

Talking With Children About Cancer



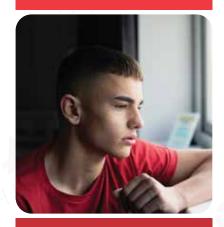
We know that talking with a child about an adult's cancer is not easy. Children have many questions and often will feel anxious when they learn of a loved one's cancer. This booklet is designed to help you talk with children about an adult's cancer. It was written with input from members of our staff and is meant to be a useful resource for you and your loved ones.

The booklet includes:

- Things to think about before you talk with children
- Common questions that children may ask and suggested answers
- An outline of the developmental stages of children and their needs
- Useful resources such as other books, websites and local support groups
- A list of common cancer words and their meanings

We are here to support you and the children affected by cancer. University Hospitals Seidman Cancer Center has social workers who can help. If you need support, please ask to speak with one of our social workers.





Contents

Taiking with Children4
Things to Think About Before You Talk4 When You're Ready to Talk
Children's Developmental Stages 10
Common Questions Children May Ask16
When a Grandparent Has Cancer 22
When Cancer Spreads24
Coping and Support26
Resources
Common Words and Terms Defined 36 Cancer Team Members

2 University Hospitals Seidman Cancer Center • UHSeidman.org



Talking with Children

Things to Think About Before You Talk

Like adults, children are affected by changes and major life events. When an adult they care about has cancer, it is important to know how children are feeling and allow them space to express their feelings and ask questions.

Children benefit when adults give them honest facts that are best suited to their age. Adults can help them talk about their feelings and be on hand when questions or concerns arise. Parents and other caregivers are often the best people to help children during this time. They know their children better than anyone and can tell which behaviors are not normal for them.

Before talking with your children, give yourself time to gather your own thoughts and feelings. Think about your journey so far if you are the one who has been diagnosed with cancer. You may want to have a plan in place before you talk with them. If you are the primary caregiver and you have cancer, you may want to consider who will assist in caring for your children, including getting them to school and other activities when you are not feeling well.

You may also want to think about:

Should I tell them?

It's normal to want to protect children. It may seem keeping the cancer diagnosis a secret is best. Keep in mind that children can often tell when something has changed or is wrong. They can also sense when a loved one is not acting the same. Many times children will make up their own explanations. This can be much worse than what's really going on. Of course, each situation and every child is unique but, when possible, it is recommended to be as open as the child's age and understanding allows.

How should I tell them?

Talking with children about cancer is not easy, but it's important to use the word "cancer." Children need to know the difference between cancer and "being sick."

Children in the same family often react in their own way when hearing about cancer based on their personality. If there is more than one child in the family, you may want to talk with each child one-on-one.

Other things you may want to do:

- Stay calm and go over what you'll say ahead of time with family and/or friends.
- Use words and concepts that match the age of the child. See the section "Children's Developmental Stages" on page 10 for more details.
- When you are ready, find a comfortable place to talk with the child as soon as possible after the diagnosis. This will help them avoid hearing it from someone else and getting the wrong idea about what is going on.
- Ask staff at UH Seidman Cancer Center for help if needed.

What if I can't answer a question?

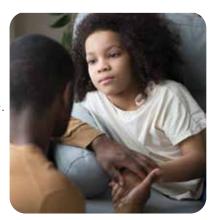
It's perfectly OK to tell your children "I don't know" when you really don't know the answer to their question. Children may ask questions that you're not yet ready to talk about. They may ask something you don't know the answer to. If this happens, acknowledge their question, tell them you don't know the answer, but you will get back to them.

Giving honest answers helps children feel safe. It helps them keep their trust in the adults in their lives. It also helps them understand the changes that are taking place.



When You're Ready to Talk

Keep in mind that open communication is needed so each family member can face the illness. Cancer often changes life for everyone. Good communication between parents or caregivers and children can help each person adjust and cope.



Tips for good communication

- Be sure the children understand that they can't "catch cancer" and they didn't cause the cancer.
- Express your own feelings openly and encourage your children to do the same. Show that you're OK with your own feelings. Tell them that each person shows their feelings in their own way. This can help your children accept their own feelings.
- Allow free expression of feelings, fears and longings. Promote creativity based on the children's skills or hobbies to help them express their feelings. They can try things like art, music, creative writing and physical activities.
- Don't wait for the children to ask questions. Quiet, very good children may really be sad, angry or confused. Instead of waiting, say, "I wonder what you are thinking about."
- Help smaller children express their feelings and concerns with creative play.
- Give children examples of how things may change because of your illness. For instance, there may be changes to their daily routine. Someone else may have to pick them up from school or make them lunch.
- Carefully listen to your children.
- When you can, involve children in decision-making.



