
Home Medical Record

Introduction

Your child has a special health care need. Medical appointments are a part of your life. You may be involved with one or with many physicians. Your child may require additional services recommended by the physician, such as occupational or physical therapy. Laboratory studies, x-rays or other specialized testing may be recommended to assist the physician in learning more about your child's medical condition. Over the course of time you will find that you need to keep track of information regarding the medical services your child receives. This information will be useful when you take your child to a new physician, when your child becomes involved in a school program, or for some other reason you need to share information about your child's medical history. It may also assist you in keeping track of his or her progress, in order that you can gain an overall perspective on your child's medical care.

Tips

- Sometimes a physician may mention a possible diagnosis for your child's medical condition. Be sure that you understand whether a diagnosis is only suspected or is actually confirmed.
- Don't hesitate to ask questions.
- If—between visits—you think of questions you would like answered by your child's physician, write them down and take them with you to the next appointment.
- If you are not able to understand the medical language used by your child's physician or other professionals, ask them to explain it. If you do not have the opportunity to ask, obtain a medical dictionary to use as a reference book, or

use a medical dictionary at your local library.

- There may be more than one medical treatment option for your child's condition. Ask what the options are and what can be expected from each option. Then decide which treatment you think will be best for your child.
- Ask if a second opinion would be helpful, if you are uncomfortable or confused about the diagnosis or treatment and uncertain about the correct decision as a parent.
- While second opinions can be helpful, be careful you do not become a medical "shopper," hunting for the doctor who says what you want to hear.
- Be sure you know what the specialist expects you to do next and what you can expect the specialist to do. Write those expectations down in the plan section of this book (CCR.42).
- Ask the specialist to whom he or she will send medical reports. Make a list of persons to whom you would like to have reports sent. Be sure that your child's pediatrician or your family doctor receives copies of reports from specialists, therapists, etc.
- If your child is seen by more than one specialist, be sure that they are each aware of the others involvement and that they share reports.
- When your child is referred to another doctor or specialist, ask about the purpose of the referral. Also find out what will be involved in the specialist's examination (such as lab work and x-rays). Ask about the reports the specialist will want to see

and take them with you or ask (in writing that they be sent).

- Most physicians and hospital social service departments who work with "special needs" children and their families are aware that other, non-medical services are sometimes needed (for example, counseling services for financial support) and will be able to help with referrals for such services when they recognize the need or when parents request such assistance. Don't hesitate to ask them to explain other services which you may be eligible to receive.
- Have the physician tell you the name of any medication that is prescribed. Then, be sure that this is the same medication that the pharmacist is providing. Handwriting can occasionally be misinterpreted.
- Ask the physician, nurse or pharmacist to explain to you any side effects of medications prescribed or situations in which a specific medication should not be used.
- Check to make sure that all prescriptions are filled correctly by reading the label and looking at the medicine's color and consistency. Check the size, shape and color of pills, if they have previously been prescribed, to see if they appear to be the same. If an error has been made, contact the pharmacist immediately.
- Learn how to change milliliters (ml) into teaspoon measurements (1 teaspoon = 5 ml or 5 cc). This will be helpful when liquid medication is prescribed.
- When possible, use the same pharmacist or pharmacy to fill all your child's prescriptions. This will permit the pharmacist to check readily to see what other medications your child is taking or has taken in the past and alert you and the doctor to possible medication interactions.

He or she can also become familiar with any problems your child has with taking medication (such as reactions).

- Become familiar with any medication prescribed for your child, its purpose, side effects, etc. Pharmacists are required to provide printed information regarding the medications they dispense. Be sure to read what is provided and ask the pharmacist any questions you may have about the medication.
- Check with physicians, nurses and therapists to learn if there is any equipment that could assist with your child's care or development at home.
- Obtain maintenance information on any special equipment that your child uses.
- When replacing equipment, be sure that the replacement item is the same as the original. Be sure that the equipment dealer provides a replacement item that meets the specifications of the original.
- Ask other parents about helpful tips they may have.

