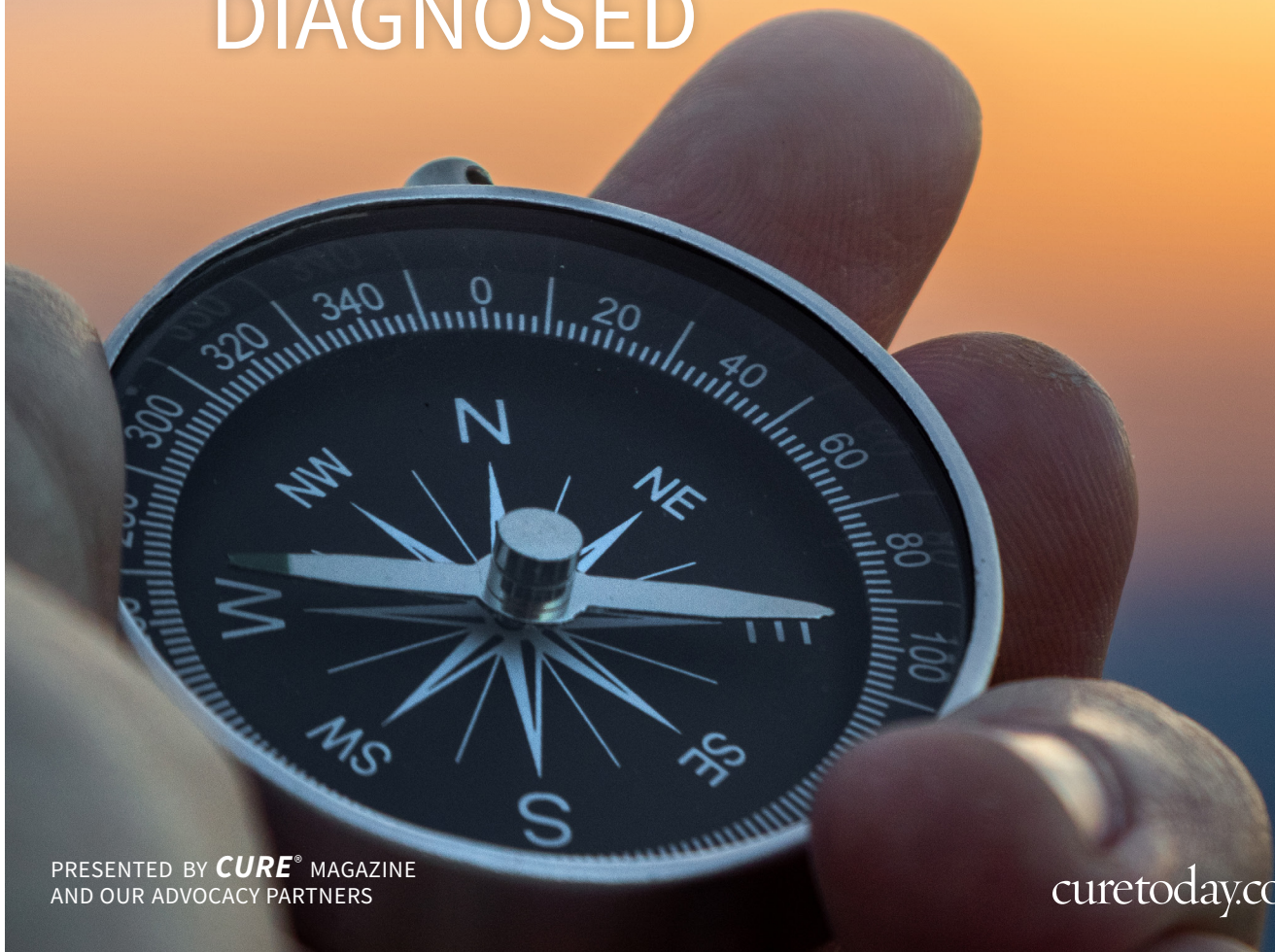


cure[®]

14TH EDITION
**CANCER
GUIDE**
for the **NEWLY
DIAGNOSED**



PRESENTED BY **CURE**[®] MAGAZINE
AND OUR ADVOCACY PARTNERS

curetoday.com

FOR ADULTS WHO RECEIVED 2 OR MORE TREATMENTS FOR HER2+ METASTATIC BREAST CANCER

HOPELESS



ENHERTU helped shrink tumors in

60%

of people with HER2+ mBC

In a clinical study of 184 women, most people treated with ENHERTU (60%) saw their tumors shrink.*

- Some people (4.3%) achieved what is known as a **complete response**, meaning their tumor could not be seen on imaging tests
- Most people (56%) achieved a **partial response**, which means the **tumor shrank by at least 30%**

In the same clinical study, half of the 111 people who responded to ENHERTU were able to maintain their response for 14.8 months or longer.† However, how long responses lasted varied by person.

Ask your doctor if ENHERTU is right for you and visit [ENHERTU.com](https://www.enherthu.com) to learn more.

HER2 stands for human epidermal growth factor receptor 2; mBC stands for metastatic breast cancer.

*111 of 184 people saw their tumors shrink, including 8 of 184 people who achieved a complete response and 103 of 184 people who achieved a partial response.

†14.8 months is the median length of time people maintained their response to ENHERTU. This is called the duration of response.

Median is the middle number in a group of numbers arranged from lowest to highest.

What is ENHERTU?

ENHERTU is a prescription medicine used in adults to treat human epidermal growth factor receptor 2 (HER2)-positive breast cancer that cannot be removed by surgery or that has spread to other parts of your body (metastatic), and who have received two or more prior anti-HER2 breast cancer treatments.

ENHERTU was FDA approved for this use based on a clinical study that measured how many patients responded and how long they responded. ENHERTU is still being studied to confirm these results.

It is not known if ENHERTU is safe and effective in children.

Important Safety Information

What is the most important information I should know about ENHERTU?

ENHERTU can cause serious side effects, including: Lung problems that may be severe, life-threatening or that may lead to death. If you develop lung problems your healthcare provider may treat you with corticosteroid medicines. Tell your healthcare provider right away if you get any of the following signs and symptoms:

- Cough
- Trouble breathing or shortness of breath
- Fever
- Other new or worsening breathing symptoms (e.g., chest tightness, wheezing)

Please see additional Important Safety Information and a Brief Summary of full Prescribing Information, including Boxed WARNINGS, on following pages.



ENHERTU[®]

fam-trastuzumab deruxtecan-nxki
20 mg/mL INJECTION FOR INTRAVENOUS USE

Important Safety Information

What is the most important information I should know about ENHERTU?

ENHERTU can cause serious side effects, including:

Lung problems that may be severe, life-threatening or that may lead to death. If you develop lung problems your healthcare provider may treat you with corticosteroid medicines. Tell your healthcare provider right away if you get any of the following signs and symptoms:

- Cough
- Trouble breathing or shortness of breath
- Fever
- Other new or worsening breathing symptoms (e.g., chest tightness, wheezing)

Low white blood cell count (neutropenia). Low white blood cell counts are common with ENHERTU and can sometimes be severe. Your healthcare provider will check your white blood cell counts before starting ENHERTU and before starting each dose. Tell your healthcare provider right away if you develop any signs or symptoms of an infection or have fever or chills during treatment with ENHERTU.

Heart problems that may affect your heart's ability to pump blood. Your healthcare provider will check your heart function before starting treatment with ENHERTU. Tell your healthcare provider right away if you get any of the following signs and symptoms:

- New or worsening shortness of breath
- Coughing
- Feeling tired
- Swelling of your ankles or legs
- Irregular heartbeat
- Sudden weight gain
- Dizziness or feeling light-headed
- Loss of consciousness

Your healthcare provider will check you for these side effects during your treatment with ENHERTU. Your healthcare provider may reduce your dose, delay treatment or completely stop treatment with ENHERTU if you have severe side effects.

Harm to your unborn baby. Tell your healthcare provider right away if you become pregnant or think you might be pregnant during treatment with ENHERTU.

- If you are able to become pregnant, your healthcare provider should do a pregnancy test before you start treatment with ENHERTU.
- **Females** who are able to become pregnant should use effective birth control (contraception) during treatment with ENHERTU and for at least 7 months after the last dose.
- **Males** who have female partners that are able to become pregnant should use effective birth control (contraception) during treatment with ENHERTU and for at least 4 months after the last dose.

Before you receive ENHERTU, tell your healthcare provider about all of your medical conditions, including if you:

- Have lung or breathing problems.
- Have signs or symptoms of an infection.
- Have or have had any heart problems.
- Are breastfeeding or plan to breastfeed. It is not known if ENHERTU passes into your breast milk. Do not breastfeed during treatment with ENHERTU and for 7 months after the last dose.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How will I receive ENHERTU?

- You will receive ENHERTU into your vein through an intravenous (IV) line by your healthcare provider.
- ENHERTU is given 1 time every three weeks (21-day treatment cycle).
- Your healthcare provider will decide how many treatments you need.
- Your healthcare provider may slow down or temporarily stop your infusion of ENHERTU if you have an infusion-related reaction, or permanently stop ENHERTU if you have severe infusion reactions.
- If you miss a planned dose of ENHERTU, call your healthcare provider right away to schedule an appointment. Do not wait until the next planned treatment cycle.

What are the possible side effects of ENHERTU?

ENHERTU can cause serious side effects. See “What is the most important information I should know about ENHERTU?”

The most common side effects of ENHERTU, when used in people with breast cancer, include:

- Nausea
- Low white blood cell counts
- Low red blood cell counts
- Feeling tired
- Vomiting
- Hair loss
- Increased liver function tests
- Low platelet counts
- Constipation
- Decreased appetite
- Diarrhea
- Low levels of blood potassium
- Cough

ENHERTU may cause fertility problems in males, which may affect the ability to father children. Talk to your healthcare provider if you have concerns about fertility.

These are not all of the possible side effects of ENHERTU. Call your doctor for medical advice about side effects. You may report side effects to Daiichi Sankyo at 1-877-437-7763 or to FDA at 1-800-FDA-1088.

What is ENHERTU?

ENHERTU is a prescription medicine used in adults to treat human epidermal growth factor receptor 2 (HER2)-positive breast cancer that cannot be removed by surgery or that has spread to other parts of your body (metastatic), and who have received two or more prior anti-HER2 breast cancer treatments.

ENHERTU was FDA approved for this use based on a clinical study that measured how many patients responded and how long they responded. ENHERTU is still being studied to confirm these results.

It is not known if ENHERTU is safe and effective in children.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see a Brief Summary of full Prescribing Information, including Boxed WARNINGS, on following pages.

Medication Guide
ENHERTU® (en-HER-too)
(fam-trastuzumab deruxtecan-nxki) for injection

What is the most important information I should know about ENHERTU?

ENHERTU can cause serious side effects, including: Lung problems that may be severe, life-threatening or that may lead to death. If you develop lung problems your healthcare provider may treat you with corticosteroid medicines. Tell your healthcare provider right away if you get any of the following signs and symptoms:

- cough
- trouble breathing or shortness of breath
- fever
- other new or worsening breathing symptoms (e.g., chest tightness, wheezing)

Low white blood cell count (neutropenia). Low white blood cell counts are common with ENHERTU and can sometimes be severe. Your healthcare provider will check your white blood cell counts before starting ENHERTU and before starting each dose. Tell your healthcare provider right away if you develop any signs or symptoms of an infection or have fever or chills during treatment with ENHERTU.

Heart problems that may affect your heart's ability to pump blood. Your healthcare provider will check your heart function before starting treatment with ENHERTU. Tell your healthcare provider right away if you get any of the following signs and symptoms:

- new or worsening shortness of breath
- coughing
- feeling tired
- swelling of your ankles or legs
- irregular heartbeat
- sudden weight gain
- dizziness or feeling light-headed
- loss of consciousness

Your healthcare provider will check you for these side effects during your treatment with ENHERTU. Your healthcare provider may reduce your dose, delay treatment or completely stop treatment with ENHERTU if you have severe side effects.

Harm to your unborn baby. Tell your healthcare provider right away if you become pregnant or think you might be pregnant during treatment with ENHERTU.

- If you are able to become pregnant, your healthcare provider should do a pregnancy test before you start treatment with ENHERTU.
- **Females** who are able to become pregnant should use effective birth control (contraception) during treatment with ENHERTU and for at least 7 months after the last dose.
- **Males** who have female partners that are able to become pregnant should use effective birth control (contraception) during treatment with ENHERTU and for at least 4 months after the last dose.

See “**What are the possible side effects of ENHERTU?**” for more information about side effects.

What is ENHERTU?

ENHERTU is a prescription medicine used in adults to treat human epidermal growth factor receptor 2 (HER2)-positive

- breast cancer that cannot be removed by surgery or that has spread to other parts of your body (metastatic), and who have received two or more prior anti-HER2 breast cancer treatments.
- stomach cancer called gastric or gastroesophageal junction (GEJ) adenocarcinoma that has spread to areas near your stomach (locally advanced) or that has spread to other parts of your body (metastatic), and who have received a prior trastuzumab-based regimen.

It is not known if ENHERTU is safe and effective in children.

Before you receive ENHERTU, tell your healthcare provider about all of your medical conditions, including if you:

- have lung or breathing problems.
- have signs or symptoms of an infection.
- have or have had any heart problems.

- are breastfeeding or plan to breastfeed. It is not known if ENHERTU passes into your breast milk. Do not breastfeed during treatment with ENHERTU and for 7 months after the last dose.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How will I receive ENHERTU?

- You will receive ENHERTU into your vein through an intravenous (IV) line by your healthcare provider.
- ENHERTU is given 1 time every three weeks (21-day treatment cycle).
- Your healthcare provider will decide how many treatments you need.
- Your healthcare provider may slow down or temporarily stop your infusion of ENHERTU if you have an infusion-related reaction, or permanently stop ENHERTU if you have severe infusion reactions.
- If you miss a planned dose of ENHERTU, call your healthcare provider right away to schedule an appointment. Do not wait until the next planned treatment cycle.

What are the possible side effects of ENHERTU?

ENHERTU can cause serious side effects. See “What is the most important information I should know about ENHERTU?” The most common side effects of ENHERTU, when used in people with breast cancer, include:

- nausea
- low white blood cell counts
- low red blood cell counts
- feeling tired
- vomiting
- hair loss
- increased liver function tests
- low platelet counts
- constipation
- decreased appetite
- diarrhea
- low levels of potassium
- cough

The most common side effects of ENHERTU, when used in people with stomach cancer, include:

- low red blood cell counts
- low white blood cell counts
- low platelet counts
- nausea
- decreased appetite
- increased liver function tests
- feeling tired
- diarrhea
- low levels of blood potassium
- vomiting
- constipation
- fever
- hair loss

ENHERTU may cause fertility problems in males, which may affect the ability to father children. Talk to your healthcare provider if you have concerns about fertility.

These are not all of the possible side effects of ENHERTU. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of ENHERTU.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about ENHERTU that is written for healthcare professionals.

What are the ingredients in ENHERTU?

Active Ingredient: fam-trastuzumab deruxtecan-nxki.

Inactive Ingredients: L-histidine, L-histidine hydrochloride monohydrate, polysorbate 80, and sucrose.

Manufactured by: Daiichi Sankyo, Inc., Basking Ridge, NJ 07920 U.S. License No. 2128

Marketed by: Daiichi Sankyo, Inc., Basking Ridge, NJ 07920 and AstraZeneca Pharmaceuticals LP, Wilmington, DE 19850

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For more information, call 1-877-437-7763 or go to

<https://www.ENHERTU.com>

This Medication Guide has been approved by the U.S. Food and Drug Administration.

Revised: 01/2021

cure[®] CONTENTS

CANCER GUIDE • 14TH EDITION

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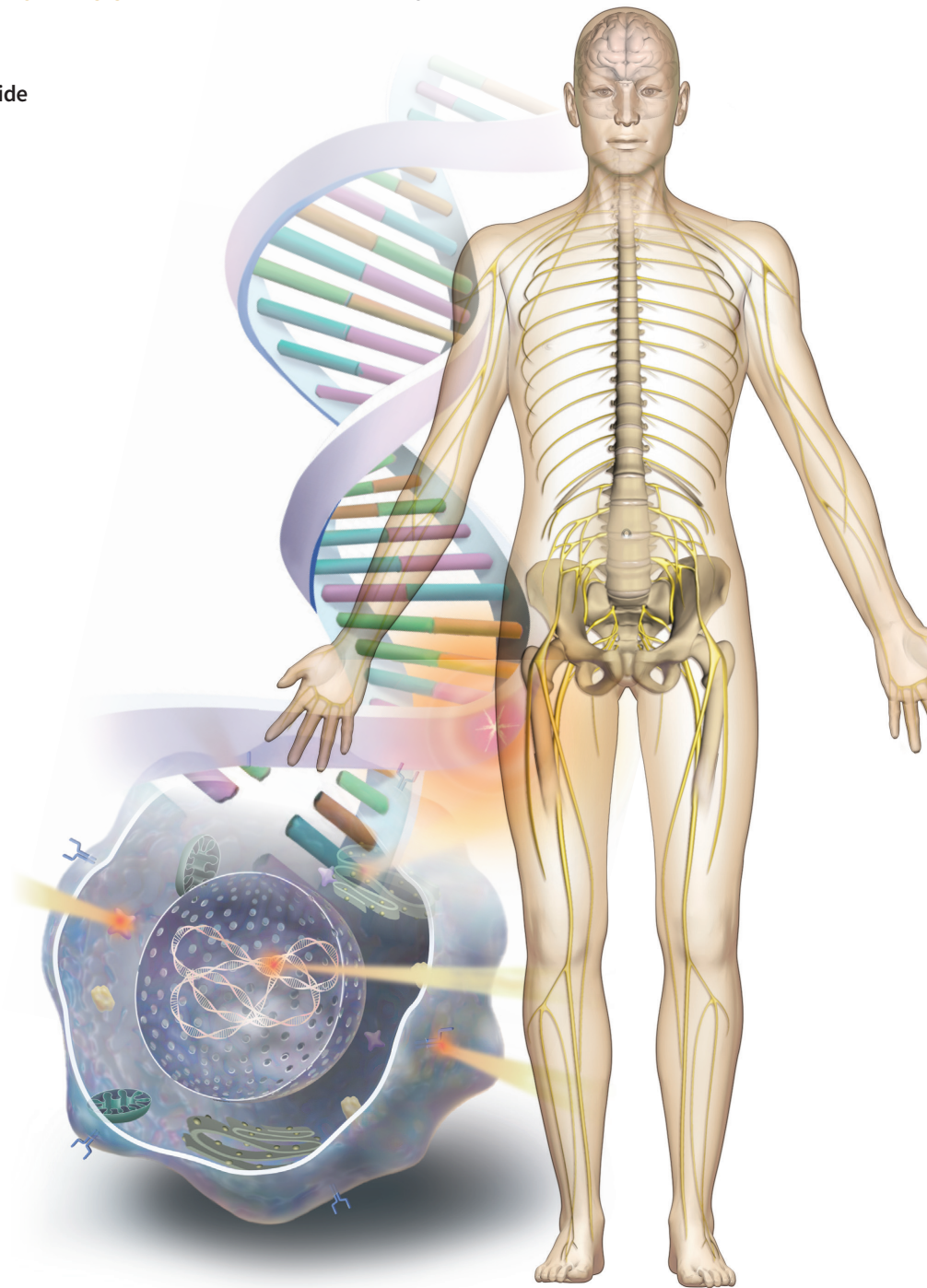
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For a comprehensive list of organizations that offer educational, emotional and financial support to patients with cancer and their loved ones, visit the resources section of our Cancer Guide at curetoday.com/journey.



KEYTRUDA IS A BREAKTHROUGH IMMUNOTHERAPY.



FOR TODAY

KEYTRUDA is a potential first treatment for **3 out of 4 patients** with advanced non-small cell lung cancer (NSCLC).

KEYTRUDA is also used to treat **more patients** with advanced lung cancer than any other immunotherapy.

FOR THE FUTURE



Ongoing clinical trials are exploring if KEYTRUDA can help treat more patients.

KEYTRUDA may be your first treatment for advanced NSCLC, either in combination with chemotherapy or used alone as a chemotherapy-free option.

Ask your doctor if KEYTRUDA is right for you.

KEYTRUDA is a prescription medicine used to treat a kind of lung cancer called non-small cell lung cancer (NSCLC).

▶ KEYTRUDA + CHEMOTHERAPY, NONSQUAMOUS

It may be used with the chemotherapy medicines pemetrexed and a platinum as your first treatment when your lung cancer has spread (advanced NSCLC) **and** is a type called “nonsquamous” **and** your tumor does not have an abnormal “EGFR” or “ALK” gene.

▶ KEYTRUDA + CHEMOTHERAPY, SQUAMOUS

It may be used with the chemotherapy medicines carboplatin and either paclitaxel or paclitaxel protein-bound as your first treatment when your lung cancer has spread (advanced NSCLC), **and** is a type called “squamous.”

▶ KEYTRUDA USED ALONE, PD-L1 POSITIVE

It may be used alone as your first treatment when your lung cancer has not spread outside your chest (stage III) and you cannot have surgery or chemotherapy with radiation, **or** your NSCLC has spread to other areas of your body (advanced NSCLC), **and** your tumor tests positive for “PD-L1” **and** does not have an abnormal “EGFR” or “ALK” gene.

▶ KEYTRUDA AFTER CHEMOTHERAPY, PD-L1 POSITIVE

It may also be used alone for advanced NSCLC if you have tried chemotherapy that contains platinum and it did not work or is no longer working **and**, your tumor tests positive for “PD-L1” **and** if your tumor has an abnormal “EGFR” or “ALK” gene, you have also received an “EGFR” or “ALK” inhibitor medicine that did not work or is no longer working.

PD-L1 = programmed death ligand 1;
EGFR = epidermal growth factor receptor;
ALK = anaplastic lymphoma kinase.

IMPORTANT SAFETY INFORMATION

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen any time during treatment or even after your treatment has ended.

Call or see your health care provider right away if you develop any signs or symptoms of the following problems or if they get worse. These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA:

- **Lung problems:** cough, shortness of breath, or chest pain.
- **Intestinal problems:** diarrhea (loose stools) or more frequent bowel movements than usual; stools that are black, tarry, sticky, or have blood or mucus; or severe stomach-area (abdomen) pain or tenderness.
- **Liver problems:** yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); dark urine (tea colored); or bleeding or bruising more easily than normal.
- **Hormone gland problems:** headaches that will not go away or unusual headaches; eye sensitivity to light; eye problems; rapid heartbeat; increased sweating; extreme tiredness; weight gain or weight loss; feeling more hungry or thirsty than usual; urinating more often than usual; hair loss; feeling cold; constipation; your voice gets deeper; dizziness or fainting; changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness.
- **Kidney problems:** decrease in the amount of your urine; blood in your urine; swelling of your ankles; loss of appetite.
- **Skin problems:** rash; itching; skin blistering or peeling; painful sores or ulcers in your mouth or in your nose, throat, or genital area; fever or flu-like symptoms; swollen lymph nodes.
- **Problems can also happen in other organs and tissues.** Signs and symptoms of these problems may include: chest pain; irregular heartbeat; shortness of breath; swelling of ankles; confusion;

Important Safety Information is continued on the next page.

Teresa is a
real patient



keytruda.com/lung

IMPORTANT SAFETY INFORMATION (continued)

sleepiness; memory problems; changes in mood or behavior; stiff neck; balance problems; tingling or numbness of the arms or legs; double vision; blurry vision; sensitivity to light; eye pain; changes in eyesight; persistent or severe muscle pain or weakness; muscle cramps; low red blood cells; bruising.

- **Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feeling like passing out, fever, and back pain.
- **Rejection of a transplanted organ.** Your health care provider should tell you what signs and symptoms you should report and they will monitor you, depending on the type of organ transplant that you have had.
- **Complications, including graft-versus-host disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your health care provider will monitor you for these complications.

Getting medical treatment right away may help keep these problems from becoming more serious. Your health care provider will check you for these problems during treatment with KEYTRUDA. They may treat you with corticosteroid or hormone replacement medicines. They may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

Before you receive KEYTRUDA, tell your health care provider if you have immune system problems such as Crohn's disease, ulcerative colitis, or lupus; have had an organ transplant or have had or plan to have a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic); have had radiation treatment in your chest area; have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome. If you are pregnant or plan to become pregnant, tell your health care provider. KEYTRUDA can harm your unborn baby. If you are able to become pregnant, you will be given a pregnancy test before you start treatment.

Use effective birth control during treatment and for at least 4 months after your final dose of KEYTRUDA. Tell them right away if you think you may be pregnant or you become pregnant during treatment with KEYTRUDA.

Tell your health care provider if you are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Common side effects of KEYTRUDA when used alone include feeling tired; pain, including pain in muscles, bones or joints and stomach-area (abdominal) pain; decreased appetite; itching; diarrhea; nausea; rash; fever; cough; shortness of breath; and constipation.

Common side effects of KEYTRUDA when given with certain chemotherapy medicines include feeling tired or weak; nausea; constipation; diarrhea; decreased appetite; rash; vomiting; cough; trouble breathing; fever; hair loss; inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs; swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina; mouth sores; headache; weight loss; stomach-area (abdominal) pain; joint and muscle pain; and trouble sleeping.

These are not all the possible side effects of KEYTRUDA. Talk to your health care provider for medical advice about side effects.

Please read the adjacent Important Information About KEYTRUDA and discuss it with your oncologist.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Having trouble paying for your Merck medicine?

Merck may be able to help. www.merckhelps.com

IT'S TRU. KEYTRUDA®
(pembrolizumab) Injection 100 mg

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Important Information About KEYTRUDA® (pembrolizumab) injection 100 mg. Please speak with your healthcare professional regarding KEYTRUDA (pronounced key-true-duh). Only your healthcare professional knows the specifics of your condition and how KEYTRUDA may work with your overall treatment plan. If you have any questions about KEYTRUDA, speak with your healthcare professional. **Rx ONLY**

What is the most important information I should know about KEYTRUDA?

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen anytime during treatment or even after your treatment has ended.

Call or see your healthcare provider right away if you develop any new or worsening signs or symptoms, including:

Lung problems

- cough
- shortness of breath
- chest pain

Intestinal problems

- diarrhea (loose stools) or more frequent bowel movements than usual
- stools that are black, tarry, sticky, or have blood or mucus
- severe stomach-area (abdomen) pain or tenderness

Liver problems

- yellowing of your skin or the whites of your eyes
- severe nausea or vomiting
- pain on the right side of your stomach area (abdomen)
- dark urine (tea colored)
- bleeding or bruising more easily than normal

Hormone gland problems

- headaches that will not go away or unusual headaches
- eye sensitivity to light
- eye problems
- rapid heartbeat
- increased sweating
- extreme tiredness
- weight gain or weight loss
- feeling more hungry or thirsty than usual
- urinating more often than usual
- hair loss
- feeling cold
- constipation
- your voice gets deeper
- dizziness or fainting
- changes in mood or behavior, such as decreased sex drive,

Kidney problems

- decrease in your amount of urine
- swelling of your ankles
- blood in your urine
- loss of appetite

Skin problems

- rash
- itching
- skin blistering or peeling
- painful sores or ulcers in your mouth or in your nose, throat, or genital area
- fever or flu-like symptoms
- swollen lymph nodes

Problems can also happen in other organs and tissues. These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA. Call or see your healthcare provider right away for any new or worsening signs or symptoms, which may include:

- chest pain, irregular heartbeat, shortness of breath, swelling of ankles
- confusion, sleepiness, memory problems, changes in mood or behavior, stiff neck, balance problems, tingling or numbness of the arms or legs
- double vision, blurry vision, sensitivity to light, eye pain, changes in eyesight
- persistent or severe muscle pain or weakness, muscle cramps
- low red blood cells, bruising

Infusion reactions that can sometimes be severe or life-threatening. Signs and symptoms of infusion reactions may include:

- chills or shaking
- dizziness
- itching or rash
- feeling like passing out
- flushing
- fever
- shortness of breath or wheezing
- back pain

Rejection of a transplanted organ. Your healthcare provider should tell you what signs and symptoms you should report and monitor you, depending on the type of organ transplant that you have had.

