Brothers Sisters Together

A workbook for siblings

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of siblings who are sick

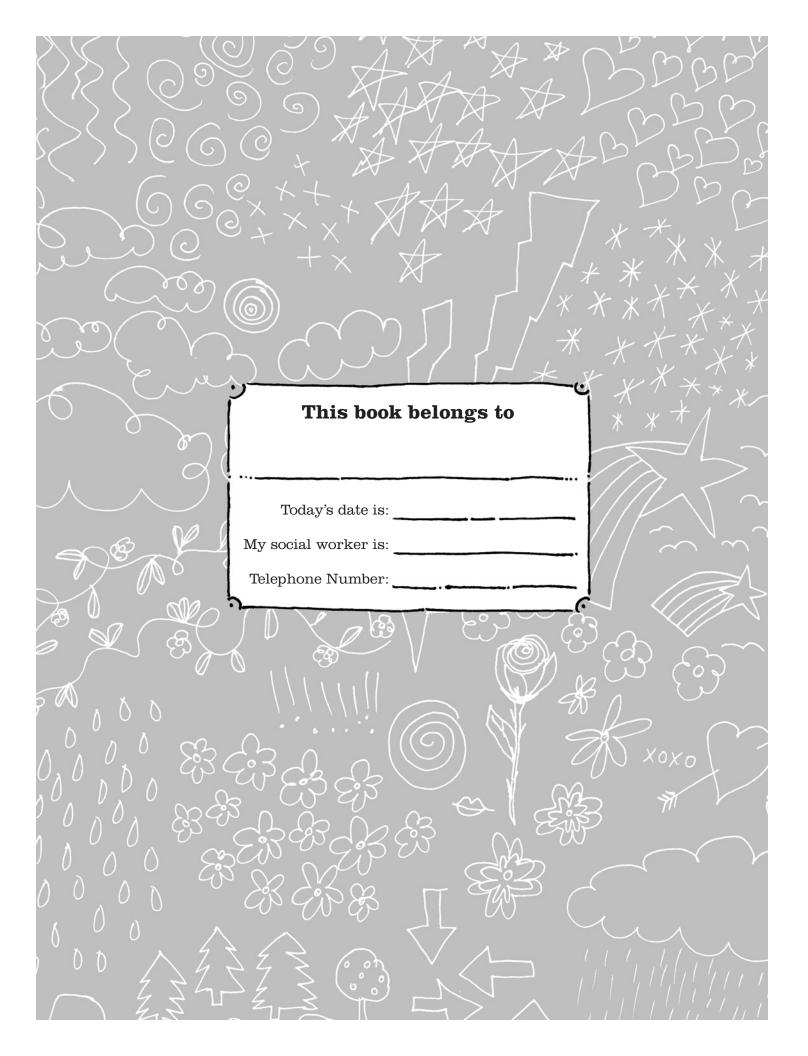


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Why is this book for me?

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.

