

Community Resources



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Needing Help at Home

Maggie's 8-year-old son Peter just had surgery to fix his dislocated hips. During the surgery he was put into a spica cast, which covers his legs and his body up to his chest. He will be in the cast for several weeks. Peter is recovering nicely. The doctor says he will be able to go home in three days. Now Maggie is starting to think about all the things she'll need to do to take care of Peter at home.

Before he was in the cast, Maggie could lift Peter. With the cast he is too heavy. Peter's dad can help when he is home, but he works during the day. Maggie wonders how she will move Peter from his bed to his wheelchair on her own. She doesn't know how she will bathe him since he can't get his cast wet.

Peter needs to come back to the hospital for checkups and go to school. In his cast, Peter doesn't fit into his usual car seat. Maggie wonders how Peter will go to school. They can't afford to take a taxi and don't have any family nearby to give them rides.

Maggie tells a friend who visits them at the hospital that she is worried about taking care of Peter at home. Her friend says that she thinks there are programs that could have a nurse or personal care worker come help at home. She also says that there are transport companies that might be able to drive them to and from the hospital and school. Maggie wants to get help, but doesn't know where to start.

- What community resources are available for Maggie and Peter?
- How can Maggie learn more about resources to help her care for Peter?



What's It All About

Your child brings joy to your family but also changes your day-to-day life. When a child has a long-term health condition the whole family is affected. It may change how family members relate. If you have other children they may feel jealous, confused, or worried. Perhaps you wonder if you will ever have time to go out and do the things you used to do for fun. Feeling tired and stressed may be your new normal. There can be days when you feel sad and wish you had your old life back.

You are not alone. Many caregivers have felt the same way as you. No one can care for a child with special health care needs alone. Taking care of you and your family means you must ask for and accept help. Finding information, resources, and services in your community can make a difference for your entire family.

You may worry about your job or money. It may seem as if the things you need to do each day never end. Your days are filled with calling insurance companies or doctors, picking up medicines, meeting with teachers, taking your child to appointments, and giving treatments. There are many resources to help you.

Finding resources is like going through a maze. Information is not in one place. Programs have different rules and do different things. Providers don't always know about resources that are out there. Not every resource is right for your child. Sometimes the best resources and programs have long waiting lists.

It can help to gather tips and ideas from teachers, health care providers, case managers, librarians, and friends. Often the best way to learn is to ask other parents of kids with health conditions about resources and services. Asking questions and looking for help may take time but it is worth it.

Steps to Learn about Resources

1. List your family's needs.
2. Find resources and services that may help.
3. Do what is needed to get resources.
4. Use resources to meet your family's needs.

Take Action

Talk with your health care provider.

List Your Family's Needs.

Every family has needs. Your family may have needs due to your child's health condition. Some of the things your family may need help with are child care, paying bills, daily tasks, mental health care, transportation

Know your family's needs.

You know what your child and family need better than anyone else. Use form 9.1 as a starting point or write your family needs on paper. Remember to list needs that you already get some help for, if the help is not enough or the right kind.

Get ideas from other families of kids with similar conditions.

Many families aren't sure what their needs are or what help they can get. Other families are good sources of information. What helps one family may not help another. Questions to ask other families include:

- What are some needs your family has?
- What services and resources help you?
- What have been the most helpful resources for your family?
- How did the resources help your family? How could they help mine?
- How did you get that service or resource?
- How have your family's needs changed over time?

Questions to Think About

- What kind of help might make a difference?
- How long is help needed? A few weeks, a year?
- When is help needed? A certain day of the week, time of day?
- Where is help needed? At home, outside the home.
- Is there a cost? Do I have money to pay? Do I need it to be free? How much money can I afford if there is a cost?
- What is my past experience with help? What has helped the most? What has not been helpful?
- Do I know anyone who can give that help? Who can help me find help? Is there a person or a place like a resource center I can get help from?

Take Action

Talk with your health care provider.

Get help when needed.

Do your best to make sure your family's needs are met. Always ask for help when you need it. It is never too late to ask for help, but the sooner you ask the better. Meeting every need may not be possible. For example, sometimes insurance won't pay for therapy treatments or equipment even though your child needs it.