Complications, including graft-versus-host-disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic). These complications can be serious and can lead to death. These

complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your healthcare provider will monitor you for these complications.

Getting medical treatment right away may help keep these problems from becoming more serious. Your healthcare provider will check you for these problems during treatment with KEYTRUDA. Your healthcare provider may treat you with corticosteroid or hormone replacement medicines. Your healthcare provider may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

Before receiving KEYTRUDA, tell your healthcare provider about all of your medical conditions, including if you:

- have immune system problems such as Crohn's disease, ulcerative colitis, or lupus
- have received an organ transplant
- have received or plan to receive a stem cell transplant that uses donor stem cells (allogeneic)
- have received radiation treatment to your chest area
- have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
- are pregnant or plan to become pregnant. KEYTRUDA can harm your unborn baby.

Females who are able to become pregnant:

- Your healthcare provider will give you a pregnancy test before you start treatment with KEYTRUDA.
- You should use an effective method of birth control during and for at least 4 months after the final dose of KEYTRUDA. Talk to your healthcare provider about birth control methods that you can use during this time.
- Tell your healthcare provider right away if you think you may be pregnant or if you become pregnant during treatment with KEYTRUDA.
- are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How will I receive KEYTRUDA?

- Your healthcare provider will give you KEYTRUDA into your vein through an intravenous (IV) line over 30 minutes.
- In adults, KEYTRUDA is usually given every 3 weeks or 6 weeks depending on the dose of KEYTRUDA that you are receiving.
- In children, KEYTRUDA is usually given every 3 weeks.
- Your healthcare provider will decide how many treatments you need.

- Your healthcare provider will do blood tests to check you for side effects.
- If you miss any appointments, call your healthcare provider as soon as possible to reschedule your appointment.

What are the possible side effects of KEYTRUDA? KEYTRUDA can cause serious side effects. See “What is the most important information I should know about KEYTRUDA?”

Common side effects of KEYTRUDA when used alone include: feeling tired, pain, including pain in muscles, bones or joints and stomach-area (abdominal) pain, decreased appetite, itching, diarrhea, nausea, rash, fever, cough, shortness of breath, and constipation.

Side effects of KEYTRUDA when used alone that are more common in children than in adults include: fever, vomiting, upper respiratory tract infection, headache, and low levels of white blood cells and red blood cells (anemia).

Common side effects of KEYTRUDA when given with certain chemotherapy medicines include: feeling tired or weak, nausea, constipation, diarrhea, decreased appetite, rash, vomiting, cough, trouble breathing, fever, hair loss, inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs, swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, mouth sores, headache, weight loss, stomach-area (abdominal) pain, joint and muscle pain, and trouble sleeping.

Common side effects of KEYTRUDA when given with axitinib include: diarrhea, feeling tired or weak, high blood pressure, liver problems, low levels of thyroid hormone, decreased appetite, blisters or rash on the palms of your hands and soles of your feet, nausea, mouth sores or swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, hoarseness, rash, cough, and constipation.

These are not all the possible side effects of KEYTRUDA.

Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of KEYTRUDA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about KEYTRUDA that is written for health professionals.

Based on Medication Guide usmg-mk3475-iv-2107r043 as revised July 2021.

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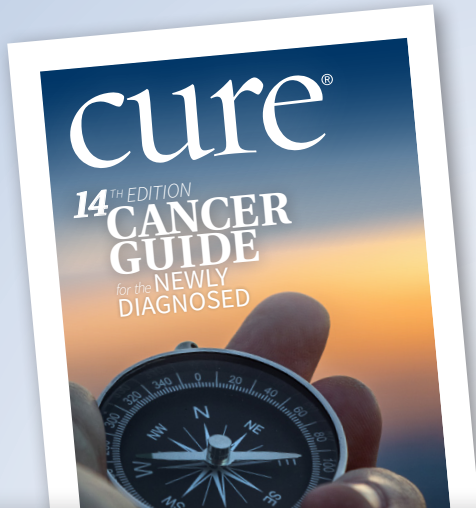
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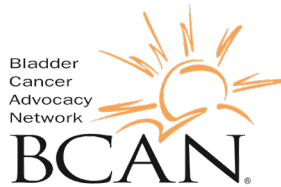
The 14th edition of the *Annual Cancer Guide for the Newly Diagnosed* is proudly presented by *CURE*® magazine

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Welcome to *CURE*[®]'s Annual Cancer Guide

A CANCER DIAGNOSIS CAN transform a person's life in an instant. During this time of shock and disbelief, crucial treatment decisions must be made. Involving patients in the decision-making process is an important and welcome trend, because it incorporates their values and preferences in situations where there are no black-and-white answers as to which path is best.

This requires that the patient, family and friends be as informed as possible about the nature of the disease and the proposed care plan. Having the right tools and the ability to use them quickly and confidently can be quite a challenge, and not one that patients should have to confront alone.

The 14th edition of *CURE*[®]'s *Annual Cancer Guide for the Newly Diagnosed*, produced in partnership with eight essential patient advocacy groups, provides a framework for understanding how cancers are diagnosed and staged, and for coping with emotions that arise after a cancer diagnosis. Treatments, and their benefits and side effects, are discussed, as are the rapid evolution of targeted biologic drugs and immunotherapies, and refinements in surgical and radiation techniques.


Throughout the guide, survivors share advice on how to navigate the various phases of the cancer experience. The team of writers, editors and illustrators at *CURE*[®] magazine, along with their collaborators at the patient advocacy groups, have delivered a timely and useful handbook that offers proven guidance through a difficult time.

In this edition, we feature sections on seven specific cancer types, describing their causes, the diagnosis and treatment process, side effects of therapies and how these diseases affect the lives of patients. New among those is a section on myelofibrosis in patients who are newly diagnosed or have not been treated for it yet.

An additional article identifies barriers to cancer care for underserved populations, as well as resources available to help overcome these issues.

Further, the guide also shares updated insights on identifying genetic mutations that drive cancer and using targeted drugs to capitalize on these aberrations and kill cancer or slow its growth.

For almost 20 years, *CURE*[®] has combined science and humanity to promote learning, awareness and discourse about the challenges of cancer and the opportunities to improve options for patients and their loved ones. Quarterly and special issues of *CURE*[®] focus on specific cancer types and highlight rapidly advancing science, technology and research, accompanied by thoughts about the emotional, practical and financial aspects of cancer — all of which are interrelated.

A subscription to *CURE*[®] magazine is free for patients with cancer, survivors and caregivers, as is the rich array of information we offer at **curetoday.com**, including breaking news, videos, podcasts and blogs. In our unique way, we hope to make cancer understandable and to support patients and the loved ones who care for them through every phase of the journey. 



DEBU TRIPATHY, M.D.

Editor-in-Chief, CURE[®] Magazine

Professor of Medicine

*Chair, Department of Breast Medical Oncology
The University of Texas MD Anderson Cancer Center*

PART ONE

Understanding Cancer

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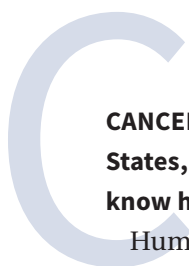


Find organizations that can teach you about your cancer type and offer disease-specific support. Visit the resources section of our Cancer Guide at curetoday.com/journey.

What Is Cancer?

Understanding cancer means knowing it's more than one disease

Adapted with permission of the American Cancer Society



CANCER AFFECTS 1 IN 3 PEOPLE in the United States, so chances are you or someone you know has been affected by the disease.

Humans are made up of trillions of cells that over a lifetime normally grow and divide as needed. When cells are abnormal or get old, they die. Cancer starts when something goes wrong in this process — the cells keep making new cells and the old or abnormal ones don't die when they should. As the cancer cells grow out of control, they can crowd out normal cells. This makes it hard for the body to work the way it should.

For many people, cancer can be treated successfully. In fact, more people than ever before lead full lives after cancer treatment.

CANCER IS MORE THAN ONE DISEASE

Cancer can develop anywhere in the body and is named for the part of the body where it started. For instance, cancer that starts in the breast is still called breast cancer even if it spreads (metastasizes) to other parts of the body.

There are two main categories of cancer:

- Hematologic (blood) cancers are cancers of the blood cells, including leukemia, lymphoma and multiple myeloma.
- Solid tumor cancers are cancers of any of the other body organs or tissues. The most common solid tumors are breast, prostate, lung and colorectal cancers.

These cancers are alike in some ways but can differ in the ways they grow, spread and respond to treatment. Some cancers grow and spread fast. Others grow more slowly. Some are more likely to spread to other parts of the body. Others stay where they started. Some types of cancer are best treated with surgery; others respond better to drugs such as chemotherapy. Often two or more treatments are used to get the best results.

WHAT IS A TUMOR?

A tumor is a lump or growth. Lumps that are not cancerous are called benign. Lumps that are cancerous are called malignant.

What makes cancer different is that it can spread to other parts of the body, whereas benign tumors do not. Cancer cells can break away from the site where the cancer started. These cells can travel to other parts of the body, ending up in the lymph nodes or other body organs and causing problems with normal functions.

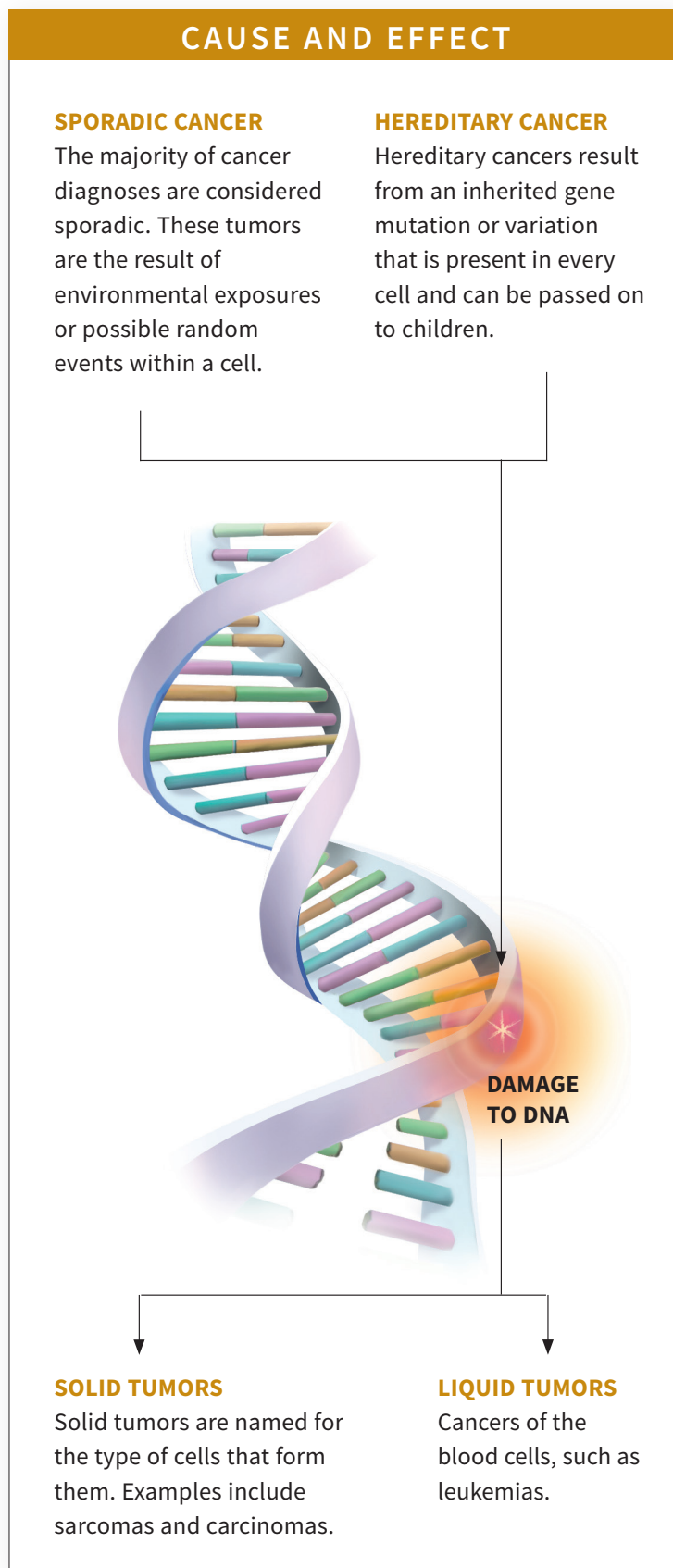
WHAT CAUSES CANCER?

Cancer cells develop because of multiple changes in their genes. These changes can have many possible causes. Lifestyle habits, genetics and being exposed to cancer-causing agents in the environment can all play a role. Many times, there is no obvious cause.

WHAT IS THE CANCER STAGE?

When a cancer is found, tests are done to see how big the cancer is and whether it has spread from where it started. This is called the cancer's stage.

A lower stage (such as a stage 1 or 2) means that the cancer has not spread very much. A higher number (such as a stage 3 or 4) means it has spread more. Stage 4 is the highest stage. »



PART 1: UNDERSTANDING CANCER

The stage of the cancer is very important in choosing the best treatment.


HOW DOES CANCER SPREAD?

Cancer may spread from where it started (the primary site) to other parts of the body.

When cancer cells break away from a tumor, they can travel to other areas of the body through either the bloodstream or the lymph system. Cancer cells can travel through the bloodstream to reach distant organs. If they travel through the lymph system, the cancer cells may end up in lymph nodes. Either way, most of the escaped cancer cells die or are killed before they can start growing somewhere else. But one or two might settle in a new area, begin to grow and form new tumors. This spread of cancer to a new part of the body is called metastasis.

In order for cancer cells to spread to new parts of the body, they have to go through several changes. They first have to become able to break away from the original tumor and then attach to the outside wall of a lymph vessel or blood vessel. Then they must move through the vessel wall to flow with the blood or lymph to a new organ or lymph node.

WHERE IS HELP AVAILABLE?

The American Cancer Society offers resources to learn more about treatment, staying healthy, support groups and more. To find this information, visit **cancer.org**, call their Cancer Helpline (**800-227-2345**) or use their online chat for one-on-one support. 

HOW TO USE

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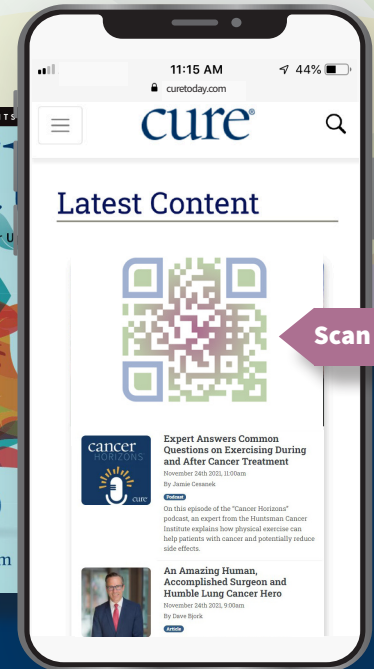
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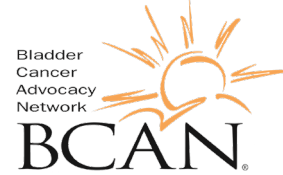
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Bladder Cancer

In collaboration with



NO ONE EXPECTS TO RECEIVE A diagnosis of bladder cancer. Many patients tell the Bladder Cancer Advocacy Network, “I had no idea you could get cancer in your bladder until my doctor told me that’s what I had.” Yet each year more than 80,000 Americans will receive that diagnosis.

WHAT IS BLADDER CANCER?

Bladder cancer is also known as urothelial carcinoma. Urothelial cells line the urinary tract, including the urethra, bladder, and ureters and renal pelvis in the kidneys. These urothelial or transitional cells are in contact with urine. Bladder cancer happens when those cells in the bladder start to grow out of control.

WHAT ARE THE RISK FACTORS?

Smoking and being exposed to secondhand smoke increases the risk of developing bladder cancer. In addition, people exposed to occupational or environmental chemicals may have a higher risk of developing bladder cancer.

White people are twice as likely to develop bladder cancer as are Black people or Hispanic people, and older age is another risk factor.

Health history also matters, with chronic bladder inflammation, such as urinary tract infections or kidney stones, as well as a personal or family history of bladder cancer, associated with risk of the disease.

Learn more about the signs, symptoms and risk factors for bladder cancer at bcan.org/bladder-cancer-signs-symptoms-risk-factors/.

WHAT ARE THE SYMPTOMS?

Many people are unaware of the common signs of bladder cancer, such as blood in the urine, known as hematuria. If blood in the urine can be seen, this is called gross hematuria. When a physician runs a urinalysis test as part of a routine checkup, tiny amounts of blood may be detected. This is microscopic hematuria. Any blood seen in the urine should be checked by a physician.

Irritation when urinating, urgency and frequency are other warning signs. These signs may also be from other causes, such as a urinary tract infection, kidney stones or aging.

HOW IS BLADDER CANCER DIAGNOSED AND STAGED?

A urologist will make a bladder cancer diagnosis. Urologists use a cystoscope to examine the lining of

the bladder and the tube that carries urine out of the body (urethra).

If bladder cancer is diagnosed, the doctor needs to know the stage, or extent, of the disease to plan the best treatment. Staging is a careful attempt to find out whether the cancer has invaded the bladder wall or spread beyond that, and, if so, to what parts of the body. Grade refers to how abnormal the cancer cells look and how many cells are multiplying. A higher grade means the cells are more uneven and are multiplying more. Knowing the grade can help your doctor predict how quickly the cancer will grow and spread.

Doctors usually describe and treat bladder cancer by how far it has grown into the bladder wall.

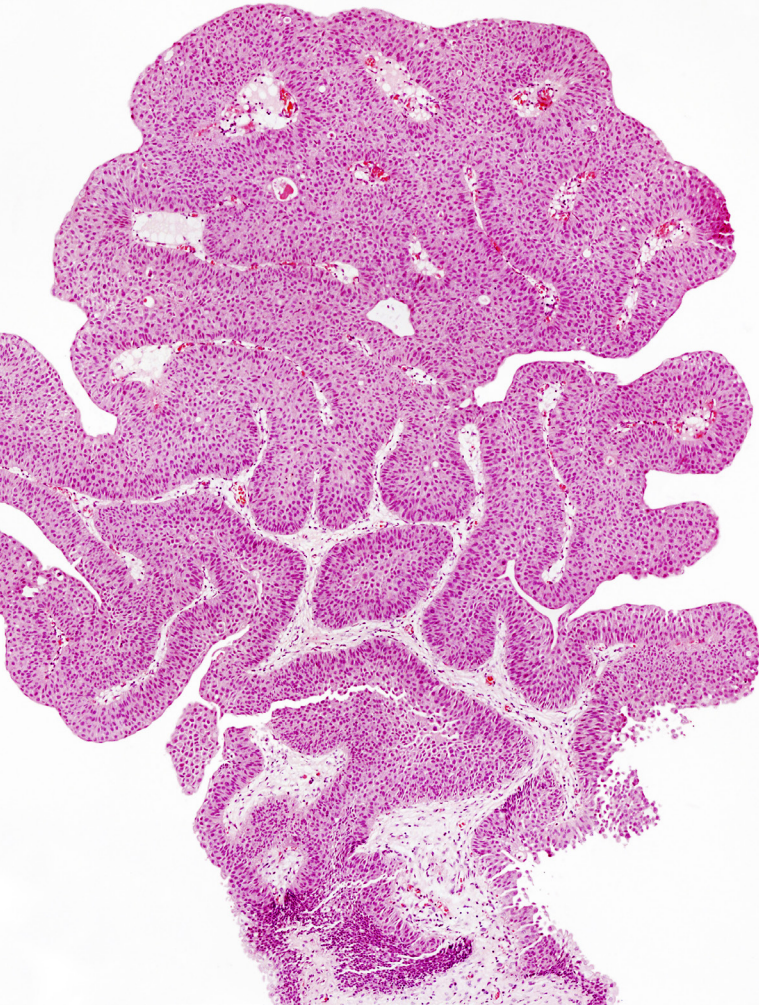
- ▶ NMIBC (non-muscle invasive bladder cancer) is cancer that remains in the urothelial cells that line the bladder.
- ▶ MIBC (muscle-invasive bladder cancer) is cancer that has grown into the deeper layers of bladder muscle.
- ▶ If bladder cancer has spread to other parts of the body outside the urinary tract, it is advanced disease, or metastatic.

HOW IS BLADDER CANCER TREATED?

When bladder cancer is classified as NMIBC, surgery to remove the tumor is often the first step. A transurethral resection of the bladder tumor uses a special instrument inserted through the urethra to remove the tumor. If the tumor is low risk/grade and has not invaded the muscle wall of the bladder, it may not require more treatment. Unfortunately, bladder cancer has a high rate of recurrence so most of those who receive diagnoses must return to their urologist at regular intervals for surveillance using cystoscopy to see if the tumors return.

If the tumor cells appear aggressive under the microscope and the pathologist determines that the cancer is high risk/grade, it is more likely to return or worsen. In these cases, further treatment to keep the cancer from returning or worsening is required. Most often, patients with high-grade NMIBC receive intravesical (inside the bladder) treatments. Bacillus Calmette-Guérin (BCG) is an early form of immunotherapy that uses a weakened form of bacteria. When these bacteria are put into the bladder, the immune system goes on alert. It responds by killing cancer cells on the bladder lining. Though BCG is very effective, »

📖 This is how a bladder tumor appears under a microscope.



it doesn't work for all tumors. If BCG doesn't work, there are other options such as mitomycin C, an antibiotic that helps fight tumors.

When bladder cancer grows into the deeper layers of the bladder (MIBC), it is more difficult to treat. In many cases, a urologist may suggest radical cystectomy, which is surgery to remove your bladder. Removing the bladder also involves removing lymph nodes around the organ. As part of the surgery, it will be necessary to create a urinary diversion, a new way for urine to leave your body.

Systemic chemotherapy is medicine that treats cancer throughout the whole body. Neoadjuvant chemotherapy is chemotherapy patients get before bladder removal surgery. Clinical trials have shown that cisplatin chemotherapy before bladder removal improves survival for patients with MIBC because it helps kill bladder cancer cells that may be outside the bladder. Adjuvant chemotherapy is the chemotherapy patients get after surgery.

Recently approved targeted therapies can block the growth and spread of cancer. They focus on stopping the cancer-driving activity caused by specific genetic mutations that are found in some bladder cancers.

Some patients may benefit from combined modality therapy, which uses surgery to remove the tumor, plus chemotherapy and radiation to help kill the cancer while keeping the bladder intact. This option can be used for some patients who are ineligible for bladder removal surgery. Those with advanced or metastatic disease may benefit from chemotherapy and a variety of immunotherapies that can help the body fight off the cancer.

There are many talented researchers and clinicians working to improve the diagnosis and treatment of the disease. Clinical trials are an essential part of bladder cancer research. They may provide treatment alternatives to patients who have not had success with standard and approved therapies. To learn more and find a trial, visit clinicaltrials.bcan.org.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

Every treatment for bladder cancer has potential side effects. Some, such as systemic chemotherapy, are well known because they are similar across all cancers (hair loss, nausea, fatigue and infections). Others are related to surgeries (bleeding, catheterization and continence issues). The newer immunotherapy treatments approved for bladder cancer can offer great promise to patients, but side effects such as diarrhea or nausea can be signs of life-threatening reactions when using these drugs. All these possibilities should be discussed with the medical team and considered carefully before treatment options are selected.

HOW DOES BLADDER CANCER AFFECT A PATIENT'S LIFE?

Bladder cancer has a high rate of recurrence, which implies the need for regular surveillance with cystoscopy over the course of a patient's lifetime. For some patients, the new normal after bladder removal surgery is adjusting to life with a urinary diversion. A patient should always feel comfortable talking with their health care team about any issues or questions. If the team can't help, they can usually find someone who can.

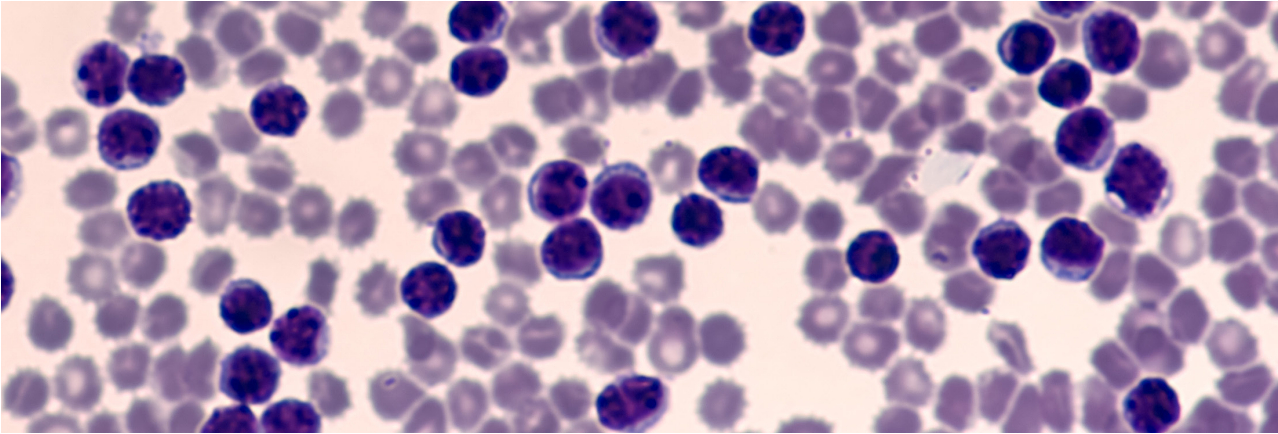
WHERE IS HELP AVAILABLE?

To learn more, visit BCAN.org. You can receive a free print or electronic copy of the Bladder Cancer Advocacy Network's Bladder Cancer Basics and its Tips for Caregivers by visiting bcan.org/handbook or calling 888-901-2226. And don't forget to visit *CURE*'s resources guide at curetoday.com/journey to learn about additional help that is available. 📖

Chronic Lymphocytic Leukemia

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➤ Most patients with chronic lymphocytic leukemia can be treated with a watch-and-wait strategy.

CHRONIC LYMPHOCYTIC LEUKEMIA (CLL) is the most common leukemia in adults and has been the focus of headlines over the past few years because of enormous progress in its treatment. In 2015, the American Society of Clinical Oncology recognized these developments as its Cancer Advance of the Year. Four targeted drugs had been approved, giving patients with CLL treatments that are more effective and produced fewer side effects than older therapies.

Those improvements introduced meaningful options for older patients who likely could not have withstood the harsher regimens of the past. They also made it more possible to treat CLL long term as a chronic condition.

But what exactly is CLL? What are the warning signs, and who should be on the lookout for them?

WHAT IS CLL?

