

Marie's Voice

Marie's stirring up dust in Sandy Springs! I have lived in Sandy Springs since 1995 when I had to sell my steps. (I lived in an upstairs flat in Tucker.) I found Sandy Springs to be a difficult community in which to make friends. And like too many of our Metro Atlanta communities and neighborhoods, the pedestrian access was (and still is) almost non-existent. I have told the city council that I live on an island with no bridge to the community.

In 2005 when Sandy Springs was in the process of voting on forming a city, I jumped into the fray and raised a lot of questions which, by the way, did not make me popular with the person who is now our mayor. After we incorporated, I made up my mind that accessibility is a now or never issue. We have spent the past year developing a comprehensive plan. The first draft was void of the word *accessibility*. The plan will be the basis for future improvements and redevelopment. So I continuously hack away at the need for access, trying to do it in a friendly way. But on the other hand I intend to be relentless. Most people have quit rolling their eyes when I speak up on access at public meetings. The good news is that we have a Deputy Director of Community Development who understands the need and looks to me for guidance and encourages me to raise the necessary issues. Two city council women have actually responded to me and ask questions.

On February 11, 2007, the Atlanta Journal Constitution did a feature story on my advocacy work in Sandy Springs. They even put a slide show online. Here's the scoop if you want to take a peek.

Story

<http://www.ajc.com/metro/content/metro/northfulton/stories/2007/02/12/0211nfxlatta.html>

Photos <http://lpe.ajc.com/gallery/view/metro/0207/nfxlatta0211>

Marie's twin tubes update. Since I have dubbed the feeding tube the unruly child and the trach the good child, I'll refer to them that way. The unruly child has calmed down a great deal. After I had it changed in September and figured out how to stop the flow from the leaky port on the new one with a bread bag twister, I haven't had any tube falling out incidents. When I had the tube checked by my GI doctor recently, he marveled at how clean it was. I thanked him, but I really wanted to say, "It would have been nice if you had taught me how to care for it instead of my having a 6 month learning curve getting it under control."

What about the good child? I would never have understood how easy it is to care for the trach if I had not had the feeding tube as comparison. I have scrapped the idea of a stainless steel tube which had been recommended by my (then) ENT and others. My tube is a size 8. Dr. Kenny had said absolutely not to go lower

than a 6. The ENT wanted to place a size 4 stainless steel. I was told by a respiratory therapist at Shepherd that a scope would not even fit in a size 4. And I also discovered that a standard universal fitting which allows for oxygen and other little things to be connected to the trach in an emergency is not available. Dr. Zadoff's advice, that I should use what works for me took all the stress off. Dr. Zadoff goes into the "good guys" category along with Dr. Kenny and Dr. Leslie.

What difference have the tubes made? A world of difference. I am nutritionally so much better off. All of the health/nutritional levels they draw blood to test for are in a strong normal range. And I am so happy to find breathing an easy thing to do. I feel stronger and just all around healthier. The really exiting news is that since January I can wear my voice valve. I am guessing it is because I am stronger and have very little secretion. I don't feel that suffocating resistance I did the first few months.

And what about the challenges? I still have my ever present post polio fatigue, but the degree has really lessened. And I don't feel or sound like I'm going to give out of air any minute. The new challenge is that I am having some overuse stress in my hands, primarily from all the feeding tube regimen. An occupational therapist is helping me sort things out and figure out different ways to do things. I have stopped using the plunger. That means I get to wait for the speed of gravity for my formula to crawl its way through the small opening of the tube into my stomach. God has all sorts of ways to keep reteaching us patience! ☺

Staying strong into the future. I have recently gotten speech therapy and am getting OT and PT to learn new ways to keep all my muscles awake. It has been wonderful. If you are wondering about speech, I've learned oral exercises that make me use my muscles in my head and throat. Yes, I even exercise my tongue (Have a good laugh!!). To activate muscles all over my body, we are using stretching and isometric exercises. I do it all from my chair or lying down. It has helped me so much overall that I've begun thinking there needs to be an overall program of stretching and isometric exercises for polio survivors. This is not just for when we are having trouble, but it helps keep unused muscles active.

We should all pat ourselves on the back for being bold enough, and dare we say pushy, to keep asking questions and putting the brakes on when medical folks make decisions that would be bad for us. Look around you and your community. What are your biggest community needs? And what are your medical care providers not doing for you personally that you think they should? Now that you have decided on your priorities, jump into the fray. Be an advocate for yourself and others. Even as we manage our fatigue, I hope we can always find ways to speak out, to make a difference. For the sake of all of us, we must have a voice. I believe that the boldness of polio survivors will help masses of people who are afraid to speak up. Cheers for life, breath, and a voice!
