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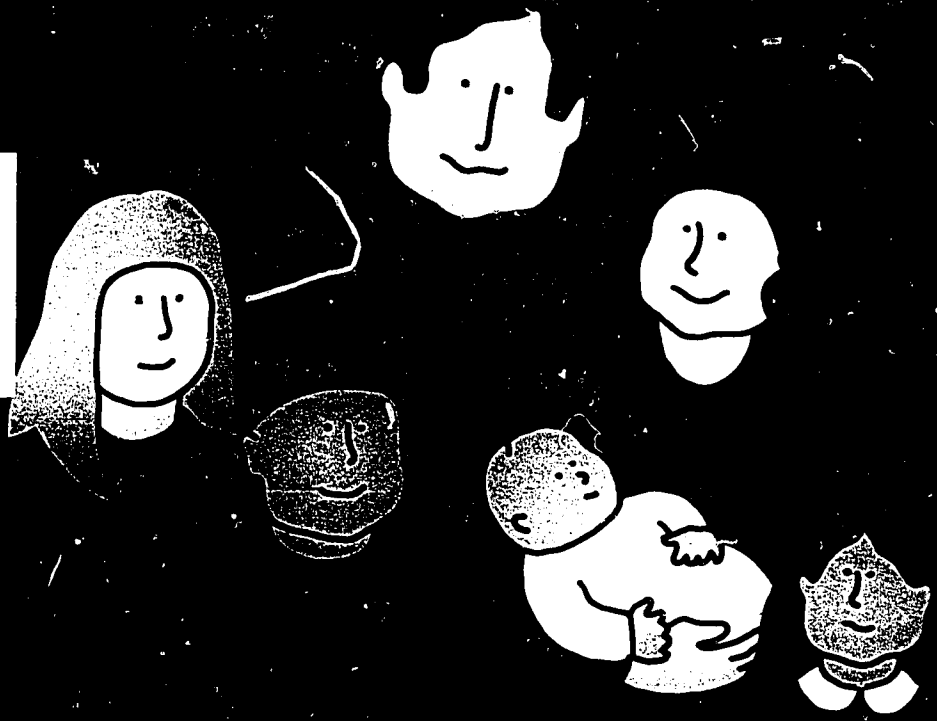
ABSTRACT

This booklet was written for children who have a parent or sibling with cancer. It is intended to help readers understand more about cancer, how it is treated, and changes that may be happening in the family's life because of cancer. In addition, it is intended to help readers understand and deal with their feelings about cancer and about the person in the family who has cancer. Sections discuss cancer in the family, whether cancer can be cured, and learning more about cancer. A section on cancer treatment explains surgery, chemotherapy, radiation therapy, and side effects of treatment. Reading and learning more about cancer are discussed. A section on cancer in the family considers the difficulty in talking about cancer; feeling scared, guilty, mad, neglected, lonely, and embarrassed; answering questions; dealing with side effects; and changing. Other sections describe how parents may feel; putting it all together; and other sources of cancer information, including a toll-free telephone line to answer questions and other booklets. Sidebars throughout the text focus on: (1) some things you should know; (2) words used when talking about cancer; (3) words used in talking about cancer treatment; (4) doctors who work with cancer patients; (5) people besides your parents you can talk to; and (6) remember. (NB)



Special thanks to all the young people, parents, and health professionals who shared their experiences and opinions with us, and to Jane Lewis, who made sure their ideas were included in this booklet.

When Someone in Your Family Has Cancer

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Public Health Service
National Institutes of Health

Office of Cancer Communications
National Cancer Institute

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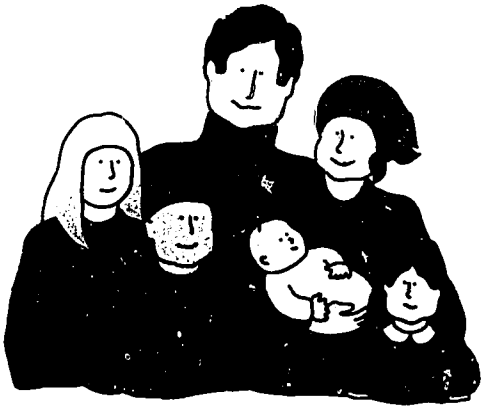
Contents

Sidebars

Introduction

When someone in your family has cancer things can change for everyone — sometimes a little, sometimes a lot. What having a parent or a brother or sister (sibling) with cancer is like depends on a lot of things, such as:

- Who in your family has cancer
- What type of cancer the person has and how it's treated
- How old you are
- If you have relatives or close friends nearby who can help
- Whether you live with two parents or with one
- If you have brothers and sisters at home and how old they are
- How far the person with cancer goes for treatment — across town or to another city or state — and if you can visit or call them
- How long the person has to stay in the hospital
- How well or sick the person with cancer feels
- Whether your parents know the answers to your questions about cancer
- How easy it is for your parents to talk with you about cancer
- How comfortable you feel talking about cancer
- Whether your friends understand what's going on and how they treat you



Any of these can make a difference, and only you know how cancer has affected your life. No booklet can answer all your questions. This one was written to help you understand more about cancer, how it's treated, and the changes that may be happening in your life. It also may help you understand and deal with feelings you have about cancer and about the person in your family who has it.

Cancer and the Family

Any illness changes family life for a while. A parent or a brother or sister who is home sick with the flu can't spend as much time with the family as usual. The sick person may get special attention and you may need to help around the house. But most illnesses don't last long and family life soon goes back to normal.

When someone has cancer, however, it is different. He or she needs special medical treatment and may go to the hospital or clinic often. Everyone in the family may worry, both for the person who has cancer and for themselves. Cancer is a serious illness, and it is scary if you don't know for sure whether the person will get well or not.

Every member of your family may react differently. They may be afraid or angry that their life has changed, or tired, or nervous about the future. They may be tense, and not as easy to talk to as before because they're worried. Some people may go on just as if nothing has happened and they may not seem different at all. If you're upset, this may make you wonder if they care about the family member who has cancer. It's important to remember that everyone reacts in their own way. You may get mad at other members of your family for the way they're acting. If you do, talking with them so you can better understand each other is better than just staying mad.