CLL originates in the bone marrow where cells form blood. This causes blood cells to produce B lymphocytes, a type of white blood cells that are not normal, healthy or able to effectively fight infection. These leukemia cells may look basically normal under a microscope, but they may reproduce too rapidly, survive longer than normal cells and crowd out healthy white blood cells. CLL cells may also grow in the lymph nodes and the spleen. Eventually, the cancerous cells may spill into the bloodstream and reach a threshold that defines the patient as having CLL, though it may be years before any symptoms arise.

Each year, approximately 21,000 people receive a diagnosis of CLL and approximately 4,500 die from the disease. The average risk of developing CLL is approximately 1 in 175. Scientists are not certain what causes the disease but have identified some risk factors. People over age 50 have a higher likelihood of developing CLL and so do those people who have had significant exposure to the herbicide Agent Orange. People with a family history of the disease among first-degree relatives, people living in North America and Europe compared with those in Asia and men in general all are also at higher risk.

However, screening for the disease is not recommended because most cases are random without any clear risk factor. Also, most patients receive diagnoses of early- to intermediate-stage CLL and can be treated with a watch-and-wait strategy.

WHAT ARE THE SYMPTOMS?

Among people with CLL, 80% have no symptoms when they receive their diagnosis. Typically, the disease is found when a blood test ordered for an unrelated health condition or a routine checkup reveals a high number of lymphocytes. In CLL, the overall white blood cell count also may be elevated.

It doesn't happen often, but patients sometimes detect CLL themselves. They may notice enlarged lymph nodes, which feel like lumps, typically in the neck or above the »

collarbone, or in the armpits or groin. As the disease progresses, other symptoms may emerge: fatigue, weight loss, chills, unexplained fever, night sweats and bleeding or bruising easily, as well as an enlarged spleen or liver that causes gastrointestinal symptoms and increased risk of infections. Those symptoms warrant a visit to a doctor. Any lymph node that reaches a width of two fingers or more should be evaluated if it persists. An enlarged node may accompany a cold or the flu, so it's reasonable to wait until the illness resolves to see if the node shrinks to its normal size.

HOW IS CLL DIAGNOSED AND STAGED?

Unlike most leukemias, CLL does not require a bone marrow aspiration for diagnosis; rather, a doctor can check for the disease via blood tests. CT scans are also usually not needed at time of diagnosis.

Doctors determine how advanced the disease is by using a staging system based on the presence of any enlarged lymph nodes in addition to lymphocytes; an enlarged liver or spleen; low hemoglobin, also known as anemia; or a low count of platelets, blood cells that help form clots to stop bleeding.

That assessment doesn't reveal everything doctors need to know, however. Approximately 30% of patients will never need treatment for their CLL; to differentiate, doctors conduct prognostic tests on leukemia cells circulating in the blood. Chromosome analysis and other blood tests can suggest the likelihood of disease progression in the near future because certain chromosome abnormalities in CLL cells are known to be favorable for slow-moving disease and some for the opposite.

Genetic tests may be used to look for a mutated immunoglobulin gene, present in 50% of patients with CLL, which indicates that the disease will progress more slowly. Testing for mutations of TP53 is recommended before any treatment because it can help determine which therapies are the most appropriate.

HOW IS CLL TREATED?

Treatment for CLL typically includes single drugs or combinations of medications. The many possible options include oral targeted drugs (kinase inhibitors and BCL-2 blockers) and chemoimmunotherapy, in which an intravenous monoclonal antibody is given with chemotherapy. Experimental drugs or novel combinations of new and old drugs, given in clinical trials, or "off label," may be a good option.

Patients who have experienced disease progression while taking other lines of therapy might consider a stem cell transplant.

In some very rare circumstances, the spleen or lymph nodes become so enlarged that treatment with radiation or surgery might be warranted.

All drugs can have side effects, and each drug in each class has a different side effect profile.

BTK (Bruton tyrosine kinase) inhibitors are oral targeted therapies that have revolutionized the care of CLL. Their side effects may include low white blood cell counts, increased risk of infection, bleeding, musculoskeletal pain, hypertension, mouth sores, nausea, rash and headaches. PI3K inhibitors may cause diarrhea, liver inflammation, colitis, lung inflammation and infections, rash and low white blood cell counts. When first started, BCL-2 blockers can cause tumor lysis syndrome by killing the cancer so quickly that the body can't cope, and this can later cause low blood counts, pneumonia and other infections. Monoclonal antibodies can cause reactions at the time of the infusions, plus diarrhea, nausea, constipation, fatigue, shortness of breath, increased risk of new or reactivated infections such as hepatitis B and a drop in blood counts. Chemotherapy for CLL may be associated with bone marrow, nerve, heart or bladder damage, low blood counts, hair loss, nausea and increased risk of second cancers.


HOW DOES CLL AFFECT A PATIENT'S LIFE?

Even in the early stage of disease, patients with CLL have diminished immune systems. It's important for them to alert their care team if they believe they're getting an infection, even if it's just a cold. Patients with CLL have a high rate of hospitalization and even death from COVID-19 infections and should follow all the guidelines to minimize their risk. Vaccinations should be reviewed and updated, but patients should receive no live vaccines. Also, age- and sex-appropriate cancer screening is recommended as patients are at higher risk of a second cancer, especially skin cancers.

With attention to these kinds of details and the new therapies available for advanced CLL, it is now possible for some with the disease to achieve an average life span. In fact, new treatments and better understanding of the biology of the disease are improving outcomes for nearly all patients with CLL, regardless of their age or risk factors.

WHERE IS HELP AVAILABLE?

For more help understanding CLL, navigating treatment decisions including clinical trials, information about support groups and financial program and more, contact The Leukemia & Lymphoma Society for free one-on-one support. An information specialist is available by phone at **800-955-4572**, online chat (www.lls.org/support-resources/information-specialists) or by email (www.lls.org/form/contact-us). A full list of support services can be found at www.lls.org/support-resources.

And don't forget to visit CURE's resources guide at curetoday.com/journey to learn about additional help that is available. 



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CLL=chronic lymphocytic leukemia; SLL=small lymphocytic lymphoma.

Select Safety Information

CALQUENCE is a prescription oral treatment for adults with chronic lymphocytic leukemia or small lymphocytic lymphoma. May cause serious side effects including: serious infections, bleeding problems, decrease in blood cell count, new cancers, and heart rhythm problems. Some may lead to death. Tell your doctor if you experience infections such as flu-like symptoms; unexpected bleeding such as blood in your stool or urine; or heart rhythm problems such as fast or irregular heartbeat. Use sun protection when outside.

If you cannot afford your medication, AstraZeneca may be able to help. Visit [AstraZeneca-us.com](https://www.astrazeneca-us.com) to find out how.

Please see Brief Summary of Prescribing Information on adjacent pages.

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CALQUENCE[®]
(acalabrutinib) 100 mg capsules

PATIENT INFORMATION

CALQUENCE® (KAL-kwens) (acalabrutinib) capsules


CALQUENCE
(acalabrutinib) 100 mg capsules

What is CALQUENCE?

CALQUENCE is a prescription medicine used to treat adults with:

- Chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).

It is not known if CALQUENCE is safe and effective in children.

Before taking CALQUENCE, tell your healthcare provider about all of your medical conditions, including if you:

- have had recent surgery or plan to have surgery. Your healthcare provider may stop CALQUENCE for any planned medical, surgical, or dental procedure.
- have bleeding problems.
- have or had heart rhythm problems.
- have an infection.
- have or had liver problems, including hepatitis B virus (HBV) infection.
- are pregnant or plan to become pregnant. CALQUENCE may harm your unborn baby and problems during childbirth (dystocia).
 - If you are able to become pregnant, your healthcare provider may do a pregnancy test before you start treatment with CALQUENCE
 - Females who are able to become pregnant should use effective birth control (contraception) during treatment with CALQUENCE and for at least 1 week after the last dose of CALQUENCE.
- are breastfeeding or plan to breastfeed. It is not known if CALQUENCE passes into your breast milk. Do not breastfeed during treatment with CALQUENCE and for at least 2 weeks after your final dose of CALQUENCE.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking CALQUENCE with certain other medications may affect how CALQUENCE works and can cause side effects. Especially tell your healthcare provider if you take a blood thinner medicine.

How should I take CALQUENCE?

- Take CALQUENCE exactly as your healthcare provider tells you to take it.
- Do not change your dose or stop taking CALQUENCE unless your healthcare provider tells you to.
- Your healthcare provider may tell you to decrease your dose, temporarily stop, or completely stop taking CALQUENCE if you develop certain side effects.
- Take CALQUENCE 2 times a day (about 12 hours apart).

(continued)

- Take CALQUENCE with or without food.
- Swallow CALQUENCE capsules whole with a glass of water. Do not open, break, or chew capsules.
- If you need to take an antacid medicine, take it either 2 hours before or 2 hours after you take CALQUENCE.
- If you need to take certain other medicines called acid reducers (H-2 receptor blockers), take CALQUENCE 2 hours before the acid reducer medicine.
- If you miss a dose of CALQUENCE, take it as soon as you remember. If it is more than 3 hours past your usual dosing time, skip the missed dose and take your next dose of CALQUENCE at your regularly scheduled time. Do not take an extra dose to make up for a missed dose.

What are the possible side effects of CALQUENCE?

CALQUENCE may cause serious side effects, including:

- **Serious infections** can happen during treatment with CALQUENCE and may lead to death. Your healthcare provider may prescribe certain medicines if you have an increased risk of getting infections. Tell your healthcare provider right away if you have any signs or symptoms of an infection, including fever, chills, or flu-like symptoms.
- **Bleeding problems (hemorrhage)** can happen during treatment with CALQUENCE and can be serious and may lead to death. Your risk of bleeding may increase if you are also taking a blood thinner medicine. Tell your healthcare provider if you have any signs or symptoms of bleeding, including:
 - blood in your stools or black stools (looks like tar)
 - pink or brown urine
 - unexpected bleeding, or bleeding that is severe or you cannot control
 - vomit blood or vomit that looks like coffee grounds
 - cough up blood or blood clots
 - dizziness
 - weakness
 - confusion
 - changes in your speech
 - headache that lasts a long time
 - bruising or red or purple skin marks
- **Decrease in blood cell counts.** Decreased blood counts (white blood cells, platelets, and red blood cells) are common with CALQUENCE, but can also be severe. Your healthcare provider should do blood tests to check your blood counts regularly during treatment with CALQUENCE.

(continued)

- **Second primary cancers.** New cancers have happened in people during treatment with CALQUENCE, including cancers of the skin or other organs. Your healthcare provider will check you for skin cancers during treatment with CALQUENCE. Use sun protection when you are outside in sunlight.
- **Heart rhythm problems (atrial fibrillation and atrial flutter)** have happened in people treated with CALQUENCE. Tell your healthcare provider if you have any of the following signs or symptoms:
 - fast or irregular heartbeat
 - dizziness
 - feeling faint
 - chest discomfort
 - shortness of breath

The most common side effects of CALQUENCE include:

- headache
- diarrhea
- muscle and joint pain
- upper respiratory tract infection
- bruising

These are not all of the possible side effects of CALQUENCE.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store CALQUENCE?

- Store CALQUENCE at room temperature between 68°F to 77°F (20°C to 25°C).

Keep CALQUENCE and all medicines out of the reach of children.

General information about the safe and effective use of CALQUENCE.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use CALQUENCE for a condition for which it was not prescribed. Do not give CALQUENCE to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for more information about CALQUENCE that is written for health professionals.

What are the ingredients in CALQUENCE?

Active ingredient: acalabrutinib

Inactive ingredients: silicified microcrystalline cellulose, pregelatinized starch, magnesium stearate, and sodium starch glycolate.

Capsule shell contains: gelatin, titanium dioxide, yellow iron oxide, FD&C Blue 2, and black ink.

For more information, go to www.CALQUENCE.com or call 1-800-236-9933.

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US-34063 11/19

AstraZeneca 

Lung Cancer

In collaboration with



LUNG CANCER IS THE LEADING CAUSE of cancer death among men and women. Tobacco is the biggest risk factor for lung cancer, but approximately 20% of people who receive a diagnosis have never smoked or used any other form of tobacco.

Many new therapies, including targeted drugs and immunotherapies, have been approved in recent years to treat lung cancer, improving outcomes for many with the disease.

WHAT IS LUNG CANCER?

Lung cancer occurs when cells inside the lungs grow out of control.

The cancer can start in the bronchi, the tubes that allow air to move from the trachea into the lungs; bronchioles, the tiny tubes that carry air farther inside the lungs; or alveoli, the air sacs within the lungs.

There are two types of lung cancer: non-small cell and small cell.

Non-small cell lung cancer, by far the most common type, is divided into three subtypes.

- ▶ Adenocarcinoma starts in the cells that secrete substances such as mucus. Although it occurs mainly in people who have smoked, it's also the most common kind of lung cancer in people who never smoked. It is found in the outer part of the lungs and most likely to be discovered before it has spread.
- ▶ Squamous cell carcinoma occurs in the center of the lungs in cells that line the inside of the airway and is often linked with a history of smoking.
- ▶ Large cell, or undifferentiated, lung cancer can appear anywhere in the lungs and tends to grow and spread aggressively.

Small cell lung cancer tends to grow and spread faster than non-small cell lung cancer. More treatments are available for non-small cell lung cancer than for small cell lung cancer.

WHAT ARE THE RISK FACTORS?

Smoking is the leading risk factor for lung cancer. Others include secondhand smoke; exposure to radon, asbestos or workplace chemicals; radiation therapy to the lungs; air pollution; and a personal or family history of lung cancer.

WHAT ARE THE SYMPTOMS?

Lung cancer often causes no symptoms until it has grown past the early stage. Symptoms can include a persistent,

worsening cough that may bring up blood; chest pain, especially with deep breathing or laughing; hoarseness; loss of appetite; shortness of breath; fatigue; wheezing; and bronchitis or pneumonia.

Lung cancer that spreads to other parts of the body can cause bone pain, such as in the back or hips; nervous system changes such as headache, dizziness or seizures; yellowed skin or eyes; or swollen lymph nodes.

HOW IS LUNG CANCER DIAGNOSED AND STAGED?

Most lung cancers are found because a patient has symptoms, although some are detected through screening. Health insurers will cover periodic screening via low-dose CT scan for people with a history of heavy smoking. Screening can reveal lung cancers when they are still too small to cause symptoms and are more likely to be curable. If lung cancer is caught before it spreads, the likelihood of surviving five years increases to 60%.

Although only low-dose CT scans are recommended to screen for lung cancer, doctors who suspect lung cancer can use a chest X-ray, MRI, positron emission tomography scan or bone scan, which uses radioactive material to pinpoint abnormal areas.

If any of those points to lung cancer, pathologists can look at the cells to determine whether they are cancerous. The cells can be from mucus coughed up from the lungs, fluid removed from the area around the lungs, or a needle or surgical biopsy of lung tissue.

If cancer is present, determining whether it has spread past the lungs can be revealed through additional tests: ultrasound of the lymph nodes; mediastinoscopy or mediastinotomy, which checks between the lungs; and thoracoscopy, which checks the spaces between the lungs and chest wall.

Patients with lung cancer should request that their treating physician conduct comprehensive biomarker, or genomic, testing of their tumor tissue, which can help determine which treatments are likely to be most effective. Genomic testing looks for altered genes that drive cancer and can be treated with targeted therapies. There are approved targeted therapies for alterations in these genes: EGFR, ALK, ROS1, RET, NTRK, MET and BRAF. Testing may also look for gene alterations that do not have approved therapies but have drugs being tested in clinical trials. Comprehensive biomarker testing includes looking at levels of certain proteins called PD-1 and PD-L1, which may influence whether a patient should receive immunotherapy. »

Non-small cell lung cancer is divided into stages from 0, the least advanced, through 4, the most advanced. Small cell lung cancer is divided into two stages: limited and extensive.

HOW IS LUNG CANCER TREATED?

Non-Small Cell Lung Cancer

For early-stage disease, surgically removing part of the lung may be the only treatment needed. Surgery may be followed by chemotherapy and/or radiation.

Treatment for stage 2 non-small cell lung cancer entails surgical removal of part or all of the affected lung and any cancerous lymph nodes followed by chemotherapy to kill any remaining cancer.

The mainstays of stage 3 treatment are chemotherapy and radiation given together, sometimes followed by surgery if the cancer can be removed, and then more chemotherapy and radiation. If the cancer has grown too much to be completely removed by surgery, chemotherapy and radiation alone may control or even cure it. These treatments may be followed by immunotherapy to help keep the disease stable.

Stage 4 non-small cell lung cancer has spread extensively and is difficult to cure. The goal of treatment is to prolong life and increase physical comfort. Therapies are selected based on the number of tumors and their location. The same treatments used in earlier stages, plus targeted therapies and immunotherapies, can be considered depending on the results of tests on the tumor cells. Some of these newer biological therapies can extend lives.

Small Cell Lung Cancer

Chemotherapy and radiation therapy to the chest are typical treatments; sometimes surgery is performed first, but it is not possible in many cases.

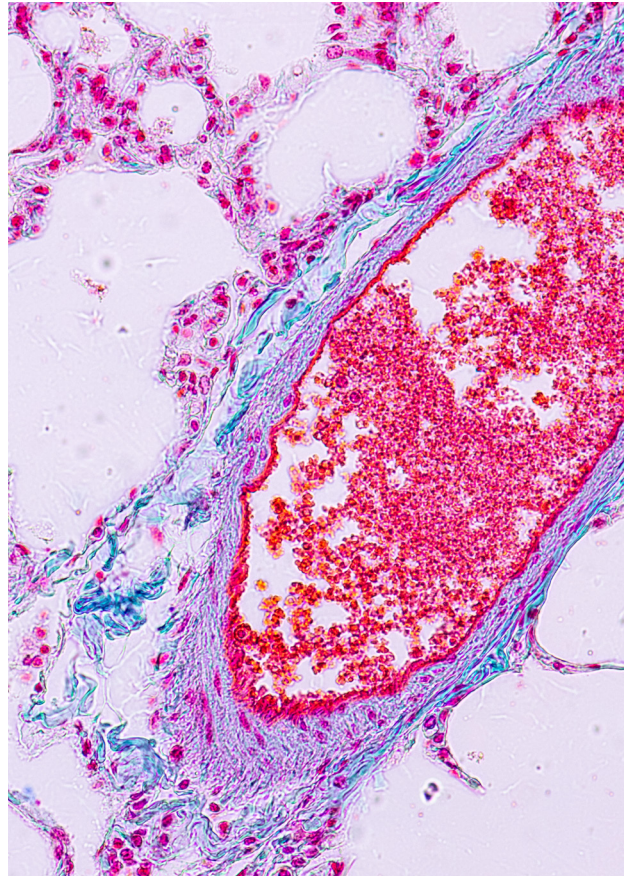
Radiation therapy to the head may be used to help prevent the cancer's spread to the brain.

If the cancer is extensive, chemotherapy plus immunotherapy is usually the first treatment. This may be followed with radiation to the chest and brain.

Clinical trials of new treatments can be considered for either limited or extensive small cell lung cancers, which may shrink significantly with standard therapy but have a high likelihood of recurring.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

Side effects of surgery can include pain, cough, fatigue and difficulty breathing. Chemotherapy can cause low blood counts that can lead to infection, nausea, diarrhea, hair loss, fatigue, mouth sores and numbness or tingling in the extremities. Those who receive radiation may experience mild skin reactions, nausea, fatigue or sore throat.




➤ A diagnosis of lung cancer before it spreads can increase the likelihood of five-year survival to 60%.

Targeted drugs can cause high blood pressure, bleeding, headaches, mouth sores, diarrhea, skin problems, constipation, vision changes and dizziness. Immunotherapy can cause fatigue, nausea, cough, itching, joint pain, constipation and diarrhea. A palliative care specialist can help patients with lung cancer manage side effects at all stages.

HOW DOES LUNG CANCER AFFECT A PATIENT'S LIFE?

Lung cancer stigma can affect patients who are seeking support. Symptoms from the disease or side effects that arise from treatment can affect quality of life, so patients should talk with their providers about the importance of emotional and physical support during this time.

WHERE IS HELP AVAILABLE?

The American Lung Association (lung.org/lung-cancer, 800-586-4872) offers information about lung cancer, online support communities, initiatives to raise awareness and funding, and more. Visit lung.org/lung-cancer to learn more. And don't forget to visit CURE's resources guide at curetoday.com/journey to learn about additional help that is available. 

Ovarian Cancer

In collaboration with



OVARIAN CANCER IS DIFFICULT to diagnose early. There is no good screening method for detecting it, and its symptoms often mirror those of a normal menstrual cycle or other conditions such as irritable bowel syndrome. Most women with ovarian cancer receive the diagnosis after their disease has reached advanced stages. But just one in 78 women will get ovarian cancer, making it a rare disease.

WHAT IS OVARIAN CANCER?

Cancer arises when cells begin to grow out of control. Historically, ovarian cancer was thought to begin in the ovaries, but it is now known that most cases of ovarian cancer begin in the fallopian tube.

Three types of cells can lead to separate subtypes of ovarian cancer: epithelial, germ cell and stromal. Up to 90% of ovarian cancers are epithelial, which has four subtypes: serous carcinoma (the most common), clear cell carcinoma, mucinous carcinoma and endometrioid carcinoma.

WHAT ARE THE RISK FACTORS?

Being postmenopausal is a risk factor for ovarian cancer, as is older age. Having a first full-term pregnancy after age 35 or never carrying a pregnancy to term is also associated with a higher risk. Taking estrogen without also taking progesterone for five to 10 years after menopause can also raise risk.

Family history is another important factor. Women with family members who have ovarian, breast, colorectal or certain other cancers, as well as women who have a personal history of breast cancer, may be at higher risk of ovarian cancer. Women who have inherited mutations in specific genes, including BRCA1, BRCA2, BRIP1, RAD51C/D or the Lynch syndrome genes, are at higher risk for ovarian cancer.

Although some women have an inherited risk of ovarian cancer, most ovarian cancers are due to mutations in ovarian, fallopian or peritoneal cells that a woman acquires during her lifetime. The causes of acquired mutations associated with ovarian cancer remain unknown; they may occur by chance over a woman's lifetime. Study results are not clear about the role of other factors, such as being obese or using *in vitro* fertilization drugs, as potential contributors to the development of ovarian cancer. Breastfeeding and using birth control pills can lower the risk of ovarian cancer.

WHAT ARE THE SYMPTOMS?

The most common symptoms of ovarian cancer are bloating, pelvic or abdominal pain, feeling full quickly when

eating and having to urinate more urgently or more often. Other symptoms include fatigue, back pain, pain during sex, upset stomach, constipation, changes to bleeding during the menstrual period and belly swelling accompanied by weight loss. In many cases, these symptoms do not indicate ovarian cancer. However, if you have any of these symptoms, it is important to get them checked out by a doctor if they are a change from your normal experience or occur more than 12 times in a month.

HOW IS OVARIAN CANCER DIAGNOSED AND STAGED?

No screening test for ovarian cancer is considered accurate enough to use on the general population.

A manual pelvic exam can reveal several health problems but is likely to miss many ovarian cancers.

Those at high risk of ovarian cancer may be screened with transvaginal ultrasound, which can find a mass in the pelvis but not determine whether it is cancerous. A blood test for elevated levels of the cancer antigen (CA)-125, a protein, is useful in women known to have ovarian cancer but is not an accurate way to diagnose the disease. High CA-125 levels can occur in people who have conditions unrelated to ovarian cancer, and tests for this antigen can miss people with ovarian cancer who don't express a lot of this protein.

If screening or symptoms suggest ovarian cancer, a doctor will use imaging to look for a tumor. This can include CT, MRI or positron emission tomography scans or laparoscopy, in which a thin, lighted tube is threaded through a small abdominal incision to send images of the ovaries and other pelvic organs to a video monitor.

If a mass is found, a piece will need to be removed (biopsied), usually surgically, and then analyzed in a lab. If ovarian cancer is present, it will be given a stage ranging from 1 (indicating that the cancer hasn't spread beyond the site of origin) to 4 (indicating that it has spread to distant parts of the body). These cancers are also assigned a grade of 1 through 3 or classified as low grade or high grade to indicate how different from normal the cancer cells are. High-grade cancers are more likely to grow quickly and spread.

A patient who receives a diagnosis of ovarian cancer should undergo genetic testing using blood or saliva to find out if an inherited gene mutation is the cause of the disease. This information can help guide treatment, alert a woman that she should be screened for additional cancers and make family members aware that they might also have an inherited predisposition to cancer. »

HOW IS OVARIAN CANCER TREATED?

Most ovarian cancers are treated the same way regardless of stage: surgery followed by chemotherapy. Stromal tumors are treated with surgery followed by chemotherapy or hormone therapy.

In most cases, the surgery removes the tumor, or as much of it as possible, plus the uterus, fallopian tubes and ovaries. Chemotherapy is sometimes given directly into the abdominal cavity rather than by infusion into the bloodstream through an arm.

If a woman isn't well enough to undergo surgery, she may get chemotherapy first and then have surgery when she is able. In some cases, if the cancer has spread far beyond the ovary — for instance, to the liver — chemotherapy may be given before surgery to shrink the cancer and make surgery easier.

In later-stage disease, surgery may involve removing the lining and boundary tissues from inside the upper abdomen, as well as parts of the intestines, liver, bladder or gallbladder.

Maintenance Therapy for Ovarian Cancer

Maintenance therapy is a type of treatment given after chemotherapy has been completed to try to keep the cancer from returning. The goal of maintenance therapy is to extend the length of time before the cancer returns or even to turn a temporary remission into a long-term cure.

Two types of drugs — poly adenosine diphosphate-ribose polymerase (PARP) inhibitors and the targeted drug Avastin (bevacizumab) — have been approved by the Food and Drug Administration for use as maintenance therapies in women with advanced ovarian, fallopian tube and primary peritoneal cancer if they have an inherited or tumor mutation in BRCA1 or BRCA2 or if the ovarian cancer has a tumor feature called homologous recombination repair deficiency. A relatively new type of ovarian cancer treatment, PARP inhibitors are oral drugs that block the PARP enzyme, which cells use to repair DNA damage. Clinical trials of other PARP inhibitors or new therapies may also be an option for some patients.

Treatment for Other Types of Ovarian Cancers

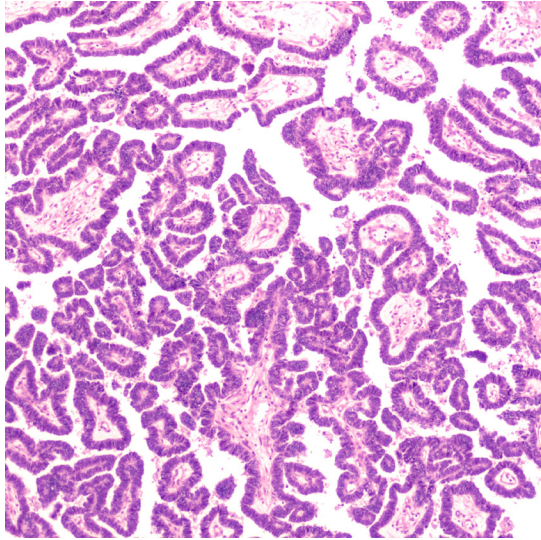
Germ cell tumors are also treated with surgery followed by chemotherapy. Stromal tumors are treated with surgery followed by chemotherapy or hormone therapy.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

Women who were not in menopause before surgery for ovarian cancer will experience it afterward, which can bring on symptoms such as hot flashes, sweats, fatigue and skin and vaginal dryness. There are treatments available to alleviate some of these symptoms. Younger women also may experience distress over their loss of fertility following surgery.

