



Directions: Resources for Your Child's Care

Third Edition

For information and to obtain this book,
visit www.dph.state.ct.us.

For *Directions: Resources for your Child's Care*,
look under Publications/Statistics.



CONNECTICUT DEPARTMENT OF
PUBLIC HEALTH

Keeping Connecticut Healthy

How to Use Directions

Directions was created for you, a parent of a child with special health needs. It can help you plan and coordinate care for your child. In *Directions* you will find:

- Ways to organize your child's health information
- Information about caring for your child's special needs
- Resources
- Tips from other parents of children with special health care needs

Directions has many forms to fill out and a lot of information to read through. Take your time to fill out the forms that are useful to you, gather your child's records, and read through the chapters. You may want to use different forms and sections at different points in your child's life. This notebook can be very helpful to you and your child's health care providers.

Organizing Tips:

- Keep your child's ***Immunization Record*** with this book. Take it with you every time you go to a health care visit, whether it is a check-up or an emergency visit.
- Use the calendar to write down important dates and appointments.
- Write down information about your child's health and health care in *Chapter 1*.
- Keep your child's health records in *Chapter 2*. Include copies of letters, bills, receipts, prescriptions, and other documents. If you run out of space, it is time to buy another 3-ring binder!
- Keep copies of your child's school records and care plans in *Chapter 3*.
- The ***Glossary*** at the end of this book has the meaning of some words and terms.
- Ask for help. There are many people that can help you organize this note book, such as your child's primary care provider, nurse, care coordinator, case manager, teacher, other parents, or other family members.

Bring this notebook to your child's appointments and meetings with health care providers.



Internet Tips

The Internet is a good way to communicate and find information about your child's special needs. If you have access to the Internet, you can use a computer to:

- Find information about health and health care on the World Wide Web. Many excellent websites are listed in this notebook.
- Download (transfer) information from the Internet onto your own computer (like *Directions*, for example).
- Send email (electronic mail) with text and other types of files, including documents, images, and sounds.

How to Access the Internet

The Internet can be accessed from a home computer, or from:

- **Public Libraries** – Most public libraries have computers that are connected to the Internet and free to use.
- **Your Child's School** – Most schools have computers that are connected to the Internet. Ask your child's teacher or principal whether you may use a school computer to access health information for your child.
- **Family Resource Centers** – Many sites (such as your child's school, hospital, or primary care provider's office) have family resource centers or libraries that have access to the Internet. Check with one of these sites to find out if you can use a computer to access health information for your child.

Learning to Use the Internet?

There are many books and classes. If you are new to the Internet and the World Wide Web, contact your local library or school system for help.

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Calendar

Use these monthly calendars to write down important dates and appointments, such as:

- Health care appointments
- School schedules and meetings
- Medical supply and equipment deliveries
- Due dates for applications or requests
- Dates of conversations with insurance company staff, and hospital billing offices

Keep your old calendars at the end of the month or year. They contain important information about past appointments, tests, and meetings.

If you need more copies of the calendar, they are available from the Connecticut Department of Public Health. Download them from www.dph.state.ct.us.

If you need more forms, they are available from the Connecticut Department of Public Health. Download them from www.dph.state.ct.us.

Information

Important Information about Your Child

This chapter has many forms to help you organize and plan your child's care. Use them to write down your child's health care information, medical history, and other important facts. If you write everything down in one place, it will be easy to find when you need it.

Information Forms Checklist

- Parent/Guardian and Emergency Contact Information
- Health Insurance Plan
- Diagnoses
- Allergies
- Emergency Information Form for Children with Special Needs
- All about Me
- Birth and Development: About Mother's Pregnancy
- Birth and Development: About Your Baby
- Family Health History
- Health Care Providers
- Hospitals
- Other Health Care Providers
- Home Health Agency
- School/Day Care Center
- Pharmacies
- Medications
- Event Diary
- Supplies/Equipment
- Hospital Stays
- Important Tests
- Meeting/Appointment Log
- Phone Log
- Important Information for a Sitter

Important Information about Your Child

This chapter has many forms to help you organize and plan your child's care. Use them to write down your child's health care information, medical history, and other important facts. If you write everything down in one place, it will be easy to find when you need it.

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- Emergency Information Form for Children with Special Needs
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- Birth and Development: About Mother's Pregnancy
- Birth and Development: About Your Baby
- Family Health History
- Health Care Providers
- Hospitals
- Other Health Care Providers
- Home Health Agency
- School/Day Care Center
- Pharmacies
- Medications
- Event Diary
- Supplies/Equipment
- Hospital Stays
- Important Tests
- Meeting/Appointment Log
- Phone Log
- Important Information for a Sitter

If you need more forms, download from the Connecticut Department of Public Health at www.dph.state.ct.us.

Parent/Guardian and Emergency Contact Information

Child

Name _____ Nickname _____

Address _____

Social Security # _____ Date of Birth _____

First Language _____

Other Languages Spoken _____

Parent(s)/Guardian(s)

Name _____ Relationship to Child _____

Address _____

Telephone: Home _____ Work _____ Cell _____

First Language _____

Other Languages Spoken _____

Additional Parent(s)/Guardian(s)

Name _____ Relationship to Child _____

Address _____

Telephone: Home _____ Work _____ Cell _____

First Language _____

Other Languages Spoken _____

Does your child have more than one residence? Yes No

If yes, please explain _____

Emergency Contact

Name _____ Relationship to Child _____

Address _____

Telephone: Home _____ Work _____ Cell _____

Child's Name _____ Date of Birth _____

Health Insurance Plan

Primary Insurance

Name of Plan _____

Telephone _____

Address _____

Subscriber (Name of Policy Holder) _____

Subscriber ID# _____

Group # _____

Case Manager/Care Coordinator _____

Telephone _____

Other Contacts _____

Telephone _____

Secondary Insurance

Name of Plan _____

Telephone _____

Address _____

Subscriber (Name of Policy Holder) _____

Subscriber ID# _____

Group # _____

Case Manager/Care Coordinator _____

Telephone _____

Other Contacts _____

Telephone _____

Child's Name _____

Date of Birth _____

Allergies

Food

Reaction

Date Noted

Drug

Reaction

Date Noted

Other

Reaction

Date Noted

Emergency Information Form for Children with Special Needs

The following form gives emergency providers the information they need to properly care for your child. Ask your child's primary care provider (PCP) to fill out and sign this form. Give a copy of this form to anyone who may take care of your child in an emergency.

It is very important to **update** the form after any of the following events:

- Important changes in your child's condition or diagnosis
- Any major surgical procedures
- Major changes in medications or dosages
- Changes in health care providers

After updating the form, remember to give new copies to emergency medical services (EMS), your child's providers, and caregivers.

Suggestions on where to keep copies of this form:

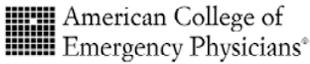
- **Health Care Provider's Office:** On file with each of the child's health care providers, including specialists.
- **Home:** At the child's home in a place where it can be easily found, such as on the refrigerator.
- **Car:** In the glove compartment of each parent/guardian's car.
- **Work:** At each parent's workplace.
- **Purse/Wallet:** In each parent's purse or wallet.
- **School:** On file with the child's school, such as in the school nurse's office.
- **Child's Belongings:** With the child's belongings when traveling.
- **Emergency Contact Person:** At the home of the emergency contact person listed on the form.
- **Local EMS:** Give to local ambulance services and hospital emergency departments. Keep more copies on-hand to give to emergency service providers during an emergency situation.

Tip:

Find more information on preparing for emergencies in Chapter 4.

Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

All about Me



My name is _____
First Middle Last

My nickname is _____

I live at Home School Foster home
 Hospital Other _____

The names of the people in my family are

First	Last	Relationship to me
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Other people who know me well are (friends, babysitter, neighbors)

First	Last	Relationship to me
_____	_____	_____
_____	_____	_____
_____	_____	_____

My Pets

My Pet is a _____ Name of Pet _____

My other pet is a _____ Name of Pet _____

Tip:

This form can help providers learn more about your child. It can also teach your child to describe his or her needs, likes, and dislikes. Give your child as much help as he or she needs in filling it out. Update it as your child grows and changes.



All about Me

Child's Name _____

Date of Birth _____

My "Favorites"

Toys _____

Games _____

Hobbies _____

Songs _____

TV Shows _____

Other _____

Things I like to do during my free time

Foods I like are

Foods I don't like are

I usually go to bed at _____ o'clock.

Before bed, I usually _____

Things I need help with are (for example: washing up, brushing teeth, dressing, etc.)

Things I can do myself are _____

Child's Name _____ Date of Birth _____

Birth and Development: About Mother's Pregnancy

Please describe any illnesses or problems during pregnancy.

Method of delivery Vaginal Caesarian Breech

Were there problems at delivery? No Yes

If yes, please describe _____

Mother's Obstetrician/Nurse Midwife _____

Telephone _____

Mother's Primary Care Provider _____

Telephone _____

Delivery Setting

Name of Hospital/Birth Center _____

Telephone _____

Address _____

Was child transferred to another hospital? No Yes

If yes, Name of Hospital _____

Telephone _____

Address _____

Child's Name _____ Date of Birth _____

Birth and Development: About Your Baby

Birthweight _____ lbs _____ oz Length _____ inches

Was baby full-term (37 or more weeks)? Yes No If no, weeks of gestation _____

Child's Apgar scores at 1 minute _____ at 5 minutes _____

Child's age at first discharge from hospital _____

Baby was fed breast milk formula

If fed formula, list brand _____

Developmental Milestones

My Child	Age:	Notes
Smiled		
Held up head		
Rolled over		
Sat up		
Got first tooth		
Started solid food		
Crawled		
Spoke first word		
Waved "bye bye"		
Walked		
Spoke first sentence		
Toilet trained		
Other:		
Other:		

Tip:

Ask your child's primary care provider (PCP) for information you don't know (such as Apgar scores and growth measurements).

Tip:

Document your child's height and weight in their *Immunization Record*.

Child's Name _____

Date of Birth _____

Family Health History

Is there anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) with a similar disability or chronic illness? No Yes

If yes, who? _____

Does anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) have:

	<input type="checkbox"/> Yes	<input type="checkbox"/> No	If yes, relationship to child
1. Genetic conditions	<input type="checkbox"/>	<input type="checkbox"/>	_____
2. Heart problems	<input type="checkbox"/>	<input type="checkbox"/>	_____
3. Developmental disability	<input type="checkbox"/>	<input type="checkbox"/>	_____
4. Seizure disorder	<input type="checkbox"/>	<input type="checkbox"/>	_____
5. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	_____
6. Blood disorder	<input type="checkbox"/>	<input type="checkbox"/>	_____
7. Cancer	<input type="checkbox"/>	<input type="checkbox"/>	_____
8. Vision and/or hearing impairment	<input type="checkbox"/>	<input type="checkbox"/>	_____
9. Metabolic or nutritional disorder	<input type="checkbox"/>	<input type="checkbox"/>	_____
10. Other _____	<input type="checkbox"/>	<input type="checkbox"/>	_____

Has anyone in the family had genetic testing or counseling?

Yes No Don't Know

If yes, please describe _____

Is there any other family health information that might be related to your child's special health needs? _____

Child's Name _____ Date of Birth _____

Health Care Providers

Tip: Instead of filling out the form, staple your provider's business card onto the space provided.

Primary Care Provider

Name _____ Specialty (if any) _____

Clinic/Hospital Name _____ Telephone _____

Address _____

Fax _____ Email _____

Medical Specialists and Health Care Providers

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Child's Name _____ Date of Birth _____

Health Care Providers

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Name _____

Specialty _____

Address _____

Telephone _____

Fax _____

Email _____

Clinic/Hospital Name _____

Frequency of Visits (how often) _____

Child's Name _____ Date of Birth _____

Hospitals

Main Hospital

Name of Hospital _____

Address _____

Medical Record # _____

Hospital Operator Telephone _____

Emergency Department Telephone _____

Contact Person Name _____ Title _____

Telephone _____ Fax _____

Email _____

Other Hospital

Name of Hospital _____

Address _____

Medical Record # _____

Hospital Operator Telephone _____

Emergency Department Telephone _____

Contact Person Name _____ Title _____

Telephone _____ Fax _____

Email _____

Child's Name _____ Date of Birth _____

Other Health Care Providers

Use this form to list service providers such as therapists, counselors, Birth to Three providers, care coordinators or case managers, personal care attendants (PCAs), respite providers, state agency contacts, etc.

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Child's Name _____ Date of Birth _____

Other Health Care Providers

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Service(s) _____

Agency Name _____

Address _____

Contact Person _____ Telephone _____

Fax _____ Email _____

Frequency of Visits (how often) _____

Child's Name _____ Date of Birth _____

Home Health Agency

Agency Name _____

Contact Person _____ Telephone _____

Address _____

Fax _____ Email _____

Service(s) to be provided (for example, nursing, therapy, home health aides, etc)

Service	Frequency (how often)	Amount (hours per visit)
	visits/week	hours/visit

Notes/Comments

Child's Name _____ Date of Birth _____

School/Day Care Center

Name of School _____

Address _____

Principal _____ Telephone _____

School Nurse _____ Telephone _____

Teacher(s) _____ Telephone _____

Aide(s) _____

Special Education Contacts _____ Telephone _____

Therapist(s) _____ Telephone _____

School Psychologist _____ Telephone _____

Guidance Counselor _____ Telephone _____

Parent Advisory Committee (PAC) Contact _____ Telephone _____

HEAD START Contact _____ Telephone _____

Is there a school-based health center at your child's school? Yes No

If yes, Name of Center _____ Telephone _____

School Transportation

Agency Name _____

Contact Name _____ Telephone _____

Address _____

Child's Name _____ Date of Birth _____

Pharmacies

Main Pharmacy

Name _____

Address _____

Telephone _____

Fax _____

Hours of Business _____

Contact Person _____

Other Pharmacy

Name _____

Address _____

Telephone _____

Fax _____

Hours of Business _____

Contact Person _____

Child's Name _____ Date of Birth _____

Supplies/Equipment

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Child's Name _____ Date of Birth _____

Supplies/Equipment

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Description of Item _____

Provider/Vendor Name _____

Contact Person _____ Telephone _____

Prescribed by _____ Telephone _____

Reason Prescribed _____

Contact Person for Service/Insurance Approval _____

_____ Telephone _____

Comments (for example: kinds of service needed, part numbers, costs) _____

Child's Name _____ Date of Birth _____

Hospital Stays

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Child's Name _____ Date of Birth _____

Hospital Stays

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Date of Admission _____ Date of Discharge _____

Name of Hospital _____ Telephone _____

Address _____

Doctor(s)/Surgeon(s) _____

Reason for Admission _____

Outcome _____

Child's Name _____ Date of Birth _____

Important Tests

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Child's Name _____ Date of Birth _____

Important Tests

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Blood X-ray CT MRI Other _____ Date Performed _____

Description _____

Doctor who Ordered Test _____ Telephone _____

Results _____

Location of Test Record _____ Telephone _____

Comments _____

Important Information for a Sitter

Parent(s)/Guardian(s) Name(s) _____

I/We will be at _____ I/We will be home around _____

Telephone _____ Cell Phone _____ Pager _____

Special instructions _____

Significant events during past 48 hours _____

Medications to be given and time(s) _____

In Case of an Emergency: CALL 911

Child's Name _____

Home Telephone _____ Date of Birth _____

Address _____

Doctor's Name _____ Telephone _____

Other person to call in case of an emergency (i.e. relative, neighbor, friend) _____

Allergies _____

Extra equipment/supplies are located _____

Fuse box or breaker is located _____

Fire extinguisher is located _____

Flashlight is located _____

Fill out a new form and give it to your child's sitter each time.
More forms are available from the Connecticut Department of Public Health.
Download them from www.dph.state.ct.us.

Health Records

Put copies of health records, letters from health care providers, and other health information in this chapter.



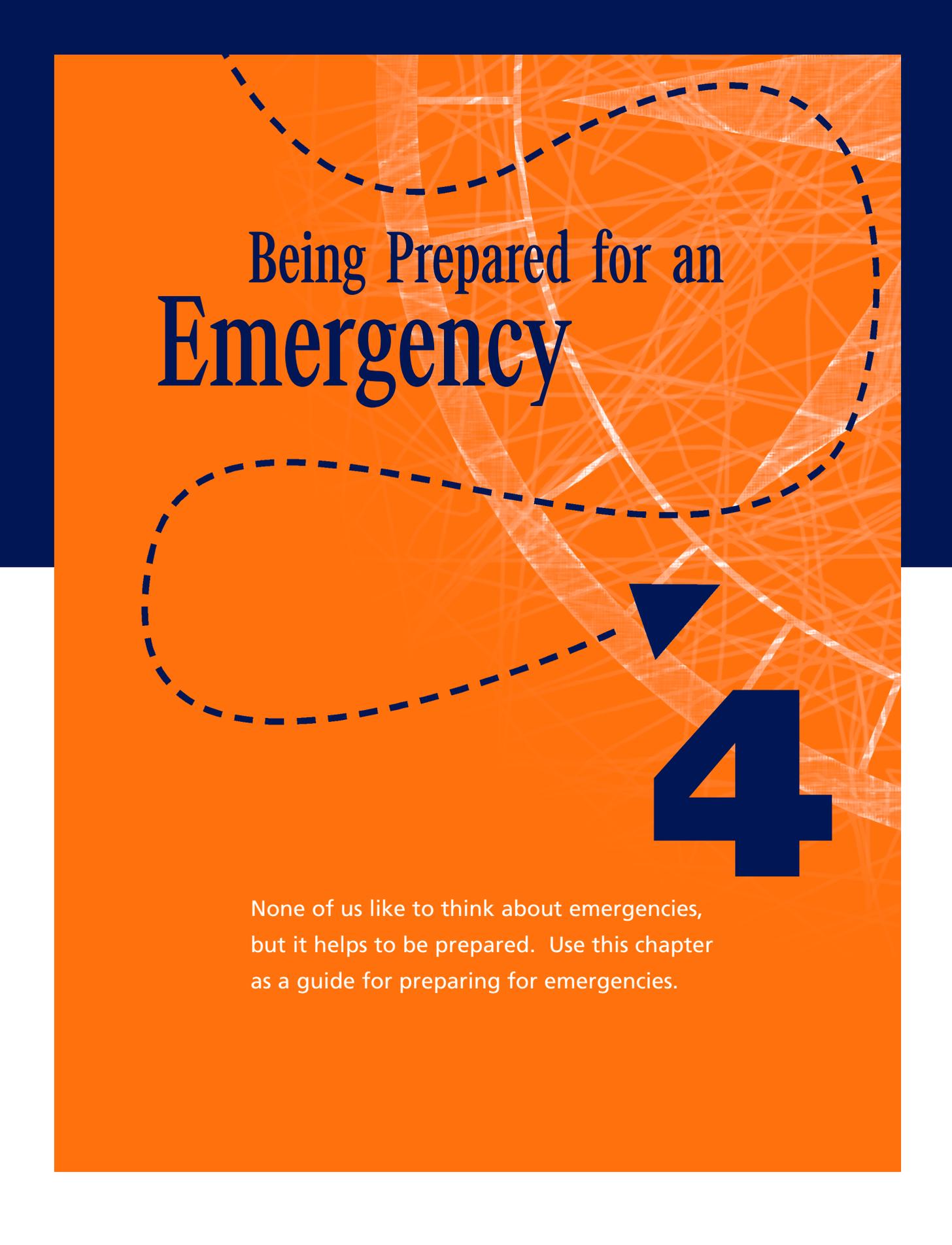
2

School Records

In this chapter, put copies of school records, assessments, evaluations and other educational information, such as:

- Individualized Family Service Plans (IFSPs)
- Individualized Educational Programs (IEPs)
- Individualized Health Care Plans (IHCPs)
- 504 Plans
- Notes from school meetings (with teachers, IEP Team meetings, and school providers)
- Progress reports and report cards

3



Being Prepared for an Emergency

4

None of us like to think about emergencies, but it helps to be prepared. Use this chapter as a guide for preparing for emergencies.

Preparing for a Medical Emergency

If your child has a medical emergency, call 911 or go to the emergency room at the nearest hospital right away.

A medical emergency is a serious medical condition that results from injury, sickness or mental illness.

A medical emergency is sudden, severe, and needs immediate treatment.

Some examples of possible medical emergencies are when your child:

- Loses consciousness (passes out)
- Has convulsions or seizures
- Has eaten poison of any sort
- Has severe or unusual shortness of breath or difficulty breathing
- Has severe or unusual vomiting
- Has heavy or sudden bleeding
- Feels sudden, severe or unusual pain or pressure
- Has had a serious fall, car accident, or blow to the head
- Is trying to harm himself or herself, or harm others

Tip:

Make a list of possible emergencies related to your child's condition. Review it with your child's primary care provider (PCP). Ask the PCP to share the list with other on-call providers who may take care of your child during an emergency.

Visiting the Emergency Room

Learn about your child's health plan policies for emergency room visits before an emergency happens. Check the benefits handbook or call a Member Services Representative at the plan for more information.

Remember to call and tell your child's PCP about the emergency. Ask the emergency room staff to send a copy of the record from the visit to your child's PCP.

Emergency Information Form for Children with Special Needs

The following form gives emergency providers the information they need to properly care for your child. Ask your child's primary care provider (PCP) to fill out and sign this form. Give a copy of this form to anyone who may take care of your child in an emergency.

It is very important to **update** the form after any of the following events:

- Important changes in your child's condition or diagnosis
- Any major surgical procedures
- Major changes in medications or dosages
- Changes in health care providers

After updating the form, remember to give new copies to emergency medical services (EMS), your child's providers, and caregivers.

Suggestions on where to keep copies of this form:

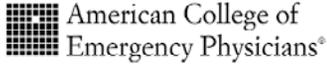
- **Health Care Provider's Office:** On file with each of the child's health care providers, including specialists.
- **Home:** At the child's home in a place where it can be easily found, such as on the refrigerator.
- **Car:** In the glove compartment of each parent/guardian's car.
- **Work:** At each parent's workplace.
- **Purse/Wallet:** In each parent's purse or wallet.
- **School:** On file with the child's school, such as in the school nurse's office.
- **Child's Belongings:** With the child's belongings when traveling.
- **Emergency Contact Person:** At the home of the emergency contact person listed on the form.
- **Local EMS:** Give to local ambulance services and hospital emergency departments. Keep more copies on-hand to give to emergency service providers during an emergency situation.

Tip:

You can also find a copy of the **Emergency Information Form** in *Chapter 1*.

Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings:
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs:
_____	_____
4. _____	_____
_____	_____
Synopsis:	Baseline neurological status:
_____	_____
_____	_____
_____	_____

*Consent for release of this form to health care providers

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

Significant baseline ancillary findings (lab, x-ray, ECG):

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Prostheses/Appliances/Advanced Technology Devices:

Management Data:

Allergies: Medications/Foods to be avoided

and why:

1. _____
2. _____
3. _____

Procedures to be avoided

and why:

1. _____
2. _____
3. _____

Immunizations

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem

Suggested Diagnostic Studies

Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature:

Print Name:

Emergency Response Plan

Talk to your child's primary care provider (PCP) about what to do when an emergency happens.

Create an Emergency Response Plan with your child's PCP, specialty health care, school, and home care providers. Take this plan with you on an emergency room visit and give to emergency medical services (EMS) providers.

The plan may include:

- **Medical information about your child**
- **The name(s), signature(s), and contact information of your child's PCP and other important providers**
- **Where your child should be taken in an emergency**
- **Treatment that should be provided to your child in certain situations (including specific instructions and tips for emergency room staff)**

Before an emergency, give a copy of the **Emergency Response Plan and Emergency Information Form for Children with Special Health Needs** to EMS providers in your local area. Keep more copies of the plan on-hand to give to emergency service providers during an emergency situation. Update the form as needed.

