

Coping with Childhood Cancer Procedures

Procedures are needed to make diagnoses, check for spread of disease, give treatment, and monitor response to treatment. Interventions range from figuring out the best way for your child to take numerous pills to having multiple and time-consuming body scans. Some procedures are pain-free, and the family merely needs clear explanations about what to expect. Others can cause both physical and psychological distress. These reactions can be avoided or minimized by medication and/or good coping skills.

A family-centered approach works best when planning and implementing procedures. The procedures are often as (or more) frightening for parents than for patients. Memories of them can be long lasting. For this reason, children, parents, and staff should work together toward planning for and coping with procedures.

As soon as possible after your child's diagnosis, find out if the hospital has a child life program or other such team (of nurses, psychologists, social workers) that helps prepare families for procedures. The purpose of these programs is to minimize psychological trauma, promote optimal development, and maintain, as much as possible, normal living patterns during hospitalizations. They attempt to minimize the child's stress by giving the child developmentally appropriate explanations of the reasons for procedures and hospital routines, as this parent describes:

Matthew was in sixth grade when he was diagnosed, and he was worried about the surgery for implanting the port. He didn't know what the scar would look like, and he was concerned about AIDS, because it had been in the news a lot that year. The child life specialist came in and really helped. She showed him what a port looked like; then they explored the pre-op area, the actual surgery room, and post-op. She showed him on a cloth doll exactly where the incision would be and how the scar would look. Then she introduced him to "Fred," the IV pump. She said that Fred would be going places with him and that Fred would keep him from getting so many pokes. She told Matthew that he could bring something from home to hang on Fred. Of

course, he brought in a really ugly stuffed animal. Throughout treatment, she really helped his fears and my feelings about losing control over my child's daily life.

Many child life specialists or other team members accompany children to and provide support during procedures. They establish relationships with children based on warmth, respect, empathy, and understanding of developmental stages. They also communicate with the other members of the healthcare team about the psychosocial needs of children and their families.

Your response, as well as your child's, depends on temperament, age, previous medical or dental experiences, and other factors. Discuss with the child life professional or social worker when and how to prepare your child for upcoming procedures. Usually, parents need to experiment with how much advance notice to give younger children about procedures. Some children do better with several days to prepare, while others worry themselves sick. Sometimes, needs change over the course of treatment, so good communication and flexibility are essential.

Together, this parent and child found a method that worked:

I started giving my four-year-old daughter two days notice before procedures. But she began to wake up every day worried that "something bad was going to happen soon." So we talked it over and decided to look at the calendar together every Sunday to review what would happen that week. She was a much happier child after that.

Try to schedule procedures so that the same person does the same procedure each time. Although it may not always be possible, try to arrange for the same doctor to do each of your child's procedures, the same nurse to access the Port-a-Cath, and the same technician for blood work. Call ahead to check for unexpected changes to prevent any surprises. Repetition can provide comfort and reassurance to children.

Parents can ask for the medical professional with the most experience to perform procedures such as spinal

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taps. In the hospital hierarchy, attending physicians are above fellows and residents. However, at some large teaching facilities, attending physicians may not do these procedures very often. Many times, the fellow or resident (and in states where it is allowed, the nurse) is more skilled, because they do the vast majority of these procedures.

Parents should have a choice whether to be present or not during a medical procedure. Parents set the tone. A calm parent and a well-prepared child give the best chance for a quick, peaceful procedure. If you find that you are unable to be of help to your child during procedures, ask the child life specialist or other member of the healthcare team to be present solely to comfort your child.

Giving children some control over what happens helps tremendously, as this parent describes:

Katy and I wrote down her requests for each procedure that first week in the hospital. For example, during spinal taps she wanted me (not a nurse) to hold her in position, she wanted lidocaine to be given with a needle, not the pneumatic gun, and she had a rigid sequence of songs that I sang.

Oncology clinics usually have a special box full of toys for children who have had a procedure. It sometimes helps for the child to have a treat to look forward to afterward. Some parents occasionally bring a special gift to sneak into the box for their child to find.

Pain management

The goal of pediatric pain management should be to minimize discomfort while performing the procedure. The two methods to achieve this goal are psychological (using the mind) and pharmacological (using drugs). These two methods can be used together to provide an integrated mind/body approach.

