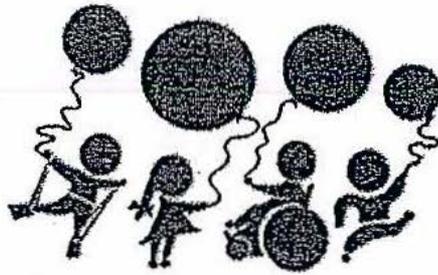


EXPECTING SURGERY

Even a minor surgery can be a big event in a family's life, especially when it involves their child. The following suggestions are ideas to help prepare for the event and take away some of the anxiety.



Compiled by: California Children's Services of Alameda County
Family Resource Network of Alameda County
Through the Looking Glass



**Alameda
County
California
Children's
Services**

**Family Resource
Network of
Alameda County**

**Through the
Looking
Glass**

Dear Parent,

Facing surgery for your child is a major life event for any family. There are many questions, a lot of medical terms, great anxiety, and children and siblings who need to be prepared for the journey ahead. We wondered how we could help families through this sometimes scary and lonely process. So we asked some families like yours who have survived the experience to help us. They were wonderful in sharing their ideas and felt that you would be helped by information regarding

- What needs to happen before surgery
- How parents, children and siblings can get ready
- Where parents can find support
- Questions to ask before you get to the hospital
- What to anticipate after the surgery

We hope the materials in this folder will help you prepare and strengthen your confidence for the big day and the days that follow. Like all parents, you know best what your child will need. Your knowledge and love make you the most important member of the team, and often the person who can make the biggest difference. Remember, our staff is also prepared to be your partner along the way.

Staff

Alameda County California Children's Services
Family Resource Network of Alameda County
Through the Looking Glass

CONTENTS

SECTION 1 *Getting Ready*

- Expecting Surgery
- Parent/caregiver checklist
- Questions to ask the Surgeon
- Letter for children

SECTION 2 *Resources*

- Parent Contact List
- Child Life Specialist
- Parent Resource Center
- Hospital Social Services
- Web Site

SECTION 3 *What's Normal?*

- My Child's Profile

SECTION 4 *Coming Home*

- Hospital Discharge Questions
- Medication Information
- Need a Break?
- Transportation
- Back to School

SECTION 5 *What Does That Mean?*

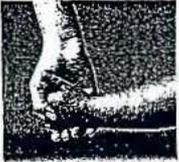
- Glossary

EXPECTING SURGERY

Even a minor surgery can be a big event in a family's life, especially when it involves their child. The following suggestions are ideas to help prepare for the event and take away some of the anxiety.

Preparing your child

- Try to stay calm and relaxed. Your child will pick up on your level of comfort or anxiety and feel anxious as well.
- Encourage your child to ask questions and answer those questions honestly. Keep your answers simple and appropriate for your child's developmental level.
- Talk with the doctor or surgeon about your child's concerns.
- If your child will have general anesthesia let them know that they will fall asleep before the surgery begins and be asleep through the whole procedure.
- Remind your child that they will get a special ID bracelet to wear while they are at the hospital.
- Read books about the hospital or surgery with your entire family.
- Tour the hospital with your child before surgery. The experience can help your child see the sights, sounds, and events they will experience the day of surgery.
- Make an appointment for your child with the hospital's Child Life Specialist who can explain what will happen in terms your child can understand.
- Talk with your child about any special equipment they may be using following the surgery, like a cast, crutches, catheter, etc.
- Give your child as many choices as possible to increase their sense of control.
- Avoid making promises you might not be able to keep, like how long your child will stay at the hospital.
- Help your child choose some favorite items to bring to the hospital. Familiar books, toys, games or snuggle items can add comfort to a strange environment.



