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Welcome back! Helping young children return to your program after hospitalization

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Welcome back! Helping young children return to your program after hospitalization

Every week I'm lucky enough to spend a couple of hours reading to hospitalized children. Sometimes I also get to be with other formerly hospitalized children as a camp volunteer. In spite of their incredibly varied experiences, one thing stands out: kids will be kids! This can mean many things, but to me as a volunteer—who just happens to be a developmental psychologist—it means that young children want to feel safe, want to explore their world, and want to have fun.

My background investigating early child environments has led me to wonder how child care programs can support young children returning to care after they have been hospitalized. A supportive setting would allow children to do the following: 1) have a sense of normalcy; 2) enjoy opportunities to gain mastery and have some control; 3) build self-esteem; and 4) lessen their identification as patients (Harris 2009).

What we know

Let's explore what we know about hospitalized children as a starting place for helping young children adjust.

Every day children of all ages are hospitalized—and for many reasons. Medical advances have led to shorter stays, but of course not all children are average and many stay much longer than the 3.5 day average (Weiner, Hoffman, and Rosen 2009). These children may have chronic or acute illnesses, they may have injuries, and sometimes they are facing life-threatening conditions. So it isn't surprising that there are limits to their activities and that they are more at risk for adjustment issues than children who aren't facing serious illness (DuPaul, Power, and Shapiro 2009).

What do we know about hospitalized children returning to early child care? Unfortunately, studies

on this topic focus almost exclusively on school age children (grades K-12). But we know that younger children face hospitalization too. For example, children younger than 5 are more likely to have cancer than children between 5 and 14 years of age (Harris 2009). In fact, children 4 and younger are twice as likely to be hospitalized as children between the ages of 5 and 14 (Child Life Council 2006). Plus, some health conditions require one or more surgeries in the first years of life (Cardon Children's Medical Center).

Researchers have found that social anxiety can affect younger children in elementary school more than older children when returning to school after cancer treatment (Bessell 2001). Children are often kept from physical activities because gym teachers and coaches don't know what a child can or cannot do (Schwartz, Denham, Heh, Wapner, and Schubrook 2010). Children may not be able to speak up for themselves about their abilities and limits;



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they just want to be seen like other children (Weiner, et al). Yet, because returning to school is a return to normalcy, it makes sense that Bessell found that nearly half of children treated for cancer experienced “positive and rewarding friendships” after coming back to school.

The good news is that formalized programs for reentry into schools can help a child have positive outcomes such as improved self-concept and feelings of peer support (Harris 2009). This happens, in part, if the hospitalized child’s peers are well-prepared, which helps them have more positive attitudes toward the returning child (Cantor and Roberts 2012).

It also helps when teachers prepare by learning about specific illness or injuries (Bessell 2001). Children want their teachers to be caring and supportive, but they don’t like drawing attention to their illness. When children can be with their friends and do much of the same things other children are doing, they have a sense of normalcy that helps them thrive.

What can we do?

Planning a reentry for a hospitalized child can be daunting for caregivers and teachers who aren’t likely to be trained in working with children with medical issues. Such training is rare for teachers of older children as well (Clay, Cortina, Harper, Cocco, and Drotar 2004). Plus, child care programs typically don’t have a range of professionals to create and

support reentry programs. While teachers often wear many hats, they can’t be librarians, nurses, nutritionists, and counselors all at the same time.

Here are suggestions to consider:

Be prepared. Get ready for a child’s return while the child is still in the hospital. Gather some basic information about the relevant illness or injury. Websites such as Band-Aides & Blackboards (www.lehman.cuny.edu/faculty/jfleitas/ban- daides/) and Kids Health (www.kidshealth.org) provide information about illnesses, treatments, and real life stories from affected children. In addition to the local library, local hospitals often have family resource centers with relevant information to share.

Easing a child’s return can also be done by the other children in the class if they are encouraged to get involved. Weiner (2005) has suggested that children can send artwork, photographs, digital voice messages, or videos to their hospitalized friend. Consider developing a project that engages both the hospitalized child and all the children in the class or group. For example, in a lengthy hospitalization, children can create books about themselves. You can create a book template with prompts for children to use. When children share their completed books, they find out how much they have in common with each other. This helps everyone recognize that the challenges that may come with the child’s health issues can be seen as just one part of who the child is.

