



Coping Support for Siblings of Very Sick Children

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The Stress Puzzle

What does stress feel like?

When you feel stress, sometimes you feel nervous, angry, sad, or scared.

Sometimes your stomach hurts or you have a headache. It might be hard to sleep. Sometimes you might feel more than one of these things at the same time. Scientists are still trying to figure out how stress works. There are different pieces of stress.

Feelings, thoughts, and actions are pieces of the stress puzzle. Your feelings, thoughts, and actions can make the stress better or worse. Right now, you have stress because your sibling is very sick and may be dying. That is a piece of your stress puzzle too.

Feelings like being worried, sad, left out, alone, or angry can make stress worse. You might worry about your sibling. You may feel like no one understands what you are going through. You might also feel angry that your sibling is sick or that so many things have changed from the way they were before. Sharing your feelings with others can help you feel better.

Thoughts are what you tell yourself about your feelings. Some thoughts can make your stress worse. You might have thoughts like:

- "I can't stand this"
- "I will never feel better"
- "This is my fault"

But helpful thoughts make stress easier to deal with, like, "I don't like that my sibling is very sick, but I can do things to help myself feel better".

Your actions, the things you do when you have stress, are important. Sometimes when you feel upset, you might say or do things that you feel bad about. These could be yelling, teasing, or hitting someone. There are other things you can do when you feel upset. For example, when you have stress, you can:

- Tell someone how you feel
- Ask for help
- Write a letter or a story
- Draw
- Relax

Match a piece of the stress puzzle (feelings, thoughts, actions) with each of these statements:

1. Worried
2. I don't think I'll ever feel better
3. Jealous
4. Hitting someone or something
5. Angry
6. Talking to an adult or friend
7. Things seem awful now, but they will get better
8. Drawing
9. I'm so mad right now. I think I will talk to an adult about what is going on.
10. Yelling at someone
11. Sad
12. Is this my fault?

Answers:

Feelings: 1, 3, 5, 11

Thoughts: 2, 7, 9, 12

Actions: 4, 6, 8, 10

Relaxation

This is a very hard time for you. Feelings that are parts of grief and stress can make your body tense. Tense is another word for tight. When you make your arm muscle as hard as it can be, it is tense. Stress can make your muscles tense without you knowing it is happening. Being tense can make your stress harder to deal with. Relaxation is a way to take a break from your grief and stress.

When you learn how to relax, you lessen the effect of stress on your body. You also feel less stressed.

Feelings that can make you tense

How do you feel when you think about your sibling being very sick? Pick 3 of these:

- | | |
|--|--|
| <input type="checkbox"/> Angry | <input type="checkbox"/> I can't pay attention |
| <input type="checkbox"/> I can't think | <input type="checkbox"/> Tired |
| <input type="checkbox"/> Sad | <input type="checkbox"/> On fire |
| <input type="checkbox"/> Empty | <input type="checkbox"/> Lonely |
| <input type="checkbox"/> Confused | <input type="checkbox"/> Hurt |
| <input type="checkbox"/> Guilty | <input type="checkbox"/> Worried |
| <input type="checkbox"/> Sick | |

Muscle relaxation

When you are stressed, you might notice your muscles feel tense or tight. Many people feel stress in their back or neck first. This tension can make you feel even worse.

Here are the muscle groups you will learn to relax:

- Your face and neck
- Your stomach and back
- Your legs and feet

Find a quiet place, put on some music, and change into comfortable clothes. Do what helps you relax. To create the feeling of tightness (tension), squeeze a tennis ball in your hand. Squeeze it tight for a few seconds. Then relax, or loosen, your grip. Now try it again. Tense and relax.

Notice the difference between tension and relaxation. Put down the tennis ball and lie down. While you are lying down, try tensing your other muscle groups like you did with the tennis ball.

1. Tense your arms and hands. And relax them.
2. Try it again. Squeeze and relax.
3. Tense your face and neck. And relax them.
4. Try it again. Squeeze and relax.
5. Tense your stomach and back. And relax them.
6. Try it again. Squeeze and relax.
7. Tense your legs and feet. And relax them.
8. Try it again. Squeeze and relax.

