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Answers to Common Questions

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This booklet has a companion flipchart for health workers to use with patients and caregivers.
Instructions for Download and Printing: To download a print-ready copy of this booklet, or its companion flipchart, visit: cancer.org/globalpatientsupport

If you have any questions, please reach out to: globalpatientsupport@cancer.org

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1 East African partners include: Ministry of Health of Kenya, Kenyan Network of Cancer Organizations, Aga Khan Hospital, Kenyatta National Hospital, Moi Teaching and Referral Hospital, Ministry of Health of Uganda, Uganda Cancer Institute, Uganda Cancer Society, Ugandan cancer organizations coordinated by the Uganda Cancer Society, Federal Ministry of Health of Ethiopia, and representatives from Ethiopian cancer organizations.

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"May your choices reflect your hopes, not your fears."

– Nelson Mandela

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This book is dedicated to all those who have been touched by cancer.

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Introduction

If you have been told you have cancer, this booklet is for you. It is also for your family members or any other person who is helping you. Finding out you have cancer can bring many changes and raise many questions.

This booklet answers many questions about cancer and cancer treatment. It also explains some of the words used by health workers when they talk about cancer, describes the different types of cancer treatment you might get, and shares information about what has worked well for other people with cancer.

Knowing you have cancer can be frightening and worrisome. You might have different feelings like shock, shame, fear, or anger, and you might wonder, "Why me?" These feelings are normal, but it can help to know there are things you can do to fight the cancer and to feel better. This booklet talks more about these common feelings on pages 28 to 31.

This booklet does not replace the advice of your doctors or nurses. Talking with them is the best way to understand what is going on with your body and how your treatment works. This booklet can help prepare you to ask any questions you may have at each visit, for example: How long will treatment last? How much will it cost? How will I feel during and after treatment? When will I know that the treatment is working?

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Often people compare cancer treatment to going on a journey to somewhere new. The tests and treatment can take a long time and what will happen next is not always certain. Preparing yourself, having good people support you along the way, and focusing on taking care of yourself can make the journey easier.

Share this booklet with people who are close to you so they can also find answers to their questions and be better able to support you. Everyone with cancer needs love and support.

I have been a breast cancer survivor for 16 years and I would not be here if I had not braved surgery and gone for treatment.

Outreach worker,
Uganda women's cancer support organization

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If you are helping or caring for a person with cancer, this booklet will help you better understand cancer and become familiar with the questions, problems, and decisions facing a person who is sick.

While taking care of a person with cancer, try to take care of yourself too. Find other helpers so you are not the only one. And choose someone to talk to when you are feeling sad or worried yourself. While cancer is a physical illness, love and support from others can make all the difference to a person who has cancer.

In addition to becoming familiar with the different topics in this book, also see the section in the back of this booklet for more ideas about giving care and support.

Finding out you have cancer

What is cancer?

Cancer is a disease which causes cells to grow out of control. This makes it hard for the body to work the way it should.

What are cells?

The human body is made of millions of tiny cells. Normal cells grow and divide to make new cells as the body needs them. Usually, when cells get too old or damaged, they die and new cells take their place.

The body makes new cells as the body needs them, for example to heal a scratch or wound and then grow new skin.

Cancer cells are abnormal

Cancer cells grow and divide faster than normal cells. These cancer cells crowd out normal, healthy cells. This causes problems in the body where the cancer started. Cancer cells can also move to other parts of the body and cause problems there. Normal cells cannot do that.

The fast-growing cancer cells often become a lump inside the body or, with skin cancer, a growth on the skin.

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Types of cancer

Cancer can start in any part of the body. It can spread from where it started to other parts of the body and continue to grow. Cancer spreading in the body is called metastasis.

Cancers are named for where they start. If cancer starts in the breast, then it is called breast cancer. If it spreads to the lymph system or to the bones, it is still called breast cancer. Cancer often starts in the breast, lungs, throat, prostate, liver, intestines, cervix, uterus, or skin. Cancers can also affect body systems such as the lymph nodes of the immune system or the blood of the circulatory system.

When someone has cancer, doctors use tests to find out what kind of cancer it is and how fast it is growing. This helps determine what kind of treatment will work best.

Some cancers grow quickly and spread. Others grow more slowly. For some cancers, treatments work very well, and the cancer can be cured or controlled. When treatment is painful or when cancer cannot be cured or controlled, health workers can help by giving treatments that help decrease the pain and discomfort.

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What is a tumor?

A tumor is a lump or a swelling. Most cancers form tumors, but not all lumps and tumors are cancer. Lumps that are not cancer are called benign. Lumps that are cancer are called malignant.

There are some cancers, such as leukemia (a cancer of the blood), that do not form tumors. These cancers are in the blood or other parts of the body but do not form lumps.

Not all lumps are cancer but it is always best to have them checked by a health worker, as soon as possible.

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What causes cancer?

Cancer begins when a change inside the body causes cancer cells to grow. Different things can cause the change that led to cancer, including specific infections, chemicals, or other things that get into the body.

Although it may take many years to develop, these are some things that can cause cancer:

- Having certain infections, such as HIV and human papillomavirus (HPV).
- Breathing in chemicals, such as smoking tobacco, breathing tobacco smoke from others, smoke from cookstoves, or breathing in fumes from diesel engines.

- Chemicals polluting the air or water, or used at work or at home, can cause cancer.
- Drinking too much alcohol can also cause cancer.
- Not getting enough nutritious food in our diets, including enough fruits and vegetables.
- Growing older. As our bodies age, cancer is more common.

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What have you heard about cancer?

Rumors or stories you hear from friends, family, or on social media may not be true. Ask your health workers or organizations that help people with cancer about them so you can find out what information is true.

Cancer is not caused by magic spells, the evil eye, or any supernatural force. And cancer is not a punishment for having done something wrong.

Cancer is a disease that can affect anyone, anywhere, in any country, at any time. Cancer is not a disease only for the old or the rich. Young people and poor people also get cancer.

Plant medicines may help lessen the discomfort of cancer (see page 26), but they cannot treat or cure cancer. Do not waste money on plant, herbal, or other remedies sold by people claiming they will cure you. Talk to your health workers to find out what they know about how herbs or plant medicines might affect your treatment, and if it is safe for you to use them.