Parent Care

- Pack your cell phone and the charger.
- Do not be afraid to ask family and friends to help. Simplify your life as much as possible. Remaining positive and calm can help the entire family.
- Be sure to take your own medications. In a hospital, medications are strictly controlled and it may be hard to find even an aspirin if you are in need.
- Bring at least one change of clothes for yourself. Remember to include something warm as most hospital wards are chilly.
- You will probably spend some time waiting. Bring some things to do, like books, crossword puzzles, knitting, catalogs—whatever. Keeping busy helps long hours pass more quickly.
- Don't forget your reading glasses!
- Take a break! This is stress at its best! You will be most effective if you take time to take care of yourself. Take a moment for a short walk, a cup of tea, a snack.
- Check to see if there is a Parent Resource Center at the hospital. It is a good place to go for research, recreation, or respite from the hospital hum. You will also find

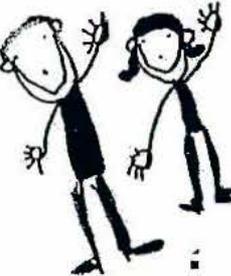
*Compiled by: California Children's Services of Alameda County
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information about resources in or near the hospital including where to eat, shop, do laundry, etc.

- Set up a website to convey information to family and friends and allow them to easily respond with encouraging and thoughtful messages to the patient. There are several web enterprises available to help you set up the site (one example is included in this packet). Typing a few words each day can help keep a large number of people informed and save your phone time for managing things at home.

Preparing Siblings When your child goes to the hospital, brothers and sisters may feel worried or confused. Their concerns may have to do with not understanding what to expect as well as anxiety for their sibling's welfare. These suggestions may help:

- 
- Include siblings in conversations about their brother's/sister's surgery in words they understand.
 - Make sure your children know why their brother/sister is going to the hospital.
 - Assure brothers/sisters that some other responsible adult will be caring for them during the time you have to be at the hospital.
 - Read books about going to the hospital with the entire family.
 - Give many compliments and hugs. Take extra time to notice good school work or jobs done at home.
 - Give the siblings the choice of visiting. If they choose to visit, help prepare them for what to expect (sights, sounds, etc.). The Child Life Specialist can be helpful.
 - Keep care routines at home as normal as you can.
 - Have children at home draw pictures or make cards to send to the hospital.
 - Set up times for your children to talk to each other on the phone.

On the day of the surgery

- 
- Be on time. Allow extra time for parking, traffic, bus or BART delays or other confusion. If the surgery is at a location new to the driver, a practice run before the day of the surgery can help calm nerves.
 - Make sure you have your child's medical ID and any important documents with you.
 - Help your child follow directions about not eating and drinking before the surgery. Your child may be uncomfortable, but it is important to avoid unwanted complications.
 - Bring an up-to-date list of all medications your child uses.
 - Prepare a list of any remaining questions you or your child may have.
 - Be sure your mobile phone is charged and ready for use. You will want to be in touch.
 - Ask a family member or friend to come to the hospital with you for support.

Coming home

- Understand which medications your child is to take and when. Give pain medicines **exactly** as directed. Remember, **no one younger than 20 years should take aspirin.**



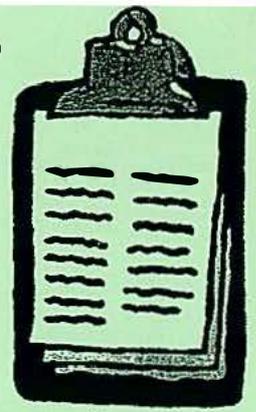
- Know early signs or symptoms that may indicate a problem after surgery. Signs of infection include:
 - Increased pain, swelling, redness or warmth around the incision site
 - Red streaks extending from the incision site
 - Puss draining from the incision site
 - Fever or chills with no other known cause
- Be sure you understand the level of activity that is safe for your child.
- Get instructions on the best way to bathe and protect the incision. How can you cover the area if needed? When is it safe to shower or bathe your child?
- Practice with medical staff regarding how to care for the incision and change your child's dressing. Remember, **do not**:
 - Scrub or rub the incision site
 - Remove tape strips
 - Use powder or lotion on the incision site
 - Expose the incision site to sunlight
- Be sure you know how to contact your child's doctor/surgeon or other important medical staff. Put the information in a place where you can see it easily.
- Schedule a follow-up appointment for your child.