Ideas for the book template may include the prompts below.

A book all about me

- These are the people in my family.
- This is my favorite animal.
- Here is something fun that I like to do.
- This is something that I’m really good at doing.
- This is something that is very hard for me to do.
- This is what makes me sad.
- This is what makes me happy.
- This is what I would build if I could build anything in the world.
- This is when I was really brave.

The hospitalized child’s family can create a more detailed book about the child’s hospital experiences. Beware: this incredibly helpful classroom tool is ambitious! It is a rare family that can construct a book that explains their child’s health issues to the child’s young friends.

One family did it with a book called *Aoife’s Heart*

PHOTO BY SUSAN GAETZ



Story. Aoife (pronounced Eee-fah) was born with a heart defect and has had heart surgeries. The book describes what Aoife needed medically and how she responded to her care. The book contains many pictures of Aoife, including ones with her family in the hospital and at home. Aoife's teacher shared the book with Aoife's friends after she returned to school.

IT HELPS WHEN TEACHERS PREPARE BY LEARNING ABOUT SPECIFIC ILLNESSES OR INJURIES.

Many large hospitals employ child life specialists to help children and families understand and cope with the medical situations children face (Gold 2012). These staff members can help young patients get ready for their return to school while they are still in the hospital. The job of these pediatric care professionals is to put children more at ease with child-friendly explanations of medical concepts, positive distraction during treatments, as well as opportunities for play.

Play can take place in treatment areas, at bedside, or in hospital playrooms. Treatments and procedures are never part of hospital playrooms. So the hospital playroom is a safe bridge for children who will return to child care because they have play opportunities and possibly play partners too. The positive emotional climate encourages children to be themselves and have a sense of normalcy again (Butler, Weinberger, Schumacher, McGee, and Brown 2015).

Don't be afraid to ask questions

The best way to help children is to know what they need and recognize that their needs will change over time. That's why having many conversations is important. Be ready to speak with the child's family, the other children in the child care program, hospital staff, and of course, the affected child.

Ask the family. Parental stress from caring for seriously ill children can last even after children regain their health (Klass 2013). For many parents, the child's transition back to child care may provoke

anxiety. Wilson, Gaskell, and Murray 2014 recommend communicating with the family before the child returns, a strategy based on reintegration research about young children with burn injuries.

Early communication provides families opportunities to share their concerns and gives teachers time to describe how the concerns will be addressed. You can ask specific questions about the child's needs. It may be helpful to create checklists to minimize the risk of missing something important such as unique safety precautions (Gawande 2009). The checklists can be helpful for communicating with families before, during, and after reintegration at the child care program (Harris 2009).

Ask the child's peers. You may easily recognize that the children in your care have some fears and anxieties about their hospitalized friend. But you can ask children what they want to know about hospitals and illness or injury. Respecting a child's perspective and being a patient listener are important elements of having difficult conversations with children (Henderson and Stockall 2014).

In addition, children may need some new language to talk about their friend. It can be empowering for children to use the correct medical terms (*leukemia* or *epilepsy*, for example). It can also reduce the risk that they will become anxious when general terms about their friend are used in other situations. For example, if children know only that their friend was in the hospital because she was "sick," then they may become worried if a sibling becomes sick.

Ask hospital staff. Even if the family doesn't suggest a particular hospital staff member to contact, the hospital usually will have selected staff who are well prepared to help children and families by communicating with professionals outside the hospital. In particular, clinical social workers, child life specialists, and family resource center librarians are available to participate in reentry programs.

Their involvement may include explaining medical conditions and treatments, suggesting reference materials, making suggestions to put the child at ease, and advocating for specific services that will optimize adjustment success.

You may have some questions that feel too difficult to ask the family without some preparation. Child life specialists, mentioned earlier, can help you know which questions are appropriate to ask the child and family and which are not. They can help you figure

out how to ask difficult questions too. In some cases, staff members even come to a child's classroom to talk to the other children and help explain what to expect when the child returns to school.

