Your Child's Everyday Care

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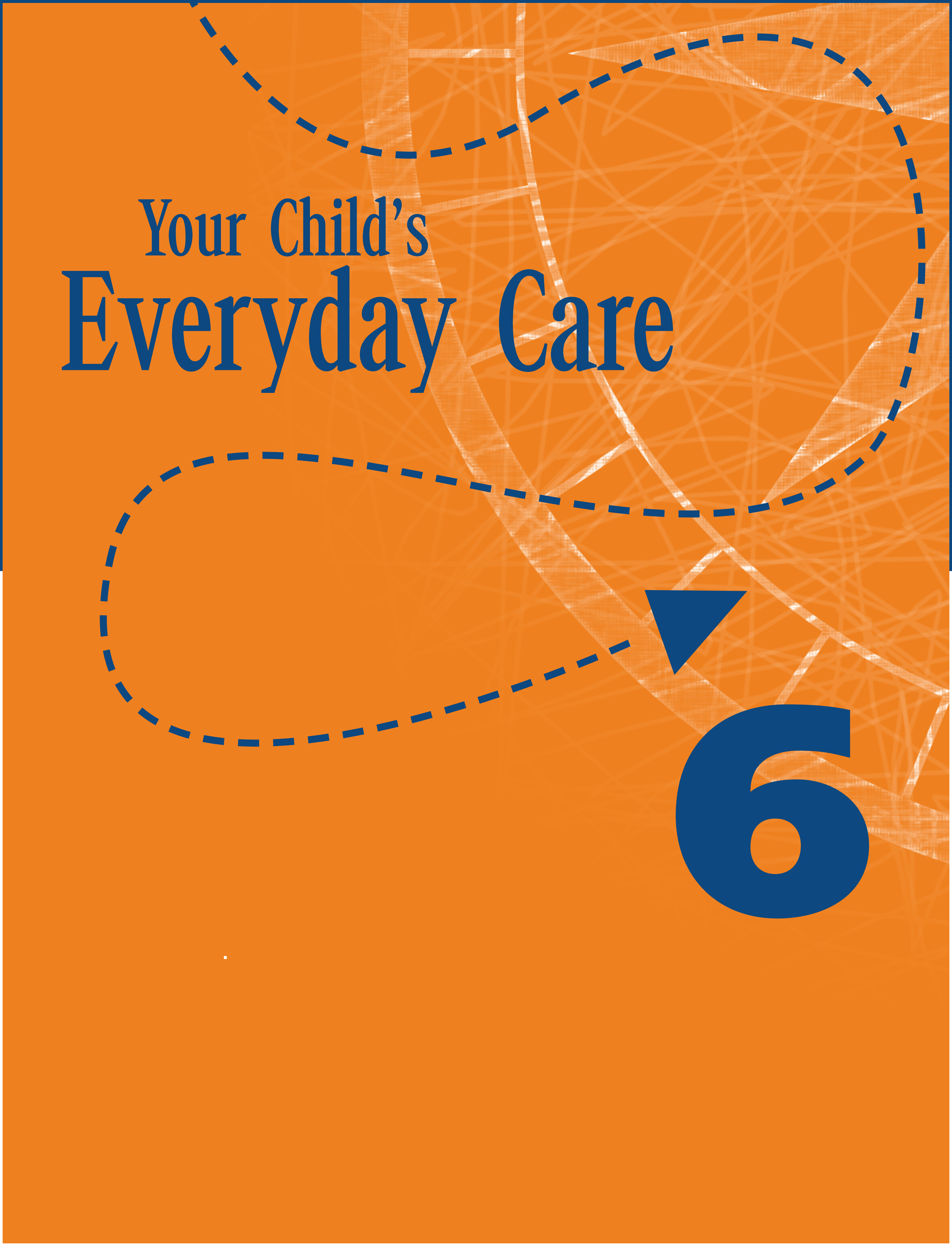

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Your Child's Everyday Care

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)
- Massachusetts Family TIES at 800-905-TIES, 617-624-5992 (TTY), look in the ***Family TIES Resource Directory***, or visit www.massfamilyties.org
- Massachusetts Family Voices at 800-331-0688 x 210, 617-624-5992 (TTY), join listserv by sending email to massfv@fcsn.org, or visit www.massfamilyvoices.org
- Massachusetts Department of Public Health Community Support Line at 800-882-1435 (in MA only), 617-624-5070, 617-624-5992 (TTY), or visit www.mass.gov/dph/fch/directions