Cast Care Following surgery, a cast is sometimes needed to hold bones, muscles and tissue in place until enough healing can occur. Casts can, however, become uncomfortable and a challenge to keep clean and dry. Here are some tips that may help:

- If your child uses ice packs, be careful not to get the cast wet. Bags of frozen vegetables or gel packs can be the best choice when a cast is involved.
- When bathing, cover the cast with at least two layers of plastic. In addition, place a towel under the covering to catch any leaks. Water can cause soreness and itching and can lead to infection.
- Blowing cool air from a hair dryer or fan into the cast may help itching.
- **Never** stick items under the cast to scratch the skin.
- Prevent small objects or toys from finding their way into the cast. Kids will be kids and a crayon or game piece can become a small nightmare if it is inside the cast.
- Do not use oils or lotions near the cast.
- If your child's skin becomes red or sore around the edge of the cast, pad the edges with a soft material like moleskin or use tape to cover the edges.
- Do not use powder on your child's skin under the cast.
- Call for help if
 - Your child has increased or severe pain.
 - The skin outside the cast becomes unusually cool, pale or changes color.
 - Your child complains of tingling or numbness.
 - The cast feels too tight.
 - Your child develops a fever, drainage or a bad smell from the cast.



Parent/Caregiver Check List for Surgeries/Hospitalizations



Before Going to the Hospital

- Understand your rights as a parent
- Have your physician write a letter authorizing you to give your child's medications, etc
- Ensure that orders are written re: authorizing, family to give meds, complete personal care, etc.
- Make contact with the social worker
- Write a list of questions to ask the physician
- Write down what you would like the nursing staff to know about your child. (See list below for ideas.) Review the handout "A picture of how your child looks when he/she is in a stable condition."
- What support will you/your child need when s/he goes into the hospital and afterward? Talk with friends, family, the physician, therapists, and social workers (e.g. equipment, extra help, follow-up appointments for the physician and for therapy).
- Will you need translation services? They are available at most hospitals.

Bring to the Hospital

- Favorite toys, books, art supplies
- Things your child uses for bedtime ritual
- Video/audio tapes
- Toiletries (hair brush, lotion and fun things like nail polish and hair clips)
- Favorite pjs, tops, hats
- Your child's medication for 1 week
- Your own comfort objects (food, books, etc.)
- The letter from your child's physician
- The list for the nursing staff
- The list of questions for the doctor
- Child's medical ID and any other important documents
- Up-to-date list of all medications child uses

Information to give the Admitting Nurse

- What comforts your child?
- What things are especially scary for your child?
- Do you want to administer the medications to your child?
- What level and type of information and reassurance does your child need before a procedure?
- Are there night time rituals that are important (e.g., reading a special book)?

During the Hospitalization

- Locate Parent Resource Center
- Locate the computers within the hospital available to the public
- Contact the Social Worker
- Understand patient rights
- Locate play room/teen room
- Understand how to borrow toys/games/movies from these rooms

After Discharge from the Hospital

- Do you have medications and understand how to give them and the possible side effects?
- Do you have a follow up appointment scheduled with the doctor?
- Do you have orders for therapy?
- Do you have all the equipment you need such as a bedside commode and wheelchair? Are they rented or purchased?
- Do you understand all precautions?
- Do you know who to contact if there are any problems? Put the information where you can find it easily. **Don't hesitate to use it.**

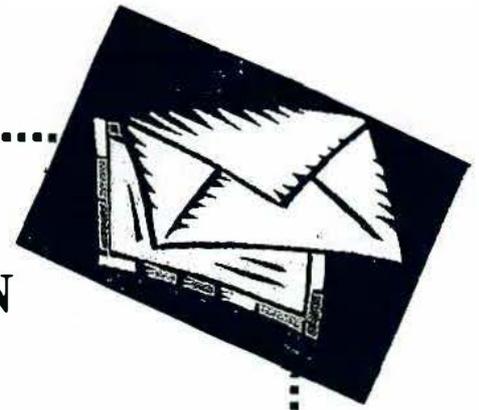
Parent Liaisons from Family Resource Network are available to answer questions or attend physician visits. Please contact 547-7322.