Preparing for an Emergency at Home

Make sure emergency medical service providers (EMS) in your community know about your child's condition ahead of time, such as: ambulance, fire, police, and utility companies. Then, in an actual emergency, EMS providers will be more familiar with your child's health needs. Contact them before an emergency happens.

Contacting EMS Services in Your Community

- Your ambulance company may be operated by the fire department or by a private or municipal company. To find the name of the EMS Director or ambulance company, call:
 - the local fire department**
 - the local police department**
 - the town or city hall**
- Ask what level of EMS (basic or advanced life support) is available.

Basic life support (BLS) is provided by an Emergency Medical Technician (EMT-Basic or EMT-B). EMT-Bs are trained to provide the following care:

- Assessing a person's condition
- Providing first aid
- Giving oxygen
- Performing heart and lung revival, called CPR (cardiopulmonary resuscitation), which can include the use of an automated external defibrillator (AED) to shock the heart back to normal
- Use epi-pens in case of a severe allergic reaction
- Change a trach tube for a person that is having trouble breathing
- Taking a person to the hospital

Tip:

Learn CPR, first aid, and other procedures that could help your child during an emergency.

Preparing for an Emergency at Home

Advanced life support is provided by an EMT-Intermediate and EMT-Paramedic (under the direction of a doctor). In addition to everything an EMT-B can do, they can do the following:

- Give intravenous (IV) fluids
 - Use AEDs to give lifesaving shocks to a stopped heart
 - Use advanced airway techniques and equipment to help a person who has trouble breathing
 - Give some drugs by mouth or by IV
 - Read heart monitoring equipment, such as electrocardiograms (EKGs)
 - Insert breathing tubes (endotracheal intubations)
-
- Ask your ambulance service if their EMTs have pediatric training and pediatric equipment to perform some of the procedures that your child might need. Ask whether ambulances are staffed by EMT-Basics, paramedics, or both.
 - Fill out the **Emergency Information Form for Children with Special Health Needs**. Make copies for all EMS providers.
 - Discuss your child's **Emergency Response Plan** with EMS. The plan can help prepare the EMTs and paramedics for the kinds of medical procedures your child may need in an emergency.

Tip:

Clearly mark your house or apartment number. Then, EMS can easily find your home, even in the dark.

*Check in with your community EMS providers at least once a year. Update your child's **Emergency Information Form** as needed and send them a copy.*

Contacting Police and Fire Departments

- Call your local police and fire departments to give them information about your child's special health care needs. For example, tell them where your child's bedroom is located. Describe the types of life-sustaining medical equipment your child uses. Let them know if your child is verbal or nonverbal, and if your child is able to walk.

Contacting Utility Companies

- Call your local utility (electricity) company if your child has specific equipment that requires electricity (such as a ventilator, nebulizer, kangaroo pump, apnea monitor, or refrigerated medication). You can be put on a priority list to restore electricity as soon as possible in case of a power failure.
- Ask your town's fire department about portable generators. You might need one if your child uses electric equipment. You may also call your child's durable medical equipment (DME) provider or the social work department at the local hospital to learn more about portable generators.

Contacting Public Works and Telephone Companies

- Call the local Department of Public Works office and your local telephone company. Let them know about your child's special needs.
- Ask the public works department to put your street on a priority list for snow removal. This can help make sure an ambulance has quick access to your home in an emergency.
- Ask the telephone company to put you on a priority list. This can help make sure that your phone service will not get completely shut off. Then, you will always be able to call for help if there is an emergency.



Sample letters to community providers are available from the Connecticut Department of Public Health. Download them from www.dph.state.ct.us.

Preparing for a Disaster Emergency

Disasters can happen anytime, anywhere, and sometimes without warning. A winter storm could keep your family at home for days. A fire, flood, tornado, or any other disaster could stop water, electricity, and telephone services. You could have to leave your home.

Be prepared for a disaster emergency before it happens. Make a Disaster Supplies Kit for your child and your family. Keep these supplies on hand:

- Water – a 3-day supply for each household member
- Food – a 3-day supply for each household member
- First Aid Kit
- Essential medications – prescription and over-the-counter
- Special equipment and supplies for your child with special needs
- Generator, if your child is dependent of machines using electricity
- Sanitation supplies (toileting and hygiene)
- Flashlight with extra batteries
- Radio with extra batteries
- Cellular phone with extra battery
- Cash
- Extra clothing and bedding
- Important documents
- A copy of the Emergency Information Form for Children with Special Needs
- Important phone numbers
- Other tools and supplies

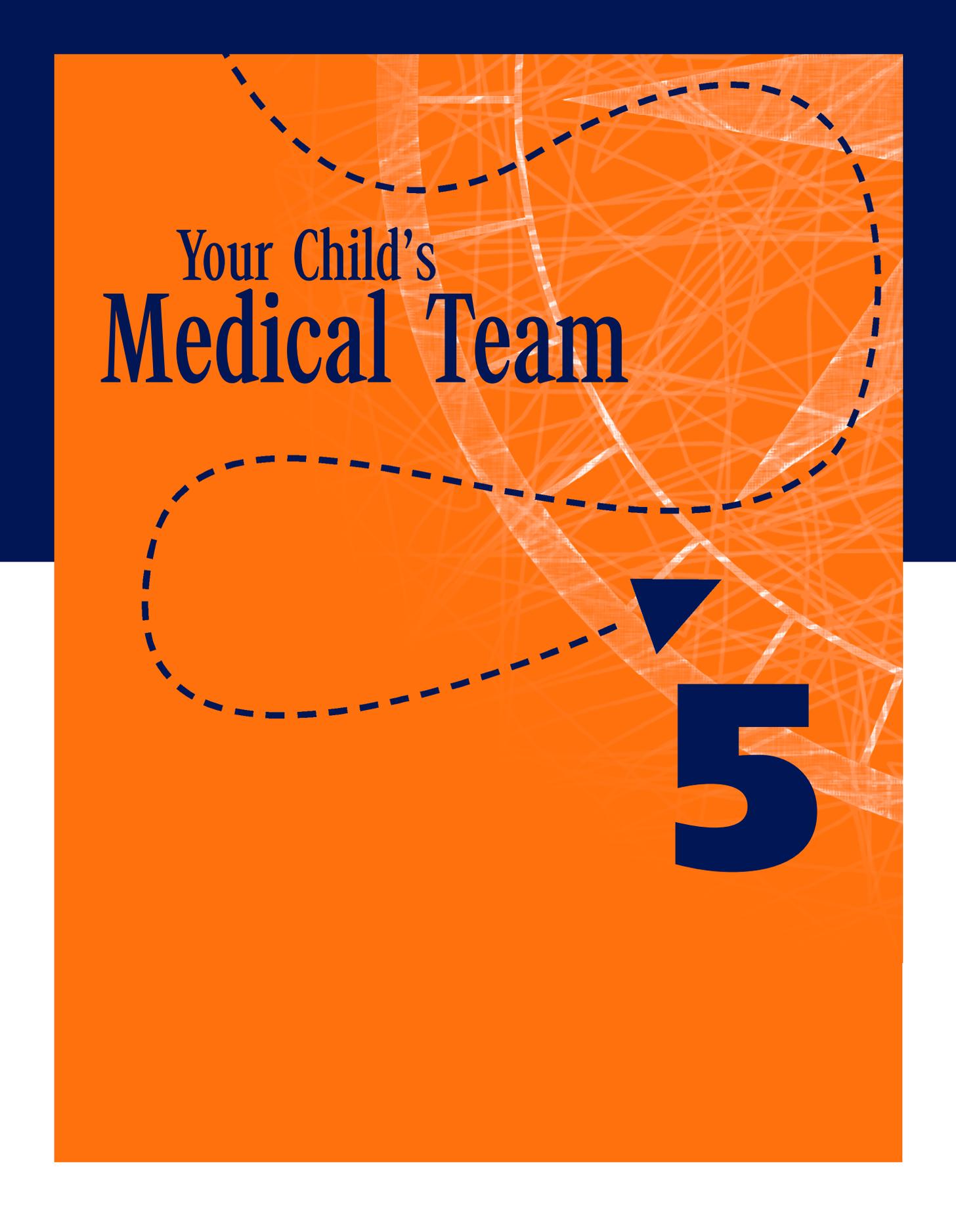
For more information on Disaster Planning, contact the Federal Emergency Management Agency (FEMA) at 800-480-2520, 800-621-3362 (TTY), or visit www.fema.gov. You can also contact your local American Red Cross Chapter or visit www.redcross.org. Many communities have community emergency or disaster teams that work with FEMA and can give families local help.

Tip:

Keep the phone number of an out-of-state contact person in your Disaster Supplies Kit. Sometimes, it is easier to contact a person out-of-state during a disaster.

Notes



The background is a vibrant orange color. A dashed blue line starts at the top left, curves down and right, then loops back down and left, ending with a solid blue triangle pointing downwards. A large, bold blue number '5' is positioned in the lower right quadrant. The text 'Your Child's Medical Team' is written in a dark blue, serif font, with 'Your Child's' on the top line and 'Medical Team' on the bottom line.

Your Child's
Medical Team

5

What is Primary Care?

Primary care is the routine (regular) health care your child gets from a doctor or nurse. The goal of primary care is to keep your child as healthy as possible. This is done by preventing health problems or by treating them right away.

There is a recommended schedule for regular check-ups and immunizations. You and your child's primary care provider (PCP) may decide that more frequent visits are a good idea for your child.

What is a Primary Care Provider (PCP)?

A PCP may be a:

- Pediatrician – a doctor who cares for children and adolescents
- Family physician – a doctor who cares for people of all ages
- Specialty physician – a doctor who cares for people with special conditions
- Nurse practitioner – a specially trained nurse who cares for children or whole families
- Physician's Assistant – a health care provider who cares for people of all ages and works under a doctor's supervision

Your child's PCP should:

- Know about your child's overall health, growth, and development
- Provide regular check-ups, immunizations, and tests
- Give you suggestions for keeping your child healthy
- Treat your child when he or she is sick
- Refer your child to specialists, benefits, or services
- Help you coordinate care with specialists and other providers
- Help connect you with community resources
- Provide telephone access for medical advice and emergencies 24 hours a day, 7 days a week
- Answer your questions – and your child's questions – about health and medical care

Tip:

Remember: your child's PCP is the doctor or nurse you choose in your health plan.

What is a “Medical Home?”

In a Medical Home, families and providers work together as partners to access all the services needed for a child – both medical and non-medical. Medical Home is as much an attitude as it is a way of delivering care. Families are recognized as the main caregivers and the center of strength and support for children.

According to the American Academy of Pediatrics, a Medical Home is a primary care practice that is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective, and for which the primary care pediatrician shares responsibility.”

Medical Home is an important part of the U.S Department of Health and Human Services’ “Healthy People 2010” plan. The goal of Healthy People 2010 is to improve the health of all people – including children with special health care needs.

What does Medical Home mean to you and your child?

Medical Home is a helpful way to think about your child’s whole system of care. If your child has a condition or disability that requires extra care, referrals to specialists, and/or other services, ask your child’s primary care provider (PCP) about Medical Home. You can also find out more information about Medical Home from:

American Academy of Pediatrics
at 847-434-4000 or visit
www.medicalhomeinfo.org

American Academy of Pediatrics,
Tools/Resources for Families
[www.medicalhomeinfo.org/
tools/family_index.html](http://www.medicalhomeinfo.org/tools/family_index.html)

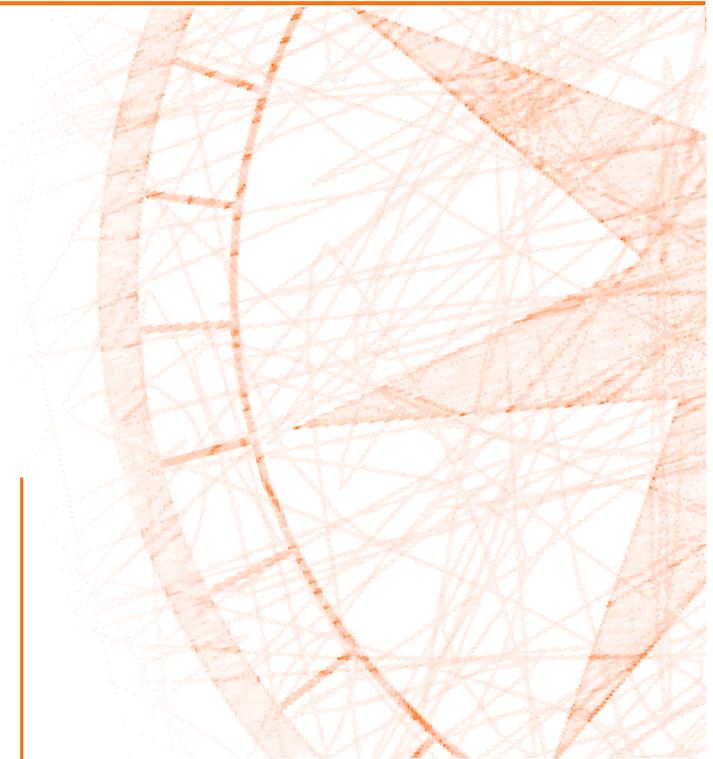
Connecticut Department of
Public Health at www.dph.state.ct.us

Talking with Your Child's Health Care Providers

You know your child better than anyone else does. Your child's health care providers need your help to give the best care. It is your health care provider's job to listen to your concerns and answer your questions. *It is your job to speak up for your child.*

If you want more information, *ask your child's health care provider.* No question is silly or dumb. If you do not understand something, *ask your child's health care provider to explain it to you.* Your child's health care provider will not know that you have a question unless you ask it. Many parents find it helpful to write down questions ahead of time. Some health care providers have special "call-in times" to answer questions.

(Adapted from *Growing Up Healthy*.
Massachusetts Department of Public Health, 1998.)



It is your job to speak
up for your child

Questions to Ask Your Child's Primary Care Provider (PCP)

As you plan for your child's medical care, use these questions as a guide for learning more about your PCP's practice. You may want to use them whether you are choosing a new PCP for your child or if your child already has one. You can use them when meeting with a specialist or other health care provider too.

1. Who in your office will be involved in my child's care?

2. Who do I talk to about:

- Scheduling or changing an appointment?
- Medical information?
- Insurance and billing information?
- Help in an emergency?
- Services related to my child's special needs?
- Getting letters of medical necessity?

3. Who do I talk to when you are not available?

- Will I be speaking to a nurse or a doctor?
- Can you introduce me and my child to other PCPs in the practice so they will know about my child's special health needs?
- What if I absolutely need to reach you?
- What hospital(s) do you work with?

4. What if my child needs to see a specialist?

- How do you choose a specialty doctor or a therapist?
- How do you choose a counselor or mental health provider?
- How will you communicate with the specialist caring for my child, and how will you keep me informed?

5. How do you work with other people caring for my child?

- Will you help develop health care and education plans for Birth to Three and my child's school?
- If my child needs to be hospitalized, will you visit us in the hospital? Will you be involved in discharge and home care planning?

6. How will decisions be made about my child's care?

- What role will I have in making treatment decisions?
- Will you help me make decisions about specialty care options?
- I have certain beliefs about my child's care. How do you feel about them?
- If I want to get a second opinion regarding my child's diagnosis or treatment, will you help me?
- Can you advise me if I have questions about new treatments or procedures that could be helpful for my child?

7. How will I be kept informed about my child's special health needs?

- How will I get basic information about my child's diagnosis?
- Will you tell me about research developments that might affect my child's care?
- Who will train me if I need to give my child special medication or treatment?

8. Will you help me plan for my child's short and long-term needs?

- Will you help me understand what to expect about my child's development and long-term health needs?
- Will you be honest with me even if it means saying, "I don't know?"
- What if I am having trouble dealing with the stress of parenting my child? Are you willing and able to help me?
- As my child grows older, how can you help us prepare for the transition to adolescence and adulthood?
- Are you comfortable discussing sexuality, alcohol and drug use, and other risky behaviors with my teen?
- What will happen when my teen needs to transition to adult-oriented health care?

Tip:

When you ask a question and the answer is not clear, ask for it to be explained again (and again if necessary!).

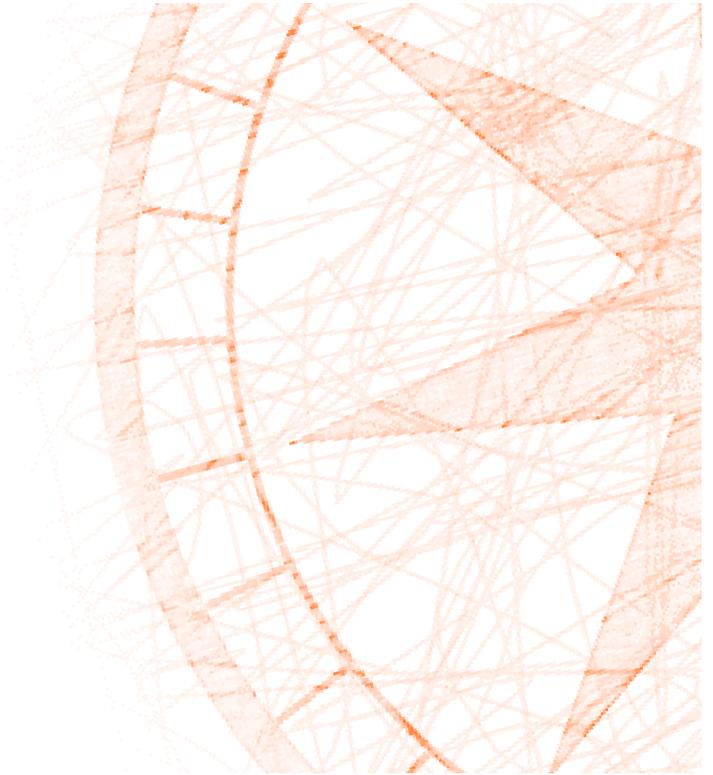
Tips on Making the Most of a Health Visit

Before the visit	During the visit	After the visit
<ul style="list-style-type: none"> • When making the appointment, tell the receptionist your child will need extra time. • If you need to cancel the appointment, call your provider <u>at least 24 hours</u> beforehand. • Ask your provider whether your visit needs a referral and/or authorization. • Think about the purpose of the visit. What matters to you most? • Make a list of questions and concerns to talk about. • Bring paper and pen to take notes during the visit. • Bring along any medical records you might need. Bring <i>Directions</i>. • Bring your child's medications or medication list. • Prepare your child for the visit. Encourage your child to ask questions too. 	<ul style="list-style-type: none"> • Be on time. • Bring health insurance referral and/or authorization paperwork, if needed. • Talk about your list of questions and concerns. • If your child is a teen or young adult, encourage your child to talk to the provider alone. • Discuss any changes in your child's health since the last visit. • Talk about important events that have occurred lately. • Ask about any treatments or procedures you may have questions about. • Take notes. • Leave paperwork (such as school physical forms, nursing orders, etc.) with your health care provider to be filled out and sent back to you later. • Ask about future medical tests and appointments. 	<ul style="list-style-type: none"> • Review your notes. Think about whether your questions were answered. • If you have more questions after the visit, it's okay to call your provider. • Did your provider give you any new instructions about your child's care? If so, share these and other things you learned at the visit with those who need to know— like caregivers and family members. • If you were given a referral to see another provider, make sure to call and make that appointment. • On your calendar, write down the next appointment or when to call for the next appointment. • Update <i>Directions</i>.

(Adapted from *Health Care Visit Checklist*. Bright Futures for Families, www.brightfuturesforfamilies.org, and *Making the Most of a Ten Minute Office Visit*. Massachusetts Family TIES, www.massfamilyties.org.)

Seeing a Specialist

Your child's primary care provider (PCP) may refer your child to a specialist. A specialist is a doctor or other provider with "special" training in a certain area of medical care. (See **Health Care Providers by Specialty** table on page 26.) A specialist will evaluate and treat your child's special condition. The specialist usually sends a written report of the visit back to your child's PCP. Ask the specialist to send a copy of this report to you. If you have questions about this report, ask your child's specialist or PCP.



Tip:

Your child's specialist may want you to bring results of lab tests, x-rays, and other tests to the first visit. Organize these tests before your child sees the specialist.

Seeing a Mental Health Provider

If you worry about your child's behavior or emotions, ask for help.

Find out what the problem is and where to get services that will help. Talk to your child's primary care provider (PCP), care coordinator, or teacher to learn more. Your child may be referred to a **mental health or behavioral health provider** (sometimes known as a counselor or therapist). There are different types of mental health services and they are provided by a variety of people. A mental health provider may be a:

- **Psychiatrist**
- **Psychologist**
- **Social worker**
- **Mental health counselor**
- **Nurse practitioner**

All of these providers are trained in understanding feelings and behaviors. They know ways to work together with you to support your child (such as counseling and/or medication therapy). Try to find a mental health provider who makes you and your child feel comfortable. (See **Health Care Providers by Specialty** table on page 26 and **Glossary** for more information on these providers.)



Finding a Mental Health Provider

Counseling and therapy are provided in many different settings, including:

- The home
- Community health centers
- Hospitals
- Schools
- Private offices
- Churches and religious communities
- State agencies

- Contact 2-1-1 Infoline or <http://www.infoline.org/referweb/>
- Department of Children and Families Statewide KidCare Resource Directory at <http://www.ct.gov/dcf>
- FAVOR – a statewide Family Advocacy Organization for Children’s Mental Health <http://www.favor-ct.org>

(Adapted from Making Sense: A Parent’s Guide to Mental Health Resources. Boston Public Health Commission, www.talklisten.org.)

Your first step is to call a Member Services Representative at your child’s health plan. Find out which mental health providers in your area accept that insurance. **If you have decided to use health insurance to pay for your child's treatment, you must choose a provider from their list.**

You may also want to ask people you trust for referrals. You may be able to get suggestions from your child’s primary care provider (PCP), your child's school, your religious leader, your friends, and members of your family. You can talk with your child's teacher or school principal to get information about what services are available at school.

Seeing a Dentist

Dental health, the care of teeth and gums, is an important part of your child's well being.

A dentist is a key member of your child's health care team. Your child may need to be followed by a pediatric dentist, a dentist who specializes in the treatment of children. Also, you may have to find a dentist who specializes in caring for children with special health care needs.

Ask your child's primary care provider (PCP) about finding a dentist that meets the needs of your child. You can also find the names of pediatric dentists in your local area by contacting:

- **The Connecticut State Dental Association at 860-378-1800 or visit www.csda.com.**
- **The American Academy of Pediatric Dentistry at 312-337-2169 or visit www.aapd.org.**

Tip:

If you are having trouble finding a dentist that accepts your child's health insurance, contact Infoline at 2-1-1 or <http://www.infoline.org/referweb/>

Before your child's first dental exam, tell the dentist about your child's special needs, health history, and current medications. Some children with special health care needs are at-risk for bacterial infection during dental procedures. Ask the dentist whether your child needs antibiotics before the visit to protect against infection.

Have your child's teeth checked regularly by a dentist. Schedule the first visit to a dentist by your child's first birthday. Talk to the dentist about how often your child needs a check-up.