Some women whose lymph nodes were removed may experience lymphedema, a pooling of fluid in nearby parts of the body.

Chemotherapy for ovarian cancer can cause hair loss, nausea and vomiting, diarrhea and/or constipation, and tingling or weakness in the extremities. It can also result in fatigue, a feeling of brain fog and low blood counts that can lead to infection. PARP inhibitors can cause fatigue, nausea and low blood counts.



➤ Most patients with ovarian cancer are treated with surgery then chemotherapy regardless of stage.


HOW DOES OVARIAN CANCER AFFECT A PATIENT'S LIFE?

Patients with ovarian cancer

that has spread to other parts of the body can experience remission after treatment but are likely to face a recurrence that requires additional therapy. This can cause worry and disappointment. Women who were not in menopause before surgery will experience it afterward, which can be a big adjustment.

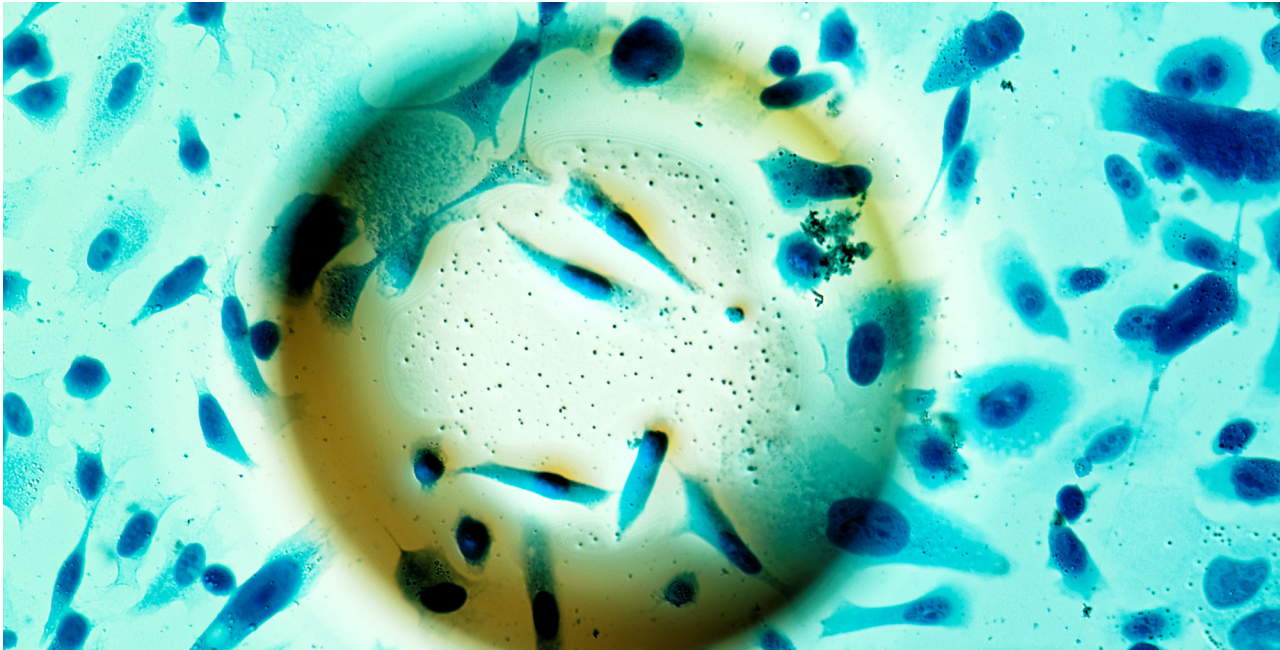
If a woman finds out that her disease stems from an inherited gene mutation, it could mean she is predisposed to other kinds of cancer and should consider more frequent screenings or preventive treatment, such as lifestyle changes, medicine or surgery. Patients with inherited predispositions to cancer are encouraged to share that information with family members so they can seek genetic testing and counseling.

WHERE IS HELP AVAILABLE?

Facing Our Risk of Cancer Empowered (FORCE) is a non-profit organization dedicated to improving the lives of people affected by inherited cancers. It offers a wealth of information about hereditary cancers, a search engine to help patients find clinical trials, and support services including personalized guidance and a help line (facingourrisk.org; 866-288-7475). And don't forget to visit CURE's resources guide at curetoday.com/journey to learn about additional help that is available. 

Prostate Cancer

In collaboration with



⤴ Treating prostate cancer depends on a patient's risk and preferences.

AFFECTING ONE IN EIGHT MEN, prostate cancer is the most common cancer in men after skin cancer.

In many cases, prostate cancer grows relatively slowly, often taking years to become large enough to be detectable and even longer to spread outside the prostate. Some cases are more aggressive and need more urgent treatment. Fortunately, there are many treatment options for all stages of the disease.

WHAT IS PROSTATE CANCER?

Prostate cancer starts in the prostate, a small gland located below the bladder that is responsible for secreting one of the components of semen. Prostate cells may grow out of control and become cancerous when stimulated by male hormones, including testosterone.

WHAT ARE THE RISK FACTORS?

Men who are older, are Black, have a family history of the disease or have certain inherited genes are at higher risk for prostate cancer. Lifestyle matters, too: Smoking increases the risk of fatal prostate cancer and excess body weight increases the risk of aggressive and fatal prostate cancer.

WHAT ARE THE SYMPTOMS?

Prostate cancer rarely causes symptoms. When it does, symptoms can include frequent urination or other urinary issues, problems with erection or ejaculation, weakness or numbness in the legs and feet and pressure or pain in the rectum or pelvis. Because symptoms are uncommon, it's important that men make a prostate cancer screening plan with their doctor.

HOW IS PROSTATE CANCER DIAGNOSED AND STAGED?

The prostate-specific antigen (PSA) blood test and digital rectal exam (DRE) can be used to detect prostate cancer when no symptoms are present. They may catch the disease at an early stage when treatment may be more effective and potentially have fewer side effects. Average-risk men should talk to their doctor about PSA screening at 45; Black men and those with a strong family history of prostate or other cancers should have this discussion at 40.

If the PSA is elevated, a doctor may order an MRI or other tests. A needle biopsy — commonly done through the rectum, or, increasingly, through the perineum — is needed to establish the diagnosis. If cancer is detected, doctors assess its stage using five important pieces of information: »

- ▶ How much and how quickly PSA rises over time.
- ▶ How aggressive the cancer cells look under a microscope, expressed as a Gleason score (range of 6-10; 10 is the most abnormal) or a Grade Group score (range of 1-5).
- ▶ Number of biopsy cores, or samples, with cancer.
- ▶ Whether the cancer cells are limited to inside the prostate or have spread into the neighboring pelvic areas.
- ▶ Whether the cancer has invaded lymph nodes and/or spread to more distant parts of the body.

Localized and locally advanced prostate cancer (cancer that is in the prostate or the region around it) is assigned a risk group ranging from very low to very high based on these criteria. Doctors may recommend patients with high-risk or metastatic cancer may receive a recommendation to have additional testing of their tumor for gene mutations (e.g., alterations to BRCA1 or BRCA2), as well as genetic testing for inherited cancer risk.

HOW IS PROSTATE CANCER TREATED?

There is no single approach to treating prostate cancer. Treatment options depend upon the risk group and patient factors and preferences.

A patient who receives a diagnosis of localized or locally advanced prostate cancer has three primary treatment options:

- ▶ **Active surveillance:** Follow the cancer closely with regularly scheduled PSA checks, DREs, MRIs and biopsies so that definitive treatment is administered only if and when necessary. This is an option for patients with low-risk disease and for select patients with intermediate-risk prostate cancer.
- ▶ **Surgery:** Remove the entire prostate gland and seminal vesicles (radical prostatectomy). This is an option for men with intermediate- or high-risk cancer that has not spread.
- ▶ **Radiation therapy:** Precisely kill cancer cells with ionizing radiation. As with surgery, it is very effective for localized or locally advanced prostate cancer and has the same cure rate as surgery.

For men with more-aggressive disease, certain treatment combinations may be recommended. Hormone therapy may be added. Also known as androgen deprivation therapy (ADT), this medication stops testosterone from being produced or directly blocks it from acting on prostate cancer cells.

In some cases, at initial diagnosis, prostate cancer is already aggressive and is metastatic, meaning it has spread outside the prostate. Furthermore, in men who already have been treated for prostate cancer, it can recur. Fortunately, men with advanced prostate cancer have several treatment options, including ADT alone or in combination with newer, second-generation anti-androgen medications. For patients with a low volume of metastatic disease at diagnosis, radiation therapy may be combined with ADT. Chemotherapy drugs can help manage pain and may improve survival in

patients with metastatic disease. Other, newer treatments include immunotherapy drugs known as checkpoint inhibitors; a vaccine for prostate cancer that has spread to other parts of the body (sipuleucel-T; Provenge); treatments targeting cancer in the bones, such as radium-223; and poly adenosine diphosphate-ribose polymerase (PARP) inhibitors, which were approved in 2020.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

Localized prostate cancer and its treatments can disrupt normal urinary, bowel and sexual functioning. Prostatectomy may result in urinary incontinence or leakage. Nearly all men will have some form of leakage immediately after the surgery, but this can improve over time and with strengthening exercises. Radiation therapy may cause a mild increase in urinary frequency and urgency and/or the need to urinate at night.

Erectile dysfunction remains the most common side effect after treatment. Fortunately, there are many excellent treatments for managing erectile function. After surgery or radiation, men are unlikely to be fertile.


Treatment of advanced disease carries other side effects. ADT causes side effects related to reversing all of the normal functions of testosterone. Although most men may experience only a few of these symptoms, the list of potential effects is long, including hot flashes, decreased sexual desire, metabolic changes, and changes in mood and thinking. For chemotherapy, reactions to drugs can vary widely, so it's important to pay attention to any side effects — the most serious, but uncommon, being fever with a low white blood cell count.

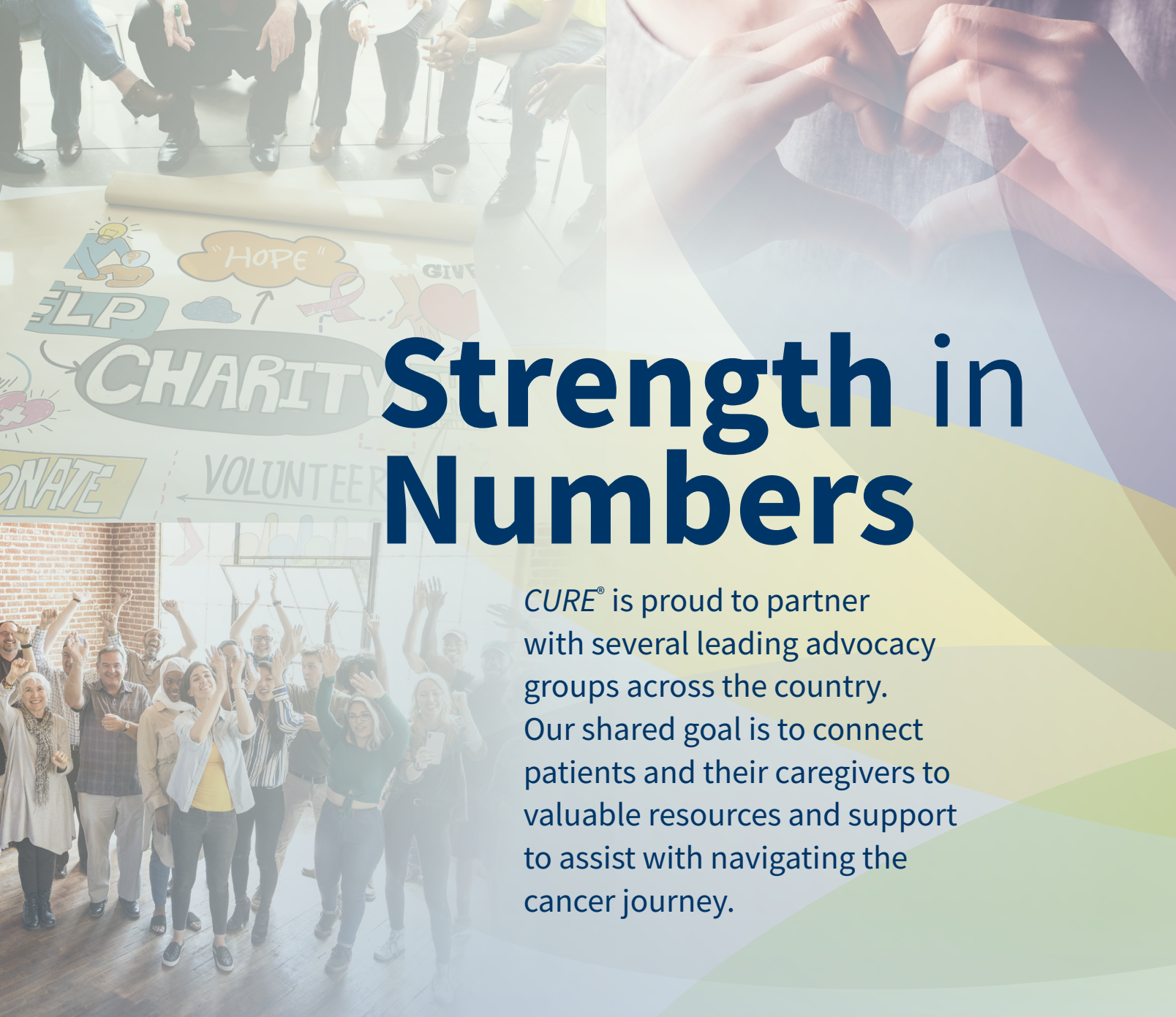
HOW DOES PROSTATE CANCER AFFECT A PATIENT'S LIFE?

The two most common side effects of treatment for localized prostate cancer are incontinence and erectile dysfunction. They can be managed and may be temporary, but for those affected, learning to live with these issues can be challenging. Men on active surveillance to monitor early-stage prostate cancer face a small risk that the disease will become aggressive and spread, and some may feel worried about this.

It's important that patients make mindful everyday choices about diet and lifestyle. There is growing scientific evidence that good nutrition and moderate to vigorous exercise may actually slow the growth and progression of prostate cancer.

WHERE IS HELP AVAILABLE?

The Prostate Cancer Foundation (pcf.org; 800-757-2873) offers extensive information about the disease and patient resources for every stage of the journey. For more details on the topics mentioned above, download the Prostate Cancer Patient Guide. And don't forget to visit *CURE*'s resources guide at curetoday.com/journey to learn about additional help that is available. 



Strength in Numbers

CURE® is proud to partner with several leading advocacy groups across the country. Our shared goal is to connect patients and their caregivers to valuable resources and support to assist with navigating the cancer journey.



Scan the QR code with your mobile device to visit curetoday.com and check out our advocacy group partnerships.



Multiple Myeloma

MULTIPLE MYELOMA IS A relatively uncommon cancer, affecting one in 132 people.

Because of progress in its treatment, many patients can live with myeloma as they would a chronic disease, treating it with medicine over a number of years.

WHAT IS MULTIPLE MYELOMA?

Multiple myeloma develops when plasma cells grow out of control with the capacity to spread and sometimes become resistant to treatments. Plasma cells, a type of blood cell, are found in bone marrow (the soft inside part of bones) and are part of the immune system. These cells start out as lymphocytes, including B cells that mature into antibody-producing plasma cells when they fight an infection.

When these cells grow out of control, they produce an abnormal protein known as monoclonal protein, or M protein. The same protein is also known as monoclonal immunoglobulin, M spike or paraprotein. This is the hallmark of multiple myeloma.

The uncontrolled growth of myeloma cells crowds other blood-forming cells out of bone marrow, leading to low blood counts and a decreased ability to fight certain infections. It can also interfere with cells that keep bones strong. M protein can circulate in the blood and lead to organ damage, including the kidney and nerve cells.

WHAT ARE THE RISK FACTORS?

Being older is a risk factor for myeloma; the average age at diagnosis is 69. Being male, obese or Black also are risk factors. A family history of the disease slightly raises risk, but most people who get myeloma do not have relatives with the disease.

Having other plasma cell diseases such as monoclonal gammopathy of undetermined significance, which is considered a precursor to myeloma, also raises risk.

WHAT ARE THE SYMPTOMS?

Myeloma often causes no symptoms until it reaches advanced stages, or it might cause vague symptoms that can be confused with those generated by other conditions. Sometimes patients receive a diagnosis when a routine blood test shows an abnormally high level of M protein.

Those who experience symptoms might have bone pain, weakness or breaks; low blood counts that cause ane-

mia or excessive bleeding; high calcium levels that cause extreme thirst; sudden severe back pain or leg weakness due to broken bones in the spine; numbness or tingling in the extremities; thick blood, which can cause confusion or dizziness; shortness of breath, weakness or leg swelling due to kidney damage; or infections such as pneumonia.

HOW IS MULTIPLE MYELOMA DIAGNOSED AND STAGED?

Doctors who suspect myeloma will conduct a series of blood and urine tests to check blood counts and kidney function in addition to protein, calcium and antibody levels. If these numbers suggest that myeloma is present, doctors will take a bone marrow biopsy. This can be done by inserting a needle into the back of the pelvic bone and taking out a core — approximately the size of the tip of a lead pencil— that contains a small amount of marrow. This allows a pathologist to look for myeloma cells.

An X-ray, MRI, CT or positron emission tomography scan can sometimes show bone changes or destruction caused by myeloma.

An echocardiogram might be used to check heart function, which can be affected by myeloma.

To diagnose myeloma, a doctor must find malignant plasma cells or 10% plasma cells in the bone marrow and at least one of the following: high blood calcium level, poor kidney function, anemia, holes or lesions in the bones, a specific level of increase in one type of light chain antibody fragment in the blood, or 60% or more plasma cells in the bone marrow.

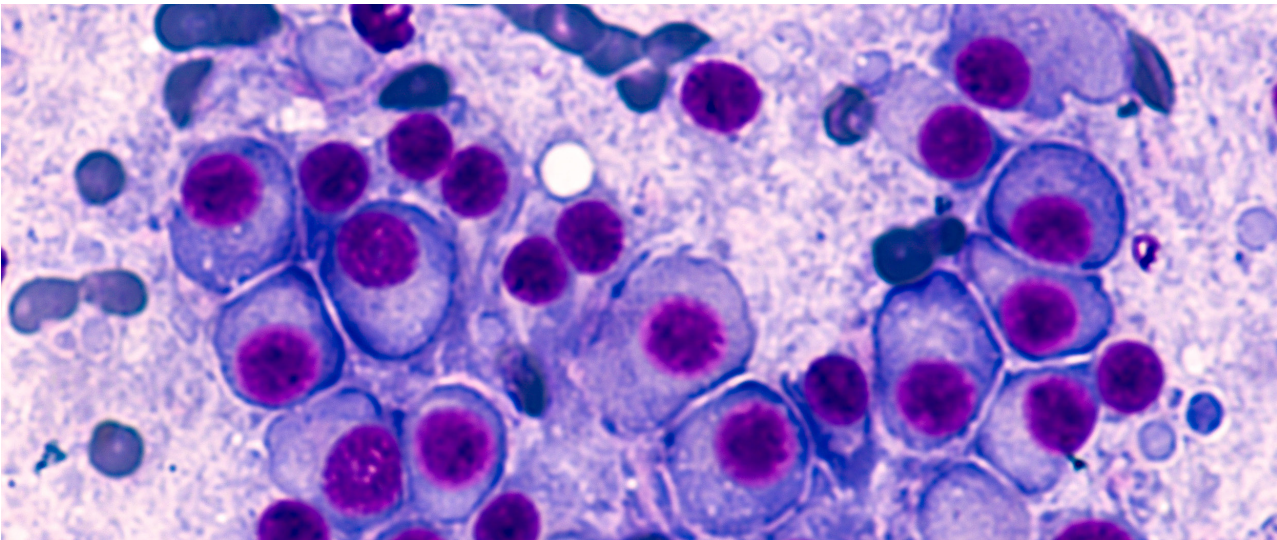
Myeloma is classified in stages 1 through 3, with 3 having spread the farthest and representing the highest risk. Additional genetic and chromosomal testing can help determine treatment.

HOW IS MULTIPLE MYELOMA TREATED?

If there is only one tumor in tissue or bone, a patient may be treated with radiation or surgery.

If there is more than one tumor, patients are treated with a combination of drugs — typically, two types of targeted drugs plus a steroid. In some cases, a chemotherapy is included in the mix. Sometimes patients stay on one of the targeted drugs longer to help prevent a relapse.

Patients with bone disease also get a bisphosphonate, which slows bone loss and lowers the risk of fracture. They also may receive radiation.



Staging the disease and genetic testing can help determine the best treatment for patients with myeloma.

Those with myeloma also receive supportive treatments, such as transfusions to deal with low blood counts and antibiotics to fight infection.

After a number of rounds of combination drugs, some patients undergo stem cell transplant preceded by high-dose chemotherapy, and this is sometimes followed by more medical treatment. Smoldering myeloma, a precursor to myeloma that doesn't always progress, is treated with close observation, although there is evidence that treating these patients with medications when they are asymptomatic extends their lives and may decrease organ damage. More research is needed on this.

All patients getting treatment undergo monitoring of their disease status with checks of organ function and blood tests to measure the proteins made by myeloma cells. Scans also may be done, and together these tests can indicate whether the treatment is working or if a change in the therapy regimen is needed.

WHAT ARE THE POTENTIAL SIDE EFFECTS OF TREATMENT?

The side effects of radiation can include skin irritation or blistering, fatigue, nausea or diarrhea, numbness or tingling in the extremities, increased risk of blood clots and low blood cell counts, which can lead to infection. Surgery may cause temporary weakness, swelling, pain and infection.

Chemotherapy can cause fatigue, nausea, vomiting, mouth sores and low blood cell counts. Steroids can generate a feeling of hunger, trouble sleeping, loss of muscle mass, upset stomach and swelling in the extremities.

Patients taking combinations of targeted drugs might experience fatigue, nausea or vomiting, constipation, diarrhea, a low white blood cell count, rash, blood clots, muscle aches and numbness or tingling in the extremities.

HOW DOES MULTIPLE MYELOMA AFFECT A PATIENT'S LIFE?


For some patients, multiple myeloma can progress in severity and over time the disease can become resistant to treatment with many approved therapies. For these patients, it is important to be seen by a myeloma specialist who can provide the most updated information on new treatments and clinical trials that may be appropriate for them.

For many, multiple myeloma can be managed like a chronic condition, with medicine given for years. Others who have no detectable cancer after initial treatment for myeloma may move forward without medication unless their disease recurs.

Symptoms such as bone pain and loss, kidney problems, anemia and infection may interfere with everyday life and require palliative treatment. For many patients, involvement of the bone may cause lost height or change the curvature of the spine.

WHERE IS HELP AVAILABLE?

The Multiple Myeloma Research Foundation (themmrff.org) offers a wealth of information about myeloma and connects patients to resources such as Myeloma Mentors, support groups, a clinical trial finder and patient navigators who can give guidance by phone (888-841-6673) or email (patientnavigator@themmrff.org). The nonprofit organization also collects deidentified data from patients who volunteer to share it; the information is used in research studies such as the CureCloud (mmrfcurecloud.org) to advance understanding of the disease and how to treat it.

And don't forget to visit CURE's resources guide at curetoday.com/journey to learn about additional help that is available. 

Myelofibrosis

MYELOFIBROSIS, A TYPE of myeloproliferative neoplasm or blood cancer, is rare and typically affects patients older than 60, with an estimated incidence between 0.5 and 1.5 cases per 100,000 people in the United States, according to the National Cancer Institute. Its treatment is different from other cancers because symptom management is the major focus.

WHAT IS MYELOFIBROSIS?

Myelofibrosis is a rare type of blood cancer that causes the body to form excess scar tissue in bone marrow and, as a result, impairs the proper control of production of blood cells.

This disease may be caused by abnormal blood stem cells in the bone marrow that produce mature cells that grow rapidly and overtake bone marrow. This leads to chronic inflammation and scar tissue formation. This also prohibits bone marrow from creating normal blood cells and moves blood cell production to the spleen or other areas in the body.

In most cases, myelofibrosis is not inherited genetically.

WHAT ARE THE RISK FACTORS?

Risk factors for myelofibrosis include the following:

- ▶ being older than 60, although cases have been observed in younger patients.
- ▶ exposure to ionizing radiation and petrochemicals, such as toluene and benzene.
- ▶ JAK2 mutation (seen in approximately 50% to 60% of patients with myelofibrosis).
- ▶ CALR mutation (seen in 24% of patients with myelofibrosis).

WHAT ARE THE SYMPTOMS?

Some patients with myelofibrosis have no symptoms, especially early on in the disease. Patients who are asymptomatic may have no symptoms for years. Patients with suspected myelofibrosis may have several symptoms, particularly an enlarged spleen and/or abnormal blood cell counts, in addition to symptoms brought on by inflammation. Patients may feel weak or tired, and they may experience shortness of breath with mild exertion. Other symptoms include fever and night sweats; discomfort, fullness or pain in the left upper abdominal area; bone pain; malnutrition or weight loss; itching, bruising

or easy bleeding; gout or joint pain; higher rates of infection; and compromised liver function.

HOW IS MYELOFIBROSIS DIAGNOSED?

Routine medical examinations are helpful when diagnosing myelofibrosis. This includes a thorough clinical evaluation, patient history and several tests assessing blood counts. Although blood tests can indicate some clues pointing toward a myelofibrosis diagnosis, a biopsy to remove bone marrow tissue is needed to confirm the diagnosis. An ultrasound may be performed to see whether the spleen is enlarged, which also can be an indicator. Physicians test blood cells for gene mutations such as CALR, JAK2 and MPL, which will help determine prognosis and treatment options.


HOW IS MYELOFIBROSIS TREATED?

Unlike other cancers, where treatment is focused on a cure, myelofibrosis is treated with symptom management. Patients who do not display many, or any, symptoms of myelofibrosis may not need to be treated immediately.

Patients with intermediate-risk myelofibrosis can undergo treatment for symptoms and side effects such as anemia (androgen therapy, blood transfusions and medications to improve blood cell counts) and an enlarged spleen (surgical removal or targeted drug therapy).

High-risk disease should be treated aggressively, which can include a bone marrow transplant, also known as a stem cell transplant. With this, a patient's diseased bone marrow is replaced with healthy blood stem cells after they undergo chemotherapy or radiation to destroy diseased bone marrow. However, there is significant risk involved. A decision to move forward with a transplant is made based on many factors discussed by patients, their families and doctors.

WHERE IS HELP AVAILABLE?

For more help understanding myelofibrosis, living with the disease, research in the area or navigating treatment decisions, visit the MPN Research Foundation at mpnresearchfoundation.org. For more news on myelofibrosis, visit CURE®'s resource center at curetoday.com/tumor/mpn. And don't forget to visit CURE®'s resources guide at curetoday.com/journey to learn about additional help that is available. 

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Relaxation techniques can ease difficult emotions. Scan the QR to read more.



Dealing With Emotions

How to recognize normal reactions at diagnosis and know when to get help

EACH PERSON'S EMOTIONAL RESPONSE to cancer will depend on various factors, including an individual's support system, coping style and perception of illness. As patients struggle with issues of diagnosis and treatment, they could also face the social pressures that come from well-meaning friends who want more than anything for them to be OK. Psycho-oncologists, who address the emotional needs of patients with cancer, have determined that a healthy emotional response to a cancer diagnosis includes three phases — initial reaction, distress and adjustment — that will take patients through a typical grieving process.

