Having a child who is frequently in and out of the hospital is extremely stressful—not only for the patient, but for the entire family. As a child life specialist, I work in the hospital setting to help reduce this stress and provide families with more positive ways of coping with their emotionally intense circumstances. I partner with patients, families, and hospital staff to advocate for the sick child, helping to serve his or her best interests through play, education, and support.

I recognize, too, that even when patients and families are not in the hospital there are challenges at home related to the child’s specialized care, such as medications, tube feedings, catheter care, and other complex tasks. Listed below are developmental considerations for different age groups, as well as some distraction and relaxation strategies you may find helpful when your child is hospitalized or not feeling well.

Infants/Toddlers (0–3 years)

Developmental Considerations
- Try to maintain the child’s normal routine as much as possible.
- Provide tactile and other sensory stimulation. Examples include rocking, holding, speaking and singing to, and playing with the child.
- Have only one toy or activity available at a time to prevent overstimulation.
- Infants like to put objects in their mouths, so make sure toys are safe and clean.
- Human contact is most important. Toys can be a secondary source of stimulation.
- Designate space for treatments and medications—somewhere other than the child’s bed or play space, so that those areas remain “safe.”

Distraction/Relaxation Strategies
- Swaddle infant in a blanket.
- Use soothing touch or infant massage.
- Utilize a comfort item, such as pacifier, stuffed animal, or blanket.
- Play soothing music or sing quietly.
- Look at pop-up books together.
- Use rattles or teethers.

Preschoolers (3–5 years)

Developmental Considerations
- It is difficult for children at this age to differentiate between reality and fantasy. The child may blame herself for becoming sick or may think being in the hospital is punishment for bad behavior. The child may also blame family members for causing the illness or injury.
- Child may exhibit behavior changes or regress to earlier childhood behaviors, such as sucking thumb, clinging, tantrums, withdrawal, wetting the bed, or requesting a pacifier.
- Try to maintain a normal routine as much as possible.
- Provide activities and games that will use fine motor skills as well as gross motor skills.
- Provide constant verbal support and encouragement to show the child you are there for her.
- A sticker chart or reward system may help increase compliance with medications with this age group.
- Play medical kits are beneficial to help the child better understand the equipment she will commonly see at home, a doctor’s office, and/or during hospitalization.

Distraction/Relaxation Strategies
- Utilize comfort item, such as a stuffed animal or blanket.
- Use soothing touch or massage.
- If child must be restrained, do so in a comforting way, i.e. hug hold.
- Watching cartoons or a movie.
- Listening to music, singing.
- Bubbles.
- I Spy, lift-the-flap, or push-button books.
- Kaleidoscope, glitter wand, etc.
Developmental Considerations

School-Age (6–11 years)

- At this age, a child may resent the loss of control, autonomy, and competence that come with hospitalization or illness.
- May interpret medical procedures as punishment for past mistakes or bad deeds.
- Important school routines may be interrupted.
- Prepare and educate child regarding diagnosis and/or treatment plan to reduce feelings associated with the fear of the unknown.
- Provide choices and control when possible.

Distraction/Relaxation Strategies

- Use soothing touch or massage.
- Use comfort positioning versus restraining.
- Bubbles, books, interactive toys.
- Stress ball, play dough, clay to squeeze.
- Music, movie, video game.
- Deep breathing (have child pretend he is blowing out candles on a birthday cake).
- Guided imagery—have the child imagine a place he would rather be.
- Provide choices and control when possible.

Adolescents (12 years and up)

- Self-esteem, independence, and body image may be negatively impacted.
- Loss of control and privacy are hard for this age group.
- Adolescents struggle with dependence vs. independence issues.
- Hospitalization or illness may require an adjustment to separation from peer group and lack of emotional support.
- Very aware of physical changes due to illness or injury. The adolescent is frequently self-conscious about her tubes, an ostomy, and/or surgery scars.
- Changes in behavior may occur. Withdrawal, isolation, anger, aggression, low frustration/tolerance threshold, lethargy, and difficulty with authority are common.
- Encourage teens to ask questions and be involved in their care.
- Educate them about noncompliance and the negative impact it can have on their future.

Distraction/Relaxation Strategies

- Use soothing touch or massage.
- Music, movie, video game.
- Deep breathing (have child breathe in through her nose and out through her mouth).
- Progressive muscle relaxation (tighten and release each muscle group in succession).
- Guided imagery—you can purchase cds or go to itunes online for imagery scripts with relaxing music.

