

Helping Hand: A Guide for Siblings to  
Understand, Cope, Grieve, and Heal

by

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## Abstract

Children are greatly affected by the impacts of a sibling in the hospital. There is a lot of research discussing the importance of helping children who have a sibling in the hospital, but there is a lack of tangible resources available for the child specifically. This paper discusses the research that suggests why children who have a sibling in the hospital are deeply affected by it to support the need for a resource for the child. It includes warning signs, coping strategies, ways to handle grief for the hospitalized child's sibling.

## Siblings of the Hospitalized Children: Effects on School-Aged Children

### **Introduction**

Hospitals can be a daunting place for children and their families. The time spent in hospitals can be long and create stress and anxiety for families. There are many outlets and resources for medically fragile children their families to get the help and information they need to make the overall experience less stressful and daunting. Doctors and nurses can provide helpful medical information that allows parents or guardians of a child to understand the logistics and steps on their child's medical journey. Additionally, doctors, nurses and other medical professionals, such as Child Life Specialists, can be a resource for the children in the hospital. Child Life Specialists "help infants, children, youth and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss and bereavement" (Child Life Professionals, 2018). Child Life Specialists are also amazing aids that can help children understand what is happening on a level that they can comprehend, and they can also provide coping strategies and activities to help relieve the stress on the child, deal with pain, and understand their situation. There are many resources targeted towards medically fragile children and their parents or guardians, but resources specifically for siblings of hospitalized children are limited.

When I was brainstorming ideas for my Honors Thesis I wanted to create something that was a tangible resource that would benefit families who have children in the hospital. During my research, I narrowed my focus on siblings of hospitalized children. Throughout this research when referring to siblings who are not in the hospital they will be referred to as siblings and children who are in the hospital will be referred to as medically fragile or hospitalized children. Medically fragile children may have siblings within their families.

Siblings can be affected by hospitalized children. Having medically fragile children in the hospital can cause stress and anxiety on the sibling. A handbook can serve as a resource to help guide and lead siblings to manage stress, cope, and gain a better understanding. I believe this is something that might be often overlooked or even forgotten, which is why I have chosen to develop a handbook for siblings for my Honor's Thesis.

The handbook is called *Helping Hand: A Guide for Siblings to Understand, Cope, Grieve, and Heal*. It is written for children between the ages of six and nine years, because this is a critical point in development where children are just now grasping their emotions and feelings, but still need guidance and direction. The handbook includes activities and conversation starters for siblings of hospitalized children and their parents or guardians. The handbook also provides information such as coping strategies, preparing for visits in the hospital, and how to get support outside from the children's family. The handbook is a tool and resource for siblings to have on hand and be able to rely on.

### **Development of School-aged Children**

School-aged children are going through a critical part of their development where they are learning new things every day and trying to figure out the world and their purpose in it. The age of school-aged children can range from four to eleven or twelve years old. For the purpose of my research, I am focusing on children between the ages of six and nine years, which is also referred to as the "middle childhood" substage of school-aged children (Center for Disease Control and Prevention, 2017). Children in this age range are going through many social and emotional changes. They are beginning to become more independent from their family and developing their own ideas and opinions (Center for Disease Control and Prevention, 2017). During this time, children are looking to the future and they are

developing an understanding that happen in their life now have an effect on their future (Center for Disease Control and Prevention, 2017). Additionally, children are gaining a better understanding of who they are and their place in this world. School-aged children in this age range are developing concrete thinking (Center for Disease Control and Prevention, 2017). They are still learning how to talk about their feelings and thoughts but have a better understanding of how to express themselves (Center for Disease Control and Prevention, 2017). Additionally, these children are less focused on themselves and more focused on the people around them. They become more invested in the well-being of others than they had in the past (Center for Disease Control and Prevention, 2017).

