Lives Interrupted: A Sibling’s Guide to Cancer

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By
Robin Sweeney

Dr. Bernard K. Duffy
Senior Project Advisor
Signature
Date

Dr. Bernard K. Duffy
Department Chair
Signature
Date

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It was two weeks before the end of my freshman year of college and the only worries I had were studying for finals and finding a summer job. As a freshman in college what other worries could I possible have? Little did I know my life was about to change. I received a call from my parents on a Tuesday afternoon, informing me that my younger brother, who at the time a junior in high school, had been diagnosed with Leukemia, a cancer of the blood cells. I did not believe it was true; I had been home just two weeks before and he had seemed perfectly fine, health wise. At the time I felt scared; I had no idea what to expect, for me when I heard cancer the only thing I could think about was death. My parents started reading handbooks on how to deal with a child who has cancer and joined support groups, but I felt there was nothing available that could help me cope with and understand what me, my brother, and my family were going through. I did not know anyone else whose brother or sister had cancer and I felt that no one could understand what I was going through. I was not sure how I was supposed to feel, or how I was supposed to act around my brother. But worst of all I felt helpless; I thought that because I was not a doctor or had any experience in the medical field there was nothing I could do to help him. After all my family went through, I realized there is a lot we as teens can do for not only our siblings but our family and friends as well.

**Purpose:**

For my project I propose to write a handbook for teens to help them cope with the difficult challenges they may experience while having a sibling who has been diagnosed with cancer. I also hope to help them discover the positive that can happen throughout this experience. The purpose of this handbook is to help eliminate some level of uncertainty, to prepare a teen with the feelings they and their sibling will be going through, to prepare
them for their different changes in roles and responsibilities in their family and friends, to show them ways to help, how to continue with life after cancer, and to bring them insight on how to find further support through social media.

**Justification:**

There are only a limited number of handbooks dedicated to this field and they are extremely outdated and not very useful. According to an article by KidsvCancer.com each year around 13,500 children are diagnosed with cancer in the U.S. Putting it in a better perspective for us that is more than an average size classroom of kids a day. Most of these children have siblings, which is why this handbook is something that can be useful to a new large group of people everyday. In the past fifteen to twenty years, researchers have found that healthy siblings often receive the most negative effects from the childhood cancer experience and often times seem to bear the greatest hidden burden of stress in the family system (“Cooper Trooper Is…”). This handbook is not intended to be an exhaustive instruction manual on how to feel but instead a guideline for teens to turn to in times of need. For every person's experience is different and each individual will take away something different from this handbook. I intend for this handbook to be updated continually with new research findings when available and the input of others experiences.

**Communication Theories:**

“Communication is at the heart of health care and health promotion” (Parker 23). My handbook directly relates to the communication studies discipline through societal health communication, Uncertainty Reduction theory, and the Cultivation Theory. “Societal health communication examines the generation, dissemination, and utilization of relevant health information communicated through a diverse media to a broad range of professional
and lay audiences to promote health education, promotion and enlightened health care practice” (Kreps 4). With this handbook I am attempting to communicate health information, the ways for a teen to cope with a sibling who has cancer, to a mass amount of people with a goal of promoting a form of health education. With this handbook teens will also be able to find more information and support through multiple forms of media. The communications theory, uncertainty reduction theory also relates to my handbook. The uncertainty reduction theory claims that people reduce their uncertainty by gaining more information (”Uncertainty Reduction Theory”). Uncertainty reduction theory also correlates with a study that found that target receptiveness was positively related to uncertainty reduction management (Thompson 345). This same study also found that advice optimism was positively related to coping processes, which means that people who wished to seek advice and were able to find it were able to reduce their stress and uncertainty as well as find a better way to cope. With this handbook I wish that people who, like me, searched for some advice to help them get through this tough time can find it. The Cultivation Theory is another communication theory that applies to my handbook. The cultivation theory claims that “the more television a person watches, the more their perceptions of social reality reflect the realities portrayed on TV” (Nabi 75). Rashid, age fourteen, said “I was so scared when I found out that my brother had cancer. In the movies cancer always seems so terrible. Then I realized I didn't really know that much about cancer” (When Your Brother or Sister Has Cancer 14). Like Rashid I felt most things I knew about cancer I had learned from what happens in movies. Movies like a “A Walk to Remember,” “Sisterhood of the Traveling Pants,” and “My Sisters Keeper” are all popular movies about kids who have cancer and they all die at the end of the movie. When we
watch movies like these we can often believe television’s reality of cancer, that not many children survive it, when in reality cancer survival rate in children is around 80% (“Surviving Childhood Cancer”). With this handbook I hope to provide facts where teens can get real information about their siblings’ cancer.

**Method:**

To create this handbook I researched what few outdated handbooks are available for teens and families with siblings and children who have cancer, as well as handbooks for parents of children with cancer. I then searched through heath communication textbooks and online articles about different studies done on communication theories I have listed above. Finally I searched for different online social media sites like support chat rooms, profile sites and other websites where teen’s who have a sibling with cancer can find more information on their sibling’s illness and find support. I will also interview other siblings to see how they felt and what they did to help them cope with their sibling's illness.
Lives Interrupted:

A Sibling’s Guide To Cancer
Introduction

Your brother or sister has been diagnosed with cancer, no matter what kind of cancer it is, or how old they are they need you and that is why you are now in possession of this handbook. The main thing to remember is that you are not alone, currently at this moment this may be how you feel, but that is what this handbook is for, to remind you that many of us have gone through this and that there are many people going through it right now who are just like you, feeling just the same looking for a way to cope with this new change. This handbook is written for teens that want to be there for their siblings who have been diagnosed with cancer, and who are seeking advice and information on how to cope with this new challenge in their lives. Combining personal anecdotes and the experiences of others, with information from professionals in medical, psychological, and family relationships this handbook will provide you with strategies to help eliminate some level of uncertainty, to prepare you with the feelings you and your sibling will be going through, to prepare you for the different changes in roles and responsibilities in your family and friends, to show you ways to help, how to continue on with life after cancer and finally to bring insight on how to find support through social media. This handbook is just the beginning; it will not be able to give you all the answers or everything you need but I hope that it will be a start, something to comfort you and to a be there to turn to when the time gets tough and mostly to help you help your brother or sister.