Questions to ask the Physician Prior to Surgery

1. What functional difference will there be as a result of the surgery?
2. What is the long term prognosis?
3. What types of complications can be expected?
4. How much therapy will my child need after surgery? How long will it take? Will my child need to be hospitalized for the therapy?
5. What types of equipment will my child need after therapy? For how long? Who orders the equipment?
6. How will my child be helped in managing pain after the surgery? How will hospital staff communicate with my child to determine their comfort?



LETTER FOR CHILDREN



Dear Parents,

The following is a letter to your child who is going to have surgery. Read it with them or to them if you think it would be helpful. Feel free to substitute language that is appropriate to your child's developmental level, or just use the ideas to start a discussion. After you share the letter remember to stay with your child to share feelings and encourage dialogue. Call Through the Looking Glass to speak with a therapist if intense feelings are expressed, or if you feel you need help in speaking with your child. (510-848-1112, X154)

Hi,

You and your family are getting ready for you to have surgery. Although this may be a pretty exciting event, you may also feel nervous. Believe me, this is one of the bravest things you will ever do. If you have had surgery before, you have some idea of what to expect and you already know how much courage you have inside you. It's OK to be brave and feel scared at the same time. In fact, your parents might be nervous too, which is normal since they are also experiencing something new.

You know many people who care about you: your family, your friends, people at school or in your faith community. These people wish you didn't have to have surgery, but they are glad you have good doctors who will take special care of you. It is important that you tell people who care about you when you feel scared or worried, and let them know what would help you feel better. It is also important when you have any questions at all about the surgery or the hospital that you ask the questions you have. Your parents, your doctor or your therapists will be happy to answer your questions. Everyone wants to help you feel safe and well cared for during this time.

When you come home from the hospital, you will have many exciting stories to tell about what it was like to be in the hospital and have surgery. You can tell the stories as many times as you want to, and you will be able to tell other kids who may be having surgery what helped you most.

With warm regards,
Beth Smith, LCSW
Through the Looking Glass
(510) 848-1112, X154

**Alameda County
California Children Services
Medical Therapy Program**



**Surgeries
Parent Contact List**

The parents listed below agreed to be a contact person for families considering surgery or their child/young adult. They have and did have children/young adults in the Alameda County CCS program; and surgery was recommended for each of them. All but one child/young adult has undergone at least one surgery.

Bart Bastian Parent Liaison (510) 444-4444

Son's birth year: 1991

Type of Surgery: External fixation post leg fracture, spica cast for 6mo.

Cathy Crumb Parent Liaison (510) 222-2222 (day)

Daughter's birth year: 1996

Type of Surgery: Declined

Danielle Daring Parent Liaison (925) 555-5555

Son's birth year: 1998

Type of Surgery: Multiple surgeries

Eric Everyoung Parent Liaison (510) 333-3333

Daughter's birth year: 2003

Type of Surgery: Spinal surgery

Fergus Fitzsomething Parent Liaison (510) 999-9999

Son's birth year: 2000

Type of Surgery: Kidney transplant

Gloria Glue Parent Liaison (925) 777-5555

Daughter's birth year: 1997

Type of Surgery: Hip surgery

CHILD LIFE SPECIALIST

The Child Life Specialist can be a great source of help, education, information and support to your family before and throughout the hospital stay. You can contact them before arriving at the hospital to help answer questions and put all the pieces into place. They are very skilled in working with children and can help young patients understand and adapt to the hospital experience.

