

Tips for Teaching Your Child Medical Advocacy

Building the Foundation

- 1. Keep a Journal.** Write down questions before doctor appointments and document symptoms as they occur. This creates a reliable record and helps you communicate clearly with medical providers.
- 2. Video Episodes.** If your child experiences periodic symptoms, record them on video. Visual documentation can be invaluable for showing doctors what's happening between appointments.
- 3. Remember: Practice Makes Better.** Every time you advocate for your child, it gets easier. Your voice will shake less, your face won't flush as much, and your mouth won't get as dry. These physical responses are completely normal—and they will diminish with practice.

Empowering Your Child

- 4. Talk Openly About Their Diagnosis.** Have age-appropriate conversations about your child's condition and continue these discussions as they mature. Open communication builds understanding and confidence.
- 5. Empower Through Education.** Teach your child about their medications, dosages, and allergies. Help them learn to administer their own medications from a young age. Encourage them to use their phone's notes app to list medications and allergies, or take photos of medication bottles for quick reference.
- 6. Develop a Prepared Script.** Create a concise summary of your child's medical background to share with new providers. As your child grows, encourage them to practice delivering their own script to medical professionals.
- 7. Create a Comprehensive Health History.** Document medications, allergies, surgeries, hospitalizations, diagnoses, and learning preferences (audio/visual/kinesthetic). Include information about social activities (scouts, dance, clubs) to remind providers that your child is a whole person, not just a diagnosis. This document is essential for new providers and emergency situations.
- 8. Create a "Get to Know Me" Bio.** Develop a personalized document explaining how your child's diagnosis impacts their education, sports, or therapy. As they mature, let them write it in their own voice.
Example: "I prefer to sit up close and away from doors/windows—I get distracted easily. My hands don't work well, so I use a computer to type my responses."

Your Guide to Medical Self-Advocacy

Transitioning to Independence

9. Step Back When the Time Is Right. Even at a young age, let your child answer medical questions first, then fill in gaps. They will make mistakes. We all do...but that's part of growing as a self-advocate.

10. Be Patient with the Process. As children develop advocacy skills, they'll challenge you—because you've taught them to stand up for themselves! They may skip infusions or miss appointments. This is normal developmental behavior. They will learn from these experiences.

11. Consider Adding a Counselor to the Team If you haven't already, explore adding a mental health counselor to your child's medical team. Living with a chronic condition or disability affects emotional well-being, and professional support can be invaluable.

These tips emphasize gradual empowerment, helping your child move from parent-supported advocacy to confident self-advocacy as they mature.