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Does cancer spread to other people?

Cancer is **NOT** contagious. It does not spread from person to person.

You cannot get cancer by being near or caring for a person with cancer, spending time or eating with them, or by washing their clothes.

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For a few types of cancer (for example, breast cancer), having one person in the family with that cancer makes it more likely that another person will have it too. But most people who get cancer do not have any family member that has had the same cancer because most cancers do not “run in the family.” And for those few that do, cancer does not pass from parent to child during birth.

How does the doctor know I have cancer?

You may have gone to the doctor to get help for a health problem or for a routine check-up. While examining you, the doctor may have looked for signs of cancer or recommended that you have some tests. (See Common signs and symptoms of cancer, page 42).

When a health worker thinks a health problem you have could be cancer, they will want to make sure. They may ask you to have a test. Common tests include: a biopsy, x-ray, ultrasound, scan, or blood test. Often they will want you to have more than one test.

Ultrasound

Drawing blood for a blood test

Scan

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What is a biopsy?

A diagnosis —certain proof that cancer is or is not present— can only be made through a biopsy.

During a biopsy, the doctor removes a small piece of the tumor to look at its cells carefully under a microscope. The tumor could be on or near your skin or deeper inside your body. Sometimes, this is done with a needle. The doctor will give medication so that you feel no pain during the biopsy.

Taking cells in a biopsy

Often people delay getting a biopsy because they are afraid it might bring bad news, or worry it may be painful. But the longer you wait to get a biopsy, the more time you give the cancer to get worse.

Biopsies do not cause cancer to spread to other parts of the body. In fact, acting on the results of a biopsy can prevent cancer from spreading. Biopsies remove only a very small piece of the tumor and do not leave a big wound. Talk about these or any other worries with a health worker.

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Examining biopsy cells with a microscope

What are stages of cancer?

When doctors find cancer in the body, they try to determine how big the tumor is and whether the cancer has spread from where it started (metastasis). They usually use the numbers 1 to 4 to describe how much the cancer has spread. Knowing the stage of the cancer and how much cancer is present will help the doctor decide what type of treatment is best, and the chances for it to be cured or controlled.

For most cancers, there are four stages

A lower number (stage 1 or 2) means that the cancer has not spread at all or has not spread too much. Cancer in its early stages is easier to treat.

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A higher number (stage 3 or 4) means the cancer has spread more, making it harder to treat. Stage 4 is the highest stage.

Ask your doctor to explain the stage of your cancer and what it means for you.

Treating your cancer

Can my cancer be cured?

A cure means that the cancer has gone away with treatment and no more treatment is needed. It also means the cancer is not expected to come back. Whether a person's cancer can be cured depends on the type and stage of cancer, the type of treatment the person gets, and other health conditions that the person might have.

If you start treatment at an early stage, it's more likely that the treatment will be successful.

Several factors affect how long a person lives after getting cancer. These include:

- The type of cancer and where it is in your body
- How long the cancer has been in your body
- If your cancer is fast-growing or slow-growing
- Your age and whether you had other health problems before getting cancer
- How well the treatments for your type of cancer work against the cancer in your body

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How is cancer treated?

There are different treatments for cancer and not everyone needs the same type. Doctors recommend treatments based on the type of cancer you have, the stage of the cancer, and your age and overall health.

The goal of giving cancer treatments can be to try to cure a cancer, to help control a cancer so a person can live longer, and to help a person with cancer feel more comfortable. There may be more than one treatment to choose from or other important decisions to make. Finding out the goal of the recommended treatment will help you decide what to do.

To treat your cancer, you may have more than one doctor as well as several health workers with special training to help. For example, there are doctors that mostly do surgery and others that help if new problems appear while getting treatment. There are even health workers who help coordinate the work of different doctors to make sure you know what will happen next. The types of doctors, nurses, and others helping you will depend on your cancer and your health system.

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Cost of treatment

Unless your country's health system or your insurance pays for your care, the cost of treatment depends on your type of cancer, how many treatments you need, and how long the treatment continues. After treatment, cancer may come back again and require a different type of treatment. If you live far from the treatment facility, you may need to pay for transportation, food, and a place to stay. Ask at the hospital or clinic if there are government programs, charitable or other not-for-profit groups, social workers, or other resources available to cancer patients and their family members to help with costs and other needs during treatment. See page 45 for more ideas about finding support where you live.

Types of treatment

The most common treatments for cancer are surgery, chemotherapy, and radiotherapy. In some countries, hormone therapy, targeted therapy, and immunotherapy are also used.

A person with cancer may have any one, or a combination of these treatments. Often 2 or more treatments work well together. For example, after surgery is used to remove a tumor and most of the cancer cells, a person might get chemotherapy medicines to kill any cancer cells that remain.

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Surgery

Surgery is used to remove cancer from the body. The surgeon might take out some or all of the body part the cancer affects. For example, with breast cancer, part or all of the breast might be removed. For prostate cancer, the prostate gland might be taken out. Surgery may be used to cure the cancer, keep it from getting worse, or treat problems it is causing. You might need other treatments before or after surgery.

Surgery is not used for all types of cancer. Doctors will also consider the tumor size and where it is located in the body before deciding if surgery is the right treatment.

Chemo (chemotherapy)

Chemo (short for chemotherapy) is the use of medicines to kill cancer cells or slow their growth. Because chemo medicine travels to nearly all parts of the body, it is useful for treating cancer that has spread. Chemo may be used to cure cancer, keep it from getting worse, or treat problems a cancer is causing. Chemo medicines are used in hospitals or treatment centers. Usually they are given slowly through a tube into a vein in your arm. Chemo can also be given as pills, liquid, or as an injection.

Chemo treatments may be repeated for several days, on and off, for several weeks or months.

Radiotherapy (radiation therapy, radiation)

Radiotherapy, also called radiation therapy, is another way to kill cancer cells. Radiotherapy may be used to cure cancer, to slow the cancer's growth or to make the person with cancer more comfortable.

