Brothers & Sisters Together

A workbook for siblings of siblings who are sick

NIH Clinical Center
This book belongs to

Today's date is: _______________________
My social worker is: ___________________
Telephone Number: ___________________
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Why is this book for me?

You have a brother or sister who has been diagnosed with a serious illness. Maybe you just found out about your sibling’s illness. Maybe you have known for a long time. Your brother or sister may seem healthy, or your sibling may be ill. You may be a teenager. You may be a little younger.

No matter what your age, you have a lot in common with other kids whose brothers or sisters are ill. This workbook can help you learn from others who are in your situation.

You are an important part of your family, and just as your sibling’s illness affects the rest of your family, it will affect you, too.

What good can a workbook be for me?

No one would wish for your brother or sister to be sick. But this can be a time when you can learn a lot about yourself, your sibling, and your family.

It can also be a time when you wish you had another family to call your own! You are not the only person who has these feelings!

Sometimes you may need to find a way to express what you are feeling. This workbook can help you do that.

So how do I use this workbook?

This workbook is easy for you to use. Each page covers a topic for you to think about, for example, when you feel angry or sad. Each page lists questions to help you think about your feelings or space for you to write or draw what’s on your mind. Some pages have both. The quotes in this workbook come from real siblings.

If you do not want to work on a page, skip it and go on to the next. If you need more room to finish what you want to do on a page, add extra paper.

If your feelings change over time, you may want to do a page again. That is perfectly okay. It is normal to feel one way one day, and to feel completely different the next day. You may want to do one page several times as you grow and learn about yourself.

Maybe you would like to keep the pictures and notes that you write here and look at them later. Maybe you want to share them with another person—your mom or dad, your sister or brother, your social worker or counselor, or your best friend or teacher. This is your workbook to create or share as you please.

How to get the most out of your workbook:

1. Find a quiet place where you can work.

2. Have a lot of colored pens or crayons on hand so that you can work on a page without stopping to get more supplies.

Note to Teenagers

You may think that some parts of the workbook are silly or that they don’t apply to you. Each page will help you think about a topic, but it doesn’t matter if you work on a specific page or not.

If you prefer just to write your feelings about each topic in your own journal or on separate sheets of paper, do it! Whatever you want to do is okay.

Note to Parents/Guardians

Children of all ages can use this workbook.

A young child may need an adult to help with reading and writing and give encouragement to draw pictures.
My Family

Your family and friends are very important parts of your life, so having a picture of them is a good way to introduce your workbook.

Start your workbook by drawing a picture of your family or by pasting in a photograph. Write down the names of everyone who is in the picture.

Where are you in the picture?

What are you doing?

Is there a pet in the picture?

Is your family happy, sad, scared, or worried in the picture?
My closest friend

Now, draw a picture of you and your closest friend. Write in your friend’s name. If you do not have a close friend, draw a picture of someone you think is a really good friend.

What is your friend doing in the picture?

Does your friend know about your brother’s or sister’s illness?

☐ yes  ☐ no

If Yes, Has your friend helped you feel better? How?
Learning about the diagnosis

Do you remember when you found out what was wrong with your brother or sister? □ yes □ no

Where were you? ____________________________________________

Who told you? ____________________________________________

How did you feel? ____________________________________________

Were you surprised? □ yes □ no

What are the words you remember the most?

____________________________________________________________________

Were there people available to talk to you and answer your questions? □ yes □ no

Did your brother or sister find out the diagnosis at the same time you did? □ yes □ no

Did you cry or feel like crying? □ yes □ no

Kids of all ages feel conflicting feelings when they find out. Some do not want to think about it. Some cannot stop thinking about it. Write a short description about what this time was like for you.

"It was just so terrible when I found out. I cried and cried, and I was kind of hysterical. My sister was in the hospital, and we were with her when my mom told me, and my mom ended up having to take me home because I couldn't get control."
Talking with my parents, guardians, or foster parents

Look back to the picture of your family. Your relationship with the adults in that picture is very important. Are they your parents?

☐ yes  ☐ no

Write their names

Which adult(s) do you live with?

Do you think they treat you and your sibling the same as always since they found out about the diagnosis?

☐ yes  ☐ no

If no, how do they treat you differently?

How do they treat your brother or sister differently?

Do you treat your parents differently?

☐ yes  ☐ no

If yes, how do you treat them differently?

Many children feel that their parents are different now than they were before. Do you feel like your parents have changed?

☐ yes  ☐ no

If there has been a change, do you like the change?

☐ yes  ☐ no

Why?

Describe how you would best like your parents to treat you.
Do you spend as much time with your parents as you did before?

☐ yes  ☐ no

Can you tell your parents how you feel?

☐ yes  ☐ no

If no, what don’t you tell your parents?

If you were your parents, what would you do differently?

What is one thing you wish your parents would say to you?

Who understands how you feel the most?

