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Your Child's Medical Team

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.

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

What is a “Medical Home?”

In recent years, you may have heard the slogan “Every Child Deserves a Medical Home.” A Medical Home is not a building or a place. It’s an idea for a whole system of care for children.

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
- New England SERVE at 617-574-9493 or visit www.neserve.org
- Massachusetts Family TIES at 800-905- TIES (8437), 617-624-5992 (TTY), or visit www.massfamilyties.org
- Massachusetts Family Voices at 800-331-0688 x 210, 617-624-5992 (TTY), or visit www.massfamilyvoices.org
- Massachusetts Department of Public Health at 800-882-1435 (in MA only), 617-624-6060, 617-624-5992 (TTY), or visit www.mass.gov/dph/fch/directions

For tips on Medical Home, see the brochure *A New Way...A Better Way. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs*, available from www.neserve.org or 617-574-9493.

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.)

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 Early Intervention 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.) 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 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
- Schools
- Churches and religious communities
- State agencies
- Hospitals
- Private offices

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.

Contact the Parent/Professional Advocacy League (PAL) Parent Resource Network Line at 866-815-8122, 617-542-7860, or visit www.ppal.net for more information about mental health resources. Also, check the *Family TIES Resource Directory* for more mental health resources.

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

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 Massachusetts Dental Society at 800 342-8747 or visit www.massdental.org.
- 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 Health Law Advocates at 617-338-5241 or 800-272-4232 x 2980.

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

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)

See **State Agencies** in the *Family TIES Resource Directory* for more information about Care Coordination services that may be available to you.

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 | |
| Immune System | Immunologist Allergist Infectious Disease Specialist | Nurse Practitioner |
| Kidney | Nephrologist | |
| Lungs/Chest | Pulmonologist Pulmonary Specialist | Respiratory Therapist |

| Specialty | Physician Specialist | Non-Physician Specialist |
|--|---|--|
| 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 Physiatrist | 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/family.

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. One way to do this is to contact:

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 the listserv by sending email to massfv@fcsn.org, or visit www.massfamilyvoices.org

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

You may also see:

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

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

Learn more about different types of providers in the **Health Care Providers by Specialty** table. 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?
- Do you have the supplies and equipment your child will need at home? 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: DPH Care Coordination, Early Intervention, 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. 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 Massachusetts 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.

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.