Radiotherapy machines send high doses of radiation to the area of the cancer cells or tumors. Radiation may harm some normal cells near the cancer cells, but the normal cells can repair themselves while the cancer cells cannot. To receive treatment, usually the person lies on a table under the radiotherapy machine. Radiotherapy does not feel hot and is usually not painful, but your skin might get irritated.

Radiation treatments may be repeated for several days, on and off, for several weeks or months.

Radiation can also be given through a small device (implant) placed inside the body in or near the tumor. This ensures that the radiation reaches exactly the area that needs treatment. When treatment ends, the implant is usually removed.

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Hormone therapy

Medicines that affect the body's hormones can cause certain tumors to shrink or certain cancers to grow more slowly.

Targeted therapy

Targeted therapy uses medicines to find and disable parts of cancer cells. This is different from chemotherapy medicines that affect the whole body.

Immunotherapy

The body's immune system fights off infection and disease so the body can regain health. Immunotherapy medicines help a person's immune system work better to find and stop cancer cells from growing nd spreading.

Hormone therapy medicines usually come as pills, but some are injected.

When targeted therapy and immunotherapy are used in hospitals or treatment centers, the medicines may be given slowly through a tube into a vein, often in your arm.

Targeted therapy and immunotherapy are also given as pills, liquids, or as injections. Immunotherapy may also be given as a cream that you rub onto your skin.

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Making decisions about your treatment

To help you make important decisions about your care, find out the goal of the treatment that your doctor has suggested. It may be to cure the cancer, control it so that you live longer, or to make you more comfortable, even if it might not take away the cancer completely. Although doctors usually cannot be sure that a treatment will work, ask if there is a good chance or a small chance of success.

While thinking about your personal situation and what is important to you, talk with your health workers to get as much information as possible. This will help you make the decisions that are best for you and your family.

"I have young children. The doctors believe the treatment will work. My family will help with the treatment costs and will care for my children when I am at the clinic. With their support, I will overcome this cancer because I have so much to live for!"

"At first my fear of the hospital was stronger than my fear of cancer, but my family and doctors helped me decide that fighting this cancer was most important. They were right and here I am!"

"I found out my cancer is unlikely to be cured but that surgery and chemo can help me stay alive for 1 year or more. I decided I want the treatment so I will be here when my first grandchild is born."

"I have had a very long and good life. I want to spend the time I have left at home with my family, not in a hospital. I will only use treatment to prevent pain and make me comfortable. My family has accepted that this is what I want.

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Other treatments

In addition to surgery, chemo and the other treatments described in this booklet, there are other ways to lessen pain or discomfort of cancer. Often called complementary or integrative therapies, these work well to ease some effects of cancer, lessen the side effects of treatment, or help you feel calmer and worry less. See page 26 for more information on these helpful methods.

If you hear about other ways to cure cancer, always ask a trusted health worker before you spend money or delay getting a treatment that would help you more. Unfortunately, there may be people who try to take advantage of the hope or desperation of a person with cancer with false promises and by claiming they have special or secret treatments to cure cancer.

Questions to ask about treatment

Your health workers will be giving you lots of information about your cancer and how they plan to treat it. Often it can be difficult to understand and remember it all. So if you feel something was not clear or got left out, ask questions. By asking questions, doctors and other health workers can see that you are involved in your treatment. Although they may be very busy, they want you to understand your situation. They cannot know you don't have all the information you need unless you ask.

It can help to write down your questions and bring them to your appointment. You will probably have new questions to ask at each appointment. These examples will give you ideas about what you can ask:

- What kind of cancer do I have?
- What stage is my cancer? Has it spread to other parts of my body?
- What are the treatment options for this type of cancer?
- What are the risks and possible side effects of each treatment option?
- What treatment do you recommend? Why?
- Is the aim of treatment to cure or to control the cancer?
- How successful is the treatment for my type and stage of cancer?
- What medicines will I be taking? How will they affect me?
- Where will I get the treatment?
- How long will the treatment last?
- What type of changes should I make in my work, family, and sex life?
- How will we know if the treatment is working?
- What symptoms or problems should I report right away?
- What will happen if I choose not to have treatment?
- How much will the treatment cost me? Is there any program that can help with the expense?

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What are side effects of treatment?

All the medicines and treatments that fight cancer and improve a person's health may create side effects – new and uncomfortable problems, such as itching, nausea, or feeling very tired. These problems usually go away after treatment ends.

Some side effects are common; others can be hard to predict. Two people getting the same treatment often have different, weaker, or stronger side effects. Ask your health workers about the medicines, home cures, or things you can do to prevent or manage the common side effects for your treatment.

Surgery: Ask about side effects for your type of surgery. Surgery can be minor and fast-healing, or be complicated and require a longer hospital stay. Common side effects of surgery include pain, bleeding, or infection. Surgery may leave a scar.

Chemo: Ask your health worker about ways to deal with the uncomfortable side effects of chemo, which can include nausea, changes in taste or appetite, lower blood cell counts that increase chances for infection or bleeding, feeling weak and tired, diarrhea or constipation, fever or chills, mouth sores, tingling in the hands or feet, skin problems, and hair loss. Side effects usually end after chemo ends. For example, hair that fell out starts to regrow.

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While chemotherapy destroys cancer, it temporarily may lessen your body's ability to fight other illnesses and infections. People having chemo should take care to wash their hands frequently, and avoid people with colds or other illnesses that can spread. Wearing a mask protects you even when you don't know if others are ill.

Radiotherapy: Radiation is painless but it may cause skin changes on or near the treatment area, loss of appetite, low blood cell counts, feeling very tired, or other side effects. Tiredness can last for weeks after treatment ends.

Hormone therapy: Possible side effects are tiredness, weight gain, changes in mood, weakening of bones, sweating or feeling hot, and lack of desire for sex.

Immunotherapy: Possible side effects include skin rashes or itchiness, feeling chilled or hot, tiredness, and diarrhea or other stomach problems.

Targeted therapy: Possible effects include skin rashes, dry or itchy skin, changes in hair growth or color, swelling in the face, feet, legs, or hands, bleeding, blood clots, high blood pressure, and heart damage.

What can I do about side effects?

Health workers have good ideas about how to prevent or manage many side effects. Ask for their suggestions. They can also tell you who to call if your problems seem like an emergency.