Some Things You Should Know

- More people are living with cancer now than ever before, and new ways to treat cancer are being discovered
- Having cancer doesn't necessarily mean a person will die from it
- Nothing you did or didn't do caused your family member to get cancer
- Nothing you thought or said caused your family member to get cancer
- Cancer is *not* contagious — you *can't* catch it from someone else
- You or your parents could not have protected your brother or sister from getting cancer
- If one of your parents has cancer, that doesn't mean that someone else in your family will get it too
- If you have a sibling with cancer, that doesn't mean that you or someone else in your family will get it too
- There's no answer to any questions you may have about why your parent or sibling is sick and you're healthy
- The way you behave cannot change the fact that someone has cancer or that your family is upset
- If you are sick that doesn't mean you have cancer too
- It is good for you to continue with school and outside activities

Cancer: Can It Be Cured?

Some people think that because a person has cancer he or she is going to die. Although some people do die from cancer, many do not. More people are living with cancer today than ever before. In many cases, cancer treatment can cause a remission (ree-MISH-un),* which means there are no more signs or symptoms of the cancer. A remission can last for months or years, and sometimes lasts so long that the person is said to be cured. Sometimes, however, the cancer comes back. If this happens, it is called a relapse (REE-laps) or recurrence (re-KUR-unce), and treatment aimed at another remission usually starts.

Whether the person in your family can be cured of cancer depends on many things, and no booklet can tell you exactly what to expect. If you wonder how your parent or sibling is doing, ask an adult who you think will know — someone in your family or someone who works with people who have cancer. If your parents agree, you may want to talk to the doctor, nurse, or social worker at the hospital where your family member goes for treatment. Nobody can tell you why someone in your family has cancer or exactly what will happen in the future, but you can get help to better understand and to live with what is happening today.

Some people with family members who have cancer have found that it helps to hope for the best. A lot of cancer research is being done and progress is always being made in treating cancer.

*Groups of letters surrounded by ( ) are here to help you pronounce words that might be new to you.

One Way To Help Yourself: Learn About Cancer

One thing that has helped other young people to understand what is happening to their family member is learning about the type of cancer that person has and the treatment being used for it. Both of these are important to know about because there are more than 100 different types of cancer and the treatment for each type is different. In addition, there may be more than one way of treating a type of cancer, so people who have the same type of cancer may not even get the same type of treatment. Treatment will depend on how old the patient is, if the cancer has spread to other places in the body, and what the doctors believe is best for each patient.

Treatment will usually follow a protocol (PRO-to-kol), which is a plan for treating cancer. However, even if two people have the same type of cancer and the same treatment, the treatment may not work the same way for both of them. Therefore, if you know or hear of someone who has had the same type of cancer and treatment as your family member and that person didn't do well, it doesn't mean that your family member isn't going to get well. It is important to remember that each person is different and can react to treatment differently.

Cancerspeak 1
Words Used When Talking About Cancer

Biopsy (BY-op-see) — A test where a piece of tissue (a group of cells) is taken from a person's body and looked at through a microscope to see if the cells are normal or not. This is one way to see if a person has cancer. A biopsy can also tell what type of cancer a person has.

Cancer (KAN-ser) — Over 100 diseases where cells that are not normal grow and divide rapidly. They crowd out and destroy normal cells the body needs. Cancer cells can spread to other parts of the body.

Diagnosis (dy-ag-NO-sis) — Identifying a disease. A diagnosis is based on tests and doctors' experience and knowledge.

Growth — A tumor, whether it is benign (not cancer) or malignant (cancer).

Hematology (hee-ma-TOL-o-gee) — The study of the blood, the parts of the body where blood is formed, and blood diseases.

Lump — A thickness under the skin that can be felt by the fingers, either by the person who has it or by a doctor. Lumps can be a sign of cancer, but most lumps are not cancerous.

Lymph (limf) **System** — The network of parts of the body that make and store cells that fight infection, and of vessels that carry lymph fluid through the body to bathe its tissues.

Malignant Tumor (ma-LIG-nunt TOO-mur) — A tumor that is cancer.

Metastasis (me-TAS-ta-sis) — The movement of cancer cells from the original tumor through the bloodstream and lymph system to another part of the body. Metastasis also is the word used for a new tumor caused by this movement of cancer cells.

Oncology (on-KOL-o-jee) — The study and treatment of cancer.

Prognosis (pro-NO-sis) — A prediction of what might happen in a specific case of disease.

Recurrence (re-KUR-unce) — The return of cancer cells and signs of cancer after a remission.

Relapse (REE-laps) — Recurrence.

Remission (ree-MISH-un) — The disappearance of cancer symptoms and cells. When this happens to a person, he or she is said to be "in remission."

Tissue (TISH-u) — A group of cells.

Tumor (TOO-mur) — Cells that group together and keep growing and crowding out normal cells. A tumor can be benign (not cancer), or malignant (cancer).

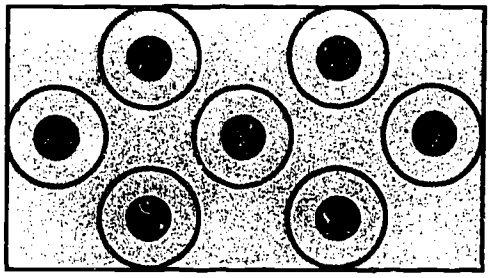
What Is Cancer?

Cancer is a word used to describe a group of diseases. Each has its own name (such as lung cancer, breast cancer, leukemia), its own treatment, and its own chances of being cured. Although each type of cancer is different from the others in many ways, every cancer, whatever it's called or whatever part of the body it's in, is a disease of the body's cells.

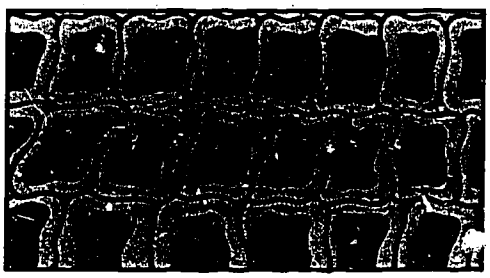
The millions of tiny cells that make up the human body are so small that they can be seen only by looking through a microscope. There are different kinds of cells — some are hair cells, some skin cells, some blood cells — but they each make new cells by dividing into two. This is how worn-out old cells are replaced with strong new ones.