Is there someone whom you wish understood you more?

☐ yes  ☐ no

If yes, who is that person?
What can this person do to help you feel more understood?
Living with my brother or sister

"To My Dearest Brother,

We sure have been through a lot together lately, haven't we? You are the greatest brother anyone could have. You have had your ups and downs over the past few years, and you have kept your sense of humor through all of it. That, and the fact that you pick yourself up and carry on, are probably the two greatest qualities I admire about you. It has helped Mom, Dad, and me very much to know that you have the strength to keep smiling even when you're down.

I just heard a song on the radio called "That's What Friends are For." You may think you are just my little brother, but you are also my best friend. Next time you hear that song, please listen carefully to the words because they express exactly how I feel about you. Please always remember to be brave and listen to the wonderful doctors, nurses, Mom, and Dad, because they know what's best for you.

I Love You!!"

"I don't think I could ever be as strong as my brother is. David has gone through many hard times, but he and my family have always been there to cheer him on. I think he has become a very strong person inside, and he keeps on getting stronger with every battle he fights against his disease. Some day, I know he'll go to heaven, but that doesn't mean he has lost the battle. It'll just mean that he got tired of fighting. I know I'll miss David when he goes, but I also know that he won't hurt any more. I would like to say one thing to David before he goes: "I Love you."

The bravest person I know is my little brother who is adopted. He is very ill and has to be in the hospital all the time. He has had surgery eleven times, and he has had to have a tube in his chest so that he gets his medicine. He has to have so many shots and needles. I know how much I hate them, so he must be the bravest person I know to keep fighting this disease and not give up."
Some people love their brothers or sisters very much, but they still don’t like to be around them for very long! Some people feel bad when they get angry with their brothers or sisters because they are sick. These feelings are normal.

How did you treat your brother or sister before you found out that he or she was sick? Were you friends? Were you enemies? Did you go to school together? Did you have the same friends? List 5 words that tell how you and your brother or sister got along before you found out about the diagnosis.

Sometimes, we want to say certain things but we can’t find the right words or the right time to say them.

In the space below, write your brother or sister a poem, a letter, or draw a picture that says what you would like your brother or sister to know.

"When my sister is well, she and I aren’t close, and she drives me crazy sometimes. My sister is such a pest! Then, when she is sick, it gets so that I wish she were just well enough to stop bugging me again. I miss that when she’s so sick, and I feel terrible when she suffers. It’s awful."
When I feel sad

Most siblings who have a brother or sister with an illness sometimes feel sad. This is totally normal. Sometimes, you may want to be alone when you feel sad. Sometimes you may need to be with other people.

If you feel sad most of the time, it is important to tell an adult and to let the adult help you feel better.

Do you feel sad **a lot?** **all the time?** **once in a while?**

What makes you feel sad?

Do you feel like crying **once in a while?** **every day?** **some days?**

What do you do when you feel sad?

Here are some activities that have helped some siblings feel better. Check off all those that you think might help you feel better when you are sad.

- Spend time with Friends
- Play with my pet
- Listen to music
- Play an instrument
- Write a poem
- Read
- Watch TV
- Call friends
- Eat
- Do yoga
- Swim
- Draw
- Play basketball
- Go shopping
- Cook
- Sleep
- Write music
- Keep a journal or diary
- Talk to someone I trust
- Cry
- Take a bath or shower
- Write a letter to my brother or sister or parent(s) telling them how I feel
- Go for a walk

What other things can you do when you feel sad?
When I feel guilty

While you may understand that you did not cause your sibling's illness, some siblings still feel guilty—as if they could have prevented it.

**Why do some siblings say they feel guilty?**

- You may feel guilty for wanting attention from your parents when they have to spend time with your sibling.
- You may feel guilty for wishing life was different or that negative thoughts about your brother or sister could have caused him or her to get sick.
- You may feel guilty that you are healthy and that your sibling is not.

Guilt is one of the hardest things to talk about with other people.

Sometimes, it helps to be specific about what causes you to feel guilty. When you talk about it, the source of your guilt will no longer be trapped in your head.

Is there something that you did or said in the past that you would like to take back?

[ ] yes   [ ] no

If yes, what was it?

Did you ever think that something you thought or said caused your brother or sister to get sick?

[ ] yes   [ ] no

If yes, describe it:

Who knows about these feelings?

If you do feel guilty, try talking to someone you trust about these feelings. Write down in a notebook that you did not cause your sibling to be sick and anything else you might feel guilty about. Be nice to yourself and praise yourself for all the kind things you have done and can do in the future.

Do you worry about what other people think about you?

[ ] yes   [ ] no

What is the best thing that someone could say about you?
When I feel

Everyone feels angry once in a while. Some people feel angry a lot of the time. You may find that you are angrier now than when you were before your brother or sister was diagnosed. You may even feel mad that other people think that your problems are not as important as your brother's or sister's problems. You may feel left out.

