

AJ Blood: Welcome to the American Heart Association's Exploring Supraventricular Tachycardia Podcast Series. This episode is entitled From the Heart, a Patient Living with SVT. This podcast will feature a patient's experience with her diagnosis and management of PSVT.

The views and opinions in this activity are those of the speakers and reflect the synthesis of science. Content should not be considered as official policy of the AHA.

Greetings. My name is **AJ Blood**. I am a cardiologist and intensivist at Brigham Women's Hospital in Boston, Massachusetts and Associate Director of the Accelerator for Clinical Transformation research team.

Today we're joined by a PSVT patient and registered nurse **Mary Velthouse**. We will get to know more about Mary's background and experience with PSVT from her teenage years into today.

Mary, would you please introduce yourself.

Mary Velthouse: Thanks, Dr. Blood.

My name is **Mary Velthouse**. I have been diagnosed with PSVT for the last 30 years, but I have been living with it since about 1963. It was a long journey for me, and I will be glad to share that with all of you today.

AJ Blood: Thank you so much. We're really excited to learn from you.

So, you mentioned you started experiencing symptoms of PSVT in your youth. Can you tell us a little bit more about that?

Mary Velthouse: Yes, in the mid-sixties, I developed palpitations. I could feel my heart beating rapidly in my throat. I would become very light-headed and turn white according to my friends. There were times that the light-headedness brought me literally to my knees.

My parents brought me to my pediatrician that I was seeing yet at the age of 15, and he said it was nothing to worry about, but the symptoms kept coming. So, when I became an adult and saw an adult doctor, I related all of those symptoms to him. He told me I was identifying with my mother who had a serious disease, Lupus erythematosus. She had become very ill with it, and also had many heart issues, so I was embarrassed by that and did not seek another physician's advice for quite a while – several years into the 70s.

AJ Blood: I'm so sorry to hear about that experience. And obviously, that is not something that we hope or expect would be happening in this day and age.

So you took many that really it sounds like, made you averse to seeking out medical care when your what sounds like quite severe symptoms were being attributed to a non-physiologic cause.

Mary Velthouse: That's right.

AJ Blood: And how often was this happening to you.

Mary Velthouse: It varied. There would be like – I call them sieges. I would have many bouts during the day and it could proceed like that for approximately 2 to 3 weeks even and then I'd have respite for a while, and then it would start over again.

AJ Blood: Was there anything that you could do, or you noticed would either bring on the symptoms or help them go away?

Mary Velthouse: Nothing brought them on. What I did was vagal maneuvers and just lived with it. That's all I had at that time. I knew about vagal maneuvers. I knew they slowed my heart rate, since I'm a nurse and I used those. You have to remember also the problem with getting a diagnosis in the 1960s: there were no technological advances besides an EKG. There were no portable monitors, holter monitors, patched monitors.

You had to try to catch the rhythm while you're in the doctor's office on an EKG and that was about all there was. There was not even a lot of treatment available for it. The only Beta Blocker was propranolol and that had a lot of adverse symptoms. So that wasn't even used so terribly much with patients at that time.

AJ Blood: And before you even received your formal diagnosis you were practicing as a nurse. Is that right?

Mary Velthouse: Yes, I've been a nurse since 1969. I just this week celebrated my 55th anniversary with the same hospital. I was born in that hospital, and had my tonsils out at the age of 3 in that hospital, and decided I would be a nurse at that hospital at that time. So it's been 72 years of that I was convinced that I would be a nurse, and I have been one.

AJ Blood: That's fantastic. Well, thank you for all that you've done for your patience and for all you're doing for us here helping to learn about your journey. So, you became a nurse, and even while you were acting as a healthcare provider, you still didn't have an answer to these episodes. How did you eventually come to a diagnosis?

Mary Velthouse: Well, I didn't do a whole lot in the seventies, because I was still kind of reeling for being told that it was all in my head, and it's embarrassing to go to a doctor. Say, there's nothing wrong with you, so I kind of let it go, and most of the time I could just live with it just fine. But around 1989 the symptoms became worse again. So, I really did seek help and this time they had a Holter monitor that I could wear. And it actually showed PSVT, along with some non-sustained V-tach, some other atrial tachycardias, PAT and a variety of other things like bigeminy and trigeminy. So I was placed on atenolol and that really helped. I was amazed at how my symptoms abated.