All of these developmental factors impact how children cognitively and emotionally process and respond to having a hospitalized sibling. In a study conducted by Knafl and Dixon (1983) “[t]he most negative reactions of siblings occurred between the ages of 4 and 11 years. The nature of the illness itself is concerning to the siblings who may worry about the outcome, fearing that their brother or sister might die” (Rollins, Bolig, & Mahan, 2017, p. 28). School-aged children may be consumed by their own thoughts and ideas of what is happening to their sibling. In a study by Craft (1989) researchers found that “siblings of an ill child were most concerned about being separated from their brother or sister worried over the illness, and feared the outcome” (Gaynard, 1998, p. 224). School-aged children’s are trying to understand the complexities of their sibling’s illness and they contemplate why this is happening. These children may understand that something is wrong, but are struggling to grasp it in its entirety. In Sourkes study (1980), it states that “siblings also may have a fear that they as well might get such illness” (Rollins et al., 2017, p. 232). This is why it is crucial to have a resource to help explain what is happening to the hospitalized child to the

sibling. Usually, children at this age “tend to revise their appraisal of the sick child’s state of health in a positive direction unless they continue to be exposed to negative reminders” (Rollins et al., 2017, p. 232). School-aged children are at a critical developmental period that requires delicate care to help the children fully understand, communicate, and cope with their sibling being in the hospital, which is why I have created a handbook specifically for siblings between the ages of six and nine years.

**Application of research.** The decision to direct the handbook towards school-aged children was so that siblings could use it as a resource for themselves as well as with their parents or guardians. School-aged children are able to read and write and the handbook is a tool for them to reflect and have a personal item for themselves.

### **Recognizing Triggers and Warning Signs**

The parent and child relationship is important throughout the duration of a siblings stay in a hospital. School-age children are just starting to understand what illness is, how a hospital may work, and that death is permeant and universal (Adler & Taylor, n.d.). When a child is in the hospital the sibling is strongly affected. Research conducted by Holt and Rollins suggests that “[c]hildren may feel physically or emotionally abandoned, interpreting these events as a loss of love, or they may feel they are being punished. They may be similar to those symptoms of separation anxiety” (Rollins et al., 2017, p. 29). One of the tools that Child Life Specialists use in their therapy is the concept of open communication and helping siblings understand their feelings (UCLA Children’s Hospital, n.d.). Validating feelings and having open communication with parents and their sibling can help children understand what is going on and feel supported (Gaynard, 1998).

When helping siblings of hospitalized children, it is important to understand their individualized needs. Sometimes it is difficult for a child to verbalize exactly how they are feeling or even understand fully themselves how to communicate. There are some typical triggers or warning signs when a sibling may feel uneasy about their sibling being in the hospital. Noting and recognizing these signs can reduce stress and anxiety on the sibling and help guide them to outlets and resources to manage them. Some of these signs include the following: changes in their eating habits, acting out and playing aggressively or becoming withdrawn from activities that they normally feel engaged in, clinging to parents or loved ones more than usual, regressing to habits that were in their early childhood, and, even possibly, saying that they feel sick like their sibling (UCLA Children's Hospital, n.d.). Some of the emotions that a child may feel when their sibling is in the hospital may be confusion, guilt, fear, anger, jealousy, rejection, lonely, and worried (UCLA Children's Hospital, n.d.). All of these feelings may be hard for children to understand or even know what they mean.

**Application of research.** The handbook is used as a guide for children who may be experiencing these triggers or warning signs. Children who have siblings in the hospital may feel a sense of abandonment as mentioned previously. They might feel separation anxiety from their parents or guardians. The handbook is aimed for children and parents to work together as a way for them to reconnect, start conversations, and create opportunities for children to ask questions, prepare children when they visit their siblings, and reflection.

### **Emotions and Feelings**

Understanding one's feelings is something that even as adults is a struggle. Being able to identify their feeling fully can help the sibling understand and cope. The Center on the Social and Emotional Foundations for Early Learning, or CSEFEL, is a program that

focuses on the social and emotional development of children (Hemmeter, n.d.). CSEFEL has resources and activities to help children identify, express, and understand their feelings.