To identify appropriate staff, look for terms such as *child life* or *pediatric care* on the hospital's website.

Ask the child. More than likely, the child will want you to understand everything but may not want to be the one to fill you in. That's where talking with family members and child life specialists in advance is especially helpful. Let the child know that you care, and show what you have done to prepare for the return. You can say something like, "I want to help you to be happy and do your best."

Ask what the child would like you and the other children to know about and what she is going through. Ask the child to explain her condition to you in her own words in a private conversation. Don't ask the child to explain her own health to other children. It's up to you to communicate information to the class, but recognize that some children may spontaneously share information with their friends on their own.

Young children returning to child care may not be able to clearly talk about their worries. But by thinking about some of their possible worries, you will be better prepared to support returning children. Here are some potential concerns.

I worry that...

- everyone is going to be looking at me.
- my friends may be afraid of me.

- someone may tease me.
- no one will play with me.
- my friends will ask me too many questions.
- everyone will feel sorry for me.
- my teachers won't understand me.
- my teachers won't let me climb or run or jump.
- my teachers will talk too much about my private stuff.

Have fun and include play

Children want to return to play as fully as they can, as soon as they can. Helpful play can come in many forms with a variety of materials such as typical age-appropriate toys, art materials, puppets, role play items, including medical items. But don't be surprised if the healthy peers are more interested in the medical play than the child who has been hospitalized.

CHILDREN WANT TO RETURN TO PLAY AS
FULLY AS THEY CAN,
AS SOON AS THEY CAN.

Some children can jump right in with their friends and get back to playing. Others may need to your help. In that case, invite the child to a separate play area to play a game or share an activity with just one or two other children. Select the activity strictly for the fun of it and not to teach special lessons about the child's health. This will show the children that they can relax and once again have fun together.

Of course books are another important feature in any child care program, and you can supplement the collection to include books on children's health. There are abundant book options for young children, including those in the table below suggested by Lisa Nadeau, who coordinates the Family Resource Center at Hasbro Children's Hospital in Rhode Island. But be prepared for the children who haven't been in the hospital to be more interested in the medically oriented books than the children who have been hospitalized.

When I'm reading to children in the hospital, I find that children generally prefer familiar stories or stories that are silly or funny. For example, any book

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Recommended children's books about hospitalization

Book title and author	Topic	Brief summary
<i>Jessica's X-Ray</i> by Pat Zonta	Accidents, diagnostic equipment	A girl breaks her arm and needs an X-ray. She also tours the hospital seeing X-ray rooms and looking at actual X-ray, CAT-scan, MRI and ultrasound images. Real X-ray images are printed on Mylar.
<i>Franklin Goes to the Hospital</i> by Paulette Bourgeois	Accidents and surgery	Franklin the turtle needs an operation to repair his broken shell. Franklin is worried that his X-rays will show just how scared he is inside.
<i>Little Tree: A Story for Children with Serious Medical Problems</i> by Joyce C. Mills	Accidents or serious illness	Little Tree loses some of her branches in a storm but faces her concerns and is able to thrive.
<i>Peter, the Knight with Asthma</i> by Janna Matthies and Anthony Lewis	Asthma	An imaginative tale about a boy who gets some help with his asthma so he can fight off the dragon.
<i>I'm a Kid Living with Cancer</i> by Jenevieve Fisher	Cancer	The child explains many facets of having cancer including common treatment details.
<i>When Billy Went Bald</i> by Julie C. Morse	Cancer	Billy is bald when he goes to kindergarten. The other children learn about Billy's illness and treatment but also that he is still just like all his friends.
<i>Toilet Paper Flowers: A Story for Children with Crohn's Disease</i> by Frank J. Sileo	Crohn's Disease	A young girl gains support and understanding from her friend as she shares her creations and explains her disorder.
<i>Mallory's 65 Roses</i> by Diane Shader Smith	Cystic Fibrosis	A creative young girl explains her lung disease and treatments.
<i>Taking Diabetes to School</i> by Kim Gosselin	Diabetes	A school-age boy tells his peers about his diabetes and how he manages the disease.
<i>Mommy, I Feel Funny! A Child's Experience with Epilepsy</i> by Danielle M. Rocheford and Chris Herrick	Epilepsy	A young girl has a seizure and describes her experiences with medical tests and medications.
<i>Joey Panda and His Food Allergies Save the Day: A Children's Book</i> by Amishi S. Murthy, Vivian Chou, and Joseph Cannon	Food allergies	Joey Panda is worried about his first day of school because of all his food allergies. The story includes Eppy, Joey Panda's epinephrine auto-injector.
<i>When Molly Was in the Hospital: A Book for Brothers and Sisters of Hospitalized Children</i> by Debbie Duncan	Surgery	Anna tells about a younger sister who becomes ill and needs surgery.
<i>My Brother Needs an Operation</i> by Anne Marie Jaworski	Surgery—heart	Life changes when the younger brother goes to the hospital for surgery.
<i>The Surgery Book for Kids</i> by Shivani Bhatia	Surgery—tonsils	A boy's fears are relieved as he learns more about the surgery he will need to remove his tonsils.