Working with a Care Coordinator

Working with a Care Coordinator

Sometimes it can be hard to get the information, care, and services your child needs. A specially trained individual such as a **care coordinator** or case manager may help you:

- Identify the needs of your child and family
- Understand the full range of available public benefits
- Identify community resources to help you
- Find access to specific programs and services
- Become a more effective advocate for your child
- Find other families to talk to who have some of the same experiences

Finding a Care Coordinator

You may find a care coordinator or case manager by contacting:

- Your child's primary care provider (PCP)
- Your child's health plan
- Organizations in your community
- Hospitals
- Health centers in your community
- State agencies (such as the Department of Public Health)

Health Care Providers by Specialty (What They Do)

Specialty	Physician Specialist	Non-Physician Specialist
Blood	Hematologist	Phlebotomist
Bones and Joints	Orthopedist Orthopedic Surgeon Physiatrist Rheumatologist Sports Medicine Specialist	Physical Therapist Occupational Therapist Chiropractor Orthotist
Breastfeeding	Primary Care Provider Obstetrician/Gynecologist	Lactation Consultant
Cancer Care	Oncologist	Nurse Practitioner Hospice Workers
Case Management	Primary Care Provider	Social Worker Care Coordinator Case Manager Nurse
Complementary and Alternative Medicine	Medical Doctor Osteopathic Doctor	Chiropractor Acupuncturist Homeopath Herbalist
Critical/Intensive Care	Critical Care Specialist Intensivist	Nurse Practitioner
Diet/Nutrition	Gastroenterologist	Dietitian Nutritionist
Ears, Nose & Throat Hearing & Speech	Otolaryngologist (ORL)	Audiologist Speech & Language Therapist
Emergency	Emergency Physicians	Emergency Medical Technician (EMT) Paramedic Nurse Practitioner
Eyes/Vision	Ophthalmologist	Optometrist
Foot Care	Podiatrist	Orthotist/Prosthetist
Genes	Geneticist	Genetic Counselor
Head/Neck/Back	Orthopedist Physiatrist	Chiropractor Physical Therapist Orthotist
Heart	Cardiologist	Nurse Practitioner
Hormones and Glands	Endocrinologist	

Specialty	Physician Specialist	Non-Physician Specialist
Immune System	Immunologist Allergist Infectious Disease Specialist	Nurse Practitioner
Kidney	Nephrologist	
Lungs/Chest	Pulmonologist Pulmonary Specialist	Respiratory Therapist
Medical Imaging (x-rays, CT, PET, and MRI scans)	Radiologist	X-ray Technician
Mental, Emotional, or Behavioral Health	Psychiatrist Neuropsychiatrist Behavioral Neurologist	Psychologist Clinical Social Worker Nurse Practitioner Counselor/Therapist
Muscles	Rheumatologist Physiatrist	Physical Therapist
Nervous System	Neurologist Neuropsychiatrist Neurosurgeon	Occupational Therapist
Newborn Babies	Neonatologist	Nurse Practitioner
Pain Management	Rheumatologist Palliative Care Specialist Anesthesiologist Neuro Physiatriist	Acupuncturist Hospice Nurse
Rehabilitation	Physiatrist Rehabilitation Medicine Specialist	Physical Therapist Occupational Therapist Orthotist/Prosthetist Exercise Physiologist Speech Pathologist
Reproductive Health (female)	Gynecologist Obstetrician	Nurse Midwife Nurse Practitioner
Reproductive Health (male)	Urologist	
Skin	Dermatologist Plastic Surgeon	
Stomach, Colon, Intestines, and abdominal organs	Gastroenterologist (also called GI Specialist)	
Surgery	Surgeon Anesthesiologist	Nurse Practitioner Nurse Anesthetist
Teeth and Gums	Dentist Orthodontist Periodontist Oral Surgeon	Dental Hygienist
Urinary Tract	Urologist	

Tip: For more information on specialists, ask your child's primary care provider (PCP). You may also want to visit the American Academy of Pediatrics web site, www.aap.org/parents.html.

Changing Health Care Providers

There may be a time when you are not happy with the care your child is getting. Maybe you disagree with the provider's recommendations or you just don't get along. If this happens, try to talk about your concerns with the provider. Sometimes, talking together can resolve the problem and improve your relationship.

If you still disagree, you can always decide to change your child's primary care provider (PCP) or other health care provider.

Here are some things to keep in mind:

- Contact a Member Services Representative at your child's health plan to find out how to make the change. The health plan can give you names of other PCPs and specialists in its network.
- Ask your child's PCP to help you find other providers who can care for your child. The PCP will usually need to make a referral for another specialist.
- Ask parents of other children with special health care needs for advice.

You can also call:

- Infoline 2-1-1 or <http://www.infoline.org/referweb>

Your Child's Hospital Care

If your child ever needs to stay in the hospital, learning your way around can be a challenge. Your child's hospital team may include many health care providers –

doctors, nurses, therapists, and others. At a teaching hospital, medical students and other providers in training may be involved too.

Understanding “who’s who” in the hospital means learning some new names and terms. For example, you may be dealing with:

- An attending physician
- A medical resident
- A medical fellow
- A medical student
- A hospitalist

You may also see:

- Nurses
- Child life specialists
- Social workers
- Phlebotomists
- Occupational therapists (OTs)
- Respiratory therapists
- Physical therapists (PTs)

And all of these people may be called “doctors.”

Learn more about different types of providers in the **Health Care Providers by Specialty** table on page 26. Look in the **Glossary** for information about specific providers.

Tip:

Hospital stays are very anxious times and it's hard to remember everyone. When a new doctor, other provider, or “team” of providers comes to see your child in the hospital, ask them their name and role. Write down names—or ask for a business card.

Tips on Supporting Your Child During a Hospital Stay

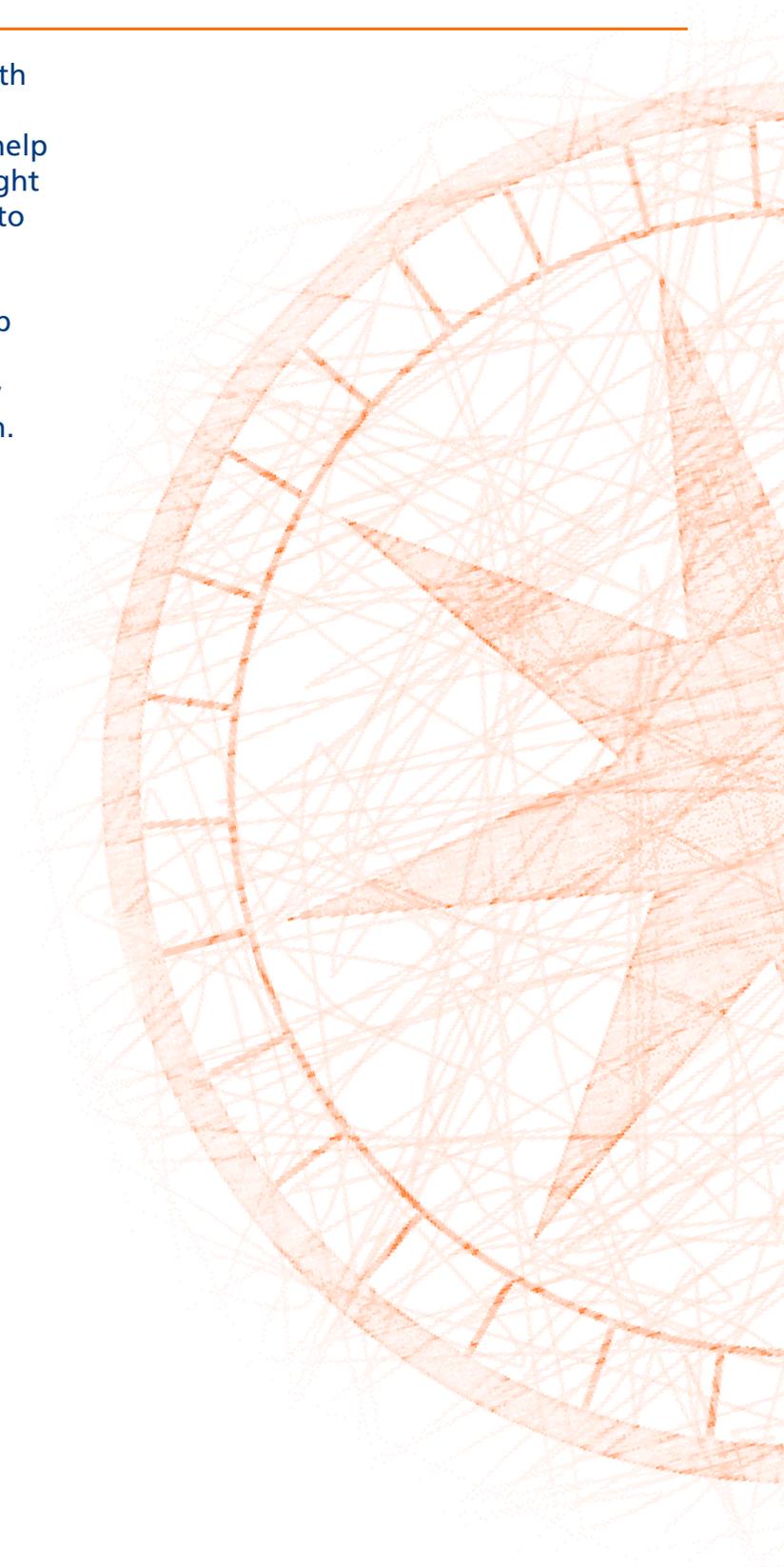
- **Prepare your child ahead of time.** As much as you can, explain to your child what will happen in the hospital. You may want to use an age-appropriate book or video. (Ask someone at your local library or the hospital family resource center for ideas.) Depending on your child's age and needs, you may also want to ask one of your child's providers to use a doll to act out tests or procedures before the real thing.
- **Know your rights.** Hospital regulations allow you to stay in your child's room overnight and during tests or procedures.
- **Tell the hospital team about your child's favorite foods, most enjoyed activities, toileting, and sleeping habits.** Bring a copy of the **All About Me** form from *Chapter 1* to give to the team.
- **Bring your child's familiar objects and reminders of home** (such as toys, pictures, music, books, and pajamas).
- **Ask to have non-routine procedures that might be painful or uncomfortable done in a treatment room,** rather than in your child's room. This way your child can feel better about his or her hospital room.
- **Think about how to schedule visits** from relatives and friends so your child receives important emotional support but does not get too tired.
- **Bring Directions to the hospital** as a resource and to organize information and papers/reports given to you during the hospital stay.

(Adapted from *Working Toward a Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs*. Project School Care, Children's Hospital. Boston: Harvard University, Office of the University Publisher, 1992.)

Preparing for the Hospital Discharge

Your child should leave the hospital with a written discharge plan prepared by hospital staff. The discharge plan will help to make sure that your child has the right support to stay healthy when it's time to leave the hospital.

The checklist on the next page can help you prepare for your child's discharge from the hospital. Some questions may not apply to your child's discharge plan. Use the checklist to make sure your child's discharge plan is complete.



Hospital Discharge Checklist

Use this checklist to make sure your child's discharge plan from the hospital is complete. Note that some questions may not apply.

- Have you received written information about your child's current condition? Do you understand it?
- Have you been trained on how to care for your child's special needs? Do you know how to care for your child in the case of an emergency (such as CPR, first aid, and other emergency care)?
- Do you have prescriptions for all of your child's medications and services?
- Have you been told about public benefits and services, and how to get them?
- Have you had a discharge-planning meeting?
- Has a home health care agency been identified? Has nursing coverage been confirmed?
- Have you identified back-up caregivers (home health agency or others trained to care for your child)?
- Have you talked about making your home accessible for your child? What type of equipment will your child need?
- Have you been set up with a durable medical equipment (DME) provider? Has a delivery date been set?
- Has an Emergency Response Plan been developed? Have your child's community providers been contacted (including your child's primary care and specialty providers, local hospital, and ambulance provider)?
- Have public utilities (such as electricity, gas, water, etc) been contacted about your child's needs? Has your child been put on a priority list to restore utilities during emergencies?
- Have you discussed the importance of getting support for yourself (from family, friends, community, house of worship, etc.)?
- Do you have referrals to other programs and services, such as: care coordinators, Birth To Three, community agencies?
- Has your child's school been contacted?

Resources to Help During a Hospital Stay

The hospital may have resources to help you and your family.
Ask the hospital staff about:

- Family resource centers and libraries
- Interpreter services
- Support groups and counseling
- Activities and care for siblings
- Educational tutoring
- Religious services and counseling
- Meal tickets
- Parking vouchers
- Check cashing and ATMs
- Laundry and cooking facilities
- Lodging or short-term housing for parents
- Blood donation

Medical Privacy and Communication

Under federal law, health plans and most health care providers are required to ensure the privacy and security of your child's health care information.

A federal law that protects a person's health information is called HIPAA. HIPAA stands for the Health Insurance Portability and Accountability Act of 1996. This law requires most entities that provide or pay for health care (like most doctors, hospitals, and insurance companies) to protect the privacy of health information, and to standardize the way they exchange health information.

Generally, they may use and share your child's health information for limited purposes including:

For treatment:

Your child's health care provider may share health information with doctors, nurses and other health care personnel who are involved in your child's care.

For payment:

Your child's health care provider may use or share health information with your child's health plan in order to bill and collect payment for your child's health care services.

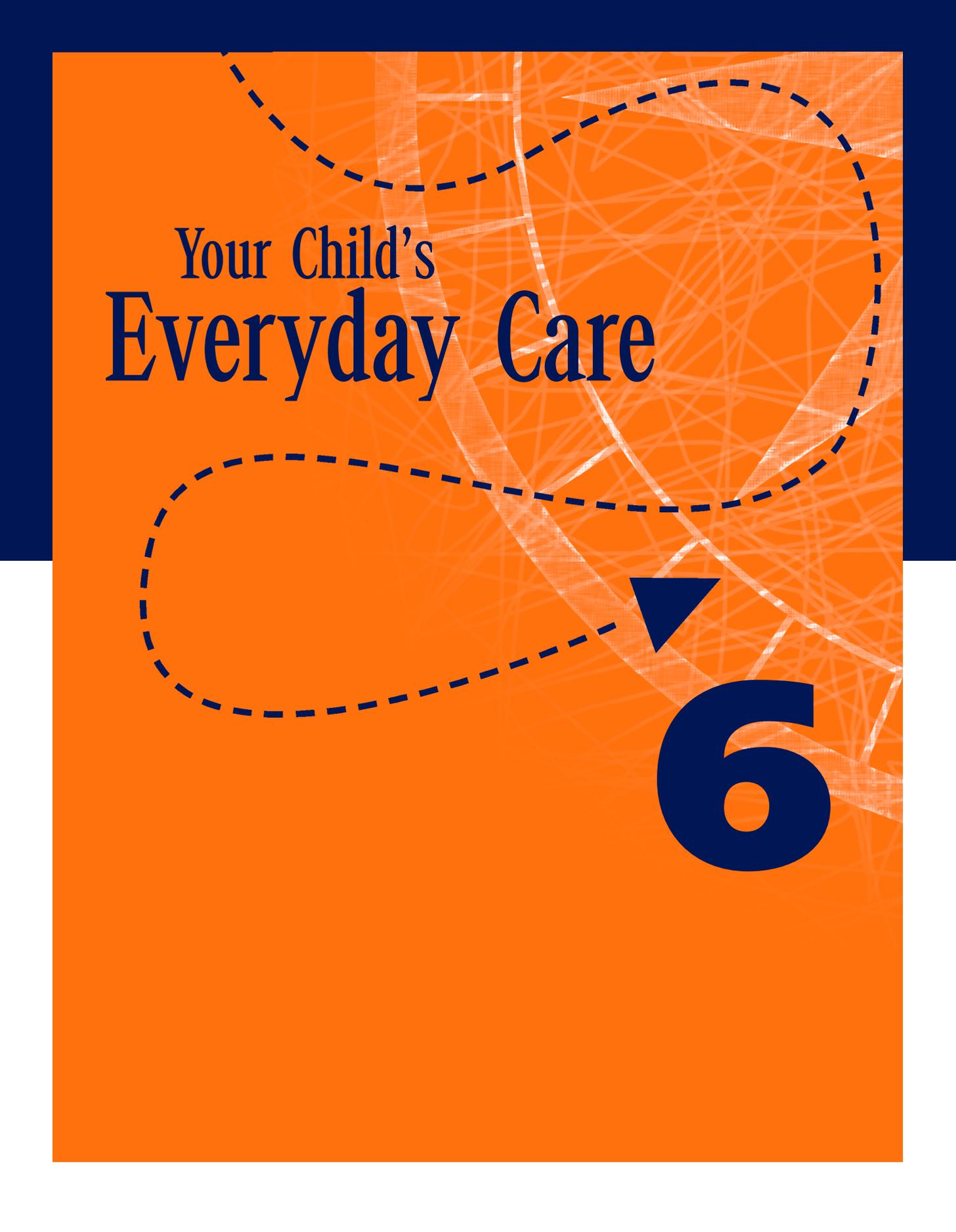
For health care operations:

Your child's health care provider or your health plan may use or share information in order to better manage his or her program and activities, such as improving treatment for your child.

For public health activities:

Your child's health care provider may share information for public health activities, including sharing your child's immunization records with the school nurse to meet the requirements of Connecticut law.

As a parent you have rights regarding your child's health information. You may request a copy of your child's medical records. Also, there are certain times when your child's health care provider or health plan may need your permission before sharing your child's health information. If you have questions about medical privacy, ask your child's health care provider or health plan about how they protect your child's privacy.

The background is a vibrant orange color. It features a complex pattern of thin, light-colored lines that form a dense, web-like structure. Overlaid on this are several larger, semi-transparent geometric shapes, including a large circle and various triangles. A prominent dashed blue line curves across the upper and middle portions of the page. In the lower right, a solid dark blue triangle points downwards towards a large, bold number '6'.

Your Child's
Everyday Care

6

6

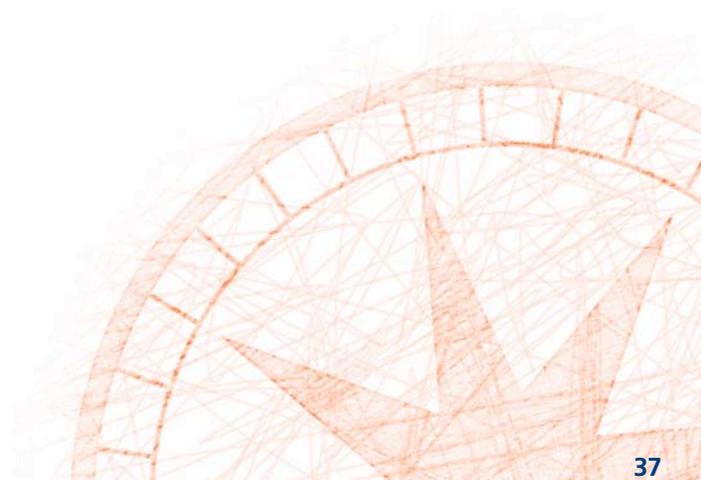
Your Child's Everyday Care

This chapter provides information and resources for taking care of your child's daily needs. It includes information about some health care services used at

home that may need extra planning. Many of the following ideas and tips come from other parents based on their own experiences.

Some of these services are covered by your health insurance plan and some are not. There may be other ways to pay for some of these services. To find out more, contact:

- Your child's primary care provider (PCP)
- Your child's care coordinator or case manager (state, community, or health plan)
- Infoline 2-1-1 or www.infoline.org



Medication

Your child's health provider may order different kinds of medications for your child. These medications might include:

Prescription medications. These are medicines you get from a pharmacy only with a prescription (a written order from a health care provider). Ask your child's provider to refer to the health plan's list of covered medications when writing prescriptions. This may affect the amount of your copayment (also called "co-pay," which is the amount you pay) for medications.

Over-the-counter medications. These are medicines you can buy on your own at a pharmacy without a prescription (such as aspirin or cold medicines).

Vitamins and Dietary Supplements. These are nutritional products that may be needed for your child's diet and health. You can usually buy them on your own at a pharmacy or health food store.

A co-payment may be required for all prescription medications. Some health plans may pay for certain over-the-counter medications, vitamins, and dietary supplements when prescribed by a provider. Check the benefits handbook or call a Member Services Representative to learn more about medication coverage by your child's health plan.

Questions to ask a health care provider or pharmacist when a medication is prescribed:

1. What is the name of this medication?
2. What does this medication do?
3. How much medication (what dose) will my child take?
4. How many times a day will my child take this medication?
5. Are there any special instructions for taking this medication?
6. How long will my child take this medication?
7. What are the side effects?
8. Can this medication be taken with other medications my child already takes?

(Adapted from *Prescription for Success: Massachusetts Family Voices*, www.massfamilyvoices.org.)

Keeping Medications Organized

When your child takes many medications, keeping track of them can be tricky. Ask your child's primary care provider (PCP) or pharmacist to help you get organized. Here are a few tips from other parents:

- Try to arrange to have the same refill date for all prescriptions. This reduces phone calls and trips to the pharmacy.
- Check with your child's health plan about using a mail order pharmacy. If your child takes a prescription medication on a regular basis, you may be able to get more medication at a time and with less hassle.
- Buy a pill organizer that has space to hold your child's medication for each time of day and each day of the week.
- Keep track of medications on the **Medications** form in *Chapter 1*. To prevent problems with medications, bring this form with you to all medical appointments.
- Tell all of your child's providers about every medication your child is taking, including:
 - Prescription medications**
 - Over-the-counter medications**
 - Vitamins**
 - Nutritional supplements**
 - Herbal remedies**

Tips to help your child take medicine

Ask your child's PCP about using different forms and flavors of medications.

Ask about:

- **Pills that need to be taken only one time per day**
- **"Quick dissolve tablets"**
- **Capsules that can be opened and mixed in food**
- **Flavored syrups**

Tip:

Many employers offer Flexible Spending Accounts for medical expenses (including over-the-counter medications). It is a way to set aside pre-tax income for medical expenses. Ask your employer about Flexible Spending Accounts.

Nutrition

Good nutrition and healthy eating helps your child to grow and develop. A child who has a medical condition, developmental delay, or takes certain medications regularly may be at risk for nutritional problems. Discuss your child's dietary needs with the primary care provider (PCP).

Does your child

- Have trouble gaining weight?
- Take medications, vitamins, and/or food supplements regularly?
- Have trouble breastfeeding or using a bottle regularly?
- Have trouble sucking, swallowing, chewing, drinking from a cup, or eating different textures?
- Have trouble feeding himself or herself?
- Take longer than 30 minutes to eat?
- Refuse to eat, or eat too much?
- Eat non-foods (such as dirt, chalk, or soap)?
- Have nausea, vomiting, constipation, or diarrhea?
- Use formula after age 1?
- Use a feeding tube?

If the answer is **YES** to any of these questions, or if you have any other concerns, talk with your child's PCP. Your child may be referred to a nutritionist or dietitian. A nutritionist can help you and your child with:

- Feeding and feeding equipment
- Special formula or diet
- Meal planning
- Other nutrition services

Check the benefits handbook from your child's health plan to learn about covered nutritional services. For other resources on nutrition, including help with family resources to buy food, contact:

- Infoline 2-1-1 or www.infoline.org
- Connecticut Association for Human Services (CAHS) has the CT Food Guide. Call 860-951-2212 or visit www.cahs.org.

Tip:

If your baby is having trouble breastfeeding, a lactation consultant can help. Ask your PCP, your child's PCP, or hospital family resource center how to find a lactation consultant.

Durable Medical Equipment

Durable medical equipment (DME) means items, supplies or equipment designed for particular medical needs. It is called durable because it is meant to last a long time.

Examples of DME:

- Leg and body braces
- Crutches
- Wheelchairs
- Hospital beds
- Some medical or surgical supplies
- Intravenous pumps
- Nutritional supplements

Usually, your child will need a prescription from a health care provider for DME. DME is provided by companies (usually called DME vendors or providers) that have a contract with your child's health plan. Contact a Member Services Representative or your child's case manager at the plan to learn more about DME services. Refer to the health plan benefits handbook for more information.

