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Caregiver Testimonial: A Day in the Life of the Bronchiectasis Patient

Announcer:
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Dr. Basavaraj:
Hi, my name is Ashwin Basavaraj, Section Chief of Pulmonary Critical Care and Sleep Medicine at Bellevue Hospital Center in New York City, and Associate Director of our Bronchiectasis and NTM Program at NYU Langone Health. Today we're going to be talking about a Patient Caregiver Testimonial: A Day in the Life of the Bronchiectasis Patient. With me today is Mrs. K. Mrs. K, thank you so much for joining me today.

As you know, a lot of patients with bronchiectasis have chronic symptoms, chronic cough, phlegm production, they have a lot of difficulty bringing out mucus, and they need extra help, something that we call airway clearance, nebulizers, high-frequency chest wall oscillation or vest therapies, positive expiratory pressure devices. Was your husband on any of these devices? And what were some of the challenges with the airway clearance and managing his symptoms?

Mrs. K:
Oh, he was prescribed by a pulmonologist. He had two different kinds of inhalant and he had a pleural valve and the nebulizer treatment. And he went for the vest therapy because he has a spinal surgery. It was a big challenge for my part because I had to watch them put the PICC line in. Finally, they said that he ran out of vein and he had to have a port put in. He put them vinyl vest on. And when he vibrate, his pain and his back, and the shaking his body, it was very, very, sometimes it's unbearable. I medicate him with the - he was on pain management, pain specialists that he was taking methadone by then. And he was - in between he would take Tylenol, and but he was able to walk. He was limping, but he was able to walk. It started with walker, and then later on his was in wheelchair and I have to make sure I carry oxygen tank, extra tank in the car because his oxygen requirement increases slowly. And he was getting like a 7 liters, and I was calculating how many left over in the tank. So how many hours it's going to last.

And that I have to get how many extra tanks I have to carry in my car trunk. And sometimes in the middle of his doctor's visit, I have to go downstairs and bring his oxygen tank and change his oxygen tank. And I had to carry oxygen tank and push wheelchair. And that was a big thing to do. We foresee this kind of situation in the home if you - I know that we had to in the tub, we placed the bars and so he can hold on to it. And the shower, he could sit on the stool, and he was sitting and I was giving bath. And at nighttime, I have to make sure he keep oxygen tube in his nose. Because sometimes while he's sleeping, he take it off or while he was dreaming, I do not know. So I have to make sure he has oxygen in his nose. I hired the healthcare like home nurse aide coming and sitting with him so I can get at least some sleep during the night. But it's difficult to sleep while all those things are going on. And he I discover like the nursing aide was sitting outside of the door sitting and looking at phone and then I go inside of the room on the bed. He was complaining about the mattress situation and the oxygen is out and slightly a little bit delirious and maybe his lack of oxygen in his system. So I had to pick it up. I put it in his nose. I have to remind him, and I make sure it's the side rails are up and I have to even take – I sleep during the night and I have to think about him. It was a very, very difficult situation.

Dr. Basavaraj:
It sounds like it.

Mrs. K:
And if nobody could help me, so I had to think about like, going the stairs. Coming down the stairs, he had the chair to sit down and going down the stairs and then take shower, come up. Anyway, it's been very, very challenging. And I had to think about everything, every single situation. Thankfully, he refused to sit on the commode. He had to go to the bathroom toilet. And I have to watch him, walking with a walker to the bathroom. And he cannot wipe himself, I helped him and I placed urinals, like a couple of urinals at bedside to make sure he used one at nighttime, and he can use the other one. And many things, and then nobody could really suggest or helped me, except I had to think everything myself. And that was a big challenge for me.

Dr. Basavaraj:
Yeah. No, it sounds like a big challenge and a lot of difficulty that you faced. And now you know, to learn more about this, patients can go to various websites that are available. Now, for example, there's the COPD Foundation that is listing a lot of resources and websites to try to learn more about bronchiectasis. They're a great foundation that's providing a lot of bronchiectasis education, there's NTM Info, or NTMIR, which is a patient advocacy group that, you know, gives a lot of information on bronchiectasis and nontuberculous mycobacteria. So there's various resources that are out there for patients and caregivers to learn more about bronchiectasis. In in case there are, you know, caregivers that are listening, those are some great resources to reach out to, to learn more about it.

Mrs. K, thank you so much for joining us today. I know it was a lot of challenges. And it was very difficult to come on and talk about this but you did a great job. And you know, providing insight into how it is to take care of these patients with bronchiectasis and the difficulty involved. So, thank you so much for joining me today.

Mrs. K:
Thank you, sir. Have a good day.

Announcer:
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