

How to Advocate for Your Child With Special Health Care Needs

Become an advocate

Advocating for your child with special health care needs is an ongoing process. It requires being informed, calm, and direct. You can learn to disagree respectfully and say “no” without feeling guilty or embarrassed. It is up to you to advocate for what your child needs and make decisions that ensure the well-being of your son or daughter.

To be a good advocate, it is important to:

- Be persistent and focused
- Express your feelings with “I” phrases instead of “you,” which implies ownership of your own feelings
- Stay up to date on your child’s condition by reading newsletters or researching appropriate sites online
- Attend workshops and informational meetings
- Talk to other parents who have similar concerns

Focus on one goal at a time, and be willing to make some compromises to get started. You will become more confident with each success, but be realistic about what to expect. Change happens slowly over time. Be a good listener and understand the perspectives of other team members as well.

Keep your own medical records

Having a complete copy of medical records along with your own notes is an important part of being a good advocate. Having a copy of medical records helps keep you informed and up to date on your child’s condition. It will also serve you well in an emergency, and will help remind you of medications or treatments that have been tried. If your child sees several specialists, it provides a comprehensive and historical record of all of their medical information.

You have the right to request all of your child’s health records (see PACER handouts: [“Accessing Your Child’s Health Records”](#) and [“Keeping and Organizing Medical Records”](#) or order at PACER (952)838-9000). This allows you to review them for accuracy. Public insurance applications require submission of all medical records. These records are also useful to appeal private insurance decisions that require documentation for services.

It is also helpful to keep your own notes during a new illness, recurrence of an underlying condition, or medication changes. Keep track of who you talked to, what they said, and what instructions were given, so that you have a record when you talk to your primary doctor or visit an emergency room.

A one-page summary with the most up to date information can be very useful. This should include a list of diagnoses, current medications, known allergies, recent changes, recent hospitalizations, the names and phone numbers of key physicians, etc. It should include the critical information needed to fill in the blanks in an emergency situation.

Some families choose to keep this information on a flash drive that goes to the hospital with their child in an emergency. It might be taped to their bed or wheelchair, or placed where someone is always able to access the information.

Conclusions

For the best outcome, learn how to become a good advocate for your child. The best way to do this is to become educated about their conditions and become proactive in seeking out resources and keeping good medical records. Being an advocate requires learning how to speak up and share your concerns in a calm but direct way. This helps to ensure the best quality of care for your child.

Resources

PACER's Health Information Center:

www.PACER.org/health