

## **Overcoming Barriers: Talking to Patients About Chronic Kidney Disease**

**Andrew S. Narva, MD, Theresa Kuracina, MS, RD, CDE**

Dr. Narva: So the question is, what are the barriers to talking to patients about kidney disease?

I think the main barrier is the fear and loathing that both patients and providers have about kidney disease. People are scared of kidney disease, not only the patients but also the providers. So I think it's important to overcome that and to sort of have permission to talk about kidney disease and actually intervene in the patient's management. I think many providers are worried that if they mention kidney disease that the patient's going to freak out and many patients, when they hear the words "kidney disease", they immediately think of dialysis and then they immediately think of death. So unless you give them more information, once you bring up kidney disease, they can walk out with this feeling that they are going to die. So, I think it's important to bring the topic up but then also to follow it up with information that really gives the patients some kind of realistic grasp on the nature of the problem, their prognosis, and the fact that interventions are available and that it needs to be addressed. I don't think there's any way to tell people news like this and for it to be okay. It's not okay; it's not okay to have kidney disease, it's not okay to have cancer. But what you can do by bringing this up early, in the primary care setting, it so give people time to come to terms with the diagnosis.

Teresa Kuracina, RD, CDE: And we also have to keep in mind that patients don't always feel that good. As kidney disease progresses, information that we give them, it may not be as understandable to them because of the complexity and they're scared as Dr. Narva said earlier. And when we do tell them that they have chronic kidney disease, sometimes they just don't want to hear it, that denial is a powerful thing. And again, if we mention it a little bit at a time, that might work a little bit better, you think?

Dr. Narva: Well I don't think it should be tiptoed around. I think that it's important to be sort of straightforward and to expect that people don't want to hear this and push back and sometimes people can be really stubborn. And I think sometimes the best thing you can do is acknowledge that stubbornness and say, I realize you don't like hearing this, and it's not easy and you may decide that you don't want to do what I'm suggesting because it means that you have some bad disease, that something bad is going to happen to you. And you don't want that to happen and you want to continue with your life. But I think acknowledging that, you can say, you know, right now it makes it hard but being stubborn is actually good, up to a point, because people who are stubborn are fighting and to live with any chronic disease, you have to fight. And one other issue, I know some people don't feel well but in fact most people don't feel any way as the patients say. And they will often say, why are you telling me this? It's scaring me, I feel fine. You're making me feel anxious and why? I'm feeling great. And I think it's important to say, look I'm really glad you feel great I'm not wishing this on you but by the time you feel sick, the way it works is that by the time you feel sick, you're really close to needing dialysis and there's no time for you to get ready. So if you're going to be prepared, we have to talk about it before you feel sick because waiting until you feel sick is too late.

Teresa Kuracina, RD, CDE: I can agree with you on some of that but I think, I guess what I meant about that they don't feel well is that there is so much information that it can be overwhelming and sometimes an approach that I take is a little bit of information at a time. I might tell them one word; today we're going to talk about phosphorus or we're going to talk about sodium. Because if you start telling them about all the nutrients at one time or all of the labs at one time, one they don't feel well and two they just won't be able to take it. It's kind of like when someone's blood sugar is really high and I'm trying to teach them something, they sit

there and they seem to understand but then when I ask them what it is that you're going to do differently at the end, they think they're thinking quite clearly but maybe they're not.

Dr. Narva: Actually I agree with you completely, whether people feel ill or not, they're scared and there's only so much information that they can take in. And the very first time you mention kidney disease, no matter what you say after that, it's not going to be remembered. So really the best thing you can do is to see people frequently and give them small chunks of information. Not because you're breaking it to them easily, but because there's so much information that you just give them a little bit at a time and you keep repeating it. And I used to think that you could somehow say things the right way so that everything would be fine and you can't. What you can do for the patient is to be as clear as you can and be there for them, keep showing up and keep explaining it to them. And they'll go through a period, they may get angry and be scared and get angry and not show up for six months. But if you started to explain things way ahead, even in six months when they come back and say well I've come to terms with this, they still don't need dialysis. But I think as Woody Alan says, 90% of things is showing up. If you're there for the patient, if you are present and you don't let things get in the way and you're willing to keep seeing the patient, you can make progress and sometimes you end up with somebody who is quite well prepared and actually does amazingly well even though they may have really resisted for awhile. And I think just like the patients, because there is so much information, sometimes as providers, we also have to be aware that there is a lot of information for us to remember and all the labs we need to check and all the different reasons that this or that may be happening. So if it's scary for you as well, I think that's normal too.