What happens when someone has cancer is that a cell changes and doesn't do the job it is supposed to do for the body. When it divides, it makes more cells like itself, cells that are not normal. These cells keep dividing into more cells and eventually they crowd out and destroy the normal healthy cells and tissues the body needs.

A group of runaway cells is called a tumor (TOO-mur). There are two kinds of tumors. A benign (bee-NINE) tumor is not a cancer. The cells of a benign tumor can crowd out healthy cells but they cannot spread to other parts of the body. A malignant (ma-LIG-nunt) tumor is a cancer. Like a benign tumor, it can take over other healthy cells around it, but it can also spread to other parts of the body. To do this, a cell or group of cells from the tumor separates and moves, usually through the bloodstream, to other parts of the body. There they divide and grow and start tumors made up of malignant cells like those from the original tumor. When this happens it is called a metastasis (me-TAS-ta-sis).



Normal Cells



Cancer Cells

Cancer: It's Not Contagious

Scientists know that you can't "catch" cancer from someone who has it. It is not a contagious disease like chicken pox or the flu, and you can't catch it from being with someone who has cancer or by drinking from the same glass as that person.

You may know that cancer isn't contagious, but you may wonder if having someone in your family who has cancer means that you are going to get cancer yourself. Instead of worrying, it is best to talk with your parents and the doctor about this. They can tell you that cancer usually doesn't run in families, and you can talk about your fears.

Cancer Treatment

There are three major kinds of treatment for cancer — surgery, chemotherapy, and radiation therapy. These are used to destroy cancer cells and bring about a remission. Depending on what type of cancer your parent or sibling has, he or she could have one kind of treatment or a combination of them.

Treatments for cancer sometimes cause unwanted side effects. Side effects are problems caused by the treatment, not the cancer itself. This happens because when cancer treatment aims at cancer cells, it can affect some normal cells too.

Surgery

Surgery (SIR-ja-ree) is an operation. In cancer surgery, all or part of the cancer, or tumor, may be cut out. Sometimes healthy tissue around the tumor is also removed. When people have major surgery, they often have to stay in the hospital until they are strong enough to come home. When they do come home, they may still be weak from the surgery. There may be some things they shouldn't do for awhile, such as lifting heavy things or climbing stairs, because the body needs time to heal after surgery.

Chemotherapy

Chemotherapy (kee-mo-THER-a-pee) is the treatment of cancer with special drugs that destroy cancer cells. These drugs go into the bloodstream and move through it to cancer cells anywhere in the body. Chemotherapy is usually given repeatedly for several months. Even after the person is in remission, the treatments may continue in order to destroy any scattered cancer cells that may still be in the body.

Chemotherapy is most often taken through a needle inserted into a vein, called an intravenous (in-tra-VEE-nus) or IV for short; or into a muscle (a shot); or by mouth (liquids or pills). Many different drugs are used in chemotherapy. Doctors

Cancerspeak 2
Words Used In Talking About Cancer Treatment

Chemotherapy (kee-mo-THER-a-pee) — Treatment with anticancer drugs.

Intravenous (in-tra-VEE-nus) — in the vein. Also called IV for short. A common way of getting medicines into the bloodstream is by having them drip down from a container through a tube and needle and into a vein. Medicine can also be injected into the vein through a syringe. (Veins are tubes that carry blood back to the heart from all parts of a person's body.) After surgery, blood or fluids to help a patient recover can be given through IVs.

Protocol (PRO-to-kol) — A detailed plan doctors follow in treating cancer patients.

Radiation Therapy (ray-dee-AY-shun THER-a-pee) — Treatment of cancer with X-rays or rays from other radioactive sources. This treatment can be beamed through a machine or implanted in a body part. Radiation therapy does not make the patient radioactive.

Side Effects — Problems caused when cancer treatment affects healthy cells in the body. The most common side effects are hair loss, being tired, and having nausea, vomiting, and mouth sores.

Surgery (SIR-ja-ree) — An operation. Cancer surgery is done to remove cancerous tissue from the body.

decide which drug or combinations of drugs to use depending on what type of cancer the person has. The names of some of these drugs — vincristine (vin-KRIS-teen), Adriamycin (A-dree-a-MY-sin), methotrexate (meth-o-TREKS-ate), Cytoxan (sy-TOK-sin), or many others — may become common words around your house.

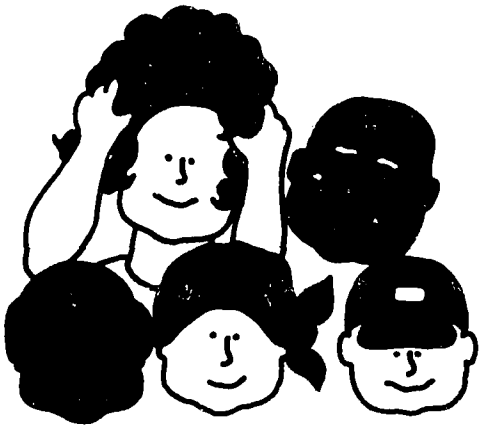
Chemotherapy works mainly on the rapidly dividing cancer cells. But healthy cells, especially those that also divide rapidly, can be harmed as well. This can cause unwanted side effects, and almost all people taking chemotherapy will have side effects. Most side effects are temporary and will gradually go away after treatment is stopped. The doctor can tell your parents or the person with cancer which side effects their chemotherapy is most likely to cause.

Side Effects of Chemotherapy

When chemotherapy acts on normal cells in the stomach and the rest of the digestive tract, from the mouth on down, it can cause nausea and vomiting and sometimes make people lose their appetites. If they have mouth sores on the tongue, gums, or inside of the cheeks, that also makes it hard to eat, especially if the food is too hot, cold, or spicy. People often lose some weight from these side effects.

Nausea and vomiting will usually stop within a day or two after the drug is taken. Mouth sores may last longer and may not even start until 1 or 2 weeks after taking certain drugs. Many people with mouth sores use special mouthrinses to ease the pain.

Temporary hair loss is another common side effect of chemotherapy. Sometimes the hair falls out all at once, and other times it slowly thins out. There's no way to know whether all the hair will come out or not. Even if it does, it will grow back after treatment has stopped. Some



people wear a wig, cap, or scarf until their hair grows back.