Feeling very tired (fatigue)

Cancer can leave you feeling weak, exhausted, slow, and without energy. This can make it difficult to focus or do anything. You may feel irritable and unable to sleep, or find you are sleeping too much.

- Save your energy and do only the basics. Follow a simple daily routine. Do things slowly and ask for help when you need it.
- Eat nutritious food and drink about 8 glasses of water a day, unless health workers give other instructions about eating and drinking.

- Begin a gentle exercise routine if your doctor says it is OK. Instead of tiring you, a 15-minute walk or other gentle movement can give you more energy.
- Try walking, sitting in a peaceful setting, deep breathing, meditation, or prayer.

- Talk to your doctor about how to manage any pain, nausea, depression, or any other side effect you may have.
- Sleep is very important. Improve your rest by keeping your sleeping area quiet, turning off your phone, and slowing down for a while before going to bed.

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Nausea and vomiting

Nausea makes you feel sick to your stomach and can lead to vomiting. These ideas may help you control these problems.

- See if dry crackers, breads or plainly cooked grains taste good and calm your nausea.
- Wear loose-fitting clothes.

- Avoid the sounds, sights, and smells that cause nausea and vomiting.
- Eat small meals or snacks throughout the day rather than 3 large meals.

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- Keep your mouth clean; brush your teeth and rinse your mouth out every time you vomit.
- Ginger tea helps many people calm nausea.
- Doctors can give medicines to stop nausea and vomiting. Let them know if the medicine is not working.

Sores in the mouth

Small cuts or ulcers in the mouth may hurt just a little or be so painful that you will not want to eat or drink anything. The sores may be very red, or may have small white patches in the middle. Sometimes they bleed. Your food may taste too sweet or too bitter or you might have a metallic taste.

Tell your health worker if you have mouth sores so they can check them. They may give you a medicine to coat the mouth sores to numb them so you can eat without pain.

Some ways to get relief or avoid problems:

- Drink liquids through a straw to bypass the mouth sores.
- Eat soft foods or mash foods to make them easier to eat.

- Take a pain medicine 30 minutes before eating.
- Rinse your mouth several times a day with a mixture of: 1 cup of safe or boiled water cooled to just warm, ¼ teaspoon baking soda, and ⅛ teaspoon salt. Then rinse with clean water.
- Brush your tongue, gums, top of your mouth, and teeth with a soft toothbrush. every morning, after eating and at bedtime.

- Avoid foods that are very spicy, very hot or very cold, and very hard or crunchy.
- If your mouth bleeds, use a cloth dipped in ice water to press on the place where it is bleeding, or rinse your mouth with ice water.

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Diarrhea

Diarrhea is common during cancer and cancer treatment. Besides being uncomfortable and tiring, diarrhea drains your body of the nutrients and liquids you need to regain your health. When you have diarrhea, it is important to:

- Eat foods that restore salt and nutrients, examples include broths and soups; potatoes with the skin; and bananas, fruit juices, cooked carrots, white rice, and yogurt.
- Avoid foods that are sweet or spicy. Also avoid alcohol, coffee, and acidic drinks such as tomato juice and citrus juices. Though yogurt is usually okay, avoid milk and foods made with milk if they make the diarrhea worse.

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- Drink at least one cup of water or another liquid after each loose bowel movement.
- Clean your bottom with a mild soap after each bowel movement, rinse well, and pat dry. Apply petroleum jelly to your bottom if it is irritated. And always wash your hands with soap each time after you use the toilet and before preparing or eating food.

When diarrhea is too often or too much it can be a serious problem. Ask your health workers for a list of signs that show if diarrhea is serious and when you should to call them. Signs include dizziness, blood in your stool or around your rectum, a swollen belly, not passing urine for 12 hours or more, or a fever.

Hair loss

Some chemo medicines and radiation cause you to lose hair on your head, face, arms, legs, underarms, or pubic area. This may happen suddenly or gradually. Usually, hair grows back after the treatment ends. Many people use wigs, scarves, or hats to cover, warm, or protect their heads.

Cancer can change how you feel about sex.

Some people feel like having sex less often, and others physically cannot have sex because of the cancer or the treatment and that might make them sad. Others find sex to be an important way to stay close to a partner during cancer treatment.

Changes in how you feel about sex may be caused by stress, feeling tired, or other treatment side effects. Hormonal treatment may cause hot flashes and the vagina to feel dry, making sex uncomfortable.

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You can feel close to your partner while having cancer and cancer treatment by hugging, touching, holding, and cuddling.

Talk with your health workers about when it is safe to have sex during treatment and what precautions you should take. If you have surgery, ask your doctor how long you should wait for your body to heal before having sex.

Because cancer is not contagious, a sexual partner cannot catch it from you. And if you get pregnant, you cannot pass cancer on to your baby.

Will cancer treatment cause birth defects or make me infertile?

Cancer treatment can sometimes cause birth defects. Doctors recommend that both men and women use a contraceptive method (family planning) during treatment and for some time after treatment ends.

Cancer and cancer treatment can sometimes make having a child harder or impossible. Radiotherapy and chemotherapy for prostate, testicular, cervical, or ovarian cancer often cause permanent infertility. Cancer surgeries involving removal of reproductive organs can also lead to infertility. Many cancers do not affect fertility at all.

Cancer treatments may damage or reduce the number of sperm cells, affecting fertility. Sperm production usually returns to normal after treatment ends.

Menstruation (monthly periods) may become irregular or stop during cancer treatment. However, it may still be possible to become pregnant, so contraception is still needed.

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Talk to your doctor before treatment starts to find out how it will affect your fertility and what choices you have, including steps to take before cancer treatment that help give you the option to have a baby later.

Living with cancer

Will I have pain?

Many patients worry about pain from biopsies, treatment, and from the cancer itself.

Health workers will give patients pain medicine before surgery or a biopsy so these procedures will not be painful. The other treatments — radiotherapy, chemotherapy, and hormonal therapy— are not painful.

Your doctor can give you medicines to relieve the pain caused by cancer. While medicines might not remove all the pain, they can make you more comfortable. Many people worry they will become addicted to pain medicines. This does not happen when the right dosages and medicines are used.