Once You've Talked

Keep them informed

Give them updates on an ongoing basis. Be honest and use age-appropriate language that children can understand. Tell them what is going on and how it will affect them. Explain things in a way that is clear and easy to understand. For instance: "Mommy is getting medicine for the cancer. It will make her hair fall out. It will make her tired and want to take naps."

Plan for times that your children can talk about concerns privately with you. If you can, use the children's past experiences to help them cope with what's going on now.

Keep day-to-day routines

Any illness can change a family's life and daily routines. As much as you can, try to keep your family's home life consistent and stable. This is very helpful when the adult is in the hospital or going through treatment. It is also important to keep your normal rules about your child's actions and schoolwork. Decide who will assist in caring for your children, including getting them to school and other activities when you are not feeling well.

Count on family or friends

Ask someone whom your children know well to spend special time with them. They can provide extra outings while you or your loved one is getting treatments or resting.

Keep talking to children on their level

As children get older, they go through many stages of physical, mental and emotional growth. Be sure to use words and actions that match the children's age and needs. You can use the next section as a basic guide.

Children's Developmental Stages

Infants: Birth – 18 months

Normal needs:

- Trusting relationships with people that they know
- Consistent routines
- Being near to parents and caregivers

Signs of stress:

- Upset
- Fearful response
- Problems eating or sleeping

What you can do:

- Arrange for the baby to be cared for by only a few caregivers. They should be people the baby knows.
- If you are going to be away a lot, give the baby something that has your scent on it such as a shirt or blanket. This will help promote bonding and attachment.



Toddlers: 18 months – 3 years

Normal needs:

- Parental guidance
- Chance to have some control
- Consistent routines
- Wants their needs met right away

Signs of stress:

- Anger
- Acting out
- Being more clingy
- Problems eating or sleeping

What you can do:

- · Arrange for caregivers who know the child.
- Limit the number of caregivers.
- · At the start of each day, let the child know what real things to expect for the day such as: "Aunt Erin will be taking care of you today." Daddy will see you after lunch."
- · If you are going to be away a lot, record your voice singing or telling a story so it can be played for your child.





Preschoolers: 3 – 5 years

Children at this age have vivid imaginations. They sometimes make up their own story about what is going on with someone who is sick. They may also pretend to be sick or blame themselves for a parent's illness.

Normal needs:

- Simple and repeated explanations; this helps them identify their feelings
- Chances for play about life's events
- Reassurance about their own health

Signs of stress:

- Sleeping and eating problems
- Acting-out responses
- Being quieter than normal
- Clingy, baby-like responses
- Nightmares
- Going back to younger actions such as loss of toileting and self-dressing skills

What you can do:

- Talk about what will happen. Tell them who will take care of them when the loved one is sick or in the hospital.
- Tell the truth simply and briefly.
- Use and define health care words that they may hear with a real, basic explanation.
 - When talking about a brain tumor or cancer, say, "Mom has something in her head that is causing her to be dizzy. You can't catch it or cause it to happen. The doctors are giving her medicines to help it go away."
 - Use specifics that the children may have noticed. If there aren't any, use the word sick instead.
- Help them work through and express their feelings through art or play. Ask them to draw a picture of what they think the hospital looks like.
- Ask open-ended questions to learn more about what they're thinking, such as:
 - "Why do you think dad has cancer?" and "What's it like for you that dad has cancer?"
- Involve them in simple choices to help them feel more control.
 - "We are going to the park. Do you want to walk or ride your bike?"
- Tell their teacher or daycare what's going on at home.
- Keep parenting and discipline styles the same.



School Age: 6 – 12 years

Normal needs:

- Correct information
- Reassurance about their own health
- Clear rules and expectations

Signs of stress:

- Worry and sadness
- Complaints of bodily illness
- Anger
- School problems
- Isolation

What you can do:

- · Give your children honest information and time to ask questions.
- Use real, hands-on items to explain the illness, such as books and videos.
- Involve your children in choices about their schedule and routines.
- Give reassurance about your children's own health.
- Help them stay close to their peer group through school and sports.
- Tell their teachers or school counselor what's going on at home.
- · Let them decide if and how they want to tell their classmates and friends.