Children's Hospital Oakland (510) 428-3520

University of California San Francisco (UCSF) (415) 353-1203

Kaiser Oakland (510) 752-7338

Lucille Packard (650) 497-8336



PARENT RESOURCE CENTERS

Need a moment away from the frenzy of the hospital? Many hospitals offer a quiet place for families to regroup, take a breath, gather information or chat with another parent. Be sure to check out these locations and give yourself a well-deserved break!

Lucille Packard (650) 497-8102

Located third floor next to 3 North

Kaiser Oakland

Library

Parent Lounge west side of 10th floor

Children's Hospital Oakland (510) 428-3549

Located across from the Friendly Café on second floor

University of California San Francisco (UCSF)

Family Resource Room has fax, computers with Internet access, laptop jacks.

Coffee, tea, cookies served daily. Contact Child Life Department (415) 353-1203

HOSPITAL SOCIAL SERVICES

The hospital social worker can be not only another great source of information, but also someone who can help with some of the extra burdens of a hospital stay. Be sure to contact the social worker for any of the following needs:

- Any financial assistance for the hospital stay
- Overnight parking
- Food vouchers
- Chaplain/ religious requests/needs
- Mental health/counseling needs

Is surgery in your child's future???

Check out www.caringbridge.org to set up a website for your child

The website can help families get information to a lot of people without phoning everyone. It is also a way for therapists, teachers and friends to get information about the child's status and express support and well wishes.



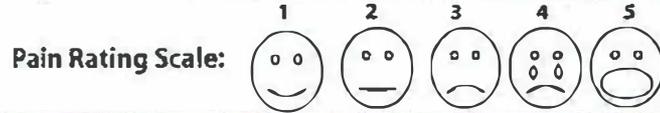
My Child's Profile

Child's Name: _____ DOB: _____

VIII. GATE 1: Original Normal Status

Date completed: _____

The Child Profile is your portable medical record. Record you child's original Gate 1 normal status here. Then you will have a record of changes in your child's status for one year. We have included a pain rating scale to help you communicate your child's pain to his/her physician. If your child has no special needs in a certain area, put "not applicable" in the normal status or "normal."



Areas to Check:	My Child's Normal Status is:
<ul style="list-style-type: none"> • Cardiovascular • Circulation • Eyes • Skin 	Skin Temperature
	Skin Color
	Rash
	Drainage
	Heart rate
	Nose
	Eyes
	Ears
<ul style="list-style-type: none"> • Neurological 	Fontanel
	Seizure Activity
	Verbal Skills
	Activity Level
<ul style="list-style-type: none"> • Respiratory 	Breathing
	Vent Dependent / Tracheostomy / C-Pap
	Oxygen
<ul style="list-style-type: none"> • Musculoskeletal 	Motor Skills
	Upper Body Extremities
	Lower Body Extremities
<ul style="list-style-type: none"> • Gastrointestinal • Urinary 	Stool
	Urine
	Feeding behaviors / appetite / source
	Ostomy Sites
<ul style="list-style-type: none"> • Behavior 	Behavior/Attitude
	Sleeping Pattern
<ul style="list-style-type: none"> • Miscellaneous 	Temperature
	Blood Sugars
	Other



PROFILE / VIII. GATE 1 NORMAL STATUS

NEED A BREAK????



Getting desperate for
a nap?
a little time with your spouse?
running needed errands?
doing laundry?

Arrange for additional respite care

- Call your child's RCEB case manager as soon as you can
- Let them know that your child will be having surgery and will require a more intensive level of care
- Give the case manager an idea of how much extra time and how many days
- Send along any documentation (doctor's note/therapist's report)
- Make arrangements in advance with your regular respite provider

OR

Call:

George Mark Children's House

A respite care facility located in San Leandro which provides a beautiful environment with lots of activities and staffed by a skilled care team.