If you are in pain, tell your health worker so they can help relieve your pain with medicines. If the medicines are not working well, let them know.

Therapies to feel better and lessen discomfort

Along with pain medicines, there are other ways to relieve the side effects of pain, stress, and discomfort caused by cancer treatments. These methods are sometimes called complementary or integrative therapies. They include prayer or spiritual healing, meditation, herbal remedies, special diets, exercise, hypnosis, acupuncture, and massage.

While these therapies will not make the cancer go away or stop harm that the cancer is causing, used alongside surgery, chemotherapy, or radiotherapy, they may help the body recover faster and reduce side effects from cancer or cancer treatment. They also may lessen the anxiety or depression that is common for people with cancer, so they can make you feel better. And they can help a person feel more comfortable if they are dying from cancer or choosing not to get other treatment.

Talk with a health worker about which methods will help most in your situation and also if any might be harmful. If you are already using or planning to use a complementary therapy, tell your health worker to make sure all your treatments work well together.

Review Copy

Taking care of you, not just your cancer

Where possible, hospital and cancer programs help people with cancer in many ways beyond treatment. People need help solving problems, such as finding resources, making decisions, managing side effects, and lessening pain. When the goal of a treatment or other kind of assistance is not intended to cure the cancer but can still make the person feel better, it is called palliative care. Radiotherapy, surgery, and other cancer treatments can relieve pain and discomfort so sometimes they are used for palliative care even if they cannot destroy the cancer.

Everyone with cancer deserves to feel better. Because the goal of palliative care is to make a person feel better, it is not only for people who are dying. No matter what type or stage of cancer you have, palliative care can be a useful part of your care at any phase of treatment, starting when you first find out you have cancer. Palliative care focuses on your well-being, your comfort, and getting support to make decisions that feel right to you.

Review Copy

Palliative care includes many helpful services, such as:

- medicines to control pain, nausea, and other symptoms.
- complementary therapies to feel better, such as massage, acupuncture, special diets, and others.

- support with emotional and spiritual needs.
- learning the details about your cancer and treatment.
- support making medical decisions and making sure the different health workers are sharing with each other up-to-date information about your situation.

Feelings about having cancer

People with cancer often ask, “Why me?”, “What did I do wrong to get cancer?” If you’re having these feelings, you’re not alone. Thoughts like this are common for people with cancer.

Learning you have cancer, undergoing treatment, and accepting that you are sick can be very difficult emotionally. It is common to have feelings such as disbelief, shock, worry, fear, and anger. These feelings can make it even harder to pay attention to and understand the medical information shared by the doctors and nurses. Care for the mental and emotional effects of cancer are as important as physical treatment and medicines.

Look for activities and people that make you feel better:

- Spend time with loved ones
- Talk about your feelings and fears with someone you trust
- If you are religious, pray or participate in activities with your congregation or group
- Continue activities that you enjoy
- Relax with music, meditation, and gentle exercise

Review Copy

Depression

With cancer, it is common to get sad at times and have other feelings that are hard to handle. Depression is when those feelings are there all the time. You may have depression if sadness lasts for weeks, if you feel useless or hopeless, or when you don’t want to leave the house or even get out of bed. Depression can also make it hard to make decisions.

Some people are embarrassed that they are depressed and do not want to admit how bad they feel. But depression is not a sign of weakness and is no one’s fault. In fact, depression may be the result of physical changes caused by cancer or treatments.

Because depression can make it much harder to keep up with cancer treatment plans, it is important to talk about it with your doctor, nurse, or social worker. They can treat your depression with medicines, counseling, or both to help you feel better and feel more control over what is happening.

How will I manage?

Each person faces finding out about cancer and then getting through cancer treatment in their own way, just like with many other problems in life. Most find ways to go on with their work, family, and friendships and to enjoy their life.

Try some of these ideas to find what works best for you:

Learn as much as you can about your cancer and its treatment.

Learning about your cancer and its treatment can prepare you for and give you more control over what happens.

Take care of yourself.

Care for your body and your mind by eating and sleeping well, getting exercise, and doing something you enjoy every day. For example, spend time with a friend or loved one, meditate, help others, or listen to music or your favorite radio program.

Review Copy

Reach out to others who understand.

Joining a cancer support group can help you feel less alone with your cancer. Speaking and listening to others with cancer can give you ideas about how to get through treatment. You may find relief by sharing what you are experiencing with others who can understand how you feel.

Talking with family and friends

It's hard to go through cancer and even harder to do it alone. It is important to tell your loved ones and let them know how they can help. Sometimes people with cancer fear they will be rejected when their family or friends find out about their illness. Most often others will want to help and support you, but if people do react in hurtful ways, it is usually because they have wrong information about cancer. With time, or if someone keeps talking to them, their ideas may change.

Other people don't want to be a burden on their families and try to hide their cancer. But friends and families almost always find out, and hiding your cancer just makes it harder to follow your doctor's advice and get the treatment you need.

Your loved ones may have a hard time talking about cancer. They may not know what to say or do to help you and make you feel better. The more you can tell them about your illness and what to expect, the more comfortable they will be speaking with you about it. Showing them this booklet may also help them understand your situation.

Review Copy

IDEAS TO HELP TALK ABOUT CANCER

- Tell your family and friends about your cancer soon after you learn you have cancer. They will feel better if they hear about it from you rather than finding out about it another way.
- When you talk to them, explain what kind of cancer you have and how it will be treated. Make sure they know that no one can catch it from you.
- Think ahead about what you may need so you will be ready when people offer to help. Perhaps they can give you a ride to the treatment center, take children to school, do some shopping, or prepare a meal. Consider having someone with you for doctor and other health clinic visits.
- Tell those closest to you about your feelings and worries. This may not be easy, but it can be an important way to get the support you need when you need it most.
- You may not be able to do some things you were doing before you got cancer. Be sure to let your family and friends know. Also let your family and friends know they should not feel guilty about doing the things they normally do, as they did before you had cancer.
- If you're feeling sad or depressed, talk to your nurse, doctor, spiritual or religious leader, or others who have experience listening and counseling.