The bone marrow, the inner core of the bone, makes new blood cells. If chemotherapy affects the bone marrow, it cannot produce as many blood cells as usual. There may be a temporary decrease in the red blood cells, white blood cells, or platelets (PLAYT-lets), which are different kinds of cells in the blood.

Red blood cells carry needed oxygen to the tissues. When red blood cells are low, the person may be more tired, pale, or cranky than usual.

White blood cells fight infection. When they are low the person is more likely to

get sick and may need to stay out of crowded places or away from people who have something they could catch — like a cold, the flu, or chicken pox. Because of this, you may need to stay away from them if you get sick. If you are exposed to something contagious at school or a friend's house, tell your parents so they will know to watch for signs of you getting sick.

Platelets help stop bleeding. People who don't have enough platelets may bruise or bleed more easily. They may have to stay away from rough play. If they get a nosebleed while their platelets are low, don't panic. They may bleed a little more than someone else would, but it will stop.

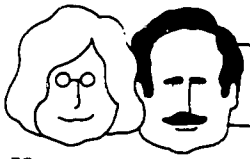
You may notice changes in how the person who is getting chemotherapy acts sometimes. Everyone has ups and downs, but these may be more extreme in a person taking some kinds of chemotherapy. People may feel depressed or nervous or especially hungry because of the chemotherapy. Of course, every change like this isn't due to chemotherapy. Just like others in the family, the person with cancer may be sad or worried about the changes it is bringing to his or her life.

The side effects people have depend on the drugs they take. They may have some or none of the side effects mentioned here, or they may have others. Young people who have had a parent or sibling with cancer have found that it is best to find out what to expect by talking to your parents or the person with cancer.

Side effects of chemotherapy are not pleasant, but they don't last forever. The drugs do not destroy all of the normal cells. Once chemotherapy is over the hair grows back and the bone marrow produces the normal amount of new blood cells. People with cancer begin to feel and act like themselves again.

Radiation Therapy

In radiation therapy (ray-dee-AY-shun THER-a-pee), high energy X-rays or rays from radioactive substances are aimed at a malignant tumor to damage the ability of the cancer cells to divide. Some normal cells close to the tumor also will be damaged. But most healthy cells are protected by placing special lead shields over them.



Cancerspeak 3
Doctors Who Work With Cancer Patients

Hematologist (hee-ma-TOL-i-jist) — A doctor who is a specialist in the study and treatment of blood diseases.

Oncologist (on-KOL-o-jist) A doctor who is a specialist in treating people with cancer.

Pathologist (pa-THOL-o-jist) — A doctor who is a specialist in the study of cells and tissues removed from the body, as well as in making a diagnosis based on the changes disease causes in these cells.

Radiation Therapist (ray-dee-AY-shun THER-a-pist) — A doctor who is a specialist in using radiation to treat diseases.

Radiologist (ray-dee-OL-a-jist) — A doctor who is a specialist in the use of radiation for diagnosis or treatment.

Surgeon (SIR-jun) — A doctor who is a specialist in doing operations.

To be sure the radiation is aimed right at the cancer, dye or felt tip markers are used to mark the target area on the skin. These marks stay on until treatments are finished.

If you've ever had an X-ray, you know something about what radiation therapy is like and that it does not hurt. Any X-rays taken to look at teeth or for broken bones are not as strong as the X-rays used to treat cancer. The treatments take only a few minutes and often are given over a period of several weeks.

In some cases, radiation is not beamed through a machine but instead comes from a source implanted or placed in the tumor. Surgery is used to insert radiation implants in the tumor so cancer cells will be destroyed from inside the body.

The person who gets radiation therapy is not radioactive during or after radiation therapy, and none of the treatments he or she is getting will hurt other people. When people have an implant in place, however, you will not be allowed to get too close to them until it is removed. They will be in the hospital during this short period of time.

Side Effects of Radiation Therapy

Although radiation therapy isn't painful, it can cause unwanted side effects. The person may be more tired than usual. Cells on the skin where radiation is aimed may feel like they would when sunburned and need to be protected from the sun. Hair may also fall out, but only in the area receiving radiation. If the radiation therapy aims at the stomach or head, the person may have nausea or vomiting, headaches, diarrhea, or a sore mouth.

Side Effects: What You Can Do To Help

There's nothing you can do to prevent side effects from cancer. But you can help to make them a little easier to live with. Just knowing that your parent or sibling may feel cross or tired or sick from side effects may help you to be more patient if this happens. And if the person with cancer is tired or sick but wants company, you can spend time with them doing quiet things — talking, reading, watching TV, or playing games like checkers.

The most important thing you can do, however, is to remember that your parent or brother or sister is still the same person as before, even if he or she looks different or can't do what they used to. It is important to treat your parent or sibling as you did before.

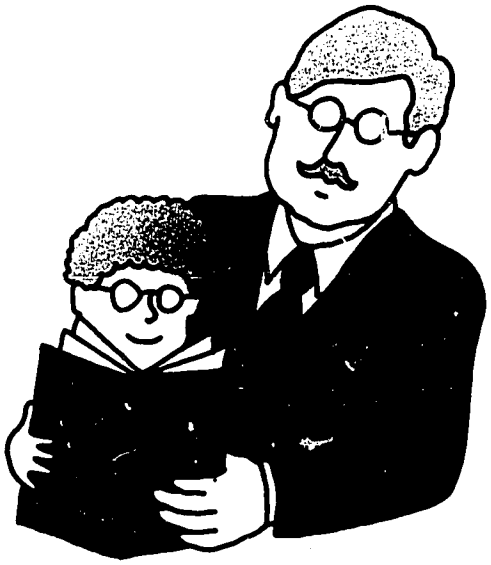
Learning More on Your Own

Now you know something about cancer, how it's treated, and about side effects from treatment. You may want to know more about your family member's cancer — like what kind it is, its treatment, and what that means for all of you. If you want to know more, ask someone who knows answers to such questions as:

- What kind of cancer is it? What is it called?
- Where is the cancer?
- Are they going to get better?
- What kind of treatment are they having? Will the treatment hurt? Will they have other kinds?
- How do they feel when they get the treatment?
- Will the treatment change the way they look?
- Will the treatment or cancer change how they feel and act — will they be weaker or grouchy or the same as before?
- How often will they go back for treatment? How long will treatment for the cancer last?
- How long will they have to stay to have each treatment — a morning, a week? Can I come and visit?
- What is it like where they go to have treatment? Can I come?
- What will happen to me while they're gone?
- Will they be able to go back to school or work while they're having treatment? Will they be at home?
- Will they be able to eat the same foods as the rest of the family?
- What can I do to help?