My inspiration for writing this handbook is based on my experience of attempting to find some sort of help and comfort during my own brother's diagnosis with cancer. I was eighteen and he was seventeen when he was diagnosed with Leukemia. During his treatment I failed to find any sort of handbook to help guide me through my brother's
cancer, which is how I got the idea to write my own, with the thought to help others who are in the same situation I was. I hope with this handbook to help you lessen the fear of the road ahead, and to give you insights on ways you can help and where to find further support. The journey you have before you is a long one, but it does not mean it can not be filled with fun, laughter and positive outlook.

What is Cancer?

Learning about your brother or sister’s cancer and treatment can often reduce your uncertainty level and help you feel less afraid. Often times the “facts” you think you know about cancer are not always true or applicable to your situation. One of the first things that is important to know, is that the survival rate of children who have cancer has increased dramatically. The survival rate for children increased from 58.1 percent in 1975 to 79.6 percent in 2003 (“Childhood Cancers”).

There are many different types of cancer, but most cancer begins in the cells, which are the body's basic units of life. Our bodies are made up of cells, and each cell has its own identity and responsibility for making something in our body: skin, hair, etc. (Brombeck 27). To understand cancer you must first understand how normal cells work. Normal body cells grow, divide, and die. When you are young these cells divide faster to help you grow and when you become older they divide to replace worn out or dying cells. Cells become cancer cells due to damage in your DNA, which is what controls all the cells’ actions. When DNA gets damaged in a normal cell, the cell either repairs the damage or the cell dies. In a cancer cell when the DNA is damaged the cell is not repaired and does not die; instead the cell makes damaged DNA cells that the body does not need, continuing to create these unwanted damaged DNA cells. These cancer cells can also attach on to other tissues,
something that normal cells cannot do. It is rare to know exactly what causes any one person’s DNA damage. People can inherit damaged DNA or it can be caused by something that happened while the normal cell was reproducing or by something in the environment like sun exposure or cigarette smoke (“Learn About Cancer”).

This is just a general understanding of what cancer is and how it starts. It is important to remember that all cancer is different and some facts you know or hear about cancer may not always apply to the type of cancer that your sibling might have. It is important to be informed on the specific type of cancer that your sibling has. For more information on different types of cancers, turn to the “Further Support” section of this handbook to find websites that can help answer some further questions you may have, or talk to your sibling’s doctor.

**The Emotions You and Your Siblings Might Go Through**

This section will address what feelings you may be experiencing and how to cope with them, as well as what feelings your sibling may be experiencing, how to help them cope, to better understand what they are going through and why they may be acting the way they are.

**Your Feelings**

There are many different emotions you will experience during your sibling’s cancer, such as guilt, fear, anger, loneliness or neglect, embarrassment, jealousy, and sadness. You first must understand that there is no “right” way to feel. Some of these emotions you will experience and others you might not. There may also be some emotions you feel that are not on this list, but that does not make it any less ok to feel them. Remember you are not alone, as many other teens in your situation have experienced these emotions. Though
some of the feelings you may be experiencing are not positive ones, this section of the handbook is to help you understand where these feelings are coming from and help you cope with them, even turning some of these emotions into more positive ones. Having a brother or sister with cancer can change the way you look at things in life.

Guilt

There are many different reasons as to why you may be feeling guilty. Siblings claim they often feel guilty because they believe it is somehow their fault that their sibling has cancer (When Your Brother or Sister Has Cancer 6). You may also feel guilty because you believe that your sibling got cancer either from something you did, said, or wished upon your sibling out of anger. A doctor, interviewed by Emma Bombeck, claimed that “the one thing that is important for families to know from day one is that even if we knew that this was going to happen, there is absolutely nothing that we could tell you that you should have done differently that would have made any difference because we just don’t know where it (cancer) comes from. They need to know that” (Brombeck 25). Doctors often do not know the specific cause of the cancer but like this doctor states you should not blame yourself, nothing you did caused your siblings cancer. Another reason you may be feeling guilty is because you are healthy or that you somehow “escaped” the illness. This guilt may come from the fact that you are able to participate in activities or attend events that your sibling cannot due to their illness. Enjoying some of these positive activities a valuable thing for you to do for your own health benefits (“Cancer In Teens”). Know that it is both okay and important for you do things that make you happy. Having emotions such as anger, jealousy or shame is another reason why many teens said they felt guilty. In this situation, a great thing to do is to communicate to your parents, a sibling, or someone you trust (When
Being able to share how you feel may help you get a better sense of why you are feeling this way. You may realize that other people may feel this way or maybe that this feeling is irrational. Another reason you may feel guilty is due to the fact that you cannot protect or cure your sibling from cancer. We will address how to deal with these feelings and how to help under the section of “Ways You Can Help Your Brother or Sister.”

**Fear and Anxiety**

It is reasonable for you to feel scared or afraid. Some of your fears may be real, while others are based on things that may not happen. Finding out more information on your sibling’s cancer or treatment can help eliminate or lessen some of your fears. Fifteen year old Mathew says that when he went with his brother to get his treatment, he saw “the machine that he gets radiation from and got to meet his doctor and nurses and see a lot of other kids with cancer” he claimed that by seeing all of this and finding out more information he “feels better knowing more about what is going on” ([When Your Brother or Sister Has Cancer](#) 27).

The fear of “catching” cancer seems to run high amongst teens with a brother or sister who has cancer. You may see many similarities between yourself and your sibling, such as the same family and similar past experiences. Such similar backgrounds can leave you questioning if you have cancer as well. This often happens when you cannot come to a conclusion cognately or emotionally about a cause for the illness. In order to prevent an over identification with your sibling, you must be able to participate in some of your own day-to-day activities and relationships. This independent aspect of your life can counter
balance the sense of similarity and identification often felt in a sibling relationship (Kellerman 58).

