



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

(Part Two)

April, 2019

INTRODUCTION

Managing appointments, procedures and inpatient hospital stays can be a major cause of stress for children and families facing childhood cancer. However, carefully managing and planning for approaching hospital visits can have a calming affect for everyone involved. As Dr. Julie Lerwick [found](#), doing so can ease fears, increase chances for the best possible outcomes from treatments and potentially reduce costs.

The National Children's Cancer Society (NCCS) ensures families get their child to the cancer treatment they need and offers emotional support for greater strength in a difficult time. Toward that effort, [the first part](#) of this two-part series explored beneficial ways to better prepare children for healthcare experiences. The paper offered recommendations for addressing a child's cancer or other serious illness while inspiring the kind of emotional and mental strength that can improve physical health.

The NCCS has many [programs](#) ready to guide and assist families including a program to support families and children in treatment.

The Family Support Program provides a case manager to offer guidance during difficult times, educate parents and caregivers on how to best advocate for their child and provide referrals when needed. Case managers are social workers with a master's degree, or they possess a bachelor's degree with previous experience in pediatric oncology. In addition, the NCCS Mentoring Program offers an opportunity for children ages 10-17 who are in treatment to be partnered with a childhood cancer survivor in the NCCS Beyond the Cure Ambassador Scholarship program. Recipients of the scholarship, which helps survivors with the costs of college, are an uplifting source of friendship and support to their mentees.

"I can't say enough nice things about our NCCS case manager. She approached us with the mentor service. She found a college student named Abigail who had gone through a similar circumstance as London and introduced them. They are two peas in a pod! Abigail goes to college in another state so they facetime and text, they read books together. Their relationship has been so important,"

—Art, father of London, diagnosed with a rare form of sarcoma.

In this second part of the series, the NCCS will provide additional resources outside the organization for families battling childhood cancer. This includes information on the growing role of child life specialists' effective ways to enhance medical care, and recommendations on how pain can be managed. The NCCS is providing this information as a service to families facing childhood cancer, but those dealing with many other conditions may also find it useful. As with Part One, ideas are presented with the goal of helping lower stress and anxiety for kids during care, resulting in a greater chance of positive long-term results.

CHILD LIFE SPECIALISTS

Many hospitals, especially children's hospitals, are finding innovative ways to help children cope with potentially traumatic treatments or procedures. This often involves child life specialists who have expertise to coach parents on helpful ways to communicate with their children about upcoming medical procedures. NCCS families have reported that meeting with a child life specialist at the start of their journey was very beneficial as their diversionary tactics reduced fear, stress and pain throughout medical procedures.

[Child life specialists](#) typically work in hospitals, but they can also work in schools or other community settings. They have specific training in child development, psychology and counseling as well as an understanding of medical terminology and practices. This background is used to help explain a diagnosis or procedure, offer coping strategies and provide emotional support. They also plan and facilitate activities to create a comfortable environment within a medical setting to encourage a child's well-being.

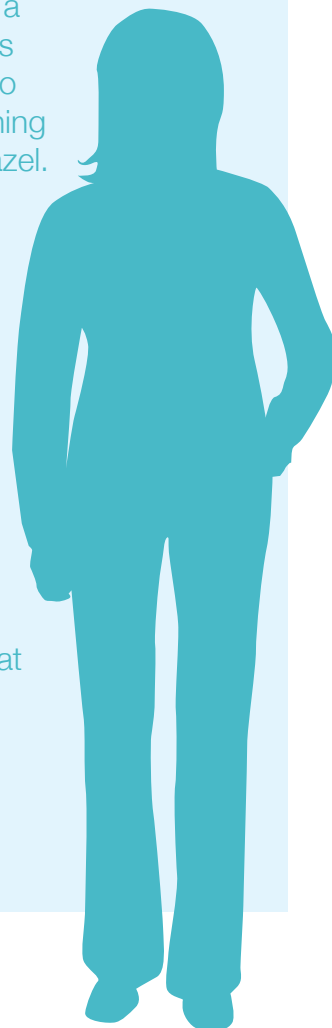
Child life specialists recognize the entire family feels the effects of a major medical experience. They bring value to a child's team of care providers by moving beyond the physical needs of a child to also attend to the mental and emotional health of the child and their family.

