

Parent Organizer

TIPS from PARENTS... real tips from real parents:

- Stay organized... write down EVERYTHING
- Always have an overnight bag packed just in case
- Encourage your child to stay up-to-date with school work so he's more confident when he returns to school
- Work out appropriate accommodations with your child's school before treatment so school re-entry will be less stressful
- Keep a change of clothes, paper towels, wipes and a water bottle in a bag in your car
- Try to keep a few favorite toys or books in a special "hospital" bag to make the stays less stressful
- Find a pharmacist who you can trust and will be at the pharmacy regularly. He/she will get to know your child and become familiar with the medications. Also, try to find a pharmacy that will deliver.
- Take a lot of pictures, even of things that seem unpleasant at the time. It makes the rest of the family feel in the loop.
- Encourage your child to keep a journal, even if it's just a few words here and there.
- Encourage your child's teacher to keep the school connected to the child. The classmates can send cards and letters; the patient can send pictures and descriptions of his/her experiences.
- Be honest all the time; it alleviates stress.
- Find friends that can help you with specific jobs... cooking, cleaning, dog walking, babysitting, errands, bringing you coffee, talking, listening.
- Don't waste your time with people who bring you down.
- Ask QUESTIONS no matter how silly they seem
- Keep Purel and baby wipes in your purse for hand-washing
- Keep up with Thank You notes in the waiting room, during treatment, etc. BUT... no one expects you to write thank you notes; do it only if you want to

Parent Organizer

- Send a tray of bagels and cream cheese to the hospital floor as a nice way to thank the staff
- Basketball pants with side snaps are perfect to fit around the fixator
- Cut boxer shorts and then attach them with Velcro to fit around the fixator
- Don't hesitate to designate a friend/family member to communicate your child's progress... email is a great way to keep friends/family in the loop when you're too tired or busy to talk yourself
- Use the waiting room/hospital stays as a chance to catch up on magazines, book lists or even to learn how to knit... you'll feel productive

Parent Organizer

[TIPS from KIDS... real tips from real kids:](#)

- Ask someone to bring your favorite food to the hospital for when you can eat
- Bring your own pillow to the hospital
- Drink lots of water
- Don't be afraid to ask for more pain medication
- Do your homework at the hospital so you're not behind when you go back to school
- Take deep breaths through your nose when you don't feel well
- Don't be afraid
- Wear your favorite PJ's in the hospital
- Take "before and after" pictures
- Tell all your friends everything that's happening to you so they understand how you feel
- Never give up
- Bring a comfortable fleece blanket to the hospital
- Bring your own slippers to the hospital
- Make friends with the nurses
- Don't be too crabby to your mom even when you don't feel well
- Bring a pillow to school to prop up your leg
- DO YOUR P/T as much as Dr. Rozbruch tells you
- Put wet washcloths in the microwave and put them on your leg to feel better and loosen before p/t
- Wear snap-up wind pants to put over your fixator
- Snip boxers and then attach it with Velcro to fit around your fixator
- BE POSITIVE!!!

Parent Organizer

Suggestions for how to help the family

There are many ways to help the family when a child is facing a major medical situation. Remember that they are probably all overwhelmed. The most important thing is to take their lead, and to offer help that will truly be “helpful” to that individual family. Also remember that a lot of help flows during the initial diagnosis. Often the help wanes just when the family needs it most.

These are just some suggestions that come from families who have had ***a child undergoing a major medical procedure***:

Food -

- **Convenience** – it’s helpful for the family to be able to order food when they need it; often food comes all at once when the family either doesn’t need it or already has enough.

Suggestion – collect a bunch of gift cards and/or “lines of credit” at local restaurants (especially those that deliver) so the family can order what, when and from where they want to order to satisfy their needs.

- **Comfort** - remember that too much unfamiliar food (especially when you don’t feel well or are stressed out) is not helpful. Try to provide food that the patient, siblings and parents prefer.