Loosing your sibling to cancer may be among your highest fear. Just because your sibling has been diagnosed with cancer does not mean they will die. There are many ways to treat cancer, and new treatments are being discovered every day. Discuss your fears with someone you trust: a friend, parent, therapist, or even your sibling’s doctor, as they may be able to eliminate or reduce some fears you may have about your sibling’s condition. If you are not yet ready to talk about your fears you can write them down, it can feel good just to let your feelings out. When my brother was diagnosed with cancer I had a hard time talking to people about how I felt. I wrote down the fears I was having in a notebook, then when I was ready to talk to someone I read a lot of the things I had written out loud. After hearing my self read my feelings I realized many of them were irrational and it helped me to feel less afraid.

Anger

There are many reasons as to why you may feel angry, you may even be angry with yourself for feeling angry. Teens claimed they felt angry is due to the fact that their parents are spend a lot less time and attention on them (When Your Brother or Sister Has Cancer 8). If you feel this way, express these feeling to your parents and help work out a way you guys can spend more time together. With your parents now spending more time with your sibling there are many changes going on in your family’s life. These changes may cause you to feel angry, like the fact that you might have to do more chores, or the amount of time your family now gets to spend together. Know that anger is a natural response to change (“Teen Health—Health Topics”). Anger can often cover up feelings that are harder to show,
but do not let this anger build up inside you. Try talking it out with someone or do an activity you enjoy, like reading, jogging or hanging out with friends. When you feel angry remember that it does not mean you are a bad person or you don’t love your siblings.

**Loneliness and Neglect**

During the time of your sibling’s diagnosis you may go through a time of loneliness or feel as if you are neglected. You may feel left out of family activities, especially if they are centered around hospital stays and doctor visits. Your parents may be spending a lot more of their time and focus on your sibling. It is common for the family’s focus to change. Your parents do not mean for you to feel left out, but this can often seem like the case. If you are feeling neglected talk to your parents about how you feel, and work out when you can spend time together. Your family loves you and just because they are not spending as much time or energy on you, it does not mean that they love you any less. It is not only your family that can make you feel neglected or lonely, but your friends may be the reason you are feeling this way. I will address this in the “Changes In Friends and Family” section of this handbook. A great thing to do is reach out to them and let them know how you are feeling. You may also feel a sense of loneliness from your sibling who has cancer, especially if they have to stay for long periods of time in the hospital, or you may just miss the way it used to be between you two. If your sibling needs to stay in the hospital for long periods of time, you can keep in touch through email, Skype, cards, letters, text messages, or forms of social media. Just because you may not get to see your sibling everyday does not mean your communication has to stop.
**Embarrassment**

You may also feel embarrassed at times during your sibling’s diagnosis. Fourteen-year-old Caroline, talked about her feelings of embarrassment, claiming, “now that my brother lost his hair and is so skinny, I don’t want my friends to come over anymore. I don’t want them to see how Tim looks” (When Your Brother or Sister Has Cancer 68). There is a chance that your brother or sister now looks different and like Caroline you may be embarrassed to be in public with your sibling because of how they now look. Remember that your sibling may also be embarrassed, but it is important to act confident to help them feel better about themselves. It can get easier with time when you find yourself feeling more comfortable with how your sibling looks. Feeling embarrassed may also come from not knowing how to answer people’s questions about your sibling’s illness. In this situation try to find out and understand it as much about your sibling’s illness as you feel comfortable knowing can so you can help others understand what is going on and help answer the questions they might have. Ask your parents or doctors for frequent updates so you have a better understanding of what is going on and feel more confident about answering others’ questions.

**Jealous**

Your sibling may now be getting more attention and gifts from family and friends. The fact that your sibling is getting all the attention can cause you to feel jealous. Even if you understand why you are getting less attention it is still not easy. Share your feelings with your parents; talking to them or someone you trust can help you find the source of your jealousy. This can be an opportunity to take the extra time you have and spend it with friends and family members who are also getting less attention.
Sadness

Sadness is a common emotion that is felt by teens with a sibling who has cancer. You may feel sad for your brother or sister who is sick or even for your parents. Your life has changed, and the loss of normal family life and a carefree childhood may cause you to feel upset. Try doing activities that make you happy like, playing sports, crafting or calling up an old friend. Talking to someone your trust can make also help you feel better about what you are going through. If this sadness persists and starts to get in the way your day-to-day activities, it is best to speak with a professional, like a therapist or social worker. They can help you feel better and get you back to enjoying your life.

Dealing with your feelings

Though all these emotions are normal to feel, “viewing stressful events in a more positive way; engenders acceptance of the reality of the situation, optimism about the future, and creates a sense of meaning and purpose” (Kayser 42). It can be hard to stay positive throughout your sibling’s entire diagnosis and treatment. Having these negative emotions is not a bad thing, but you have the opportunity to turn these feelings into positive ones. Siblings who were able to turn their negative emotions into more positive claimed that they had an “increased capacity for empathy and compassion, better coping skills, enhanced self-esteem, confidence in responding to adversity, closer relationships with siblings and parents, and greater insight into the things that really matter” (“Teen Health—Health Topics”). Talk with someone you trust about your feelings whether it is a family member, a friend, or someone your trust can help you turn around your emotions. It is amazing how just letting your feelings out can make you feel. It is also a good idea to talk to a professional, such as a psychiatrist, therapist or social worker. Often it is easier to talk
to someone we do not know for fear of placing a burden on our family member or friend. Many hospitals have sibling support groups or can recommend counseling for siblings and families of children with cancer. You should never feel embarrassed to reach out for help, ignoring your feelings will not make them go away. A lot of people are uncomfortable with sharing their feelings. If you are not yet comfortable with sharing your feelings a good thing to do is to write all the thoughts and feelings you have down in a journal. Sometimes you might not be ready to speak openly with someone or are not sure what to say, so writing them down can help you organize your thoughts and see a pattern of your feelings. It is also extremely important for you to continue to do the things you love. Sometimes a great thing to do is something that makes you happy. Have fun and enjoy time away from the worries of home: grab ice cream with a friend, go for a run, participate in a hobby, or do something that brings you joy. It may be hard to imagine right now, with what you may be feeling, but if you let yourself, you can grow stronger as a person through this experience.