Do you feel more relaxed?

If you don't feel more relaxed, try again later. Practicing makes relaxation easier, like practicing how to play an instrument. Relaxation helps most people feel better and it is easy to do anywhere. You can use relaxation at school, church, the hospital, at home, or anywhere.

Deep breathing

Deep breathing is another thing you can do anywhere! When you think about your breathing, you become more relaxed and think less about your stress.

1. Take a slow, deep breath in through your nose. Keep your shoulders relaxed. Do not raise your shoulders up to your ears!
2. Place your hands on your belly. As you breathe in, raise your hands by pushing your belly and chest outward.
3. Slowly breathe out through your mouth, like you are blowing out a candle.
4. Start again! Try to count 10 breaths. Pretend like you are breathing in a white cloud and breathing out a gray cloud.

You can practice in bed, waiting in line, in class, at the hospital, walking down the hallway, anytime and anywhere!

Breathing and Relaxing at the Same Time

Breathe in slowly and, as you breathe in,
Tense your arms and hands.

Breathe out slowly and, as you breathe out,
Relax your arms and hands.

Breathe in slowly and, as you breathe in,
Tense your face and neck.

Breathe out slowly and, as you breathe out,
Relax your face and neck.

Breathe in slowly and, as you breathe in,
Tense your stomach and back.

Breathe out slowly and, as you breathe out,
Relax your stomach and back.

Breathe in slowly and, as you breathe in,
Tense your legs and feet.

Breathe out slowly and, as you breathe out,
Relax your legs and feet. How do you feel?

Your Imagination

Think of your favorite ice cream. Think of the ice cream until you can see it clearly like a picture in your head.

- Can you see the ice cream in your mind?
- What does it look like?
- What flavor is it?
- Is there whipped cream on top?

Some pictures are helpful and fun, like ice cream, and others are not. When you have stress, you might see sad or scary pictures in your head. Some kids see their sibling in the hospital. Some kids imagine about death or other scary things.

You can pick what pictures are in your head. Choose a picture that makes you feel better.

If you have sad or scary pictures in your head, you might imagine yourself in another place. Some people have trouble imagining.

Do you have a favorite place where you feel safe? Use your imagination! What do you:

- See?
- Hear?
- Smell?
- Feel?
- Taste?

Close your eyes and imagine you are at:

- A beach
- A park
- The mountains
- A lake

Self-Talk

Self-talk is what you say to yourself about yourself.

Helpful thinking:

I am feeling down today, but I don't have to talk about it unless I want to. I can make it through my day at school if I take deep breaths, relax, and think about something happy. I can deal with this.

Unhelpful thinking:

I don't want to go to school today. Kids will look at me funny because they will know that something is wrong. I am tired and sad. I am just going to stay home.

My thoughts affect how I feel. Change your unhelpful self-talk into helpful self-talk. Which statements are helpful? Which are not?

- Even though I hurt, I can do some activities I have learned to help me feel better.
- I will never feel better. Why me?
- When I take a couple of deep breaths, I can help myself feel better.
- I feel so tired. I don't want to be around anyone. When will this pain go away?
- Will I ever feel better? No one else has it as hard as I do!
- When I start to feel bad, I can close my eyes and go to my favorite place in my mind. I notice I start to feel better. I can control some of my stress.

Stress and Grief

Share your feelings

You can help yourself by learning to deal with stress through your actions, feelings, and thoughts. You can help yourself by learning how to relax your muscles and breathe deeply.

You can look to other people for help. Everyone has different feelings when someone they love is very sick or dying. Some people feel better when they share their feelings with other people. You don't have to, but you might want to try it.

How do you describe how you feel when something stressful happens? Here are some situations to get you started:

- When I see my sibling at the hospital, I feel _____
- When my parents spend lots of time with my sibling, I feel _____
- When people ask me how my sibling is doing, I feel _____
- When I see people laughing and having fun, I feel _____
- When I think about my sibling being so sick, I feel _____

You can share your feelings with:

- Your parents
- A relative
- A friend
- Your sibling
- Anyone else you want

Do you have questions?

You likely have questions. You might have questions about how other people in your family are feeling. You probably have questions about your sick sibling. You will learn how to ask questions and who might be the best person to ask.

