

## Having a “Family Plan” for Medical Care

Powerful Patient Event

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### **Andrew Schorr:**

Now some people get into very severe problems where they have breathing problems. Now it could be COPD. It could be asthma, or it could be things that happen even at end of life. Typically pulmonologists are very involved in that care, and we have the director of Respiratory Care Services, but he also is on patient councils that UW Medical Center has. So for years, and you'll hear more about it later, they have councils where there are patients and doctors, like Josh, who sit across the table, how can we make things better, and that's not typical, so we're going to talk more about that. Josh, why don't you talk more about from your point of view in your area but also your experience and also talk a little bit about the dialog between patients and even UW in trying to make things better?

### **Dr. Benditt:**

Absolutely, thank you. Let me describe my practice a little bit first, and then I'll give some pointers kind of from each of those parts and then I'll talk a little bit more about the patient-doctor councils and things like that that I think are very important.

I am a pulmonary and critical care physician. I work at the University of Washington Medical Center, and my practice is really of two parts. When I work in inpatient I work in an intensive care unit with medical patients who have pneumonias, bad infections, bleeding from their gastrointestinal tract. They are in severe enough condition where they have to come to a place where they can be monitored closely and have basically one-on-one nursing.

As an outpatient doctor I work a lot with people with amyotrophic lateral sclerosis, and so you might ask well what's a lung doctor doing with patients like that, and the reason for that is that people with neuromuscular diseases, the thing that really gets them into trouble is their breathing muscles, and when those muscles do not work well they can get pneumonia, respiratory failure, and even die from that. So I do a lot of work with people with those conditions and therefore a lot of end-of-life work.

I have tips for kind of both areas. So as an outpatient I like to kind of term it sort of a polite or respectful assertiveness. That is I find it very, very helpful when the patient comes to me with kind of demands. That is that they would like to understand more about their disease or how do I see the progression or what kinds of things do I suggest. A lot of times they'll come with questions written down, which I think is fantastic. It means they've been doing thinking about it beforehand.

I also suggest that people keep a notebook of their healthcare. I actually do this. So when I get test results, so cholesterol levels or blood pressure or things like that, I'll write them down in a book. It can be a small notebook or even a little spiral bound, and you keep that and bring it to the appointments.

For people who have kind of more complicated conditions I suggest they actually get the printed records from the hospital, and those are totally available. You can get those printed up for you. You can keep them. So if you have multiple medical problems, that's a great thing to have for instance if you go to a new doctor and they need to know information you can give them copies of that. It's really a great thing.

I think most physicians find that very helpful, and if they don't I would agree with Dr. Van Gelder, you might want to seek another physician because I think they really need to accept that you are going to advocate for yourself.

So that's kind of in the outpatient setting. What about in intensive care? That's a little different because oftentimes people who are in intensive care are sick enough where they are not actually able to advocate for themselves at that moment in time, and that's where the family comes in, and I think it's very important that your family be an advocate for you as well. The families where I've found where it's most productive are those again who are respectfully assertive. So for instance in the ICU we round with each patient every single day at least once or twice. After that we have time to do other things, and one of those is meeting with the families, and I really enjoy it when a family comes to me and says, 'I'd like to meet with you every day even if it's just for a brief update of how my husband/wife/father is doing.' I think that can make a lot of difference. It keeps your relative in the forefront of the doctor's minds, and it's not something where they want to ignore anyone, but it's just that if we have 20 patients in the intensive care unit, you know, we're running around a lot. So that can be very helpful.

I think in the same way asking questions. 'Why are we doing this? What do you think the progression of this disease is going to be?' and so the family members kind of take the role of the patient in the outpatient department. So critical care, as it says, it's a very critical issue, and I think putting energy into that is important.

**Andrew Schorr:**

Could I ask a couple of questions?

**Dr. Benditt:**

Sure.

**Andrew Schorr:**

So in critical care unfortunately when we get really sick and maybe are older and infirm; like with my dad, he died there, he did not get out.

**Dr. Benditt:**  
Right.

**Andrew Schorr:**

So I know there are living wills and advanced directives and all that, but sometimes if we can't communicate for ourselves there is a debate among family members as to what to do about Mom or Dad or what were our wishes? So for those of us who, let's face it, life is a one-way trip, and we hope our demise is not in your unit and in intensive care, but what could we do so that there's more clarity?

**Dr. Benditt:**

That's a superb question, and a lot of effort has gone into that. I think practically the best thing that can be done is that you sit down with your family and have a discussion beforehand. As Americans we're not that used to it. I think in other cultures there's a lot more acceptance of the end of life, but in America we're not quite so attuned to that, but I think sitting down and saying, 'Well, if I had a disease where I was in the intensive care unit and I was on a breathing machine for two weeks, I think if it looked like I wasn't going to be able to come off the breathing machine I'd really want to stop and be kept comfortable.'