Normal needs:

- Privacy
- Respect
- Complete information
- Involvement in family choices
- Strong bonds with friends

Signs of stress:

- Unusual anger and defiance
- Withdrawal
- Intense mood swings
- Trouble with friends

What you can do:

- Speak with your teens directly rather than through a family member. This helps show your trust and confidence in them.
- Involve them in family choices.
- Remind your teens that it is OK to show feelings. Also say that it's OK to have fun.
- · Respect your children's needs and privacy.
- Support healthy bonds with their friends. Let them do activities outside of school that they want to take part in.
- Tell their teachers or school counselor what's going on at home.
- Let them decide if and how they want to tell their classmates and friends.
- They may look online for cancer information themselves. To make sure they have the right up-to-date information, be open with them and answer all their questions.



Common Questions Children May Ask



Why are you sick?

Why is mommy, daddy or a grandparent sick?

Keep in mind that children often will overhear parts of conversations or phone calls about the person who has cancer. They often will only get a partial understanding or be confused about what is going on.

From time to time, it may be helpful to find a quiet, comfortable place to talk with your children. For younger children, you can ease into talking by playing a game or drawing. Kids are more likely to talk with you while they are playing or doing something else at the same time.

First, ask your children questions to find out what they know and think.

For instance: "What do you know about mommy's sickness?" or "Why do you think she is sick?"

Then ask further questions such as: "Why do you think that?" or "Can you tell me more about that?"

If there is something you can see as part of the cancer, such as a tumor or bruising, start with talking about that. It is something the child will understand. For example, a conversation could be: "Mommy has had a lot of bruises on her arms and legs. All people can get bruises from bumping into things. Mommy's bruises happened because she has a sickness called cancer. You can't catch it from her and she didn't catch it from anyone. You also didn't make it happen. There is nothing that mommy or you did to make it happen. The medicine that the doctors give her is called chemotherapy or chemo for short. It is helping her to get better. It also can make her feel tired, have an upset stomach or be grouchy sometimes. It may also make her hair fall out in a few weeks, but it will grow back. The doctors are helping her. We will make sure that you are taken care of, too."

If I get sick, will I have to come to the hospital, too? One response to this question is to say:

"Mommy's cancer is not the same as being sick like having a cold. You can't catch cancer. Some medicines for cancer can only be taken in the hospital. When you have a cold, we have medicines to give you at home."



I got mad at Dad and threw a ball at him. Is that why he has a tumor inside?

Adults know the answer to this question is clear, but young children often believe their thoughts and actions can cause things to happen.

You can answer this question simply by saying: "The doctors don't know why it happened to him. We do know that it is not anyone's fault. Throwing a ball at him did not give him cancer."

Can I visit Grandma in the hospital? Most hospitals let children visit, but they may have guidelines on visitation. It is very important that children know what they are going to see at the hospital before they arrive. If allowed, take pictures of the person in the hospital, the room, and the nurses or doctors. Showing children pictures can be very helpful. Children should be given the choice about going to the hospital or not.

Here are some ways to describe what they might see:

- "Daddy has something called an IV. It is a small, plastic straw joined to a thin tube that gives your dad medicine and water. It is there to help him and it doesn't hurt."
- "Grandma has a special TV in her room called a monitor. It tells the doctors and nurses how her heart is beating and how much air she is breathing. Small wires with stickers are on her chest. They attach to the special TV and it sometimes beeps. She doesn't feel anything from them but they give the doctors information."

Stress how the children can interact with the person they are visiting. Can they hold their hand or talk to them? They should also be given the choice of how close they want to be. First, do they want to visit the hospital? Then would they like to stay in the lobby? Would they like to go to the room but stop at the doorway? Do they want to stand at the bedside? Give them the choice to leave at any time.



Is Mommy going to die?

This can be a hard question. It is one that a lot of children are thinking. They may wonder this even if the situation is not bad. Before giving an answer, it may be helpful to first explore the question more with the children. Start with some questions to figure out what the children are thinking.

For someone who is doing well on treatment:

"I can hear that you are wondering if mommy is going to die. Tell me more about why you are asking that guestion." This helps you know how well the children do or don't understand the situation. You can then say something such as, "The doctors and nurses are working really hard to try to keep mommy healthy. Right now, the medicine is working. The doctors expect mommy to get better. We are not worried about her dying. We will always be honest with you. If things change we will talk about it." Saying this last statement is important as it helps children to trust. They won't worry each day if something is worse or wrong.