Tip:

Keep track of your child's DME on the **Supplies/Equipment** form in *Chapter 1*.

Assistive Technology (AT)

Assistive technology (AT) is any kind of tool or piece of equipment that helps a person live more independently. AT also provides a way for people to participate more fully in life activities. AT can be high tech — a computer operated by eye movement — or low-tech — a specially designed door handle. It can be big — an automated van lift for a wheelchair — or small — a Velcro-attached grip for a fork or pen.

AT can help someone:

- Travel
- Participate in recreational and social activities
- Study
- Work
- Communicate with others

Examples of Assistive Technology are:

- **Home equipment**, like a seat for using the bath, or adapted eating utensils
- **Educational and work aids**, like book holders and adapted pencil grips
- **Travel equipment**, like a wheelchair or an adapted car seat
- **Communication systems** for people who need help with seeing, hearing, and/or speaking
- **Computer technology**, like programs that convert speech to text or enlarge words on a screen
- **Sports and recreation equipment**, like bowling balls with handgrips and one-handed fishing reels

Ask your child's primary care provider (PCP) about getting a professional evaluation for AT services.

Some types of AT may be covered by your child's health plan under the durable medical equipment (DME) benefit. Check the benefits handbook or call a Member Services Representative at your child's plan to find out what types of AT are covered. See *Chapter 8* for more information about using AT in school. For other resources on AT, check **The New England Assistive Technology Marketplace (NEAT)** at <http://www.neatmarketplace.org> or call toll-free 866-526-4492.

Transportation

Transporting your child to medical appointments is your job. Plan ahead whenever you can. Arrange for transportation to medical appointments before your scheduled appointments. If you cannot get there by yourself or with the help of family or friends, there are resources that may help.

You can learn about transportation resources from:

- **Your child's care coordinator or case manager**
- **A case manager at your child's health plan**
- **Community service organizations in your area (for example, Knights of Columbus and Handikids)**

Car Seat Safety

To keep your baby and young child safe, always use a child safety seat (car seat). A safety seat can only protect your child if you use it correctly. To make sure you install the car seat correctly, follow the directions that come with it, or contact CT Safe Kids at <http://www.ctsafekids.org>.

A child with special health needs may need a special, adapted car seat depending on the condition or diagnosis. Ask your child's primary care provider (PCP) about the kind of car seat your child needs. You can find information about special car seats from the American Academy of Pediatrics website at www.aap.org.

Tip: Using Public Transportation

Contact Infoline at 2-1-1 or <http://www.infoline.org> for more information on transportation for people with disabilities.

Tip:

Call your local police or fire department to find out if your town has a car seat safety program. There may be a professional who can help you install your child's car seat in your car.

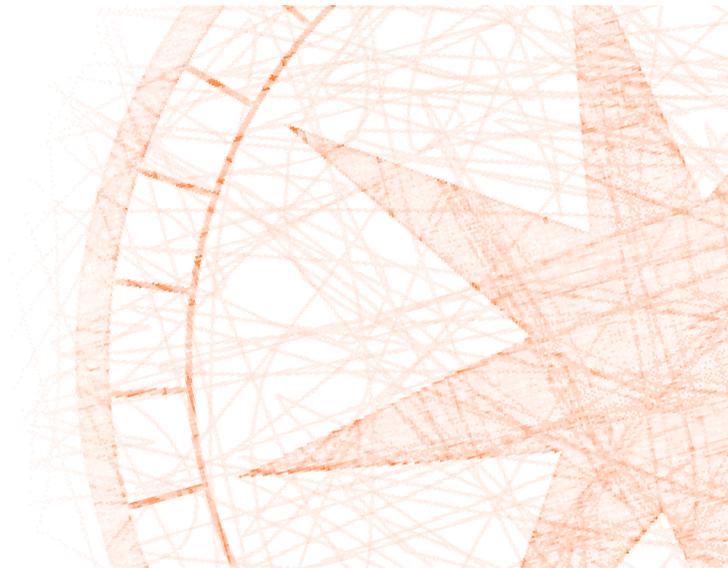
Using Home Health Services

There may be a time when your child needs home health care services. These services can be important in helping keep your child healthy and safe. A home health care agency may provide:

- Skilled nursing
- A home health aide
- Private duty nursing
- Physical therapy
- Occupational therapy
- Speech and language therapy
- A personal care attendant
- A respite worker
- Hospice care

See Glossary for more information about these home health services.

Your child's health insurance plan may offer home health services as a covered benefit. Check the benefits handbook or contact a Member Services Representative to ask about services covered by the health plan.



Important Information about Home Health Services

You will need a prescription (written order) from your child's primary care provider (PCP) before using home health services.

Make sure that the home health agency you choose is in your child's health plan network.

Talk to your PCP about which agency to use if there is more than one choice.

The home health agency will do an assessment of your child's special needs.

The assessment is usually done by a registered nurse (RN). It can be done either at home or while your child is in the hospital. Ask lots of questions. (See **Questions to ask your Home Health Agency** on page 47.)

There are two types of nursing services:

- "Short-term," also called "intermittent"
- "Continuous," also called "private duty," "block," or "shift"

Important Information about Home Health Services

Your home health agency should give you information about your rights and responsibilities. You have the right to expect high quality services. You also have the right to privacy and respect from anyone who comes into your home. If you have a complaint or grievance, you should call the agency first. You may also report a complaint to the CT Department of Public Health, Division of Health Systems Regulations at 860-509-7400. You can also submit your complaint online at http://www.dph.state.ct.us/BHCS/Complaints/complaint_form.htm.

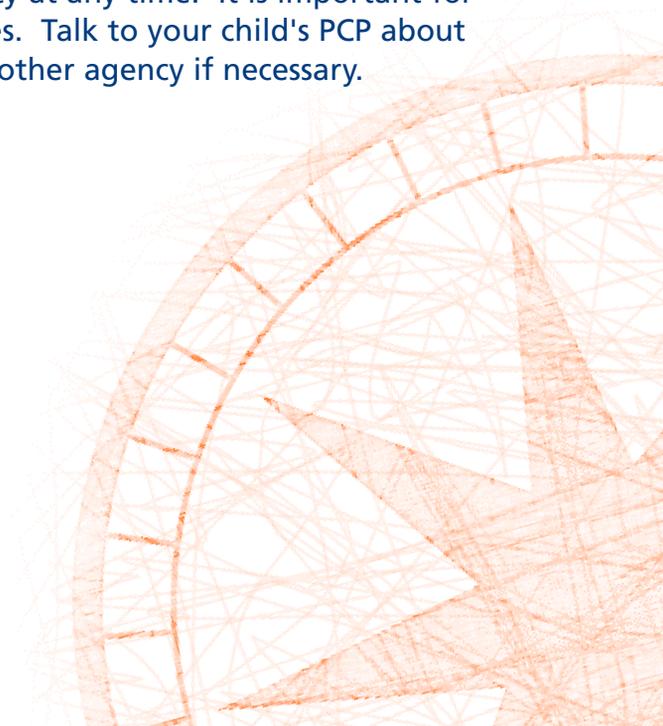
Keep your child's primary care provider (PCP) informed and involved.

A home health agency should do everything possible to provide needed services. However, there may be times when this is not possible – like during a snowstorm or if a staff member is sick. Talk with the agency ahead of time about what to do if this happens.

Develop a schedule with the agency. Make sure that the agency staff comes to your home at the times of the day when your child needs care the most.

If you child is admitted to the hospital, contact the home health agency and your child's PCP to let them know.

You can stop services from a home health agency at any time. It is important for you to identify why you want to stop the services. Talk to your child's PCP about your concerns. This will help you in selecting another agency if necessary.



Questions to Ask a Home Health Agency

General Information:

- What services can the agency provide?
- Does the agency accept my child's health insurance plan?
- Can I get names of parents who have used the agency to call for references?
- How do I stop or change services?

Experience of Staff:

- Is the agency licensed by the Department of Public Health?
- Does the agency have staff with the specific training to meet my child's needs? If not, are they willing to add or train staff?
- Can I interview the caregiver? Who will pay for the caregiver's time during the interview and training? Have the caregiver's references and criminal history been checked?
- Who will supervise my child's home health caregivers?

Communication and Planning:

- How will the agency communicate with my child's primary care provider (PCP) and specialty providers?
- How are schedules made? Can the schedule be changed?
- Will my child have a single caregiver or a different one every time?
- What does the agency do about back-up services?
- How will I be involved in developing my child's nursing care plan?
- Who can I talk with if I have concerns about my child's caregiver?

Types of Services:

- Who at the agency will coordinate care and help solve problems for my child?
- Can the caregiver take my child to medical appointments and to school?
- How do I get a copy of my child's clinical record, including care and nursing care plans?
- Will the agency take care of my child's equipment needs, or do I need to arrange for an outside equipment company?
- Will related services, such as nursing, physical or occupational therapy be coordinated through the agency?
- Will home health agency staff help with my child's transition from home to school?

Using a Personal Care Attendant (PCA)

A personal care attendant (PCA) is an independent caregiver who can help with activities of daily living (like getting in or out of bed, bathing, dressing, and going out into the community).

It is your responsibility to hire, train, supervise, and pay for a PCA for your child. Since this process can sometimes be more challenging than families expect, here are some suggestions on hiring and working with a PCA. Check with your child's health plan about other ways to pay for a PCA. Also, make sure to get legal and tax guidance from appropriate sources before accessing PCA services.

Steps to Success with a Personal Care Attendant (PCA)

1. List tasks.

Identify the kinds of assistance your child needs from the PCA. Describe how much time it takes to do each task. Ask for input from other people who care for your child.

2. Make a budget.

Determine how you will pay the PCA. If another party is paying, learn about the policies and guidelines. If you are paying yourself, determine how much you will pay. Contact your local Independent Living Center at the Department of Social Services, Bureau of Rehabilitation Services at 1-800-537-2549, or 860-424-4839 (TDD/TTY) for more information.

3. Create a job description.

Write a description of what you expect the PCA to do. Be specific when you describe the tasks. Develop a sample daily schedule that lists what the tasks are and when they are done.

Make a list of the kinds of training and work experience that you wish the PCA to have. This may include special training and/or certification, such as First Aid or CPR. Keep in mind that the more qualified the PCA, the more the services will cost. Sometimes training an inexperienced PCA to do things the way you want them done is better than retraining a PCA with experience.

4. Find a PCA.

Consult your local Independent Living Center, an employment agency, or another source to find a PCA. If you decide to place an advertisement in a local paper, newsletter, or bulletin board, list the minimum qualifications for the PCA. You may also want the candidate to tell you what kind of transportation he or she has. Provide a phone number or email for responses. (For safety reasons, don't include your home address.)

5. Get information from a PCA candidate before an interview.

- Legal name, address, phone number
- Social security number, driver's license number
- Date the applicant can begin working
- Previous work experience, including name, address, and phone number of employers
- Education and training
- Disclosure of previous criminal convictions
- Names and phone numbers of references

6. Interview your candidate.

Prepare a list of questions before the interview. Discuss the list of tasks you made in Step 1. Describe your child's daily schedule. If your child is old enough to participate, bring him or her to the interview. You and your child need to be comfortable with the PCA, because some of the tasks may be very personal.

For safety reasons, you might think about holding interviews some place other than your home. Also, think about requesting a Criminal Conviction Record check. Contact the Connecticut Department of Public Safety, State Police Bureau of Identification at 860-685-8480 or on-line at <http://www.ct.gov/dps/site/default.asp>. There is a charge for each request.

7. Train the PCA.

Take the time to train any PCA you hire. Make it clear what you expect. Let the PCA know if there is personal information that is confidential. Make sure to tell the PCA about your (and your child's) needs, feelings, and decisions.

8. Be a good employer.

- Show the PCA respect. You and the PCA have the right to different feelings, opinions, or points of view. Remember that you are in charge.
- If there is a problem, don't put off dealing with it. Make sure that you explain the problem clearly to the PCA and tell him or her what needs to change.
- Provide the PCA with feedback about the work, including what is done well and what needs improvement. Be sure to thank the PCA for their work.

9. Keep a list of backup PCAs in case of illness or emergency.

(Adapted from the *Kentucky TEACH Project*. Kentucky Commission for Children with Special Health Care Needs, chs.ky.gov/commissionkids.)

Childcare

There will be times when you decide to ask other people to take care of your child. When using childcare, it is important to think about both your child's needs and your own. Different types of childcare work best for different types of children and families. The three basic types of childcare are:

- At-home childcare – a caregiver comes to your home to care for your child. This could be a friend, relative, nanny, or babysitter.
- Family childcare – a licensed caregiver provides care for a group of children in her home. Care may be provided to children of all ages.
- Center-based childcare – a licensed professional organization that provides care for children in a group setting. Care may be provided to children between the ages of 1 month to 16 years.

Your child cannot be denied childcare from any *licensed* childcare provider unless they don't have any openings. According to federal law, all childcare providers must accept an application from any interested family. Childcare providers must try to include any child in their program—regardless of the ability level or disabling condition of the child. To refuse or terminate services to a child with a disability, a childcare provider must present proof of financial or other hardship caused by caring for that child.

To learn more about licensed childcare in your community, contact the Connecticut Department of Public Health at 1-800-282-6063 or online at <http://www.dph.state.ct.us>.

Contact Infoline at 2-1-1 or online at <http://www.infoline.org> for childcare options in Connecticut, including the ability to do an advanced search for a match of special needs providers.

Tips on getting ready for childcare:

- Talk to the staff to find out how your child's needs will be met. Start working with the staff 3-6 months before your child plans to start.
- Work with the staff to set up your child's Individualized Education Program (IEP) and an Individualized Family Service Plan (IFSP) for special services by age 3. (See *Chapter 8*.)

Tip: Many employers offer Flexible Spending Accounts for dependent care (such as childcare). It is a way to set aside pre-tax income for dependent care. Ask your employer about Flexible Spending Accounts.

Choosing a Sitter

There are times when you may need to spend time away from your child. Talk to your child's primary care provider (PCP) about what kind of sitter is best for your child. For some families, a teen-aged neighbor may be fine. For other families, someone with clinical expertise (like a nurse) may be better. Remember that most health insurance plans do not pay for childcare services.

A sitter should be mature and prepared to deal with an emergency. Look for someone who is comfortable with and can handle all of your child's equipment and special care needs.

Tell the sitter about your child's care needs and teach the sitter how to work with your child. A good way is to let the sitter watch you.

Use the **Important Information for a Sitter** form in *Chapter 1*. Fill out and give this form and the **Emergency Information Form for Children with Special Needs** to the sitter every time.

Suggestions on how to find a sitter:

- **Call a local hospital** to find sitters with clinical training. Ask about part-time or retired staff who may wish to care for your child. Ask if you can post a note for a "special" sitter on the hospital's bulletin board.
- **Call a local school or community college** with a program that trains nurses, physical therapists, or early childhood education specialists. Students in these programs may be available to care for your child (and might even get course credits for doing so). Most colleges will accept job postings by phone or email.
- **Contact local colleges** and post advertisements in their Student Employment offices. Often these postings can be done by phone or email.
- **Friends or other family members** may want to care for your child.
- **Put an ad in your local newspaper.**
- **Contact parent groups, community centers, churches, and other religious communities in your area.** Ask if they have a list of sitters.
- **Other parents may also be willing to care for your child.** Some parents form "babysitting co-ops" to exchange childcare services.

Tip:

To request a Criminal Conviction Record check for a sitter you wish to hire, contact the Connecticut Department of Public Safety, State Police Bureau of Identification at 860-685-8480 or on-line at <http://www.ct.gov/dps/site/default.asp>. There is a charge for each request.

Respite Care

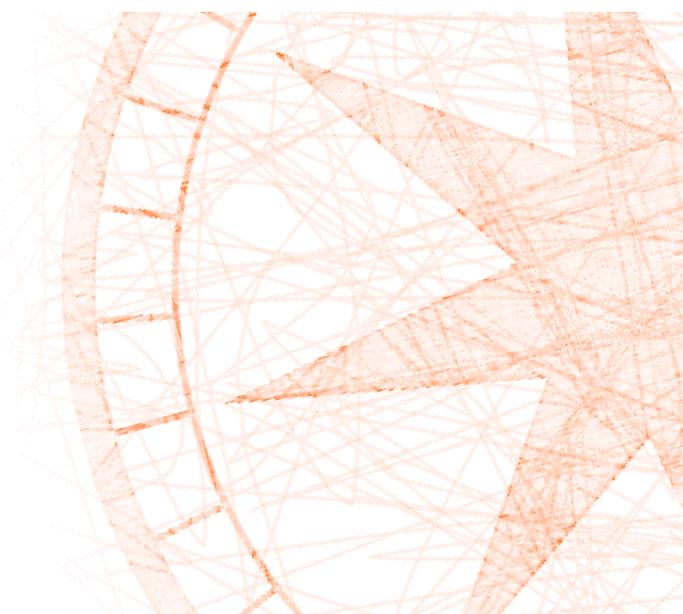
Sometimes, families need time away from the day-to-day responsibilities of caring for a child with special health needs.

Respite means “taking a break.” **Respite care** provides temporary care to a child by anyone that is trained to take care of your child – another family member, friend, or a professional caregiver. Respite can occur in the home or in out-of-home settings for any length of time, depending on the needs of the family and available resources.

Your child may be eligible for state agency funding to pay for respite care. Eligibility may vary from one agency to another.

Ask your child’s primary care provider (PCP), care coordinator, or case manager for information on how to get respite care. Contact the Connecticut Lifespan Respite Coalition (CLRC) at 860-247-2572 or www.ctrespice.org for more information.

To get a copy of the “Get Creative about Respite” manual, go to the Connecticut Department of Public Health’s web site at www.dph.state.ct.us. Look under publications/statistics.



taking a
break

Hospice Care

Hospice care, also called palliative care, is a special kind of care for people facing life-limiting (terminal) illness. Hospice and palliative care follow the belief that a person has the right to live life pain-free and with dignity. Hospice helps to provide families with the support they need during this time.

Hospice focuses on caring, not curing. In most cases, care is provided in the person's home. Hospice care is also provided in hospice centers, hospitals, and other long-term care facilities.

Hospice usually offers a team approach to home health care that includes:

- Medical care
- Pain management
- Emotional and spiritual support

A hospice team usually includes:

- Your child's health care provider
- Hospice physician (or medical director)
- Registered nurses
- Home health aides
- Social workers
- Clergy or other counselors
- Trained volunteers
- Speech, physical, and occupational therapists, if needed

Members of the hospice team make regular visits to assess and provide care. Hospice staff is on-call 24 hours a day, seven days a week.

Ask your child's primary care provider (PCP) about hospice and palliative care services. You will need a prescription (written order) from the PCP before using hospice care. Hospice care may be covered by your child's health insurance plan. If so, make sure that the hospice agency you choose is in the plan's network.

(Adapted from the Hospice and Palliative Care Federation, 800-962-2973, www.hospicefed.org and the National Hospice and Palliative Care Organization website, www.nhpco.org)

Moving to a New Community

Moving is often a stressful time for families. The following list of tips and checklist will help you arrange for your child's health care during a move.

- **Contact your child's health insurance plan.** Give your new address and arrange services in your new community. Don't forget to tell your child's case manager about the move.
- **Find a primary care provider (PCP) for your child in the new community.** Ask your child's **current** PCP to help you. Also, check with the Member Services Representative at your child's health plan. After you find a **new** PCP, ask the **current** PCP to speak with the **new** PCP about your child's medical history. Make sure the **current** PCP sends your child's medical records to the **new** PCP.
- **Tell your child's specialty health care providers about your move.** This includes any doctors, nurses, therapists, hospitals, and agency staff involved in your child's care. They may be able to contact other providers or agencies in your new community. Ask for complete copies of your child's records to take with you.
- **Ask the new health care providers and schools to accept your child's previous test results** until you are settled into your new home. Give them copies of current x-rays and test results. If possible, ask them not to repeat tests done recently.
- **Learn about support groups and parent organizations** in your new community. If possible, talk to them before you move. Ask them what to do and whom to contact before you move. Contact state agencies (like the Department of Public Health) to help you find support groups and parent organizations in your new community.

Tip:

If you are moving outside of Connecticut, call the National Information Center for Children and Youth with Disabilities at 800-695-0285, 202-884-8200 (TTY), or visit www.nichcy.org.

- **Contact your child's new school.** Bring or send copies of your child's school records to the new school. Give the school information about your child's special health care needs.

- **Make copies of everything!** This includes medical records, immunization records, school reports, care plans, and information about equipment and supplies. Give copies of these records and anything else related to your child's care to your child's new providers—and be sure to keep copies for yourself in *Chapters 2 and 3* of this manual.

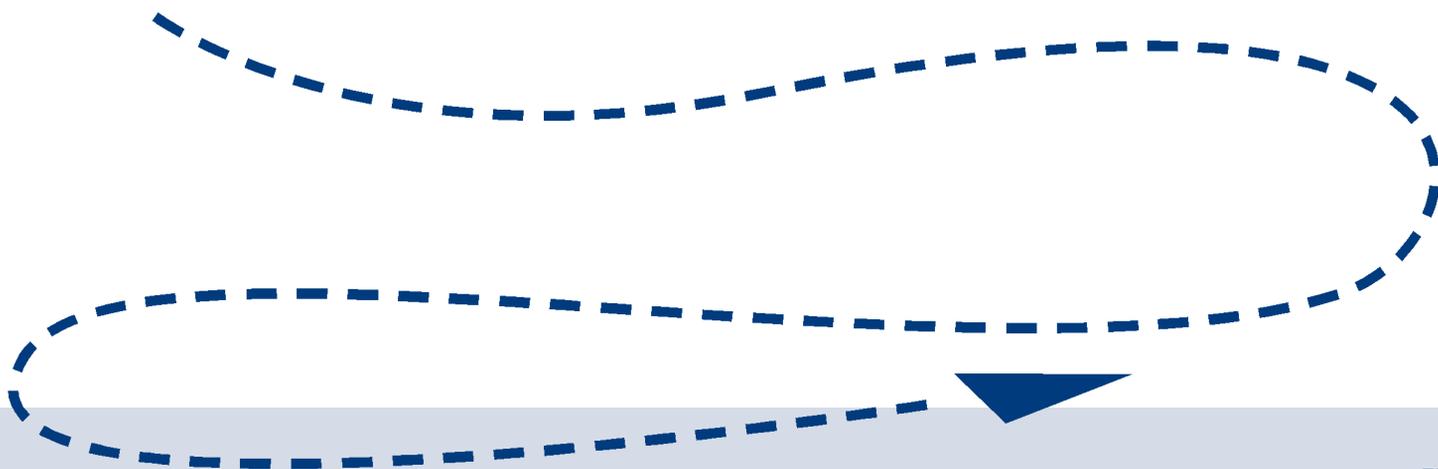
- **Refill your child's prescriptions a few days before your move** to make sure your child has enough medication during the move.

- **Get new written prescriptions** for all medications from your child's **current PCP** to bring with you when you move.

- **Get medical equipment set up in your new home.** If your child uses electric medical equipment, ask your new supplier to check if your new home can meet the equipment needs. Check that electrical outlets are grounded and conveniently located. Call an electrician if you're not sure or if you have questions. Ask the new supplier to set up the equipment before your child arrives.

- **Notify the electric and telephone companies of the date you will arrive.** Ask them to turn on the phone and electricity before you move in. Make sure the companies are aware of your child's special health needs. (See *Chapter 4*.)

