20 Tips to Help you to be a Part of the Healthcare Team:

A Guide for Parents and Caregivers

Developed by the health care professionals of the Department of Quality, Safety and Risk Management with assistance from the Department of Learning and Development and in conjunction with Partners in Care, the family advisory committee to BC Children's Hospital.

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Hospitals and other healthcare facilities are very busy places. There may be more than one or two healthcare providers caring for your child. Your child may need a lot of tests and procedures and the amount of information you get could be overwhelming and not clear to you.

This pamphlet will give you suggestions to help make sure that the communication between you, your child and healthcare providers is clear. When you understand the information that you get from healthcare providers, there is less chance that an error can happen. We thank you for your active participation in your child's care and welcome any suggestions you may have.

What can you do?

1. The single most important way you can help is to be an active member of your child's healthcare team.

This means taking part in every decision about your child's healthcare. Ask questions when you do not understand something. Do not be satisfied until you completely understand what is happening and why.

Medicines

2. Make sure that all of your child's doctors and nurses know about all of the medicine your child is taking.

This includes prescription and over-the-counter medicines (medicine that you buy without a prescription). It also includes dietary supplements such as vitamins and herbs. Make sure that they know how much your child weighs, because this will help the doctor figure out the correct dose for your child.

Keep a record of the medicine that your child is taking. You can get charts at pharmacies (drug stores) to fill in. If you can't get a chart, use the one at the back of this booklet and fill in the following information:

Name of Medication	Date started	Amount and Time(s) Taken	Date ended
Medicines often have two names (generic and brand names). This information can be found on the medicine package (bottle or box) or the information sheet that comes with it. Record both names, whenever possible.	Write down the date that your child started taking this medicine.	Record the amount of medicine your child takes and each time of day the medicine is to be taken. It is best to mark in the dosage in milligrams (mg) or other dosage units instead of the number of pills taken each time. The dosage can be found on the label of the medicine.	Write down the date that your child stopped taking this medicine. You should also record why your child stopped taking it.

Keep this chart with you at all times. It makes it easier for all of the healthcare providers to see clearly what medicines your child is taking. If your child is taking more than one or two medications, including vitamins or herbs, review them all with your doctor at least once a year. "Brown bagging" (putting ALL medicine in a bag and taking it to your child's doctor) your child's medicines can help you and your child's doctor talk about them and find out if there are any problems.

3. Make sure your child's doctors and nurses know about any allergies or reactions your child has to foods and medicines.

This helps to avoid getting a medicine that can harm your child. When a new medicine is prescribed, ask the doctor if the new drug is 'related to' any of the medicines your child is allergic too. Even drugs with different names can contain the same ingredient that your child reacts too. Keep a record of your child's allergies on the medicine chart (see point #2) and share it with all healthcare providers that are caring for your child.

4. When your child's doctor writes you a prescription, make sure you can read it.

If you can't read the doctor's handwriting, your pharmacist (druggist) might not be able to either. Ask the doctor to use block letters to print the prescription so you can read it.

5. When you pick up your child's medicine from the pharmacy, repeat the name of the medicine and the dose to the pharmacist (druggist) so that you can double check that you have the right one.

For example, say "Is this the Sucralfate (Sulcrate) 200 mg, my child is to take four times a day before meals and at bedtime?"

6. Ask for information about your child's medicines in terms you can understand.

Ask the following questions when a medicine is prescribed by your doctor. Repeat these questions when you pick up your medication at the pharmacy.

- What is the name of the medicine?
- What is the medicine for?
- Is the dose of this medicine appropriate for my child based on his or her weight?

- How often is my child supposed to take it, and for how long?
- What side effects are likely? What do I do if they occur?
- Is this medicine safe for my child to take with other medicines or dietary supplements my child is taking?
- What food, drink, or activities should my child avoid while taking this medicine?
- When should I see an improvement?

When your child is in the hospital, ask the nurse what medicine he/she is giving your child before each dose, whenever possible. Ensure to double check that it is:

- the right medication,
- the right dose,
- the right time,
- the right route (by mouth, through a feeding tube or intravenous (IV) line, or by injection, for example).

Review the medication label with the nurse, whenever possible.

Ask your nurse to review any changes in your child's medicine with you each day to ensure you know about any changes in your child's schedule.

Do not be afraid to ask questions or voice concerns if something is unclear.

7. When you have questions about the directions on your child's medicine labels, ask for clarification.

Medicine labels can be hard to understand. For example, ask if "four doses daily" means taking a dose every 6 hours around the clock or just during regular waking hours, or before meals and bedtime.