For someone whose future is uncertain:

"I can hear that you are wondering if mommy is going to die. Tell me more about why you are asking that question." You can then say, "The doctors and nurses have been trying really hard to help mommy get better. But, the medicines are not working and there are no other medicines to make her better. We hope that mommy lives as long as she can. We know there are no medicines that will cure her right now and she may die."

Give the children a chance to respond or ask questions. They may even ask what dying feels like or other direct questions. You can reassure them. Say: "I don't know what it feels like to die. The doctors and nurses know how to help mommy be really comfortable. They are giving her medicine for cancer pain that makes her really tired and not hungry. Mommy can still hear you when you talk to her."

It can be very hard to talk about this. Most children have an easier time talking about death and asking questions than adults do. Children need chances for expression and closure with a loved one who is dying, just like adults do. This will help them work through the experience of a loss. Please ask your health care team to help you if you are in this situation. They can help you and your children with ongoing support.



When a Grandparent Has Cancer

Children may also pick up on the worry that happens when a grandparent has cancer. They can see how the adults in the family are acting. They may listen to phone calls, but they only hear one side. Children may think up something worse than cancer if no one explains what's going on.

You can talk to your children about their grandparent's cancer. Find ways that will be helpful to them and comfortable for you. Things to think about when talking to your children are:

- How old is the child? See the section on Developmental Stages for more details on page 10.
- How close are the children and grandparent? What is their bond like? How will the grandparent's cancer change the children's daily routine?
- How serious is the cancer?

Younger children may think that they caused the cancer. Remind them that they did not cause their grandparent's cancer. Tell them the doctors are doing everything they can to help the grandparent get better.

Children will take their cues from their parents. You may be feeling a lot of emotion about the grandparent's cancer. It is OK to show your children how you feel. They will learn that it is OK to feel sad or upset when someone they love is ill.

You can explain that the grandparent is sick and may not act normally. For instance, the grandparent may be very tired or even grouchy. He or she may not be able to give a lot of attention to the children.

When the grandparent is feeling well, encourage children to spend time with him or her. They may like to take pictures, or write or make a memory book together. The grandparent could tell stories of his or her own childhood. This will create good memories for everyone.

If your children are old enough, you can ask them to help the grandparent. Children can help make meals or do simple household chores.

Your child may ask if grandma or grandpa is dying. You can say, "Many people with this kind of cancer do die, but some people get better."

When Cancer Spreads



Getting bad news is not easy. Learning that cancer has spread or that treatment is not working is very difficult to hear. It is hard for everyone involved. Telling children the news can seem impossible.

Children can sense what is going on around them. They watch and listen to how the adults around them are acting. It is important to be honest and clear with your children.

When talking, keep in mind the children's age and stage of development. You may need to speak to each child in a different way, or give them different amounts of information.

Some things you can say and do:

- Give your children examples of how things may change. This may include changes in their routines, caregivers or living situation.
- You can say that the doctors cannot make the cancer go away. You can say that the person may get sicker, not better.
- Try to do or say something positive each day. This can be something easy like drawing pictures, singing together, writing notes, playing games or helping in the kitchen.
- Find ways to make moments meaningful for each child.
- Tell your children that even though the cancer will not be cured, you are now hopeful that the person with cancer will be comfortable.

If you're talking with young children...

- You do not have to tell your children everything at once.
- Younger children may think that when cancer treatment stops, it means the cancer is better. You can tell them the cancer is not better. You can say the treatment is not helping.
- For younger children, you do not have to say the person is dying unless the child asks. It is not useful to talk about death until it is near. If a younger child asks about dying, you can say that when people cannot get better, they sometimes die.

Coping and Support

Give comfort with care and understanding

It is OK to tell your children that you don't know exactly how the treatment will make you feel. Children will take your lead about what you want them to know. Your children will look to you to keep them safe and to maintain their way of life as much as you can.

- Remember that you have control over what you tell your children. You can decide how, when and where you give them the information.
- When you talk with your children, it is helpful to have a family member and/or friend present. They can give comfort to you and your children. Choose someone who will be able to stay calm during the talk.
- Keep your information and answers honest. Be mentally ready for any kind of question. It is not uncommon for children to ask you if you are going to die. Remember not to make promises that you may not be able to keep. A simple answer could be: "I am fighting cancer the best way I can. I am hopeful that my treatments will work."
- Be sure that your children understand that they did not cause cancer. It is important to let young children know that you did not "catch cancer." Let them know they cannot catch it either.



