should work. And when they expressed wishes, all of those wishes came true, as it were. We were able to make that happen for them. But then, when the funding ran out, we went back to look six months later, and everybody had stopped again, and nobody was having these conversations anymore. So that was really kind of heartbreaking for us, because we thought this was going to really take off. The cultural issue had reasserted itself.

So here's the pitch: I think it's important that we don't just get on this freeway to ICU without thinking hard about whether or not that's where we all want to end up, particularly as we become older and increasingly frail and ICU has less and less and less to offer us. There has to be a little side road off there for people who don't want to go on that track. And I have one small idea, and one big idea about what could happen.

And this is the small idea. The small idea is, let's all of us engage more with this in the way that Jason has illustrated. Why can't we have these kinds of conversations with our own elders and people who might be approaching this? There are a couple of things you can do. One of them is, you can, just ask this simple question. This question never fails. "In the event that you became too sick to speak for yourself, who would you like to speak for you?" That's a really important question to ask people, because giving people the control over who that is produces an amazing outcome. The second thing you can say is, "Have you spoken to that person about the things that are important to you so that we've got a better idea of what it is we can do?" So that's the little idea.

The big idea, I think, is more political. I think we have to get onto this. I suggested we should have Occupy Death. (Laughter) My wife said, "Yeah, right, sit-ins in the mortuary. Yeah, yeah. Sure." (Laughter) So that one didn't really run, but I was very struck by this. Now, I'm an aging hippie. I don't know, I don't think I look like that anymore, but I had, two of my kids were born at home in the '80s when home birth was a big thing, and we baby boomers are used to taking charge of the situation, so if you just replace all these words of birth, I like "Peace, Love, Natural Death" as an option. I do think we have to get political and start to reclaim this process from the medicalized model in which it's going.

Now, listen, that sounds like a pitch for euthanasia. I want to make it absolutely crystal clear to you all, I hate euthanasia. I think it's a sideshow. I don't think euthanasia matters. I actually think that, in places like Oregon, where you can have physician-assisted suicide, you take a poisonous dose of stuff, only half a percent of people ever do that. I'm more interested in what happens to the 99.5 percent of people who don't want to do that. I think most people don't want to be dead, but I do think most people want to have some control over how their dying process proceeds. So I'm an opponent of euthanasia, but I do think we have to give people back some control. It deprives euthanasia of its oxygen supply. I think we should be looking at stopping the want for euthanasia, not for making it illegal or legal or worrying about it at all.

This is a quote from Dame Cicely Saunders, whom I met when I was a medical student. She founded the hospice movement. And she said, "You matter because you are, and you matter to the last moment of your life." And I firmly believe that that's the message that we have to carry forward. Thank you. (Applause)