

Advocating for yourself is the hardest thing someone with a disability can do. As a 16 year old girl, I have been taught to advocate for myself and my health since I was a baby. Now I would like to share some important tips and tricks that I have personally learned through advocating for myself in hopes that this can help someone else.

1. Write down questions to ask doctors

a. Going to the doctor can be hard, especially if you don't know what to ask. For me what I personally like to do is before going to the doctor, I go into a notes app and write down some questions I might have. An example of a question I have asked a surgeon was "What are the risks and complications of this surgery." It is helpful to have a parent to help craft these types of questions, since they have had to ask your doctors questions as well.

2. Write down responses doctors give you

a. In coordination to the first tip, writing down your doctor's answers to your own questions is extremely helpful. When you write down the answers you have been provided you can then look back on those answers and that is always helpful.

3. Bring a trusted person to medical visits

a. When going to the doctor I always have one of my parents with me. Having a trusted adult with you, especially as a teenager, is very valuable. For me, my parents always chime in with things I may have forgotten. Some of the things they mention are medication I take, or what medical issues I experience, or about anything that my doctor just might need to know in general. Having someone with you can also make medical trips less daunting if you're a very anxious person.

4. Don't be scared to find a new doctor

a. When you have a doctor that does not fulfill your own needs, then you have to find a new one. Finding a new doctor is scary and hard, but there are some amazing resources that can help. One resource my family uses is SBANYS. Being able to find a doctor that specializes in what you need helps your health greatly, which is why researching doctors is so important.

5. Practice explaining your disability

a. Some doctors might not know about your disability and how it affects your body. Practicing explaining your disability helps to prepare you for the real world for when you do end up meeting a doctor that does not know about your disability. You can practice with family, or you can practice with friends.

Being able to educate others and yourself is the most important thing in advocacy. Constantly learn about your own disability, educate your medical team about what happens in your own body, and always ask questions if you don't know what your doctors are talking about. Advocacy is a skill that needs to be learned, but the more you practice the easier it gets.

Francis Lee-Ciano

SBANYS Intern

