

Your Guide to Medical Self-Advocacy

Disclaimer: These strategies have helped many young people successfully advocate for themselves. Your journey is unique—use what works for you and adapt these tips to fit your needs.

Getting Organized

- 1. Keep Your Own Journal** Write down questions before doctor appointments and track your symptoms. This helps you remember what you want to say and gives doctors important information about what's happening with your body.
- 2. Use Video When Needed** If you have symptoms that come and go, record them on video. Showing your doctor what's happening is often more helpful than trying to describe it.
- 3. Practice Makes Better (Not Perfect!)** The first time you speak up for yourself might feel scary. Your voice might shake, your face might get red, or your mouth might feel dry. This is totally normal. Every time you advocate for yourself, it gets easier. You've got this!

Know Yourself, Know Your Needs

- 4. Learn About Your Diagnosis.** Understanding your condition helps you explain it to others and make informed decisions. Ask questions...it's your body and your health.
- 5. Know Your Medications and Allergies** Memorize (or keep a list of) your medications, dosages, and any allergies. Use your phone's notes app to list them, or take photos of your medication bottles. This information could be lifesaving in an emergency.
- 6. Create Your Personal "Script".** Develop a short summary of your medical background that you can share with new doctors, teachers, or coaches. Practice saying it out loud until it feels natural.
Example: "I have [condition]. I take [medications]. The main things that help me are [accommodations/strategies]."

- 7. Build Your Health History Document.** Create a document that includes:

- Current medications and dosages
- Allergies
- Past surgeries or hospitalizations
- Your diagnoses
- How you learn best (listening, reading, hands-on)
- Activities you enjoy (sports, clubs, hobbies)

Keep this updated and bring it to new appointments. It shows you're organized and helps providers see you as a whole person.

- 8. Write Your "Get to Know Me" Bio** Create a short description of how your disability affects you in different settings (school, sports, work). Write it in your own voice and be specific about what helps you succeed.

Example: "I prefer to sit near the front and away from windows because I get distracted easily. I use a computer to take notes. I'm really good at problem-solving when I have extra time."



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Taking the Lead

9. Answer Questions First. When you're at appointments, try answering the doctor's questions yourself before your parent jumps in. It's okay to make mistakes—that's how you learn. Your parent can fill in anything you forget.

10. Be Patient with Yourself. Learning to advocate for yourself is a process. You might forget to take medications sometimes or not want to go to appointments. That's part of growing up. Learn from these experiences and keep moving forward.

11. Consider Talking to a Counselor. Living with a disability can be challenging emotionally. Talking to a counselor or therapist can help you process your feelings, develop coping strategies, and build confidence. It's a sign of strength, not weakness.

Remember:

- ✓ You are the expert on your own body and experiences
- ✓ Asking questions is a sign of intelligence, not weakness
- ✓ Self-advocacy is a skill that improves with practice
- ✓ You deserve to be heard and to have your needs met
- ✓ It's okay to ask for help when you need it

Self-advocacy empowers you to take control of your health, education, and future. Start small, practice often, and celebrate your progress along the way.