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:

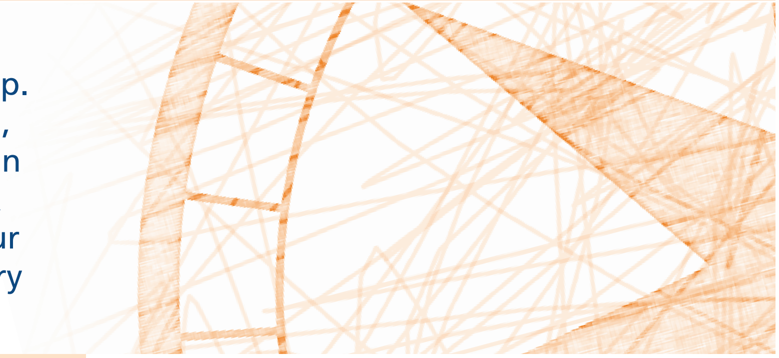
- **Pills that need to be taken only one time per day**
- **"Quick dissolve tablets"**
- **Capsules that can be opened and mixed in food**
- **Flavored syrups**

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, see the **State Agencies** section in the ***Family TIES Resource Directory***.

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 **Assistive Technology and Adaptive Equipment** section of the ***Family TIES Resource Directory***.

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 call 800-CAR-SAFE or 617-624-5992 (TTY).

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 in the **Assistive Technology and Adaptive Equipment** section of the ***Family TIES Resource Directory***.

Tip: Using Public Transportation

If you live in Boston, contact the Massachusetts Bay Transit Authority (MBTA). Ask about accessible buses, trains, and **The Ride**.

If you live outside of Boston, contact the local transit authority and ask about special transportation. For example, in Brockton there is **Dial-A-BAT** (Brockton Area Transit) and in Western Massachusetts there is PVTA (Pioneer Valley Transit Authority).

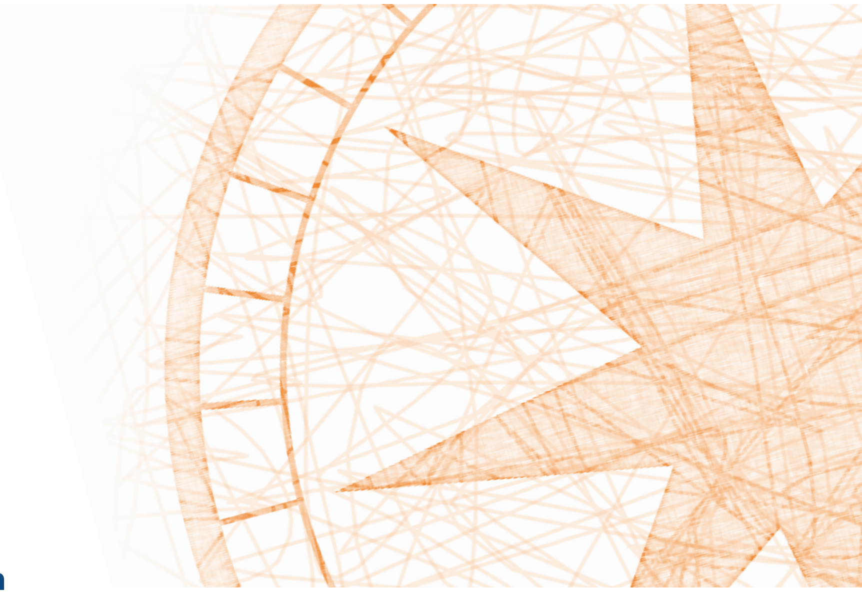
Tip:

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 MA Department of Public Health, Division of Health Care Quality, 800-462-5540 or 617-753-8170 (TTY).

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?

(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.)

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 for more information. (See the **Independent Living Center** section of the ***Family TIES Resource Directory*** for a listing in Massachusetts.)