Review Copy

Talking with children

How a child reacts to upsetting news often depends on how the adults are handling it. When adults appear strong and calm, children often respond that way too. When talking to children about cancer, give them truthful information they can understand based on their age and level of understanding. Share small amounts of information over time as the child adjusts to what they see going on.

Give children a chance to ask questions and answer their questions honestly. Let them know it is OK to have feelings about cancer and to share them. Show them understanding and affection: praise them when they do something well, spend time with them, and give them the attention children need.

Staying healthy

You will feel better and stay stronger by eating nutritious food, exercising, and avoiding unhealthy activities like smoking or drinking alcohol.

Food

Eating foods that are nutritious for your body before, during, and after treatment can help you maintain your body weight, lessen the side effects of treatment, and heal and recover faster. Ask the health workers for the list of foods found where you live that are best during cancer treatment and find out which common foods and drinks to stay away from.

Eat 3 main meals or have smaller meals throughout the day. Each day try to have a mix of foods from each of the three food groups: food with protein for strength, starchy foods for energy, and vitamin-rich vegetables and fruits.

Eat healthy foods

Do not eat a lot of foods with oils, fats, sugars or salt because too much can be harmful to your health especially when you have cancer.

Review Copy

Treatment may cause you to lose your appetite. But, you should still try to eat a mix of healthy foods, finding those that taste best to you. If nausea is affecting your appetite, there are ways to prevent and lessen it. See pages 20 to 24, What can I do about side effects?

Drinking enough water is vital to health. Try to drink about 8 large glasses of water each day. Soup, teas, and other drinks with water are good too. You may need more fluid if you're vomiting, have diarrhea, or if you are just not eating much. You should avoid alcohol, soft drinks (sodas, fizzy drinks) or other sugary drinks, and also avoid lite or diet drinks with artificial sweeteners.

Exercise

Physical activity, moving as much as you can, helps keep your body strong and can lessen stress, tiredness, nausea, and constipation. It can also help improve your appetite and even improve your thinking and ability to focus. Even if you are mostly at home, get up to move around or do something at least once an hour.

Talk with your health workers to find out if there is any reason your cancer or treatment might affect your exercise. If you exercised regularly before learning that you have cancer, and your doctor approves, try to keep up the same exercise routine. If you are not used to much exercise, start with just 5 to 10 minutes per day and gradually add more.

After talking with your health workers about your cancer and how much exercise to try, you are ready to begin. But:

- do not do too much the first few times
- always pay attention to how your body feels and rest when you need to
- try short periods of exercise with frequent breaks

Review Copy

How to add physical activity to what you do every day:

- take a walk with a friend
- dance or move to your favorite music
- sweep and clean your home or yard

- work in your garden
- get off the taxi or bus several stops early and walk the rest of the way or, if not too far, walk to where you need to go

Healthy choices that make cancer treatment work best

Living a healthy life is not only about eating healthy food and exercising. It also means changing habits that are not good for your health. Two important habits to change are smoking and drinking alcohol. If you smoke or drink during cancer treatment, you might make more problems for your body when it already is working hard to get well

There is no safe form of tobacco.

If you smoke cigarettes, cigars or chew tobacco, stop! Encourage the people around you to quit. Breathing tobacco smoke, whether your own or another person's, damages your lungs, heart and other parts of your body. Tobacco smoke also increases cancer risk for smokers and everyone near them. E-cigarettes and vaping devices also put cancer-causing chemicals into the body.

Review Copy

It is best to avoid alcohol.

Too much alcohol causes emotional, social, and health problems. When you have cancer, alcohol can make treatment less effective, increase side effects, cause depression, and isolate you from friends and family. It is best not to drink alcohol during treatment. But if you want to, ask your nurse or doctor if a small amount of alcohol is OK or if your cancer, cancer treatment, or other health problems are reasons to avoid it altogether.

When treatment is successful

When treatment is successful, it can mean your cancer has been cured or maybe it is under control. Doctors often call this being in remission, which means that the signs of cancer have gone away or are reduced. They will usually examine you in a few months and then once a year or in a few years to check that the cancer has not returned.

Remission can be partial or complete. With partial remission, the cancer shrinks and may no longer cause problems but has not gone away. Because the cancer could come back, you and your doctors will be on the lookout for new or returning problems and you may need to make changes to care for yourself in other ways. In the same way that many people learn to live with long-term health conditions, you can adjust to this new situation.

In a complete remission, all signs and symptoms of cancer have disappeared.

Review Copy

After your successful treatment:

- find out how often to come back for check-ups. That way you can get timely treatment if the cancer comes back.

- find a group of people to talk to who have been through cancer treatment. They can help you adjust to your health situation after cancer and manage worries about whether the cancer will come back.
- if you remain in complete remission for many years, your doctor may say you are cured because they feel more certain the cancer will not come back.

Cancer that cannot be cured

Some people's cancers cannot be cured or controlled, no matter where they live or how much money they spend. If you're told there is no more treatment that can help you, think about how to make the most of the time you have remaining. Having people around you with a positive attitude can help lift your spirits and improve your days. You will need strength to get through each day, whether you are getting treatment or not.

If you have fears, regrets, or unsettled feelings, it can help to talk about them and perhaps resolve them. For example, if you regret something you did, telling someone might bring relief. If you are afraid of dying alone, telling others can allow them to plan to be with you so it won't happen.

Decide what steps you can take to ease your mind and ask family or friends to help you carry them out. If you want to speak with a specific person, a trusted friend, or a spiritual leader, make that known. Decide who you want to make health and other decisions for you when you become too sick to make them yourself. Health workers can give you a list of possible situations so you can prepare for them. Be sure to complete the legal paperwork about who will take care of your children, your property, and belongings.

Review Copy

Caring for someone with cancer

More information for family, friends, and other helpers

Many people can help and there are many ways to help

If you are looking at this booklet, you may be a family member, friend, neighbor, or any other person giving time or hired to help someone with cancer. Every situation and every family are a little different, but in addition to other topics in this booklet, these pages may give you useful ideas.

Ways to help a person when they first learn they have cancer:

- arrange to get them to and from medical appointments.
- offer to go to appointments with them and take notes or translate as the nurses and doctors explain about the cancer, tests, and treatment.
- take time to listen to your loved one. They will have many feelings and may have trouble talking about them. If they don't want to talk, show you are ready to listen if they change their mind.
- find out about groups and resources that help people with cancer and their families.