It is important to know when you are angry, and to have some ways to use the anger without hurting yourself or anyone else. It is also important to let your parents know when you feel left out.

Do things bother you □ a lot □ all the time □ once in a while

Do you get mad easily? □ yes □ no

When you feel angry, whom do you often feel angry at?

Some people stomp their feet, slam doors, yell, or say nasty things when they get angry. Other people hold it all in and get very quiet. How do you act when you are angry?

When was the last time you got really mad?

Can you do anything special to make yourself feel better when you are angry, for example, listen to special music? □ yes □ no

Add some things from page 10 that you think may be able to help when you feel angry.

Name at least one more activity that can help you when you are angry.
Some people see “red” or “black” when they are angry. Color these boxes the color you see when you are angry.

“My brother gets a lot of attention and I feel left out. When he gets new toys I often get nothing. Sometimes, I feel angry when my mother is busy and can’t help me with my homework. I also get angry when I don’t have anyone to play with, and he gets to bring his friends over.”

Write a letter to your sibling’s disease. For example, if your brother or sister has cancer, you can begin with:

Dear Cancer,

There are some things I want to tell you. The first thing I want you to know is...

Write letter here!
when I feel scared

Everyone who has a brother or sister who has ever been very sick gets scared from time to time. You may not always know what scares you the most, but you feel scared and worried. Most people worry most about their brother or sister dying. You may worry about what your life would be without your brother or sister. Some people also worry about their parents, or how their lives would be different.

Do you worry □ once in a while  □ a lot  □ all the time

Do you worry about what will happen to your brother or sister?  
□ yes  □ no

Do you think that your brother or sister will ever be cured from the illness?  
□ yes  □ no

When you get scared or worried, do you feel sick in your stomach?  
□ yes  □ no

Is it hard for you to keep your mind on schoolwork?  
□ yes  □ no

Do you worry that something bad will happen to you?  
□ yes  □ no

If yes, what are some of the things that you worry can happen to you?

Do you worry when you go to bed at night?  
□ yes  □ no

Do you have bad dreams?  
□ yes  □ no

Do you have good dreams?  
□ yes  □ no

If yes, tell about one good dream and/or one bad dream. If you like, keep this workbook by your bed and write the dream as soon as you wake up. That way, you will not forget it.

Good Dream

Bad Dream

"Sometimes when my sister goes to the hospital, I get real scared because I am afraid she will not come home again."

"I am scared to go to sleep. I dream that my sister is dead, and I’m at her funeral. I dream about terrible things happening to my family all the time."
Reaching out for help

Have you been having trouble getting along with your friends?

- [ ] yes  - [ ] no

Have you been having trouble getting along with your parents?

- [ ] yes  - [ ] no

Do you feel alone?

- [ ] yes  - [ ] no

If yes, do you feel alone:  
- [ ] a lot of the time
- [ ] some of the time

Knowing that your brother or sister loves you and that you love them is a topic that concerns many siblings. It is not easy to think about on your own. You may want to keep a list of ways that your sibling shows love to you, or ways that you show love for your sibling. Not everyone says, “I love you.” Some people show it, instead.

Ways I show love to my brother/sister

Ways my brother/sister shows love to me

Everyone needs things and people to feel good about.

One thing that may make you feel better is talking to someone when you are feeling sad or lonely. If you cannot figure out how to bring this up, you might want to show someone the work you have done in this workbook. If you do not want to bother your parents, talk to another adult you trust. For example, your school guidance counselor, a member of the clergy, or a social worker at NIH are all specially trained to understand your feelings and concerns. Remember too, that your social worker may be able to find another sibling for you to talk to on the telephone. Sometimes, it can be helpful to talk to someone else who is going through the same thing.

It is important to remember that you are not alone. Many siblings like you have these confusing feelings. It is very hard to grow up having a sister or brother who has a serious illness.
a picture of me and my sibling
Conclusion

Draw a picture, put a photograph, or write a paragraph on the cover of this workbook you have made. Put today’s date on the inside cover.

Has this workbook helped you?  yes  no
Why or why not?

You may find that this workbook makes you want to start a journal or keep a scrapbook of pictures and poems. You could even make an audio- or videotape. Ask your social worker or another adult to help you take pictures, use a tape player or a video camera.

Write questions or exercises you think should be added to this workbook.
Books you might like to read

All ages:

Ages 4-7:

Ages 8-11:
Buscaglia, L. The Fall of Freddie the Leaf: New Jersey: Charles B. Slack, Inc.; (1982).

Ages 12 and over:
Colgrove, M., Bloomfield, H.H., McWilliams, P. How to Survive the Loss of a Love: 58 things to do when there is nothing to be done. New York: Bantam Books; (1981).

For Parents:
Dawson, Mildred L. “Remember the Well Sibling.” InTouch Magazine; Vol.4, No. 5, September 2002 (p.29)

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