Your Sibling’s Feelings

You are not the only person in your family going through many different emotions, most likely everyone in your family is, especially your sibling. Your brother or sister may feel afraid, sad or depressed, angry, guilty, or embarrassed. You may both be experiencing a lot of the same feelings. Knowing how your brother or sister feels can help you get a better understanding where they are coming from, why they may be acting differently at different times, and help you figure out how to help them. We have an amazing opportunity to be there for our siblings, to share our strength, our hope, and our affection for our sibling. This section will go over some of the feelings your brother or sister may have and some tips on how to help them get through it
Fear and Anxiety

Just like you, your sibling will also be feeling afraid. They will be worried about many things, such as whether their treatment will work, if it will hurt, and if they can still do the things they enjoy. There are many things that your sibling will be afraid of and the best thing you can do is to be there to listen and support them. Encourage your brother or sister to ask the doctor questions so that they have a better understanding of what they are going through. The doctor may be able to lessen and resolve irrational fears.

Sadness and Depression

Your sibling can feel sad or even depressed. Your brother or sister may not be able to do some of the things they used to do, and they might miss these activities and their friends. Find out why they are upset and try to find a way to solve it. If missing their friends is what is causing them to be upset, take action and call their friends up and invite them over, or plan something fun like a game at the hospital for your sibling and their friends. My brother loves bikes and was upset about not being able to ride his bike due to a long stay in the hospital My mom and I talked to the doctor and he was able to get a stationary bike in his room a few days a week so he could ride if he was feeling up for it. Try to do something a few times a week to brighten their day, because a little act of kindness can go a long way. Sometimes this sadness can turn into depression. There are professionals though, usually already at the hospital, who can help treat the symptoms of onset depression that your sibling may be experiencing. Encourage them to talk to someone if you notice signs of depression.
Anger

The cancer treatment side effects can cause your brother or sister to be angry or grumpy. Treatments can cause your siblings to be extremely tired causing them to become slightly irritable and quicker to snap at you. Jeremy, a sixteen year old cancer patient, admitted it to these feelings, claiming “I am not nice a lot of days. I feel ticked off. People get on my nerves... Some days I just feel mad about everything” (When Your Brother or Sister Has Cancer 38). Anger can also come from feelings that are hard to show, like being afraid, sad, or feeling helpless. Your sibling may be angry that they are sick in general or angry at whatever caused them to feel this way. The chances are that your sibling is not angry with you but instead this anger may be driven from something else. Try not to snap back at your brother or sister or feel offended, but instead give them time to cool down and possibly attempt to find where this anger is actually coming from.

Guilt

Your brother or sister may feel guilty that they caused such a big change in your family's life. They may feel like they are a burden to the family, especially if family and friends have to give up a lot to take care of them. Remind them that they did not cause this to happen and that it is not their fault. Instead try to help them think of good things that are happening due to their illness, like maybe your family is spending more time together, your relationship with your sibling has gotten stronger, or you have a better outlook on life.

Embarrassment

A sibling may also feel embarrassed about how they look. A lot of cancer patients lose their hair and drop or gain weight due to their treatment. Your sibling may be too embarrassed to do the things they used to enjoy because they do not want others to see
how they look. What you can do is to help them feel confident during this time. Help them find wigs or ways to cover up the loss of their hair with hats and scarves. Find clothes that are flattering on them and have make over days to help them feel beautiful on the inside and out. It is important for your sibling to continue to do the things they love and should not miss out because they are embarrassed, so do the best you can to help them feel confident.

Helping Your Siblings Cope With Their Emotions

All of these feelings are normal for a person living with cancer. You have the opportunity to help them deal with these feelings and create more positive ones. One of the best ways to help them stay positive is by being positive yourself. Being around someone in a positive mood can help put others in a positive mood. It is hard to be positive all the time, but do not feel the need to act happy if it is not currently how you are feeling. Be open with your siblings but also try to keep some emotions under control, find a balance and the right time to address certain issues.

Many of your sibling’s emotions may come from the fact that they are able to participate in a lot of the activities they used to enjoy. This is a chance for you to help them discover new activities that are approved by the doctor. Another thing that is important to remember is that your brother or sister is still the same person you knew before, so try to treat them the same, which is something that they will greatly appreciate. Most of the time you will not be able to come up with solutions to your sibling’s problems, but one of the greatest gifts you can give to them is your time and ability to listen (“Teen Health—Health Topics”). Sometimes just listening to someone’s problems can help them feel better.

Changes In Family and Friends
Your family may be going through a lot of changes; whatever situation your family was in before your sibling’s diagnosis has most likely or will most likely change. The change in your family is due to the fact that your family has lost a healthy child who had an active role in the family system. The present family system has now changed, including each individual family member’s role to change. This section of the handbook will look at some of the changes your family may go through and how others in your situation have dealt with them.

**Family**

Most likely one of the biggest changes is that your parents are spending more time with your sibling, which leads you to take on more responsibility. One important thing to do during this time of change is to touch base with your family about the things that are changing. Fifteen-year-old Brandon shared how he handled the role changes:

> It wasn’t fair that I had to watch my little brother and clean. I felt like I was going to lose it, but I tried to stay cool and told my mom how hard things were. Now I still have chores, but my brother goes to a friend’s after school, so that I can play soccer.

> My mom is awesome and really understood (When Your Parent Has Cancer 24).