Find available resources.

Get the help you need to find resources and services that best support your family. Within your community there are people and places that can help. Every community offers different services. Examples of the type of help resources may provide are:

- Give information.
- Make referrals to people or places that can best meet your needs.
- Help you get services because they know the rules, providers, and how to get services quickly.
- Give direct help. People, groups or places that can meet your family's need.

You may get different ideas from a variety of sources. These are some good starting places:

- "Blue Pages" in phone book (social service section)
- Internet
- Books, newsletters, magazines and other printed information
- 2-1-1 Phone Service (available in some areas)
- County Department of Human Services office

Use the table on the next two pages to help you think of some different ways that your family's needs can be met. Your family probably does not need everything listed. Your community may not have every resource listed. For contact information please see the Resources page.



Take Action

Talk with your health care provider.

Needs	Resources
<p>Case manager A person who helps to find and coordinate care and services. (Sometimes called Care Coordinators.)</p>	<p>Ask if there are case managers at:</p> <ul style="list-style-type: none"> • Hospital • Insurance company • Local public health department <p>Other people who can help coordinate care:</p> <ul style="list-style-type: none"> • Nurse or social worker at a doctor's office • School nurse or other school staff • Home care nurse • Personal health nurse at insurance company • Coordinators at community agencies • Family member or friend
<p>Child care Day care Trained caregivers</p>	<p>At-home childcare—a friend, relative, nanny, or babysitter</p> <p>Licensed caregivers who provide care for a group of children</p> <ul style="list-style-type: none"> • In their home. • In a center such as a school, church, or agency <p>Babysitting co-ops</p>
<p>Respite care Short-term care to give you a break</p>	<p>Group respite care in the community:</p> <ul style="list-style-type: none"> • Organizations such as Easter Seals or United Cerebral Palsy Association • County or state • Park and Recreation Department • Places of worship • School aides, nurses, nursing or medical students <p>Family members or friends, in or outside your home</p>

Needs	Resources
<p>Emotional support</p>	<p>Online and face-to-face support groups</p> <p>Disability or health condition specific organizations (American Lung Association, American Heart Association)</p> <p>Other families at school, at hospitals or clinics, parent meetings, children's activities, or conferences and trainings</p> <p>Parent-to-parent matching programs</p> <p>Community or hospital-based resource centers</p> <p>Books and videos about having a child with special health care needs</p>
<p>Home health Health care providers in the home</p>	<p>Nurses:</p> <ul style="list-style-type: none"> • Public health department • Home health agency • Private duty nurse (website listings) • Parish nurse <p>Therapists (Physical, Occupational, Respiratory, Behavioral)</p> <p>Students (nursing or medical schools)</p> <p>Hospice</p> <p>Personal care worker/Home health aide</p> <p>Family or friends</p>
<p>Durable Medical Equipment</p>	<p>Home health agency</p> <p>Pharmacy</p> <p>Manufacturer</p> <p>Lending closet or equipment exchange</p> <p>Condition-specific organizations (Muscular Dystrophy Association, Spina Bifida Association)</p> <p>Hospital</p> <p>Ebay, Craigs List, or online stores</p> <p>Other families</p>

Take Action

Talk with your health care provider.

Needs	Resources
Recreation Social and physical activities (such as camps, adaptive sports, play groups, Special Olympics)	Park and Recreation Department Resource centers Libraries Schools Health care providers YMCA Friends and other families Online social networking Special opportunities (Wish granting organizations, special events, arts or sports tickets, discounts for activities)
Emotional support for siblings	Online and face-to-face support groups Online social networking SibShops Community or hospital-based resource centers Other siblings at school, hospitals or clinics, sibling meetings, activities, or trainings Respite or therapy Counseling services Books and videos about having a sibling with special health care needs
Mental health Care and services for behavioral and emotional issues	School counselors Child Life Employee Assistance Programs Counseling services (psychiatrist, psychologist, social worker) Friends, family, teachers, faith leaders Mental health organizations Group therapy Mental health facilities and organizations

