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Knowing the Facts: Advance Directives and End-of-Life Care

Female Speaker:

You're listening to ReachMD Radio on XM 160, the channel for medical professionals. Welcome to Advances in Long Term Care Medicine, produced in cooperation with AMDA. Your host is Dr. Eric Tangalos, Professor of Medicine at the Mayo Clinic in Rochester, Minnesota and a Certified Medical Director in Long Term Care.

Dr. Eric Tangalos:

What do physicians need to know about advanced directives in caring for patients at the end of life? Joining us to discuss Knowing the Facts: Advanced Directives and End of Life Care is Dr. Carl Steinberg, Associate Medical Director for Skilled Nursing Care at Scripps Coastal Medical Center in Vista, California.

Carl, welcome to the program.

Dr. Carl Steinberg:

Thank you.

Dr. Eric Tangalos:

Let's start with talking about advanced directives in the general population. How common and what do we mean by advanced directives?

Dr. Carl Steinberg:

Well advanced directives cover kind of a broad range of documents, and I would say in the public at large, just the general community dwelling population of all ages, it's pretty unusual for people to have one. Far less people have one than don't have one. For most people, it's just something that's not on their radar, even though of course any of us could go out and get hit by a car or something along those lines, but we have not necessarily made up a document that designates somebody else to make decisions on our behalf or tells physicians what we would want to be done, and those are basically the two things that advanced directives can do.

Dr. Eric Tangalos:

I know that the last time my wife and I had our will and trust updated, the lawyer gave us an advanced directive, and it actually freaked my wife out. I mean and this is after, you know, 28 years of marriage. I understand that people just don't do these things.

Dr. Carl Steinberg:

Right, and since the Patient Self-Determination Act back in the early 90s, it's something that basically every time a new patient presents to a new doctor's office, they're supposed to be informed that they have the right to formulate an advanced directive or designate a durable power of attorney for healthcare, but in fact, most people just sign a form saying okay I've been told that I can do it and then they don't do it, but we hear about the disaster cases where you know like Terri Schiavo, where the family members are warring over what she would have wanted or what they think God would want or things of that nature, and you know, it would be a lot better if you had a written document that stated what the person actually wanted.

Dr. Eric Tangalos:

We'll come back to some of those stories in a few minutes as we try to illustrate what's going on, but the umbrella term I think is advanced directives, and there's a bunch of different things under that. Let's talk about that for a while because some seem to close more holes than others.

Dr. Carl Steinberg:

Right. Well, I mean you've got your Durable Power of Attorney for Healthcare where basically you're just designating another person to act in your stead if you're incapacitated, and most of those forms don't designate that person to start acting in your stead until you're actually incapacitated. That also can present problems because I guess a lot of people, they just don't know for sure that they can rely on their loved one or whoever it is that they designate to make the decisions that they would want to, so in that type of document, a Durable Power of Attorney for Healthcare, they can also write specific wishes, like for example, I don't ever want to be fed on a feeding tube or things of that nature. So, that can help tighten that up a little bit. The other type of advanced directive would be something like a living will or a directive to physicians, and I should say this varies a lot from state to state. You know, the actual power that these various documents have, so that's something that listeners should be aware of and there's a lot of variability among the different states. And then there's this sort of newer concept, the POLST concept, which has also different names in different states, but POLST is Physician Orders for Life-Sustaining Treatment, at least that's what we call it in California and in Oregon where it started, but I think about 10 states now have fully implemented and legally-recognized documents like these and what they are, it's kind of like the old prehospital Do Not Resuscitate form, but they're much broader than that because they aren't just a DNAR. They may say that the person does want resuscitation. They also may say the person does or doesn't want tube feeding or transport to the hospital, things of that nature.

In other states, they have different names like Medical Orders for Life-Sustaining Treatment or MOLST. There's Physician Orders for Scope of Treatment or POST and several other names like that, but they tend to be these brightly colored forms that are portable, so essentially they're supposed to go with the patient wherever he or she goes, and it's a valid physician or practitioner order. That is meant to be honored no matter where they are, so I think this is a big step in the right direction.

Dr. Eric Tangalos:

Well let's stay with that. I'm sure our audience is interested in those new activities. I know that there's traction gaining with regards to POLST forms, West Coast more than elsewhere I think. What's the uptake in let's say general population hospitals versus nursing homes?

Dr. Carl Steinberg:

Well a lot of the nursing homes here, at least in southern California, have actually begun to I don't want to say require, but it's part of the admission paperwork for essentially every patient. If a patient doesn't want to fill one out or a family member doesn't want to, of course, they can't be forced to do it and then your default position is full code, you know, do everything. In other states, I'm not really sure. I should mention, although I think 10 states have it fully implemented and you know with legislation that has formalized it, there are a lot of other states, probably about 20 or so other states, that do have these documents but they're in various stages of moving through the legislatures and so on, but these forms are meant to be followed. For example, traditionally in a skilled nursing facility, if I write a no CPR or DNR order, that only goes as far as the door of the nursing facility, and when the person goes to the hospital, it may not carry any weight. Hopefully it does, at least locally, but it doesn't necessarily carry any weight, whereas these POLST forms, the physicians at the hospital are essentially legally bound to follow them. Now they can reassess, and of course, people do change their minds sometimes, but I think it really goes a long way in helping ensure that people's wishes are actually honored.

Dr. Eric Tangalos:

So if a facility uses this or the hospital uses this, that should stream, from what you describe, should streamline their responsibility to ask the questions about Do you have an advanced directive? This should fit there. This should substitute for that.