The initial reaction to a cancer diagnosis is often shock and disbelief, followed by a period of distress characterized by mixed symptoms of anxiety, anger and depression. As patients learn about

their options and begin to see a treatment plan form, they will enter an adjustment phase. Following a diagnosis, they might experience persistent sadness, in addition to anxiety or depression; decreased interest in sexual activity; fatigue; difficulty concentrating, remembering or making decisions; insomnia or oversleeping; weight and appetite loss; and restlessness or irritability.

Usually, many of these symptoms might be considered unhealthy, but for a person with a new cancer diagnosis, they are a normal part of the process of dealing with a new reality. However, feelings of hopelessness and guilt, or feeling stuck in one of the stages above, could indicate more serious distress.

Online or in-person support groups or professional counseling can help.

ANXIETY

Patients with cancer participate more today in determining their treatment plans than in past years. But with that power comes the anxiety of making a decision, particularly when there are multiple options and no clear advantage to any one choice. The number of therapy options depends on the type of cancer. In addition, doctors might disagree about the best course of action when a standard of treatment does not exist for a certain cancer, adding another layer to a complex decision.

Some people find that researching their cancer helps relieve anxiety. The internet has made it easier and faster for people to find cancer information and support online, but it can also expose people to false and misleading claims. Many hospitals and treatment facilities have libraries or patient education centers that provide reliable resources, and nonprofit organizations often have support groups that enable patients to talk with others who share their diagnosis.

Often, patients cope with their situation by concentrating on the things they can control, such as taking good care of their bodies by eating a healthful diet and exercising. Some patients find relief in completing practical tasks, such as setting up a system to deal with insurance, making sure wills and other legal issues are finalized or talking with friends and loved ones about unresolved problems or feelings.

A cancer diagnosis is stressful, and few people successfully manage it by themselves. Most seek encouragement from friends, family members or support groups. Others seek support from clergy, nurses or mental health professionals. Another useful resource offered by some hospitals is a patient navigator, typically a registered nurse, social worker or trained community member (sometimes a cancer survivor), who can help patients “navigate” the health care system, appointments and financial issues. In most cases, patient navigators won’t tell patients what to do, but will suggest questions to ask their doctors and

ADVICE FROM *a* SURVIVOR

JANE BIEHL, PH.D.



“Hope is the one emotion we can control (even) when a cancer is terminal. There is always hope for a new clinical trial, a new chemo or a new immune booster. And if one is really ill and ready to let go, hope remains for relief in the next unknown step.

It is hope and the 'why' that keep us going. More than any medicine, radiation or chemo, one thing is especially important: A reason for being, for staying alive, for loving life can be miraculous. This love can be for a family member, a close friend, a pet or a cause.

In my depressive moods, which hit with a vengeance, the ray of hope to get me through is usually a small but important gesture, like a phone call from a friend, a card from a family member, my dog putting her face in my lap or my cat crawling into bed with me. All these things make me feel good. Grab this gesture, seize the day and never give up hope. Try to do the same for others. If one has the why, the how will happen. Never forget that.”



SCAN THE QR CODE TO
READ JANE'S STORY

help them establish priorities. Being prepared can decrease stress and anxiety.

It's important to remember that each patient's cancer and situation are unique. So when it comes to support, one size does not fit all. Patients should »

PART 2: AT DIAGNOSIS

talk with their health care teams to learn about available resources.

A cancer diagnosis also affects a patient's loved ones, so support could be needed for coping with family dynamics. Patients might feel too ill to fix a meal or might need a ride to the clinic. They might need to take time off from work, temporarily thwarting career aspirations and conceivably placing a greater financial burden on a spouse or partner.

Whether patients have early-stage or advanced cancer, the diagnosis will likely bring up feelings of mortality, which can also cause anxiety. Addressing practical end-of-life issues, such as drawing up legal documents, can help lessen anxiety.

GUILT

Upon receiving a cancer diagnosis, some patients have a sense of guilt that they did something to cause their cancer — or that their family has to also go through it.

Although some cancers are linked to certain behaviors, it doesn't do any good to look back. It's not unusual for patients to try to understand why their cancer developed, but focusing on the cause can lead to unnecessary stress. A study of women who had recently received a breast cancer diagnosis showed that those who blamed themselves for their cancer had higher levels of distress than those who didn't. The findings also suggested self-blame made it harder to psychologically adjust.

Guilt is a barrier to living life fully, so experts recommend that patients work through those feelings by talking to a social worker or counselor, keeping a journal or participating in a support group.

DEPRESSION

Studies indicate that nearly one-fourth of patients with cancer will have symptoms of depression during treatment, which is understandable. Feelings of sadness about cancer and the changes it brings are normal and could actually help patients cope. However, persistent feelings of helplessness or

hopelessness and a sense of worthlessness are not typical, so patients experiencing these feelings should notify their doctors.

To distinguish between normal sadness and depression, patients should note their mental state and determine if, after two weeks, they feel better emotionally. If not, the patients should be evaluated to find out if the problem is clinical depression. Remember, some cancer therapies are associated with mood disturbances.

People with mild to moderate depression are often responsive to talk therapy. For these patients, support groups, buddy systems, cancer education programs and psychotherapy can be useful for regaining a sense of competence and control.

For those with moderate to severe depression, medication and psychotherapy are an effective combination. A range of antidepressants is available that varies significantly in terms of side effects, tolerability and safety, and their use should be monitored. Depression is a treatable disorder of the brain. It's an illness, so patients shouldn't be afraid to get the help they need to manage it.

MANAGING DISTRESS

Just as there's no single way to treat cancer, there's no one prescription for dealing with distress. Some patients benefit from speaking with a counselor or social worker, others from taking antidepressants or anti-anxiety medications, exercising or meditating. For details about distress screening and management, visit [CancerSupportCommunity.org](https://www.cancersupportcommunity.org).

Strategies known as integrative and complementary therapies can help with both the emotional and physical side effects of stress, worry and the disease and treatments themselves. These can include massage, yoga, acupuncture, meditation and therapies centered on music, art, writing or dance. Many hospitals offer such services, and others led by trained experts can be found in communities.

Integrative therapies may be, but are not always, part of palliative care plans, which are care strategies



➤ **Managing distress from a cancer diagnosis can come in many informs including speaking with a counselor, yoga and integrative therapies.**

that don't aim to cure disease, but are meant to improve quality of life for patients during and after treatment by relieving symptoms. Experts agree that palliative care should be available early in the cancer journey, regardless of someone's diagnosis or prognosis.

In addition, there are several programs designed to boost the physical appearance of women and men with cancer — through methods including makeup and wig application, stenciling in eyebrows for those who have lost hair, and even the staging of fashion photo shoots — that can also go a long way toward lifting spirits.

TELLING FAMILY MEMBERS

When deciding when, what and whom to tell about their cancer, patients should gauge their feelings about their diagnosis, their need to talk to someone about what they're going through, and what tasks they anticipate needing help with. The American Cancer Society recommends creating a list of people to tell in person and others who should get the news from a friend or family member. Decide in advance how much detail to give.

When telling children about a health threat that will affect the whole family, consider the family's usual way of dealing with sadness, as well as each child's age and preparedness for difficult situations, suggests Karen Hurley, Ph.D., a psychologist at Cleveland Clinic. Giving children information in small chunks, conveyed with positivity but a note of realism, can work well, Hurley said in a talk to people with predispositions to hereditary cancers.

Once the immediate family has been told, the American Cancer Society suggests that the patient consider the types of responses that make him or her feel angry or upset, and planning answers that will quickly put such conversations to rest.

To avoid repeated discussions about treatments and health status, patients can ask a loved one to set up a page on a website such as CaringBridge.org and share group updates with friends and relatives.

Those finding it difficult to discuss their feelings with loved ones may benefit from joining an in-person or online support group or consulting with clergy, nurses, mental health professionals and/or patient navigators.

THE NEGATIVE OF POSITIVE THINKING

As patients begin to tell others about their diagnosis, they could feel pressured to maintain a positive attitude, which can be difficult when they are scared, anxious or not feeling well. False optimism is not only unrealistic, but an unnecessary burden. There is no solid evidence that emotional outlook affects survival, yet people unaffected by cancer often expect and encourage those with the disease to stay positive despite how they are really feeling. People's reactions to cancer differ greatly. Patients should remember that it's their experience and there is no need to feel they have to please others by the way they cope with it. 🗨️



LEARN MORE!

As patients aged 65 or older receive a diagnosis of cancer, their treatment course and priorities may differ from their younger counterparts. **Scan the QR code** to learn more.



Considering Age-Related Issues

Regardless of when patients receive their diagnosis, their age affects the next step

EVERY PATIENT faces unique issues during and after treatment. In the past, oncologists focused primarily on treating the cancer, overlooking some issues related to the patient's age. But now, doctors are increasingly concerned about the effect of treatment on a person's future, including treatment-related long-term effects.

YOUNGER PATIENTS AND FERTILITY

Younger patients often have to contend with challenges related to coping skills, social concerns, behavioral issues, employment matters and treatment-related infertility. Doctors should broach all of these issues, taking particular care to mention fertility preservation options to all fertile patients — male or female — or, in the case of children, to their parents or guardians.

A single cancer treatment can affect fertility, so it is essential that patients and their doctors develop fertility preservation plans before treatment starts. This might mean delaying treatment to accommodate fertility preservation methods, such as banking sperm or freezing eggs.

For example, prostate and testicular cancer therapies can affect sperm production, resulting in low sperm count or infertility. Banking sperm is a proven technique for men wanting to preserve fertility. If sperm count is low, a process called intracytoplasmic sperm injection requires only one sperm to fertilize an egg. Another technique is testicular sperm aspiration, in which sperm is taken directly from the testicle or from resected testicular tissue. It is used in men with low sperm count. »

CANCER IN CHILDREN



Kids and Adults: What's the Difference?

THE DIFFERENCE BETWEEN CHILDHOOD AND ADULT CANCERS rarely comes down to simply age. Most tumors in children differ biologically from those in their adult counterparts, typically due to the cell type from which the cancer originates.

In the weeks after fertilization, the embryo develops into layers: ectoderm, mesoderm and endoderm. These layers are the foundation for the development and maturation of tissues and organs in the body.

Adult cancers, such as lung, breast and colorectal, typically develop from epithelial tissue (adenocarcinomas), which come from the ectoderm or endoderm. Epithelial cells make up the skin and lining of the internal organs and glands. Alternatively, childhood cancers, including sarcomas (cancers of the bone or muscle) and leukemias (blood cancers), most often develop from the mesoderm.

Like adult cancers, many childhood cancers form from genetic changes in cells. Only a small number of childhood cancers are caused by a genetic change inherited from a parent. It isn't clear what causes the rest, but unlike cancers in adults, cases in children don't typically result from lifestyle factors, such as smoking

or sun overexposure. It's important for parents and children to know that there's nothing they could have done to prevent the cancer.

Researchers have proposed that biological differences could point to why childhood cancers are often more responsive to chemotherapy, which is designed to target rapidly dividing cells. Epithelial cells are normally resilient because they are exposed to environmental influences, making them more resistant to treatment if they become cancerous. Vulnerable childhood cancer cells, however, are ideal targets for chemotherapy. Indeed, childhood cancer survivors are less likely to experience recurrence than adults, and the five-year survival rate across all childhood cancers for the years 2008-2014, 83%, is higher than that for adult cancers, 69%.

Childhood cancer is rare, with 11,060 new cases having been expected during 2019, according to American Cancer Society data. Although the incidence of these cancers has risen by 0.6% per year since 1975, the death rate for cancer in children ages 0 to 14 declined by two-thirds from 1970 to 2016, mainly because of better treatments and more participation in clinical trials.

PART 2: AT DIAGNOSIS

For women, certain chemotherapy drugs and hormone treatments, as well as radiation to the pelvic area, can damage the ovaries and other reproductive organs or cause early menopause. Because women are born with a limited number of eggs, or oocytes, damaging them during cancer treatment can leave a woman infertile.

If treatment calls for radiation to the pelvis, the doctor may be able to preserve the ovaries by doing a procedure that moves them away from the radiation field. Treatments that temporarily shut down ovarian function during chemotherapy are also being studied as a means to prevent damage to eggs.

Another option may be in vitro fertilization (IVF), in which an egg is fertilized in the lab and frozen, or cryopreserved, and later thawed and inserted into the uterus. Egg retrieval must be done before treatment and could require several weeks to obtain viable

eggs. Hormone injections might be given to promote egg development, but natural methods are also available. IVF can be performed with donor sperm and embryos.

While freezing unfertilized eggs is possible, the success rate is lower than it is for freezing embryos. Once thawed, the egg is fertilized by intracytoplasmic sperm injection and inserted into the uterus, and better freezing and fertilization techniques are improving success rates. Researchers are also exploring ways to freeze testicular and ovarian tissue to be transplanted back into the patient after therapy.

Insurance coverage of fertility care varies, and the cost can be high. Depending on a patient's plan, some treatments might be provided, especially if they are part of a necessary medical procedure being performed anyway.

Recently, laws requiring health insurers to cover fertility preservation for patients with

CANCER IN ADOLESCENTS AND YOUNG ADULTS

Special Centers May Help Teens, Young Adults



TEENAGERS AND YOUNGER ADULTS MAY BENEFIT from care in hospital sections dedicated specifically to adolescent and young adult (AYA) patients.

These inpatient and outpatient care units support the medical, social and psychological needs of patients facing the interruption of their schooling, newfound independence, careers and/or family planning. Patients with cancer who fit into the AYA population may want to consider seeking treatment at a facility that has one of these units, or ask what kind of specialized support their treating institution offers to people in their age group.

Teen Cancer America has a list of a number of these facilities at [teencanceramerica.org/our-work/hospitals](https://www.teencanceramerica.org/our-work/hospitals).

cancer have been enacted in California, Connecticut, Delaware, Illinois, Maryland, New Hampshire, New York and Rhode Island. To find out if your state has proposed or passed such legislation, visit allianceforfertilitypreservation.org/advocacy/state-legislation.

To complicate matters, many older people who receive a cancer diagnosis already suffer from at least one other illness, or comorbidity, such as heart disease, diabetes, hypertension or arthritis — some of which could be life-threatening. »

OLDER PATIENTS AND HEALTH CHALLENGES

Cancer is primarily a disease of aging. For many common cancers, the development of a tumor takes considerable time, dependent on a series of often unrelated events at the cellular level. Over the course of years, genetic changes and environmental toxins, such as tobacco, can cause DNA-damaging effects on cells. Meanwhile, the body's ability to repair damaged cells appears to decline with advancing age. At the same time, the aging tissue around those damaged cells appears to play a role, creating a more conducive environment in which malignancies can grow. As cells age and stop dividing, it's speculated that they develop a micro-environment that fosters cancer's development. Another potential contributory factor, researchers say, is the declining immunity that naturally occurs with advancing age.

CANCER AND OTHER ILLNESSES

PATIENTS WITH CANCER OFTEN HAVE OTHER ILLNESSES that can have an impact on treatment decision-making, some of which are considered here.

Patients who have cancer and **heart problems** might not be able to receive anthracyclines or some targeted agents because of the risk of heart damage.

Certain drugs can cause nerve damage, so patients with **diabetes**, a disease that can also cause nerve damage, are at greater risk for neuropathy.

Patients with cancer receiving treatment for **depression** must be aware that some antidepressants can decrease the effectiveness of cancer drugs.

Surgery might not be an option for patients who have lung cancer and **emphysema**, because impaired lung function can cause complications.

Hormonal therapies can increase the rate of bone loss, so patients with **osteoporosis** could be at increased risk for fractures and additional loss of bone mass.



Comorbid illness affects all aspects of cancer care, from early diagnosis to treatment options and prognosis. In fact, as patients with cancer are living longer, comorbid illnesses have a greater effect on long-term health. Patients with pre-existing illnesses may be less likely to survive their cancers and may face a greater risk of recurrence.

To get appropriate and effective cancer treatment, patients should be evaluated, not only in terms of the physical effects of the cancer, but also for any other health issues they might have. Cancer drugs often have side effects that aggravate other medical conditions, and drug contraindications can create additional problems.

For example, one proteasome inhibitor treats multiple myeloma and mantle cell lymphoma, but can cause pain and numbness in the hands and feet — known as neuropathy — that could be worse in people with diabetes, who are prone to nerve damage.

Hormone therapy blocks the production of male or female hormones. For instance, aromatase inhibitors for breast cancer block estrogen production. Because estrogen helps maintain healthy bones, blocking it can increase the risk

for osteoporosis or cause problems if a patient already has osteoporosis.

Other cancer drugs, including monoclonal antibodies for HER2-positive breast cancer and anthracyclines for leukemia and some solid tumors, could worsen heart conditions, which are more common among older people. These drugs can injure the heart muscle, so patients must be monitored closely, and the dose of the drug might be limited based on heart function.

Side effects do not always mean that certain cancer drugs cannot be given if patients have another illness. Instead, doctors might adjust the dosage of medication — both for the cancer and other illnesses — so that patients can receive the most effective cancer therapy.

Older patients with cancer should not automatically receive less aggressive therapy than younger patients. Age no longer matters as much as general fitness when it comes to eligibility for cancer treatment. Despite the prevalence of other common illnesses and the perception that older people are less likely to benefit from and cope with the stress of treatment, they typically fare equally well in overall survival and quality of life as their younger counterparts. [■](#)

CANCER

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Black and Latino patients are more likely to receive a diagnosis of and die of cancer than White patients. How can we end this disparity? **Scan the QR code to learn more.**



Overcoming Barriers to Care

Members of underserved populations may need to take action to overcome obstacles to cancer care

IT'S UNFORTUNATE BUT TRUE that minority populations within the cancer community sometimes have trouble accessing appropriate care or experience worse health outcomes after treatment. Some groups experience a higher relative incidence of cancer and a greater chance of disease complications or death. Also, patients who face barriers to health care may miss out on the chance to be screened for cancer so that the disease can be discovered in its earliest and most treatable stages.

So, it's helpful for members of these underserved groups to be aware of any obstacles and, if faced with them, speak up or seek support.

Geography: It can be difficult to obtain consistent, expert health care for people who live in rural areas, which often face a shortage of oncologists and are far from top cancer hospitals.

These patients should know that they may be able to have an oncologist at a large cancer center direct their care largely from afar with the help of telemedicine, so that they can receive most of their treatments at local facilities.

Socioeconomic status: Statistically, patients with lower education and income levels experience worse health outcomes after cancer than do their counterparts who've had more years of schooling, bring in higher salaries and have some form of health insurance. People affected by poverty also may have higher rates of smoking, lower rates of exercise and breastfeeding, more obesity and drinking and a greater risk of exposure to dangerous pollutants in their neighborhoods, all of which are risk factors for cancer.

It's particularly important for these individuals, if they don't have a diagnosed cancer,

to get annual well visits, report any unusual symptoms and get all the cancer screenings for which they are eligible. Those in this group who do have cancer can ask for help from a patient navigator or social worker at their care facility if they are having trouble making, keeping, affording or getting to appointments or sticking with the treatments prescribed to them. Patient advocacy groups may also be able to offer help; check our list of resources at curetoday.com/journey.

Insurance status: Not surprisingly, health opportunities and outcomes tend to be worse for those who are uninsured or underinsured. People in this group can check the national health care marketplace website, healthcare.gov, to see if they qualify for insurance that is subsidized by the government or free through Medicaid. In addition, some patient advocacy groups may offer financial help or other support programs to individual patients and pharmaceutical companies may offer discounted or free medications.

Ethnic or racial background: Ethnic and racial minorities who have cancer don't always benefit from full access to care or participate in clinical trials at the same rates White patients do. This can mean that trial results don't fully represent the usefulness of drugs in those populations. Socioeconomic factors can be one reason for the lack of participation, but another could involve a cultural reluctance to pursue treatment.

For instance, distrust of the health system among Black patients dates, in part, to the 1932-1972 study of untreated syphilis in Black men, conducted by the U.S. Public Health Service and the Tuskegee Institute. Participating men were not given the opportunity to provide informed consent or given adequate treatment to cure their illness, even when penicillin became the standard of care in 1947, according to the U.S. Centers for Disease Control and Prevention (CDC). One resource working to alleviate this concern is BlackDoctor.com, which helps readers find doctors who are likely to be culturally sensitive.

Language and cultural barriers may also stand in the way of care. For instance, Spanish-speaking

Hispanics are less likely to be screened for colorectal cancer than Whites or English-speaking Hispanics.

Furthermore, in some instances, members of specific ethnic or racial groups have worse health outcomes because of genetic predispositions for aggressive or hard-to-treat cancers. Triple-negative breast cancer, which disproportionately affects Black women, is an example of this. In addition, some skin cancers that are difficult to treat affect Black patients disproportionately, and Black patients are twice as likely as White patients to get multiple myeloma. American Indians/Alaska Natives, meanwhile, are the most likely to get liver cancer and cervical cancer and to die from kidney cancer.

Patients who are in these groups or have family histories of cancer can speak with their doctors about increased screening or other preventive measures. They can also call their state health departments to ask about any free cancer-screening programs available for underserved populations. The CDC offers one that provides breast cancer screening, which can be found at cdc.gov/cancer/nbccedp/screenings.htm.

Gender or sexual identity: Members of the LGBTQ+ community, which includes people who are lesbian and gay, also face barriers to good, consistent health care. LGBTQ+ people face a higher risk of cancer and a lower likelihood of having health insurance. Furthermore, they may face discrimination and isolation, which could lead to a higher likelihood of smoking and drinking, behaviors that raise the risk of cancer. Finally, discrimination from health care providers, or the fear of it, may lead patients to delay or avoid medical care.

Some patient advocacy groups that may be able to help are the National LGBT Cancer Network (cancer-network.org) and *CancerCare* (cancercare.org/questions/242), which offers support groups and other resources.

Overall, patients who are aware of these disparities and willing to serve as their own advocates are the most likely to contribute to the protection of their health and obtain appropriate cancer care. ■



LEARN MORE!

CURE® spoke with a cancer rights attorney about employment rights and how patients and their caregivers can learn more to ensure they are being protected. **Scan the QR code to learn more.**



Balancing Cancer & Work

Choosing to stay in the workforce through treatment requires planning ahead

M

MANY PATIENTS WORRY ABOUT JOB SECURITY and maintaining their health insurance coverage, and push themselves to work through cancer-related pain and fatigue. Yet balancing cancer treatment and work is possible with a proactive plan, accommodating employers and medical advances that include less toxic treatments and medication to alleviate side effects. Almost half of all patients with cancer receive their diagnosis before age 65; up to 60% will continue to work during treatment. Of those who stop working during treatment, up to 80% might return to the workforce at some point.

HOW TO MAKE IT WORK

Cancer stereotypes have changed dramatically, but patients, as well as employers, might still

make assumptions about how a diagnosis will or will not affect work. Experts recommend having a plan in place before discussing a cancer diagnosis at work. Patients should:

- ▶ Enter into the conversation with supervisors and coworkers with as much knowledge as possible and not be afraid to suggest what would work best for them during treatment.
- ▶ Develop a communication strategy with supervisors and coworkers that includes goals, a treatment schedule, possible side effects, delegation of or change in job duties, whether to tell anyone about the diagnosis and whom to tell about any medically related limitations.

- ▶ Explore the company's policy on sick leave, telecommuting and flex time.
- ▶ Talk with your medical team about what would make treatment easier, such as whether oral medication is available and how to alleviate side effects.
- ▶ Explain to supervisors that the situation could change depending on how treatment goes and how it affects work performance in the long run. Be upfront about what can and cannot be expected.
- ▶ Ask to decrease the workload, work from home or take time off from the job because of treatment schedules or side effects, such as fatigue or nausea. Scheduling chemotherapy late in the week can provide a weekend to recover.

KNOW THE LAW

The rate of job discrimination against patients with cancer and survivors has decreased, partly because of protections from the Americans with Disabilities Act (ADA) and other antidiscrimination laws that keep survivors from being treated unfairly in the workplace.

Discrimination that does occur is often a result of misconceptions regarding cancer and a patient's ability to work. Experts recommend that patients experiencing discrimination take legal action only as a last resort. Instead, they should familiarize themselves with their company's policies and talk with the human resources department about their issues and possible solutions. Often, information from social workers or the medical team and support from coworkers can resolve a situation. If legal action is the only alternative, patients should keep written records of all actions and communications.

Although patients have the right to keep their diagnosis confidential, it is recommended they disclose their cancer history to their employer in case it affects their job performance and they want accommodations under the ADA. Patients who work for companies with at least 15 employees must be reasonably accommodated, which can include a change in job duties or flex time.

ADVICE FROM *an* EXPERT

JEFF BARES,
RETURN-TO-WORK CASE MANAGER,
ALLSUP EMPLOYMENT SERVICES



“Returning to work after an absence is always a scary time frame.

Before returning, it's very important to keep in contact with the employer and express the intent to return; give them updates along the way. If you are going to need any accommodations from the employer (such as a modified work schedule, telecommuting or reduced amounts of heavy lifting), it should be in writing from a physician and provided to the employer's human resources department. Don't divulge too much information (about your illness or accommodations) to your coworkers, because that could cause animosity. Be smart about what you share.”



**SCAN THE QR CODE to hear
Jeff speak with the CURE® team.**

The Family and Medical Leave Act (FMLA) also protects jobs at companies with 50 or more employees for up to 12 weeks of unpaid leave and guarantees the continuation of benefits.

Caregivers can also take advantage of the FMLA. To qualify, they must have worked more than 1,250 hours for more than one year and intend to return to the job when their leave is over. [☑](#)



LEARN MORE!

CURE® frequently focuses on financial issues related to cancer care and ways to address them. **Stay informed by subscribing to CURE® magazine and visiting curetoday.com.**



Knowledge Is Power

Understanding federal and state laws can protect workers who have cancer

By Dara Chadwick

CANCER TENDS TO PRODUCE a ripple effect: Its impact on physical and emotional health often leads to changes in how and when people work, which, in turn, can create significant financial challenges.

Among the work-related questions of people who have cancer: Can I keep working? Will I lose my paycheck or my health insurance? Could I get fired if I take time off to have treatment or because I don't feel well? Can my work tasks, hours or environment be modified?

Fortunately, both state and federal laws protect the rights of working people with cancer, but it's important to understand which laws might apply to an individual's situation, says Rebecca Nellis, executive director of Cancer and Careers, a New York City-based national nonprofit organization that helps

people navigate the intersection of work and cancer. "The law is a tool that can make things easier," she says, "but understanding your rights and dealing with them at work are two very different things. You need to know what you have access to and how to make it work for you in your job at your company."

Lack of a specific legal protection, however, doesn't mean a person who has cancer can't work. "All hope isn't lost if the law isn't a tool for you," Nellis says. Some patients find protection and help via company policies and supportive supervisors. Each workplace has its own culture, and it's critical to understand what that entails, she says. "Someone's work experience and their response to it is as unique as their cancer treatment plan and response to it," Nellis says.

FEDERAL LAWS TO PROTECT

If someone is concerned about the effect of a cancer diagnosis on their job or health insurance, they should learn how federal and state laws may protect them. Generally, three major federal laws offer protection to workers: the Americans with Disabilities Act (ADA), the Family and Medical Leave Act (FMLA) and the Affordable Care Act.