Questions you don't have the answers to can raise your stress. Think about the questions you have. Sometimes people aren't sure who can answer the questions they have.

Who can you go to for answers?

1. Your family

Your parents are experts on your family. Other adults and children in your family can be good people to ask questions. Your sibling might know quite a bit about them being sick.

2. Medical people

Doctors and nurses are experts on being sick, the hospital, medical equipment, and medical tests. Social workers and counselors work in many hospitals. Social workers and counselors are good at answering questions about feelings. They can find different ways to help you or your family.

3. Spiritual leaders

Spiritual questions are about the meaning of life and what happens after death. If you are religious, you might want to ask your religious leader spiritual questions. Religious leaders are people like priests, elders, rabbis, pastors, reverends, monks, chaplains and preachers. Spiritual questions can also be discussed with your parents and adults in your family.

4. People from school

Teachers, classroom aides, school social workers, school nurses, and counselors are all people who work in schools. Your school might not have all of them. If you have a question while you are at school, these people will help you find the answer.

5. Other adults

There might be other adults to ask questions. Any adult you trust in your family, school, neighborhood, or church will likely be a good person to ask questions.

There are lots of different people who might have answers to your questions. What questions do you have? Who could help you answer:

1. What are all the medical machines and tests for?

Your parents might know. Doctors and nurses in your sibling's room know a lot about medical things too. Your sibling might know a lot about the medical equipment and tests as well.

2. What happens to my sibling if they die? Does dying hurt?

Your parents may be able to answer this question. Your parents may also want to go with you to talk to a doctor, nurse, counselor, or social worker to answer these questions.

Spiritual leaders are good at talking about dying, too.

3. How do I feel about this? How are the people in my family feeling?

If you have questions about your own feelings, talk to an adult you trust about them. If you have a question about someone else's feelings, ask that person how they feel.

4. What other questions do you have?

Ask an adult you trust about your question. If they cannot answer it, they can help you decide who can answer your questions and help you find that person.

Remember, unanswered questions can raise your stress. Ask about what you don't know to deal with your stress more easily. Asking questions can be hard, but it will be worth it.

Your Sibling's Condition

When a sibling is very sick or dying, it is always sad. You might have other feelings, too. Some kids are jealous, angry, or guilty. Some kids are scared to be around their sibling. They are afraid they will get sick, too, or think it hurts too bad to see their sibling.

What feelings do you have about your sibling who is very sick?

What questions do you have about your sibling's condition? You can ask your sibling, your parent, someone at the hospital, or anyone you trust.

Some ways to express your feelings are spending time with someone else, doing an activity together, or doing something special for another person. These activities can help you and your sibling can talk, remember, and ask questions.

- If your sibling feels well enough, play a board game or video game with them
- Would your sibling like to color or draw with you
- Are there questions you have that your sibling could answer
- Make your sibling a picture for their room
- Make a collage for your sibling. A collage is a collection of pictures. You can use pictures from magazines or a camera. Paste them together in a way your sibling would enjoy on a piece of poster board. You need an adult's help to do this activity.
- Write your sibling a story.
- Ask your sibling's friends and family to write letters to your sibling. Deliver the letters yourself in a fun box or envelope.
- Make your sibling an album of pictures or stories.

Death and Dying

Everyone has different grief feelings. Grief is the feelings you have when you know someone is going to die. All people have grief when a loved one dies. Grief lasts after that person dies.

Grief doesn't feel the same each day. Grief feelings might change every few hours or even more often. Grief can be feelings like sadness and anger and confusion. It can also be feelings in your body like:

- Feeling tired
- Not feeling hungry
- Not being able to sleep very well

Grief sometimes lasts a long time. You can take a break from it by relaxing and using pictures in your head when you need to.

What is death?

Death happens when the body stops working. The heart stops beating. The brain doesn't get or send any more messages to the body. Sight, hearing, taste, touch, and smell don't work anymore.

When someone is dead, their body doesn't have thoughts or feelings. When people die, their bodies can't move or play anymore. After death, the body will never be able to do these things again.