Holiday Hospitalization

- Having a child admitted to the hospital or sick at home during a holiday can create havoc for families. Remember that most traditions that are celebrated at home can be incorporated into the hospital environment (i.e., bring a Thanksgiving meal to a child's hospital room or decorate his room for the holiday you are celebrating). Even though you may have to modify certain traditions, try to include the sick child in whatever way you can. Provide opportunities he can look forward to.
- At Children's Memorial Hospital, we have a playroom space with special activities and regular play programming that occur on a daily basis. These provide unique opportunities to patients and their families can look forward to and participate in. If your hospital does not have these resources, pack a special hospital bag for your child with games, activities, and some of her favorite things to make the experience more familiar and positive.

It's a good idea to keep some special toys that your child can only use during procedures or dressing changes. These toys will continue to capture the child's attention, unlike everyday toys he is used to seeing and playing with.

Importance of Routine

- Remember that children of all ages benefit from a consistent caregiver presence and a familiar routine. Several patients with whom I have worked have benefited from having a visual schedule posted in their bedroom or hospital room so they can anticipate upcoming medical events, when to take medicine and fun activities, as well as activities of daily living, like bathing and teeth brushing. Have the child participate in making this schedule, including items she feels are important, and allow her to decorate it with photos and stickers.

- Continue to set limits with your child so his behavior does not get out of control. Again, children need structure and guidance to thrive. They depend on their caregiver(s) to provide clear expectations for them in a caring and loving way.

- Provide clear choices when they exist, but be clear that with certain tasks the child's choices are limited. With taking of medication, for example, a choice of whether or not your child takes it does not exist. You can, however, incorporate choices into the taking of medication by allowing her to choose how she wants to take her medication or what she
wants to take it with (i.e., spoon or syringe, juice or water). The choice can even be to choose what activity she wants to engage in once she has been cooperative in taking her medicine (i.e., watching a favorite cartoon, doing a project, reading a book).

Expression of Feelings

As caregivers, you should speak honestly and openly with your children. Research has proven that it is better for children to know what is happening versus dealing with feelings associated with fear of the unknown. Some caregiver(s) think it is best to express their own emotions in private. At times, it is good to show kids that adults are only human too! It gives children permission to more openly share their feelings in front of others instead of keeping them all bottled up inside.

Keep in mind that, depending on the age of your sick child, he may want to express his feelings in other ways besides just talking to a trusted adult. Ofentimes kids I work with will relay that they don’t want to share their feelings with their caregiver(s) because they don’t want to make them more upset or burden them with their feelings.

Peer support groups are a great outlet, especially for school-agers and adolescents. Through peer support groups they can come to realize they aren’t the only ones dealing with a difficult time or a chronic illness—or the only ones with tubes or catheters. Encourage your child to keep a journal where she can write about her feelings or use art, poetry, or music as an expressive outlet.

For younger children, you can read a feelings book with them, which may help them to identify the feelings they are having. It can often be confusing for them to verbalize their feelings. So frequently, because they don’t know or understand why they are feeling a certain way, they will act out as a way to gain positive attention. Caregivers may have difficulty pinpointing the root cause of the behaviors and may respond in a negative way, which is not what the child is hoping for. Provide verbal reassurance and let the child know that what he is going through is really hard and that you are there to help him get through it. Lots of hugs and kisses are good, too!

If your child is opting to act out physically, make sure you let her know it is not okay to hurt herself or anyone else. If she wants to punch something because she is very angry, provide a pillow as a punching bag or give her play dough to pound as a more positive way of dealing with aggressive feelings.

Conclusion

In closing, caring for a child with specialized needs can be demanding and draining. Remember to take time for yourself, ask others for help, and seek out support services.

Helpful Web Sites/Resources:

- [www.infantmassageusa.org](http://www.infantmassageusa.org)—Learn more about the benefits of infant massage.
- [www.wish.org](http://www.wish.org)—The Make-a-Wish Foundation is a wish-granting organization.
- [www.familycrafts.about.com](http://www.familycrafts.about.com)—Cute craft ideas.
- [www.childlife.org](http://www.childlife.org)—Child Life Council is the professional organization for child life specialists.

Guided Imagery Books:
- *Healing Images for Children*, by Nancy Klein and Roger Klein
- *Ready, Set, Relax*, by Jeffrey Allen and Roger Klein

Feelings Book:
- *The Way I Feel*, by Janan Cain