Generally, the ADA protects someone who works for a private employer with 15 or more employees or for a state or local government, labor organization or employment agency. (In federal agencies, employees are typically covered by the Rehabilitation Act of 1973.) To be protected by the ADA, an employee must be considered a “qualified individual” — someone who can perform the job’s essential functions, with or without reasonable accommodations, and has a disability. According to the ADA Amendments Act of 2008, a disability is defined as a physical or mental impairment that substantially limits a “major life activity,” such as the ability to walk, breathe, concentrate or sleep. Individuals with disabilities also include those who have a history of a substantially limiting impairment. According to the U.S. Equal Employment Opportunity Commission, people who have cancer or are in remission typically are protected by the ADA.

In addition to making discrimination in employment practices unlawful, protections under the ADA include “reasonable accommodations,” such as changes to workspaces or schedules, using technology to assist with job duties, more frequent breaks and telecommuting.

The FMLA allows eligible employees to take up to 12 weeks of job-protected unpaid leave each year, with continuation of group health insurance coverage, for their own serious medical condition or to care for a child, parent or spouse with a serious condition. Generally, this applies to private employers with 50 or more employees, along with certain public agencies and employers, regardless of number of employees. To learn more, visit dol.gov/whd/fmla. »

WHERE CAREGIVERS STAND

Caregiver Rights

WHEN A LOVED ONE receives a diagnosis of cancer, many people want to take time off work to assist with transportation to treatment and post-treatment care. Unfortunately, caregivers don’t have access to the same legal protections as patients.

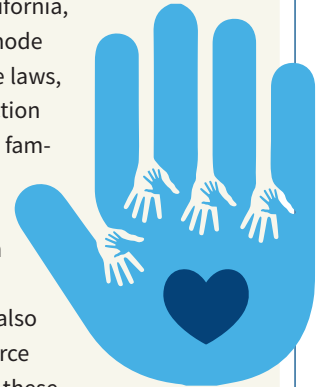
Caregivers are not entitled to accommodations under the Americans with Disabilities Act, according to Monica Bryant, a cancer rights attorney and chief operating officer for Triage Cancer, a national nonprofit organization. The Family and Medical Leave Act (FMLA) provides up to 12 weeks of job-protected unpaid leave, with continued group health insurance coverage, to care for a seriously ill family member, but its definition of family includes just a child, parent or spouse. “FMLA does not include grandmothers, mothers-in-law, siblings or grandchildren,” Bryant says.

Some states, including California, New Jersey, New York and Rhode Island, have paid family leave laws, which may offer some protection to employees caring for an ill family member. People should check with their state’s Department of Labor to learn more about state laws that may protect them. They can also turn to a Triage Cancer resource to help patients sort through these issues, which is available at triacancer.org/quickguide-caregiving.

Triage Cancer also offers other caregiving resources, which can be found at triacancer.org/caregiving.

Although legal protections are fewer for caregivers, Bryant encourages people to talk with their employers. “These requests often fall under the ‘it can’t hurt to ask’ umbrella,” she says. “Employers want to keep valuable employees.”

She also encourages caregivers to advocate for legal changes. “We have the existing rights we have because of advocates who came before us,” Bryant says, adding that there’s always room for improvement. “We encourage advocacy because no law is perfect. Let’s get some more rights for caregivers.”



PART 2: AT DIAGNOSIS

And to learn about how this law might protect employees during the COVID-19 pandemic, visit tragecancer.org/eligible-paid-fmla-leave.

Additional information about returning to work or taking time off due to the COVID-19 pandemic can be found at <https://tinyurl.com/y5qwf2cc>, and a host of relevant articles are archived at tragecancer.org/category/covid-19 and at cancerfinances.org in the COVID-19 module.

The Affordable Care Act gave consumers of health care new rights and benefits, offering additional health insurance options for people with employer-sponsored insurance if they need to leave a job, according to Monica Bryant, chief operating officer for Triage Cancer, a national nonprofit organization that provides education on the practical and legal issues of people with cancer. The law also helps people qualify for a special enrollment period to buy insurance on an exchange, go back on their parents' insurance plan if they're under age 26 or potentially qualify for Medicaid. To learn more, visit healthcare.gov.

Another federal law of note is the Genetic Information Nondiscrimination Act of 2008, which prohibits employers with at least 15 employees from using genetic information to make decisions about hiring, promotions, compensation, termination and other employment matters. The law helps protect employees from discrimination based on genetic testing — for example, if an employer with a self-funded insurance plan inadvertently gains access to medical information through claims data. “Your company might know if you’ve had a BRCA test,” Bryant says. “Ultimately, they’re not supposed to make decisions based on that knowledge.”

Other federal laws that help people keep and use their group health insurance include the Employee Retirement Income Security Act of 1974, which offers appeals protections to people who’ve been denied coverage, and the COBRA health insurance law. Officially called the Consolidated Omnibus Budget Reconciliation Act, it helps peo-

ple maintain their health insurance after they’ve left a job or reduced their working hours.

STATE LAWS AND EMPLOYER POLICIES

Although federal laws provide protections to employees who qualify, it’s important to understand applicable state laws, too. “I cannot stress the importance of state laws enough,” Bryant says. “The problem is that so many times, people don’t know what they don’t know.”

Comprehensive online resources like Triage Cancer provide a good starting point by listing state resources. A person can also contact their state’s Department of Labor or Equal Employment Opportunity Commission.

Another important source of protection might be found in a company’s employee manual. “Know your employer’s policies and follow their processes,” Bryant says. “If other employees are already telecommuting, it’s easier to get that as an accommodation. Laws are the bare minimum of what an employer has to provide.”

Nellis suggests pulling together all information about possible aid, including benefits and company policies. “Think about your own work environment and come up with a strategy,” she says. “If you want to stay at work, think strategically about how to make it work. It’s easier to do when you’re protected by state or federal law, but the law is just one way.”

WORKPLACE RIGHTS

One of the biggest concerns for people with cancer is disclosure — how much they need to tell their employer. The short answer? Less than a person might think. “Disclosure doesn’t mean every detail of what you’re going through,” Nellis says. “Disclosure isn’t all or nothing. It’s a spectrum.”

Approaches regarding disclosure are as individual as workers themselves. “Some folks want to keep things private and schedule all their treatments in the early morning or evening,” says Shelley Fuld Nasso, chief executive officer for the National

PROTECTING YOUR RIGHTS

Get Connected

DO YOU NEED MORE information about protecting your rights in the workplace? Here are a few places to start:

- ▶ **Cancer and Careers**
cancerandcareers.org
646-929-8032
- ▶ **CancerLinc (for residents of Virginia)**
cancerlinc.org
804-562-0371
- ▶ **Job Accommodation Network**
askjan.org
800-526-7234
- ▶ **National Coalition for Cancer Survivorship**
canceradvocacy.org
877-622-7937
- ▶ **Triage Cancer**
triagecancer.org
424-258-4628

Coalition of Cancer Survivorship in Silver Spring, Maryland. “Some survivors want to continue working for the sense of normalcy, while others don’t have a choice.”

Those who want to keep information about their illness private are entitled to do so; however, they may have to disclose some information to access reasonable accommodations or rights under the FMLA, Bryant says.

Pay attention to medical certification forms, she advises. An employer is entitled to have a health care provider certify a medical condition before providing a reasonable accommodation, but Bryant encourages people with cancer to have a conversation with their doctor about what will be disclosed. “For example, a health care provider can certify that an employee has severe nausea or fatigue,” she says. “The certification doesn’t have to mention chemotherapy.”

If someone decides to disclose their illness, Nellis suggests framing the situation as fluid. “Be clear that this is what you know right now, but things can change,” she says. “Set up an open line of communication.”

BE PROACTIVE

For people who worry about how treatment might affect their ability to do their job, Nellis suggests a proactive approach, such as keeping a work diary. “You might keep a record of the date you decided to disclose and who you disclosed to,” she says. “You might acknowledge that you had a challenge at work that involved slipping up on a project.”

She also suggests recording details about projects, keeping emails and voicemails as reminders regarding work in progress, and scheduling blocks of time for focused work.

“Done together, these things might create a safety net,” she says. “Remember the employer’s lens. Set expectations by saying ‘I recognize that we need to get X, Y and Z done. Here’s how I think this could happen.’”

Both Nellis and Bryant advise people with cancer to consider their employment future when deciding how much to disclose on the job. “We have people say, ‘My employer is so great,’” Bryant says. “But you may not have that job or supervisor forever. Disclosure is a bell you can’t unring. You have the legal right to access benefits without disclosing.”

And if someone feels they have been treated differently or discriminated against because of their cancer? The response depends on a person’s goals, Bryant says. “If all you want is to be the best employee you can be, you might have a conversation with your supervisor,” she says. “Other people no longer want to work for that employer and want to teach them a lesson.”

Still, she encourages people to pause before taking legal action: “We don’t want people to jump to filing a lawsuit if there are things in between they can do.” ■



LEARN MORE!

CURE® uses plain language to describe every aspect of the cancer experience. Stay informed by subscribing to *CURE*® magazine and visiting curetoday.com.



Understanding Pathology & Staging

The extent of cancer, what it looks like and where it is will guide diagnosis and treatment

A NUMBER OF THINGS must be considered before a doctor can offer treatment options for cancer. The doctor must know how much cancer is in the patient's body, where it is located, whether it has spread, and the specific type of cells that make up the tumor and how aggressive they are.

THE PATHOLOGIST

In addition to conducting laboratory tests to diagnose diseases in general, pathologists also conduct specific tests on the cancer to determine a number of factors, including the type of cancer cells, the grade of the cancer, the size of the tumor, the extent the cancer has invaded the surrounding tissue and whether the cancer

has spread to lymph nodes and other locations in the body. This information, compiled in a pathology report (see box, page 51), provides patients and their medical teams with essential information to help them determine the best treatment. The pathologist first looks at the tissue with the naked eye in a “gross examination.” Its appearance and characteristics, such as size, weight, color and texture, are recorded.

If an entire tumor or lesion has been removed, it is microscopically measured from the edge of the malignancy to the edge of the removed tissue, which should include healthy tissue. If cancer cells are found at the edge, that is considered a positive margin, suggesting that more cancer cells could remain in the

IMPORTANT INFORMATION

Translating a Pathology Report

BY LAW, PATIENTS ARE ENTITLED to a copy of their pathology report, and most hospitals will provide a copy free of charge. It's important to keep a record of the pathology report to have documentation of the diagnosis; this information will be helpful in researching the disease.

Below is a brief explanation of information found in a pathology report.

Demographics: Information about the patient, such as the patient's name, age, sex and date of procedure.

Specimen: The origin of the tissue sample.

Clinical history: The patient's medical history, including how the cancer was found.

Clinical diagnosis: The diagnosis doctors were expecting before the patient's tissue was tested.

Procedure: How the tissue sample was removed.

Gross description: Details of the tissue sample, including its size, weight and color.

Microscopic description: How the cancer cells look under a microscope, including tumor characteristics, such as grade, tumor margins, lymph node involvement and pathologic stage.

Special tests or markers: Results of tests that look for proteins, genes and how quickly the cells are growing. These findings are often contained in a separate report.

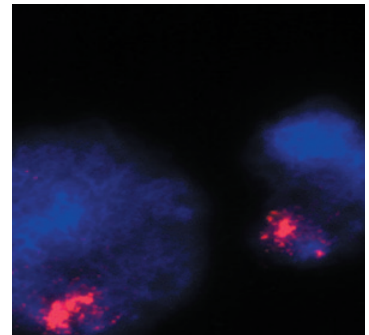
Summary: A pathologic diagnosis based on the information from the entire pathology report.

body. This means that more surgery or other treatments might be needed to try to remove or kill any remaining cancer cells. A negative or clean margin means there are no cancer cells found at the edge of the removed tissue.

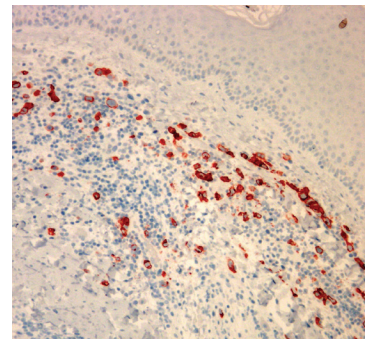
Once removed, the specimen is cut into thin slices by the pathologist for further testing. The pathologist examines the tissue under a microscope, but other techniques are sometimes used to identify factors involved in the abnormal growth of cells, including fluorescence in situ hybridization (FISH) and immunohistochemistry (IHC) or other molecular tests to identify mutated genes that might help to drive the cancer. Many tumor characteristics identified by these tests can be important in choosing the right treatment.

As the technology to examine cells has become more advanced, pathology offers more extensive information about which treatments will be most effective.

Patients should ask their doctors about the cancer's pathology to learn as much as possible about why a certain treatment is recommended and how it will work against the cancer. »



FISH uses fluorescent molecules to “paint” genes, allowing the pathologist to determine genetic mutations or how many copies of a particular gene are present in each cell.



IHC is a staining test that helps detect and classify cancer cells.

PART 2: AT DIAGNOSIS

If the patient's cancer is very rare or if the doctor thinks the pathologist's diagnosis is inconsistent with the patient's symptoms and other test results, a second opinion might be appropriate.

GRADING SYSTEMS

The pathologist provides a number of evaluative elements that can help patients understand their tumors. A tumor's grade describes how abnormal the cancer cells appear under the microscope.

Factors that go into deciding the grade vary, but usually include the size and shape of the cell's nucleus, the proportion of cancer cells that are dividing and the patterns the cells form as they join. If many cells are dividing, it can be a sign that the cancer is aggressive.

Cancer cells that look more like normal cells usually grow and multiply slowly and are described as being low grade, well differentiated or grade 1. Conversely, cancers that do not resemble normal tissues are called high grade, poorly differentiated or grade 3 or 4. The attributes are combined into an overall tumor grade that ranges from 1 to 4 depending on the cancer type.

Grading systems vary depending on if the cancer is a solid or liquid tumor (see page 53), and what type of cancer has been identified. For example, the grading system for prostate cancer ranges from 2 to 10. Patients should

THE ROSTER

Meet the Team

THE PATHOLOGIST IS ONLY one member of a patient's care team; cancer treatment and care involve many people with a variety of knowledge and skills. The makeup of the team will be determined by which specialties are best for treating the patient's type of cancer. Patients should remember that they are at the center of their team, and they have the final voice in making decisions about what happens to them.

Patients might encounter these professionals:

- ▶ Medical and radiation oncologists, radiologists, pathologists and surgeons;
- ▶ Oncology nurses, advanced practice nurses, nurse practitioners, clinical nurse specialists and physician assistants; and
- ▶ Social workers, oncology clinical pharmacists, dietitians, occupational and physical therapists, clergy, psychologists and psychiatrists.

Each doctor is supported by a specialized team that plays a major role in the patient's care.

Patients should try to understand the role of each person on the team (or teams), so that they can take full advantage of the skills and personal attention available to them.

HOW BIG IS THE TUMOR?

Peanut-Sized
[2 cm]*



**Sizes are approximate*

Grape-Sized
[3 cm]*



Walnut-Sized
[5 cm]*



Lime-Sized
[7 cm]*



ask their doctors what factors go into grading the tumor and the scale used.

Regardless of the system used, lower numbers signify less aggressive cancers, and higher numbers more rapid growth. Tumor grade is an important indicator of prognosis in some cancers, such as brain, breast and prostate, as well as lymphoma and soft-tissue sarcoma.

STAGING SYSTEMS

Many cancers are also staged from 0 to 4, with 4 usually indicating that the cancer is metastatic. Solid and liquid tumors are staged differently, and the staging of certain cancer types may differ. So, patients should try to understand how their cancer is staged and how important this information is for their cancer type.

Staging for most cancers is based on the following:

- ▶ Location and size of the primary tumor.
- ▶ The number of tumors and whether the cancer has spread to nearby organs and tissues, including the lymph nodes.
- ▶ Whether the cancer has spread (metastasized) to distant organs or tissues.

For some cancers, such as bone and soft-tissue sarcomas, the grade is considered when the cancer is staged. In addition to what is contained in the pathology report, data used for staging are gathered from physical examinations and imaging tests, such as X-rays, computed tomography (CT) scans, positive emission tomography (PET) and bone scans and magnetic resonance imaging (MRI) scans.

TNM staging uses three characteristics of the cancer. The T refers to the primary tumor (the place where the cancer began); the N refers to the level, if any, of lymph node involvement; and the M refers to the presence or absence of metastasis. The meaning of these letters and numbers might vary for different

types of cancer; some cancers might not have N3 as a category, and in other cancers, the classifications might have subcategories, such as T3a or T3b. Patients should ask their doctors about the staging system for their cancer.

Once these factors are known, an overall number is assigned. Patients who are treated and then experience a recurrence might have their cancer restaged. A restaged cancer often is indicated by inclusion of the letter “R.”

Newer chromosome tests and the analysis of multiple genes at a time (known as gene profiling) could subclassify the cancer and help determine prognosis and individual treatment. That's why the 8th edition of the American Joint Committee on Cancer staging system integrates grade and biomarker/molecular data, as well as anatomical indices.

Besides stage and grade, the patient's cancer type, treatment and health influence prognosis. But understanding what is the cancer's stage and grade mean can help patients and their care teams choose the best course of action. ■

OVERALL STAGE GROUPINGS	
STAGE	DESCRIPTION
Stage 0	Carcinoma in situ (noninvasive)
Stage 1 to 3	More extensive disease indicated by higher numbers (could include larger tumor, cancer present in nearby lymph nodes and/or cancer present in organs next to the organ in which the cancer began)
Stage 4	Usually means that cancer has spread to a distant organ (metastasized)

Lung Cancer

Navigating Discussions at Diagnosis

The views and opinions expressed in this article do not constitute medical advice. Patients should always seek medical advice and guidance from their doctors. Teresa has a paid relationship with EMD Serono.

AFTER SPENDING MORE than 25 years living in France, Teresa* was excited about returning to her home state of California – to spend more time with her brothers and to see her daughter graduate from her former high school.

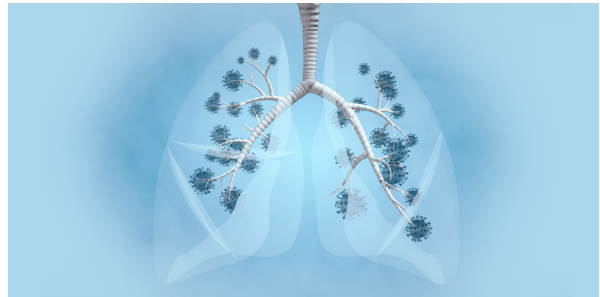
While settling back into life in San Francisco, Teresa developed a persistent cough. She thought perhaps her time in France had made her more susceptible to the California allergens. Through visits with her general practitioner, Teresa was initially treated for allergies and then later acid reflux disease – but her symptoms persisted, and she knew something still wasn't right. Teresa continued to cough constantly, and she was coughing up yolk-sized and -colored spots and blood. A concerned friend urged her to see a new doctor to get to the bottom of her symptoms.

"I had noticed I was rapidly losing weight and had a sudden aversion to food, which was unusual for me," Teresa recalls. "After an X-ray revealed a large mass in my right lung, I had further testing that confirmed I had stage 4 metastatic non-small cell lung cancer, due to the size of the tumor (15 centimeters) and having spread to the lymph nodes, as well as a few nodules in the pleura."

As she began consulting with oncologists, Teresa learned that non-small cell lung cancer (NSCLC) is the most common type of lung cancer. Teresa was part of the more than 50% of people with NSCLC who have metastatic disease at the time of diagnosis, meaning the cancer has already spread beyond the lungs. For those with metastatic disease (stage 4), the 5-year relative survival rate is just over 6%.

"I was completely overwhelmed at first. But slowly, with the support of my friends, my son and daughter, and resources from patient organizations, I began to understand the tools available to help me navigate my diagnosis," she says.

Teresa realized that her initial diagnosis only told part of the story. She learned about the role of biomarker testing in NSCLC, which can help doctors make decisions about appropriate treatment plans. In recent years, researchers have identified several different genetic alterations, or mutations, in NSCLC cancer cells that drive the cancer's growth. This includes the alteration Teresa was diagnosed with, mesenchymal-epithelial transition (*MET*) exon 14 skipping alterations, a type of alteration that is estimated to occur in 3-4% of people with NSCLC. Such a tumor alteration can be identified through biological



markers, or biomarkers – and may be used to identify appropriate treatment options.

"I am so grateful I was able to learn about and understand that *MET*ex14 skipping was playing a role in my cancer," Teresa said. "Though I hadn't started treatment yet, I recognized early the value of seeking out community resources and advocating for oneself to ensure a comprehensive diagnosis, including biomarker testing."

Evolution of Targeted Treatments for NSCLC

More than half of people with NSCLC may have genetic alterations driving their tumor growth. Using comprehensive biomarker testing is important to identify these genetic mutations or other markers that may help doctors make decisions about appropriate treatment plans. Biomarker testing may also be called genomic testing, genomic profiling or molecular testing. With a full picture of their disease, people with lung cancer can work with their health care providers to develop an appropriate care plan for their specific cancer type. Recent advancements in targeted treatments have increased the treatment options available to people with metastatic NSCLC.



Dr. Matrana has a paid relationship with EMD Serono, Inc.

Dr. Marc Matrana, Director, Ochsner Precision Cancer Therapies Program in New Orleans, says targeted therapy for NSCLC has changed the way doctors manage the disease, providing more hope for patients with limited treatment options.

"The treatment of lung cancer is, arguably, leading the way in terms of progress for personalized medicine in oncology. As our understanding of lung

cancer on a molecular level has continued to grow in recent years, more of the genetic mutations that drive some forms of this cancer—as well as therapies that can specifically target them—have been identified,” said Matrana.

“Comprehensive biomarker testing is a crucial part of cancer care. The opportunity to identify an actionable rare mutation in one of my patient’s tumors is incredibly exciting because it opens treatment possibilities that can impact the trajectory of that person’s disease, and potentially improve their prognosis.”

For adults with metastatic NSCLC with *MET*ex14 skipping alterations, the U.S. Food and Drug Administration has approved a targeted treatment option called TEPMETKO® (tepotinib).** TEPMETKO® is indicated for the treatment of adult patients with metastatic NSCLC harboring *MET* exon 14 skipping alterations. This indication is approved under accelerated approval based on overall response rate and duration of response. Continued approval for this indication may be contingent upon verification and description of clinical benefit in confirmatory trial(s).

The views and opinions expressed in this article do not constitute medical advice. Patients should always seek medical advice and guidance from their doctors.

*Teresa has not received treatment with TEPMETKO.

• What is TEPMETKO used for?

TEPMETKO is a prescription medicine used to treat adults with non-small cell lung cancer (NSCLC) that:

- has spread to other parts of the body (metastatic), and
- whose tumors have an abnormal mesenchymal epithelial transition (*MET*) gene. Your healthcare provider will perform a test to make sure that TEPMETKO is right for you. It is not known if TEPMETKO is safe and effective in children.

• What Warnings should I know about TEPMETKO?

TEPMETKO may cause severe or life-threatening swelling (inflammation) of the lungs during treatment that can lead to death. Tell your healthcare provider right away if you develop any new or worsening symptoms of lung problems, including: trouble breathing; shortness of breath; cough; or fever.

TEPMETKO may cause abnormal liver blood test results. Your healthcare provider will do blood tests to check your liver function before you start treatment and during treatment with TEPMETKO. Tell your healthcare provider right away if you develop any signs and symptoms of liver problems, including: your skin or the white part of your eyes turns yellow; dark or “tea colored” urine; light-colored stools (bowel movements); confusion; tiredness; loss of appetite for several days or longer; nausea and vomiting; pain, aching, or tenderness on the right side of your stomach-area (abdomen); weakness; or swelling in your stomach-area.

TEPMETKO can cause harm to an unborn baby in pregnant women.

Females who are able to become pregnant:

- Your healthcare provider may do a pregnancy test before you start treatment with TEPMETKO.
- You should use effective birth control (contraception) during treatment and for 1 week after the final dose of TEPMETKO. Talk to your healthcare provider about birth control methods that may be right for you.

Males with female partners who are able to become pregnant

should use effective birth control during treatment with TEPMETKO and for 1 week after the final dose of TEPMETKO.

• What should I tell my health care provider?

Tell your healthcare provider about all of your medical conditions, including if you:

- have or have had lung or breathing problems other than your lung cancer
- have or have had liver problems
- are pregnant or plan to become pregnant. TEPMETKO can harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if TEPMETKO passes into your breast milk. Do not breast-feed during treatment and for 1 week after the final dose of TEPMETKO.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

• What are the side effects of TEPMETKO?

The most common side effects of TEPMETKO include: swelling in your face or other parts of your body; tiredness; nausea; diarrhea; muscle and joint pain; and shortness of breath. Your healthcare provider may change your dose, temporarily stop, or permanently stop treatment with TEPMETKO if you develop serious side effects during treatment. These are not all of the possible side effects of TEPMETKO. Call your doctor for medical advice about side effects. **You may report side effects to FDA at 1-800-FDA-1088 or at www.fda.gov/medwatch.**

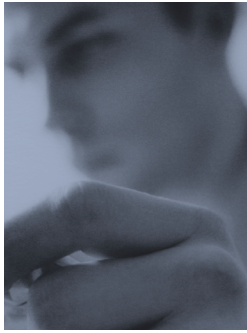
Please see the full Prescribing Information and Medication Guide for additional Important Safety Information for TEPMETKO.

For more information on metastatic NSCLC with *MET*ex14 skipping alterations, visit: www.TEPMETKO.com.

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US-TEP-00458 October 2021



LEARN MORE!

Patients and their families need to know if they have an inherited predisposition to cancer, but it can help to do some planning before getting tested. **Scan the QR code to learn more.**



Understanding the Genetics of Cancer

Knowing what genetic alterations drive a cancer can guide treatment

WHEN CANCER IS DIAGNOSED — whether the condition is inherited or not — it's essential that patients and their doctors consider whether the disease is driven by any faulty genes or proteins that are treatable with targeted drugs or immunotherapies.

If tests of tumor tissue at biopsy or before surgery show this is the case, patients may be able to take drugs that specifically target these glitches, rather than chemotherapies that affect their whole bodies. For some, targeted drugs or immunotherapies can be more effective and cause fewer side effects than chemotherapy, or sometimes they are given with chemotherapy. Targeted drugs work by disabling the activity of genes, proteins or tissue environment that con-

tributes to cancer. Immunotherapy boosts the body's natural defenses against cancer.

The Food and Drug Administration (FDA) has approved targeted drugs for the treatment of a variety of cancers, including lung, which can be driven by EGFR mutations, ALK rearrangements or the very rare ROS1 mutations; melanoma, which can arise from BRAF mutations; breast, which can overexpress the protein HER2; and colorectal, which can feed off the overexpressed proteins EGFR or VEGF. Targeted drugs known as PARP inhibitors have been approved by the FDA in advanced or previously treated breast, ovarian, prostate and pancreatic cancers driven by mutations to the BRCA or other genes. There is a growing

number of cancers for which targeted therapies have been approved, including lung, stomach, bladder, cervical, brain, head and neck, skin, kidney, liver, gastrointestinal stromal tumor, endometrial, colorectal, esophageal, thyroid and some blood diseases.

In addition, immunotherapies known as checkpoint inhibitors work against a growing number of cancers, including lung, melanoma, head and neck, bladder, liver, stomach, cervical, Hodgkin lymphoma, squamous cell carcinoma of the skin and some kidney and breast cancers, mainly by targeting the proteins PD-1 or PD-L1. Two of these drugs are approved to treat several advanced cancers that have abnormalities in their ability to repair damage to their own DNA, including certain colorectal and endometrial cancers.