Psychological methods

Preparation for every procedure is essential. Unexpected stress is more difficult to cope with than anticipated stress. If children understand what is going to happen,

where it will happen, who will be there, and what it will feel like, they will be less anxious and better able to cope. Methods to prepare children are:

- Verbally explain each step in the procedure.
- If possible, meet the person who will perform the procedure.
- Tour the room where the procedure will take place.
- Small children can “play” the procedure on dolls.
- Older children can observe a “demonstration” on a doll.
- Adolescents may observe a videotape describing the procedure.
- Encourage discussion and answer all questions.

Preparing a child for medical procedures through play helped this child a great deal:

For my child, playing about procedures helped release many feelings. Parents can buy medical kits at the store or simply stock their own from clinic castoffs and the pharmacy. We had IV bottles made from empty shampoo containers, complete with tubing and plastic needles. Several dolls had accessed ports, and many stuffed animals in our house fell apart after being speared by the pen during countless spinal taps. Katy's younger sister even ran around sometimes with her own pretend port taped onto her chest.

My daughter (three years old) took an old stuffed animal to the clinic with her. Having the nurse and doctor perform the procedure first on “bear” helped her immensely.

Hypnosis is a well-documented method for reducing discomfort during painful procedures. If performed by a qualified healthcare professional (psychologist, physician, nurse, social worker, or child life specialist), hypnosis can help your child control painful sensations, release anxiety, and diminish pain. The professional helps guide children or teens into an altered state of

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consciousness that helps focus or narrow attention. To locate a qualified practitioner, call the American Society of Clinical Hypnosis at (837) 297-3317.

Imagery is a way to deliberately create a mental image of sights, sounds, tastes, smells, and feelings. Imagery is an active process that helps children or teens feel as if they are actually entering the imagined place. Focusing on pleasant images allows the child to shift attention from the pain. It can also allow the child to actually alter the experience of pain, which simultaneously gives the child control and diminishes pain. Ask if the hospital has someone to teach your child this very effective technique.

Distraction can be used successfully with all age groups, but it should never be used as a substitute for preparation. Babies can be distracted by colorful, moving objects. Parents can help distract preschoolers by showing picture books or videos, telling stories, singing songs, or blowing bubbles. Many youngsters are comforted by hugging a favorite stuffed animal. School-age children can watch videos or TV or listen to music. Several institutions use interactive videos to help distract older children or teens.

This parent and child developed an approach that acknowledged the pain but made it bearable:

Matthew had many bone marrow aspirations, all but two performed without the aid of sedation. Through a little bit of trial and error, I learned that it was best for me to not make him aware that the procedure would be needed until a few hours before it was actually performed. We developed a ritual that helped him a great deal. I would place a finger puppet on one of my fingers and tell him that he could squeeze the puppet as hard as he felt was necessary. I asked him to try and keep eye contact with me at all times, and we would practice deep breathing during the aspiration. I also told him it was okay to cry or scream as loud as he wanted to if he felt like it. The oncologist would always tell Matthew that he was sorry that it hurt so much. I remember once, Matthew

reached up from the treatment table and put his arms around his doctor's neck. "That's okay," he said. "I know you didn't want to hurt me."

Other adjunctive therapies that are used successfully to help deal with medical treatments are relaxation, bio-feedback, massage, and acupuncture. Ask the hospital's child life specialist, psychologist, or nurse to discuss and practice different methods of pain management with your child.

Medical methods

Most pediatric oncology clinics offer the option of sedation and/or anesthesia for painful procedures. Sometimes anesthesia is available only for infants or overwhelmingly anxious children. If you find that your child is distressed by painful procedures (bone marrow aspiration and lumbar puncture for example), it is reasonable to explore all available options for pain relief.

One father, a doctor just completing his anesthesia residency, explained:

That first bone marrow was horrible. To have my little three-year-old look up at me with tears in her eyes and ask, "What else are you going to let them do to me, Daddy?" was just too much. It was the worst day of my life.

His wife, a nurse, said:

We really made waves by insisting that Meagan be sedated for her spinal taps and bone marrows. It was mostly a logistical problem, but we held firm, and now it has become much more routine for many other kids as well.