Needs	Resources
Non-medical emergency planning Preparing for power failures, natural disasters, or illness outbreaks	Utility companies Public health departments Community emergency medical services Fire department Red Cross Social services City or county works departments FEMA (Federal Emergency Management Association) National Weather Service
Other needs	Travel <ul style="list-style-type: none"> • Car seats: Fire department, police department, hospital, or DME company • Medical mileage through county human services Medications <ul style="list-style-type: none"> • Drug company compassionate use program Food <ul style="list-style-type: none"> • Food pantry • WIC (Women Infants and Children program) • State food stamps (FoodShare) Housing: Home modification (building wheelchair ramps) help from churches, community organizations and businesses Equipment <ul style="list-style-type: none"> •Glasses: Lions Club, Center for the Blind •Hearing aids: Organizations for the hearing impaired Legal: Legal aid society, state bar association, community advocacy groups

Take Action

Talk with your health care provider.

Make a plan for learning about resources.

Think about what kind of help you need the most right now. What will make the biggest difference for your family? Start by looking for help with those things. Use Form 10.2 to keep track of information you find about each resource.

- Name
- Contact information
- What help they could provide
- Who do they help? (Age, health condition, financial status rules, where you live)

Always ask if they have written information. Get the name and contact information of people you talk to.

Questions:

- What services do other children and families get? Has it helped them?
- What's available in my community? What's the best way to contact them?
- What has your experience been?

Do what is needed to get resources.

Once you have the information, your next step is to gain access to the resources you need. For some resources, the process is easy. For a support group, you might just need to make a call to find out the day and time they meet. Other resources have a much more complicated application process. You might have to fill out forms, have health care providers sign them, or have a home visit.

Questions to ask

- What is the cost? Is there a sliding scale? Do they bill insurance?
- What kind of training does the staff have?
- How involved are caregivers in deciding services?
- Is there a waiting list?
- Can they suggest other resources?

Take Action

Talk with your health care provider.

Contact the resource to learn the steps you need to take.

Give complete and honest information when applying for resources. Be prepared to give a short, simple description of who your child is and what their need is. They usually need to know name, diagnosis, and where you live.

- Do you need to fill out an application?
- Do you need to send them documentation (such as tax, medical, or insurance records)?
- Do they need to do a home visit?
- Does anyone else need to give information or fill out forms (doctor, nurse, case manager)?
- If there's a waiting list, how long will you have to wait?
- When will you find out?

Before you end any conversation, summarize what will happen next, what you will do, and what they will do.

Use resources to meet your family's needs.

Now that you have decided what resources you and your family need, have gathered information, and have applied, use them appropriately.

Keep in contact with the agency or resource. Building a relationship with a key contact person at the agency can help your child and family. They will get to know you and understand your family's needs. Let them know if there are problems and also when things are working well. Check that your expectations match those of the agency.

Tips for Talking with Resources

- Describe your child's needs and strengths, your child and family goals, and your hopes.
- Tell the person what you need from them to reach those goals. You want them to understand what you need and see why it is important.
- Use words that the person will understand to describe your child's health condition. With a medical resource you might need to use the medical terms, while simple words may work better with non-medical people.
- If you are not able to get a resource for your child, look for other sources of help.

Check Yourself

- I made a list of my family's needs.
 - I thought about the kind of help we need.
 - I talked to other families to get ideas.

- I have found resources and services.
 - I contacted sources of information to learn more.
 - I found out how to use or apply for the resources.

- I did what was needed to get resources.
 - I applied for resources, including filling out forms if needed.

- I am using resources to meet my family's needs.



More Information and Resources

Child Care and Respite

- **Child Care Resource and Referral Centers:** Each state has an agency that refers to childcare: http://www.naccrra.org/for_parents/
- **ARCH National Respite Network:** National Respite Locator gives information about different types of care and lists providers by state and county: www.respitelocator.org
- **Easter Seals:** Provides a number of services for children with disabilities, including respite care: http://www.easterseals.com/site/PageServer?pagename=ntl_cdc_main
- **UCP (United Cerebral Palsy):** Services for children with disabilities, including respite care: <http://www.ucp.org/resources/parents-and-families>