Scientists are finding that cancers that originate in different parts of the body may share the same mutations. That means that, even if there is no targeted treatment approved for a particular cancer, there may be one on the market, or in clinical trials, that could work for a patient based on the mutations their disease expresses. Furthermore, new treatable mutations may emerge as a cancer progresses, or in response to therapy.

Therefore, it's important that patients diagnosed with cancer or a recurrence ask their doctors to test them for any mutations that are known to be targetable with drugs.

TREATING GENETIC MUTATIONS, NOT CANCER TYPES


Although most treatment is based on where the disease developed in the body, such as the breast, colon, prostate or liver, a growing trend focuses on treating a cancer based on the genetic mutations that drive it.

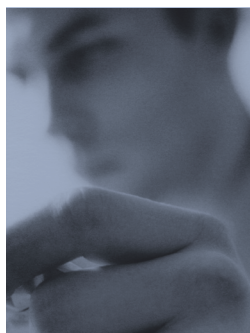
The FDA has approved a number of drugs to treat several cancer types that develop due to the same mutations. A few examples: Herceptin (trastuzumab), which treats cancer that expresses too much of the protein HER2, can be used for both breast and

stomach cancers. Avastin (bevacizumab), which slows the growth of blood vessels needed to support a tumor, is approved to treat colorectal, lung, kidney, cervical and ovarian cancers, as well as the brain cancer glioblastoma. A combination of Tafenlar (dabrafenib) and Mekinist (trametinib), which stop the proteins MEK and BRAF from stimulating out-of-control cell growth, can treat melanoma, non-small cell lung cancer and thyroid cancer.

Recently, the FDA approved some immunotherapies for broader use. Keytruda (pembrolizumab) and Opdivo (nivolumab) can treat any cancer with microsatellite instability-high or mismatch repair-deficient status. These tumors have trouble repairing their own damaged DNA. The immunotherapies can treat any cancers that have this status, regardless of where they started in the body, marking the first FDA approvals of drugs to be given based on a cancer's genetic mutations, rather than its type.

Another first occurred when the FDA approved a different drug for use across cancer types. Vitakvi (larotrectinib) stops abnormal proteins that are generated by an NTRK gene alteration that stimulates cancer cells to grow. The agent is approved to treat any advanced solid tumor with the NTRK alteration. Also approved to treat that gene alteration is Rozlytrek (entrectinib).

Some clinical trials follow a similar principle when testing new cancer treatments. Basket trials enroll patients with any cancer type, as long as it is driven by a specific genetic mutation, and give them a medication that targets the problem. Alternatively, umbrella trials enroll patients with the same underlying origin of cancer, such as breast or pancreatic, but gives them different targeted therapies based on the mutations that make their cancers grow. In Lung-MAP (lung-map.org), for example, patients with lung cancer are receiving different medications based on the mutations driving their disease, and NCI-MATCH (<https://tinyurl.com/ydcxbdv>) is enrolling patients with various types of solid tumors and lymphomas and treating them based on the mutations their cancers express. 



LEARN MORE!

A three-time cancer survivor discusses the importance of genetic testing, listening to your body and teaching family members about your experiences to potentially protect them from future cancers. **Scan the QR code to learn more.**



Identifying Inherited Genetic Risk

Patients should consider genetic testing when cancer runs in the family

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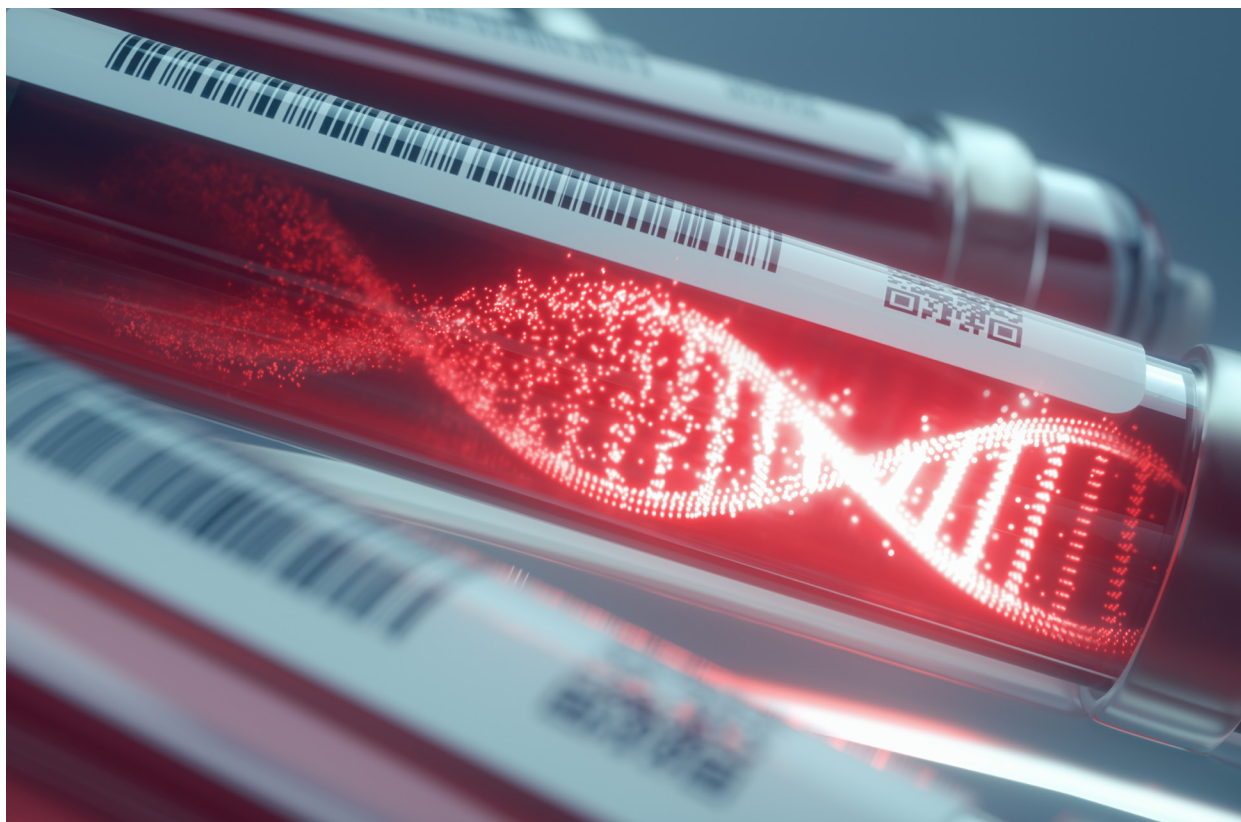
MANY CANCERS BEGIN as a fluke mutation in a single cell. Yet in up to 10% of cancer cases, one or more mutations wind their way through family trees with a chance of affecting each new member. When mutations are deemed hereditary, also known as "germline," they are present in every cell, including egg and sperm, and can thus be passed on to subsequent generations.

Each person has 46 chromosomes — 23 from each parent — that contain 20,000 to 25,000 genes. These chromosome pairs allow for a backup, so a mutated gene's healthy counterpart can code for the correct protein. For a hereditary cancer to develop, both copies of the gene must be affected, although it is also possible to develop such a cancer if one mutated

gene is inherited and its backup develops a mutation later in life.

Inheriting a mutation doesn't mean it's certain that someone will develop cancer, but it does put that person at risk. Researchers have identified many inherited mutations that account for more than 50 hereditary cancer syndromes.

For instance, the lifetime risk of developing breast cancer or ovarian cancer is significantly increased for a woman if she inherits a BRCA mutation. In addition to breast cancer and ovarian cancer in women, BRCA mutations are associated — to a lesser degree — with an increased risk of fallopian tube cancer and peritoneal cancer in women,



breast cancer and prostate cancer in men, and pancreatic cancer in both men and women.

For patients with breast cancer and ovarian cancer, early identification of a BRCA mutation will significantly help in creating a treatment plan. Patients who test positive for a BRCA mutation may respond to certain therapies better than those who do not have the mutation, and may be eligible for different clinical trials.

Inherited gene mutations can't be repaired, but they can be found through genetic testing. Requiring little more than a simple blood draw or saliva sample, genetic testing is now available for dozens of hereditary cancer syndromes, which are caused by alterations in genes that suppress or activate tumor growth. But genetic

testing should only be done within the framework of genetic counseling.

Genetic counselors help patients decide whether to undergo genetic testing and help them understand the results and provide context. Working with genetics professionals, patients and their families can explore the possible consequences of genetic testing and develop realistic expectations of what might or might not be learned in the process.

Patients might be candidates for genetic testing if they have one or more of the following:

- ▶ Early-onset cancer (usually before age 50).
- ▶ More than one cancer diagnosis.
- ▶ A strong family history of cancer or the presence of rare cancers. »


PART 2: AT DIAGNOSIS

The details of what constitutes “early-onset” or “strong family history” vary according to the cancer type or specific genetic mutation. A pedigree is created based on family history of cancer to determine who will most likely benefit from genetic testing.

Testing can provide information that either confirms high-risk status or rules out the presence of a genetic alteration found in other family members. For those who test positive for certain genetic mutations, increased screening might be needed. Some patients might also consider chemoprevention strategies to help

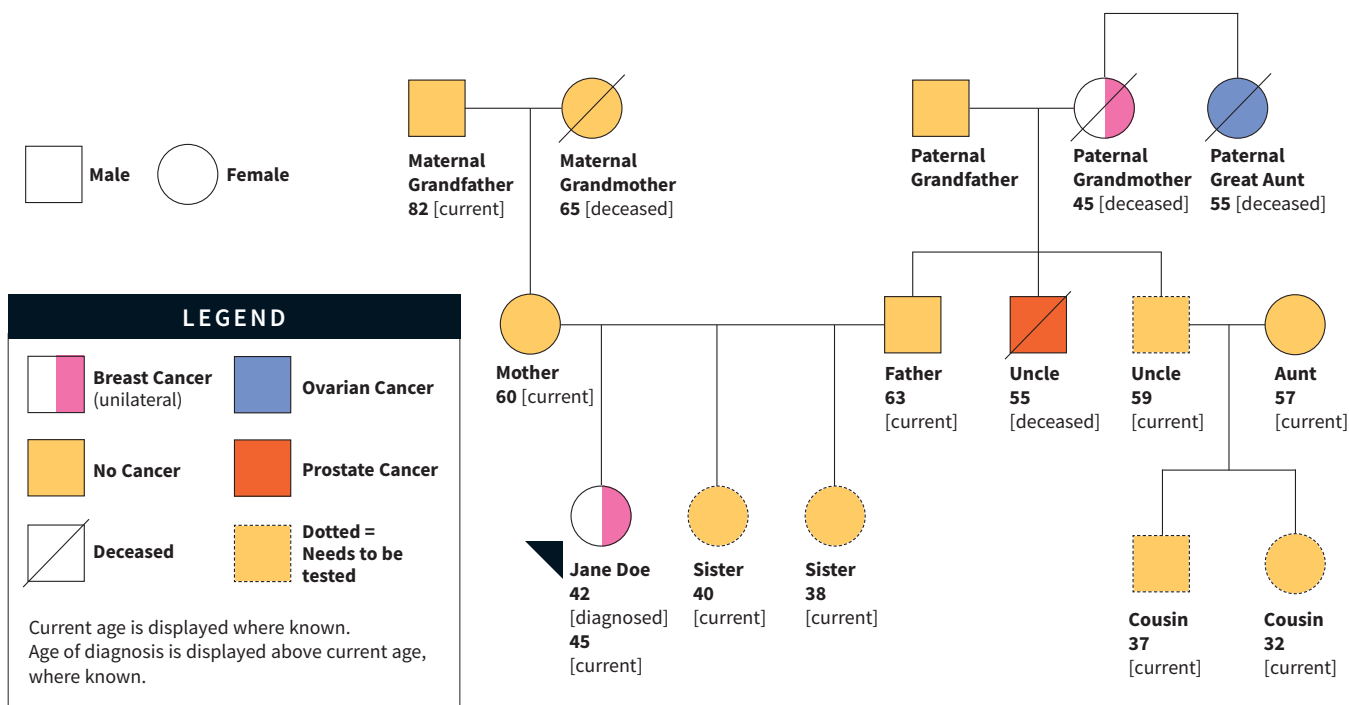
lower their risk of second cancers or recurrence. In other cases, cancer could be prevented with prophylactic procedures, such as surgery, or behaviors.

Because gene alterations often predispose individuals to many types of cancer, identifying genetic status early can aid in diagnosis and medical decision making. It can also alert relatives that they might benefit from genetic testing, cancer screening and prevention measures.

Patients considering genetic counseling should visit [cancer.gov/cancertopics/genetics/directory](https://www.cancer.gov/cancertopics/genetics/directory) to find a local genetic counselor. 

FAMILY PEDIGREE FOR JANE DOE

GENETIC COUNSELORS work with patients to develop a pedigree of family relationships that uses lines and symbols to create a visual diagram of links among family members who have a genetic disease, such as cancer.



OPTIONS FOR TESTING

Taking Charge of Your Own Genetic Testing? Take Some Precautions, Too.

PEOPLE WHO SUSPECT THAT THEY are predisposed to a certain inherited cancer, and who want to be tested to find out if they carry specific gene mutations, have a growing variety of genetic tests from which to choose.

Testing of a person's DNA is offered for many of the more common inherited syndromes that can cause cancer, including hereditary breast cancer and ovarian cancer syndrome, caused by mutations in the BRCA1 or BRCA2 genes. Others, each caused by specific gene mutations, include Li-Fraumeni syndrome; Cowden syndrome; Lynch syndrome; familial adenomatous polyposis; retinoblastoma; multiple endocrine neoplasia type 1 (Wermer syndrome); multiple endocrine neoplasia type 2; and Von Hippel-Lindau syndrome.

The tests for these mutations, many of which can look for multiple mutations associated with a specific disease, are often prescribed by a physician and require a small sample of body fluid or tissue, such as blood, saliva, cells from inside the cheek, skin cells or amniotic fluid. The tests are then sent to a lab and later returned to a doctor or genetic counselor, who can explain the results to patients.

However, there are tests out there that can be taken without a doctor's prescription or guidance. These are called direct-to-consumer (DTC) genetic tests that are often marketed to people online. They can be purchased via the internet or at local drug stores and may require a cheek swab or saliva sample that people can send through the mail. Test results are then sent back via mail, online or over the phone. These tests look for mutations to the BRCA genes, to those linked to Lynch syndrome and to others associated with a few health issues not related to cancer.

While people are hoping to find answers about their genetic risks, they may not fully comprehend the results. This is a problem that the Food and Drug Administration and Centers for Disease

Control and Prevention have pointed out with DTC genetic tests. Both agencies have stated that some of these tests lack scientific validity and should be taken in context only after a full medical evaluation.

The National Cancer Institute (NCI) advises seeing a genetic counselor, doctor or other health care professional trained in genetics to discuss results and what the next steps should be. These may include preventive care, screening, referral to support groups, the provision of emotional support and help with decisions about whether other family members need to be tested.

For those who do choose to go with a DTC genetic test, the NCI suggests using a laboratory that meets both state and federal testing guidelines. Currently, labs that perform genetic testing are subject to the federal Clinical Laboratory Improvement Amendments.

While their ease of access may make these tests appealing, they do not come without a price. The cheaper tests run about a couple of hundred dollars, and panels testing for multiple conditions or gene mutations can cost into the thousands. It's important to note that, often, these costs are not covered by health insurance.

Before ordering a test, check the company's privacy policy, including its rules about giving data to police who request it.

Furthermore, there has been an uptick in unqualified "health advocates" promoting DTC genetic tests to consumers with promises of free testing to people who don't qualify for it, and who may use personal health care information to fraudulently bill insurance companies. To stay safe, start by asking questions of health professionals such as your primary care doctor, OB/GYN or oncologist, or checking the website of Facing Our Risk of Cancer Empowered at tinyurl.com/yxmfzjrw.

BEING PROACTIVE

Starting a Conversation

By SHANNON PULASKI

WHEN I WAS 27, my husband and I welcomed our twins into the world two months early. Ten days later, in the same hospital, my mother received a diagnosis of ovarian cancer. I spent my days visiting my mother and my daughters. One generation up; one generation down — just two floors apart, but their stories were more closely connected than we understood.

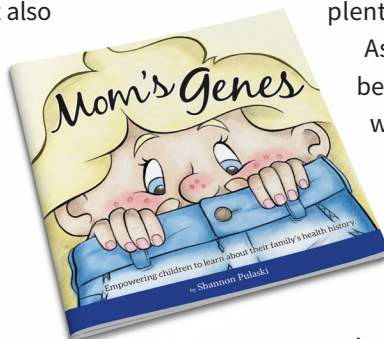
Not long after my mother's initial diagnosis, we discovered that she was BRCA1 positive. Being positive for a mutation in the BRCA gene meant that she faced up to a 72% chance of developing breast cancer and up to a 44% chance of developing ovarian cancer over the course of her life. It also meant that there was a 50% chance that she had passed this genetic mutation on to me.

When my daughters were 4 months old, I decided to undergo genetic testing. Weeks later, when my results were in, I took one look at my genetic counselor's face and knew that I, like my mother, am BRCA1 positive.

Today, I am blessed with three children: twin daughters and a son. I often think about whether they have inherited the same gene mutation I carry. There is no doubt that my children will have questions. I knew I would have to find a way to provide answers without overwhelming them with all the information they'll need to make screening decisions as adults.

I decided I would tell them a story — our story.

My children love telling stories so much that they often create small picture books for my husband and me. It was from their works that I was inspired to create a picture book for young children, "Mom's Genes," that would help us start a much-needed conversation about our family's health history.



Because my children are still quite young, I knew I would have to approach this conversation slowly and in a way that they would understand. By lightly introducing the concepts of genetics and family health history, "Mom's Genes" was meant to ignite that first conversation so that we could eventually dive deeper into these issues.

The book helped my children recognize and talk about genetic traits that they may have inherited from members of the family. Then, when the children were concerned about my frequent medical visits, the book helped me explain that my doctors know my family's health history and use it to do plenty of checkups to keep me healthy.

As genetic information and testing become more readily available, they will have a tremendous impact on medical decisions going forward.

Families with certain genetic mutations face many complex and personal choices, including how and when to share such information

with their children. It is my hope that "Mom's Genes" will help parents start conversations with their young children about their own families' health histories and encourage their sons and daughters to be proactive about their health and wellness from a young age.

SHANNON PULASKI is an attorney, patient advocate, wife and mother of three. She volunteers as an ambassador for Bright Pink, a nonprofit organization focused on early detection and prevention of breast and ovarian cancers, and serves on the Young Leadership Council for the Basser Center for BRCA at Penn Medicine's Abramson Cancer Center in Philadelphia. Pulaski is the author of "Mom's Genes," a book that aims to empower children to learn their family health histories. "Mom's Genes" is available on Amazon in print and as an e-book. Learn more about Pulaski's story and the experiences of other previvors, as well as survivors, at proactivegenes.com.



We are helping to move mountains for myeloma patients

Moving Mountains for Multiple Myeloma (MM4MM) is an award-winning collaboration between CURE Media Group and the Multiple Myeloma Research Foundation (MMRF), which raises funds and awareness for myeloma research.

Since its inception in 2016, Moving Mountains for Multiple Myeloma teams have climbed Mount Kilimanjaro, hiked the Grand Canyon, summited Mount Fuji, trekked the Inca Trail to Machu Picchu, reached Everest Base Camp and conquered Iceland's many landscapes. Our team members have raised over \$3.5 million, 100% of which goes directly to the MMRF, which spearheads and funds critical myeloma research. These amazing journeys are captured via blogs, social media posts and video.

After pausing for the global pandemic, we are back with a new schedule of exciting climbs. Patients, caregivers, loved ones with myeloma, and others impacted directly by multiple myeloma will trek through the wilderness of Alaska's Kenai Peninsula, summit Mount Washington and discover the dynamic terrain of Colorado's Backcountry Continental Divide. They will raise funds for multiple myeloma research and demonstrate that the advancements being made in recent years, led by the MMRF, are helping patients live longer with a higher quality of life than ever before.

To learn more and join a MM4MM team visit:
MovingMountainsForMultipleMyeloma.com

To learn more about the MMRF, visit TheMMRF.org

LEARN MORE ABOUT OUR CLIMBS!

2021-2022 TREK SCHEDULE

Alaska Trek
 August 16-21, 2021

Mount Washington
 July 8-22, 2022

Greenland Trek
 July 17-23, 2022

Sweden Trek
 August 12-20, 2022

Mount Kilimanjaro
 September 3-13, 2022

Colorado Trek
 September 8-15, 2022

endurance.themmrf.org/MM4MM





In searching for cancer information online, don't forget to check out the resources section of our Cancer Guide at [curetoday.com/journey](https://www.curetoday.com/journey) for a list of organizations that offer educational, emotional and financial support to patients and their loved ones.

Finding Cancer Facts Online

Consider the source when evaluating cancer information found on the internet

Adapted with permission of the American Cancer Society

FOR PEOPLE WITH cancer, the internet often is the first place they go for information. Whether they're looking for help in making decisions about their illness or news about the latest treatment options, patients have greater access to cancer information than ever before. Many websites provide basic knowledge about types of cancer, current clinical trials and available support. Some offer information on research articles, doctors and hospitals, treatment guidelines, drugs, and complementary and alternative therapies. Always remember, not all information is good information. And bad information can hurt when it comes to cancer.

USER, BEWARE!

Cancer information on the internet comes from many different sources such as expert health organizations, government agencies, universities, merchants, interest groups, the general public and scam artists. Many of these sources really want to help others learn more. But because anyone can post information on the internet, information that is wrong can be passed along. Some information may be posted deliberately to try to deceive people.

This is not to say that anything on the internet can't be trusted — just that it's important to choose sources carefully. Even on trusted,

ASK THE EXPERTS

How to Evaluate Information Found Online

WHEN EVALUATING information about cancer online, take these into consideration:

- ▶ **Source:** Reputable websites tell visitors, often on an “About Us” page, who’s running the show. Are they health professionals? What are their credentials?
- ▶ **Red flags:** *No contact information, no physical address.*
- ▶ **Funding:** The funding source should be clearly stated or apparent. The endings on web addresses — .com (commercial), .org (noncommercial organization), .edu (education), .gov (government) — are clues to the website’s funding source, target audience and motives.
 - ▶ **Red flag:** *Unclear or unverified funding sources.*
- ▶ **Origin of content:** Is content based on research findings published in reputable medical journals? Are there citations in the text that enable visitors to verify those findings? Nonprofessional opinions and advice, as well as individual case histories and testimonials (some of which might not be genuine), are poor substitutes for rigorous science.
 - ▶ **Red flag:** *Information collected from unidentified sources.*
- ▶ **Objectivity:** Information should be unbiased, unless otherwise labeled, and complete. Reliable resources acknowledge that experts sometimes disagree about cancer causes and treatments.
 - ▶ **Red flags:** *Capital letters, exclamation points, descriptions such as “miracle cure,” “secret ingredient” and “natural” (which doesn’t necessarily mean safe or effective).*
- ▶ **Currency of information:** Content must be routinely updated because cancer research moves quickly. What was considered sound medical knowledge just a few years ago might not be valid today.
 - ▶ **Red flags:** *Undated content, broken links.*
- ▶ **Quality safeguards:** At the best websites, an editorial board of top professionals with relevant expertise reviews the content.
- ▶ **Privacy protections:** A visitor’s health information should remain confidential. Credible websites explain what they will and will not do with such information if they ask for it. Many commercial sites sell it to other companies.

highly regarded websites, the health information may not apply to a specific situation.

Information found on the internet should not take the place of medical advice. Anyone with a health-related problem should talk to a doctor. There is no other way to get the same level of experience and personalized care with doctors offering advice tailored to a patient’s health history and unique medical situation.

Online searches produce not only what’s asked for but also commercial results, meaning that search engines may return sponsored findings with their results. Often, these links are at the top of the results list. They might be in a box, in a different color, above a line or below a header, but users should be able to distinguish these links from the regular search results. The sponsored results are actually ads for other websites. Sometimes users will find the links helpful, but many of the sponsors are just trying to sell a product.

ONLINE SUPPORT GROUPS, MAILING LISTS AND CHAT ROOMS

People use online support groups to share information and support over the internet through chat rooms, discussion boards and mailing lists. These websites allow people to connect with others like them who might otherwise be difficult to reach. They also allow users to keep their real identities private if they choose to do so. »

PART 2: AT DIAGNOSIS



Some people find online support groups and chat rooms helpful for sharing their experiences with other people facing the same things. Still, these places may not be the best sources of health information, especially if they are not monitored by trained professionals or experts. Patients should discuss any information they get with their health care teams to see if it applies to their situation.

EMAIL MESSAGES

If patients share their contact information on websites, emails may start pouring in. Well-meaning friends and family also may send emails with cancer information and treatment options from various sources. Patients should carefully evaluate any email messages they receive. Consider the source of the message and its purpose. Many companies and organizations use email to advertise or attract people to their websites. The information's accuracy could be influenced by their desire to promote their product or service.

One way to sift through the information is to identify respected, reliable sources of health information and use them as primary resources. ■

JUST THE FACTS

Reality Checkers

IF A STATEMENT OR CLAIM SEEMS TOO GOOD TO BE TRUE, it probably is. When conducting online research, check unsubstantiated claims through reliable resources, such as these:

✓ **American Cancer Society**

“Where Can I Find Trustworthy Info on Alternative Medicine?”
cancer.org/treatment/treatments-and-side-effects/treatment-types/alternative-medicine/finding-trustworthy-info.html

✓ **Memorial Sloan Kettering Cancer Center**

“About Herbs, Botanicals & Other Products”
mskcc.org/cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs

✓ **American Society of Clinical Oncology**

“Myths & Facts About Cancer”
cancer.net/sites/cancer.net/files/asco_answers_myths_facts_about_cancer.pdf

✓ **National Cancer Institute — Office of Cancer Complementary and Alternative Medicine**

“CAM Therapies: A-Z”
cam.cancer.gov/health_information/cam_therapies_a-z.htm

PART THREE

Choosing Treatment

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CURE[®] strives to provide current, unbiased and accurate information to help patients make treatment decisions. **Stay informed by subscribing to *CURE*[®] magazine and visiting curetoday.com.**



Making Medical Decisions

Taking the right steps can help patients handle the stress of treatment selection

THE DOCTOR-PATIENT RELATIONSHIP has changed. In times past, patients dutifully followed doctors' orders with few questions. Today, more patients are making medical decisions in partnership with their health care teams. It's not easy, due in part to the ever-increasing number of treatment options available.

For some patients, the right choice is treatment with a goal of cure, as long as there is some chance that outcome is possible, and regardless of the risks and costs of treatment. For others, cure is not the best goal because the chance of achieving that outcome is low and the price (discomfort, travel, expense, risk of death or complications) is high.

Doctors can provide patients with statistical data for each treatment option regarding chances of remission, cure rates, complications, side effects and mortality. They might be able to give some idea of what the treatment experience will be like. Survivors who have been through similar treatments can usually offer insight into what to expect, and doctors can refer patients who are willing to share their recollections and advice.