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 (see the **Independent Living Center** section of the ***Family TIES Resource Directory*** for a listing in your area), 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 CORI (Criminal Offender Record Information) report for a PCA. Contact the Criminal History Systems Board at 617-660-4600, 617-660-4606 (TTY), or visit or www.mass.gov/chsb or your local police department. Request or download a Publicly Accessible CORI Form and send it to the Criminal History Systems Board. A fee is charged for each report you 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 Massachusetts Office of Child Care at 617-988-6600, 617-988-2454 (TTY), or visit www.qualitychildcare.org. Also, contact the Massachusetts Childcare Resource and Referral Network at 800-345-0131, 617-491-1749 (TTY), or visit www.ccrcinc.org/spneeds.shtml. These services help parents of children with disabilities to find childcare in their community and programs that help pay for childcare.

Check the **Childcare Resource and Referral Network** Section of the ***Family TIES Resource Directory*** for the names of other programs and services. For more information about at-home childcare, see **Choosing a Sitter** on the next page.

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 Health Care 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:

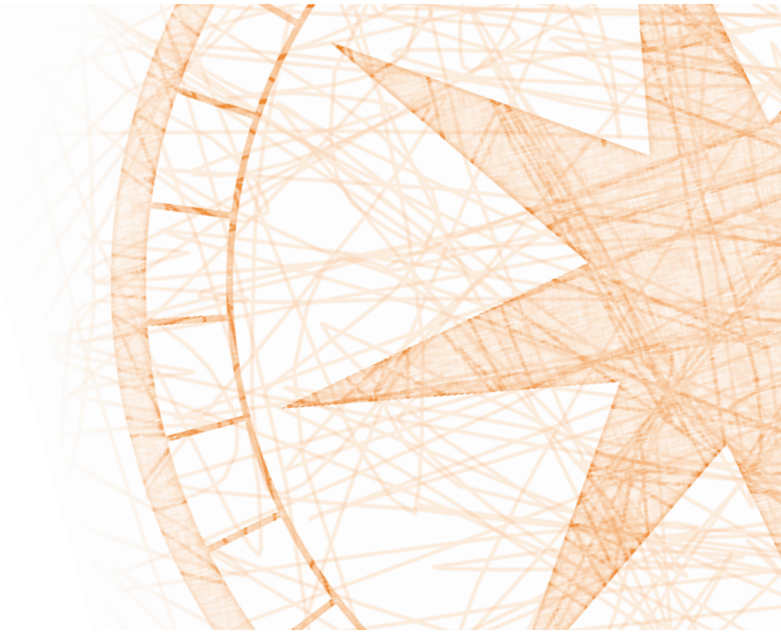
- **Call a local hospital** to find sitters with clinical training. Ask about part-time or retired staff who may wish to care for your child. Ask if you can post a note for a "special" sitter on the hospital's bulletin board.
- **Call a local school or community college** with a program that trains nurses, 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 CORI (Criminal Offender Record Information) report for a sitter you wish to hire, contact the Criminal History Systems Board at 617-660-4600, 617-660-4606 (TTY), or www.mass.gov/chsb or your local police department. Request or download a Publicly Accessible CORI Form and send it to the Criminal History Systems Board. A fee is charged for each report you 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, called Flexible Family Support or Special Medical Funding, to pay for respite care and some other out-of-pocket expenses. 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 and flexible family support funding. Contact Family TIES at 800-905-8437 or see the **State Agencies** section of the ***Family TIES Resource Directory*** for more information.

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 within Massachusetts and you have access to a computer, write a message to the Family Voices Listserve at massfv@fcsn.org as a way to find names of new providers, local support groups, and parent organizations. See www.massfamilyvoices.org.

If you are moving outside of Massachusetts, 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)____________________________

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Health Insurance Plan ____________________

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EMS__________________________________

Fire Department________________________

Police Department______________________

Electric Company_______________________

Phone Company________________________

Gas/Oil Company_______________________

School________________________________

Parent Support Group/Organizations______

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State Department of Education__________

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State Department of Public Health________

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Equipment Supplier_____________________

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Pharmacy_____________________________

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House of Worship_______________________

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Other_________________________________

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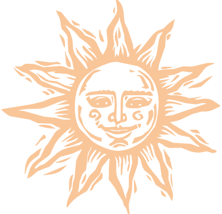


Planning a Vacation

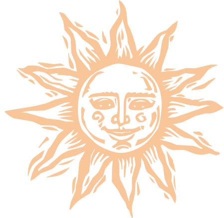
Planning a family trip with any child can be a challenge. Planning a trip when a child has special health needs can be overwhelming. Preparation is the key to a happy and healthy trip. Here are a few hints that may help.

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 Massachusetts. **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

Also, check the ***Family Ties Resource Directory***