



**Preparing for the Emotional
and Physical Challenges
of Appointments at the Hospital**

(Part One)

February 2019

INTRODUCTION

Preparing for the emotional and physical challenges of hospital visits can play a crucial role in how children view medical care and providers. Advance planning for these challenges can also be a factor in how well kids respond to treatments and procedures.

Julie L. Lerwick, PhD, LPC, NCC, RPT, [finds children are often scared or anxious](#) about their medical care. Kids are susceptible to developing trauma-based fears, depression or behavior issues if their healthcare is not carefully managed. This reaction can then impede the treatment process and increase the cost of care as more interventions are needed. Dr. Lerwick strongly advocates for well-rounded, thoughtful approaches to a child's medical care. This will help lower stress and anxiety, bolstering the chances of positive long-term results.

As Dr. Lerwick and other medical professionals have found, there are beneficial ways to care for children that address their cancer or other serious illness while encouraging the kinds of emotional and mental strength that can improve physical health.

The National Children's Cancer Society (NCCS) assists families in getting their child to the treatment they need, and connects them to additional resources for a greater level of support. In this first part of a two-part series, the NCCS provides suggestions to prepare a child for medical appointments and hospital stays. The NCCS is offering recommendations related to cancer treatment, but the information is useful for children facing many other conditions.



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HOW CAN PARENTS HELP PREPARE FOR CANCER TREATMENT?

[Parents play a very important role](#) in a child's life, and this is especially true during cancer treatment. Parents know their kid better than anyone else and are often a child's best advocate. Parents are usually the best judge of how their child feels and can do more to comfort them when they are hurting or anxious. Parents can provide this assurance even before a child has been to any appointment or started treatment.

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Appropriate language choices and conversations

One way to help a child prepare for any medical appointment, hospital visit or treatment procedure is to be aware of the language used to describe what is happening. The right language allows a child to feel more prepared, making it easier for them to participate in an appointment and be consoled during a difficult process. Language should be:

- Positive as much as possible
- Realistic and specific
- Appropriate for the child's age and developmental level

Texas Children's Hospital (TCH) [recommends communicating](#) in simple, concrete language to describe what will happen or how something might feel. TCH also encourages making the child feel they have an active role. One example could be to say "it's your job to" take deep breaths, sit very still or other action.

This [advice is echoed](#) by Becky Halagarda, MSW, CCLS, CTRS. In working at a children's hospital, she sees how preparing kids in honest, age-appropriate ways reduces fear and anxiety resulting in the child's increased compliance during an appointment. She suggests offering explanations for what an experience will involve or how something might feel. In preparing for a blood draw, she gives the example of saying, "Some kids feel a poke and others feel pressure. You let me know how it feels for you."

Patrick J. McGrath, OC, PhD, FRCS, and G. Allen Finley, MD, FRCPC, [caution](#) some language can result in a worse experience for children. Lying about what is happening, making false reassurances regarding pain and threatening a child with potential consequences can cause distrust and fear.

Drs. McGrath and Finley also tell parents not to make fun of crying or expect a child to be unrealistically brave in ways that minimize real difficulty. However, focusing on the worst or always saying a child is scared can also make it hard for a child to cope.

In general, parents are asked to avoid language that can cause confusion, and Halagarda encourages sharing details based on the child's coping style. Following that advice will help parents successfully guide their child through medical appointments.

HELPFUL	NOT HELPFUL
They need to insert a small needle to get a little blood from your vein so they can study it and see how you're doing.	They need to take some blood.
You'll feel a lot of pressure on your arm.	It won't hurt.
It's normal to be nervous. Let's do some deep breathing.	You have nothing to worry about.
I appreciate you being so still. You're doing well during this and being helpful.	You're doing fine.

Knowing a child's manner of coping

One key way for a parent to support their child is to determine how that child copes with illness and pain. Every child is different, so regularly evaluating a child's coping style can help parents understand how to interact with them in a particular moment.

In her book [*A Child in Pain: How to Help, What to Do*](#), Dr. Leora Kuttner describes four main coping styles - catastrophizer, sensitizer, minimizer and denier. Recognizing which style a child falls under will help parents in preparing them through conversations and actions.

CATASTROPHIZER:

A child with this style will collect information, but it intensifies anxieties instead of serving to reassure them. They tend to fixate on worst-case scenarios, using information only to exacerbate fears. They need opportunities, such as medical play and activities at the hospital, to talk about and work through issues. If a child has a past experience that negatively shapes how they deal with health concerns, family or other supports may not be enough to develop healthy coping skills and therapy could be required.