During and after treatment, a person may also need help with:

- physical care when they are not feeling well.
- getting and preparing nutritious foods to strengthen the body.
- caring for children or other family members your loved one usually takes care of.
- ways to cover the cost of treatment.
- getting support and information. This could be from others who have cancer too or with a counselor, health worker, or spiritual leader.

Review Copy

When you are helping a person with cancer who has pain

- Talk with the doctor or nurse so that you understand which medicines are for pain and how each is to be used.
- Check with health workers before you crush or dissolve pain pills to make them easier to swallow. Some pills work differently when broken.
- Pain medicines taken regularly work better than waiting to take them only after the pain gets bad.
- Watch for signs of pain, including facial expressions or moaning, difficulty breathing, or if someone has trouble changing positions in bed.

- Watch for signs that the person is taking too much pain medicine: sleeping too much or having difficulty waking up.

- Suggest enjoyable activities to distract the person from their pain. Warm baths, gentle massage, or other ways that make the person feel better and relaxed may also distract from pain.

Review Copy

- Offer plenty of drinking water.
- Keep pain medicines away from others, especially children.

Care for yourself is part of your care for others

Caring for a person with cancer, even when you love the person very much, can be tiring, worrisome, sad, and lonely. There can be moments of being frustrated and angry. Anyone doing this difficult caretaking work needs support too.

Take time for yourself so you are not spending every minute thinking about or being with the person. You will be able to help with more energy and patience when you take steps to stay well physically and emotionally.

Ask friends or family members for help. They can relieve some of the pressure on you and allow you time to take care of yourself.

- Make a list of specific things you need help with. Ask family and friends when and how they can best help, including who can take turns being with the person with cancer, allowing you to have some time away.
- Though it can be difficult when caregiving, plan how you can eat regular meals of nutritious foods, get some exercise every day, and get enough sleep.
- Bring family members and friends together for regular meetings to keep everyone up-to-date. Be sure to include the person with cancer too.

Review Copy

- Plan your time to include activities that are enjoyable and take your mind off your worries.
- Make sure you have someone you can talk to about how you are feeling.

Caring for someone during the final stage of life

When a person's cancer cannot be cured or controlled, they might be told there is no treatment that will work or they do not have very long to live. This is scary for the person who is sick and for those around them. Though this is always hard to hear, it is better to know this than to hide from it. It gives you and your family a chance to make plans — who will take care of the children, the farm or business, and other family matters.

As the sickness gets worse, the person with cancer may be in pain, may be bedridden, may be able to walk only a few steps, or may be confused. They will need more and more help.

Help with eating

Losing appetite is normal as the disease worsens. Offer small portions of food frequently and help them to eat if they are unable to. Help them sit up so they do not choke. Use a small spoon, and allow time for chewing and swallowing before offering more food. As the body shuts down, eating less and less food is normal so you can respect their wishes when the person no longer wants to eat much.

Help with personal hygiene

As your loved one becomes weaker, they will need help to bathe, change clothes and have fresh bedding. To prevent bedsores, help them get out of bed and sit in a chair from time to time, if possible. If they cannot leave the bed, help them change their position often, at least every few hours.

Review Copy

What is hospice care?

Some health systems include hospice programs focused on making a person who is dying more comfortable, and helping the person and the family in many ways. Hospice services may start weeks or months before the end of life nears to help the person and family make plans, find emotional and spiritual support, reduce pain, and address the different tasks described in this section. There are hospice services where a dying person goes to stay at a hospice center and those that help people stay in their own home. Helping families get through hard times by making each day as good as possible for the person with cancer is the goal of hospice care.

Losing your loved one

When death is near, both you and the person with cancer may feel angry, sad, or scared. Even though it may be hard, it is important to be there for the person with cancer. Just staying close and listening with a smile or gentle touch shows you care.

Sometimes the person wants to talk about dying. They may ask you what to expect. “Will it be painful?” “Why is this happening to me?” It is very hard to hear these questions because there are no answers. You can simply say, “I don’t know. Nobody does.” Every person’s body slows down differently as they dying process goes on. Holding their hand and letting them cry or talk about their good memories or sadness and regrets may be the best you can do.

Remind your loved one you will be there for them in living and in dying. They may need medication to reduce pain, and loving care and your presence to bring comfort and ease the transition to death.

Review Copy

More resources

Common signs and symptoms of cancer

Finding out someone has cancer makes others wonder about cancer and what to watch for. There are some symptoms that should always be checked by a health worker. You may need tests for certain symptoms. If the tests show that you do have cancer, finding it as early as possible means your treatment is more likely to be successful. If the tests show that you do not have cancer, you will be relieved that you have no serious problem. Common signs and symptoms of cancer include:

A lump or swelling

Unexplained pain

Sores or changes to your skin that do not go away

Unexplained weight loss

Review Copy

Many symptoms that might be cancer can also be caused by something other than cancer. The sooner you know the cause, whether it is cancer or not, you can find out about possible treatments.

There are other symptoms of cancer. If you notice any major changes in the way your body works or the way you feel – especially if it gets worse or lasts for a long time – get checked by a health worker.

List of common medical words related to cancer

anesthesia: medicines to make you sleep or prevent pain during surgery or other procedures. The doctor that gives these medicines is an anesthesiologist.

benign: when a tumor is not cancer or will not cause harm. Benign is the opposite of malignant.

biopsy: is done to remove a small piece of the tumor to look at under a microscope, to help doctors see if it is cancer and choose the best treatment. See page 10.

cancer: Cancer is a disease which causes cells to grow abnormally and multiply faster than usual. There are many kinds of cancers, some spread more quickly and are more dangerous than others. See page 3.