You are not alone in this journey. Ask for extra support.

Social workers

Our UH Seidman Cancer Center social workers can give guidance to help you. They are also here for your caregiver and your children during this time. Please ask to speak to a social worker if you have any questions or concerns.

Teachers and school counselors

Reach out to others who care for your children. Tell teachers about cancer in your family. Changes in home life can make it hard for children to focus at school. Certain things at school may make them uneasy, upset or emotional. There may be a change in the way they behave or perform at school. If teachers know about stress at home, they can give understanding and support.

Talk with your children's school counselor. Ask the counselor to check on your children and to give them time and a place to safely express their feelings.

Others who can help

Get more support if you think that your children are not coping well. You can ask for help from a social worker, counselor, clergy, and other family members or friends who know your children well.



Books and websites can help parents and children understand and cope with a parent's illness. The following list also includes local cancer groups and their contact information.

Please choose resources that you feel are best for your family. You can find more resources at your local library, bookstore and online.

Books for Parents

What Happens When Someone I Love Has Cancer?: Explain the Science of Cancer and How a Loved One's Diagnosis and Treatment Affects a Kid's Day-To-day Life

Sara Olsher (2019)

Join Mia and her stuffed giraffe Stuart as they explain the science of cancer and how a loved one's diagnosis and treatment affects a kid's day-to-day life. This book uses bright and fun illustrations to show how cells can turn into cancer, and helps reduce confusion about how cancer treatment affects a person and the kids in their lives. Ages 4 to 10.

How to Help Children Through a Parent's Serious Illness Kathleen McCue (2011)

This sensitive book written by a leading Child Life Specialist from the Cleveland area guides patients through the process of helping children face the challenges of parental illness. Parents are empowered to open the door to realistic communication without feeling guilty. Information is tailored to help parents meet the needs of children at different developmental stages.

When a Parent Has Cancer: A Guide to Caring for Your Children Wendy S. Harpham (2004)

Dr. Wendy Harpham is a mother, doctor and cancer survivor. She offers clear and kind advice for parents for raising normal, healthy children while the parent struggles with a possible life-threatening disease.

Just You and Me

Judy Richmond (compassionbooks.com)

This tender book by a hospice worker was written so the last days a child spends with a dying loved one could be filled with love. Parents are given 50 fun ways to say "I love you."

Raising an Emotionally Healthy Child When a Parent is Sick

Paula K. Rauch and Anna C. Muriel (2006)

A wonderful resource for parents to help their children during the difficult time of parental illness, it offers useful advice, wisdom and insight into the child's outlook. It helps parents prepare for children's questions and concerns. It then suggests loving ways for parents to respond.

Books for Children

Someone I Love is Sick

Kathleen McCue

This customizable book can be used when talking with children when a parent or grandparent has cancer. It addresses all stages of the cancer journey. (Ages 2 - 6)

Mommy Has Cancer: What I Learned about Cancer, and How I Helped My Mommy

Corey L. Stevenson, Jr.

Corey Jr. is a nine-year-old from Saint Louis, Missouri, who has chosen to share his journey during his mother's battle with breast cancer. Key takeaways from this book are to always be kind, always show love and always be thankful for your family.

Daddy Has Cancer

Sharon Coggins

Fabian Amin is just four years old. He lives in the city with his family, but has been noticing some changes with his father. Told with heartfelt concern and understanding, this story will connect any reader with the difficult reality of losing a loved one to disease and can help explain the deterioration to a young child.

Can I Still Kiss You?: Answering Children's Questions About Cancer Neil Russell

A question and answer book written by a cancer patient, using the questions he was asked by his children. (Good for all ages)

Mom and the Polka Dot Boo Boo

American Cancer Society

This book tells a story about a young mother's journey through breast cancer. (Ages 2 - 5)

Our Mom Has Cancer

American Cancer Society

This book helps children understand and cope with a parent's cancer. (Ages 5 - 12)

Our Mom is Getting Better and Our Dad is Getting Better

American Cancer Society

Each of these books helps children understand a parent's experience when recovering from treatment. (Ages 5 - 12)

Because Someone I Love Has Cancer

American Cancer Society

This book offers activities to help children get through a loved one's cancer journey. (Ages 6 – 12)

Butterfly Kisses and Wishes on Wings. When Someone You Love Has Cancer...A Hopeful, Helpful Book for Kids

Ellen McVicker, Author and Nanci Hersh, Illustrator (2006)

The story is told through the eyes of a child. It offers a simple and clear understanding of cancer. It also teaches children they can be an important part of a loved one's cancer journey.