AJ Blood: I'm so happy to hear they finally got to the diagnosis for you. And, just reflecting back, it was multiple decades between your 1st experience with symptoms before you actually arrived at a diagnosis. Is that right?

Mary Velthouse: That's right. It was approximately 26 years, 27 years before I got a diagnosis.

AJ Blood: In reflecting on your experience in this really long gap between your symptoms and arriving at a diagnosis, is there anything that you wish had happened differently or in retrospect, could have helped you get to a diagnosis sooner?

Mary Velthouse: Well, I believe there are a couple of things. Number one: I could have persisted even though I was afraid of getting slapped down. The other thing is the physician that I was going to should have listened to me and checked it out further. I know there weren't the diagnostic tools that we have today, but still something should have been able to have been done earlier. Perhaps trying the beta blocker earlier.

AJ Blood: Yeah, it's certainly – we have come a long way, you know, from the from the simple 10-second, 12-second EKG, strip now into the Holter monitors, which it sounds like eventually was how you arrived at your diagnosis and even, you know further these days into things like Patch monitors, where for weeks at a time, you know, implantable loop recorders, or, you know, really long term monitoring, or even consumer devices, you know, both in kind of passive monitoring with the watches or consumer facing EKG devices where patients frequently have access to these for years, and can be sending in strips or evaluations of much more high quality than what you were dealing with when you came to your diagnosis.

As a provider, can you tell me a little bit about, you know, what you've seen and experienced when meeting patients with PSVT?

Mary Velthouse: Yes. I worked in ICU for 35 years. I loved it. Cardiology was my favorite part. Our patients who were suffering from PSVT were treated with either adenosine or cardioversion.

We would try adenosine first, and I recall one patient that I was pushing the adenosine - first 6 milligrams, then 12 milligrams, and finally converted. But the pause on the EKG monitor was daunting. We would all be holding our breath. Is this going to work? Are they going to come back? But of course, they did.

AJ Blood: Yeah, those can be scary moments in between the strip coming back for you. And I think that's you know, especially as an ICU nurse, I'm sure that is not something you're unfamiliar with both adenosine and cardioversions, and I think anytime somebody's unstable or severely symptomatic and refractory to kind of the first line treatments, one of which you mentioned, and beta blockers, which we use frequently, both in the outpatient setting, as well as if people are unfortunate to have persistent or severe symptoms and end up in the emergency departments. Calcium channel blockers are again a very common, commonly used medication to help abate these episodes with ongoing high heart rates and symptoms. I think you mentioned vagal

maneuvers, of which there are many to help slow the heart rate down to even break the arrhythmia, can be effective for many patients. So, I think you've really helped to describe that full, you know. Fortunately, it sounds like you are able to manage your symptoms mostly with the use of the beta blocker in outpatient. Have you ever had the experience of being to the emergency department or admitted to the hospital as a result of one of these episodes?

Mary Velthouse: No, I haven't. I've mostly been able to manage these symptoms at home with a beta blocker, which is no longer atenolol, but now metoprolol and that most of the time works. There have been a couple of occasions that I have said to my husband, I think I might wind up having to go to the ER, but then I didn't because I converted.

One of the problems I have also is that I have an autonomic nervous system dysfunction in that my blood pressure can suddenly drop to systolic of 60, and I am on my knees and crawling because I can't keep my head up without passing out. And then, a couple hours later, my blood pressure could be 170, over 100. How to treat? Very difficult. In those cases, I don't take my metoprolol, obviously. I have a parameter of 110 systolic. But if I'm off it for more than 2 or 3 days, then the SVT symptoms come back in full force. So, it's a tricky balancing situation for me, but so far here I am doing just very fine.

AJ Blood: And I hope we can continue that to be the case. It sounds like you're doing very well, but it's certainly, when there's challenges with blood pressure both being too high and too low, as well as arrhythmia symptoms, you could be stuck between a bit of a rock and a hard place trying to keep your symptoms at bay but keeping your blood pressure in a safe range. So, I wonder how do you balance those things?

Mary Velthouse: Well, as I said, it's tricky. I stop as soon as my blood pressure goes down, and it's usually in the morning. It's just I can tell right away, oh, boy, I'm in trouble and it usually goes down right away. It doesn't have anything to do with, let's say, having a bowel movement, or anything like that that drops it. It just is there out of control. If I can reach my blood pressure cuff. That's about what I get. The lowest I've ever seen is 56 over 37.

