

Transcript Details

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Navigating Severe Asthma Together: A Patient-Clinician Conversation

Announcer:

You're listening to *Deep Breaths: Updates from CHEST* on ReachMD. This information is scientific and non-promotional in nature. This educational program was developed by CHEST in collaboration with and sponsored by GSK. And now, here's your host, Dr. Diego Maselli.

Dr. Maselli:

Welcome to *Deep Breaths: Updates from CHEST* on ReachMD. I'm Dr. Diego Maselli, Professor and Chief of the Division of Pulmonary Diseases and Critical Care at UT Health in San Antonio. And joining me to share her unique perspectives on challenges with identifying, treating, and managing severe asthma is our patient advocate and my friend, Stephanie Fuller. Stephanie, thank you so much for being here today.

Stephanie Fuller:

Thank you for having me. I'm so excited to do this today.

Dr. Maselli:

Thank you so much for joining me. So, to begin, Stephanie, I would like to take us back to when your asthma wasn't well controlled, back in the day. Can you tell us what you were experiencing and how it was affecting your daily activities?

Stephanie Fuller:

Yes. I was diagnosed with asthma, so I spent many days in and out of the hospital and had multiple doctor's appointments with my regular doctor and my specialist. And my mom and I traveled far, many miles, to try to find the right physician. I missed so many days of school, and I missed out on a lot of things in my childhood. So it seemed like my asthma could never get under control. As many medications and different treatments that I tried, it seemed like nothing worked.

Dr. Maselli:

It sounds to me like you had a long journey with your asthma, with long-standing symptoms and a lot of looking around for the right combination of provider and therapies. I think it's very important to mention that patients can adapt to asthma and their symptoms in ways that they may not immediately recognize. For example, they may avoid certain activities and almost accept that their symptoms are normal.

I think Stephanie mentioned something important, right? The journey can be a long journey trying to find the right therapies. And despite some of the therapies like biologics being available now, many patients that are eligible for these therapies with severe asthma are not specifically receiving them, or there might be some delays in getting them. And then, for that reason, they remain uncontrolled, like Stephanie, who had a long journey. This is despite being on high-dose inhaled corticosteroid treatments.

So, Stephanie, tell us a little bit more about what eventually helped you realize that your asthma wasn't doing well and that you really needed to do something to change it.

Stephanie Fuller:

I knew my asthma was not controlled when my home medications weren't working, and I was on steroids constantly, several times a year. I was in and out of the hospital, I was taking so many oral steroids, and I was getting not just the regular side effects, but the long-term side effects from it. I had many days where I was having so much trouble breathing, I didn't know if I would make it sometimes, like

when I had a severe attack. So I knew there was something that had to be done differently.

Dr. Maselli:

Yes. And thank you so much for sharing that, again. It seems to me like you had a lot of exacerbations and a lot of steroid use. And each patient is different, of course. Some patients may report symptoms on a day-to-day basis, like what you were describing with feeling that you couldn't breathe. But also, other patients describe what you described, really, which is frequent exacerbations and, unfortunately, relying on oral corticosteroids, going to the ER and hospital, and of course, limiting their activities of daily living.

Biologic therapy is now something that we are using more and more. Can you describe what were the steps for you getting to that advanced therapy?

Stephanie Fuller:

Yes. I had a severe attack, and I spent almost two weeks in the hospital six years ago. And during my time in the hospital, the pulmonologist felt that it would be a good idea if I would see another specialist about getting on a biologic. He thought that it would be a good choice for me with the symptoms and the constant attacks that I was having.

But sometimes, when you start a new medication, you expect things to change immediately. But with the biologic, that really wasn't the case. It actually takes time for you to see the difference. And when I first started, I was apprehensive about something different, because I had been on so many different therapies for my asthma. So it was something that I really didn't know if it was actually going work for me. I didn't see a difference right away, but I'd say after about a year or two—because I had to start getting on a regular schedule with it—I've seen a big difference, so I was very happy about that.

Dr. Maselli:

Great. I'm happy that this therapy was helpful. I think what you describe is very important, right? I think when we describe biologics to our patients, typically, our providers will describe what to expect, right? Is it going to be a quick fix? Is it going to take some time? Also, they describe what the side effects are and what to expect in the next several weeks to months as you continue this therapy.

In your case, how did the team explain if you had options, and did they talk to you about what priorities were important for you?

Stephanie Fuller:

Well, my physician that I see—my allergist—decided that one of the biologics was the best for me. So she told me about it, and she gave me information to read about.

But she told me that I would not see a difference right away. I would have to be on it for a little bit of time, and I also had to stay on schedule, which was hard for me because of transportation sometimes, or sometimes because of my schedule. So I knew that by me not being very much dedicated to getting that biologic every month, it was not going to work the way that it should. I found that I needed to become more dedicated to the therapy in order for it to start working. And once I started becoming dedicated to the therapy, I've noticed a big change in my health.

