

Child's Health Condition



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Amy's Story

Amy is holding her ten month old baby, Matt. They are waiting for Dr. King in a clinic exam room. Dr. King has been trying to find out why Matt has so many health problems. Amy hopes Dr. King will have the test results back today.

Finally, Dr. King enters the room. He tells Amy that Matt's test results are positive. That means Matt has a muscle and nerve condition. Dr. King gives Amy a long medical term for the condition. Amy has never heard of it before. Then, Dr. King explains that the condition is the cause for Matt's many health problems. He says that there isn't a cure but there are treatments that may help. Dr. King asks, "Do you have any questions?" Amy has hundreds of questions but can't think of how to ask them. She's not even sure what Dr. King said. So, she tells Dr. King that she doesn't have any questions.

Through the next week, Amy is sad. She doesn't know how to help Matt and she thinks it's unfair that he has a health condition. She is scared of what will happen in the future. Today, Matt's physical therapist introduces her to Laura. Laura, has a 5 year old with a health condition that's a lot like Matt's. Laura tells Amy that she had many of the same feelings right after her child was diagnosed. Laura explains to Amy that she felt less helpless when she started to learn about the health condition. She says that talking with parents of kids with special needs helped too.

After talking with Laura, Amy feels more hopeful. Learning about Matt's condition is something Amy can do to help Matt. Maybe she will even be able to explain things to her friends and family if she learns more.

- How can Amy learn more about Matt's condition?
- How can she find information and resources?
- Where can she look and who can help her?

The next section will help you learn about your child's condition. It will help you find information and resources.



What's It All About

Long term health conditions are also called special health care needs. They affect your child's daily life: how your child learns, behaves, plays, moves, breathes, eats, grows, or develops.

Take time to learn as much as possible about your child's health condition.

Steps to Learn About Your Child's Health Condition

1. Name your child's main health condition.
 - Know the medical term.
 - Know the layman's term.
2. Describe your child's health condition.
 - Use your own words to describe health condition.
 - Know what problems the health condition causes.
 - Know how the problems affect your child's body and daily life.
3. Explain your child's health condition.
 - Think about how you can explain to other people.
 - What you say depends on who you are talking with.
 - Health care providers
 - Teachers
 - Family, friends, and others.
4. Find information about your child's health condition.
 - Ask questions. Doctors, nurses, and other health care providers can help you understand your child's condition.
 - Talk with parents of children with special health care needs.
 - Look for resources that help you learn about the condition.

Take Action

Talk with your health care provider.

Name your child's main health condition.

- Know the medical terms.
 - Finding information and resources will be easier.
 - Talking with health care providers may be easier.
- Know the layman's terms.
 - Explaining your child's condition to people who are not health care providers will be easier.
 - Many people do not know medical terms.

Describe your child's health condition.

- Use the form *About Health Condition* as a guide.
- Use your own words to explain the condition in 1-2 sentences.
- List problems caused by the health condition.
- Explain how your child's body and daily life are affected.
- Tell how your child's condition is treated (what you and others do to keep your child as healthy as possible).
- Describe cause of health condition.
- Tell how your child was diagnosed.
 - How you found out about your child's health condition.
 - Your child's age when diagnosed.
 - Doctor who explained the condition to you.
 - Tests that showed what condition your child has.

Three main questions to ask health care providers

What is my child's health problem?

What do I need to do to treat this health problem?

Why is it important to do this?

Take Action

Talk with your health care provider.

Explain health condition to others to help them understand.

You choose what you want to tell others.

Learn to explain your child's condition in 1-2 sentences.

When you give information to others, think about:

- Who you are talking with.
- Why the person is asking.
- What you want the person to know.
- What you are comfortable saying.

Find information about health condition.

Use form *Resources for My Child's Health Condition* to write down resources.

Think about how you learn best. Is it by hearing, seeing, or reading information?

Tell others how you learn best.

Talk with others about your child's health condition.