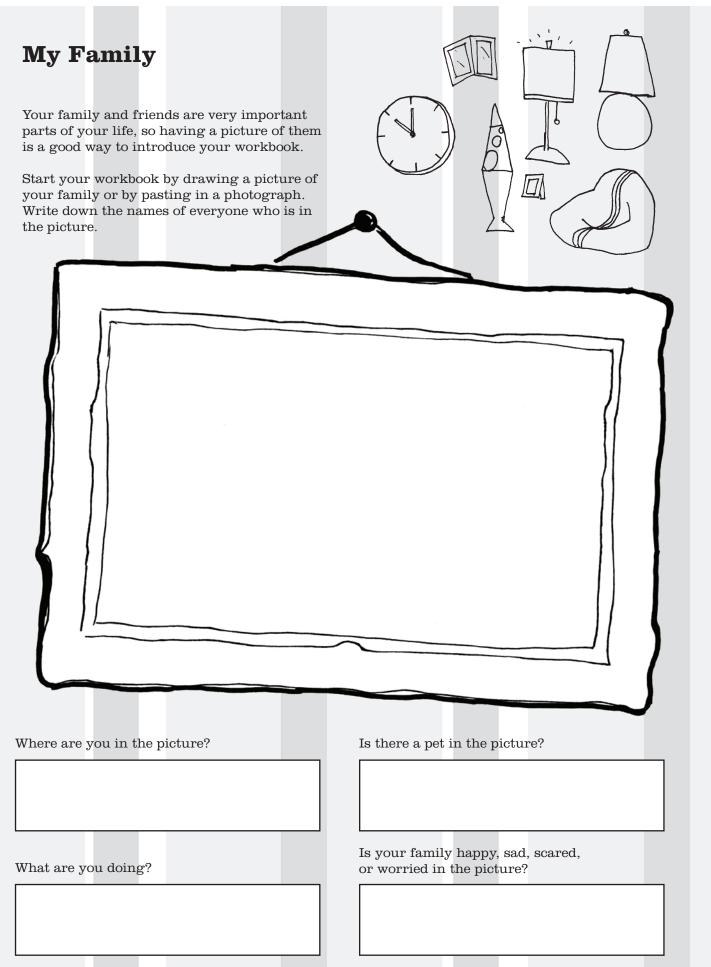
If you prefer just to write your feelings about each topic in your own journal or on separate sheets of paper, do it! Whatever you want to do is okay.

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.

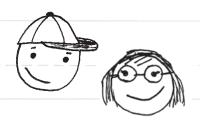




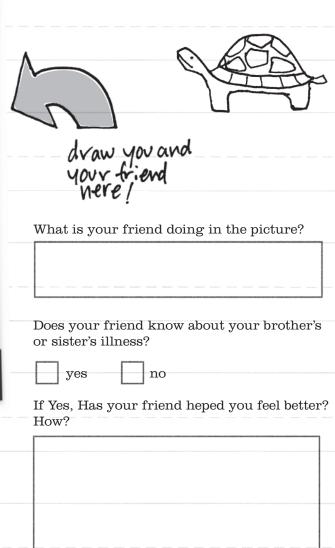
My closest friend

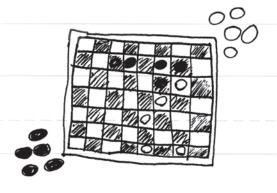


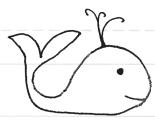
Now, draw a picture of you and your closest friend. Write in your friend's name. If you do not have a close friend, draw a picture of someone you think is a really good friend.

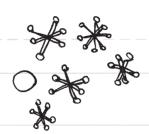












Learning about the di	iagnosis
Do you remember when you found out what was wrong with your brother or sister?	yes no
Where were you?	
Who told you?	
How did you feel?	
Were you surprised? yes What are the words you remember the	no he most?
Were there people available to talk to you and answer your questions?	
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 terrible when I found out. I cried and cried, out. I cried and cried, and I was kind of and I was kind of hysterical. My sister hysterical. My sister hysterical. My sister hysterical, was in the hospital, was in the hospital, was in the hospital, and we were with and we were with and we were with and my mom her when my mom ended up having to take me home because I couldn't get control."

Talking with my parents, guardians, or foster parents

family. Yo adults in	to the picture of your our relationship with the that picture is very t. Are they your parents?	Write their names
yes	no	* * * * * * * * * * * * * * * * * * * *
	Which adult(s) do	o you live with?
	Do you think they treat you as always since they found	9
	yes	no
	If no, how do they tre	at you differently?
	How do they treat your brot	her or sister differently?
	Do you treat your p	arents differently?
	yes	no
	If yes, how do you trea	t them differently?
N	Many children feel that their pare were before. Do you feel like y	
	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?	Can you tell your parents how you feel?
yes no	yes no
me a lot. more of ten me a lot. more of ten me a lot. it's my mom than not. it's my talks who comes and being to me about not up set me who to her me goes	If no, what don't you tell your parents?
up set who to her goes to her	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
"Sometimes I feel anary when my mother is busy and can't help me with my nomework. She is busy with all kinds of activities related to my brother."	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 Deavest Brother,
we sure have been through a lot
together lately. Naven't we? Too 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 ladmire 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
Iitle brother, but you are also my
best friend. Next time you hear
that song, please listen carefully to the words because they
fully to the words because they
express exactly how I feel about you.
Please always remember to
be brave and listen to the
be brave and listen to the
wonderful doctors, nurses, Mom,
wonderful doctors hurses, Mom,
and Dad, because they know
what's best for you.