You may have questions of your own. Use the next page to write them down so you won't forget to ask. You can also use this space to write down the answers to any of your questions or the ones already listed here.

Sometimes people who have a parent or brother or sister (sibling) with cancer can go to see the cancer treatment center instead of imagining what it's like. They can see the building and equipment and meet the people who work there, and sometimes other cancer patients. If the hospital your parent or sibling goes to is too far away or has rules against your visiting, you could ask the person with cancer and others who have gone to the hospital to tell you what it's like. They can tell you about the people they know — the doctors, nurses, social workers, and patients — and describe a typical day. They can draw you pictures and take photographs. This way they can share their experiences with you, and you can learn a little about what it's like for them.



Reading About Cancer

Reading about cancer may also be useful. If you decide to read about cancer, be sure that what you read is up-to-date. Cancer treatment is improving so fast that even good information may be out of date in less than 5 years.

And remember that, just as you're an individual, so is the person in your family who has cancer. His or her experiences will not be exactly like those you read about. If you read something or see something on TV or in the movies, don't assume that what happens to the cancer patient in the story will happen to the person in your family.

If you read something or see something on TV or in the movies that you don't understand or you want to talk about, you may want to share it with your parents or another adult you trust. Pick someone who knows you and what your family is going through. Give them the book or article to read or tell them about what you saw. It may help to talk it over and share how you feel.

Cancer in the Family: What It's Like for You

When someone in your family has cancer, it may mean many things to you. Other people who have been through it say it can be a lot of things: confusing, scary, lonely, and much more. You may find that you have feelings that are hard to understand and sometimes hard to talk about.

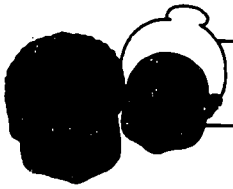
The next part of this booklet shares the experiences of others who've had a family member with cancer. Some of what you read, especially about feelings, may not make sense or seem right to you. It may even seem silly. Or it may seem pretty close to what you've felt and what's happened to you.

Remember, feelings aren't "good" or "bad." They are just feelings, and are usually perfectly normal and shared by many others. And even if you try to wish them away, to ignore them, or if you feel guilty or ashamed of them, they'll still be there.

A good way to handle feelings is to admit you have them and talk about them. Talk to your parents or other adults or with your friends or others who have been through what you're going through. You'll be surprised how much better you feel once you've gotten your feelings off your chest.

It May Be Hard To Talk About Cancer

Sometimes it's not easy to talk about what you feel or about problems. Not only is it hard to say what you feel, but other people may not be ready or able to listen or to be helpful. Some of your questions may upset your parents because they don't know how to answer or because your worries remind them of their own. It's possible that your parents may not be ready to talk when you are.



People Besides Your Parents You Can Talk To

For Support and Sharing Feelings:

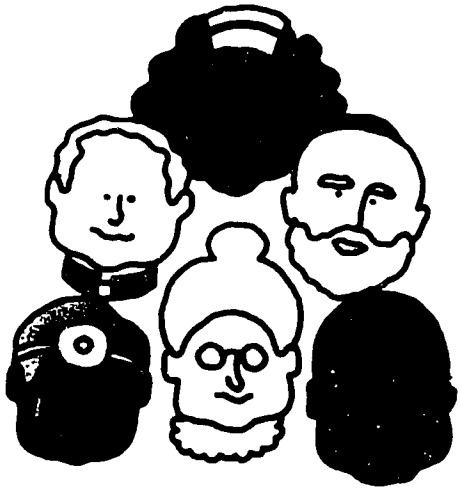
- grandparents, aunts, uncles
- neighbors
- teachers, guidance counselors
- ministers, rabbis, priests
- coaches, youth or scout leaders
- special adult friends
- older brother or sister
- friends your own age

For Support and Information About Cancer

- someone at the hospital — a doctor, nurse, social worker, or other person treating your family member
- family doctor
- school nurse

Special People You Would Add:

- _____
- _____
- _____



They may need more time to sort things out in their own minds before they can talk with you. Some parents, no matter how much they love their children, don't know how to talk about upsetting things with them. If your parents aren't able to talk with you about your feelings, they may be able to help you find someone you can talk to, such as someone at the hospital, a relative or friend, or a teacher or school counselor.

Here is what some others who've had a parent or brother or sister with cancer have said about what they felt.

Being Scared

"I really didn't understand much at first. Mostly, I was afraid that she might die, because my sister and I are pretty close. I was really scared and I also thought it might be catching or something."

— Laura, age 13

The girl who said this had a sister with cancer, but it can be just as scary for people who have a parent with cancer. When someone is first diagnosed with cancer it may seem as though your whole world has fallen apart. You may not know much about it. so you may remember

what you've heard about cancer before. Being afraid someone might die from cancer is normal, especially if the only people you've heard of who have had cancer did die. And being afraid that you or another person in the family might catch it is normal, too. Why? Because there are so many things you can catch from someone else — like a cold or the flu. It's easy to think cancer may be the same, but it's not. Learning about cancer can help you. You will feel better knowing about it than being afraid of what you don't know.

Hearing about the treatment and the tests can be hard. Some people find it's scary just to think about the needles and blood tests and radiation treatments. Sometimes learning about these things and talking to the person with cancer or someone else about what it's really like is the best way to deal with these fears. If a trip to the hospital is possible it might help.

"One day I went to the clinic with my brother for his treatment. I saw the machine that he gets radiation from and how IVs work, and I met his doctor and the nurses. I saw lots of other kids who didn't have any more hair than he does. Now when he goes to the clinic I don't have to wonder what he's going through. I know what it's like. It's no fun for a little kid like him, but it's not as bad as I thought."