Nowhere Hair: Explains Cancer and Chemo to Your Kids

Sue Glader (2010)

The book, written in rhyme, explains hats, scarves, wigs and going bald in public. It explores the idea of being nice to people who may look different than you. It ends with the idea that what is inside is far more important than how we look on the outside. (Grades K-2)

When Your Grandparent Dies: A Child's Guide to Good Grief

Victoria Ryan, Author and R. W. Alley, Illustrator (2002)

Elf-help Books for Kids. From a child's-eye view, the little elves in this book show the difficult days before, after and beyond a grandparent's death. They explore the meaning of death and heaven. They show how to stay close in spirit with a grandparent who has died. Includes ideas for action and questions for discussion. It will help you help your grieving child create comforting memories. (Ages 4 – 8)

Someone Special is Very Sick

Jim and Joan Boulden

This is an easy-to-read workbook giving support to young children concerned about the illness of a loved one. It gives useful ideas about how to talk with children. Cartoon-like pictures will appeal to this age group. (Grades K-2)

Help Me Say Goodbye

Janis Silverman

This workbook helps children think about their experience and feelings when someone important to them dies. Each page offers a prompt for drawing or writing about the expected or recent loss. Many of the activities involve others, along with family and friends, in the experience of loss. (Grades K-3)

My Many Colored Days

Dr. Seuss

Not specific to cancer, but this colorful book helps children express and understand feelings. (Grades Pre-K – 2)



Books for Teens

My Parent Has Cancer and It Really Sucks

Marc Silver

This book provides real-life advice from real-life teens designed to help teens live with a parent who is fighting cancer.

A Teen's Guide to Coping. When a Loved One is Sick and Preparing to Die.

Fairview Hospice (compassionbooks.com)

This book helps teens sort out their feelings, learn to cope and answers questions when someone is dying. Guided journal pages help record thoughts and events and keep memories. A small, but complete, handbook for teens.

Guide for Teens: When a Parent Has Cancer

National Cancer Institute (cancer.gov)

Real information for teens coping with their parent's cancer diagnosis.

Conquer Anxiety Workbook for Teens: Find Peace from Worry, Panic, Fear, and Phobias

Tabatha Chansard, PhD

Anxiety is a difficult emotion to manage, and the added stressors of teenage life can make it feel impossible to overcome. The exercises teach you practical, effective techniques to tackle worrying in the moment.





Helpful Websites

kidscope.org

Offers a booklet and video

someoneiloveissick.com

Describes the book, Someone I Love is Sick, discusses how to talk with children about cancer and offers a resource list

cancercare.org

Gives information about understanding and coping with cancer; also has a children's section

cancer.gov

This is the National Cancer Institute. You can search for information on cancer, its treatments, coping, and talking with children and teens

cancer.org

Gives information about understanding and coping with cancer; also has a children's section

grouploop.org

A support community for teens touched by cancer, along with professionally monitored discussion boards and online support groups

Local Resources

The Gathering Place

A local cancer support center offers support groups, counseling and programs for children and families. All of their programs and services are free.

The Gathering Place is in Beachwood and Westlake. To learn more, call 216-595-9546 or visit touchedbycancer.org.

Stewart's Caring Place

A cancer wellness center that provides free services such as counseling and support groups to individuals and families touched by cancer.

Stewart's Caring Place serves Summit, Medina, Stark, Portage and Wayne counties. To learn more, call 330-836-1772 or visit stewartscaringplace.org.

Yellow Brick Place

A local center that supports and educates cancer patients and those closest to them by providing individual and group services.

Yellow Brick Place serves Mahoning, Trumbull, and Columbiana counties. To learn more, call 234-228-9550 or visit yellowbrickplace.org.

Camp Kesem

Camp Kesem is a free, week-long overnight summer camp designed for children ages 6 to 18 who have been impacted by a parent or guardian's cancer. They also offer year-long services through their Kesem By Your Side program.

Camp Kesem is a national organization with local Ohio chapters. To learn more, visit Kesem.org.

UH Seidman Cancer Center Learning Resource Center

Our health librarian can provide books, pamphlets and handouts and refer you to resources. The librarian can mail items to your home or bring them to your hospital room.

To reach the librarian, call 216-286-4636.