Hospitals and researchers are [finding](#) better outcomes and reduced costs tend to be seen when child life or similar programs are involved, as opposed to care plans which only deal with treatment of a physical condition. Incorporating the needs of the whole child often gives kids more trust in their medical team which helps them be more compliant during care and can yield greater results.

In one example, [a study](#) from St. Jude Children's Research Hospital found children with central nervous system tumors had a decreased need for sedation during radiation therapy. This lessened healthcare expenses and is credited to kids' preparation with a [certified child life specialist](#).

"We worked with a child life specialist (provided by the hospital) from day one. She has monitored both Hazel's and her siblings' progress through the situation and even sat down with 'cancer books' during the first week of diagnosis to explain to the kids what was happening in Hazel's body. It was a tough situation, but this helped our older kids to have hope that everything would be alright for Hazel. Gideon and Paul took the books back to their school and asked to explain it to their class so their friends knew what was going on with their little sister. They each gave a presentation to their entire class to explain Hazel's cancer, how it was treated, and what things to avoid if they were around her,"

– Nat, father of Hazel, diagnosed with acute lymphoblastic leukemia.



EFFECTIVE PROGRAMS FOR EXTRA SUPPORT

While Child Life programs are becoming more common, they are not always available in every medical facility. Many of the examples below can be facilitated by parents if their particular hospital does not organize these creative ideas.



Youth and Pet Survivors (YAPS) gives children the benefits of pet therapy when their immune systems may not allow visits with an animal. The YAPS program creates a pen pal relationship between pediatric oncology patients and cats or dogs who are survivors of cancer and other serious conditions.

Bear in the Chair sends a stuffed bear to sit at a child's desk. The bear often goes to school events and other activities, becoming a special way for kids at the school to remember and show support for a classmate spending weeks in the hospital. Some hospitals also employ **teachers** so kids with long stays do not fall behind academically.



Clown Docs shows laughter can be a good medicine. In this program as well as in studies, getting a child to enjoy time at the hospital through tricks and jokes was found to decrease stress and improve how the child views treatment.

Yoga therapy lets children learn to relax, manage pain and expand motor skills. For some kids, it makes a difference in mood and mobility.



Art therapy allows kids to process feelings or simply explore their own creativity for fun. This can include holding concerts, publishing a literary magazine, producing music videos and operating a television studio.

MANAGING PAIN

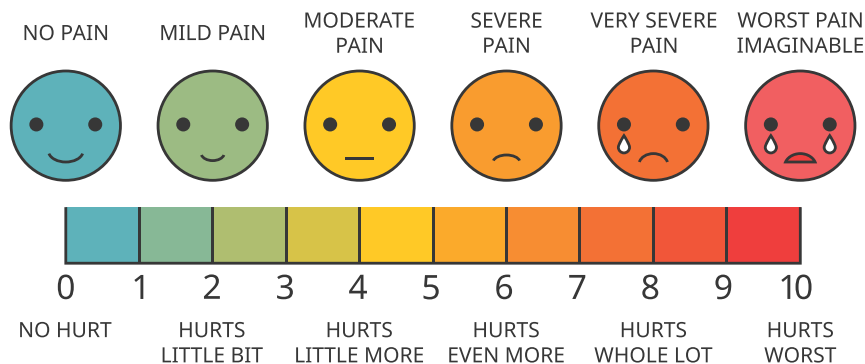
No matter how much preparation is done or who is involved, there will still be a need to comfort a child or manage pain during procedures and hospital stays. Helping children manage pain well contributes to the chance of [fewer complications](#).