- **Prepare for an emergency.** See *Chapter 4* for ways to prepare and inform emergency service providers in your new community about your child's health care needs before you move in.



Moving Checklist

As soon as you know when and where you will move:

- Contact your child's health insurance plan
- Ask all current health care providers to make referrals to new providers
- Contact the phone company for a phone book
- Contact local emergency medical services (EMS)
- Contact the local school system
- Contact the State Department of Education to learn about special education
- Contact the State Department of Public Health to learn about programs for children with special health needs
- Contact the Chamber of Commerce for information about your new community
- Visit the area and video tape it if possible
- Contact your current medical equipment supplier
- Learn about religious organizations and other special interest organizations in your area
- Locate a pharmacy that accepts your health insurance
- Contact parent organizations and support groups in the area
- Call another parent from the area

Two weeks before moving:

- Get new written prescriptions from your child's health care providers
- Contact new school again
- Send school reports
- Send medical records to new health care providers
- Notify electric company of moving date
- Call phone company to set up new phone number
- Call medical equipment supplier

Two days before moving:

- Refill prescriptions
- Make sure electricity is on in your new home
- Make sure phone is on in your new home
- Check supplies for trip
- Call new medical equipment supplier

Do you have copies of:

- Medical records
- School records
- IEPs, IFSPs, IHCPs, and other care plans
- Shots and immunization records
- List of medical supplies used
- Prescriptions
- Health insurance card
- Letter from PCP and specialty providers explaining your child's condition

New phone numbers:

Hospital_____

Health Care_____

Provider(s)_____

Health Insurance Plan _____

EMS_____

Fire Department_____

Police Department_____

Electric Company_____

Phone Company_____

Gas/Oil Company_____

School_____

Parent Support Group/Organizations_____

State Department of Education_____

State Department of Public Health_____

Equipment Supplier_____

Pharmacy_____

House of Worship_____

Other_____



Planning a Vacation

Planning a family trip with any child can be a challenge. Planning a trip when a child has special health needs can be overwhelming. Preparation is the key to a happy and healthy trip. Here are a few hints that may help.

Talk to your child's primary care provider (PCP) about any concerns you may have. Get tips about what to bring, and what symptoms might signal an emergency. Make sure to tell your child's PCP if you are traveling out of the country.

Put together a short medical history of your child. For example, bring your child's immunization record and copies of the forms from *Chapter 1* of this book with you.

Plan for an emergency. Find out ahead of time where the closest hospital or clinic is to where you will be staying. Find out about health care providers in the area. Your child's PCP may be able to help you with this. Bring the phone number of your child's PCP's with you just in case you need it. If your child requires durable medical equipment (DME), ask the DME vendor to refer you to a vendor near where you will be staying.

If traveling out of state, call the Member Services Representative at your child's health plan to find out about health care coverage outside of Connecticut. Talk to the case manager about coordinating services for your child in another state.





Planning a Vacation

Be sure you have enough medical supplies and medications. Ask your child's Primary Care Provider (PCP) to give you an extra prescription(s) in case something happens to the medications you bring. If you are traveling by airplane, bus, or train, keep all medicines and prescriptions in your carry-on bags. If any of your child's medications need to be refrigerated, put them in a thermal container.

If flying or taking a bus or train, call a few days before you leave to let the company know of any help you might need with your child. If you need to bring special equipment, ask about taking it on board.

If staying at a hotel or motel, call the management in advance. Let them know of anything they could provide that would make your stay easier. For example, if you need a room that is accessible or smoke-free, ask for it in advance. Tell them about any electrical equipment your child uses. Be sure to write down the confirmation number for your room reservation and the name of the person you spoke to.

Call the Chamber of Commerce in the town or city you plan to visit. They may be able to tell you about local agencies and activities for children with disabilities.

Make lists of things to do, things to bring, and important phone numbers. This will help you stay organized. Make extra copies of the lists for other adults traveling with you.



Tip:

For information about travel and transportation security, contact:

Disability Law Resource Project at 800-949-4232, 713-520-0232 (TTY), or visit www.dlrp.org

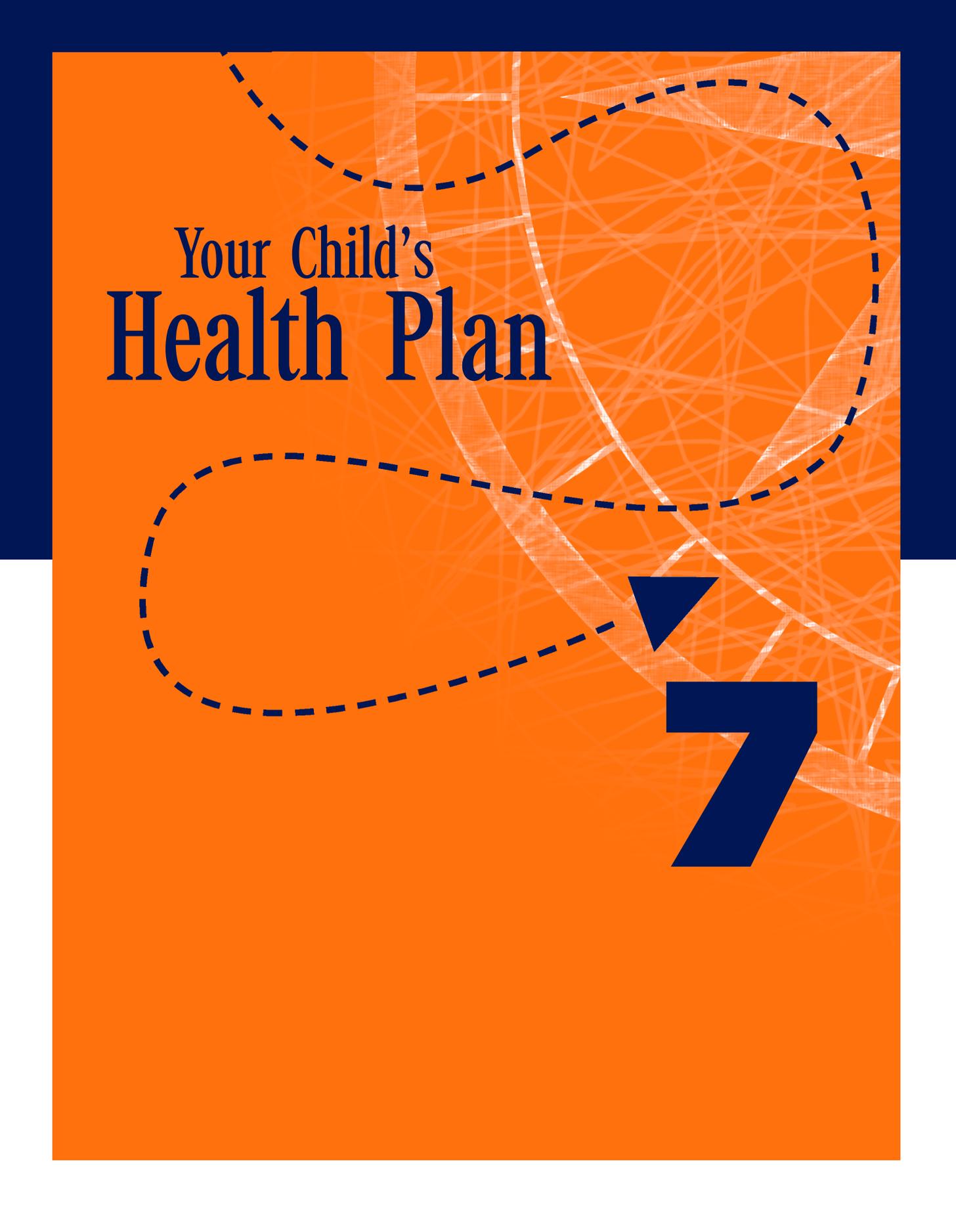
U.S. Department of Homeland Security, Transportation Security Administration at 866-289-9673 (toll-free) or visit www.tsa.gov

Notes

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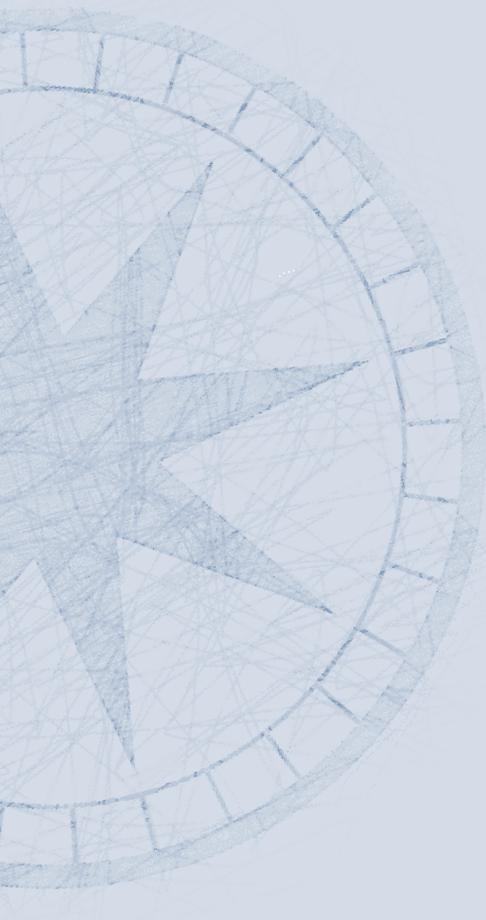
The background is a vibrant orange color. A dashed blue line starts at the top left, curves across the top, then loops down and left, ending with a solid blue arrowhead pointing towards the number 7. A large, bold, blue number 7 is positioned in the lower right quadrant. The overall design is clean and modern, with a focus on geometric shapes and a limited color palette.

Your Child's
Health Plan

7

Your Child's Health Plan

In this chapter, you will find information about your child's health insurance plan, or health plan. Place a copy of the benefits handbook from your child's health plan in this chapter. If you do not have this information contact a Member Services Representative at the plan or your employer.



For more information about health insurance, paying for your child's health care, and public benefits see:

Infoline 2-1-1 or <http://www.infoline.org>.
Look for the Health Care Resource Guide.

Office of the Healthcare Advocate
<http://www.ct.gov/oha/site/default.asp>
or call toll-free 1-866-HMO-4446.

Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs, available from New England SERVE. Order a free copy by calling 617-574-9493 or download it from www.neserve.org.

Calling a Member Services Representative

A Member Services Representative at your child's health plan can help you by answering questions about:

- Eligibility, benefit coverage, and enrollment in the health plan
- How to access other services, such as case management
- How to find a primary care provider (PCP) or specialty providers in the plan
- How to change your child's PCP
- How the prior authorization process works
- What to do if you have a complaint or grievance
- What to do if you disagree with a decision made by the health plan and you want to appeal the decision
- Coverage for services your child receives out-of-state
- Billing

Tip:

Have your child's insurance card with you when you call. You will find the plan's phone number and your child's membership number on the card. Also, write down your questions before you make the call.

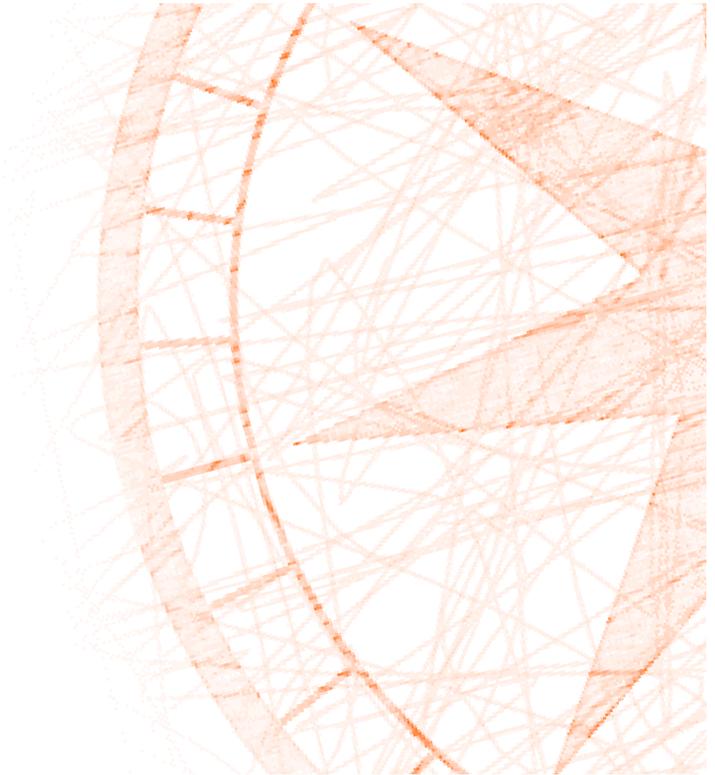
Case Management

Case management, also called **care management**, is offered through many health plans to help families access and coordinate services and benefits.

A case manager (usually a nurse or social worker) works with you to:

- **Assess your child's health care needs**
- **Plan and coordinate your child's health care with your child's primary care provider (PCP)**
- **Communicate with health care providers**
- **Find resources and services**
- **Improve your child's overall care**

Call a Member Services Representative at your child's health plan to learn more about case management services.



Mental Health Services

Mental health and substance abuse services are sometimes called behavioral health services. Some mental health services are paid for by most health plans. Different plans may have different mental health and substance abuse service benefits. Some health plans work with another health insurance plan that specializes in mental health and substance abuse.

Check the benefits handbook or call a Member Services Representative at your child's health plan to learn more about mental health benefits.

Ask About:

- How to find a mental health provider in the plan
- The number of outpatient mental health visits the plan will pay for each year
- The number of inpatient mental health hospital days the plan will pay for each year
- How authorizations for inpatient and outpatient mental health services are arranged
- What to do in case of a mental health emergency

Mental Health Parity Law

In Connecticut, Mental Health Parity means a health plan that offers coverage for medical and surgical conditions must offer coverage for the diagnosis and treatment of mental and nervous conditions. Coverage for mental health services cannot be at a greater expense than the medical and surgical coverage.

For more information about the Mental Health Parity Law, contact:

The Office of the Healthcare Advocate
<http://www.ct.gov/oha/site/default.asp> or call toll-free 1-866-HMO-4446.

The Prior Authorization Process

Prior authorization, also called prior approval, means getting permission from your child's health plan before your child uses a special service or kind of equipment. It is usually the responsibility of your child's primary care provider (PCP) or other treating provider to get prior authorization from the health plan.

Examples of services usually requiring prior authorization are:

- Most hospital admissions
- Medical procedures
- (Non-emergency) surgeries
- Some tests and consultations (such as a second opinion)
- Durable medical equipment (DME)
- Home health care
- Outpatient therapies (such as physical, occupational, and speech therapy)

Medical Necessity

In some cases, your child's PCP will need to write a letter of **medical necessity** to the health plan. This letter states the medical reasons why your child needs a special service or equipment.

*The Office of the Healthcare Advocate defines **MEDICAL NECESSITY** as the legal term used to determine what services will be provided and paid for. It describes services that are consistent with a diagnosis, meet standards of good medicinal practice, and are not primarily for the convenience of patient or provider. This definition and how it is used varies from plan to plan.*

Different plans have different prior authorization processes. Learn about the process at your child's health plan so you will know what to do if your child needs any services that require prior authorization.

Call a Member Services Representative or your child's case manager at the plan to learn more about the prior authorization process.

The Appeal Process

If you disagree with a decision made by your child's health plan, you or your child's primary care provider (PCP) may appeal to the plan. For example, you may request that a decision be reviewed if:

- The plan refuses to pay for treatment that you and your child's PCP believe your child needs
- The plan tells you that it will stop paying for treatment

Check the benefits handbook or contact a Member Services Representative at the plan for more information about how to appeal a decision. Ask for a copy of your plan's policy on prior approval and appeals. The Member Services Representative will work with you to help you find the best way to address the problem.

For more information contact
The Office of the Healthcare Advocate at
<http://www.ct.gov/oha/site/default.asp>
or call toll-free 1-866-HMO-4446.

Connecticut Insurance Department,
<http://www.ct.gov/cid/site/default.asp>
or call 1-860-297-3800.

Tip:

Federal law requires that a health plan allow you to appeal a decision up to 180 days from the service date. It is best to file an appeal as soon as you can. Remember to keep a written record of everything you do and everyone you speak to. Also, keep copies of any letters you send or forms you fill out.

What if I Have a Grievance or Complaint?

At times you may not be satisfied with the care your child has received and may want to notify the health plan with your concerns. Contact a Member Services Representative for information on filing a complaint or grievance. If you have a case manager, you may want to share the information with that person as well.

Tip:

You can also contact the State of Connecticut Insurance Department, <http://www.ct.gov/cid/site/default.asp> or call 1-860-297-3800.

Go to the State of Connecticut web site at www.ct.gov for more information.

Changing Health Insurance Plans

If your child's health insurance plan changes:

- Learn as much as you can before the change.
- Go to informational workshops about different plan options, if available.
- As soon as you can, contact a Member Services Representative at the **new** health plan. Get a benefits handbook and a list of primary care and specialty providers in the network. Find out how the **new** plan will help you to transition your child's current services.
- Learn about the network of health care providers in the **new** health plan. Check if your child's primary care and specialty providers are in the network of the **new** health plan.
- Tell all of your child's providers and vendors about the insurance change. This includes home health care, durable medical equipment, and pharmacy. Be sure to have the name and subscriber information of the **new** health plan with you when you call.
- If any of your child's **current** health care providers are **not** covered by your **new** plan, speak with your **current** providers about the change and how to find **new** providers.
- If you work with a case manager at your **current** health plan, contact that person as soon as you know about the change. The case manager may be able to help with the transition.

Making Education Work for Your Child

This chapter has information on how
to plan for your child's education.
Here you will find:

- A description of your child's legal rights in the education system
- Information about educational services for your child from birth to age 22
- A guide to creating your child's educational and health care plans
- Resources to help your child succeed in school



8

Your Child's Legal Rights

There are three major laws that relate to children with special needs and education. These laws are about the accommodations, the instruction, and the services your child may receive in school.

1) IDEA: Individuals with Disabilities Education Act is the federal special education law. It provides services to students with disabilities when their disability (or disabilities) affects the student's educational progress.

Part B of IDEA makes sure that eligible students with disabilities ages 3-21 receive a free and appropriate public education. IDEA makes sure that supports and services are provided for your child in the least restrictive environment.

Part C of IDEA makes sure that children age 0-3 who have, or are at-risk for having, a disability or developmental delay are provided with special services to help care for these needs. These are infants and toddlers who develop differently, or at a slower rate than most other children. These services are called Birth To Three. (See page 73 for more on Birth To Three.)

The Least Restrictive Environment (LRE)

The LRE is a term that means that a child should be educated in the same classroom and school as he or she would be educated in if he or she did not have disabilities.

A child is removed from the general classroom setting only if he or she is not able to succeed there with special services. If your child cannot attend his or her neighborhood school, he or she may go to another public school where there are more special services. If needed, your child may need to attend a separate public or private school. If your child cannot attend school at all for medical reasons, then your school system must provide education services either at home or in the hospital.

2-3) The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 are federal laws. These laws protect the rights of people with disabilities from discrimination. The ADA and Section 504 laws make sure that plans are made to address your child's special health needs in any program that uses federal funds. This means your child will receive special services to care for his or her needs in any public childcare center and school. For example, if your child uses a wheelchair, plans are made to make sure that the school is wheelchair-accessible. If your child takes medications during school hours, plans are made for a school nurse to give medications.

Tip:

If you ever feel that your rights or your child's rights are being ignored, speak up to your child's educational team.

Early Intervention: Services for Your Child from Birth to Age 3

If your child is under 3 years old, he or she might be eligible for Birth To Three services. Birth To Three is a program for infants and toddlers who currently have a developmental delay. That is, children who develop differently or at a slower rate than most other children.

Birth To Three uses a family-centered approach—that is, focusing on the whole family, not just the child. Birth To Three helps families recognize and understand their child's particular developmental needs, and learn different ways to help their child.

Examples of children who may be eligible for Birth To Three services include children who:

- Are born prematurely (less than 32 weeks)
- Have feeding, vision, or hearing problems
- Are slow to sit up, stand, walk, talk or do things for themselves
- Are born with a disability or health condition that affects their development

If you think your child might need Birth To Three services, discuss your concerns with your child's primary care provider (PCP). A free developmental evaluation can be scheduled to determine whether your child would benefit from, and is eligible to receive, Birth To Three services.

Parents may also refer their child for a Birth To Three evaluation themselves.

Contact Child Development Infoline at 1-800-505-7000 for more information or on-line at <http://www.infoline.org/programs/bt3.asp>.

Your Child's Early Intervention "Team"

Your child's Birth To Three "Team" may include:

- Speech therapists
- Physical therapists
- Occupational therapists
- Nurses
- Psychologists
- Social workers
- Developmental educators
- Teaching assistants

You, as the parent, must be a part of the team. Together with families, the Birth To Three team decides what type of developmental help would be most useful for your child. This information is used to create an Individualized Family Service Plan (IFSP).

You, as the parent,
must be a part of
the team.



The Individualized Family Service Plan (IFSP)

An Individualized Family Service Plan (IFSP) is created for every child enrolled in Birth To Three. Birth To Three staff work with the family to develop it. The IFSP includes assessments of the child and descriptions of both family needs and strengths. It also lists all the education, training, therapy and support services the child and family will receive and who will deliver these services.

If you believe that your child will have ongoing special education needs, you should request a special education referral at least 6 months before your child's 3rd birthday. Contact the school district in your city or town to request a special education referral. This referral can help your child transition from Birth To Three to the education system at age 3.

Tip:

Keep copies of your child's IFSP with other care plans in *Chapter 3* of this book.

