
Living with Lou: Dudley Clendinen on a Good, Short Life
Jan. 18, 2012: The Body Is Going Out

TOM HALL: Good morning. I'm Tom Hall. For almost a year now, I've been speaking every couple of weeks with the writer and journalist Dudley Clendinen. He is a former national correspondent and editorial writer for the NY Times, and the author of four books, and in November of 2010, he was diagnosed with ALS, or amyotrophic lateral sclerosis, commonly known as Lou Gehrig's disease. He used to join me in the studio, but in early December, I went to visit him in his home. The disease is taking its toll. Dudley can still walk, but his muscular function is considerably more limited than it used to be, and he has bulbar onset ALS, which first affects his voice. Because of that, Dudley is becoming much harder to understand, so sometimes I'll provide additional clarification.

We talked about Dudley's experience in the past with others who were dying, including his mother, about whom he wrote his last book, A Place Called Canterbury: Tales from the New Old Age in America.

DUDLEY CLENDINEN: I've always observed what it was like to be me in the presence of them.

TH: *Observed what it's like to be in the presence of them.*

DC: It never occurred to me to wonder what they were feeling on the inside.

TH: *What THEY were feeling on the inside.*

DC: When you're with someone who's dying, whether it's over the course of a day or two, a week or two, or years, they seemed to go out gradually like a light being turned down.

TH: Like a light being turned down.

DC: They become less emotive. Less expressive. Quieter. Eventually they just kind of wink out.

TH: *Quieter, and eventually they just wink out. Dudley then told me that when he was first diagnosed in November of 2010, at least he had knowledge on which he could act upon, which gave him energy. He said then, he felt more spirit-filled than physically dragged. Now he feels more physically dragged.*

DC: The body is going out and there's this feeling of a machine and someone is sending sand into the gears. Nothing works very well.

TH: *A machine with sand in the gears. Nothing works very well.*

DC: It's hard to talk. It's hard to breathe. It's harder to swallow pills. It's harder and harder to pick up pills. My hands are turning into claws.

TH: *Hands are turning into claws.*

DC: They look like crabs. Blue crabs. The body is getting very unreliable, and it's very distracting.

TH: *Unreliable and distracting.*

DC: It's noisy. It's raggedy. I have lots of gas. There are all kinds of impolite and irksome qualities to it.

TH: *Impolite and irksome qualities.*

DC: My face has very little expression, because the muscles of the face don't work anymore. I can't look up level because my neck is getting bent back.

TH: The muscles in your neck – it's difficult to keep your head up, isn't it?

DC: My expression is always strained. It's like wearing a mask suddenly instead of a face.

TH: *A mask instead of a face.*

DC: Instead of a smile, I have a mask, which cannot smile or show joy or animation. That has to come from my eyes, I guess.

TH: *Dudley then said that not only was his body changing, his thoughts about living with the disease were also changing.*

DC: There are ways you can measure it. I said in the piece I wrote for *The New York Times* in July that when I couldn't tie my bowtie, walk the dog around the park, have conversation at dinner with my friends, et cetera, I wouldn't want to stick around anymore.

TH: *Wouldn't want to stick around.*

DC: I can't be funny anymore. I can't be quick. I can't be spritely. I can't be spontaneous.

TH: *You anticipated even before July—we talked about it many times—being frustrated by that--to the point of not wanting to be living. Has your thinking changed about that at all?*

DC: *Laughs.* Well, yeah, because of this book.

TH: *You have the book, and it's a major animator.*

DC: *It's both -- it's a mixed blessing.*

TH: *A mixed blessing, yeah.*

DC: On the one hand, I cannot imagine any greater bore or frustration than waking up each morning to a day that will contain nothing but further deterioration and sitting around while you degrade.

TH: *Further degradation and deterioration – you don't want to sit around and do that. You have something to do now; you have something important to do.*

DC: Exactly. The book is a blessing in that respect. But on the other hand, it's hard to do because I don't have much energy.

TH: *Don't have much energy. Then we talked about the many people who have written since our series began.*

We get a lot of mail, postal mail, comments on the blog. We get emails. A lot of people send me emails that they ask me to forward to you. I've been doing this for months. The one question most people ask concerns how you're going to control your exist. So many people ask: how are you going to do it? They want to know for their own selves and their own purposes. How do you respond whne people ask you that?

DC: It's hard. I've had a lot of people who have written and called directly to me from all over America and parts of the world ...usually they're in their 80s or 90s. One man called from the ambulance. He said, 'I'm 93, I'm on the way to the hospital. How do I do it?'

TH: *93. He's in the ambulance on the way to the hospital, and he asks you how does he do it.*

DC: I feel badly. I do not help them. Because I don't want to be in the position of -- I'm not Doctor Dudley. I don't want to be Doctor Death.

TH: *You don't want to be Doctor Death. You've chosen not to respond. This is a personal decision for you isn't it?*

DC: Legally, morally, I don't think I should be advising other people how to take their lives.

TH: *Advising other people on how to take their lives.*

DC: But I would say this. The first step is: get a doctor, a specialist specializing in whatever area your problem is.

TH: *A specialist in whatever area your problem is.*

DC: One whom you trust, and who one who trusts you. Doctors have to trust their patients.

TH: *Trust. It's not a one way street. It's not just the patient trusting the doctor; it's the doctor trusting the patient.*

DC: If the doctor is going to support you and your wish to die, he has to trust you not to suddenly change your mind and cause trouble in some way. So get a doctor who can help and someone who can certify you as terminal and qualify you for hospice.

TH: *Certify you as terminal and qualify you for hospice.*

DC: At home. At home.

TH: *At home.*

DC: And then you'll have the privacy to do as you wish. By the time you get to that point, you'll know what I'm talking about. That's as much as I can say.

TH: *The writer Dudley Clendenin. I spoke with him in his home, early last month. He was diagnosed with ALS, or LGD in November of 2010. We've been speaking with Dudley about it since last February. We have all of those conversations on our website in a special section called "Living with. Lou: Dudley Clendenin on a Good Short, Life." Come to wypr.org, and click on the Maryland Morning link.*

It's Maryland Morning. On 88.1, I'm Tom Hall. Thanks for joining us.