Brandon was overwhelmed by the amount of responsibility he now had to take on, but talking to his mom helped her understand how he was feeling, and she was able to help lessen his amount of work. Talk about whose roles are changing and what is to now be expected of each person. This is a great way to make sure that everything that needs to be done gets done and a good way to make sure not one person in the family is taking on too heavy of a load. Communication can be a key to making sure things run smoothly in your family. You might find that your parents may not be sharing as much with you anymore,
especially if your family used to be very open. Most likely your parents are just trying to protect you from bad news, or are unsure about how much you want to know about your sibling’s illness and treatment. Some of you may want to know a lot while others may prefer to know less, so talk to your parents about how much information you want to know. Even if it is only for a short amount of time a week, families said that it was helpful to make time to talk to each other (When Your Brother Or Sister Has Cancer 46). Through these changes you your family has the opportunity grow stronger and closer. Thirteen-year-old Jared, talks about the positive changes in his family dynamics due to his sister’s cancer, claiming:

“My family wasn’t that close before my sister Gina got cancer. We used to go our own way and never did much together. When Gina got sick we started pulling together more. We talked about how important each day meant. Now it seems like simple things are special, like eating together as a family” (When Your Brother or Sister Has Cancer 48).

Siblings who claimed their families grew closer through their sibling’s cancer gave three tips to help a family grow stronger and closer: the first advice other siblings gave was to try to put yourself in other peoples shoes, thinking about how you would feel if you were the other person; second was to understand that everyone reacts differently to this situation, and even if they do not show it everyone is hurting; finally, they said that learning to respect and talk about each other’s differences helped them understand their feelings and work together to overcome their problems.
Friends

Your friends are some of the most important people in your life; often times they can be described as the family we choose. Now that your brother or sister has cancer it may feel like these friendships are changing, and you may feel like your friends are treating you differently or that they do not care about you anymore. Often your friends care but they don’t know what to say or they might be worried about upsetting you. In this case, the best thing you can do is to talk to them and let them know what you need from them. Also ask them what they want to know about your sibling’s illness. Some teens said they felt their friends wanted them to “get over it” and go back to how life was before their sibling was diagnosed with cancer. Others said it felt as if their friend’s lives were moving on without them. It can help to put yourself in your friends’ shoes, and think about what you would do if this were happening to one of your friends instead of you.

It may be hard to watch your friends get together and do things without you; this may be because you may be spending more time with your family and less with your friends. The best thing you can do is reach out to them when you can. Even though you now have a lot more going on in your life, it is still important to get together with your friends. This can also be a wonderful opportunity to reconnect with old friends and create new ones; you may be surprised by some of the people you connect with during this time, or people who will be there to support you. Fifteen-year-old Hamid talks about his experience with connecting with new friends:

I still see my friends, but things are different now. A lot of what they talk about seems kind of lame. They are into going to school dances or going to the mall. Sometimes I feel like an outsider. Stuff like who won the basketball game just
doesn’t seem important now. Then I found out there was another kid at school with a sibling who has cancer. I have more in common with him than I do with my friends I have known my whole life (When Your Brother or Sister Has Cancer 64).

You may realize that your interests and what you think is important has changed, which can create a great opportunity to meet new friends to help you through these times.

**Ways You Can Help Your Brother or Sister**

Through your brother or sister’s diagnoses with cancer you may be experiencing a feeling of helplessness. You might be thinking that because you are not a doctor there is nothing you can do to help your brother or sister feel better. And while there may not be a way for you to physically cure your sibling’s cancer, there are many different things you can do to help them during this difficult time, while also helping yourself. This section of the handbook will be filled with stories of things that other teens did to help their siblings, as well as things that I did that I found helpful. Not all of the examples may be applicable to your situation, but try whichever ones you want, or use these to help inspire you to come up with your own ways of helping.

Just being there with your sibling; whether or not you talk, laugh, cry, or just sit in silence, spending time with them can often be a wonderful comfort. If talking to one another is hard, you can try keeping a journal together, where you can both take turns writing, drawing, or sharing your thoughts. Another thing you and your sibling can do together if they are in the hospital is to visit the hospital’s activity room. Many hospitals have activity rooms full of games and arts and crafts. If your sibling’s doctor allows it and your sibling is feeling up for it, see if they want to go to these rooms, which can provide a great opportunity for you and your sibling to meet some people your age who are going
through the same things you are. There may be days when your sibling is too tired to go to activity room, but another thing you and your sibling can do together is watch a movie or television show together. Many websites offer full seasons of television shows for you to watch; pick a show the two of you haven’t seen and start from the beginning, watching an episode every time the two of you are together. This can give you guys something to look forward to when you are together, and still gives you guys a chance to bond when your sibling is too tired to do anything else.

Children with cancer sometimes have to spend long periods of time in the hospital. This is something that my brother had to do, and he always talked about how much he just missed being able to be at home. Though you may not be able to bring your sibling home, there are ways that you can bring your home to your sibling. Decorate your sibling’s hospital room with posters of their favorite band, sports team, or photos of them with family and friends. One thing my brother often complained about was the smell of the hospital, so we talked to the doctor about allowing him to use blankets and pillows from home. We would take them home often and wash them with our laundry detergent, because my brother said the familiar smell of the laundry detergent was comforting and made him feel more at home.

Not only can your sibling miss their home, but they might also miss getting to see their friends. One thing you can do is to for your brother or sister is help them stay in touch with their friends. Your sibling may physically farther away or just be feeling neglected by their friends, to help, ask your sibling’s friends to write notes, send pictures or send weekly texts or Facebook posts just to show that they care. If your sibling is up for it you can also invite their friends over to hang out. You can plan fun activities that your
sibling and their friends can do. For example plan, a game night, movie night, or if they are feeling up for it plan an activity outside the house or hospital like a hike or bowling. Being around friends can help them feel like a normal child again.