— Matthew, age 14

When one parent has cancer, sometimes the other one spends a lot of time at the hospital and away from the rest of the family. Having their parents at the hospital instead of at home can be scary to some young people. They may worry about their parents and need to have some special contact to feel that things are all right.

"When Dad's in the hospital Mom goes too and I stay with my Aunt Emily. She's nice, but sometimes I get scared because I don't know how Dad is, or I miss them. So now Mom and Dad call me every night before dinner and they tell me what's happening and I can tell them about my day, and I know they're all right."

— Erin, age 9

Feeling Guilty

"I got really mad at Chrissy one day. She wouldn't let me go bike riding with her and my cousin and I got mad and said 'I wish you were dead.' Now she has leukemia and she could die and I think maybe it's my fault. I was scared to tell anyone because then they'd all know what I did and be mad. But my dad heard me crying one night and he got me to tell him why. He says it isn't my fault or anybody else's that Chrissy has cancer, and you can't make somebody get cancer just by what you say."

— Katy, age 10

Until you understand what does and doesn't cause cancer, it's easy to think that anything could have done it -- even words or a fall.

"I left my junk all over the floor one night instead of putting it away and the next morning Mom fell over it. She was mad and had a lot of bruises. A little later the doctor told her she had cancer. She's in the hospital now. Maybe if she hadn't fallen down because of me she'd be okay."

— Tom, age 11

Just as words can't cause cancer, neither can bruises or bumps, or even broken bones.

Some people are afraid to tell anyone what they are thinking and may feel guilty for a long time. Even if your parents can see that something is worrying you, they may not be able to guess what it is. It's hard to talk about, especially if you think you've done something wrong and everyone will be mad at you. But it's best to get it out in the open so you and your parents or someone at the hospital can talk it over.

People sometimes feel guilty because they're well and their parent or sibling is sick. Young people may feel that it's not right for them to enjoy things they like to do when the person with cancer can't do what he or she likes. These feelings show that you care about your family, but it's important to care not only for the person with cancer, but for yourself, too. It's best for everyone if you keep being you and doing things that are important to you as long as they don't hurt anyone else. You may have to find ways to do them.

"Last year, Mom and Dad always drove me to play softball, but now Dad's sick and Mom's always at the hospital or busy at work or home. I didn't think I'd be able to play this year, and I wasn't sure I should with my dad so sick. I told my grandmom and she said I should play and she'd take me. She likes to come and she tells my folks all about the game and how I played. Next year, maybe they'll all be able to come."

— Dave, age 11

Getting Mad

"Sometimes I feel mad at my brother for having cancer. I know that's not right and he can't help it. But it's changed everything. My mom and dad don't talk about anything but him and neither does anyone else. It's just not fair."

— Sharon, age 13

People who have a brother or sister or a parent with cancer can feel angry at that person for getting sick and changing their lives. This may seem wrong, and people sometimes feel guilty about getting mad. But, if having someone with cancer in your family means you can't be with your parents as much or have to stay somewhere else or give up things you like, it can be hard. Even if you understand why it's happening, you don't have to like it. Others who have been through it say it's important to remember that things won't always be this way. And when you get mad, remember that it doesn't mean you're a bad person or don't love the person with cancer. It just means you're mad.

Feeling Neglected

One of the things that young people get mad about is feeling left out or neglected. Some feel that they don't get as much attention as they used to, and often they are right. Family members, including your parents, all have a lot on their minds and they may have to put all their energy into helping the person with cancer. This may not leave much time for you, especially if they are going back and forth to the clinic or hospital.

Siblings of people with cancer often feel that the brother or sister with cancer gets more attention from their parents.

"At night my parents go in and turn on my sister's light and kiss her good night and they don't come in my room — well, sometimes Mom will. She tells me, 'Don't think we are partial to her.' "

— Maria, age 15

And they may feel that the sibling with cancer gets away with a lot of things they don't.

"If I do something wrong, Mom yells. If my brother does, they let it pass."

— Dennis, age 13

Why do some parents do this? It's not because they don't love all their children. This is a confusing time for them, just as it is for you. They have to learn a lot about cancer and hospitals very fast. They are tired and worried. They see one of their children sick and may try to make up for it by giving him or her a little more attention. Parents know, as you do, that some people die from cancer and they could be afraid of that and want to do all they can for your brother or sister who has cancer. Sometimes they give a young person with cancer special treatment that he or she doesn't want.

"I have a sister who has cancer. She gets upset because she's treated differently now. She doesn't want to be babied, just treated normally like she was before. She and Mom always used to fight and now Mom is really sweet all the time and it's weird. Not that my sister likes to fight, but it's just not normal."

— Peggy, age 15

For whatever reason, and whether your brother or sister likes it or not, your parents may give special treatment to the one who has cancer. At times like this, it's normal to feel jealous, even if people tell you that you shouldn't because you don't have cancer and your brother or sister does. It's hard not to want time with your parents and some special attention, too.

Young people who have a parent with cancer also may feel neglected.

"Now that Mom's sick everything at our house is different. We hardly ever eat together as a family anymore and there's never anyone to help me with my homework or listen to what's been happening to me. Mom used to do that. I feel like it's sort of being left up to me to take care of myself."

— Martha, age 13

When one parent has cancer, the other one may be so busy that neither one of them can spend much time with the rest of the family.

"Sometimes my father feels like he is neglecting us because he is with Mom so much. And in a way it's true. I know he can't help it, he has to work and wants to see Mom, but he's not around like he used to be and he doesn't do things with us like he did. He's just too busy."

— Barry, age 16

If you feel like you're not getting much attention, whether you have a parent or a sibling with cancer, remember this: The person with cancer is getting more attention because they need special care, not because you are loved less.

Feeling Lonely

"I was really surprised, but a lot of my friends don't want to be with me anymore now that Mom has cancer. They act like it's some real freak thing or they're going to catch cancer from me. My dad says if they act like that they're not real friends anyway. But they were my friends and I miss them."

— Cheryl, age 15

You may be lucky and have a special friend or friends who treat you the same as before your family member was diagnosed with cancer. But many young people with cancer in their families have found that they've lost a few friends. Sometimes this happens because friends may not know much about cancer and be afraid of catching it from you. Or they may not know what to say and find it easier to stay away than to be embarrassed. Having cancer in your family may make you act a little differently because you're upset or scared or embarrassed, or because you want to be with your family.