Some kids think death is like something they have seen in a movie or a cartoon. Death is often very different than what you see on TV.

Some people think death is like falling asleep. Death is not like falling asleep. It is something very different.

If you are not sure about death, you should ask questions about it. It is hard for people to talk about death and ask questions about it. Getting answers will make you feel better and have less stress.

Ask your parents, a doctor, or your religious or spiritual leader to answer your questions about death. Do you have questions about death?

Write down what you are thinking about death and what you imagine it is like. Then, if you want, show the letter to someone you trust and see what they think about death.

Spirituality and Customs

Spirituality is a name for the beliefs people have about the meaning of life and what happens after we die. Spirituality can be a religion like Christianity, Buddhism, Hinduism, or Islam. Spirituality does not have to be a religion. It can just be your own set of beliefs.

Customs are traditions and behaviors that are special to groups of people. These could be:

- Celebrating Christmas or Hanukkah
- Setting off firecrackers on July 4th
- Wearing certain types of clothes

Many groups of people have special customs for death like funerals and special ceremonies.

What customs does your family have?

Do you have a special cake on birthdays?

Do you have special decorations you put up for holidays?

Spirituality and customs are important parts of death and dying for some people. You may have questions about spirituality and customs during this time. You know how to ask questions when you have them.

What questions do you have? Ask your parents, an adult you trust, or your religious or spiritual leader about spirituality and your family's customs for death and dying.

People believe many things about what happens after death. Even adults have questions about this. It is interesting to learn what others believe. If you ask people, you might hear a lot of opinions on what happens after death.

Different people believe different things. Some people believe that:

- When a person dies, their soul goes to be with God
- Death is the end of life
- Death is a chance for continued spiritual improvement
- People live on in the hearts and memories of those who love them
- People who die are born again in a different form

If you have questions about spirituality and what happens after death, ask an adult you trust or your spiritual leader. What do you believe happens after death? There are no "right" or "wrong" answers.

It is okay to not be sure about your answers. There are many adults who still wonder about spiritual questions and what happens after death.

There are many special ways of saying good-bye to someone who has died. Customs are different for different families, religions, and spiritual beliefs. Some people have special ways of doing things, like:

- Bury the dead person in a coffin underground in a grave. They can also be buried in an above-ground container. This is called a mausoleum.
- Have a memorial service or a wake
- Cremate or burn the dead person's body
- Burn incense and bow low in front of the grave.
- Sing and pray together at the grave.
- Gather at the grave in a circle. Part of the circle is open to honor the dead person's spirit.
- Spend several days in mourning, lighting a candle for every day.
- Gather to celebrate the dead person's life and share memories of the dead person

There are customs for remembering a loved one long after they have died. Some people visit the grave, have special religious services, say prayers, or make offerings.

What will you and your family do?

Putting it all Together

Read the story below. See how you can use the ways you have learned to deal with stress and grief. How would you help John?

John and Lisa

John has felt many things since hearing the news. He has been very sad and has been thinking about how much he will miss his sister. He has felt guilty, too, since once when they were fighting, John told Lisa he hoped she would die.

John stopped thinking that unhelpful thought and decided to ask Lisa to forgive him for saying he hoped she would die.

The next day, John went to the hospital and told Lisa he was sorry. Lisa forgave John and they laughed for a minute thinking about the silly things they used to fight about.

John couldn't stay at the hospital very long because he had homework to do. He went to stay with a neighbor while his parents stayed with Lisa.

When John was working on his homework, he started thinking about the time before Lisa was sick when their parents were around to help them with their homework and get them a snack after school.

John started to cry. He was feeling left out, sad, and angry. Since John didn't want to talk to the neighbor who was staying with him, he decided to try to make his stress less on his own.

That night, John was lonely as he tried to fall asleep. The house seemed empty even though an adult was there to take care of him. John started to think his house will never be a happy place again and he couldn't stand his life anymore.

More about John and Lisa

John was doing better adjusting to the news that his sister, Lisa, was going to die of cancer. He felt tired and worried lots of the time but remembered to use relaxation and happier images when he needed a break from his stress.