Beating cancer is a huge goal that your sibling is working at every day. Setting up small goals for them to accomplish along the way can help them feel confident, which is an amazing gift that you can give to your sibling. When my brother was in the hospital he was allowed to leave his room but not allowed to leave the pediatrics oncology floor. The floor layout was a circle, with the nurses’ center in the middle, so one day we decided to measure how long the circle was. We found that if he did 293 laps around the floor, it would equal twenty-six miles or the equivalent of a marathon. We taped up a piece of paper on his wall and every time he did a lap we would make a tally mark. Whenever he was feeling up for it throughout the day he would do a lap or two. The nurses and other patients caught wind of what he was doing and encouraged other patients to join in as well. The nurses even hung up posters in the hallway cheering on the patients who were attempting the “marathon”. Though it took a long time my brother said finishing the “marathon” made him feel good about himself for being able to accomplish something. He claimed it made him feel stronger and gave him the confidence to accomplish anything.

Another patient’s family had created a sticker chart. The patient got stickers on their chart for different things like remembering to take their medicine, finishing their meals, and doing other things that would help them get better. Each time they reached a certain number of stickers they got to pick something out from a toy box filled with little toys to entertain them in the hospital. This way the patient was encouraged, even excited, to do
things that would help them get better in the hopes of earning stickers and getting to pick out new toys.

The road to recovery is long; not only can setting goals help your brother or sister through this process, but planning fun events for your sibling to look forward to along the way can also help them cope. Giving them little things to look forward to can often give them the strength to make it through the next day. One thing I used to do for my brother every Friday night was that we would have game night in the hospital. Our close family friends would come over, trading off bringing appetizers and a different game and we would eat and play games, laughing and enjoying each other’s company. My brother said that it was nice to have something to look forward to every week, something to get him excited about. Another thing we used to do was watch The Price Is Right every morning in the hospital. Though it doesn’t seem like much, it was something we both looked forward to doing together every morning while we ate our breakfast. You can plan different activities for your sibling every day or week, like movie night, taco night or any fun activity that can get your sibling excited about the next day or week.

Another thing you can do to help keep your sibling’s spirits up and to give them something to look forward to post treatment is to refer them to The Make-A-Wish Foundation. The Make-A-Wish Foundation grants wishes to children with life-threatening illnesses. Once a child has been referred to the foundation, the Make-A-Wish Foundation will send out a “wish team” to help determine the child’s wish. After the child has decided on their wish, the wish granters get to work on making this wish the most amazing experience for your sibling as well as your family. These wishes can range from vacations, to meeting their favorite celebrity, to being a princess for a day, to whatever their creative
mind can come up with. For example, Melinda wrote a book while she was in the hospital about her experience with cancer; her wish was to travel to different hospitals across America to share her story to bring hope and inspiration to other children in the hospital. My brother wished for a surfing trip to Costa Rica. Whenever he got down about his illness or about having to be in the hospital, he said he thought about how excited he was to go on his wish trip, once he got better. It gave him something to look forward to and get excited about. Check out the Make-A-Wish website to find out more information on how to refer a sibling visit Wish.org.

During your sibling’s treatment, they may have a lot of down time; they may be out of school or have to be in the hospital for a while. Due to all of this free time, it may be beneficial to encourage them to pick up a hobby or learn something they have always wanted to do but never had time to. Finding a hobby is a great way to keep your sibling and yourself from getting bored, and gives you guys a chance to take your mind off the illness for a little while. You can even choose something to learn together, such as learning to play an instrument, painting, drawing, gaming, or anything that you or your sibling has wanted to learn. You can even turn your new hobby into a way to help others. For example, a close friend of mine and her sibling taught themselves how to knit. During their spare time they knit beanies and donated them to hospitals for children who lost their hair during chemotherapy.

Losing hair during chemotherapy is very common. Many siblings may feel embarrassed or sad about the loss of their hair. One thing you can do is get matching hats or scarves. There are many online tutorials on how to wear scarves around your head, help
your sibling find different ways to tie them. Though this may be a little more extreme,

Renee age fifteen talked about what she did:

People used to call Jessie and me 'the twins.' We are 13 months apart, but we look so much alike and we were always together. Now that Jess has cancer she’s lost all her hair and—well, unfortunately, people can tell us apart. Last week I decided to do something pretty drastic to show my sister how much I love her. I shaved my head! Now, I am not saying that is the right thing for all sisters to do—but it felt like the right thing for us (When Your Brother or Sister Has Cancer 51).

Like Renee, my brother’s friends decided to shave their heads along with him. Their support really made my brother see how many people cared about him and helped him feel less embarrassed about losing his hair. Do not feel like you need to shave your head if you are not comfortable with it, there are many other ways to show support.

Another way to show support for your sibling during their hair loss is to organize a St. Baldrick’s event. Max Magilnick, age twelve, organized a St. Baldrick’s event in Long Beach, California in honor of his older sister, a sixteen-year-old with a cancerous bone tumor in her right tibia between her knee and ankle. A St. Badlrick’s event is much like a walk-a-thon, where people collect money from family and friends, but instead of walking they show up to the volunteer-organized event and take turns in the barber’s chair, getting their heads shaved. All of the proceeds are donated to childhood cancer research. To find out how to organize your own St. Baldrick’s event go to StBaldricks.org to get more information.

Though you may not be able to cure your sibling, you do have the opportunity to plan fundraisers and raise money for organization, such as St. Baldrick’s, that can help find
a cure. There are many different events you can help plan or get involved with to raise money. For example, my brother’s friends planned a 5k around our high school’s neighborhood and charged people a small entry fee. They also had plastic band bracelets made that said “Danny Lives Stronger.” They donated all the money they raised to the hospital where my brother was being treated. Another great fundraiser to get involved in is Relay For Life, which is an organized, overnight community fundraising walk where teams camp out around a track and the members of each team take turns walking around the track for twenty-four hours. There is food, games, music and activities to provide entertainment. To find when a Relay For Life event is going to be close to you and how to create a team, visit Relayforlife.org.