SENSITIZER:

With this style, a child will often ask for details and wants to know what is happening. Gathering answers seems to assuage fear and anxiety. It is important to let this type of child guide the process of coping and give them information as it is requested since it appears to help. It is also necessary to pay attention and monitor how the child is doing on a regular basis to ensure they continue to process information in beneficial ways.



MINIMIZER:

A child using this style tends to downplay what is happening in order to mitigate feelings of uncertainty and nervousness. They typically find it easier to process information in small parts as that can make fears more manageable. This child should not be overwhelmed with details, but given key points and left to ask further questions over time when they feel comfortable. When this child does ask for additional information, it is important to give it and be responsive when the child wants to learn more.



DENIER:

In this style, the child tries to protect themselves by attempting to avoid talking or thinking about the situation. In some cases, a child may actively refuse information or ask that it not be discussed. Not knowing anything can be detrimental to the treatment process, so parents need to communicate to the child what is happening in small pieces without taking a lot of time.

If coping skills do not get to a healthier place through family support, play therapy or other outside help may be necessary.



Additional tips for parents

Gillette Children's Specialty Healthcare [recommends](#) touring the hospital or other facility to educate the child and parent on what to expect. This offers some familiarity with surroundings and is a time to meet with the healthcare provider to get a full explanation of an upcoming test or procedure.

In conversations with medical professionals, parents can learn if they are able to stay with their child during the test, treatment or procedure. The staff can also explain what preparation tactics seem to work best for most children for a particular type of visit. Going this extra step to increase familiarity with the medical facility and giving a child a preview of what to expect for their appointment can ease worries for the whole family.

During a hospital tour or at home, medical play gives the child a chance to become acquainted with various medical supplies and gain confidence in their coping skills. Texas Children's Hospital (TCH) [encourages engaging kids through play](#) saying, "Children learn and express themselves through play. In the healthcare setting, play allows children to work through their medical experiences." TCH suggests playing with a toy doctor kit and basic medical supplies such as gloves or bandages to help children explore. Adult supervision is advised to make sure the child is safe and understands the proper use of equipment. They also stress that play should never be forced.

Dr. Lerwick has developed [four principles](#) she calls CARE. She advocates for families to partner with medical providers who will use the ideas of CARE to reduce anxiety and trauma responses in children. The CARE principles are:



CHOICES

Children often feel powerless as they face medical appointments and treatments. Making sure they are given opportunities to ask questions and make small, developmentally appropriate choices can make kids feel safe and empowered which reduces fear.

AGENDA

Anxiety tends to grow when a child does not know what to expect. Letting them know what will happen and what they may need to do in terms they can understand will decrease the chances of a trauma response to a hospital visit. Preparation will strengthen rapport and let the child feel the situation is under control.



RESILIENCE

Discussing questions or concerns with a focus on a child's strengths can make them feel respected and give them confidence during treatments or procedures. Avoid discussing negative aspects in a way that would create shame or anxiety in a child. Reframing conversations to highlight a child's best qualities and their ability to deal with difficult circumstances, such as reminders of past resilience, will build trust.

EMOTIONS

Children and their families experience a wide range of emotions while facing a serious illness or disease. It is important for a child to know fears are normal and to see that feelings are validated. Recognizing when a child needs to express or process emotions and offering healthy ways to do so will let the child know they are valued. It will also increase feelings of safety and the likelihood for a good experience at the hospital.



Conclusion

All of these resources, supports and suggestions are increasingly being used by hospitals in pediatric care, especially as more medical facilities incorporate Child Life Specialists within staff teams. Parents now have many ways to join with healthcare providers to prepare kids for upcoming appointments and procedures. The benefits are many when effort is made toward preparation for hospital visits. When combined with strengthening relationships between all involved – children, parents, nurses, surgeons, social workers, Child Life Specialists, case managers – the results have positive, lasting effects on a child’s journey with cancer treatment.

In the second part of this series, the NCCS will examine the growing role of Child Life Specialists, pain management, and unique ways hospitals are improving medical care.

The National Children’s Cancer Society (NCCS), headquartered in St. Louis, Missouri, is a not-for-profit organization providing support to families making their way through the daunting world of childhood cancer and survivorship. With over 30 years of experience serving more than 43,000 children, the NCCS is able to take a “no matter what” approach to help families stay strong, stay positive and stay together. The NCCS has been recognized as a Better Business Bureau Accredited Charity and earned a GuideStar Platinum Seal of Transparency. For more information, call 314-241-1600, visit [theNCCS.org](https://thenccs.org), or on Facebook and Twitter. To read all articles and white papers published by the NCCS, visit <https://thenccs.org/articles#>.