

Transcript Details

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The Patient Voice in Adult Growth Hormone Deficiency

Announcer:

You're listening to CME on ReachMD. This special podcast featuring a patient's perspective into adult growth hormone deficiency, titled "*The Patient Voice in Adult Growth Hormone Deficiency*" is brought to you by Prova Education as a resource to complement the CME activity titled "*Clinical Advances in Adult Growth Hormone Deficiency: Patient-Centric Approaches to Improve Adherence*."

Here is Dr. Kevin Yuen.

Dr. Yuen:

Growth hormone therapy is most effective when patients can participate in the creation of their treatment plan. Feeling that their voice is being heard during the decision-making process and feeling that treatment plans are being personalized to fit their needs are critical to treatment success. I'm Dr. Kevin Yuen, and I'm joined today by Patricia Buckley. Welcome.

Ms. Buckley:

Hello, Dr. Yuen.

Dr. Yuen:

Good to have you today. So, for many patients, the diagnostic journey of adult growth hormone deficiency can be long, arduous, and frustrating. Tell me what your experience was like.

Ms. Buckley:

Long, arduous, and really frustrating. I was diagnosed with a macro pituitary adenoma in, gosh, October. I had surgery for the removal of the tumor—transsphenoidal surgery. Six weeks post surgery, I went back to see you, as you know, my neuroendocrinologist, and from there, we did a whole battery of tests and other things to see what else was causing some of my issues.

Dr. Yuen:

So knowing what you know now, what do you wish your doctors had said to you initially or had asked you to help, perhaps, speed up that diagnosis for treatment to be implemented?

Ms. Buckley:

I guess I would say this, respectfully. This is a diagnosis that is really above most people's pay grades, and this is something that you truly need to see a specialist about. So it took me about 12 months from in the door with a problem to with my first growth hormone med in my hand. And I knew after I saw you that I was, for the first time in that 12- to 14-month period, in the right place. And I remember getting in the car, and I cried my entire way home because I knew for the first time that you knew what you were telling me and that we were going to, together, find a solution. So what I would say is keep pushing your own case. Even though they tell you, no, that's not right or that can't be happening or that makes no sense, you have to be your own advocate. You have to know and understand what your symptoms are, you have to have done your own research, you have to keep asking questions, and you have to follow up with your doctor. And it does require a lot of patience on the patient's part, and you really have to stay positive.

Dr. Yuen:

What has this therapy actually meant for your everyday living?

Ms. Buckley:

It's like night and day. You know, before I had my growth hormone meds, it was more withdrawal. I was constantly tired, not able to participate in things, and even holding a full-time job became almost impossible. But when I got the growth hormone finally approved

and I could finally start taking it, in a matter of two days I could feel the difference. I was more engaged; I was more involved in what was happening in other people's lives; I could take the dog out for a walk. I could just do things that you normally do that you don't even realize that you were missing out on. So now the good news is I don't get to miss a beat.

Dr. Yuen:

That sounds all very encouraging, Patricia. Has it been easy staying on growth hormone therapy daily injections, remembering to take the shots every day on schedule? How has that been, Patricia?

Ms. Buckley:

Ha, the truth time, right? Believe it or not, I have only missed one in the two-plus years I've been on it, and I would tell you that it is a great reminder when you miss one why you're on the drug to begin with. So if you think, well, maybe you don't need it or I'm going to try this—don't go here. Just follow the regimen because the symptoms come back. And very quickly, you realize, "Gosh, there is a real reason why I'm on this." So initially, I would set my phone alarm just to remind me when to take it. But the other thing that I do have a hard time remembering—if I'm traveling or I'm going to be gone someplace overnight, I have to leave a big sign next to my car keys to remember to take my meds with me. The deal with growth hormone—many of them need to be on ice, so you have to take a little packet with you. And I have, once or twice, driven two or three times to get to my destination because I had to go back and pick up my meds, so I just put myself a sign out.

Dr. Yuen:

Well, that's certainly very impressive that you've only missed one. I'm very encouraged, and you should give a pat on your back to yourself, you know?

Ms. Buckley:

Thanks, it makes a big difference, you know? I can't do without it, honestly.

Dr. Yuen:

Yes, I'm very, very, very impressed and very proud of you, too. So, in the healthcare field, we talk about this concept called shared decision-making. So some of the areas that this encompasses is providing you a voice or a say in the care that you receive. So how have you experienced this? And how has this type of relationship with your team helped you in this regard?

Ms. Buckley:

I would say I have definitely received the shared services model with you. Not only has it helped me personally talk about it—because most people have no idea when you say pituitary adenoma and anything else that follows; there's just a vacant look. But when I met you for the first time after a long, frustrating battle with why I was feeling this way, the other piece for me was the educational component. You spent a good deal of time explaining to me what was happening, why it was happening, and I took great comfort in that. I had done a lot of my own homework, but just to hear you kind of walk through that was helpful to me. For me, trust and integrity are two big, huge things, and I get this from you tenfold. I know I joke about this, but it's really true. You are my favorite doctor in the whole wide world, and it has meant the world to me that you include me. And I know at every turn, no matter what's going on, you give it to me straight and you have a solution or a way in which to help me, and that's awesome. So I would say my voice is heard, I'm not judged, I know you understand medically what's going on and what I'm going through, and sometimes you very subtly remind me of things that I know but I don't always talk about, you know, and other times it's just that I know that you're there. All I need is to pick up the phone and say I'm having a crummy day or this or that's going on, and you're there. So what I would say is you've given me my life back, and that's really no small thing, so thanks.

Dr. Yuen:

Well, thank you. That was, indeed, very nice of you and very kind words. I'm truly appreciative of that. I try and do my best for you, and this has certainly been a wonderful conversation that we have had. Thank you for your time and for sharing your journey with us in such a candid and honest manner. Thank you.

Ms. Buckley:

You're very welcome, and thank you.

Announcer:

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