"Sometimes my friends wonder why I act strange. I wish they understood that sometimes I don't want to do what they're doing, I really want to be with my sick sister."

— Nan, age 12

But your friends may not understand and think that you don't want to see them anymore. It can be a hard time for all of you.

What can you do? You may need to reach out to your friends, even if that's hard to do. Not everyone may respond as you'd like, but it helps if you give them a chance. Often friends just don't know how to act and need you to tell them how you want to be treated. They may also need you to show that you still need them, even if you seem a little different because you're upset.

If this is a hard time for you, remember that it won't last forever. Old friends may become close to you again. And people who have lost friends have found that they also made new ones. There may be someone at school who has had a sick person in the family and will understand how you feel. That person could be a special new friend.

Answering Questions

When your friends do talk to you, some of them may not say what you want to hear. Sometimes, especially in the beginning, people ask a lot of questions that are hard to answer.

"People asked me questions all the time. They'd say things like 'I heard Jean is in a coma' or 'I heard you were hysterical.' Whenever I told them the truth, they didn't believe me. And they'd ask dumb questions like 'Can Jean walk, can she write?' They didn't know what was going on and I didn't know how to answer them. I got sick of it."

— John, age 14

One way to get answers to your classmates' questions is for you and your parents to talk to your teacher and see if the teacher or someone who knows about cancer and its treatment can talk to your class. Then your friends can ask their

questions and be sure they're getting the right answers — not about your family member, but about cancer in general.

Other people ask questions, too, and they may not know that some of them are hard for you to answer or make you feel bad. If you want to answer their questions, it's a good idea to think of what people might ask and have an answer ready. People may ask you how the person with cancer is feeling or how long they'll be in the hospital. And they can also ask questions like these: "Are you going to get cancer from your mother?" "Why does your brother always wear that cap — did his hair really fall out?" "Is your dad going to die?" "What did your sister do to get cancer?" You may want to get help when it comes to finding an answer to questions like these. Remember, you can always tell people that you don't want to talk about something. You don't have to answer their questions.

Feeling Embarrassed

"Since my brother lost his hair and got so pale and thin, I don't want to bring my friends home anymore. I don't want them to see how different Tim looks now, and I don't think he likes to see them. Besides, it's not easy to laugh and giggle at home when someone is sick."

— Caroline, age 12

Sometimes people who have a person with cancer in their family may feel embarrassed because now their family is different. It is different from what it used to be and it is different from their friends' families. And people who ask them questions they can't answer just embarrass them more. So sometimes they want to try to leave the cancer at home and hope that none of their friends lear. about it. Of course, you can't really do that because when someone you love is sick you need people you can talk to and who understand if you're upset. If you feel a little embarrassed around people because someone in your family has cancer, remember that others have felt this way too, and that this feeling often goes away once everyone has gotten used to what is happening.

Even though others feel all right about asking a lot of questions, some people with a family member who has cancer find that it embarrasses them to ask questions.

"At first I didn't ask any questions, although I had a lot of them. I thought people would think I was really dumb. But now I know it really helps to ask."

— Brad, age 14

Dealing With Side Effects

"Diane had all this hair and some nights it would fall out and be all over her pillow when she woke up, or fall out in her comb or when she washed her hair. It really kind of scared me to see that happen at first, but she took it pretty well."

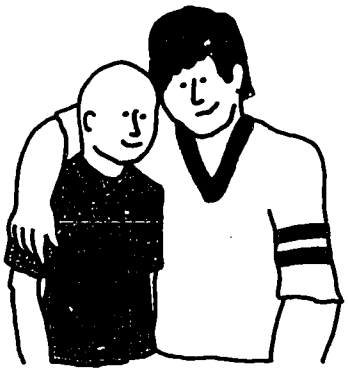
— Lois, age 16

When someone you love has side effects from cancer treatments, you have to learn to live with these changes, too. It may seem a little strange at first, or scary, but other people have found that they soon got used to it. Some people outside the family may not understand, and they may hurt the feelings of the person with cancer.

"When my little brother James went back to school he was still on chemo and had lost all his hair, so he wore a baseball cap. One day a kid pulled the cap off and teased him. James said everybody stared at him. Mom says we should feel sorry for that kid because he doesn't know any better. But I don't, I feel sorry for James."

— Amy, age 12

It's hard to imagine why anyone would want to tease James, but it's not as important to know why someone did it as it is to know that these things may happen, and you can't always protect your brother or sister. What you can do for people with cancer is try to understand how they feel and help them see that they



still have friends. And, if you tease them from time to time like you did before they had cancer, it's not a bad thing as long as you don't keep it up for long or keep doing it when you see that it really hurts their feelings. Brothers and sisters all tease each other, and it's important that, even when your brother or sister has cancer, you treat each other as much like before as you can.

You may be shocked if the person in your family who has cancer comes home from the hospital looking and acting very differently from when they left.

"My dad has cancer and he was in the hospital for a long time. When he finally got to come home, he was still really sick. I had to help him up the stairs because he was so weak. It was strange, because he had been so big and always strong and now he was weak. It bothered me."

— Richard, age 16

Even if someone tells you that your family member won't look the same, you may not be prepared for the changes. It may be hard for you, but it's important to remember that, even if they look different, they're still the same person you love.

Changing

Some young people who have a family member with cancer may change a little themselves. Sometimes they're not aware of it or don't know why. But, given all the new and different experiences and feelings, it's not surprising that people change. They may have trouble at school or be unable to concentrate or to get along with other people as well as they used to.

They may start to be a little less careful or to do things that are dangerous, maybe getting hurt more often. They may worry a lot about getting sick themselves and even get sick more often. Their school grades may fall or they may become more involved in school than they were before and make better grades.

Any of these changes can happen because young people are scared or worried, because their lives may have changed, or even because they need more attention at home. Just as with other problems or worries, talking with people who care and understand what's happening helps.

If you haven't noticed that you've changed, someone else may have, and they may want to talk to you about it. If they do, it's because they want to help. Your parents or teachers and guidance counselors or social workers at the hospital or clinic may all be able to help if you've changed in a way that isn't good for you or that makes you sad and uncomfortable.