You don’t necessarily need to get involved with a fundraising organization to make a difference; two other events you can get involved with are Blood Drives and Be The Match drives. Blood drives help save many lives everyday, donating just one pint of blood can save up to three lives (“Learn About Blood”). For more information on how to plan a local blood drive, or to find out where you can give blood visit Redcrossblood.org. My sister helped my mom plan a Be The Match Drive at our local elementary school. It is easy and all people need to do is swab their mouth with a cotton swab, which then gets sent to a lab and they are then put into a registry. This registry helps match people who need bone marrow transplant with bone marrow donors. For more information on how to plan a “Be The Match” event visit Marrow.org. There are many different fundraisers and other ways to get involved, but I hope these can at least get you to start thinking of things you can do.

These are all great and wonderful things you can do for your sibling, but save these activities for when you have extra energy to give. Do not forget to take care of yourself,
because you deserve it! Trying to be upbeat and positive can be great for you and your family, but don’t feel like you need to act this way if it’s not how you really feel, remember to be yourself!

**Life After Cancer**

When your brother or sister has completed their treatment, finding a new “normal” can often be more difficult than expected. Your family may be feeling a whole range of emotions: you may feel relieved, worried that the cancer might come back, or looking to find a deeper meaning in your current life. But most likely, most people who have gone through this experience feel changed. Your circumstances, priorities and expectations for life have been altered. Ross, age fifteen, claimed that he learned to appreciate life more, stating:

> It used to be all about having the latest stuff. If one of my friends got a new skateboard or jacket, I had to have it, too. After Jackie got sick, I realized that it was just that—stuff. Now there are more important things in life—like my sister and my family. When someone you care about is really sick, you find out what really matters (**When Your Brother Or Sister Has Cancer** 78).

These feelings, like the one’s Jackie had are normal, because you have dedicated most of your time during your sibling’s treatment to thinking and caring for them. Now that the focus on your sibling is changing, you will find yourself in new roles, and learn to resume past ones from a new perspective. Your life has been changed by the cancer experience, but cancer is no longer your main priority (Weller 52). Be prepared for the fact that your life may not go back to exactly how it was before your brother or sister was diagnosed with cancer; it may take a long time to get back to what you might consider your “old life.” This
section will give you tips on how to help you transition into life after cancer whether your brother or sister survives or passes away.

There is a sad realization that your sibling’s treatment may not work and your sibling may pass away. In this case, you and your family will face even more challenges. The death of a sibling is very difficult and will bring about many more emotions. Your life will change, and it will be different from how it was before, but you have the opportunity to make your life more meaningful, your sibling would want you to be happy. An important thing to do is to try to keep a schedule and stay connected. When people get bad news they often feel like life is moving on without them, so stay involved with school, activities and friends to help feel connected, but also allow yourself to take breaks if it ever feels like too much. Have hope; the pain will lessen with time. Though you may wonder if you will ever be happy again, time has a way of healing, though it may take longer than you want it to. Remember that everyone grieves in his or her own way. Some might cry while others will be silent, some want to be around friends while others would rather be left alone. There is no right or wrong way to grieve (When Your Brother or Sister Has Cancer 82). It is important to have people who can help you if you need it; in addition to family and friends, it can often be helpful to talk to a social worker, counselor, or a support group.

In many cases, your brother or sister will survive cancer. But just because they survive does not mean that your life will go back to how it was before they were diagnosed. Brombeck in her book I Want to Grow Hair, I Want to Grow Up, I Want to Go to Boise: Children Surviving Cancer, describes life after cancer as “being invited to the biggest party of your life and when you get there your find out you’re dressed all wrong” (Brombeck 52). You look forward to your life going back to normal after your sibling is finished with
treatment only to realize that life does not immediately pick back up right where you left it. You may not be able to completely go back to how things were but there are different ways to help with the transition. Remember to focus on the positives, and the strength that you and your family have, which you can use to pull together as a family. You may find your family has grown closer though this experience. Remember that you are continuing to grow as a person. Many teens said that having a brother or sister with cancer made them more sympathetic, more responsible and stronger. For instance, fifteen-year-old Christine said:

My brother has been in remission for two years now. Things were pretty bad at first. Then after a while, things sort of settled down and got back to the way they were before. I think Rob’s cancer brought us all closer together. I get along better with him and my sister and even with my older brother now. I’m closer to Mom and Dad. And I think we all grew up a lot while he was sick (When Your Brother or Sister Has Cancer 85).

You may notice that little things seem to have more meaning for you these days. Many teens said they learned to see the world more clearly, an appreciate things they had over looked in the past (When Your Brother or Sister Has Cancer 86). Allow yourself to cope at your own pace, just because your brother or sister is over getting treatment does not mean you need to get over their cancer immediately. Remember that you are not alone; family, friends, support groups, counselors, and social workers are there to listen and help. This is a wonderful opportunity to rebuild relationships that were strained or neglected during your sibling’s cancer. Most importantly, you do not have to pick up your life right where you left it if you don’t feel like it is the right thing to do, as this may be a chance to start your life in a new direction.
Whether or not their sibling survived cancer, some people said that they could not imagine leaving the cancer experience behind them without giving back in some way. Many people find this satisfaction in donating money, gifts, volunteering at a hospital or camp, fund-raising, forming support groups, creating websites, or founding organizations to help others in their same situation. Many of the organizations today were started from the passion of a loving family member. “Susan G. Komen For The Cure”, the largest and most funded breast cancer organization in the United States, was started by Susan’s own sister, Nancy, as a promise to her sister (Brinker 334). If you want more information on forming your own organization, call your state’s office of the Secretary of State and request forms for starting your own nonprofit organization, and contact the Internal revenue Service to apply for a 501 (c)(3) nonprofit status (Woznick 285). Not everyone feels comfortable with starting a public role that keeps painful memories around, some see it a form of hanging on instead of moving on. This can cause discomfort in a family, but it is important to remember that everyone deals with things differently, so do not get upset if someone does not want to help or do not feel bad if you are not interested in helping.