Preschool Age 3-5

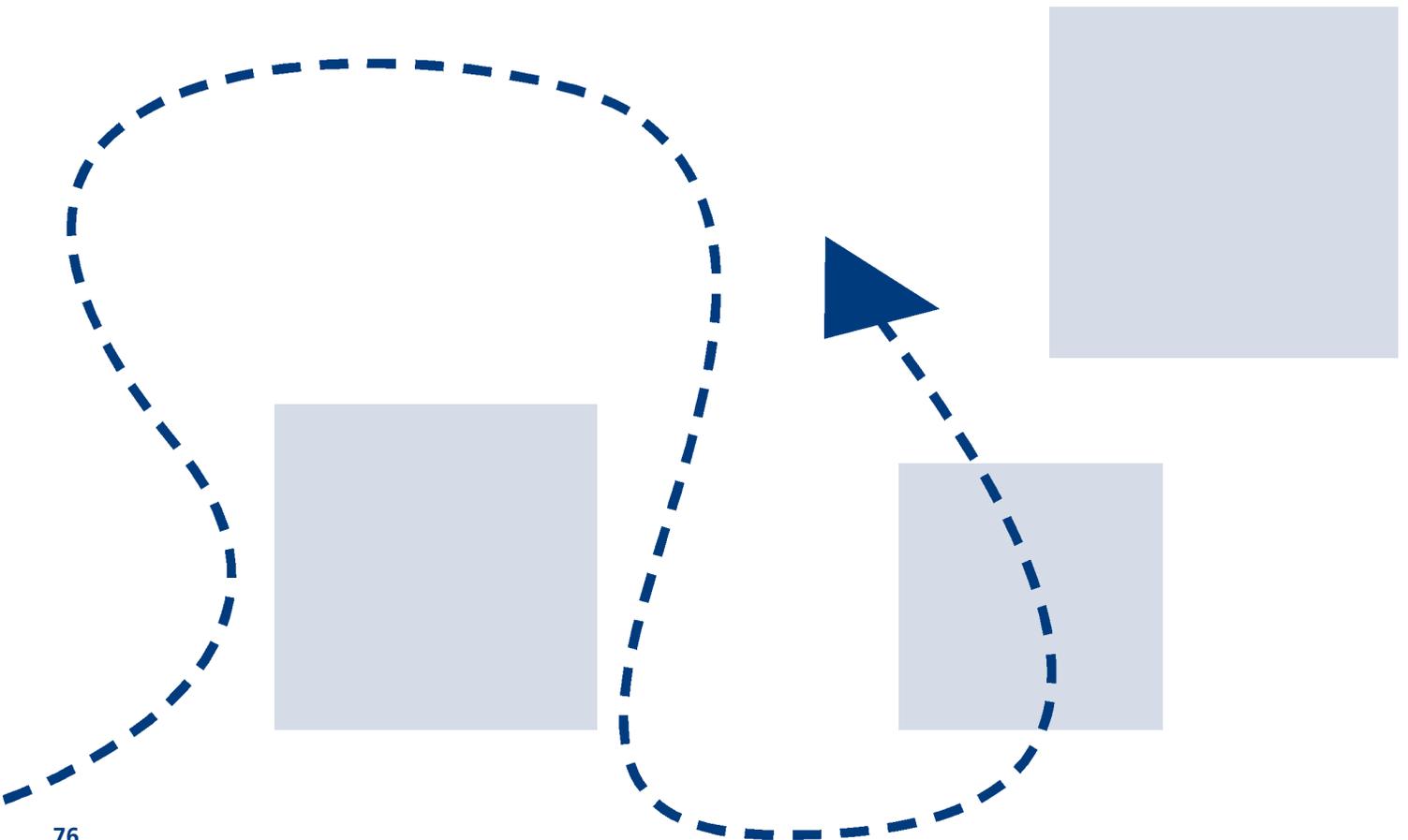
Preschool-age children with disabilities are eligible to receive a free and appropriate public education in the least restrictive environment. Make a referral for an evaluation for preschool services if:

- Your child has received Birth To Three services
- You think your child will need additional services when he or she turns 3

Any child who is found eligible for special preschool services must have an Individualized Education Program (IEP) or Individualized Family Services Plan (IFSP) set up by their 3rd birthday.

Make sure the referral for an evaluation for preschool services is made at least 45 school working days before your child's 3rd birthday.

Contact the school district in your city or town to learn more about Preschool Special Education program for children age 3-5. Ask to speak with the Administrator of Special Education at your school district. You may also contact the Connecticut State Department of Education, Preschool Special Education program at 860-807-2054 or look on-line at <http://www.state.ct.us/sde/deps>.



Services for Your School-Aged Child

If your child has significant medical needs, the education plan may be just one of many concerns. Here are steps that can help you address health and safety needs in school:

- **Contact the school’s principal, special education director and school nurse 3-6 months before your child is scheduled to enter the school.** Schedule a meeting to introduce yourself and discuss your child’s needs.
- **Provide the school nurse with health care information** about your child, including a copy of your **Emergency Information Form for Children with Special Health Needs** from *Chapter 1*.
- **Work with your child’s primary care provider (PCP), specialist, and/or school nurse to develop a list of everything your child needs on a daily basis to go to school.**

For publications including a “Parent’s Guide to Special Education in Connecticut” contact the State Department of Education at 860-632-1485 or download from www.state.ct.us/sde.

Services for Your School-Aged Child

- **Request a meeting between you, your child's PCP, and the school nurse.**
The school nurse will probably be your child's health care coordinator at school. This meeting will provide an opportunity to develop an Individualized Health Care Plan (IHCP) for your child. An IHCP explains all of your child's daily needs, lists the staff that will be working with your child, and reviews possible health problems and solutions.
- **If your child is receiving special education, request that your child's IHCP be attached to the Individualized Education Program (IEP).**
- **Contact your child's teacher and/or evaluation team leader** if your child must be away from school due to illness, including hospitalization. He or she will help plan for your child's education during this time.
- **If your child is hospitalized, send a copy of the discharge summary to the school nurse.** Also, tell the nurse if your child's health needs change.

Tip:

When going to a meeting at your child's school, think about bringing someone with you to provide support. If possible, bring a family member, friend, or advocate.

The Individualized Education Program (IEP)

According to state and federal special education laws, all children who have been found eligible for special education must have an Individualized Education Program (IEP). The IEP is a written plan that describes exactly what special educational services and accommodations your child will receive. It must be reviewed every year.

Your child's IEP is developed by a team of people at the school and includes the parent as part of the IEP Team.

The IEP should include:

- A report on how your child is doing in school.
- A list of your child's strengths and areas to improve.
- A vision statement – your and your child's hopes and goals.
- Measurable educational goals for your child and a plan for achieving those goals.
- Specially designed teaching and/or services your child needs to help reach those goals. The expected start and end dates for these services should be included (such as speech, occupational and physical therapies, in-school private duty nursing, assistive technology, and other services to be provided at school).
- The amount of time during the school day your child will spend in regular and/or special education activities.
- Beginning at age 14, a description of special instruction that will help your child transition from school to adult life activities when ready.

After the IEP is developed, the IEP Team decides on the placement for your child that is most able to provide the services identified in the IEP. This placement decision should be the least restrictive environment possible.

Throughout the school year, you are entitled to receive regular progress reports to tell you if your child is making progress towards his or her IEP goals.

Tip: Keep copies of your child's IEP with other care plans in *Chapter 3* of this book.

Your Child's IEP "Team"

If your child is eligible for special education, you will meet together with a group of people to develop the Individualized Education Program (IEP). This group is usually called the IEP "Team." The IEP is reviewed each year, but you can ask the IEP Team to meet at any time if you think a change might be needed.

You have the right to invite anyone else you like, such as a state agency case manager, a special education advocate, a family member, or a friend to participate in "Team" meetings.

Tip:

According to law, your child has a right to participate in Team meetings starting at age 14, but he or she may start earlier.

You, as the parent, are an important member of the IEP Team.

The "Team" may also include:

- Your child
- Your child's teachers
- The principal
- The school nurse
- The special education director or team leader
- Speech, occupational and physical therapists
- A guidance counselor or school psychologist
- Other providers (such as your child's primary care provider (PCP) or therapist)

For more information about IEPs or special education, call the Connecticut State Department of Education at 860-807-2005, visit <http://www.state.ct.us/sde/deps/>, or contact the special education department in your child's school system. You may also contact the Connecticut Parent Advocacy Center (CPAC) at <http://www.cpacinc.org> or toll-free 1-800-445-CPAC.

504 Plan

A 504 Plan helps a child with special health care needs to fully participate in school. Usually, a 504 Plan is used by a general education student who is not eligible for special education services. A 504 Plan lists accommodations related to the child's disability and required by the child so that he or she may participate in the general classroom setting and educational programs.

For example, a 504 Plan may include:

- Plans to make a school wheelchair-accessible
- Your child's assistive technology needs during the school day
- Permission for your child to type assignments instead of writing them by hand
- Permission for your child to hand in assignments late due to illness or a hospital stay

Your child may be eligible for accommodations under a 504 Plan if he or she has a physical or mental health disability that limits one or more major life functions. A 504 Plan is supported by the federal civil rights law, Section 504 of the Rehabilitation Act of 1973 (see page 72). A 504 Plan is to be provided in programs that receive federal funds, such as public schools.

Generally, the 504 Plan can be an option for a child if there is no identified need for an Individualized Education Program (IEP). The accommodations listed under a 504 Plan are specifically tailored to the child's needs in school, and are sometimes no different than those found in an IEP.

Each school is required to have a Section 504 Coordinator. Developing any plan requires working together as a team. Work with your child's school nurse, primary care provider (PCP), and the Section 504 Coordinator to create a 504 Plan.

In developing a 504 plan, the process should include:

- A school evaluation
- A letter from your child's PCP describing the disability, related problems, and needed medications and/or treatments
- Identification of the accommodations to be provided – physical and instructional
- Your child's Individualized Health Care Plan (IHCP)
- A copy of the **Emergency Information Form for Children with Special Health Needs** from *Chapter 1*.

Tip:

If you are having trouble creating a 504 Plan or getting appropriate accommodations for your child, contact the US Department of Education's Office for Civil Rights at, 617-223-9662, 617-223-9695 (TTY), or visit www.ed.gov/about/offices/list/ocr/index.html.

Keep copies of your child's 504 Plan with other care plans in *Chapter 3* of this book.

The Individualized Health Care Plan (IHCP)

Every child with special health care needs in school should have an Individualized Health Care Plan (IHCP). An IHCP helps to make sure your child receives the health services he or she needs during the school day.

There is no law that says your child has a right to an IHCP. If your child has a specific health problem, you should ask for an IHCP.

People who may help create your child's IHCP include:

- You
- Your child (when appropriate)
- The school nurse
- Other members of the school staff
- Health care providers
- Staff from community support services (when needed)

Contact your child's school nurse first. Schedule a meeting with the nurse to develop the plan. It is very helpful to involve your child's primary care provider (PCP). He or she can give the school nurse all the necessary medical information and specific doctor's orders for your child. If your child is eligible for special education, ask your child's school nurse to work together with the Special Education Administrator to make sure that services are coordinated.

The Individualized Health Care Plan (IHCP)

Your child's IHCP should include:

- The health services your child should receive at school.
- When, where, and how the health services will be provided.
- Who will provide the health services.
- Information about your child's transportation needs, including any special needs when taking field trips.
- An **Emergency Response Plan** that lists possible emergencies and what to do – this plan should be discussed with all school staff and the local Emergency Medical Services (EMS) providers. (See *Chapter 4* for more on the Emergency Response Plan.)
- A copy of the **Emergency Information Form for Children with Special Health Needs** from *Chapter 1*.

The IHCP should be reviewed and updated whenever your child's medical condition changes. It is very important that you notify the school nurse immediately when changes happen.

The IHCP should be kept in your child's school record. If your child receives special education, ask to have the IHCP attached to your child's IEP. That way the people who provide health care services and the people who provide education services can coordinate care for your child.

Tip: Keep copies of your child's IHCP with other care plans in *Chapter 3* of this book.

Tip: Have your child's school staff conduct an emergency drill to make sure that the **Emergency Response Plan** works.

Key People to Help with Your Child's Educational Needs

- **Members of your child's school Birth To Three or Individualized Education Program "Team"** (if your child is eligible for special education).
- **Your child's primary care provider (PCP).** If the PCP is unable to attend meetings, ask him or her to make contact with your child's school nurse.
- **Care Coordinators or Case Managers** from your community or state agencies.

It is important to identify who will make decisions and provide care or services to your child while in school. This information should be part of your child's Individualized Health Care Plan (IHCP) and/or Individualized Education Program (IEP). For example, if your child needs one-on-one nursing care while at school, be specific about who will be responsible for coordinating that care. No changes should be made to an IHCP or IEP without your written approval.

It is also important to identify back up staff in case the school nurse or caretaker is absent. Back-up staff need training and should be familiar with your child's IHCP.

School nurses must follow specific rules. There are some types of health care that can only be performed by the school nurse. Non-health professionals may perform other types of care. Discuss your child's specific care needs with the school nurse.

Some schools and families arrange for the parent to come to the school to care for their child if the school nurse is absent. You do not have any legal obligation to act as back-up staff. It is your choice if you wish to do so.

Tips on Building a Relationship with Your Child's School or Child Care Center

- **Become active in the school's Parent-Teacher Association (PTA), Special Education Parent Advisory Council (SPED PAC), or other school organizations and events.** Contact your local public school Administrator of Special Education, to learn more. Your local SPED PAC may have a listserv that you can join too.
- **Visit or talk to your child's teacher(s) and principal often.** Set up regular times to talk with the teacher and principal (by phone or email, if not in person). If needed, use a communication notebook that stays and goes back and forth from home to school. You and your child's teacher can keep in touch by writing down important information in the notebook.
- **Offer to give a training session to the school nurse and other school staff about your child's special needs.** This will give you a chance to answer questions about your child's care needs, procedures, medication and/or equipment.
- **Help organize a Disability Awareness Training at your child's school.** This is a way to provide some education for other children, teachers, and parents. Encourage the school to buy special picture books, dolls, puzzles, and toys to keep in your child's classroom to teach students about disability issues.
- **Ask your child's teachers to suggest activities to do at home that will support and strengthen your child's progress at school.**
- **Volunteer as a "classroom parent."**

(Adapted from *Working Toward a Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs*. Project School Care, Children's Hospital. Boston: Harvard University, Office of the University Publisher, 1992.)

Education Resources

The following publications (and others) are available from the Connecticut State Department of Education. You may order free copies by calling 860-632-1485 or download them from www.state.ct.us/sde.

A Parent's Guide to Special Education in Connecticut

This is a resource for parents and the organizations that serve them in Connecticut.

A Student Guide to Understanding Your Rights and Responsibilities under IDEA

Useful for a student receiving services under the Individuals with Disabilities Education Act.

Students with Disabilities and Parental Choice in Connecticut

Looks at parent choice including charter and magnet schools for students with disabilities.

Guidelines for Assistive Technology

Information about the use of assistive technology in schools.

A Resource Directory of Educational Programs and Practices

This guide was developed to lead a person through the IEP process. Information can be found on <http://www.state.ct.us/sde/deps/special/#Publications>.

IEP Forms and Notices

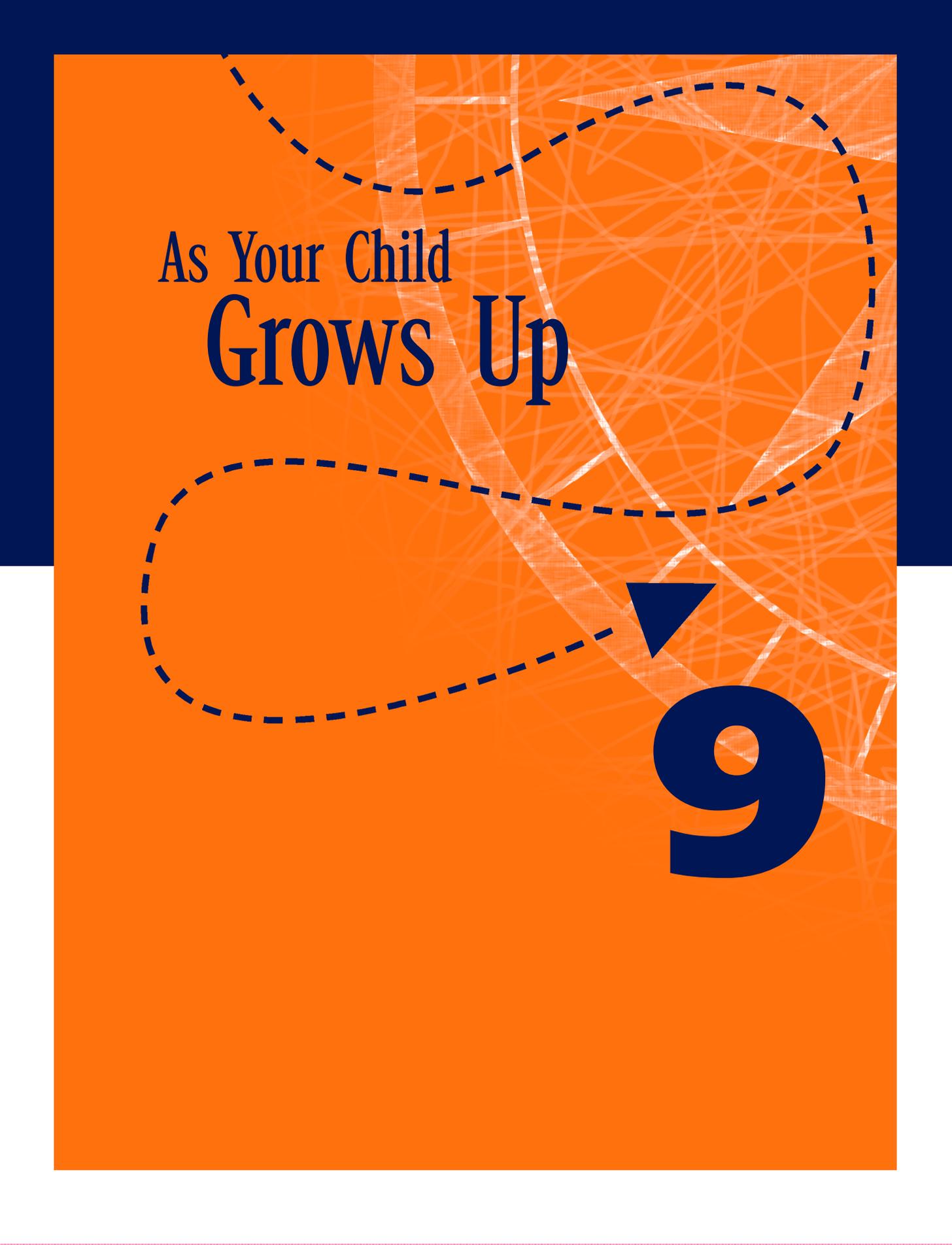
These are the forms and notices used for the IEP process. Can be downloaded at <http://www.state.ct.us/sde/deps/special/>.

Helpful Resources for Family

A brochure designed to provide families with access to organizational resources.

State Education Resources (SERC)

For more information call 860-632-1485 or visit <http://www.ctserc.org>. Provides information and support for professionals and families in the area of education.

The background is a vibrant orange color. A dashed blue line starts at the top left, curves across the top, then loops down and left, ending with a solid blue arrowhead pointing towards the bottom right. A large, bold, dark blue number '9' is positioned in the lower right quadrant. The overall design is clean and modern, with a focus on geometric shapes and color contrast.

As Your Child
Grows Up

9

Transition

Growing up is not always easy for children. It can be hard on parents, too. When your child has special health care needs, growing up may be more complicated.

Still, many parents of children with special needs find it helpful to remember the “bottom line.” You want your child to be as independent as possible. Independence in adult life (health care, employment, living, and recreation) takes preparation.

The process of growing up and becoming independent is sometimes called “transition.” The term refers to the transition from adolescence to adulthood and is often used when your child is:

- Learning to be more independent
- Learning to manage his or her own health care
- Changing from pediatric to adult-oriented medical care
- Moving from school to work and other aspects of adult life

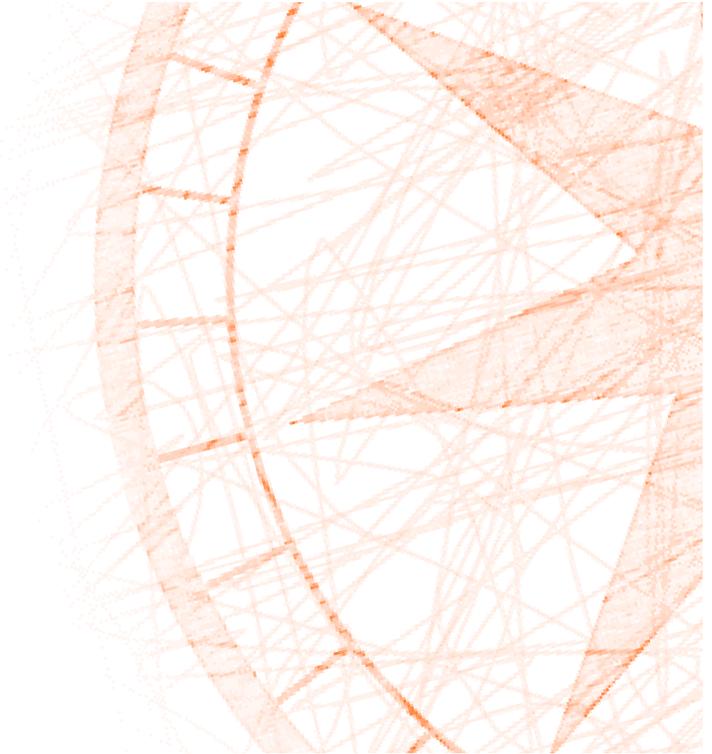
Talking with your child about growing older and being independent can make the transition to becoming a teenager and young adult much easier.

In this chapter you will find tips to help prepare you and your child for the process of transition in health care – when your child is younger, a teenager, and an adult. For information on transition in other areas of your child’s life, contact Department of Social Services, Bureau of Rehabilitation Services at www.ct.gov/dss or toll-free at 1-800-537-2549.

For more information about transition, see *Transition Planning for Adolescents with Special Health Care Needs and Disabilities: Information for Families and Teens*, a resource guide for parents and teens about growing older and the transition to adulthood. This guide gives information on health care, education, employment, and recreation and is available from the Institute for Community Inclusion. Download this guide from www.communityinclusion.org/transition/familyguide.html.

When Your Child is Younger

- Talk to your child about his or her condition or disability in words your child can understand. Help your child find a good way to explain it to others.
- Teach your child to know when he or she is having an emergency – and to tell you and others.
- Teach your child the names of the medicine(s) he or she takes.
- Talk to your child about how to stay healthy (for example: getting enough rest and eating well).
- Encourage your child to talk directly to health care providers – and to ask questions.
- Encourage your child's health care providers to talk directly to your child.



TalkTeach
ENCOURAGE

When Your Child Becomes a Teenager

- Learn more about the process of transition in health care. Ask your teen's primary care provider (PCP) and specialty providers about how they handle transition from pediatric to adult-oriented medical care.
- Talk to your teen about his or her condition in words your child can understand. Help your teen find a good way to explain it to others. Look up information together about your teen's condition (at the local library or on the Internet). You can also read through this book together with your teen.
- Talk about what it means to grow up with a disability or chronic condition. Even though you haven't got all the answers, it may help to have the conversation.
- Teach your teen what to do in case of an emergency (see *Chapter 4*).
- If it is safe to do so, teach your teen to take his or her own medications. Review the names and dosages of medications often.
- Teach your teen the names of all health care providers and how to contact them.
- As your teen gets older, encourage him or her to talk directly to health care providers – and to ask questions. As the parent, this may be hard at first. So, try staying in the waiting room for part of the office visit while your child sees the provider alone. You can always talk to the provider at the end of the visit or by phone afterwards. (See **Teen Tips** on page 95.)

Find out more information about KASA – Kids As Self Advocates at www.ckasa.com.

Tip:

Ask your teen about his or her relationships with health care providers. Your teen may want to keep on seeing his or her pediatric providers, or your teen may want to see another provider who specializes in adolescent and young adult health. Sometimes a teenager wants a change so he or she can have a more independent relationship with a health care provider.

When Your Child Becomes a Teenager

- Think about whether your teen might have trouble making independent financial and medical decisions when he or she turns 18. If yes, learn about legal guardianship, conservatorship, and health care proxy. These are legal processes that give a parent or legal guardian the right to control property and make medical decisions. Talk to your teen's primary care provider (PCP) about these issues **before** he or she turns 18. (See **Guardianship, Conservatorship, and Health Care Proxy** in the **Glossary**.)
- Call a Member Services Representative at your teen's health plan to ask about what happens when he or she turns 18. Your teen may need to meet certain qualifications to stay on the plan.
- Talk to your teen about other health issues that come up at this time, such as:

Healthy eating and body image

Relationships and sexuality

Smoking, alcohol, and drug use

Ask your teen's primary care provider (PCP) for advice on how to speak to your teen about these issues.

- Encourage your teen to take more responsibility for his or her health. For example, have your teen fill out the checklist on the next page. It asks about important tasks that your teen should do to help keep track of his or her health care. Talk about the answers together. If your teen answers "no" to any of these questions, help your teen to start doing these tasks. If needed, ask your teen's PCP for help.
- Encourage your teen to attend educational "team" meetings at school. Include health care skills in your teen's Individualized Education Program (IEP) as goals, if applicable. Also, ask the educational "team" to help with transition planning. Remember that special education services end for everyone at age 22.



