

Parents' guide to managing your child's health care

When your child gets a new diagnosis, it is important to learn all you can. You can help teach others who care for your child. Every child is special. They may have different needs and skills. This information reflects typical development.



For all ages:

- Get organized! Use a health care notebook or a smart phone health download (app).
- Ask your doctors, nurses, and counselors questions. Write down what you learn.
- Use Cook Children's patient portal for online access to your child's records and to keep in touch with your child's health care team.
- Include your child in conversations about their health.
- Buy a medical alert bracelet or necklace for your child.
- Find local and national support groups.
- Join "Parents as Partners" at Cook Children's to meet other families.

Birth to 3 years old:

- Practice talking about your child's condition to your baby and a few people you and your family trust.
- Ask to meet other families who have a child with a similar condition.
- Teach your child the names of their body parts including their private parts.
- Keep a journal or write letters to your child about decisions you are making and what you are learning.

3 to 5 years old:

- Read storybooks about children with differences and special medical needs.
- Teach your child about their health and medicine. Create a daily schedule for medicines, therapies and hygiene.
- Involve your child in their daily care.
- Encourage your child to talk to doctors during appointments.

5 to 10 years old:

- Be sure your child's phone has emergency contacts.
- Work with your child's school to create a legal 504 plan or individualized education plan (IEP).
- Give the school information about your child's condition. Teach them signs of an emergency. Have a plan for handling a health emergency at school.
- Teach your child to be aware of signs of pain, discomfort or changes in their body and when to tell an adult.
- Act out situations your child might have at school with classmates, teachers or in gym class. This will help your child practice how to answer questions about their medical condition.

14 to 18 years old:

- Remind your child of their medical needs, names of conditions, surgical history and allergies.
- Teach your child how to order supplies, manage health insurance, schedule appointments and refill prescriptions.
- Tell your child about medical care and treatments they may need as they become adults.
- Start having your child plan their own schedule to include medicine, therapies and hygiene.
- Encourage your child to share their medical information with people they trust. This may be a friend, relative, therapist or teacher.
- Bring your child to groups where they can meet other kids with their condition.
- Request to meet an older person with your child's condition.
- Sex education usually begins in 6th grade. Talk with your child and your child's health care team about any medical needs that affect puberty, sex and intimacy.
- If your child cannot make their own medical decisions, apply for a medical power of attorney.

10 to 14 years old:

- Teach your child about their medicine and what happens if they don't take their medicine.
- Teach your child how to use other supplies needed for their condition.
- Start a list of important words for your child to know about their health and medical condition.
- Let your doctors, nurses and social workers know what you are comfortable talking about with your child.
- Teach your child about puberty and what may be different about their experience. Schools often start education about puberty in 4th to 6th grade.
- Give your child books, websites and videos about their condition so they can read or watch by themselves.
- Encourage questions. Prepare your child to have one question for their doctor or nurse at every appointment.

18 and beyond:

- Provide support. Help your child become responsible for taking care of their own health needs as an adult.
- Help your child find doctors, therapists and specialists if your child is living away from home, going to college or transferring to a doctor who treats adults.
- Help your child understand and plan for health insurance.