Not all of the changes are bad; there is a good side to it too. Many young people who have had cancer in the family feel it has helped them to grow up and that it brought the family closer together.

"My brother is in remission now. Things were pretty bad at first. Then, after a while, things sort of settled down and got back to the way they were before. I think Billy's having cancer brought us all closer together. I get along better with him and my sister and even my older brother now. I'm closer to Mom and Dad. And I think we all grew up a lot while he was sick."

— Alice, age 1[illegible]

How Your Parents Feel

Young people who have a person with cancer in the family often wonder how their parents feel. There's no one answer to this question. Just as with everyone else, parents may feel many different things when they have cancer themselves or when another member of their family does. They may be worried, scared, tired, or a little confused by all the decisions they need to make and all the changes that cancer can bring. Along with this, parents feel a responsibility to keep the family together during this time. They may feel that they don't have enough energy to do all the things they'd like to do or share all they'd like to with other family members. This section shares some things parents have said about how they feel.

A parent who has cancer may worry that their being sick is upsetting the family's life.

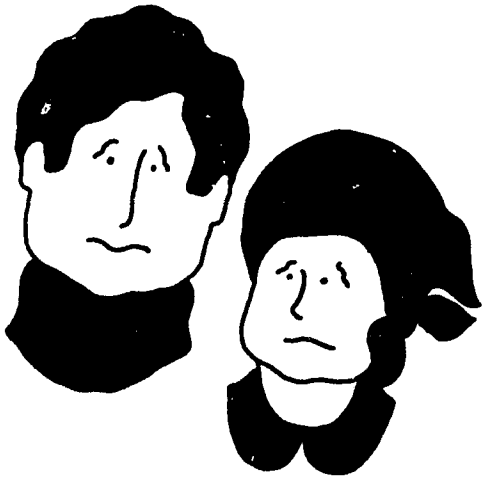
"I feel bad because now that I'm sick my husband tries to be with me a lot. I think my children's feelings are hurt but they won't say so. I just wish we could talk about it as a family."

Or they may know that being sick means that they can't do some things with their children that other parents do. They may wish they could.

"I feel like I'm letting my son down, like I'm not being a real father because I can't run around with him the way other fathers do."

When this happens, parents find they need to look for something they can do with their children that they'll all enjoy.

A parent whose husband or wife has cancer often finds that he or she needs to learn to do new things for their family and may be concerned about how well they'll do.



"Now that my wife is sick I need to be both mother and father while she's in the hospital. I'm afraid I don't do as good a job at some things as she does. The other day, our youngest son said 'Mommy never scrambled eggs like that.' I don't blame him, I'd rather eat her cooking too. I asked her how she scrambles eggs and now at least breakfast tastes a little better."

Parents don't expect their children to pretend that everything is all right or tastes great when it doesn't. Even if they get mad for a little while, most parents would rather hear what other family members feel than not know when others are upset.

Parents may know when they've been treating a child with cancer differently than the others, or when they've been short-tempered. They may feel like they can't help it, but still wish it didn't happen.

"After I spend a day in the pediatrics clinic with Lisa I'm so drained when I get home that I yell at my other kids over the least little thing. Then they get upset and I get more upset because I know that I shouldn't have done that."

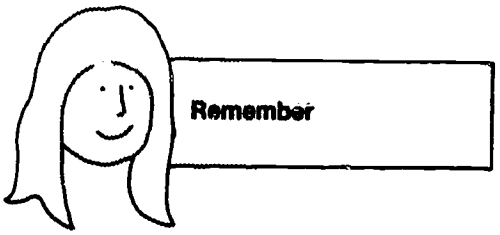
Some parents worry that their children are upset and even though they want to help their children they don't know what to do. Sometimes this is because young people don't want to talk to their parents about cancer. They may be afraid that their parents will worry or won't understand. In fact, most parents worry more if they feel you are upset but they don't know why or you won't discuss it with them.

"Since I've been sick my kids have changed. I know something is bothering them, but when I ask what it is they say it's nothing. I just wish they would talk about it. I want to help them."

Often, one thing young people can do to help is to talk about how they feel and give their parents a chance to say how they feel too.

Parents say that they want their children to know that the family is there to help even when one of its members has cancer. Your family life may change when someone has cancer. The important thing, however, is that you're a family and families solve problems together. Even if life is a little different, you're still a family and your parents are still there for you.

There are many different ways to think and feel about having a person with cancer in your family. It's important to remember that people can learn to adjust to changes in their lives. Sometimes it takes a little work, but you can almost always find something or someone who can help you when you need it. Keep on trying and don't be afraid to ask for help.



Remember

- Don't be ashamed or afraid of the way you feel. Others in your situation have felt the same way.
- Sometimes things are better if you talk about them. Share your feelings with your parents or another adult or a friend you can trust.
- Learn about cancer and the way it is treated. What we first imagine about cancer is often far worse than what is really happening.
- Try to find other people your age who have a person in their family with cancer or a serious illness. You may be able to share your feelings with them.
- If you overhear someone talking and what you hear scares you, ask them to explain what they said. Don't assume that you heard everything and understood what it meant; ask about it.
- Don't forget the adults other than your parents who can help you.

Other Sources of Cancer Information

Toll-Free Telephone Answers

If you have any questions about cancer that haven't been answered here, call the Cancer Information Service (CIS). The CIS is a group of offices around the country where people are specially trained to answer questions about cancer. Your call won't cost anything — it's free. Call 1-800-4-CANCER (if you live in Alaska call 1-800-638-6070, in Washington, D.C., and its suburbs call 636-5700, in Hawaii call 524-1234 on Oahu and collect from neighboring islands).

Other Booklets

The National Cancer Institute (NCI) has a variety of free booklets available. Two of them might be of special interest to you. These are **Young People With Cancer: A Handbook for Parents**, and **Help Yourself: Tips for Teenagers With Cancer** (booklet and tape). If you would like to receive one of these booklets or a listing of other NCI publications that you may order, write to:

National Cancer Institute
Building 31, Room 10A18
Bethesda, Maryland 20892

To find other books about cancer, check with your local or hospital library or bookstores. In addition, you may want to call the American Cancer Socicty or the Leukemia Society. Look in your telephone book for local offices of these organizations.

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