If you happen to know what your problem is, like for instance my patients with Lou Gehrig's disease, we have a fairly clear idea of what can happen, and I can talk with them about that beforehand. It's really in the unknown situation where it's harder, but I think the more your family knows what you want the better because that's what the physicians will ask them. They'll sit them down in a room and they'll say, 'If your mom, dad, husband, wife could be here what would they be telling us about what they'd want us to do?' So the more you can communicate that beforehand the better, and those are not easy conversations, and I've had that with my family members. It's not easy, but it can be so helpful at a time when things are really difficult.

**Andrew Schorr:**

One other question. So you may have somebody at UW Medical Center who's in intensive care and a son or daughter live 3,000 miles away and they're trying to figure out what's going on. So two questions about that, and we'll ask Lorie Wild in nursing about it too: How can a family member get information, and how can they make sure that they're hearing it from somebody who's really at the bedside providing care and who's leading the care such as yourself?

**Dr. Benditt:**

Sure. Well there are kind of two answers to that. One is that the nurses in intensive care are spectacular, and Lorie is in charge of all our nurses. Basically I think across the city, but at the UW Medical Center in particular the critical care nurses are fabulous. They are very interested in communicating, and they're at the bedside all the time. So kind of minute-by-minute updates can occur through them, and that's very effective.

A way to communicate with a head of the team, the attending physician in the ICU is to set up a time. So we've had people in Boston, New York, Los Angeles, and we say okay we're going to have a conference call at 1:00 p.m. for five or ten minutes on a daily basis, and most of our units have phones that can do conference calls. So we might have somebody who's a relative sitting in the room and then the people calling in from outside.

So it's quite possible to do the same kind of daily meetings with somebody who is 3,000 miles away.

**Andrew Schorr:**

Just one other question. For some of us who are kind of techno-people now, we all even have video cameras in our cell phones, how would you feel if somebody came to an exam and said, 'I want to share this with the family.' Not, you know, for the world on "YouTube," but, 'I want to put it on a website so that they know what you're saying about Mom or Dad.'

**Dr. Benditt:**

Meaning about like taking a picture of a physical...

**Andrew Schorr:**

No, no, no. A video tape of your comments for the family with the permission of the patient.

**Dr. Benditt:**

Oh sure. Oh absolutely.

**Andrew Schorr:**

Or even tape recording something?

**Dr. Benditt:**

I think that's fine. There's always an issue of kind of HIPPA compliance, so we don't want a lot of patient information on the web.

**Andrew Schorr:**

Right.

**Dr. Benditt:**

But to share with family members with permission? Absolutely, and in fact I've had people both in the inpatient and outpatient arenas who bring in a tape recorder so that they can go home and review the conversation. That's fine especially if it's kind of a summary meeting.

**Andrew Schorr:**

Right.

**Dr. Benditt:**

Like let's say you meet somebody, they have a disease, you've met with them a couple of times, and you're bringing them back in to discuss prognosis and treatment. I think that's a fantastic idea.

**Andrew Schorr:**

Okay, well stay tuned. We'll probably be doing more of that.

<<Andrew acknowledges a raised hand in the audience>>

Did you have a question young lady?

**Audience Member "Jacqueline"**

I do. My name is Jacqueline, and I've been dealing with this for a long time. I was classified as stage IV in 1987, and I'm still here.

Anyway, there are several end-of-life directives that are available now. Are there any that you would recommend over others?

**Dr. Benditt:**

There are number of documents that are available in the state of Washington but around the country. I think they're all good, and in fact the POLST form that's available from Washington State is really a great advance for us because it's very simple. I don't know if you've seen it. It's now a green colored form, and it's very specific about what you would want and what you would not want, and it's just two sides of one page. So it's fantastic in that it's simple, it's clear, it's easily readable.

The only issue that I have with advance directives is sometimes they don't deal with the specific problem that the patient has, and so I think they can't replace communication with the family or the physician about, again, for instance, 'I have Lou Gehrig's disease. I am going to have problems with breathing. If it comes to the point where I need a breathing machine with tracheostomy either, 'Yes I definitely want that or no I do not want that.' That is extraordinarily helpful in the specific instance.

Now unfortunately we don't know, many of us don't know what is going to happen to us, so you have to be general. I think the POLST form if I had to pick one is the best.

**Andrew Schorr:**

Okay. Josh thank you so much. We appreciate it.

**Dr. Benditt:**

Sure, you bet.

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