[Stanford Children's Health](#) (SCH) reminds parents and medical providers every child is different so kids will experience pain differently. SCH advises treating pain based on the unique needs of each child, which sometimes means testing until a method is found that works. SCH also notes when using medicine to deal with pain, some children can develop a tolerance requiring a dosage adjustment or new medicine over time.

Best tools to assess children for effective pain control

The first step in managing pain and determining what works best for a particular child is to assess the level of pain the child is experiencing on an ongoing basis. There are a [number of ways](#) this can be done depending on the age and communication abilities of the child. These can include:

- **Premature Infant Pain Profile (PIPP):** To measure pain in infants, care providers monitor behavioral indicators such as facial reactions along with tracking physical status like heart rate and oxygen saturation. Those are used with contextual variables such as age to determine a pain level.
- **Face, Legs, Activity, Cry and Consolability (FLACC) Scale:** A number score is assigned to facial expressions, leg movements, general activity, crying and consolability. The scores are then added together to determine the level of pain experienced by a very young child.
- **Faces Pain Scale-Revised (FPS-R):** This can be used with school-aged children to have them identify their own pain level using a pictorial scale. The six faces on the scale are designed to help children express how they feel by giving them a neutral image to accurately communicate their pain.



- **Visual Analog Scale (VAS):** Older children can use the VAS to mark on a line how much pain they feel. The further along the line a child marks, the greater the pain they indicate they are experiencing.
- **Numeric Rating Scale (NRS):** The NRS asks children to state the level of pain they feel by rating it from zero to ten on a scale. Less pain will be a lower number and a child stating closer to ten will be in a great degree of pain.

Pharmacological pain management

Once a child's level of pain is determined, the way to manage it can be found. The higher the pain level, the [more likely](#) it is that pharmacological pain management, meaning the use of medication, will be needed.

Medications include common pain relievers such as acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen, topical anesthetics that numb the skin, opioids such as morphine as well as sedation and general anesthesia. The type of medication can determine how it is given to the child. Some are taken by mouth and swallowed while others must be administered intravenously or through a special catheter.

Topical pain management can be used to anesthetize or numb a small area before a procedure such as an intravenous catheter insertion or blood draw. Topical medicines can also be used to lessen localized pain after a procedure or provide some relief from certain types of chronic pain. According to Kimberly A. Pesaturo, PharmD, BCPS and Michele Matthews, PharmD, [common topical pain management](#) for children includes:

- LMX4 and EMLA creams that are applied to the skin
- Sprays which can create a quick freezing effect to numb the skin
- Synera patch that uses warming in delivering numbing medications
- Buzzy device which combines cold temperature with vibrating movement to ease discomfort

Mild pain relievers including acetaminophen and NSAIDs are used by themselves for low amounts of pain. They can be paired with opioids as pain increases so moderate pain can be managed without a complete reliance on opioids. As pain becomes severe, often opioids like codeine, morphine and oxycodone must be used as the primary or only [pain relief](#).

SCH [acknowledges](#) families may be concerned about an addiction to pain medication and states, "There is no evidence of addiction to pain medications in children being treated for cancer." SCH encourages appropriate measures to allow a child to be as free from pain as possible in order to have higher overall quality of life.

The Hospital for Sick Children does [caution](#) against the use of codeine for children. Their site reports of safety and efficacy concerns as a reason for their staff to administer morphine, especially in oral form, as the opioid given to the children they treat.



Nonpharmacological pain management

Nonpharmacological pain management seeks to diminish pain without the use of medication. This typically involves [physical or psychological comfort methods](#) such as massage, repositioning, imagery or distraction to decrease fear and pain.

SCH [states](#) children experience less stress when they are more prepared for what is happening, so part of psychological pain management is the work done in advance. This can include hospital tours, meeting with and asking questions of a doctor, medical play and other preparations.