John's parents were so busy taking care of Lisa and working that he felt like he didn't see them enough. He decided to talk to his parents about his feelings. One evening, John sat with his parents in the living room, and he told them he felt lonely and was kind of confused about what was going on with Lisa.

The next weekend, John and his parents went to the hospital to see Lisa. John brought a favorite game from their house to play with Lisa. John and Lisa had a great time together playing the game.

When John asked, Lisa told him about the machines by her hospital bed. Lisa knew so much about her equipment! John met Lisa's nurses when they came in to check on Lisa.

When it was time to leave, John was really sad. He and Lisa hugged for a long time and they both cried a little bit.

In the car on the way home, John's parents told him they were really sad to leave Lisa, too. John talked about some of his good memories of Lisa. John remembered about the time he and Lisa had friends from school over to play games and watch movies. John told his parents about his memory and they all smiled for the rest of the ride home.

As time passed, Lisa became weaker. She didn't always wake up to see John when he went to the hospital to see her. John's dad asked John one day if he would like to come to a special meeting at the hospital to plan for Lisa's care and final days. John was a little scared to go, but he did have questions about what would happen and he wanted to understand the decisions.

At the special meeting, John saw Lisa's nurses whom he had met before in her room. John also met Lisa's doctor and a social worker.

The people from the hospital talked to John and his parents about where they would like Lisa to spend her last days and where they would like her to die.

John asked some questions about words he didn't understand. He was very sad and a little scared to be talking about Lisa dying, but he sat close to his parents and remembered he wanted to understand what was happening and do the right thing for Lisa.

In the meeting, John's parents and the hospital people decided Lisa would be moved to a hospice. John had learned that a hospice is a special sort of hospital for people who are dying and the people who work there are really good at making dying people and their families comfortable.

John thought his parents made the right decision about Lisa going to hospice. As the meeting ended, John and his mom held hands. They were all getting really sad again about Lisa dying. Talking about it had been the right thing to do, but it made them miss Lisa so much.

The hospital social worker asked John's parents if they would like to sit or pray in the hospital chapel before going home. She told them people of all religions and spiritual preferences are welcome to use the chapel.

John told his parents he would enjoy that. They headed off toward the chapel still holding hands. John's mom looked down at John with tears in her eyes. She said, "John, we will get through this together."

John hugged both of his parents and said, "That is just what I was thinking."

About This Book

This book was developed using 2 interventions: Sibling Adaptation Counseling (SAC) and Behavioral Treatment for Pediatric Pain (BTPP).

SAC

Martha Craft-Rosenberg, PhD, RN, FAAN and Lou Ann Montgomery, PhD, MAN, RN, NPD-BC, RN-BC, FAAN, created SAC. It promotes positive coping for healthy siblings of children with cancer. It is based on Selye's and Lazarus' theories of stress and data on about 400 siblings of hospitalized children.

SAC guides parents in helping their healthy children use emotion and problem-focused coping as they adapt their lives to changing events.

Suggestions for parents in SAC are:

- The importance of talking about siblings' fear of getting the illness and how to address their fear
- Using open communication and ways to increase communication
- Keeping healthy siblings in their own home with a consistent caretaker who knows them well
- Maintaining consistency and lowering changes in parenting
- Encouraging expression of feelings by the healthy sibling
- Facilitating involvement with their sibling, as indicated and comfortable

Research shows less stress responses in children whose parents were given this counseling.

BTPP

Daniel Clay, PhD, MBA, and colleagues created the BTPP intervention. It is based on Varni's model of pediatric pain. BTPP helps chronically ill children cope with pain. It uses technologies that hold promise for adaptability to coping support for siblings of dying children.

BTPP combines a cognitive-behavioral treatment intervention with computer technology to enhance acceptability for children and provide flexibility for use. Treatment materials are a video, CD ROM, workbook, and a pocket-sized cueing tablet.

The materials are meant to be used together but can also be used separately. The video uses animated characters to raise children's' interest and engagement. The video has:

- Psychoeducation
- Modeling of effective coping for both children and parents
- Modeling of coaching for parents
- Chances for rehearsal

The CD ROM has the video so that parents and children can go to the part most relevant to their problem.