in the Mo Willems collection about Gerald the elephant and Piggie the pig are adored. In Willems' book, *I Broke My Trunk*, the bandaged elephant tells his goofy story about how he hurt his nose.

Children can also enjoy books with deeper meanings if the story is a compelling one. For example, Maurice Sendak's classic, *Where the Wild Things Are*, is a popular choice for children. It is familiar to many and beautifully illustrated with a fascinating story line that has many potential underlying meanings. Imagine the possibility for a deeper meaning if a child was injured in an accident and hospitalized after misbehaving. The story line in *Where the Wild Things Are* reminds children that no matter what they have done, they are loved and will be safe and cared for. There is no need for you to directly discuss such meanings of the stories; reading the stories is helpful enough.

Apart from play and books, a returning child may find comfort in a retreat space, something common to many child care programs. The space can be a corner loaded with oversized pillows or an easy chair near a window. Young children spending full days in child care occasionally need to pull away from the activities around them (Weinberger 2006). Children use retreat spaces to regulate their emotions and their energy levels throughout the day. This is especially important when their momentary desires for engagement are different from their peers.

Children returning to the routine of child care after a hospitalization may be especially likely to use

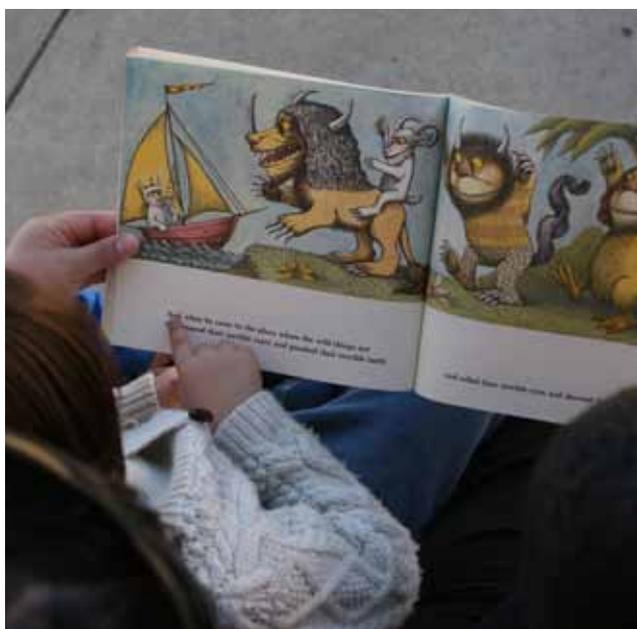
retreat spaces when available. If retreat areas are welcoming and have been a regular part of the classroom for any child to use, the returning child won't be stigmatized for using the retreat as frequently as needed.

So while young children have varied hospital experiences, one thing they have in common is that returning to child care is a return to their childhood. You can help them thrive by preparing for their return and finding ways for kids to be kids again.

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