Even though CSEFEL is targeted toward younger children, during such a difficult time the sibling may struggle even more to express and understand their feelings because of all the external stressors. In a Vanderbilt article by CSEFEL, "Teach Your Child to: Identify and Express Emotions," there are four steps to help a child understand their emotions (Hemmeter, n.d.). The first step is to identify and use the word in which the child is feeling. Identifying the word gives it meaning. Showing the child pictures or videos of facial, body, and verbal expression of this emotion will help the child understand which emotion they are feeling. Step two is to help the child learn how to handle the emotion that they identified. Learning how to appropriately express their feelings will help the child understand how to manage and seek help when needed. Using real-life examples as a teachable moment are important to the child's understanding of their feelings. Step three is to encourage and validate a child's feelings. This way they know how important it is to be honest with their feelings and will be able to communicate effectively. The final step is making sure that the child feels supported. If a child is in a difficult environment where they feel they need to mask their emotions it can lead to emotional damage (Hemmeter, n.d.). Helping a child identify and understand their emotions not only improves their way of effectively communicating, but also gives them piece of mind and helps validate their feelings. When a child has a sibling in the hospital, it can be difficult for the sibling to recognize, identify, and cope with their emotions (Hemmeter, n.d.). With CSEFEL's four steps, the child will be able to feel more comfortable and be able to manage their stressors and anxieties surrounding their sibling in the hospital.

**Application of research.** In the handbook, there is an entire section dedicated to identifying, explaining, expressing, and understanding one's feelings. The first section is an emotions chart for children to be able to find and identify their emotions in that moment. The next section helps children understand what that emotion means and how to express their emotions in an appropriate manner. There are some activities directly from CESFEL that can help children effectively express their emotions. There is the "Mirror, Mirror What Do I See" activity which helps children express their emotions and see their face in the mirror. This helps them express their emotions because they are able to see right in front of them what they feel and how they are expressing their emotions through their facial expressions. The next activity is called "Make a Face." This activity is to be played with more than one person. It not only helps children read other people's emotions but can help them practice empathy so that they can understand that other people have different feelings as well. The final activity is to "Make an Emotions Book." This book is a way for children to write down their emotions and create their own book.

### **Coping Strategies and Tips**

There are some tips the sibling can try to implement in their everyday life. One tip is to engage in conversation with parents or guardians to help fill them in on what is going on with their hospitalized sibling. Having these conversations is important for the sibling and the family because it allows them to gain a better understanding of the illness and process it. Another tip is to encourage discussion with parents, loved ones, or therapists. Children sometimes have a difficult time expressing their feelings, opinions, thoughts, and fears. As mentioned previously, there are some ways to identify these emotions, and being able to express those feelings to their loved ones or a therapist can help them cope. It is important

for the child to know that their feelings are validated and it's good to be reassured. Children who have a sibling in the hospital are still children. Children's feelings should be validated and reassured to help them know it is okay to not be okay. Keeping up a routine will help the child manage their stress and anxieties because they know what is going to happen throughout the day and that way they can be distracted for a little while and remove themselves from the situation. Having a sibling in the hospital is difficult but having a routine and making time for themselves will help them manage their stresses and anxieties. Having an item that will help with coping can be an option for some. For example, a child could get a doll or stuffed animal that reminds them of their sibling or just something to love on. Finally, visiting their siblings in the hospital is also important for the child's well-being. It will be a positive experience for both the hospitalized child and the sibling (UCLA Children's Hospital, n.d.).

Coping helps siblings process their anxieties and fears towards the medically fragile child. Coping strategies help siblings manage stressors. Specific coping strategies and activities will be described in the handbook; although, there are some overarching goals for effective coping strategies.