I don't think I could ever be as strong as my brother is. David has gotten through many hard times, but the and my family have always been there to cheer himon. 1 think he has become a very strong person inside, and he keeps on getting stronger with every battle he winks against his disease. Sameday, 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. 1 know I'll miss David J when he goes, but lalso 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 ho spital all the time. He
has had Surgery eleven times,
and he has had to have a tube
and he has had to have a tube
in his chest so that he gets his
in his chest so that he gets his
in his chest so that he gets his
medicine. He has to have so
medicine. He has to have so
medicine. He has to have so
many shots and needles. I know
howmuch I hate them, So he
must be the bravest person
I know to keep fighting this
disease and not give up. ")

If the hardest thing about all of this is my brother. It gets a lot of attention, especially when he almost died. But If I could change anything in the whole world, it would be to get rid of his disease and that no kids would be sick. I really want my brother to know that I love him even if I don't always show it. There are just same times that I have to hit him back.

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.

Before Finding out 1. 2. 3. 4. 5. How we get along now 1. 2. 3. 4. 5.

3.

4.

5.

Do you like to be around your brother or sister? Do you do things together? Circle the words on the list above that now fit how you and your brother or sister get along. If no word fits, write a new list of 5 words.

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 laren'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 start bugging me again. I miss that when she's so sick, and I feel terrible when she suffers. It's awful."



When I feel guilty

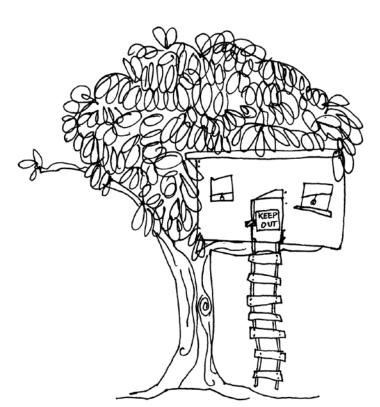
While you may understand that you did not cause your sibling's illness, some siblings still feel guilty—as if they could have prevented it.

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 guilt, 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 then 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

and part of my problem is that I don't want toget mad at nev. I just want her to be happy."

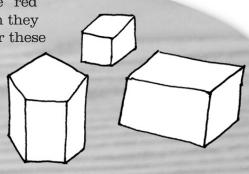


Add some things from page 10 that you think may be able to help when you feel angry.

Name at least one more activity that can help you when you are angry.

"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."

Some people see "red" or "black" when they are angry. Color these boxes the color you see when you are angry.



date: Write a letter to your sibling is 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...

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.

once in a while Do you worry a lot all the time Do you worry about what will happen to your brother or sister? yes 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? ves 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

neaching out for help	
Have you been having trouble getting with your friends?	g along
yes	no
Have you been having trouble getting with your parents? yes	g along no
Do you feel alone? yes	no
If yes, do you feel alone: a lot of	the time
some of	f the time
Knowing that your brother or sister loves you and that you love them is a topic that concerns many siblings. It not easy to think about on your own. You may want to keep a list of ways your sibling shows love to you, or wa that you show love for your sibling. It everyone says, "I love you." Some people show it, instead.	is that ays Not
Ways I show love to my brother/siste	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 showsomeone 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
Ways my brother/sister shows love to	trained to understand your feelings
	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.



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?
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:

Murray, G. Jampolsky, G., editors. Straight from the Siblings: Another Look at the Rainbow. Berkeley, California: Celestial Arts; (1892).

Mellonie, B., Ingpen, R. Lifetimes: the beautiful way to explain death to children. New York: Bantam Books; (1983).

Ages 4-7:

Dodd, Michael. Oliver's Story: for "sibs" of kids with cancer. Kensington MD: Candlelighters Childhood Cancer Foundation, 2004.