For Teens: Keeping Track of My Own Health Care

Fill out the checklist. Talk about your answers with your parent/guardian and your primary care provider (PCP). If you answered NO to any of the questions, start learning and doing these new tasks (with help from others if needed).

How well do I manage my own health care? Please circle **Yes** or **No**

1. I know my height, weight, birth date, and social security number. **Yes** **No**
2. I know the name of my condition and can explain my special health care needs. **Yes** **No**
3. I know who to call in the case of an emergency. **Yes** **No**
4. I ask questions during my medical appointments. **Yes** **No**
5. I respond to questions from my health care providers. **Yes** **No**
6. I know what kind of medical insurance I have. **Yes** **No**
7. I know the names of my medications and what they do. **Yes** **No**
8. I know how to get my prescriptions refilled. **Yes** **No**
9. I know where to find my medical records. **Yes** **No**
10. I know how the use of tobacco, alcohol, and drugs will affect my health and my ability to make decisions. **Yes** **No**
11. I know how to get birth control and protection from sexually transmitted diseases if I need it. **Yes** **No**
12. I know how to schedule a medical appointment. **Yes** **No**
13. I keep a schedule of my medical appointments on a calendar. **Yes** **No**
14. I can get myself to my medical appointments. **Yes** **No**

Adapted from the Children's Hospital Boston, Massachusetts Initiative for Youth with Disabilities Project, a Healthy and Ready to Work project of the Massachusetts Department of Public Health. Available at www.bostonleah.org/transitions.html.

As Your Teen Becomes an Adult

- Talk with your teen about making the change from pediatric to adult-oriented health care providers. Include your teen in the process. Do the planning together.
- Talk with your teen's primary care provider (PCP) and specialty providers about making the transition to adult-oriented care. Some providers, like a family doctor or specialist, may care for a person throughout their lifespan. Other providers, like pediatricians, care for children and adolescents only. Depending on your teen's medical team, transition could mean changing providers and/or health care settings.
- If your teen will need to change providers, think about when would be a good time to make the change. Try not to do this in the middle of other big changes in your teen's life or your own. Also, it may be easier to change your teen's providers one at a time, rather than all at once.
- Contact your teen's health insurance plan and ask about changing health care providers.
- Get recommendations for **new** PCP and specialty providers from **current** PCP and specialty providers if needed. You and your teen should meet with **new** providers before you say goodbye to the pediatric team.
- Make a special request to your teen's **current** health care providers to contact the **new** providers to discuss your teen's special health care needs.
- Continue to encourage your teen to take more responsibility for his or her health and health care. Talk to your child about other health issues that come up at this time, such as:

Healthy eating and body image

Relationships and sexuality

Smoking, alcohol, and drug use

Tip:

When setting up the first appointment to meet with a new health care provider, ask for a "consultation" appointment. This will allow you to meet and learn more about the new provider. Remember to tell the receptionist to schedule extra time for the appointment. Bring this book and a list of questions.

Teen Tips: Communicating with Health Care Providers

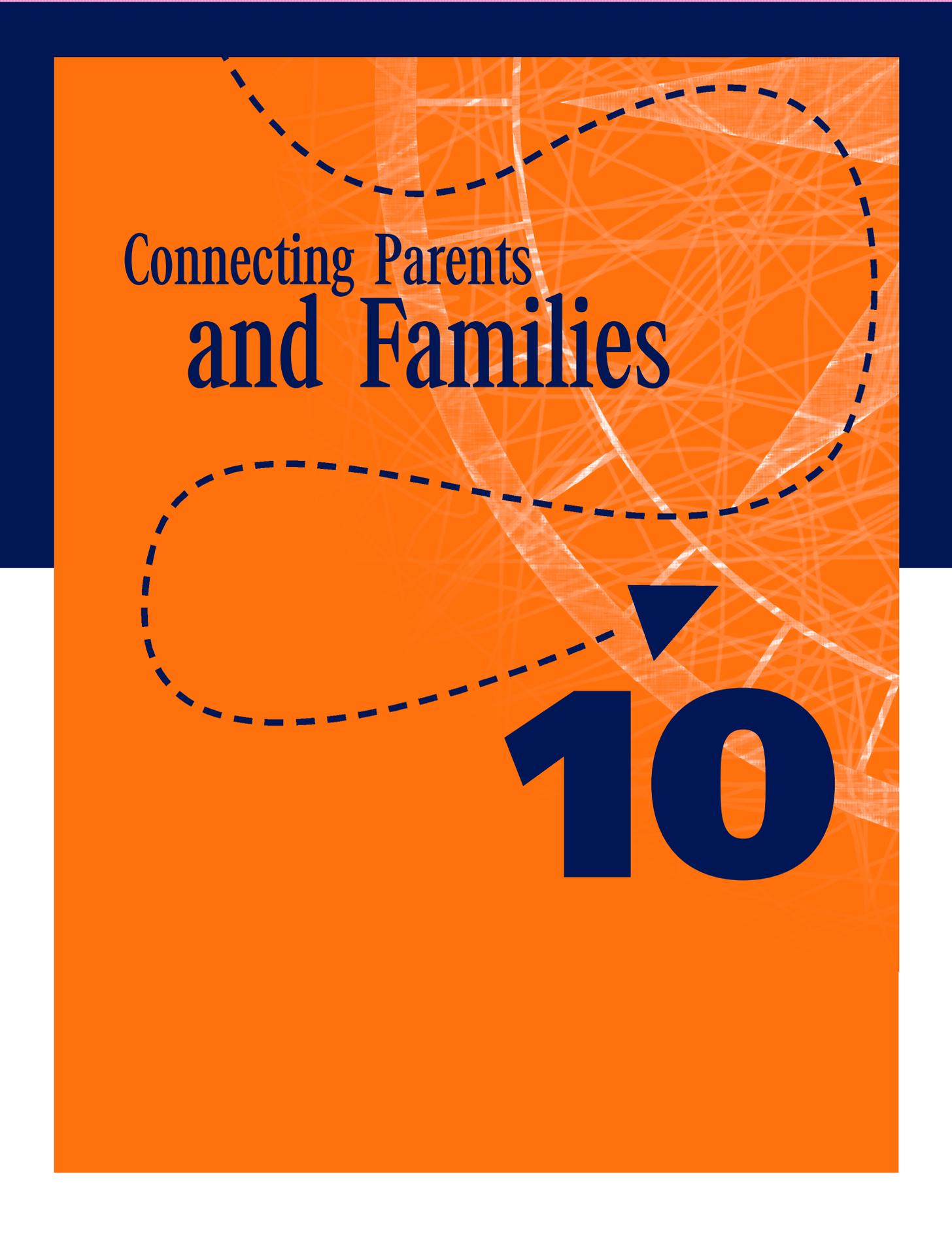
Talking to health care providers can be difficult, overwhelming and, at times, scary. Here are some tips to help you communicate with health care providers.

- **Make sure to ask for a long enough appointment.** Sometimes appointments are very rushed. If you know that you will have a lot to talk about with your provider, ask for an extended appointment so you don't run out of time.
- **Tell your provider everything you can about yourself, what you do, and how you feel.** The more information the provider has, the more helpful he or she can be.
- **Say what you think** – and be honest.
- **Be assertive.** Be nice, but persistent.
- **Bring a list of questions and concerns.** It's easy to forget things when you're sitting there, in the provider's office. A written list of questions, concerns, or other things you want to make sure to tell the provider will help you remember everything that's been on your mind.
- Tell the provider to be honest and to tell you everything. **You're entitled to know all** about your condition, your treatment, and any options that might be available to you.
- **Ask questions.** Remember – there's no such thing as a stupid question. If you don't understand an answer to a question, ask the provider to explain it again until you do understand it.
- **Write down what the provider says.** That will help you remember later on.

Teen Tips: Communicating with Health Care Providers

- **Bring someone with you**, if you'd like. Sometimes it helps to have someone else there for support, to hear what the provider has to say, or to ask questions that you might not think of.
- Ask your parents to wait outside the exam room so you **have some time alone to talk to the provider, if you'd like**. Sometimes that helps the provider focus on you and what you have to say. Your parents can come back in after you've had a chance to talk to the provider yourself. Then they can ask their questions.
- **If you need help, ask for it.**
- When visiting a new provider, **ask the provider about his or her background and experience.**
- Even if you've seen your provider for a long time, **it's ok to ask about the provider's background** and what his or her experience has been.
- Call back if you have any questions after the appointment. Sometimes questions come up after you get home, or you forget something the provider said. **It's ok to call and follow up with more questions.**
- **Learn about your insurance coverage.** What services are covered and what procedures do you have to follow to get those services?

Adapted from Transition Planning for Adolescents with Special Health Care Needs and Disabilities Institute for Community Inclusion, 2000. Available from www.communityinclusion.org/transition/familyguide.html.



Connecting Parents
and Families

10

Parenting a Child with Special Health Care Needs

Being a parent is a joyful, rewarding experience. At times, it can also be the most difficult and stressful job there is.

You probably have a lot to do every day to meet your child's needs.

When your child has special health care needs, your daily 'to do' list is even longer. In addition to taking care of laundry, meals, and giving homework help, you might also need to:

- Call your child's primary care provider (PCP) for a referral to a specialist
- Pick up medications at the pharmacy
- Give your child medications
- Take your child to medical appointments
- Call the insurance company to get pre-approval for a hospital admission
- Schedule an assessment with Birth to Three
- Meet with the school nurse to review your child's health plan
- Get your child's medical equipment fixed

Life is even more complex if you have other children.

Taking care of yourself is very important. When you are busy taking care of everyone else's needs, it is easy to forget to take care of yourself. This chapter provides information for you about:

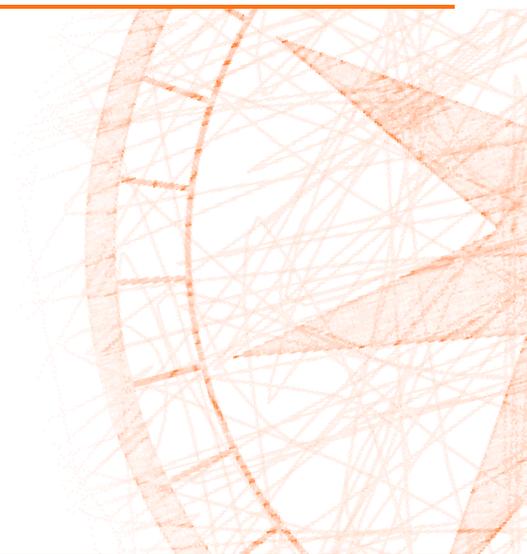
- Taking care of yourself
- Emotional Support
- Getting connected with other families
- Tips on advocating for your child and family

This information is not meant to make your 'to do' list longer. It's meant to help support you in caring for yourself and your child. Look over the suggestions in this chapter. Pick one or two activities that sound appealing. Once you've tried one, it may be easier to try others.

Taking Care of Yourself

It is hard to care for others when you're overtired, stressed-out, and rundown. Try to take some time for yourself every day. Start by taking 5 or 10 minutes to do an enjoyable and relaxing activity. Here are some suggestions from other parents:

- Take a walk, stretch, or enjoy some other type of exercise
- Read a book or magazine - just for fun
- Talk to a friend
- Sit down and have a cup of tea
- Watch a sports event on television
- Go to a movie
- Meditate, or at least take a few deep breaths
- Take a nap
- Take a bubble bath
- Go to sleep a few minutes earlier each night for a week



Asking for Help

Raising a child with special needs can be tiring and overwhelming. There may be times when you feel angry, frustrated, or when you blame yourself. Sometimes you may feel sad or anxious. ***It is normal to have any or all of these feelings at times.***

Remember that you need care too. Talk to someone you trust about your feelings.

Emotional support can come from friends, family, other parents, support groups, and health care providers. You are doing a very important job. You don't need to do it alone. There are many kinds of help and support. ***It is okay to ask for help.***

Getting Connected with Other Parents

The experience of raising a child with special needs may not be what you expected. Your hopes and dreams for your child may have taken a different path.

You are not alone, even though at times you may feel that way. There are large networks of parents raising children with special needs. They use different ways to share information and support each other—talking to each other on the phone, writing email, and going to parent groups are just a few ways.

- **Parent-to-Parent Matches** – A program that matches a parent to another parent whose child has a similar diagnosis.
- **Support Group Information** – Listings and contact information for general and disability-specific support group meetings in your local area.
- **Information and Resources** – A Parent Coordinator can provide up-to-date information, services, and resources.

**Parents Available to Help, Inc (PATH)
Parent to Parent of Connecticut**
Call 800-399-7284 or 203-234-9554 or
email PATH at P2PofCT@aol.com.

**The Connecticut Family Support
Network (Family Support Council)**
Call 860-657-8180 or email Jennifer
Carroll at jtcarroll@cox.net.

Tip:

Check to see if your child's hospital has a family center, parent group, or parent advisory committee to join and meet other parents.

Resources for Parents and Families

For parent resources and support:

PATH (Parents Available to Help, Inc.)
Parent to Parent of CT
800-399-7284 or www.pathct.com

Connecticut Family Support Network
Jennifer Carroll at 860-657-8180 or jtcarroll@cox.net

Padres Abriendo Puertas (PAP)
800-842-7303 or 860-297-4391

**African & Caribbean American Parents of Children
with Disabilities (AFCAMP)**
860-297-4358 or afcampa@sbcglobal.net

For services for your young child, birth to age 3:

Connecticut Birth to Three System
800-505-7000 or www.birth23.org

For information about mental retardation:

Department of Mental Retardation
860-418-6000 or www.dmr.state.ct.us

For mental health supports and services:

Department of Children and Families,
Statewide KidCare System
www.ct.gov/dcf

FAVOR, a family advocacy organization
for children's mental health
860-563-3232 or www.favor-ct.org

For information about special education services:

CT State Department of Education
Bureau of Special Education
860-713-6910 or www.state.ct.us/sde/deps

Connecticut Parent Advocacy Center
800-445-2722 or www.cpacinc.org

For resources in CT and around the United States:

National Dissemination Center for Children with Disabilities (NICHCY) provides disability-specific information and state-by-state listings of resources. Contact **NICHCY** at 800-695-0285, 202-884-8200 (TTY), or visit www.nichcy.org.

National Organization for Rare Disorders (NORD) provides detailed medical information, support group listings, and other resources for specific disorders. Contact **NORD** at 800-999-6673, 203-797-9590 (TTY), or visit www.rarediseases.org.

To receive a magazine about parenting a child with special needs:

Exceptional Parent Magazine provides information and support for members of the special needs community. Call 877-372-7368 or visit www.eparent.com.

For browsing the Internet:

Family Village is a web site with information, resources, and communication opportunities for people with disabilities, families, and providers. Family Village includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much more. Visit www.familyvillage.wisc.edu.

For more web sites see Quick Links to Resources, page 121 and 122



Recreation and Support for Your Child

Making friends and participating in recreational activities is important for your child – just as it is for all children. You may have to work a little harder to make sure your child has these opportunities. Here are some suggestions that may help your child with making friends:

- **Meet other families in your neighborhood and at your child's school.** Attend school events such as open houses, parent meetings, and other school functions.
- **Invite children and their families to play and do things together.** Ask them to come to your home or suggest an activity, like going to the library or a park. While the children play, you can enjoy a few minutes to talk with other parents.
- **Talk to your child about what it means to be a friend.** Encourage your child to introduce him or herself, smile, and shake hands.
- **Work with your child's teachers to help your child develop friendships in school.**
- **Participate in community recreation programs.** Work with staff at the program to develop and carry out any accommodations your child might need.

Your child may want to connect with another child or adult who has a similar disability. Many groups host activities for children and youth with special needs.

Some Internet sites host on-line communities where children with special needs can talk about their experiences, share ideas, and support each other. Take a look at:

- ***Starbright World***, an on-line community of over 30,000 kids with chronic illnesses. Visit www.starbright.org.
- ***Club Bravekids***, a web site for kids growing up with chronic illness. Visit www.bravekids.org.
- **Partners for Youth with Disabilities** has an on-line mentoring program, as well as other individual and group mentoring programs. Visit www.pyd.org.

Connecting Brothers and Sisters – Sibling Supports

Being a brother or sister of a child with special needs can be tough.

Siblings sometimes feel:

- Guilt that they are 'normal'
- Embarrassment about their sibling
- Fear that they will develop the same illness or disability
- Anger about the attention their sibling receives
- Loneliness

Brothers and sisters may also need support to help them deal with these feelings. Give them age-appropriate information about their sibling's disability or condition. This can help siblings deal with feelings about their brother or sister's special needs and answer questions they might have.

Siblings also need a chance to talk to other children who have some of the same feelings and experiences. The **Sibling Support Project** recognizes the unique needs of brothers and sisters. They offer workshops, provide educational materials, and maintain a database of other sibling supports.

Your child may want to connect with other siblings of children with special needs on the Internet. The Sibling Support Project hosts two listservs. Parents are welcome to listen in on both lists.

- **Sibnet** is a listserv for adult brothers and sisters of people with special needs.
- **SibKids** is for young brothers and sisters.

Visit the **Sibling Support Project** at www.siblingsupport.org/.

For other information about sibling support groups in your area contact your child's primary care provider (PCP) or contact 2-1-1 Infoline or <http://www.infoline.org/>.

Speaking Up for Your Child

All parents need to speak up, or advocate, for their children to make sure they are treated fairly. Just as you speak up for your child on the playground or in school, you also need to speak up for your child's special needs. This means speaking up for your child's needs with health care providers, educational professionals, and health plans.

Tips on Speaking Up for Your Child

- Remember that you are the expert about your child. Be prepared to provide information about your child's special needs, strengths and weaknesses, and accommodations that have worked.
- "Knowledge is power," says one parent of a child with special needs. Get information from more than one place and more than one person. Use all the information you have to speak up for your child's needs.
- Go to meetings, workshops and conferences. These are great places to learn ways to speak up for your child. Also, you can talk to other parents and learn about what works for them.

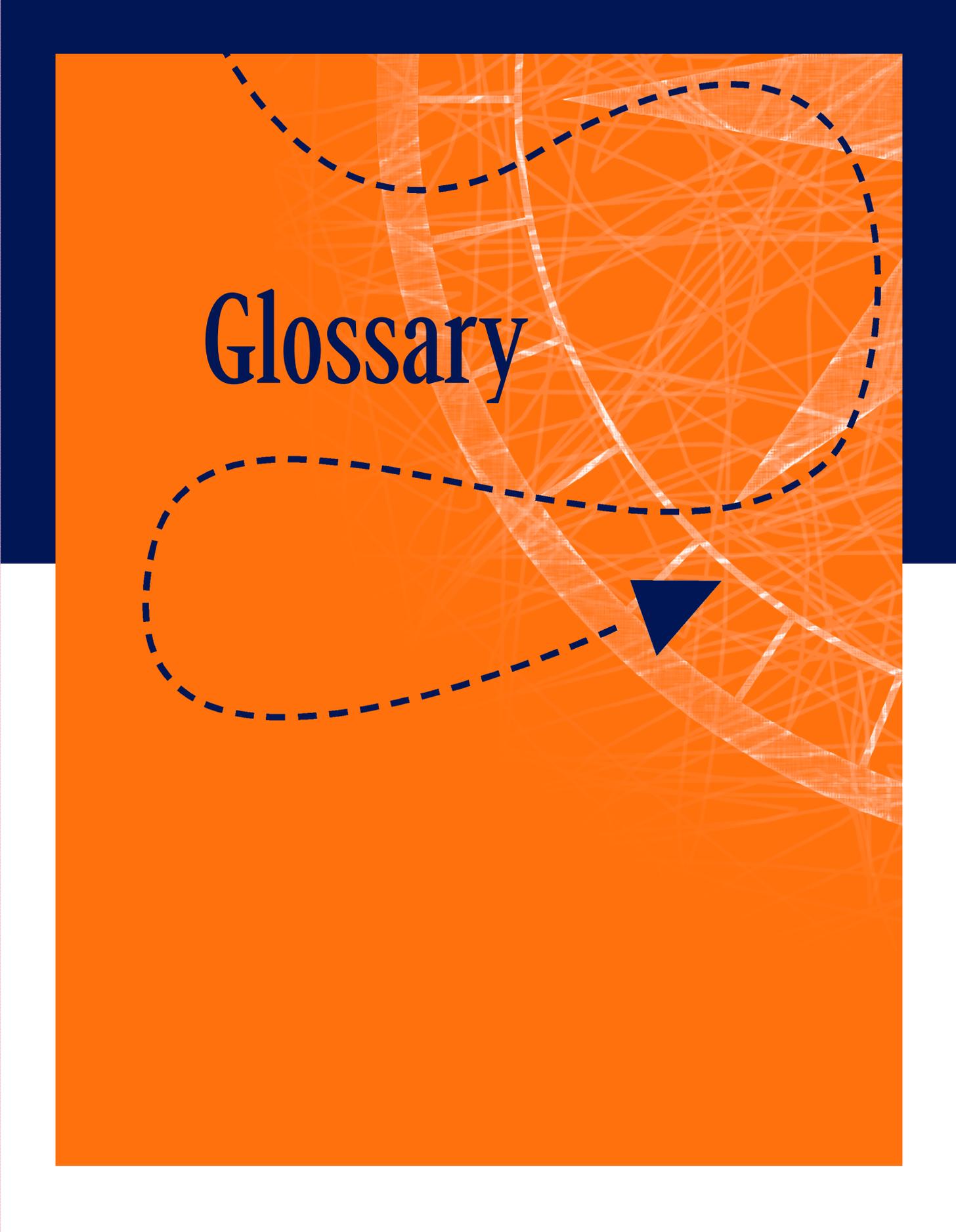
Communication

You probably have a lot to say about your child's needs. It takes practice to learn how to communicate clearly and well. The better you communicate, the more helpful and respectful your relationships will be with providers and professionals. Use these tips for meetings, phone conversations, and writing letters about your child.

Communication Tips

- At meetings, smile, introduce yourself, and shake hands.
- Bring a list of issues and concerns to discuss at the meeting, and hand it out.
- Bring a friend – two sets of ears are better than one.
- Listen carefully to what others say, and take notes.
- If you don't understand something, ask for an explanation. Don't be afraid to say, "I don't understand."
- Emphasize your child's needs instead of your own. For example, when you want a particular accommodation or modification for your child, use the phrase, "My child needs..." instead of "I want . . ."
- Talk about your child's strengths. This way, people can focus on helping your child succeed, not just get by.
- Show a photograph of your child. Sometimes pictures are worth more than words.
- Be positive. When you are asking for a service or an accommodation, try to keep a positive attitude.
- If you don't agree with decisions being made, speak up. Use expressions like, "I disagree." If you get angry or upset, try to stay focused on the discussion – not the feelings. Talk about the feelings later with people that you trust.
- Try to end meetings on a positive note. If you can't come to an agreement about a particular issue, try to 'agree to disagree' about that topic. Set another meeting time, or agree to continue the discussion on the telephone or via e-mail.
- Remember to thank people. Meeting your child's special needs can be hard work for everyone.

Glossary

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Glossary: List of Terms

504 Plan

A plan for students with special health care needs that lists accommodations related to a child's disability and required by the child so that he or she may participate in the general classroom setting and educational programs. A 504 Plan is supported by the federal law, Section 504 of the Rehabilitation Act of 1973. See Section 504. (See *Chapter 8*.)

Accessible

Easy to enter, use, or communicate with. Examples include buildings that are wheelchair accessible or programs with TTY/TDD lines for people who are Deaf or hard of hearing.