Toys/Gifts –

- **distraction at the hospital** – It’s helpful when a child needs to be admitted to the hospital or for treatment, to look forward to buying a toy or game prior to admission. It makes the situation more palatable.

Suggestion – collect cards from a variety of local stores so she can choose the gift she wants to take with her to the hospital.

- **at home** – often the child will be feeling tired and sore, and unable to participate in her normal activities when she’s home. Toys that can be played in bed or on the couch with minimal mess are best: arts and crafts, legos, movies, electronics, puzzles, books, etc.

Errands –

- **take the family’s lead** - some families need help with laundry, shopping, cleaning, etc. But some families need their space. Do not insist on domestic help unless a family approves. You could be in the way and add to their stress.

Suggestion – offer specific help: walking the dog, going to the drycleaner, filling their tank with gas, etc...let them decide.

Running Interference –

- **take calls and provide information to the community** - everyone wants to help. Designate a neighbor, friend or family member to be the

Parent Organizer

“point” person to the community. Inquiries and questions can flow through that person to minimize the stress on the family.

Child Care –

- Siblings often feel isolated and lonely, and this is an added stress on the parents. Offer to take the sibling(s) to the park, a movie, out for ice-cream on a regular basis, but only if the child is comfortable with you.

Research –

- **doctors, other patients** – the family may need help with second-opinions, internet research, etc. Offer to help compile this information if necessary.

Tip: Remember to take the family’s lead. This is a stressful time but they will get through it, thanks to the help and love of neighbors, friends, and family like you.

Parent Organizer

Check-Up Log

Keep track of your doctors' appointments with Dr. Rozbruch and your other doctors with this log.

| Doctor | Date | Procedures (i.e. xrays, scans) | Vitals (Height/Weight) | Questions/Follow-Up |
|--------|------|-----------------------------------|---------------------------|---------------------|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

* **TIP:** Always have on hand your child's height and weight.

Parent Organizer

Insurance Information

Primary Insurance

Company _____

Secondary Insurance

Company _____

Phone Number _____

Website _____

Send Claims

to _____

Policy Holder(s) _____

Member ID#(s) _____

QUESTIONS TO ASK:

1. What are my co-pays?
 - a. Are they different for different doctors?
 - b. Do I have a maximum/year liability?

2. What are my deductibles?
 - a. Is there an in-network vs. out-of-network difference?
 - b. Is there a maximum individual deductible?

3. What is my out-of-pocket liability?
 - a. Is there an in-network vs. out-of-network difference?
 - b. Is there a maximum/year liability?

4. How do I dispute a claim?

Parent Organizer

Home Care/Equipment Log

Use this log to keep track of all home care your child receives including any supplies and equipment.

Home Care Company: _____ Address: _____

Phone: _____ Fax: _____ Email/Website: _____

Contacts: _____ Relevant Insurance Information: _____

| Appointment | Nurse's Name | Supplies/Equipment | Procedure | Notes |
|-------------|--------------|--------------------|-----------|-------|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

TIP: Often the hospital requires that an appointment with the home care company be set up before discharge. Alert your home care company of any hospitalizations so they are prepared to make a visit upon discharge.

Parent Organizer

Physical Therapy Log

Include a copy of all your p/t prescription in this section and bring p/t notes to your doctor's appointments

| Facility/Therapist | Week of | Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday | Notes |
|--------------------|---------|--------|--------|---------|-----------|----------|--------|----------|-------|
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |

TIP: Make sure your child takes p/t very seriously. It's critical for a positive prognosis and effective treatment.

Parent Organizer

Help and Gifts Received

This will help you keep track of who helped you, your family and your child during treatment.

| Help/Gift | Who | What | Date thank you written |
|------------------|------------|-------------|-------------------------------|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

TIP: Don't hesitate to tell friends/family exactly what kind of assistance you need. People want to help so accept it; just make sure it's on your terms, and is what works for you and your family.