UH Seidman Cancer Center Social Workers

Our social workers can help you deal with the daily challenges of cancer. They can talk with you about your cancer, problem solve, and help with day-to-day needs. They can also suggest ways to help children cope when their parent or grandparent has cancer.

Please tell you doctor or nurse if you would like to speak with one of our social workers.

UH Seidman Cancer Center Spiritual Care Coordinator

There may be times when you would like to talk to someone about your faith or spirituality. Our spiritual care coordinator is here to listen, offer prayers, or just sit and be with you in the moment. The goal is to help you connect to your source of strength, purpose, meaning and hope. You may also ask to speak with a clergy member from your faith, which can be arranged.

To reach the UH Seidman Cancer Center spiritual care coordinator, call 216-286-3871.

United Way

Gives free and private information for help with food, housing, work, health care, counseling and more.

Call 216-436-2000 or 2-1-1, or visit 211.org.

Common Words and Terms Defined

This section includes meanings for words your children may hear during the cancer journey. Source: The National Cancer Institute – cancer.gov or 1-800-422-6237.

Cancer Team Members

WHAT THEY DO		
A health professional trained to care for people who are ill or disabled		
A health professional with special training in nutrition who can help with dietary choices		
A doctor who specializes in treating people with cancer; some oncologists specialize in certain types of cancer or certain types of cancer treatment		
Educates patients and families about illness		
Dispenses medicines for patients		
Teaches exercises and physical activities that help patients gain more muscle strength and movement		
A doctor who treats mental health problems, such as depression, with medicine and talk therapy		
Talks with patients and their families about emotional and personal matters; helps them make decisions, but does not write prescriptions for medicines		

Radiologist	A doctor who looks at X-rays and other images of the body	
Religious or spiritual leader	Addresses the spiritual and emotional health of patients and their families; this can be a chaplain, minister, priest, rabbi, imam or youth group leader	
Social worker	Talks with people and their families about emotional or physical needs and helps them find support services	
Surgeon	A doctor who operates to remove or repair a part of the body	

Tests

TEST	PURPOSE	WHAT HAPPENS
Biopsy	Used to find out whether a tumor or abnormality is cancer. Benign means it is not cancer. Malignant means that it is cancer.	A doctor removes a sample from a person using one of two methods: with a long needle (needle biopsy) or by making a small cut (surgical biopsy).
Blood test	Checks the blood to see if the balance of the cells and chemicals is normal.	A nurse or technician puts a needle into a vein, most often in the arm. Then he or she draws blood.
Bone marrow biopsy (also called bone marrow aspiration)	Collects a small sample of cells from inside a bone to be looked at under a microscope.	A needle is used to remove a small sample of tissue from a bone (most often the hip bone).
CAT scan or CT scan (computerized axial tomography)	Uses X-rays and a computer to produce three-dimensional (3-D) pictures of the inside of the body.	The patient lies flat on a table, which moves through a large tube while a series of X-rays is taken.
MRI (magnetic resonance imaging)	Uses radio and magnetic waves to make pictures of organs and other tissues inside the body. The pictures can show the difference between normal and diseased tissue.	The patient lies flat on a table, which moves through a large tube while an MRI machine scans the body for many minutes.

PET scan (positron emission tomography)	Uses computerized pictures of areas inside the body to find cancer cells. May be used to help diagnose disease, plan treatment or find out how well treatment is working.	The patient gets an injection and then a machine takes computerized pictures of areas inside the body.
Spinal tap (lumbar puncture or LP)	Collects a sample of the fluid inside the spine to be looked at under a microscope.	A needle is used to remove fluid from the spine in the lower back.
Ultrasound (ultrasonography)	Uses high-frequency sound waves to make images of organs and other tissues inside the body.	A technician moves a small handheld device over part of the patient's body. An image appears on the computer screen.
X-ray	Takes a picture of the inside of the body using high-energy waves.	The patient is put in front of the X-ray machine or lies on a table.

Other Common Words and Terms

Benign: Not cancer. Benign tumors do not spread to other parts of the body.

Biological therapy: Treatment to boost or restore the ability of the immune system to fight cancer, infections and other diseases. Also used to lessen certain side effects that may be caused by some cancer treatments. Agents used in biological therapy include monoclonal antibodies, growth factors and vaccines. These agents may also have a direct antitumor effect. Also called biological response modifier therapy, biotherapy, BRM therapy and immunotherapy.