The ideal pain relief drug for children should be easy to administer, predictable in effect, provide adequate pain relief, have a short duration, and have minimal side effects. There are three topical anesthetics in wide use for pediatric procedures. EMLA cream is put on the skin one to two hours prior to the painful procedure. Numby Stuff also uses a cream anesthetic, but a mild electrical current helps it penetrate the skin in just a few minutes. Ethyl chloride spray is used immediately before the procedure to anesthetize the surface of the skin.

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Drugs for sedation and/or general anesthesia are given intravenously. Some facilities take the child into the operating room (OR) for the procedure, while others use a preoperative area or clinic sedation room and allow the parent to be present the entire time.

Drugs used for pediatric anesthesia during procedures include:

Valium or Versed plus morphine or fentanyl. Valium and Versed are sedatives, which are used with pain relievers such as morphine or fentanyl. These drugs can be given in the clinic, but due to the possibility of slowed breathing, expert monitoring is required and emergency equipment should be present. The combination of a sedative and a pain reliever will result in your child's being awake but sedated. The child may move or cry but will not remember the procedure. Often, EMLA or lidocaine are also used to ensure that the procedure is pain-free.

Propofol. A milky liquid given by IV, propofol has rapid onset with a rapid recovery. Administration and monitoring by an anesthesiologist (doctor who specializes in giving anesthetics) are required. Propofol, a general anesthetic, will cause your child to lose consciousness. At low doses, propofol prevents memory of the procedure, but may not relieve all pain, so it is often used with EMLA or lidocaine.

Ketamine. Ketamine needs expert monitoring. It has a much longer recovery time than the drugs listed above, and upon awakening, up to 30 percent of children may become confused and/or hallucinate. For these reasons, ketamine is no longer in wide use for pediatric sedation for procedures.

There are many types of drugs and several methods used in administering them, from very temporary (ten minute) mild sedation to full general anesthesia in the operating room. Discuss with your oncologist and anesthesiologist which method will work best for your child.

A parent offers some advice:

Let's face it, kids don't care about lab work or protocols, they just want to know if they are going to be hurt again. I think that one of our

most important jobs is to advocate, strongly if necessary, for adequate pain control. If the dose doesn't work and the doctor just shrugs her shoulders, say you want a different dosage or drug used. If you encounter resistance, ask that an anesthesiologist be consulted. Remember that good pain control and/or amnesia will make a big difference in your child's state of mind during treatment.

Since treatment for childhood cancer can take many months, some children build up a tolerance for sedatives and pain relievers. Often, over time, doses may need to be increased or drugs changed. If your child remembers the procedure or feels pain, advocate for a change in drug and/or dosage. It is reasonable to request that an anesthesiologist be present to ensure adequate pain relief.

All sedation can result in complications, primarily to the airway. It is imperative that sedation occur under the care of trained, experienced personnel and that the child is monitored until fully recovered from the anesthesia.

Understanding what will occur during a procedure and what other parents do to prepare their children will arm you with essential information. Knowing what to expect will lower the anxiety level of both parent and child and lay the foundation for months of tolerable tests. The descriptions of procedures in this article may not exactly mirror your experience. Practices vary by hospital and practitioner and this variability should be expected. What should be the same, however, is your comfort in asking questions and getting the support and help you need to prepare for and cope with your child's procedures.

Questions to ask before procedures

Parents need information prior to procedures in order to prepare themselves and their child. Some suggested questions to ask the physician are:

- Why is this procedure necessary for my child and how will it affect her treatment?

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- What information will it provide?
- Who will perform the procedure?
- Will it be an inpatient or outpatient procedure?
- Please explain the procedure in detail.
- Is there any literature available that describes it?
- Is there a child life specialist on staff who will help prepare my child for the procedure?
- If not, are there parents who can come talk to me about how to prepare my child?
- Is the procedure painful?
- What type of anesthetic or sedation is used?
- What are the risks, if any?

- What are the common and rare side effects?
- When will we get the results?

This fact sheet was adapted from *Childhood Cancer: A Parent's Guide to Solid Tumor Cancers*, by Honna Janes-Hodder and Nancy Keene, ©1999 by Patient-Centered Guides and from *Childhood Leukemia: A Guide for Parents, Families, and Caregivers, Second Edition*, by Nancy Keene, ©1999 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see www.patientcenters.com.