Viorst, J. The Tenth Good Thing about Barney. New York: Atheneum; (1971).

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).

Corburn, J. Anne and the Sand Dobbers. New York: Seabury: (1967).

Gunther. J. Death Be Not Proud. New York: Harper and Row; (19480.

Kubler-Ross, E. On Death and Dying. New York: MacMillan; (1969). Beall-Sullivan, (illeglble), Park City, New Jersey. www.mynameisjack.com

Brandenberg, F. I wish I was sick, too! New York: Penguin Putnam Books for Young readers; (1978).

Perkin, A.D., Middendorf, F. What about me? When Brothers and Sisters Get Sick. Washington, D.C.; American Psychological Association; (1992).

Department of Health and Human Services, National Institutes of Health, National Cancer Institute, NIH Publication No. 05-5733. When Your Brother or Sister Has Cancer: A Guide for Teens. (2005)

For Parents:

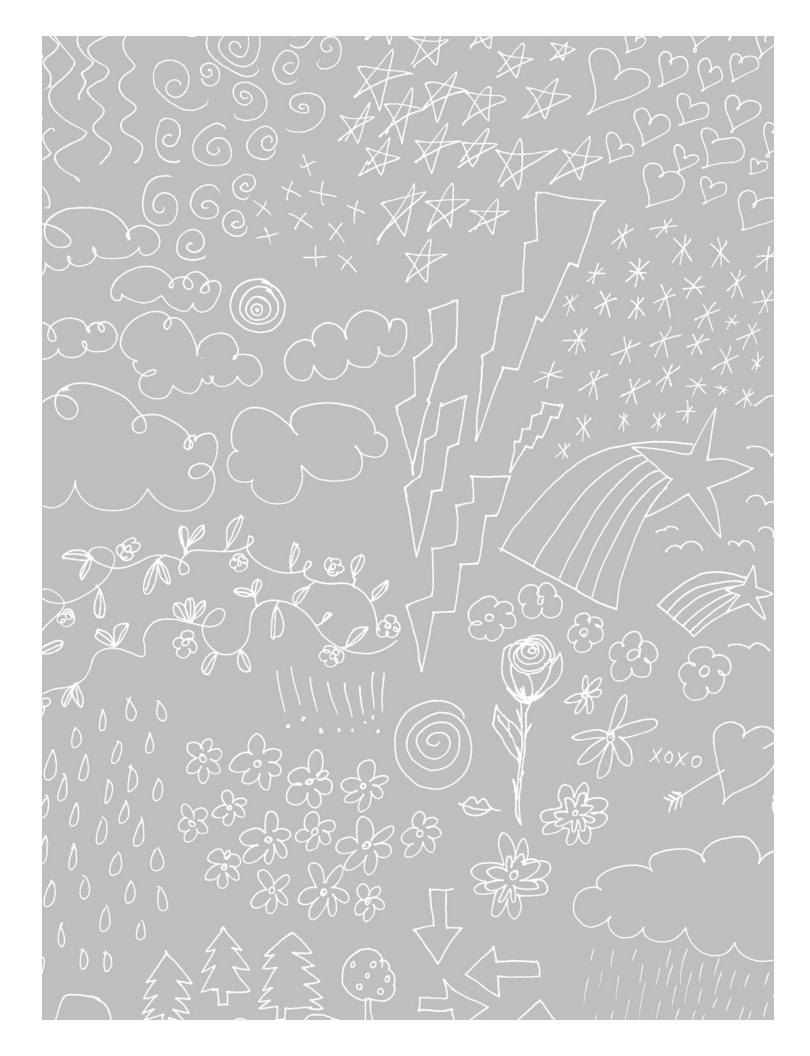
Dawson, Mildred L. "Remember the Well Sibling." InTouch Magazine; Vol.4, No. 5, September 2002 (p.29)

Fleitas, Joan. "Winds of the Hurricane: Siblings in the Storm of Illness." New York: Children's Brain Tumor Foundation, 2001.



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U.S. Department of Health& Human ServicesNational Institutes of Health