Bone marrow: The soft, sponge-like tissue in the center of most bones. It makes white blood cells, red blood cells and platelets.

Cancer: A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues. They can spread through the bloodstream and lymphatic system to other parts of the body. Also called malignancy.

Main types of cancer:

- Carcinoma starts in the skin or in tissues that line or cover organs inside the body.
- Central nervous system cancers begin in the tissues of the brain and spinal cord.
- Leukemia starts in blood-forming tissue such as the bone marrow. Large numbers of abnormal blood cells form and enter the bloodstream.
- Lymphoma and multiple myeloma begin in the cells of the immune system.
- Sarcoma starts in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

Cell: The single unit that makes up the tissues of the body. All living things are made up of one or more cells.

Chemotherapy: Treatment with drugs that kill cancer cells. Also called chemo. Most often chemo is given directly into a vein, which is called intravenous (IV). Some chemo can be given in other ways, such as a pill or a shot.

Depression: A mental condition marked by ongoing feelings of sadness, despair, loss of energy and difficulty dealing with normal daily life. Other symptoms of depression include feeling worthless or hopeless, loss of pleasure in activities, changes in eating or sleeping habits, and thoughts of death or suicide. Depression can affect anyone, and can be treated with success.

Diagnosis: The process of identifying a disease, such as cancer, from its signs and symptoms.

Hormone: A substance made by glands in the body. Hormones move through the bloodstream. They control the actions of certain cells or organs. Some hormones can also be made in a lab.

Hormone therapy: Treatment that adds, blocks or removes hormones. To slow or stop the growth of certain cancers, synthetic hormones or other drugs may be given to block the body's natural hormones.

Immune system: Organs and cells that defend the body against infections and other diseases.

Inherited: Transmitted through genes that have been passed from parents to their offspring (children).

Intravenous: Into or within a vein. Intravenous is a way of giving a drug or other substance through a needle or tube placed into a vein. Also called IV.

IV: Into or within a vein. IV is a way of giving a drug or other substance through a needle or tube placed into a vein. Also called intravenous.

Leukemia: Cancer that starts in the bone marrow and causes large numbers of blood cells to form and enter the bloodstream.

Malignant: Cancer. Malignant tumors can invade nearby tissue and spread to other parts of the body.

Metastasis: The spread of cancer from one part of the body to another. A tumor formed by cells that have spread is called a metastatic tumor or a metastasis. The metastatic tumor contains cells that are like those in the original (primary) tumor.

Radiation therapy: The use of high-energy radiation from X-rays, gamma rays, neutrons, protons and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (externalbeam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy).

Recurrence: Cancer that has recurred (come back), usually after a period of time during which the cancer could not be found. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrent cancer.

Relapse: The return of cancer after a period of improvement.

Remission: A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer are gone. In complete remission, all signs and symptoms of cancer are gone, although cancer still may be in the body.

Risk factor: Something that increases the chance of developing a disease. Some examples of risk factors for cancer are age, a family history of certain cancers, use of tobacco products, being exposed to radiation or certain chemicals, infection with certain viruses or bacteria, and certain genetic changes.

Side effect: A problem that occurs when treatment affects healthy tissues or organs. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.

Stem cell: A cell from which other types of cells develop. For example, blood cells develop from blood-forming stem cells.

Stem cell transplant: A method of replacing immature blood-forming cells in the bone marrow that have been destroyed by drugs, radiation or disease. Stem cells are injected into the patient and make healthy blood cells. Stem cell transplants can be autologous, allogeneic or syngeneic. Autologous uses a patient's own stem cells that were saved before treatment. Allogeneic uses stem cells donated by someone who is not an identical twin. Syngeneic uses stem cells donated by an identical twin.

Support group: A group of people with similar concerns who help each other by sharing experiences, knowledge and information.

Surgery: A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.

Tissue: A group or layer of cells that work together to perform a specific function.

Tumor: An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancer), or malignant (cancer). Also called neoplasm.

For more terms, visit the website of the National Cancer Institute at cancer.gov. Scroll down and click on "NCI Dictionary of Cancer Terms." This booklet was written with direction and input from:

- UH Seidman Cancer Center Office of Patient and Public Education
- UH Seidman Cancer Center social workers
- UH Rainbow Babies & Children's Hospital child life specialists
- UH Seidman Cancer Center chaplain

For comments or questions, please call the UH Seidman Cancer Center Office of Patient and Public Education at 1-800-641-2422.



UHhospitals.org/Seidman