8. Ask your pharmacist (druggist) for the best way to measure your child's liquid medicine. There are several devices that can help you to get the correct dose of medicine without spilling. Also, ask questions if you are not sure how to use a measuring device.

Measuring liquid medicines can be difficult and errors can be made if the right measuring device is not used. For example, household teaspoons often do not hold a true teaspoon of liquid. Special devices, like marked oral syringes, help people to measure the right dose. Being shown how to use the devices helps even more. Ask your pharmacist, doctor or nurse for a device that can help you give liquid medicine and make sure you know how to use it

9. Ask for written information about the side effects your child's medicine could cause.

Some medications may not have any side effects, while others may have mild or more serious ones. Before starting your child on a new medicine, be sure to talk to the doctor, nurse or pharmacist about what side effects you need to watch for. Report any problems to your doctor, nurse or pharmacist right away.

Ask your nurse or your pharmacist for medication information sheets any time your child is started on a new medication.

Hospital Stays

10. Make sure your child has the right identification bracelet on at all times.

While your child is in the hospital, make sure he or she is always wearing an identification bracelet. It is important that all healthcare providers know who your child is, and what their allergies are. If the bracelet is removed, your child could be confused with another patient. Always double check to make sure that the bracelet has been stamped with the right information.

11. When your child is in the hospital, ask everyone who has direct contact with your child to wash their hands.

Hand washing is an important way to prevent the spread of infections in hospitals. Get into the habit of washing your hands before and after touching your child or before and after being in your child's room. Remind family, friends, and healthcare providers to do the same.

12. When your child is being discharged from the hospital, ask his or her doctor to explain the treatment plan you will use at home.

This includes learning about your child's medicines and finding out when he or she can get back to regular activities. Write down all of your questions ahead of time, whenever possible. This will help you remember what you will need to know.

<u>Surgery</u>

13. When your child is having surgery, make sure that you, your child's doctor, and the surgeon all agree and are clear on exactly what will be done.

When speaking to your child's doctor and anesthesiologist (the doctor who will be helping with your child's sedation and pain management) before surgery, make sure that you discuss 'surgical site marking' and ask them to confirm the part of the body they will be operating on.

14. Know what it means to give informed consent for healthcare treatment.

Your doctor or nurse will be able to provide you with information on giving informed consent. You should not agree to any treatment without fully understanding what it means.

Other Important Things You Can Do:

15. Make sure that you know who is in charge of your child's care.

This is especially important if your child has many health problems or is in a hospital, being cared for by many healthcare providers. It can be confusing when there are many different specialists or students involved, but there will only be one person in charge (called the "Attending Physician"). Be sure you know who this person is and review your child's care with them on a regular basis.

16. Make sure that all health professionals involved in your child's care have important health information about your child.

Do not assume that everyone knows everything they need to. This may mean repeating yourself sometimes, which may be frustrating, but don't be afraid to speak up.

17. If you are feeling overwhelmed, ask a family member or friend to be with you. Choose someone who can help get things done and speak up for you if you can't.

Sometimes balancing the demands of a sick child with many other demands (such as your job or other children) can be overwhelming. If you have somebody who can help you balance these demands and advocate for your child, you may find it easier to take in information.

If you do not fully understand information because you and your family speak another language, the hospital can provide an interpreter for you. This can be arranged for you as you need.

18. Ask why each test or procedure is being done.

It is a good idea to find out why a test or treatment is needed and how it can help your child. Ask your nurse for information pamphlets on the test or procedure that is ordered. This will help you ask the right questions so that you understand what to expect.

19. When your child has a test, ask when the results will be available.

Make sure you know when you will hear from your doctor or nurse about the results of tests. If you have not heard from your doctor by the time you expect, call and find out if there is a delay. You can also ask for copies of reports for your own records, when they are available.

20. Learn as much as you can about your child's condition and treatments using reliable sources.

Ask your child's doctor if his or her treatment is based on the latest scientific evidence. Your doctor may have copies of research articles that you may wish to review. You can also get assistance with finding information from the Family Resource Library at C&W.

Adapted from:

Agency for Healthcare Research and Quality (July 2003). Five Steps to Safer Health Care. Patient Fact Sheet. Publication No 03-M007.Rockville, MD. Retrieved Jan. 2004 from: www.ahrq.gov/consumer/5steps.htm.

8

Medication Chart

Name:

Age:					
Weight:					
Last Updated On:					
Name of Medication	Date	Amount and Time(s) Taken	Date		
	-		 		
			 		
			 		
Medication Alle	ergies:	1	1		

9