

talking to your child about an upcoming surgery

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As a pediatric nurse practitioner, I realize our collective goal as parents and providers is to protect our children from painful, scary experiences—a reasonable goal and desire, to be sure. As many of you already know, however, this may not always be feasible when a child has a craniofacial condition or any medical condition that require staged surgical repairs and regular check-ups and evaluations. Surgeries can hurt, and any trip to the doctor or hospital can be very frightening for a child. Recognizing the challenges that families face when a child has a medical condition, a wise lady once said to me, “While I may not be able to stop my child from hurting, I can always be with him in his distress and show him that he is not alone.” While this may not seem like much, it is huge in the life of the child when you let them know that you will be with them through the hard times. Just being there for our children can have a truly curative power.

In addition to just being there for your child, I have learned that there are other simple things parents can do to help prepare kids (and yourselves) for upcoming surgeries. Here are some of the suggestions I offer to kids and families that I care for.

Infant and toddler age:

- Bring items of comfort with them: pacifier, blanket, stuffed animals, books and a few toys
- Parents, be sure to wear comfortable clothing (including shoes). Remember that your clothing may get stained from surgical drainage or bleeding, so choose accordingly.
- Parents, also wear layers as most hospitals have places that are either warmer or cooler.
- Bring a water bottle and snacks in addition to money to buy food from the cafeteria.
- Bring clothes that button or zip up for your child if they are having surgery on their head or face as it is

easier to get them on and off when you are leaving the hospital.

- Make sure you have Tylenol or Motrin if your surgeon uses these for pain control once you are at home.
- Make sure you have a variety of soft foods at home if your child's diet will be restricted after surgery.

Preschoolers:

- Many of the items above will apply with this age group as well.
- Check your local library or book store for children's books about going to the hospital. Some examples:
 - *Franklin Goes to the Hospital* by Paulette Bourgeois
 - *My Trip to the Hospital* by Mercer Mayer
 - *Curious George Goes to the Hospital* by H.A. Rey
 - *Hospital Friends* by Mike Berenstain
 - *Do I Have to Go to the Hospital?* by Pat Thomas
 - *A Visit to the Sesame Street Hospital* by Sesame Street

Reading some of these books to your child will prepare them for the different things they will be seeing and reassure them that other children have surgery and get better.

- Ask your local hospital if they do pre-op visits where you can tour the hospital and your child can see what the environment will look like and meet some of the nursing staff
- Have a medical play kit so they can play doctor/nurse; this is a great way for them to both prepare for and process the experience afterwards.
- Encourage them to draw pictures and tell a story about their experience before and after.
- Child Life Therapy department can help with adjustments to being in the hospital and provide activities to keep them distracted.
- Always reassure them that you will be there.

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School Age:

- Refer above and adapt to their age and personality.
- Utilize the Child Life Department. They can be very helpful in keeping your child engaged with activities that are fun and provide great distraction.
- Encourage your child to verbalize what they are thinking and ask questions about what to expect.
- Always reassure them that you will be there with them, even if you have to step out to get a bite to eat.
- Encourage them to write or draw about their feelings.
- While you as a parent cannot take this experience away from them, reassure them that many other children/people have struggles and challenges to deal with, even if we cannot see them. Example: food allergies or asthma usually cannot be seen unless they are having a problem.
- Explain to your child's teacher and class that he/she will be missing school for a surgical procedure and when they are expected to return. Keeping this explanation upbeat, short, matter-of-fact often helps prevent problems. Most children/people are curious and simply want to know what is going on and what this all means for the child. If these questions are handled openly, honestly, and simply, the curiosity is usually resolved, and then most children will respond with some element of empathy. If children's curiosity is not addressed, they will use their imaginations to explain things themselves, which is usually not going to be an accurate picture or very close to reality. This is also a way for you to bridge the subject with your child who has a facial difference who doesn't know how to answer questions about their appearance. Practice and role play at home with different responses to these questions so they do not get emotional or angry, rather, stay calm and simply explain to the person what is going on.: "I was born with this condition and I have had surgeries at different stages to correct things as I get older."

Teens:

- Child Life Department should have movies, video games, books, magazines, art projects and music to keep teens entertained.
- Encourage them to talk to their friends and teachers about what they are having done at the hospital in simple terms. For example, a teen having jaw surgery might say, "I'm having a surgery that will help me to bite and chew normally."
- Encourage them to stay connected with their friends via phone, texting and social media while they are at the hospital.
- Encourage the teen to ask questions, be a part of the medical conversations and surgical planning. This is a great time, starting in middle school, to begin teaching them to both answer the doctor's questions as well as ask their own. It is important that they be allowed the opportunity to practice the art of how to advocate for themselves and manage their medical condition starting at an early age.

It is often our nature to "feel sorry" for anyone having to go through a surgery or illness, but there is a difference between sympathy (feeling sorry for someone), which I believe hinders their progress, versus empathy (the ability to understand and share the feelings of another), which I believe we can then use to teach valuable lessons. Although having a craniofacial condition and going through multiple surgeries is hard, if we take the time to help prepare our children and support them well, these scheduled surgeries or appointments can help them learn how to handle many other challenging situations that life throws their way.