If nonpharmacological pain management is an option during an appointment, SCH offers several ways parents can try to provide a child comfort including:

- Hypnosis to reduce discomfort guided by a professional who can help the child move to an altered state of consciousness with a narrow attention focus
- Imagery to guide a child through mental images and feelings that can draw attention away from pain
- Distractions such as music, books or videos or simply moving objects for infants which can shift their focus from pain to something else
- Relaxation through deep breathing or stretching which can be used to lessen discomfort
- Alternative therapies such as acupuncture or massage to ease pain

Positive language also helps kids prepare for and manage pain. Using specific and age-appropriate wording can be another way of using psychological tools if they align with a child's coping style. For instance, saying a child is going to receive a poke and it might hurt is not really specific and does not offer any reasoning behind their appointment. It is more helpful (and less focused on pain) to say, "The doctor is going to draw some blood to look at under a microscope so we know how to help you feel better." Halagarda [suggests](#) avoiding phrases like "you're fine" or "they're almost done," instead, more meaningful observations should be used such as "This is difficult, but you are being very brave" or "The way you are being still and breathing deeply is very helpful and I like that." More information on helpful language choices can be read in the [first part](#) of this two-part educational series from the NCCS.

Comfort positions

If the appointment or procedure will allow it, holding a child in a comforting position can be a powerful way to ease anxiety and pain as kids tend to feel safer when physically held by a parent.

Children's Mercy Hospital made a video describing [comfort positioning](#). Specific positions help keep arms and legs from moving too much during procedures, give the child a sense of security and create meaningful contact between parent and child. It also offers the child a sense of control and decreases the number of people or interventions needed for a procedure. Common positions include:

BACK OF CHILD TO PARENT'S CHEST



CHEST-TO-CHEST POSITION



SIDE-SITTING POSITION



AFTER THE HOSPITAL STAY OR APPOINTMENT

It is common to have a [mix of emotions](#) once an appointment, procedure or hospital stay is over and a child is able to return home. Excitement is often combined with nervousness, especially if a diagnosis is recent, feels new or if the child has had a long hospital stay. As with other aspects of care, preparation will ease the process of going home.

Preparing for the return home

UCSF Benioff Children's Hospital San Francisco [outlines](#) several steps they take with parents before a child is released. They make sure there is an opportunity to talk with doctors and hospital staff about any needs for the home. This could range from special equipment to types of therapy. They discuss questions about medications (if any are prescribed) and activities a child or the family may want to participate in. They also clarify any follow-up needs or additional medical care that should be tended to going forward.

If chemotherapy is to be given at home, it is important to understand storage, handling and administering the medicine. Appropriate [precautions](#) should be taken to ensure the safety of all in the home.

Proper dosage of pain medication

At home, as during hospital visits, pain management is crucial. Patrick J. McGrath, OC, PhD, FRCS, and G. Allen Finley, MD, FRCPC, [advise](#), "Pain medicine should be used to keep pain away, not to catch up with pain that is already severe." They have [found](#) that pain is harder to manage once it is out of control, so medicine is used less and is more effective when given before pain is at its worst.

However, Drs. McGrath and Finley also stress medicine should be given on a regular schedule and only in the proper manner and dosage. Too much or too little can cause harm or be ineffective. They recommend monitoring the child's level of pain frequently and consulting with the healthcare provider if changes in the type of pain relief or amount may be necessary.

CONCLUSION

There are many tools and resources that can benefit children before, during and after a medical appointment or hospital stay. Parents play a key role in working with doctors, child life specialists and other care providers to determine the preparations, treatments and pain management that will meet their child's needs. When everyone works as a team to serve the whole child, long-term outcomes are often stronger.

Organizations like the NCCS can assist families in getting their child to the care they need while also providing knowledge and emotional support. *No family should face childhood cancer alone.* Equipping parents with important resources allows them to pursue the best possible results for their child and the NCCS is available to help in that effort.

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 whitepapers published by the NCCS, visit <https://thenccs.org/articles#>.