Dr. Carl Steinberg:

Yes, and historically because physicians might or might not have hospital privileges, you know with JACHO and CMS and so on, a form that was filled out elsewhere by a physician who might or might not have privileges wouldn't necessarily have to be honored, and I think this helps ensure that previously expressed wishes, previously documented wishes and it's a signed physician's order essentially, so the hospital still has to, to the extent possible, talk to the patient or talk to the responsible party, but hopefully they will follow what it says and that's what's going to be the default position as opposed to Hey we don't have a DNR so we're going to just pound the person's chest essentially.

Dr. Eric Tangalos:

If you're just tuning in, you're listening to Advances in Long Term Care Medicine from ReachMD Radio on XM 160, the channel for medical professionals. I'm your host, Dr. Eric Tangalos, and joining me to discuss Knowing the Facts: Advanced Directives and End of Life Care is Dr. Carl Steinberg, Associate Medical Director for Skilled Nursing Care at Scripps Coastal Medical Center in Vista, California.

Carl, we just finished talking about POLST, and it's very interesting to note that they are signed medical orders. I think that's a neat way to look at them as truly signed medical orders. Let's now talk about how some of these orders go astray and where families and the

hospitals reinterpret, change what plans are in place and what we might be able to do about that.

Dr. Carl Steinberg:

Sure, I think that's a topic that's on all of our minds and it's something that we've dealt with historically, even before the days of POLST, where somebody gets sent to the hospital and has a lot of things done that they didn't want to have done. And I think also from time to time, it can go in the other direction, and I just think we need to be mindful of that and particularly with the political issues that are going on nowadays and the talk of death panels and things of that nature, I think it's important to state that when there's doubt, I think you really have to err on the side of life. Now that being said, we have situations where I think most of us clinicians have taken care of patients for an extended period of time where they've said, "I don't ever want to be fed on a feeding tube." It goes against every grain of my belief system and then eventually the person, and I'm thinking of a particular case where this woman had multiple sclerosis and she said you know when I get to the point where I can't swallow, that's the point at which you know I don't want my life prolonged. She got to that point. She also not long after that became unable to communicate and then you know a family member blew in from some other part of the country and said, "Oh no, no, no, no we have to put a feeding tube in" and this is the kind of thing that it would have helped if we had a POLST on her. We did have a written document that stated she didn't want to be fed on a feeding tube but when push came to shove, her agent who she had designated as her durable power of attorney for healthcare had the right to change her previously expressed wishes, and that's a big problem. It creates a lot of conflict for us as providers.

Dr. Eric Tangalos:

All advanced directives give you the out. I mean people can change them anytime they want. It is as you point out very difficult when the person loses the ability to change their mind and they've designated somebody else that essentially acts in their behalf, so those are common things.

We were on teaching rounds earlier this week, and I was musing how you can take somebody in the hospital that's on death's doorstep and they're a DNR and then when they rally, it's changed and you have a full resuscitation and then they fail again and they're DNR again and we go back and forth and back and forth. One would think that the philosophy would be the same, either you do it or you don't, but I think most practitioners, especially in the hospital, see that this goes back and forth based on how the patient's fairing.

Dr. Carl Steinberg:

I agree, and I think that's something that we observe and certainly, you know, we've all taken care of people or maybe known people in our personal lives who say, "Gosh if I were ever stricken with some awful metastatic cancer, I wouldn't want anything done. In fact, I'd probably go swallow a bottle of morphine or something," but then when unfortunately they do get diagnosed with some terminal condition, they change their mind and they decide that they do want to live. And certainly people who have the capacity to make decisions on their own behalf are totally allowed to do that, but I think it's a totally different story when a family member comes in and says, "No I want you to perform chest compressions on my 93-year-old mom" who's got a chest full of metastatic rib lesions and things like that. I think that's very much a different story. And it's helpful sometimes to convene an ethics committee, which we do in many of the facilities where I attend residents. Certainly at the hospitals, those things are done too. But in a lot of these cases, there's not a simple solution and coming to a consensus can be a rocky and kind of protracted course.

Dr. Eric Tangalos:

It's always tough when somebody blows into town and has their own guilt that they have to work through. I would suspect that you do as we do and try to get most of the communication done way before there's any crisis situation that develops.

Dr. Carl Steinberg:

That's right, and I think in long-term care, that's one thing that having these POLST forms discussed beforehand, having that whole end of life conversation with people, can really help a lot and the more you have that consensus before something bad happens as it inevitably will in people who are particularly there to live out their days in a skilled nursing facility, you know, sooner or later their heart is going to stop just like all of our hearts are going to stop. And I think it's great to have that all talked over beforehand.

Dr. Eric Tangalos:

Listen, Carl, we're just about to finish. Any final comments for our listeners?

Dr. Carl Steinberg:

I would just say for those of us that work in long-term care, it's an honor and a privilege that we have to be able to sit at the bedside and talk over these very serious and really sacred issues with our patients and their families, and I think it's a job we shouldn't take lightly. I believe we need to do everything we can to honor what our patients want, even if it may not be exactly what we would want for our loved ones or for ourselves, and sometimes that's a very difficult path. I also think it's important for us to recognize our CNAs, our nurses, social services people that work with us in this setting may have bonds with our patients and to recognize that, for them, being part of the end of life and you know the sacred final moment of the person's life, that should be recognized and that everybody has feelings,

everybody has emotions over these things, and I think those of us that work in long-term care, we consider it sort of a passion and a calling and God bless the CNAs, the nurses, and everybody that helps care for these frail people in the final stages of their lives.

Dr. Eric Tangalos:

Well I would like to thank my guest from Scripps Coastal Medical Center, Dr. Carl Steinberg.

Carl, thanks very much for being our guest this week on Advances in Long Term Care Medicine.

Dr. Carl Steinberg:

Thanks for having me.

Female Speaker:

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