Medical Records

- It is not usually necessary to have copies of all reports at home, but it may be helpful to obtain diagnostic and surgical reports to take to new physicians any time care is being transferred. As your child's guardian you have the right to request copies of operative reports, hospital discharge summaries, and test results. You will usually need to sign a release or make a written request to obtain them. A sample request form has been included in the "Rights" section of this notebook (Form CCR.58). At times there will be a fee to cover the copying costs, so be sure to ask first! Some parents ask their family physician/pediatrician to obtain the reports and then have copies made at a lesser fee (or at no charge).

Pictures/Diagrams

- If your child has a birth defect or structural malformation, consider keeping a diagram of it in this section. You may wish to copy pictures from medical books at your local library or obtain pamphlets from national organizations pertaining to your child's diagnosis. Given an illustration of the normal structure, your physician should be able to draw in any variations to show your child's particular problem.
- If you do not have access to pictures of normal structures (anatomy) or common defects, perhaps your doctor could draw an illustration of your child's condition freehand. If your child's medical problem is something that can be seen, it may be useful to take photographs of your child before and after treatment.

Things To Take To An Appointment

- Birth/Development and Family History: You may wish to take the appropriate pages from this book each time your child sees a physician for the first time or when he or she is being admitted to the hospital.
- List of all medications and the dosages your child is currently taking. Also list any allergies or negative reactions your child has had to medications in the past.
- List of questions and concerns (you may want to make your own list of questions to keep in this book). Leave room to write in the doctor's answers! Include questions your child may have about his or her condition.
- Information about insurance coverage and other payment sources.
- Amusements, snacks, and loose change to entertain your child while in the waiting area.

- Consider taking a neighbor, friend, or baby-sitter to watch your child if you plan to speak privately or at length with the physician after your child has been examined.

What To Do If Your Child Is Hospitalized

- Prepare an information sheet about your child, including a list of favorite foods, bowel and sleeping habits, most enjoyed activities, etc. (Include the words your child uses for urinating and bowel movements.)
- Be sure that your insurance company, HMO, PPO or other third party payor has been notified and that precertification has been done (when required). If the Division of Specialized Care for Children is involved with your child, be sure to notify DSCC.
- When possible, staying with your child is a good idea. Most hospitals allow parents to stay 24 hours a day, if the child's medical condition permits it. If you cannot stay with your child in the hospital, visit regularly and as frequently as possible.
- At the end of a visit, be sure to make your child aware that you are leaving. For younger children this may be upsetting, but if you depart without saying good-bye, this can make the child feel alone and mistrustful of you when he or she realizes you are gone.

- Speak to the hospital staff who will be involved with your child's care. Share your observations and concerns with them. This will help them understand your child better and also help them be more sensitive to your needs, as well as those of your child.
- Though infants or very young children may not be able to discuss hospitalization, it is helpful to prepare older children for the experience. Let the child know whether you will be able to stay with him or her overnight, how often you will visit, what his or her room will be like, and what kind of examinations and treatment he or she will experience. Your child may not be able to absorb all this information at once, so give it in small amounts, repeat it as often as seems necessary over the course of several days and be ready to answer any questions. Many hospitals have orientation programs for children.
- If hospital regulations permit it, bring along your child's favorite toy, such as a stuffed animal, or a blanket. This will help your child feel more secure. If your child will have oxygen, check with a nurse about toys that are safe in oxygen delivery systems.
- Prior to your child's discharge, be sure to ask for written instructions from your child's hospital care staff (nurses, dietitians or therapists). Keep the instructions in this notebook. Have the hospital care staff observe you performing any special care that will need to be continued when your child returns home, to be sure that you are doing it properly.
- Children, especially younger ones, may be unusually clinging or tearful during or following hospitalization. Learn to anticipate this and recognize it as a normal emotional response of a child to separation from his or her family.