Tel: 510-346-4624

Email: info@georgemark.org

Respite Inn

An out of home respite facility for children 18 years of age and older.

Located in Concord

Tel: 925-686-5758

Email: TheRespiteInn@att.net

SAFE TRANSPORTATION

Following surgery children may temporarily need to use a cast, brace or other device to hold bones, muscles and tissue in place until enough healing can occur. The extra bulk of the cast and body positioning may make the use of a standard car seat or booster seat impossible and an adaptive child restraint may be needed for car and bus transportation. The following are some suggestions to obtain adaptive seating options:

- Get a prescription from your child's physician for an occupational therapist (OT) or physical therapist (PT) to evaluate your child for an adaptive child restraint.
- The therapist will evaluate your child and write a letter of medical necessity. A copy of a sample letter has been included on the following page.
- Your child's therapist can help identify possible vendors (companies) from which to rent or purchase the adaptive seating restraint. Adaptive child restraint examples have been included following the sample letter.
- Children receiving special education services are eligible to receive transportation and related services needed to carry out the education plan.
- Charitable agencies like United Cerebral Palsy and service organizations like the Kiwanis may also help pay for a specialized child restraint, especially if it is not covered under your medical insurance or Medi-Cal.
- You may find other options for borrowing an adaptive restraint during your child's recovery.

Remember, these steps take time, so start well before the surgery to have the adaptive seating restraint available when you need it.

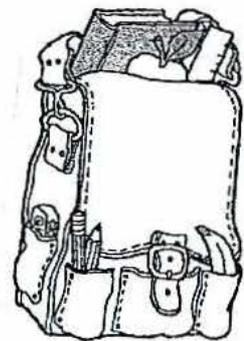


BACK TO SCHOOL

Getting back to school can provide some additional challenges following surgery. The following are ideas you may want to explore with school personnel before surgery to make any necessary arrangements before your child returns to school or during their recovery period.

- Your child may need to return to school using a modified or shortened schedule until their energy and stamina level matches the demands of the school day. Remember, the use of crutches, wheelchairs, etc. often requires extra energy, concentration and social/emotional demands.
- A child who was walking may temporarily need a wheel chair, walker or crutches. You will need to know which entrances are accessible and whether an elevator is available. Since school elevators are usually accessible only with a key, find out how your child can access that key.
- Your child may temporarily need personal care assistance or help using the bathroom. Work with the school to arrange for 1:1 support during this time. An addendum to the IEP may be necessary.
- If your child will be taking medication, a letter from the child's physician may be needed for the medication to be administered during the school day. Other forms may need to be placed in the child's school folder. A medication log may be advised to track when the medication is given and by whom (sample log is included). You may wish to consult with the physician to see if the medication schedule can be adjusted to be given outside the school day.
- While your child is out of school they may qualify for home based instruction. Home based instruction provides up to five hours/week of instruction at home with a qualified teacher. This is arranged through the school district.
- Make arrangements with your child's teacher/teachers to pick up work they can finish at home. Make sure you talk with teachers about what is a reasonable amount of make-up work and what accommodations should be made.
- Consult with your child's CCS OT / PT regarding modifications, accommodations and any needed equipment. They are a wonderful source of knowledge and support and someone familiar your child's needs. They are available for consultation and demonstration with teachers and school personnel.
- Classmates may have questions that need to be addressed. Talk with your child and his/her teacher about how to comfortably answer questions about the surgery or any new equipment.

*Compiled by: California Children's Services
The Family Resource Network
Through the Looking Glass*



FAMILY VOICES

Hospital Discharge Questions for Families of Children with Special Health Care Needs

This document was developed by Family Voices of California to help families of children with special health care needs get the information they need to take care of their child when they come home from the hospital. The questions were designed by families of children with special needs.