The goals of effective coping strategies include the following:

1. Engaging in thought stopping: the forces substitution of positive thoughts for negative ones
2. Developing empathy: the ability to assume the perspective of another
3. Having other well siblings with whom to share feelings, concerns, and household tasks
4. Using available social support network to provide physical and emotional care when needed
5. Having opening communication within family that promotes expression of feelings. (Thompson, 2018, p. 30)

**Application of research.** In the handbook, there is an emphasis on positivity. In the section called “Absolutely Positivity” in the handbook, there are examples of situations children who have a sibling in the hospital may experience, the negative thought they may have, and the way to change it into a positive thought. The next section gives children the opportunity to write their own situation, negative thought, and then change it into a positive one. Having these parts in the handbook is to not only make it personal to their experience of having a sibling in the hospital, but also work through those negative thoughts and change them into positive ones.

### **Conversations and Communication**

Something that is often difficult for children struggling with the hardships of having a sibling in the hospital is being able to have conversations with their parents. Ways that this can start is by including the sibling in conversations about the illness of the hospitalized child as well as allowing the sibling to ask questions. There will be times when age appropriateness and difficult topics may not be good for the child to hear but keeping them in the loop will help the sibling understand what is happening to the medically fragile child and make it easier to cope. It is important to know what is developmentally appropriate for school-aged children. It needs to be something that the child will understand and be able to grasp. As parents or guardians, it will be important for them to speak honestly with their child; however, it is helpful to not provide details that are not necessary for the child. The sibling is already experiencing so much, and stress, unwanted fears, and anxieties will only make the process more difficult (UCLA Children’s Hospital, n.d.).

**Application of research.** In the handbook, there is a section called “Conversations with Parents: Where to Start!” This section outlines the steps for children to take when

wanting to start a conversation about their sibling in the hospital. The next section is called, “Some Starter Questions.” This section gives children the opportunity to get some ideas of what type of questions they may want to ask their parents or guardians. Additionally, there is space for children to write down their own questions.

### **Support from Outside the Family Circle**

The hospitalized child’s sibling is faced with many challenges in their everyday life when trying to cope and understand what is happening to their medically fragile sibling. They go to school, hangout with family and friends, have sports or extra-curricular activities where they are faced with masking their feelings or not having an outlet. It is important for the caretakers of the child whether that be teachers, guidance counselors, coaches, or even other parents to understand how to help the sibling through this difficult time. Being able to have these people as a resource for the child is crucial to the child’s well-being (Thompson, 2018).

With any caretaker of the child outside of the family, it is important that they know they have a role. They play an important part to the child’s coping and management of stress. However, there are some steps before talking to caretakers outside of the home. It is important for parents and children to have conversations regarding how much they want to tell teachers or other caretakers, in what way they want or need support, and how they can effectively utilize resources at school and other facilities. All children are different, and some may want more support than others. It is important to understand not only the boundaries of what the hospitalized child wants, but also what the siblings wants to be kept confidential or not. Being able to effectively have these conversations can open up more

outlets and opportunities for the sibling to have more resources when they are not in the comfort of their family circle (Thompson, 2018).

Other ways the sibling can find support is through support groups. Families and siblings can all be involved in these groups to help them understand how to communicate with one another as well as having an outlet to express their feelings. “[Support groups] can help the child be able to socialize, gain reassurance, support, coping, education, communication, and diversion” (Thompson, 2018, p. 90). When choosing a support group for the sibling of the hospitalized child, the family needs to effectively communicate to know the needs of the sibling to see which group could fit him or her best.

**Application of research.** In the handbook, there is a section called “Support at School” which includes the steps children can take when they want to have some extra support at or after school. The section after that is called “Questions to ask myself” which is a section for children to brainstorm who they would like to be a part of their support outside of their family and how they would like those people to support them.