This interactive component of the intervention makes sure that the most appropriate treatment or coping methods are quickly and easily accessed. The CD ROM also has treatment activities that are like video games. These are meant to engage children in the material in an interactive and meaningful way.

Research Studies

1. Montgomery did a qualitative study of 13 siblings and 15 parents of 13 hospitalized children. The purpose was to identify needs of siblings of hospitalized children to help develop future interventions. Siblings reported a need for getting information like an explanation of the child's hospitalization and preparation for the visual appearance of the hospitalized child.

Common themes for siblings were:

- Getting different amounts of information from parents and others
- Feeling sad and scared
- Wanting to talk with parents or doctors as the main source of information
- Needing more unit activities
- Finding the confidence displayed by the medical team helpful.

Common themes for parents were:

- Knowing everything was important for siblings
- Asking if the child would get better was the question asked most by siblings
- Having more unit activities available was a family need
- Being at the hospital and keeping busy was helpful to siblings
- Feeling parent stress and getting incomplete answers to questions was not helpful for siblings

Siblings had different responses to separation from parents. Siblings also reported that more parents changed their parenting approach than parents self-reported.

2. Kleiber, Montgomery, and Craft-Rosenberg explored parental and family perceptions and feelings about the information needs of siblings during pediatric admission to an intensive care unit (ICU). Twelve parents and 12 school-age siblings were interviewed using open-ended questions.

There was marked similarity between the themes of information that the parents reported giving to the children to what siblings reported hearing.

Parents reported that siblings had many questions about the reason for hospitalization and impact on the family's future. Parents did not have the knowledge and skills to help the healthy siblings in the family.

The siblings reported that they did not always share their parent's feelings and concerns. The study shows that parents may not know about the impact of the ICU experience on siblings or the knowledge and strategies to support family coping.

About the Authors

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Dr. Montgomery is responsible for:

- Overseeing nursing professional practice, Magnet® recognition, and the Emergency Medical Services Learning Resource Center
- Placement of nursing students for clinical education
- Administering the department's continuing education program
- Co-directing the Nursing Clinical Education Center, a joint venture between the Department of Nursing and the University of Iowa College of Nursing

Montgomery spent 21 years in Pediatric Nursing and Children's and Women's Services where she was a staff nurse, assistant nurse manager and nurse manager of Neonatal ICU, and advanced practice nurse for Neonatal ICU and Neonatal/Pediatric Transport. Her research interests include sibling support of critically ill children and family-centered care during critical illness.

She has published more than 30 manuscripts and received several professional awards and recognitions. She has made important contributions in the biomedical ethics within the Department and hospital, serving as adjunct faculty at the University of Iowa College of Nursing and the Carver College of Medicine. She is a past-president of Sigma Theta Tau International's Gamma Chapter, was named one of 100 Great Iowa Nurses in 2006, and was named as a fellow in the American Academy of Nursing in 2021.

Martha Craft-Rosenberg, PhD, RN, FAAN

Emeritus Professor in the College of Nursing, The University of Iowa

Craft-Rosenberg's began her first program of research in 1978, focusing on siblings of hospitalized children. She then expanded to study siblings of ill children and families of critically ill adults. She studied over 400 siblings during this period and received funding for eleven studies. Her second program of research is nursing standardized language. Craft-Rosenberg served as a member of the first NIH funded research team for Nursing Interventions Classification in 1987, a President of NANDA-I, and a contributor to the Nursing Outcomes Classification. For over a decade she served as principal investigator for the Nursing Diagnosis Extension and Classification team. Craft-Rosenberg is a Fellow in the Classifications Center at the University of Iowa College of Nursing.

Craft-Rosenberg joined the College of Nursing faculty in 1980 after a 15-year practice career. She is an elected fellow of the American Academy of Nursing. She is also the author of 70 articles, four book chapters and author or editor of ten books. Her research on children and families has garnered awards from the American Association for Critical Care Nursing and the Midwest Nursing Research Society. She is the first editor of the book Nursing Interventions for Infants and Children, which was awarded the American Journal of Nursing and Pediatric Nursing Book of the Year Awards in 2000. Craft-Rosenberg recently completed editing the first Encyclopedia of Family Health, published by SAGE in 2011.

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