Use these questions as a guide or a prompt for helping you get information you might need. One person may not be able to answer all of these questions but they can help you find people that have the information. You might want to look at each question and ask yourself, "Do I have this information, and is it clear to me?" If you don't have the information yet, ask for it. If someone has given you the information but you do not understand it or it is unclear, ask to have someone go over it again until it is clear to you.

MEDICAL CARE

1. Will you go over my child's condition with me, and help me understand the medical terms?
2. What should I expect when my child comes home?
3. What symptoms or behaviors should I be concerned with?
4. What symptoms or behaviors are okay?
5. Which doctor is in charge of my child?
6. Is this the doctor I call if I have a question?
If not, who do I call?
7. How do I reach my doctors after hours?
8. Will someone answer my call 24/7?
9. Will the doctor answering have information about my child or access to my child's records?
10. Will the doctor answering know who the other doctors are who are involved in my child's care?
11. Will the doctor answering understand or have experience with my child's condition?
12. If I have questions when I get home about caring for my child, is there someone who can come to my house and help me?

13. Will my child need medical appointments or follow up care?

14. Do you know of any pediatricians that have experience caring for children with special health care needs?

15. Who will help me find a pediatrician?

MEDICATIONS

1. Will my child need special medications when we leave the hospital?

2. Will I have prescriptions for all the medications my child needs by the time I leave the hospital?

3. Will I need to get the prescriptions for all the medications filled right away?

4. Do I need to go to a specialized pharmacy to get the medications?

- If so, will you give me a list of specialized pharmacies close to my home?
- Will this pharmacy take my insurance?

5. Will you help me make a list of all the medications and tell me:

- How often my child needs to take each medication?
- How much to take of each medication?
- What the side effects of each medication might be?
- Are there any special conditions for taking the medications (before or after eating etc.)?
- What impact each medication should have on my child?
- Who do I call if I have concerns about the medications?

EQUIPMENT/SUPPLIES

1. Will my child need special equipment when we get home?

2. Who will deliver the equipment?

3. When will the equipment be delivered?

4. Will that company take my insurance? If not are there other companies to choose from?

5. Who will train me about how to use the equipment and care for it?

6. Who do I call if I have questions about the equipment?

7. If the equipment requires electricity, what do I do if the power goes out?

8. What supplies will my child need when we get home?

9. How do I get more supplies when they run out?

10. Who do I call for more?

11. Does this company take my insurance?

INSURANCE

1. My child required care and services in the hospital that we had not planned for. Will my insurance cover all these services?

2. Are there other resources or programs that can help me pay these bills?

3. Will my insurance cover the care my child needs when I leave the hospital?

4. What equipment/supplies will my insurance cover when my child leaves the hospital?

5. If my insurance doesn't cover everything are there programs that can help?

6. Do I need to send in any information or fill out forms to ensure there are no problems with my insurance paying these bills? (Hospital and home care)

RESPITE AND TRANSPORTATION (if needed)

1. Will you help me find respite care?

2. Will you help me find transportation to get home?

3. Will they help me get to follow-up doctor appointments?

REFERRALS

1. Are there agencies that will help me find family support and resources for my child when we leave the hospital?

If your family is in the military and would like assistance, call: 1-866-609-3218 or go to
for information

SAFE TRANSPORTATION

Following surgery children may temporarily need to use a cast, brace or other device to hold bones, muscles and tissue in place until enough healing can occur. The extra bulk of the cast and body positioning may make the use of a standard car seat or booster seat impossible and an adaptive child restraint may be needed for car and bus transportation. The following are some suggestions to obtain adaptive seating options:

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- Children receiving special education services are eligible to receive transportation and related services needed to carry out the education plan.
- Charitable agencies like United Cerebral Palsy and service organizations like the Kiwanis may also help pay for a specialized child restraint, especially if medical insurance or Medi-Cal denies it.
- You may find other options for borrowing an adaptive restraint during your child's recovery.

Remember, these steps take time, so start well **before** the surgery to have the adaptive seating restraint available when you need it.