### **Hospital Visits**

It is extremely important for the sibling to be able to visit the hospitalized child. It is beneficial for the child’s understanding: “This not only will allow for the sibling to see their child, but also will help the child understand more concretely what is happening to the child” (Rollins et al., 2017, p. 30). Preparation is crucial to help the sibling understand what is happening. Dolls, puppets, and photographs can be used to help aid the process (Rollins et al., 2017, p. 30). By helping them stay connected it will be beneficial to the sibling’s understanding of what is happening and could alleviate stress even if is just “a few minutes for them to talk on the phone or via video message. Encourag[ing] them to draw pictures or

make a card for their sibling. They may also enjoy sending along a favorite toy or book for their sibling” (UCLA Children’s Hospital, n.d.).

Many studies have also shown that there are a lot of benefits of sibling visitation. In Oehler’s study in 1990, researchers found that “siblings who visit their sick [sibling] are better informed about their sibling and expressed feelings that imply cooperative effort in caring for the [child] as part of the family” (Thompson, 2018, p. 225). Similarly in Conroy’s study in 1990 it further confirms that siblings can also play a large role in the overall health of the hospitalized child (Thompson, 2018, p. 226). Conroy’s findings showed that a sibling who visited their sick sibling in the hospital after heart surgery showed significant progress and was discharged three weeks after the surgery (Thompson, 2018).

**Application of research.** In the handbook, there is a section called “What to Expect” which includes some pointers on what children may need to expect when visiting their hospitalized sibling. For example, the medically fragile child may not seem as excited to see their sibling, but that is because they are working very hard to get better. This will help children be prepared to visit the hospitalized sibling and make it an easier transition.

### **Death and Dying**

One of the most difficult topics and discussions that could happen when a sibling is in the hospital is talking about death and dying. This is a concept that is different for every person. The school-aged child’s concept of death is more developed, but also confusing for them. There is an increase in wanting to understand the physical side of death and why it is happening. Children this age are very curious about the steps leading up to death and why it resulted in death. School-aged children use a concept called “magical thinking” (Adler & Taylor, n.d.). Magical thinking is when children believe that their thoughts translate into

what happens in the real world whether that is death, accidents, or illness (Adler & Taylor, n.d.). The concept that death is a possibility to many is hard for them to wrap their head around. Typically, at this age children have little to no experience with death. The way that the school-aged child understands death is through the idea that it is a sort of being such as a person or a ghost-like figure (Adler & Taylor, n.d.). All these developmental factors of a school-aged child's concept of death play a significant role in how to help prepare a child for the potential death of their sibling.

There are ways to prepare as best as one can, but obviously everyone reacts differently. "The experience of sibling bereavement is a lifelong process requiring ongoing integration into the lives of those touched by such a loss" (Rollins et al., 2017, p. 231). A child who has lost a sibling is experiencing something that is called a double loss because their parents are also grieving for the loss of their child. The child is not only confused and sad about the loss of their sibling but feels helpless and lonely because their parents are also grieving (Rollins et al., 2017, p. 231). A study that was conducted by Sourkes in 1980 states that siblings have in their mind their own ideas about what happened to their sibling when they died. They use their own observable disease or injury symptoms and try to come up with a scenario of how it happened. School-aged children struggle to grasp the concept of how this disease or injury caused the end of their sibling's life. They also fear that they might get such illness. This is why it is extremely important in an age appropriate setting for the child to understand what it is to their sibling so that they do not go down this rabbit hole of turmoil and stress (Rollins et al., 2017,).

Every child may react differently at the time of their sibling's death, but there are some signs that may show that they need extra help. In a study by Davies in 1999, it

“indicate[d] that 44% of siblings reported an inability to concentrate in school and went on to report that the longer they stayed away from school, the harder it was to re-enter the school routine” (Rollins et al., 2017, p. 234). Every child is different in how they will understand and comprehend death, but the consensus in Davies study suggest that children typically need about a week or so before returning to school. As previously mentioned, it is important to have a good relationship with the teachers and guidance counselors in the classroom of the sibling so that they are also involved in the process and create a plan (Rollins et al., 2017).