AJ Blood: Goodness.

Mary Velthouse: Or it reads error, and I know I'm really in trouble then.

So, I just stop the beta blockers for a while. I try to drink fluids, although I can't right away, because nothing will even digest with a blood pressure that low and I go off the metoprolol for a couple of days until my systolic blood pressure is greater than 110. Those are my parameters. And then by that time the SVT is back, and it's so uncomfortable with those hard palpitations, and the lightheadedness is back. But it's because of the SVT, not because of the blood pressure. So that's how I deal with it, just knowing myself and knowing what I have to do, whichever part of the rollercoaster I'm on.

AJ Blood: And for some patients and providers, depending upon the frequency and severity of the episodes, something called a pill and pocket strategy, with an antiarrhythmic medication is sometimes employed. Has that ever been something that you or your providers have discussed?

Mary Velthouse: No, it hasn't. I maybe should bring that up at my next appointment which I do see a cardiologist regularly so I think I will bring that up.

AJ Blood: Always good to have a conversation about it, at least, if something might be able to mitigate some of these rock and a hard place episodes it seems like you are suffering from. This has been really great to hear about your journey and how things have been going. I'm glad to hear that largely. It seems as if you've got a good handle on your condition.

I would love to hear any advice for healthcare providers, either in the journey in making your diagnosis or in finding an effective therapy for you. Love to hear your feedback, and how we can be doing a better job of helping you live your best life.

Mary Velthouse: First of all, I believe that the most important thing is, listen to your patient. Don't come in with preconceived ideas. Look for clues as to what could be going wrong as you're listening to them. Also, I know how busy physicians are. There's no doubt about that. But if you could take more time or as much time as you can with a back-and-forth discussion. Don't ask, do you have any questions? But rather ask, what questions do you have for me? People are intimidated going to a specialist and they are afraid to ask questions. They're afraid they're going to sound dumb. And they're afraid they won't be listened to. But if you open that conversation with what questions they know that they, the patients, know that they are expected to have questions, and that they will be heard. So that's my advice to physicians or any provider who is listening.

I also have some advice for any patients who are listening, and that is number one, you are responsible for your own healthcare. It is your responsibility to persevere in seeking a diagnosis. Also, if you have multiple health issues. look at yourself as a well patient with a few issues rather than a sick patient. It makes a huge difference in how you approach life. That is how I have chosen to live my life by the grace of God.

AJ Blood: Thank you so much for sharing those words and thoughts with us really appreciate it, and you know, from a provider perspective. I'll just reflect back. And you know, really, just try to make sure that we're taking as much time as we can, really hearing your story, understanding your concerns, answering your questions, thinking through treatment modalities as a provider. I think you mentioned for years with vagal maneuvers, were able to manage and mitigate some of the more severe symptoms and side effects that come from these episodes. Always a great first step.

Chronic therapy with things like calcium channel blockers and beta blockers can help to mitigate the burden of these episodes as well as their frequency and severity. There's things like antiarrhythmic medications, and we mentioned briefly, pill in the pocket strategies that can be effective.

If these are refractory, even things like an ablation can be considered with your local friendly electrophysiologist. If and when there's severe symptoms things like lightheadedness, dizziness, you know, feeling like you might pass out or pass out. Those are oftentimes what I give guidance to patients to consider emergency evaluation, at which points things like adenosine as well as cardioversion can be considered in patients who are refractory to first line therapy and I think those are some of the medical considerations in helping to manage and mitigate some of the more severe episodes of PSVT.

Mary, thank you so much for all your time. For sharing your experience with us, this has really been so helpful in crystallizing our thoughts and understanding, and especially of an expert nurse sharing all this, this journey with us has been really meaningful. Thank you so much.

Mary Velthouse: And thank you, Dr. Blood, for asking me to do this podcast with you.

AJ Blood: It's really been such a pleasure. And as a closing note, Milestone is a proud sponsor of the American Heart Association's Supraventricular Tachycardia or SVT Education initiative. For additional information and education, please visit, learn.heart.org. Thank you so much for your time and attention, and I hope everyone has a wonderful day. Take care!