Dr. Maselli:

For those just tuning in, you're listening to *Deep Breaths: Update from CHEST* on ReachMD. I'm Dr. Diego Maselli, and I'm speaking with our patient advocate, Stephanie Fuller, about her journey with her severe asthma management.

So, Stephanie, thank you so much for sharing that information on how you started on the biologic therapy. You did mention that you had to incorporate a new schedule into your life. Were there some practical, emotional, or other logistical factors that made it easier or harder for you to stay on track?

Stephanie Fuller:

Staying on therapy takes a lot of patience, and it takes a lot of dedication. And it became pretty emotional in a way where sometimes I felt like the medication wasn't working for me. So I was kind of questioning whether I should still be on it. But my physician reassured me by saying, "Just give it some time, and if you stay dedicated to the schedule, you will see a big difference." So I took that chance, I gave it more time, and I also became more dedicated. At first, it was hard to get there every month to get that medication, but I made a sacrifice, and I knew if I didn't get the medication, my asthma was never going to get better. So I had to really dedicate myself to trying to find a way to get there, get the medication, and stay on track.

Once I got on track, I've seen a whole difference in my health. My asthma became better. The amount of steroids I was on decreased, and the amount of hospital visits decreased.

Dr. Maselli:

Thank you so much, Stephanie, for sharing that information. And I'm very happy that you're feeling better and you have less

exacerbations and less exposure to steroids. That's great. Yes, staying on therapy can be difficult. Even after a patient and a clinician make the decision to start, it's sometimes not as easy as it can appear. It's not just prescribing medication. In a US claims analysis of nearly 10,000 patients, only about 21 percent of patients maintain a consistently high adherence to biologics over a period of 12 months. And over 50 percent of these patients discontinue biologics in the first year. So you can see how this can be tricky at times for some of our patients.

Patients have described a wide range of reasons for discontinuing therapy, including difficulty fitting treatments into their schedules, injection or device challenges, organizing the prescriptions, and getting to the clinic or infusion centers, as Stephanie described. That's why clinicians need to dig deeper and ask about treatment burden rather than assume that a patient is simply choosing not to continue therapy.

With that being said, Stephanie, as you continue on therapy, what changes, if any, did you notice in your asthma in your daily life? What do those changes mean to you, really?

Stephanie Fuller:

The changes that I've noticed are the amount of steroids that I'm on now. I may get an asthma exacerbation once or twice a year, maybe because of a cold or flu season. My hospitalizations have cut down dramatically. I've gone years without having to even be in the hospital, which, to me, is very amazing, because I used to stay in the hospital at least a few times a year, and now I go months without even having to use my rescue medications. So I see a big difference, well enough where I feel that that medication that I'm taking, the biologic, is working wonderful for me.

Dr. Maselli:

That is great to hear, Stephanie. Less exacerbation, less rescue medication use—that's music to our ears for sure. As a clinician, I really appreciate that. I think your experience also highlights why clinicians need to agree with patients in advance on what treatment success should look like and continue to reassess it over time. This is an ongoing thing. And that may include looking into your exacerbations, as you described, but also very importantly, at your symptoms. Also, as you described, you use less rescue therapy, and you see improvement in your activities and things that you want to do.

Knowing that, Stephanie, how did you and your care team decide whether the treatment was working for you?

Stephanie Fuller:

My care team and I decided that the treatment was doing well because I wasn't in the hospital as much, like I said. I didn't have to have as many doses of steroids per year anymore, and I was able to start living a normal life outside of the doctor's office and outside of the hospital, where, before, I wasn't able to do any of those things. And now, my doctor is so proud of me because she's noticing a big difference in the way that my health is now compared to when I first started the medication.

Dr. Maselli:

This is great news. Thank you for sharing that, Stephanie. From the clinician's perspective, Stephanie's story reinforces the importance of asking about exacerbations, oral steroid use, activity avoidance, treatment burden, and of course, the patient's goals. Shared decision-making should not only be a one-time conversation. It really should be an ongoing conversation with our patients. We need to never forget that this is an ongoing process where things can change.

Before we wrap up, Stephanie, if you would leave clinicians with one question they should ask every patient with severe asthma, what would it be?

Stephanie Fuller:

I want clinicians to know that having severe asthma is really scary. And it's not only physical, but it also takes an emotional toll on your mental health as well—not knowing if the next attack could be your last. So I wish more physicians would get to know their patients, not just from a medical standpoint, but also get to know their dreams, desires, and how this chronic illness affects their everyday life. When you have a physician that you feel comfortable expressing your concerns and expectations with, you feel heard, deeply supported, and included in making the right decisions for your care. So I think if more of our physicians were like that, then it would be easier for patients to be able to talk, choose, and help. The doctors could help the patient choose the right care and the right treatments for them, and that patient would be more dedicated to their treatments.

Dr. Maselli:

Thank you so much, Stephanie, for sharing your insights and your experience living with severe asthma. Stephanie, thank you so much. It was great having you on the program.

Stephanie Fuller:

Thank you also, Dr. Maselli. I really enjoyed having a talk with you today.

Announcer:

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