At the time of death, the sibling should be included. In Davies study, it states that when children are involved in the processes and rituals at the time of death, they have a better understanding of the loss and can reconcile with it (1999). They will also be able to show psychological growth and be able to grow from the death of their sibling. By including the sibling in the process and rituals, the child will have a greater sensitivity and better understanding of the value of life and the people that are involved in their life (Rollins et al., 2017). Having a space for the sibling to retreat and be able to get away from it all will be beneficial for the child’s overall healing process: “For bereaved children to ‘play out’ their grief thoughts and feelings is a natural and self-healing process” (Rollins et al., 2017, p. 235).

**Application of research.** In order to not create fear or unnecessary thoughts in children’s minds, the decision to move the sections called “My Sibling May Pass On Soon,” “Steps to Take” and “My Sibling is No Longer With Us” to an addendum is to dismantle any of those thoughts. In the addendum, there is a letter to parents stating that along with this handbook, in the unfortunate case that their child may die that this addendum can be used as a support. In the addendum, the section “My Sibling May Pass On Soon” includes a narrative that explains that sometimes children get sick and do not get better. The next

section called “Steps to Take” lists out ways a child can be included in the final rituals of the hospitalized child’s life. The final section is called “My Sibling Has Died.” The purpose of using the word “died” is to create an honest tone with children so that they can process it better. Going around the word can only lead to further confusion. In this section, there are steps children can take to help them heal through the grieving process. This handbook’s purpose is to be inclusive to all children whether that be a family who has a hospitalized child for short while, a long while, or until death.

### **Conclusion**

Families are bonded together by the close-knit relationships they have. Siblings have a bond that is sometimes hard to even put into words. Having a hospitalized child can make relationships and processing a little more difficult. The aim of this handbook is to help children and families understand what is happening. The goal is to help families understand, cope, grieve, and heal together.

## References

- Adler, L. C., MD, & Taylor, W., RN, Ph.D. (n.d.). A Child's Concept of Death. Retrieved from <https://www.urmc.rochester.edu/encyclopedia/content.aspx?ContentTypeID=90&ContentID=P03044>
- Association of Child Life Professionals. (2018). What Is a Certified Child Life Specialist? Retrieved from <https://www.childlife.org/child-life-profession>
- Center for Disease Control and Prevention. (2017, January 03). Child Development. Retrieved from <https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/middle.html>
- Gaynard, L. (1998). *Psychosocial care of children in hospitals: A clinical practice manual from the ACCH Child Life Research Project*. Rockville, MD.: Child Life Council.
- Hemmeter, M. L. (n.d.). CSEFEL: Center on the Social and Emotional Foundations for Early Learning. Retrieved from <http://csefel.vanderbilt.edu/>
- Ollendick, T. H., & Schroeder, C. S. (2003). *Encyclopedia of clinical child and pediatric psychology*. New York: Kluwer Academic/Plenum Publ.
- Rector, L. (2007). *Supporting siblings and their families during intensive baby care*. Baltimore, Md.: Brookes.
- Rollins, J. H., Bolig, R., & Mahan, C. C. (2017). *Meeting childrens psychosocial needs across the health-care continuum*. Austin, TX: PRO-ED.
- The Children's Hospital of Philadelphia. (2014, May 12). Preparing Siblings for a Brother or Sister's Surgery. Retrieved from <http://www.chop.edu/patients-and-visitors/guide-your-childs-surgery/preparing-siblings-brother-or-sisters-surgery>
- Thompson, R. H. (2018). *The handbook of child life: A guide for pediatric psycho social care*. Springfield, IL: Charles C Thomas, Publisher.
- UCLA Children's Hospital. (n.d.). Tips for Preparing Siblings for a Child's Surgery. Retrieved from <https://www.uclahealth.org/mattel/tips-for-preparing-siblings>