CAT scan (also called computed tomography scan or CT scan): a type of X-ray where a rotating machine creates a picture of the inside of the body to help doctors find cancer.

chemotherapy (also called chemo): is the use of medicines to kill cancer cells or slow their growth. See page 15.

complementary and integrative therapies: practices that help a person feel better, often given along with medical treatments that attack the cancer directly. Complementary therapies include plant medicines, changes in the foods you eat, hypnosis, acupuncture, meditation, massage, and many others. See page 26.

cure or **cured:** When cancer signs have gone away or almost gone away, it is called remission. When cancer signs have stayed away for many years, your doctors may say that the cancer is cured because they are sure it will not come back.

depression: Many people with cancer get sad at times and have feelings of hopelessness or a lack of interest in anything. Depression is when those sad or hopeless feelings do not go away. See page 28.

diagnosis: certainty about whether cancer is or is not present. Doctors make a diagnosis based on proof from tests or a biopsy.

hormone therapy: (also called hormonal therapy or endocrine therapy). Hormones are certain chemicals made naturally in the body. This treatment adds, removes, or blocks **hormones** as a way to destroy or slow the growth of cancer cells.

hospice care: programs in some health systems that focus on making a person who is dying more comfortable. Hospice care offers many ways to help the person and the family during this difficult time. See page 40.

immune system: the parts of the body that together work to fight off diseases and health problems. When a person is immunosuppressed, their immune system is not working as well so they can get sick more easily.

immunotherapy: a treatment with medicines to help a person's immune system work better to find and stop cancer cells from growing and spreading. See page 16.

Review Copy

magnetic resonance imaging (MRI): similar to an X-ray, an MRI machine takes a picture of the inside of the body, using a magnetic field and radio waves, while the person lies inside the MRI machine.

malignant: another way to say that a tumor has cancer. Malignant is the opposite of benign.

mammogram: an X-ray that shows the inside of the breast.

mass: a lump in the body.

metastasis: the spread of disease, such as cancer, to other parts of the body. A cancer that is metastasizing or has metastasized is cancer that has spread. See page 4.

oncologist: a doctor who treats patients who have cancer.

palliative care (also called **supportive care**): any treatment used to make a person who is sick feel better. This includes support for the family. See page 27.

pathologist: a doctor who uses the results of different types of tests to find out what disease a person has.

radiation therapy (also called **radiotherapy**, **irradiation**, or **X-ray therapy**): radiation is one of the most common forms of cancer treatment. Radiation machines use a beam of high energy to kill cancer cells and shrink tumors. See page 15. Brachytherapy is when radiation is given through a small device (implant) placed inside the body in or near the tumor.

radiologist: a doctor who looks at X-rays and scans to understand a person's health problems.

recurrence, relapse: when cancer that went away after treatment comes back.

remission: when signs of the cancer are mostly or completely gone. See page 35.

side effects: treatments that destroy cancer cells, allowing a person to get well, may create new and uncomfortable problems, called side effects. They usually go away after treatment is finished. Side effects may include itching, nausea, tiredness, and others. See pages 19 to 25.

stage of cancer (also called **staging**): a way of describing the progression of cancer, including where it started, if or where it has spread, and if it is affecting other parts of the body. See page 11.

surgery: when an operation is used to remove cancer from the body. See page 14.

targeted therapy: a treatment with medicines that find and attack specific parts of cancer cells. See page 16.

tumor (also called a **nodule**): a mass that forms in the body. See page 5. A tumor is cancer (called a malignant tumor) when the body's healthy cells change into cancer cells and grow uncontrollably. A tumor can also be benign, meaning there is no cancer.

ultrasound (also called **sonography** or **sonogram**): an ultrasound, like an X-ray, is a way machines create pictures of inside the body, using sound waves, not X-rays.

Review Copy

Find resources in your community

Everyone needs support to help get through cancer treatment. Many countries have government programs, community organizations, and other charitable groups that provide help. Ask your health worker what resources might be available in your community to meet these or other needs:

Accommodation

Often people must travel far distances from home to receive cancer treatment over several weeks. They and their families need an affordable place to stay that is close to the cancer treatment facility and offers a safe environment to rest during treatment. There might be patient hostels that provide a place to stay, meals, and transportation to the treatment center. Other groups might provide financial assistance to help people cover these needs.

Financial Assistance

The costs of cancer treatment can be high. In many countries, governments offer national health insurance programs that can help offset the costs of diagnosis, care, and treatment. Be sure to see what other health insurance programs are available through private companies and employers. Sometimes charitable and religious groups can sponsor or support a person with cancer.

Emotional Support

Learning that you or a loved one has cancer can affect your emotional health. Ask if there are programs or organizations that offer counselling services, support groups for people with cancer, or other forms of support.

Other Assistance

There are usually many forms of assistance to meet the needs of cancer patients. Find out what is available near you to help with transportation, patient advocacy and legal support, palliative care, prosthetics following surgery, end-of-life or hospice care, childcare, nutritional support, and other services.

Review Copy

Find more information online

Although there is a great deal of information about cancer online, not all of it is accurate. The following organizations and their websites are among those that provide trusted, accurate information about cancer and other resources that will be useful to people with cancer and anyone helping them. For additional websites to consult and information useful in your region or country, ask the person who gave you this booklet.

American Cancer Society (ACS)
cancer.org
Search this website for information about coping with a cancer diagnosis as well as information about cancer and cancer treatment. ACS also promotes healthy lifestyles and describes what people can do to prevent getting cancer. La versión en espanol es: cancer.org/es.

American Society of Clinical Oncology (ASCO)
cancer.net
This website brings the expertise and resources of ASCO to people living with cancer and those who care for and care about them.

Hesperian Health Guides
bit.ly/3tmPckI
Read easy-to-understand information about cancer, cancer treatment, what to do if you have cancer, and how to support people with cancer, in this chapter from Hesperian's *New Where There Is No Doctor*.

MacMillan Cancer Support
macmillan.org.uk
Visit this website for cancer information and access to an online community offering advice and support.

National Cancer Institute (NCI)
cancer.gov
This website provides detailed information on cancer, coping with cancer, treatment, and research.

National Comprehensive Cancer Network (NCCN)
nccn.org/patientresources/patient-resources
This NCCN Patient Resources page has updated guidelines for patients, recorded webinars for people living with cancer and caregivers, and many other resources and materials.

World Health Organization (WHO)
who.int/health-topics/cancer
Find fact sheets on common cancers and descriptions of how cancer affects different regions and countries.

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