No handbook will be able to tell you how everything in your life will work out. But for the most part, adapting to post cancer life will develop naturally and gradually, and each family will go at their own pace. Though your life might not go back to how it was, you will be able to get through it because you are strong, even if you do not always feel like it.

Further Support

Connecting with other’s in your similar situation can often provide emotional support and inspiration during this challenging time. With today’s increasing technology there are even more ways to find support, learn about your sibling’s cancer and keep
friends and family updated. Online support groups offer another option for you, if you live far from a support group that meets at a treatment center, or may not be comfortable with face-to-face groups. Several sites offer profiles where you can post updates on how your sibling is doing throughout their treatment, while other sites offer ways to allow extended family members and friends to help. If you have interest in joining an online community or want more information, here are a few options:

**National Cancer Institute (NCI)**
**Cancer Information Service (CIS)**
1-800-422-6237
[www.cancer.gov](http://www.cancer.gov)
The National Cancer Institute can offer you accurate, up-to-date information on cancer, they can also connect you with a support organization in your area. You can also call the Cancer Information Services to talk to an information specialist who can answer questions you might have.

**American Camp Association**
1-800-428-2267
[www.acacamps.org](http://www.acacamps.org)
The American Camp Association website can help you find camps that are specifically for kids who have a sibling that has been diagnosed with cancer.

**American Cancer Society (ACS)**
1-800-227-2345
[www.cancer.org](http://www.cancer.org)
The American Cancer Society is another website that can help give you current information about cancer, you can also talk to a cancer information specialist to further help you with any questions you might have.

**American Childhood Cancer Organization**
1-855-858-2226
The American Childhood Cancer Organization, provides education and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families and the professionals who care for them. They also offer an online health and wellness community called inspire where you can join one of their many discussion topics.
American Red Cross
http://www.redcrossblood.org/
The American Red Cross can help you locate the closest place for you to donate blood as well as help you plan and organize your own blood drive.

Be The Match
1-800-627-7692
Be The Match helps connects patients with their donor match for a life-saving marrow or umbilical cord blood transplant.

CancerCare
1-800-813-4673
www.cancercare.org
CancerCare offers free information and support by telephone and online to anyone affected by cancer. They also offer online support groups for teens that have a brother or sister with cancer, and help help you find face-to-face support groups in your area.

CaringBridge
1-651-789-2300
http://www.caringbridge.org/
CaringBridge is a health social network, where you can create a free webpage to give updates in a patient care journal, share pictures, and invite visitors to write messages in a guestbook. Think of it as an online space where you can connect, share news, and receive support.

CarePages
1-888-852-5521
https://www.carepages.com/
CarePages lets you publish a free web page to post updates and messages to family and friends, share photos, receive encouraging messages, and connect with others coping with a similar situation. They also offer discussion forms and blogs discussing emotional health.

Facebook
https://www.facebook.com
Searching through you facebook can multiple support groups specializing in teens with siblings who have cancer. For example Siblings of Cancer Kids is a group monitored by social workers that you can join on facebook. You also have the opportunity to create your own!
Friend For Life Cancer Support Network  
1-866-374-3634  
http://www.friend4life.org/  
The Friend For Life Cancer Support Network is a site that helps match you, your sibling or a loved one with someone who has been through a similar situation as you, to provide compassionate, one-on-one support.

Gilda’s Club  
1-800-445-3248  
http://www.gildasclubnyc.org/  
Gilda’s Club has local chapters that provide a place for you, your sibling, and families and friends to join with others to build social and emotional support. They offer support groups, workshops, and social activities for people affected by cancer.

Lotsa Helping Hands  
http://www.lotsahelpinghands.com/  
Often times during the cancer process many of your friends and relatives will want to step in and help. Managing these offers can often be stressful and time consuming. This online community helps you coordinate care giving tasks among family members and friends all you have to do is fill in requests for help on a group calendar for visitors to sign up to help with things like, rides, meals, grocery shopping, pretty much anything your family needs.

Make-A-Wish Foundation  
1-800-722-9474  
http://wish.org/  
The Make-A-Wish Foundation grants wishes to children who have been diagnosed with life threatening illnesses.

MyLifeLine.org  
http://www.mylifeline.org/index.cfm  
1-720-883-8715  
MyLifeLine.org is an online community you or a family member people, create a free web page to share details about your sibling’s cancer to keep family and friends updated. On your page you can post requests for help, such as rides to appointments or babysitting. There is also a calendar on the site that helps you keep track of doctor and treatment visits and other important appointments.

Peer Support Network  
1-561-702-0727  
http://peersupportnetwork.org/  
Peer Support Network is an internet based peer support connects people impacted by cancer with others that have undergone similar experiences and is available to anyone seeking or offering support.
Relay For Life
http://www.relayforlife.org/index
The Relay For Life website can give you more information on where the closest relay to you will be taking place. It will also give you information on how to create your own team.

SibSpeak
1-888-417-4704
http://www.sibspeak.org/
SibSpeak is a place for teens who have a brother or sister with cancer to connect with each other. You can also blog, share artwork and find tips from other siblings to help cope.

SuperSibs!
1-866-444-7427
www.supersibs.org
SuperSibs! is an organization that provides free services to brothers and sisters of children with cancer. They offer comfort and care throughout your siblings’ diagnosis.

St. Baldrick’s
1-888-899-2253
http://www.stbaldricks.org/
The St. Baldrick’s can help plan and organize your own fundraising event.

Take Them A Meal
1-800-915-7715
http://takethemameal.com/
Take them a meal helps you create a customized online sign up sheet to include phone numbers, driving directions, food allergies and more that makes it easy for friends and family to take meals for your family when things get hectic.

Cancer Support Community
1-888-793-9355
http://www.cancersupportcommunity.org/
The Cancer Support Community offers support, education, and hope you and your family. They also offer secure section of their site where teens touched by cancer can meet and connect with each other to build social and emotional support, and to regain a sense of control over their lives.
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