Emotional Support

- **Parent to Parent USA:** Emotional support and information for families of children who have special needs: www.p2pusa.org
- **Healthfinder.gov:** List of support groups for many different health-related topics: <http://healthfinder.gov/scripts/SearchContext.asp?topic=833>
- **Caring Bridge:** Free websites for connecting families and friends of a person with health concerns: www.caringbridge.org
- **Partnership for Parents:** Support and resources for parents caring for a seriously ill child or grieving a loss: www.partnershipforparents.org
- **Sibshops:** Sibling Support Project, a national program for all ages of brothers and sisters of people with special needs: www.siblingsupport.org
- **Father Network:** Support for fathers raising children with special needs: www.fathersnetwork.org

Equipment and Supply Lending Closets: Families can borrow equipment for free. Some organizations are:

- **Katy's Kloset:** <http://teamupwithfamilies.org>
- **Easter Seals:** Find your local Easter Seals. Many loan equipment: www.easterseals.com
- **UCP Infnitec Durable Medical Equipment Exchange:** <http://www.infnitecdme.org>
- **Oley Foundation Equipment Exchange:** Borrow or donate enteral (feeding tube) or parenteral (IV) supplies. <http://www.oley.org/equipexchange.html>

More Information and Resources

Recreation

- **Special Olympics:** Sports and activities for people with intellectual disabilities: www.specialolympics.org
- **NICHCY** (National Dissemination Center for Children with Disabilities): Information about many topics including recreational activities in each state: <http://nichcy.org/families-community>

Mental Health

- **National Alliance on Mental Illness (NAMI):** Information and support for those affected by mental illness: http://www.nami.org/Template.cfm?section=Find_Support
- **Family Ties:** Information, support, education, and advocacy for families of children and with emotional, behavioral and mental disorders: www.wifamilyties.org

Emergency Planning

- **FEMA:** Information to help you plan for emergencies and disasters: <http://www.fema.gov/plan/>
- **AAP Emergency Preparedness:** American Academy of Pediatrics information on preparing for emergencies for families with children with special health care needs: <http://www.aap.org/advocacy/emergprep.htm>

Other Resources (Food, housing, medical travel)

- **Benefits.gov:** Information about federal and state programs including health insurance, food, housing: www.benefits.gov
- **National Patient Travel Center:** Information about charitable long distance medical air transportation: www.patienttravel.org or 1-800-296-1217
- **Wish Granting Organizations:** List of organizations such as Make-A-Wish: <http://www.familyvillage.wisc.edu/general/wish-grant-orgs.html>
- **NORD** (National Organization of Rare Diseases): Information and assistance with affording treatment for uncommon diseases: <http://rarediseases.org/programs/medication>
- **Disabilityinfo.gov:** Information about many topics including benefits, education, housing, transportation: www.disabilityinfo.gov
- **Family Village:** Disability-related information, resources, and connections: www.familyvillage.wisc.edu
- **Exceptional Parent Magazine:** Magazine and its website have helpful information for parents: www.eparent.com

Community Resources Forms

Form	How it can be used
Needs Assessment 10.1	Use this form to think about the needs that your family already has help with, would like to get help with, or needs more information about.
Resource Notes 10.2	Use this form to keep notes of what you learn about a specific resource. You can write contact information, what the resource does, eligibility requirements, and your next steps to be able to use the resource.

Needs Assessment

Here are some of the common needs that families have. For each topic check the box that applies to you. Decide which are the most important needs to start working on now.

Type of Need	Already Have	Want to Get Help	Need More Information
Case management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child care: Day care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Equipment: Source for used equipment, lending library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial help: Utilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food: WIC, food stamps, food pantries, formula, meal programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General Information: Resource Centers, trainings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home health care: nursing, personal care worker/home health aide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing: Home modifications like wheelchair ramps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing: Places to stay near hospital, Ronald McDonald house, discounted hotels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal aid: Help with benefits, bills, school rights	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make-a-Wish, other wish granting organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent-to-parent support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreation activities: Camps, Special Olympics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
School: Information about rights and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sibling support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Special clothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Travel: Transportation, mileage reimbursement, airfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Resource Notes

Use this form to write down what you learn about resources and how you might use them.

Resource	
Contact Person	Website
Phone	Address
What they do	
Who they serve	Eligibility requirements
Notes	
My next steps	