Accommodation

Service, provision, or adaptation to meet a specific need. In special education, accommodation refers to the types of services offered to a child so that he or she can fully participate in school.

Activities of Daily Living (ADLs)

Basic everyday tasks, such as bathing, dressing, toileting, eating and moving around.

Acute

In medicine, "acute" refers to a symptom or illness that appears suddenly.

Acute Care Hospital

A hospital that provides a full range of medical care, usually over the short-term, for sickness or injury.

Advocacy

Speaking up or taking action for a person, a group, or a belief. An advocate may help a family resolve problems with a school system or a health insurance plan.

Affiliation

Membership in a group or plan. Your primary care provider (PCP) may be affiliated with a hospital and a health insurance plan.

Americans with Disabilities Act (ADA)

A federal law that protects the rights of people with disabilities from discrimination in any public program, service, or building. (See *Chapter 8*.)

Apgar Score

This is a score to rate the health and strength of a baby right after birth. It measures heart rate, breathing, color, muscle tone, and reflexes on a scale from 1 to 10.

Appeal

To formally ask or request that a decision be reviewed. (See *Chapter 7*.)

Appropriate

Right, correct, or well matched to the needs of a child or family.

Assessment

The formal process used by expert professionals to learn about a person's strengths and needs. An assessment can also be called an evaluation. Assessment results are used to recommend treatments or develop care plans. Sometimes an assessment or evaluation is used to determine whether a person is eligible for a service or benefit. See Evaluation.

Assistive Technology (AT)

Any kind of tool or piece of equipment that helps a person live more independently. AT can be high-tech or low-tech. (See *Chapter 6*.)

Attending Physician

The main doctor who is responsible for the care of your child. Also, the experienced doctor who supervises the medical team involved in your child's care.

Baseline

A starting point used to compare observations or data. Baseline physical findings are the results from your child's first physical exam. Baseline vital signs are your child's regular heart rate (pulse), blood pressure, respiratory rate (breathing rate), and body temperature. Baseline neurological status is an assessment of your child's development, cognition, motor skills, and mental health. Baseline ancillary findings are any other important issues about your child. (See **Emergency Information Form for Children with Special Needs** in *Chapter 1*.)

Benefit

A service or type of support, usually provided through a government program or health insurance plan.

Birth To Three

A program of services for children between birth and 3 who currently have a developmental delay. (See *Chapter 8*)

Block Nursing

See Continuous Nursing Services.

Care Coordinator

A professional who works with the family and the primary care physician and helps to coordinate care among different service providers. This work may also be called case management. A Care Coordinator also helps to arrange needed benefits and services. A Care Coordinator may also be called a Case Manager, Service Coordinator, or Care Manager. (See *Chapters 5 and 7*.)

Case Management

A service to help plan and coordinate health care. Case management is often provided by a Care Coordinator or Case Manager. (See *Chapters 5 and 7*.)

Child Life Specialist

A professional who works in a hospital and plays with children in a way to help them understand the hospital environment. A Child Life Specialist also provides fun activities and entertainment to keep children busy.

Children with Special Health Care Needs (CSHCN)

Children with special health care needs (CSHCN) are those from birth to 21 years old who have, or are at increased risk for, chronic physical, developmental, behavioral or emotional conditions. Generally these children also need more health and related services than most children.

Chronic

In medicine, the term refers to a long-term or recurring (comes back again and again) condition or illness.

Cognition

The mental process of knowing, including awareness, perception, reasoning, and judgment. The adjective is cognitive.

Community-Based Care

Services delivered locally, or as close to the child's home as possible. This type of care helps a child participate fully in all aspects of family and community life.

Congenital

Present at, or existing from, the time of birth.

Continuous Nursing Services

Skilled one-to-one nursing provided by a licensed or registered nurse for more than 2 hours per day. Sometimes called block nursing, private duty nursing, or shift nursing. (See *Chapter 6*.)

Copayment

Also called co-pay or co-insurance. A set amount of money a person pays towards a covered medical expense. A co-pay is usually paid during an office visit or for a prescription.

Conservatorship

Conservatorship is a court process and legally binding. It makes an adult (or adults) legally responsible for the financial decisions of a person who is unable to make financial decisions for himself or herself. (See *Chapter 9*.)

Coverage

The services or items provided or paid for, usually by a health insurance plan.

Developmental Delay

This term refers to when a child does not reach developmental milestones (such as walking or talking) within the same time range as most other children. Developmental delays may be generalized (all milestones), or they may show up in just one or two milestones. Developmental disability usually refers to a general delay, and to chronic conditions appearing in childhood which result from mental or physical impairment. Often this means major and life-long limitations in everyday functioning. See *Impairment*.

Diagnosis

The naming of a specific disease or condition according to a standard system (such as ICD-9 or DSM-4).

Dietary Supplements

Extra calories, vitamins, minerals, proteins, or other nutrients. Usually taken in the form of pills, powders, or drinks. Also called dietary additives.

Discharge Plan

A plan created by a hospital team of providers for your child before it's time to leave the hospital. The discharge plan lists the supports your child will need at the time of discharge from the hospital (such as appointments to see health care providers, plans for home health nursing, assessment for durable medical equipment). (See *Chapter 5*.)

Due Process

Due process is an important element of the state and federal legal systems. It gives you the legal right to be notified and to be heard if certain benefits or services are denied to you or your child. For example, there are regulations that make sure that parents can challenge the State's decisions about their children's eligibility for Early Intervention or special education services.

Durable Medical Equipment (DME)

Supplies or equipment that last a long time and help meet particular medical needs. (See *Chapter 6*.)

Elective Procedure

A medical test, procedure, or surgery that is not an emergency. Usually a person and doctor decide and plan the procedure together in advance.

Eligible

Meeting certain requirements for getting services or benefits.

Emergency Information Form for Children with Special Needs

The form is filled out by your child's primary care provider (PCP) and gives emergency providers the information they need to properly care for your child. (See *Chapters 1 and 4.*)

Emergency Response Plan

An emergency plan created by you and your child's primary care provider. An Emergency Response Plan includes: medical information about your child, the name(s) of your child's PCP and other important providers, where your child should be taken in an emergency, and treatment that should be provided to your child in certain situations. (See *Chapter 4.*)

Enrollment

The process of joining a health insurance plan. People enroll in health plans through their employers, through professional associations or clubs, through public benefits programs, or as individuals.

Entitlement

A service or benefit that an eligible person has a right to receive.

Evaluation

In medicine, an evaluation is a checkup, a study, or a series of tests used to determine the current status of a patient or a particular condition. An evaluation may also refer to the process used to determine whether or not a child is eligible for a service or benefit. See *Assessment.*

Family-Centered Care

Care that recognizes the family as the most central and important influence in the child's life. In family-centered care, the provider makes sure that the family participates in all health care decisions about the child. Family-centered care is one of the key elements of Medical Home. (See *Chapter 5.*)

Family Support Services

Services to meet the needs of family members. Examples include: respite care, parent networks, equipment exchanges, advocacy services, support groups, information and training, and any other assistance that enhances family life and participation in the community. See also *Family-Centered Care.*

Genetic

A trait that is hereditary, "runs in the family," passed down, or affected by genes. Genetic counseling is when a trained genetic counselor educates and counsels families about inherited genetic disorders.

Gestation

The time that a baby is carried in the uterus during pregnancy. Babies are expected to be born after 10 months or 40 weeks gestation. A premature baby is born before 37 weeks gestation. See *Premature.*

Grievance

A complaint about or dissatisfaction with a service or benefit. (See *Chapter 7.*)

Guardianship

Guardianship is a court process and legally binding. It makes an adult (or adults) legally responsible for the personal and financial decisions of a person who is unable to make these decisions alone. A guardian may or may not be a relative. Parental rights may or may not be terminated. Guardianship can be temporary or permanent, partial or complete. (See *Chapter 9.*)

Head Circumference

The measurement of length around your child's head. It helps to assess growth and development.

Health Care Proxy

Someone legally designated to make medical decisions in the event that a person cannot make them for him or herself. (See *Chapter 9.*)

Health Care Provider

Any professional who provides a health care service (such as a doctor, nurse, or therapist).

Health Insurance

A type of insurance that pays for covered health care costs. Primary health insurance is the main plan that covers most health care costs. Secondary health insurance is the additional insurance that covers costs not paid for by the primary health insurance plan. (See *Chapter 7*.)

Home Health Aide

A professional who provides home care services, including: personal care services; simple dressing changes or help with medications that do not require the skills of a nurse; help with special activities and therapies; and routine care of prosthetic and orthotic devices.

Hospice Care

The special kind of health care focused on life-limiting illness. It can be provided in the home and outside of the home in hospitals or hospice centers. Hospice care may include any of the home health services, but also usually includes both counseling services and palliative care nursing. Palliative care is focused on preserving patient comfort and dignity in the face of terminal disease. (See *Chapter 6*.)

Immunization

A substance (usually given in the form of a shot) that protects a person from viruses and bacteria. Also called a vaccine.

Impairment

An injury, deficit, or disability.

Inclusion

In the schools, inclusion or inclusive education means that all children learn together in the same schools and classrooms. Services and supports for children with special needs are built into regular school and classroom activities. See *Mainstreaming*. (See *Chapter 8*.)

Individualized Education Program (IEP)

A special education service plan for a child's school program. It is required by law for all children receiving special education services. An IEP describes an individual child's educational goals, and any services or help the child needs to meet those goals. (See *Chapter 8*.)

Individualized Family Service Plan (IFSP)

A care plan required by law for every child enrolled in Birth To Three. (See *Chapter 8*.)

Individualized Health Care Plan (IHCP)

A care plan designed to manage the medical care of a child with special health care needs in school. (See *Chapter 8*.)

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act is the federal special education law. (See *Chapter 8*.)

Least Restrictive Environment (LRE)

A term that means that your child should be educated in the same classroom and school as he or she would be in if he or she did not have disabilities. (See *Chapter 8*.)

Mainstreaming

Programs and policies to include people with disabilities in regular programs and services, such as education. See *Inclusion*. (See *Chapter 8*.)

Mandate

Something that is required by law. For example, free public education is a mandate.

Medical Emergency

A serious medical condition that results from injury, sickness or mental illness, which is sudden and severe and requires immediate treatment. (See *Chapter 4*.)

Medical Fellow

A doctor who has finished medical school and residency, and is spending 3 or more years learning to be a specialty doctor.

Medical Home

Medical Home is an idea that promotes a coordinated system of care that is accessible, continuous, comprehensive, family centered, compassionate, and culturally effective. The primary care provider shares responsibility to ensure that the child receives this kind of care. (See *Chapter 5*.)

Medical Necessity

Standards of medical practice that health plans use to make decisions about the coverage of special services or equipment. (See *Chapter 7*.)

Medical Resident

A doctor who has finished medical school and is spending 3 years learning clinical medicine. A resident is supervised by an attending doctor.

Medical Student

A student in medical school who has not yet received his or her degree. A medical student is supervised by an attending doctor.

Member Service Representative

A health insurance plan employee who can help you with questions about covered services and benefits. (See *Chapter 7*.)

Mental Health Parity Law

A special law in Connecticut that requires most health insurance plans to provide coverage for mental health services. Coverage for mental health cannot be at a greater expense than medical and surgical coverage. (See *Chapter 7*.)

Mental Health Counselor

A provider, usually with an advanced university degree in counseling or psychology, who can counsel you and your child on mental health – mood, behavior, and family issues.

Nurse

A nurse provides and coordinates the hands-on treatment and care of your child. A nurse also assesses symptoms and alerts the doctor to any changes in status by either writing in the medical chart or notifying the doctor immediately.

Nurse Practitioner (NP)

A nurse practitioner is a registered nurse with advanced academic and clinical training that provides primary and specialty medical care. A NP diagnoses and manages most common and many chronic illnesses, either independently or as part of a health care team.

Occupational Therapy

Treatment to help a person develop mental or physical skills for daily living, especially fine motor skills. Examples include dressing, bathing, writing, and using a fork or spoon. Occupational therapy often involves identifying and learning to use equipment that helps people with these activities.

Orthosis

A support or brace for weak joints or muscles.

Over-the-Counter (OTC) Medicine

Medication that is available without a prescription.

Palliative Care

Care that is provided not to cure, but to keep a patient comfortable. Examples include providing warmth, pain control measures, and appropriate nutrition and medications. See Hospice Care. (See *Chapter 6*.)

Parent-to-Parent Support

Parents of children with disabilities providing information and one-on-one support to each other. (See *Chapter 10*.)

Personal Care Attendant (PCA)

An independent caregiver who helps with the activities of daily living. (See *Chapter 6*.)

Physical Therapy

Treatment to relieve pain and to improve or restore movement skills and muscle function. Examples of methods of physical therapy include exercise, stretching, massage, heat, cold, water or electrical stimulation therapy.

Physician's Assistant (PA)

A health care provider specially trained to provide medical care under the supervision of a doctor. A PA can conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel on preventive health care, assist in surgery, and can often write prescriptions.

Prescription Drug

Medication that is available only with a written order from a medical provider who is licensed to prescribe medications.

Premature

Happening or arriving before the expected or usual time. A premature baby is usually defined as a baby born at least 3 weeks early, after a gestation period of less than 37 weeks. Sometimes, prematurity means a birth weight of less than 2500 grams (about 5 1/2 pounds), regardless of gestational age. See Gestation.

Primary Care

The routine (regular) health care your child gets from a primary care provider (PCP). (See *Chapter 5*.)

Primary Care Provider (PCP)

The term for any professional who provides primary care. A primary care provider (PCP) may be a pediatrician, family physician, specialty physician, nurse practitioner, or physician's assistant. (See *Chapter 5*.)

Prior Authorization

Also called prior approval. Getting permission for special services or equipment in advance by the health plan, usually based on medical necessity. (See *Chapter 7*.)

Private Duty Nursing

See Continuous Nursing Services.

Prosthesis

An artificial device to replace a missing part of the body.

Provider Network

A group of doctors, hospitals, and other health care providers who work together with a health insurance plan to provide health care services. (See *Chapter 7*.)

Psychiatrist

A medical doctor who can counsel you and your child about mental health – mood, behavior, and family issues. If needed, a psychiatrist prescribes medications that help with mood or behavior.

Psychologist

A provider, usually with a doctorate in psychology, who can counsel you and your child about mental health – mood, behavior, and family issues. A psychologist also does special testing to understand how your child learns, thinks, and feels.

Referral

An authorization by a health provider or health insurance plan for a person to receive care (often specialty care) from another provider. Each health plan has its own rules about referrals. Most plans have their own networks of specialists.

Rehabilitation

The process of helping a person reach the highest level of function, independence, and quality of life possible.

Respite Care

A service that provides temporary care to a child by any trained caregiver. For example, a respite care worker could be another family member, friend, or a professional caregiver. Respite care can take place in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources. (See *Chapter 6*.)

Screening

The use of basic, standardized procedures to test health, hearing, vision, developmental, behavior, and other factors to identify children with, or at risk of, disabilities or special health care needs.

Second Opinion

An evaluation by a second provider, other than your child's regular providers. You may want your child to get a second opinion if a health provider gives you a new diagnosis or tells you that your child needs a certain treatment or surgery. You may want to know if another provider agrees with the decision. Most health plans will pay for you to get a second opinion.

Section 504

A federal law that protects the rights of people with disabilities from discrimination in programs or activities that receive federal funds. See 504 Plan. (See *Chapter 8*.)

Service Date

A term used by health insurance plans for the date of an appointment, treatment, or test.

Skilled Nursing

Care and treatments by a Registered Nurse (RN) or a Licensed Practical Nurse (LPN). A nurse can provide teaching and support, perform a skilled procedure, or provide a specific therapy.

Social Worker

An individual, usually with an advanced university degree in social work, who provides counseling and aid to individuals about mental health – mood, behavior, and family issues. A social worker can also help connect you and your child with other services in your community.

Speech and Language Therapy

Treatment of conditions affecting the voice, speech, swallowing, and written communication. Speech therapy helps children who have language or speech impairments with their communication skills.

Special Education

Special education is specially designed instruction and related services that meet the unique needs of an eligible student with a disability or a specific service need that is necessary to allow the student with a disability to access the general curriculum. The purpose of special education is to allow the student to successfully develop his or her individual educational potential. Special education is free through the public school system. (See *Chapter 8*.)

Specialist

A doctor or other health care provider with “special” training in a certain area of medical care. (See *Chapter 5*.)

Specialty Care

Care from a doctor or health other provider who has special training and experience in treating certain body systems or conditions. (See *Chapter 5*.)

Syndrome

A group of symptoms or characteristics that occur together, but have not yet been classified as a disease.

TTY (Text Telephone)

A TTY, also called TDD (Telecommunications Device for the Deaf), is a special device that lets people who are Deaf, hard of hearing, or speech-impaired use the telephone to communicate, by allowing them to type messages back and forth to one another instead of talking and listening. A TTY is required at both ends of the conversation in order to communicate.

Tertiary Care Center

A hospital that provides specialized inpatient and outpatient care.

Transition

The process of moving from one stage of life or type of service to another. For children with special health care needs, transition usually refers to process of growing older and becoming more independent in areas of health care, employment, living, and recreation. Children in Early Intervention (EI) also experience transition when they leave EI and move to school services. (See *Chapter 9*.)

Urgent Care

Care given in situations that require immediate treatment but are usually not life-threatening, such as an ear infection, sprained ankle, or flu-like symptoms.

Utilization Management

A process where health care professionals review planned hospital admissions, surgery, and other procedures to make sure they are necessary and appropriate. (See *Chapter 7*.)

Vendor

A provider, supplier, or seller. For example, a durable medical equipment (DME) vendor is the company that provides your child with equipment.

(Some definitions from Merriem-Webster Dictionary, www.merriem-webster.com.)

For more information on medical terms and medical conditions, visit:

- Children’s Hospital Boston, Child Health A to Z web page, www.childrenshospital.org.
- Family Village Library web page, www.familyvillage.wisc.edu/library.htm.

Use the space below to write down additional words or terms.

Word or Term	Meaning/Definition
_____	_____
_____	_____
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_____	_____
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Abbreviations Related to Medications

Bid	Twice a day
Prn	Whenever necessary
Q	Every
Qd	Every day
Q2h	Every two hours
Q3h	Every three hours
Qid	Four times a day
Qam	Every morning
Qhs	Every night
Qod	Every other day
Tid	Three times a day

Important note: If you do not understand the directions for giving a medication to your child, call your child’s health care provider or pharmacist.

Commonly Used Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit with Hyperactivity Disorder
ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
Arc	Advocates for the Rights of Citizens with Developmental Disabilities and their Families
AT	Assistive Technology
CAT Scan	Computerized Axial Tomography Scan
CBC	Complete Blood Count
CCM	Community Case Management
CP	Cerebral Palsy
CPR	Cardiopulmonary Resuscitation
CSHCN	Children with Special Health Care Needs
DD	Developmental Disability
DME	Durable Medical Equipment
DMHAS	Department of Mental Health and Addiction Services
DMR	Department of Mental Retardation
DNR	Do Not Resuscitate
DO	Doctor of Osteopathy
DOE	Department of Education
DPH	Department of Public Health
DSS	Department of Social Services
Dx	Diagnosis
ECG or EKG	Electrocardiogram
EEG	Electroencephalogram
EI	Early Intervention
EMS	Emergency Medical Services
EPSDT	Early and Periodic Screening, Diagnosis and Treatment
FAPE	Free and Appropriate Public Education
FTT	Failure to Thrive
GI	Gastrointestinal
HHS	Health and Human Services
HMO	Health Maintenance Organization
I&O	Intake & Output
I&R	Information & Referral
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
IHCP	Individualized Health Care Plan
IV	Intravenous
IVH	Intraventricular Hemorrhage
LD	Learning Disability
LICSW/LCSW	Licensed (Individual) Clinical Social Worker

LRE	Least Restrictive Environment
MCH	Maternal and Child Health
MCO	Managed Care Organization
MD	Medical Doctor
MD	Muscular Dystrophy
MR	Mental Retardation
MRI	Magnetic Resonance Imaging
NICU	Neonatal Intensive Care Unit
NP	Nurse Practitioner
NPO	Nothing by Mouth
ORL	Otolaryngologist (ear, nose, and throat doctor)
OT	Occupational Therapy or Occupational Therapist
PA	Physician's Assistant
PA	Prior Authorization or Approval
PCA	Personal Care Attendant or Assistant
PCC	Primary Care Clinician
PCP	Primary Care Provider or Primary Care Physician
PDD	Pervasive Developmental Disorder
PDN	Private Duty Nursing
Ph.D.	Doctor of Philosophy (a non-medical doctor)
PICU	Pediatric Intensive Care Unit
PL	Public Law
PPO	Preferred Provider Organization
PT	Physical Therapy or Physical Therapist
RN	Registered Nurse
Rx	Prescription or Treatment
SIDS	Sudden Infant Death Syndrome
SLP	Speech-Language Pathologist (Therapist)
SSA	Social Security Administration
SSI	Supplemental Security Income
TA	Technical Assistance
TANF	Temporary Assistance for Needy Families
TDD	Telecommunications Device for the Deaf
TPN	Total Parenteral Nutrition
TTY	Text Telephone
Tx	Treatment
URI	Upper Respiratory Infection
UTI	Urinary Tract Infection
WIC	Women, Infants, and Children Nutrition Program

Quick Links to Resources

African & Caribbean American Parents of Children with Disabilities (AFCAMP)	afcamp@sbcglobal.com
American Academy of Pediatrics	www.aap.org
American Academy of Pediatric Dentistry	www.aapd.org
Bright Futures for Families	www.brightfuturesforfamilies.org
Connecticut Association for Human Services (CAHS) – CT Food Guide	www.cahs.org
Connecticut Birth To Three	www.birth23.org
Connecticut Department of Public Health	www.dph.state.ct.us
Connecticut Department of Mental Retardation	www.dmr.state.ct.us
Connecticut Department of Public Safety	www.ct.gov/dps
Connecticut Department of Social Services	www.ct.gov/dss
Connecticut Family Support Network	jtcarroll@cox.net
Connecticut Insurance Department	www.ct.gov/cid
Connecticut Lifespan Respite Coalition (CLRC)	www.ctrespite.org
Connecticut Parent Advocacy Center (CPAC)	www.cpacinc.org
Connecticut State Dental Association	www.csda.com
Connecticut State Department of Education	www.state.ct.us/sde
Connecticut State Department of Education, Preschool Special Education program	www.state.ct.us/sde/deps
CT Safe Kids	www.ctsafekids.org
Disability Law Resource Project	www.dlrp.org
Hospice and Palliative Care Federation	www.hospicefed.org
Infoline (2-1-1)	www.infoline.org
Institute for Community Inclusion	www.communityinclusion.org
Connecticut Department of Children and Families Statewide KidCare Resource Directory	www.ct.gov/dcf
Family Advocacy Organization for Children’s Mental Health (FAVOR)	www.favor-ct.org

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MA Department of Public Health

The mission of the Department of Public Health is to serve all the people in the Commonwealth, particularly the under served, and to promote healthy people, healthy families, healthy communities and healthy environments through compassionate care, education and prevention.

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Home Initiatives



Alliance for Health Care Improvement

The Alliance for Health Care Improvement (AHCI) is a collaboration of the Medical Directors of the Massachusetts-based not-for-profit health plans. The mission of the Alliance is to promote collaboration on cost-effective, population-wide strategies designed to improve the health status of health plan members and the community at large.

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Dennis Batey, MD
Fallon Community Health Plan

Philip Boulter, MD
Tufts Health Plan

John Fallon, MD
Blue Cross Blue Shield of Massachusetts

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Neighborhood Health Plan

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Keeping Connecticut Healthy

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