- Doctors, nurses, pharmacists, and other providers.
- Parents of children with the same condition or special needs.

Go to libraries and resource centers.

Call and/or go to organizations that provide information.

Places to look for information:

- Books, magazines, newsletters, newspapers.
- Internet.
- Teaching sheets from health care providers.
- DVDs or CDs.

To get more information, ask these questions

What is my child's health problem?

Could you explain that to me again?

Could you write that down for me?

Is there something you can give me to read?

Where can I find more information?

Can you introduce me to another parent with a child who has the same condition?

Check Yourself

- I can name my child's main health condition:
 - Using medical terms.
 - Using layman's terms

- I can describe my child's health condition in my own words.

- I can explain my child's health condition to others:
 - Healthcare providers
 - Teachers and child care providers.
 - Family, friends, and others.

- I can find information about my child's health condition.



More Information and Resources

Your child's health care team is your best resource. Ask if you have questions.

Local medical library finder: Some hospitals have medical libraries open for patient and family use. There may also be a medical library close to your home that you can use.

<http://www.nlm.nih.gov/network.html>

Local public library finder:

<http://nces.ed.gov/nceskids/tools/library/index.asp>

Resource Centers: Many hospitals and community centers have resource centers with information about special health care needs. Ask health care providers, teachers, and your local library about resource centers near your home.

Medline List of Organizations: Agencies that help patients and families often have information about special health care needs.

http://www.nlm.nih.gov/medlineplus/organizations/orgbytopic_a.html

Healthfinder.gov: Information about health conditions and health news.

<http://healthfinder.gov/>

Medline Plus: Information about health conditions, tests, treatments, drugs, and resources. Click on *dictionary* to look up medical terms.

<http://medlineplus.gov/>

KidsHealth: Information about kids' health, behavior, and development. It has a parent, teen, and child section.

<http://kidshealth.org/>

Medline: Tips for finding good information on the Internet

<http://www.nlm.nih.gov/medlineplus/webeval/webeval.html>

Children's Hospital of Wisconsin – Caring for My Child: Find information about your child's condition.

<http://www.chw.org>

Child's Health Condition Forms

Form Name	How it can be used
About Health Condition	<ul style="list-style-type: none">• Use this form to help you learn about your child's health condition.• Write what you learn about your child's condition on the form.• Use the form to help you explain your child's condition to others.• Use it as a guide when you talk.• Give it to people caring for your child.
Resources for My Child's Health Condition	<ul style="list-style-type: none">• Use this form to help you keep track of resources about your child's health condition.• Write resources that are helpful on the form.• Share the resources with people caring for your child.• Share the resources with others such as teachers, parents of children with the same condition, and your family.

About Health Condition

Main Health Condition <i>Diagnosis</i>		
Describe Health Condition <i>Use your own words.</i>		
Health Problem <i>List problems caused by health condition.</i>	How Problem Affects Daily Life and Activities	How problems are managed <i>List equipment, special diet, medicine, therapy, tests, etc.</i>

About Health Condition

Health Problem <i>List problems caused by health condition.</i>	How Problem Affects My Child <i>Explain how problems affect daily life and activities.</i>	What We Do <i>Explain how problems are managed. List equipment, special diet, medicine, therapy, tests, etc.</i>

About Health Condition

Optional Information *You might not have information to fill in every section. You can leave some or all of this page blank.*

Cause of Health Condition *Sometimes the cause is not known.*

How Condition Was Diagnosed *Child's age when you found out, doctor who diagnosed it, tests done, etc.*

Other Information *Things you want others to know about the condition and how it affects your child.*

Name _____

Resources About Health Condition

List resources that help you learn about the health condition

Resource <i>Websites, DVDs, libraries, organizations, etc.</i>	How To Find Resource <i>Phone number, website, address, name of contact person, etc.</i>	Notes About the Resource <i>How it can help, services it offers, trainings, group meeting day and time, when to check back, etc.</i>