As patients weigh their options and discuss them with their doctors, they should consider these steps:

KNOW THE OPTIONS. Patients shouldn't try to decide which choice is best at the time they receive their diagnosis — just identify

CHECKLIST

Questions to Ask Before Choosing a Treatment

AFTER LEARNING THE CANCER'S TYPE AND STAGE, but before choosing a treatment plan, it's important to understand the expected benefits, side effects and risks of each option. Patients should take written questions to each appointment. Start with:

Will you do genetic testing of the tumor to find out if it includes molecular targets that can be addressed with targeted drugs or immunotherapies?

How often do you treat this kind of cancer?

Would a second opinion be helpful in establishing the diagnosis and making decisions about treatment?

What is the goal of treatment? Is it curative? Or will it extend life or help with symptoms?

What are the chances that the treatment will work?

How will you determine if a treatment is working?

If the treatment does not work, are there other options?

What are the potential risks and side effects of the treatment, and how do they compare with those caused by other treatments?

How will the treatment be given, how often and for how long?

Are there ways to prepare for treatment to decrease the chance of side effects?

Will daily activities be restricted in any way? Diet? Work? Exercise? Sex?

Are there any clinical trials to consider?

How much will treatment cost? Will it be covered by insurance? Are there less expensive treatments with similar effectiveness?

After treatment, what are the chances of being cured, in remission or relieved of symptoms?

For additional questions to ask your doctor based on your specific type of cancer, visit the American Cancer Society at cancer.org or call **800-227-2345**.

Adapted with permission of the American Cancer Society

as many options as possible, even if some seem far-fetched. Research indicates that most patients want complete medical information from doctors and to share the decision-making authority with them by creating a true partnership. Different doctors could recommend different drug or treatment combinations at various intervals. Then again, the best treatment might be no treatment. Patients diagnosed with certain slow-growing cancers may be given the

option of being closely monitored (“watchful waiting”) if there are no serious symptoms.

LEARN THE TRADE-OFFS. Once patients have a list of options, they should weigh the positives and negatives about each one. The goal is to know the risk versus the benefit of each option.


DISCOVER THE DATA. Patients should find out as much as they can about each »

PART 3: CHOOSING TREATMENT

option by talking with their doctors and doing research. For a crash course in any cancer, as well as news of cutting-edge treatments, visit cancer.org, cancer.net or cancer.gov.

BE VIGILANT. Patients should make sure the resources they check are credible. For tips on doing internet research, see page 64.

CONSIDER THE MEANING. A medical decision can mean different things to different people. Patients should understand how medical decisions can affect their quality of life and how these choices may affect their loved ones.

ACT WITH CONFIDENCE. It can be a tremendous relief for both patient and doctor once they settle on a treatment plan, but in the world of cancer, each decision carries a measure of uncertainty. Patients soon come to understand what oncologists have always known: Their treatments might or might not be effective. But in all cases, it is important that patients follow through with their plans, knowing that they are making the wisest choices they can at that time. 

ADVICE FROM *a* SURVIVOR

FELICIA MITCHELL




“Being educated can help patients make informed treatment decisions that are right for them, and cope with any curveballs a diagnosis throws. My bookshelf grew heavier as I explored the subjects of breast cancer, wellness, chemo brain, lymphedema and exercise options. I wanted to know what was going on inside me, how to weather the treatment and how to live past a cancer diagnosis.”



SCAN THE QR CODE to read **FELICIA'S** story.

TIMELY TIPS

CURE® ASKED SURVIVORS to offer their tips for patients who have recently received a cancer diagnosis. Here are some of their suggestions:

- 
- ▶ Bring someone along to take notes at all appointments.
 - ▶ Learn how to evaluate websites and be wary of blogs.
 - ▶ Get a second opinion.
 - ▶ Consider a clinical trial.
 - ▶ Don't be afraid to ask questions.
 - ▶ Stay active.
 - ▶ Be open to experimental options because new treatments and therapies are coming up all the time.
 - ▶ Ask for help and accept it when it is offered.
 - ▶ Join a support group.
 - ▶ Get counseling to cope.
 - ▶ Ask about long-term and late effects.
 - ▶ Make a treatment plan.

BE IN YOUR **mindful** **clever** MOMENT

concerned

professional

Thousands of women with metastatic breast cancer (MBC) are taking **IBRANCE, the #1 prescribed FDA-approved oral combination treatment for HR+*, HER2- MBC**

What Is IBRANCE® (palbociclib)?

IBRANCE is a prescription medicine used in adults to treat hormone receptor-positive (HR+), human epidermal growth factor receptor 2-negative (HER2-) breast cancer that has spread to other parts of the body (metastatic) in combination with an aromatase inhibitor as the first hormonal based therapy in postmenopausal women or in men.

Important Safety Information for Patients

IBRANCE may cause serious side effects, including:

Low white blood cell counts (neutropenia). Low white blood cell counts are very common when taking IBRANCE and may cause serious infections that can lead to death. Your doctor should check your white blood cell counts before and during treatment.

If you develop low white blood cell counts during treatment with IBRANCE, your doctor may stop your treatment, decrease your dose, or may tell you to wait to begin your treatment cycle. Tell your doctor right away if you have signs and symptoms of low white blood cell counts or infections such as fever and chills.

Lung problems (pneumonitis). IBRANCE may cause severe inflammation of the lungs during treatment that can lead to death. Tell your doctor right away if you have any new or worsening symptoms, including chest pain, cough with or without mucus, and trouble breathing or shortness of breath.

Your doctor may interrupt or stop treatment with IBRANCE completely if your symptoms are severe.

Before you take IBRANCE, tell your doctor about all of your medical conditions, including if you:

- have fever, chills, or any other signs or symptoms of infection.
- have liver or kidney problems.
- are pregnant or plan to become pregnant; IBRANCE can harm your unborn baby.
 - Females who are able to become pregnant should use effective birth control during treatment and for at least 3 weeks after the last dose of IBRANCE. Your doctor may ask you to take a pregnancy test before you start treatment with IBRANCE.
 - Males with female partners who can become pregnant should use effective birth control during treatment with IBRANCE for at least 3 months after the last dose of IBRANCE.
- are breastfeeding or plan to breastfeed. It is not known if IBRANCE passes into your breast milk. Do not breastfeed during treatment with IBRANCE and for 3 weeks after the last dose.

The most common side effects of IBRANCE include:

- Low red blood cell counts and low platelet counts. Call your doctor right away if you develop any of these symptoms during treatment:
 - dizziness
 - shortness of breath
 - weakness
 - bleeding or bruising more easily
 - nosebleeds

Other most common side effects include: infections, tiredness, nausea, sore mouth, abnormalities in liver blood tests, diarrhea, hair thinning or hair loss, vomiting, rash, and loss of appetite.

IBRANCE may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider about family planning options before starting IBRANCE if this is a concern for you.

These are not all of the possible side effects of IBRANCE. For more information, ask your doctor.

Tell your doctor about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. IBRANCE and other medicines may affect each other, causing side effects.

Do not drink grapefruit juice or eat grapefruit products while taking IBRANCE as they may increase the amount of IBRANCE in your blood. Tell your doctor if you start a new medicine. Take IBRANCE exactly as your doctor tells you.

If you take too much IBRANCE, call your doctor right away or go to the nearest hospital emergency room.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see Important Facts About IBRANCE on the following page.

To learn more, talk to your doctor.

Can't afford your medication? Pfizer may be able to help. Visit IBRANCE.com.

*Hormone receptor-positive includes estrogen receptor-positive (ER+) and/or progesterone receptor-positive (PR+)

IBRANCE®
palbociclib | 125 mg tablets



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April 2021

PP-IBR-USA-3608-02



IMPORTANT FACTS

IBRANCE® (EYE-brans) (palbociclib)

The risk information provided here is not comprehensive. This information does not take the place of talking to your healthcare provider about your condition or treatment. To learn more about IBRANCE talk to your healthcare provider or pharmacist. To obtain the FDA-approved product labeling call 1-800-438-1985 or visit www.IBRANCE.com.

What is IBRANCE?

IBRANCE is a prescription medicine used in adults to treat hormone receptor (HR)-positive, human epidermal growth factor receptor 2 (HER2)-negative breast cancer that has spread to other parts of the body (metastatic) in combination with:

- an aromatase inhibitor as the first hormonal based therapy in postmenopausal women or in men, or
- fulvestrant in people with disease progression following hormonal therapy.

It is not known if IBRANCE is safe and effective in children.

What is the most important safety information I should know about IBRANCE?

IBRANCE may cause serious side effects, including:

Low white blood cell counts (neutropenia). Low white blood cell counts are very common when taking IBRANCE and may cause serious infections that can lead to death. Your healthcare provider should check your white blood cell counts before and during treatment.

If you develop low white blood cell counts during treatment with IBRANCE, your healthcare provider may stop your treatment, decrease your dose, or may tell you to wait to begin your treatment cycle. Tell your healthcare provider right away if you have signs and symptoms of low white blood cell counts or infections such as fever and chills.

Lung problems (pneumonitis). IBRANCE may cause severe or life-threatening inflammation of the lungs during treatment that can lead to death. Tell your healthcare provider right away if you have any new or worsening symptoms, including:

- chest pain
- cough with or without mucus
- trouble breathing or shortness of breath

Your healthcare provider may interrupt or stop treatment with IBRANCE completely if your symptoms are severe. **See “What are the possible side effects of IBRANCE?” for more information about side effects.**

What should I tell my healthcare provider before taking IBRANCE?

Before taking IBRANCE, tell your healthcare provider about all of your medical conditions, including if you:

- have fever, chills, or any other signs or symptoms of infection.
- have liver or kidney problems.
- are pregnant, or plan to become pregnant. IBRANCE can harm your unborn baby.
 - Females who are able to become pregnant should use effective birth control during treatment and for at least 3 weeks after the last dose of IBRANCE. Your healthcare provider may ask you to take a pregnancy test before you start treatment with IBRANCE.
 - Males with female partners who can become pregnant should use effective birth control during treatment with IBRANCE for at least 3 months after the last dose of IBRANCE.
 - Talk to your healthcare provider about birth control methods that may be right for you during this time.
 - If you become pregnant or think you are pregnant, tell your healthcare provider right away.
- are breastfeeding or plan to breastfeed. It is not known if IBRANCE passes into your breast milk. Do not breastfeed during treatment with IBRANCE and for 3 weeks after the last dose.

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. IBRANCE and other medicines may affect each other causing side effects.

How should I take IBRANCE tablets?

- Take IBRANCE exactly as your healthcare provider tells you.
- IBRANCE tablets may be taken with or without food.
- IBRANCE should be taken at about the same time each day.
- Swallow IBRANCE tablets whole. Do not chew, crush or split IBRANCE tablets before swallowing them.
- Do not take any IBRANCE tablets that are broken, cracked, or that look damaged.
- Avoid grapefruit and grapefruit products during treatment with IBRANCE. Grapefruit may increase the amount of IBRANCE in your blood.
- Do not change your dose or stop taking IBRANCE unless your healthcare provider tells you.
- If you miss a dose of IBRANCE or vomit after taking a dose of IBRANCE, do not take another dose on that day. Take your next dose at your regular time.
- If you take too much IBRANCE, call your healthcare provider right away or go to the nearest hospital emergency room.

What are the possible side effects of IBRANCE?

IBRANCE may cause serious side effects. See “What is the most important safety information I should know about IBRANCE?”

The most common side effects of IBRANCE when used with either letrozole or fulvestrant include:

- low red blood cell counts and low platelet counts. Call your healthcare provider right away if you develop any of these symptoms during treatment:
 - dizziness
 - shortness of breath
 - weakness
 - bleeding or bruising more easily
 - nosebleeds
- infections (see “What is the most important safety information I should know about IBRANCE?”)
- tiredness
- nausea
- sore mouth
- abnormalities in liver blood tests
- diarrhea
- hair thinning or hair loss
- vomiting
- rash
- loss of appetite

IBRANCE may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider about family planning options before starting IBRANCE if this is a concern for you.

These are not all of the possible side effects of IBRANCE.

Keep IBRANCE and all medications out of the reach of children.

Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

To learn more, talk to your doctor.

These IMPORTANT FACTS are based on IBRANCE® (palbociclib) Patient Information LAB-1372-1.0, Rev. 11/2019.

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Turn to Pfizer Oncology Together to learn about financial assistance resources and get personalized support from one of our dedicated Care Champions.



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**LEARN MORE!**

Second opinions may enhance your treatment plan or even change your course. **Scan the QR code to learn more.**



Seeking a Second Opinion

Why and how patients should get another opinion about their diagnosis and treatment

EVERY PATIENT HAS THE OPTION to get a second opinion about any aspect of diagnosis or treatment. In fact, getting a second opinion is common, and several situations could actually call for one.

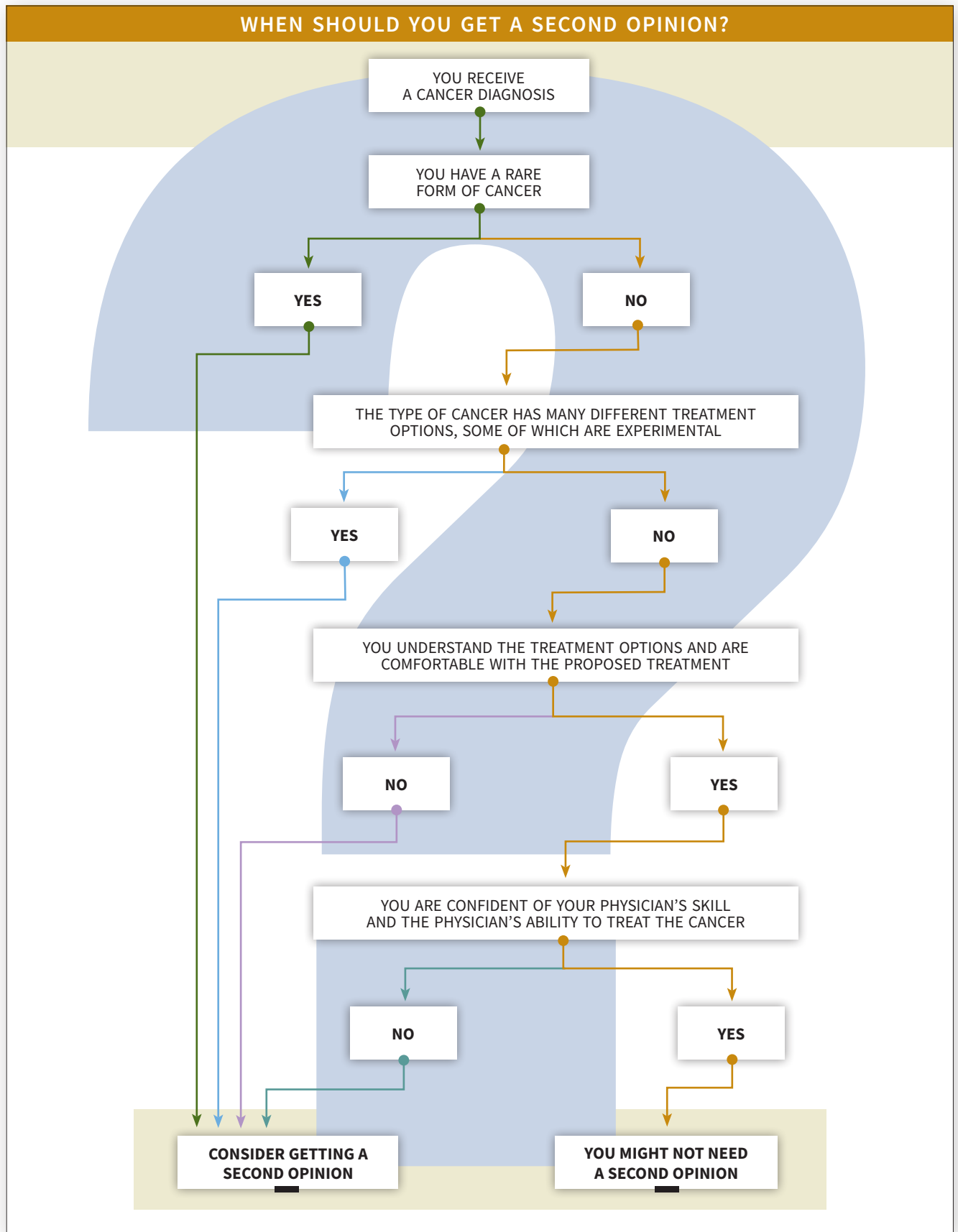
Whether there is concern about a recommended treatment or just a desire to hear the diagnosis confirmed from another physician, a second opinion is appropriate. A patient might also seek a second opinion if the pathologist is having difficulty making a diagnosis, if he or she has a rare type of cancer that the doctor is unfamiliar with, if the patient thinks the doctor underestimates the seriousness of the disease or if the medical insurance plan requires one.

Patients can request a second review of their pathology slides or another opinion about treatment if their choices are numerous and they want reassurance they have chosen wisely. A second opinion can clarify a diagnosis or provide treatment options about which a patient was not aware, including those offered through clinical trials.

FIND REFERRALS

Patients should seek a second opinion from a physician outside their current doctor's practice. They shouldn't worry about offending their doctor; most oncologists expect patients to seek a second opinion. Some suggest it and offer recommendations. »

PART 3: CHOOSING TREATMENT



Many local hospitals, regional cancer centers and institutions, including the National Cancer Institute (cancer.gov) and the National Comprehensive Cancer Network (nccn.org), have physician referral services that provide consultations for second opinions. Some large cancer centers have formal second-opinion programs designed to provide advice quickly. They do this by scheduling patients to see doctors of different specialties all in one day. In addition, some cancer centers offer second opinions from afar, based on records and images that are sent to them. This allows patients to seek second opinions from top experts without traveling.

Seeking a second opinion from an expert in the patient's specific cancer can provide another viewpoint. Such an expert could suggest clinical trials the patient's doctor might be unaware of or confirm a treatment recommendation.

People in support groups and other cancer survivors can also be good sources for recommending oncologists and specialists.

Patients can also identify experts through scientific journal articles about their cancer types. Doctors who have authored several articles on a particular cancer are generally considered experts and might be available for a second opinion and consultations. Patients should inquire about online or telephone referrals, especially if they want a second opinion from an expert at a large cancer center or one who practices far from where they live. Be aware, however, that consultations can be expensive and might not be covered by insurance.

COVER ALL THE BASES

Before seeking a second opinion, patients should obtain information about their disease, including diagnosis, staging, treatment options and how recurrence might be prevented. They should ask their physician to send test results and imaging scans to the consulting doctor. Patients might need to repeat some tests, but the

second doctor will want to look over existing test results and scans.

Some insurance plans cover, or even require, second opinions before approving payment for treatment. Some plans limit coverage to certain physicians or hospitals, so it is always best for patients to consider their plans when coordinating second-opinion appointments.

WEIGH THE OPTIONS

Some patients might get confused about what advice to follow if the second doctor recommends a different treatment, which might be likely if their cancer does not have a set standard of therapy.

For example, both surgery and radiation therapy might be suggested as options for a patient with early prostate cancer, because both treatments have excellent long-term cure rates. A urologist who specializes in prostate surgery might be more inclined to recommend surgery than a radiation oncologist would. In that case, the decision would depend on how the patient weighs the side effects of each treatment in relation to his own personal views and lifestyle. A patient's primary care physician could also have helpful advice about weighing inconsistent recommendations.

Patients might also want to seek a third opinion if they are still uncomfortable with their diagnosis or treatment options. Although it might not be necessary for their cancer to be treated by a specialist, they might want to hear the opinion of someone who focuses only on their type of cancer, especially if their first two doctors recommended different therapies or had conflicting diagnosis results.

After weighing the options, patients must decide on their medical teams. Most patients proceed with their initial doctors, but comfort level, proposed treatment options and medical expertise should all be evaluated when making a decision. ■



LEARN MORE!

Radiopharmaceuticals are one of many treatment options for certain cancer types. Scan the QR code to learn more about this treatment strategy.



Making Sense of Cancer Therapies

Proven approaches and new technologies mean individualized treatment

SCIENTISTS CONTINUE TO LEARN more about cancer's biology and how it affects each patient.

As they make new discoveries, they are able to refine existing treatments and develop new ones. In addition, research continues to lead to new combinations of different types of drugs that fight cancer more effectively together, such as pairings of chemotherapy with radiation or groupings of chemotherapy with immunotherapy and a targeted drug.

SURGERY

In many cases, surgery can be used to remove a tumor and, depending on the pathology of the cancer, the surrounding tissue. In some circumstances, patients might be eligible for less invasive surgical options.

Laparoscopic surgery requires one or more small incisions that allow a thin fiber-optic

scope, called a laparoscope, and specially designed surgical instruments to be inserted into the body to remove the tumor. Disease-free survival and recurrence rates for specific tumor types and stages seem to be about the same with laparoscopic surgery compared with traditional open surgery. The main benefits are faster recovery times, shorter hospital stays and fewer complications. A similar technique, used for lung and other thoracic cancers, is thoracoscopic surgery, during which a tiny camera and surgical instruments are inserted through a thin incision in the chest wall.

Robot-assisted surgery could have even more benefits for some patients. As with laparoscopic surgery, robot-assisted procedures require a few small incisions. But instead of directly manipulating the surgical instruments,

the surgeon sits at a console to perform the procedure by directing robotic arms. The process enables finer movements yet prevents the surgeon from feeling the tissue in the same way as in open surgery. In addition to prostatectomy (surgery to remove the prostate gland), robot-assisted surgery can be used for hysterectomy to treat cervical and endometrial cancers, and to treat some bladder, throat, thyroid and kidney cancers. When performed correctly by well-trained surgeons in appropriate patients, robot-assisted procedures have the potential to prevent some short-term complications, such as blood loss, and to reduce the length of hospital stays compared with open surgery.

Radiofrequency ablation, or RFA, is an outpatient procedure that uses heat delivered through a thin, needle-like probe inserted into the tumor to kill tumor cells. **Cryoablation** is a similar procedure that uses rapid freezing and thawing to kill the cancer cells.

RADIATION THERAPY

Radiation therapy is used alone to treat some cancers, but most often in combination with other therapies to improve the cure rate after surgery. Radiation could also be used to allow less extensive surgery or to relieve side effects of advanced cancer. High doses of radiation can cause side effects after treatment, as well as late effects, such as secondary cancers. Newer specialized techniques more accurately target radiation to tumors and minimize these effects.

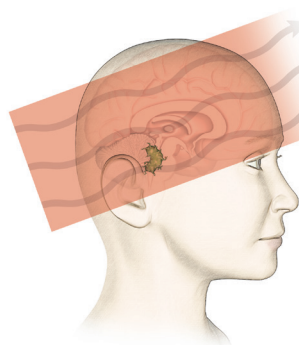
TARGETED RADIATION THERAPY TYPES

Brachytherapy radiates the cancer cells directly by implanting radioactive seeds or wires into the body in or near the tumor. Brachytherapy is used in prostate, cervical and other cancers. Brachytherapy can also be used in breast cancer. This is a type of partial breast irradiation and is sometimes used for smaller, lymph node-negative, lower-risk breast cancers. »

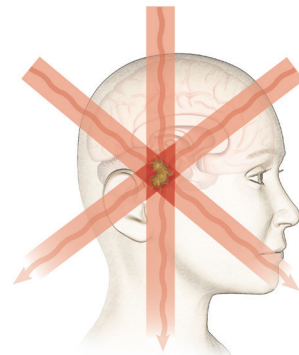
ILLUSTRATION BY ERIN MOORE

COMPARING RADIATION THERAPIES

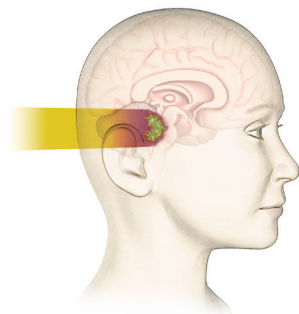
COMPARED WITH TRADITIONAL RADIATION therapy, which can kill cancer cells but also damage healthy tissue, specialized techniques deliver radiation to the tumor more precisely, with less severe side effects.



X-ray Beam
X-rays are high-energy photons created by machines, and although the beam can be aimed at a tumor, the radiation dose is also delivered to healthy tissue in front of and behind the tumor. The energy breaks DNA bonds, causing cell death.



Stereotactic Radiosurgery
Stereotactic radiosurgery uses highly focused X-rays or gamma rays that originate at many different angles and intersect at the tumor site. The tumor is hit with a high, concentrated dose of radiation, sparing surrounding healthy tissue from the full dose.



Proton Beam
The larger size of a proton particle, used in specific cases, ensures that the bulk of energy is deposited exactly at the tumor site, allowing more precise treatment and, in some cases, treatment of areas previously radiated with standard radiation.

PART 3: CHOOSING TREATMENT

Radiopharmaceuticals contain radioactive elements that deliver radiation directly to tumors. These injections are approved to treat bone metastases in prostate and thyroid cancers, as well as some types of lymphoma, and to alleviate cancer-related bone pain; these drugs can also be delivered to tumors in the liver.

Conformal radiation uses several weak radiation beams originating from different angles that intersect to produce a concentrated high dose of radiation at the tumor site. Advanced conformal therapy, such as intensity-modulated radiation therapy, uses multiple beams with varying intensity.

Stereotactic radiosurgery, such as Gamma Knife, uses a computer to simultaneously focus about 200 small beams onto a tumor in the brain while the patient's head is immobilized in a special helmet. A similar technique, known as CyberKnife, bypasses the need for the helmet by using imaging to make adjustments for movements. Gamma Knife is used for small- to medium-sized tumors in the brain, and CyberKnife is employed for larger tumors and tumors in other areas of the body.

Proton beam therapy uses positively charged particles, called protons, that only travel a certain distance. The method allows doctors to control the depth of radiation more precisely and deliver more of it to tumors while sparing nearby healthy tissue. Proton beam therapy is used for some childhood cancers and certain cancers of the brain, central nervous system, eye, head and neck, liver and lung, and some sarcomas. It's also being investigated in breast, esophageal, prostate and other cancers. More research is needed to determine if side effects are less intense than with older types of radiation.

CHEMOTHERAPY

While surgery and radiation target the tumor, chemotherapy targets the whole body systemically through a number of mechanisms of action. New chemotherapy drugs are more effective and

less toxic than agents developed 50 years ago, due to greater knowledge about how to deliver them, including optimal dose and frequency of dose, alone and in combination.

Chemotherapy can be given as the primary — or main — treatment for some cancers, such as lymphoma and leukemia. It can also be given after the cancer has been removed as adjuvant therapy, which might improve survival and delay or prevent disease progression. Neoadjuvant chemotherapy is given before surgery to shrink tumors enough to permit less extensive surgery. When cancer is not curable, palliative chemotherapy can often reduce symptoms caused by tumors and help people live longer.

CLASSES OF CHEMOTHERAPY AGENTS

Antimicrotubule agents disrupt mitosis, a phase of cell division in which a cell duplicates and separates the chromosomes in its cell nucleus. Mitotic inhibitors include taxanes and vinca alkaloids (which are approved to treat some solid tumors, as well as lymphomas and leukemias) and epothilones (which are used to treat advanced breast cancer when taxanes no longer work). Mitotic inhibitors are known for their potential to cause peripheral nerve injury (neuropathy), a potential dose-limiting side effect.

Alkylating agents are used to treat blood-related cancers, such as non-Hodgkin lymphoma, Hodgkin lymphoma, chronic leukemias and multiple myeloma, and are also effective in breast, lung, ovarian and some gastrointestinal cancers. Alkylating agents work by damaging the DNA of cancer cells to prevent them from dividing and multiplying. This group includes platinum-based chemotherapies.

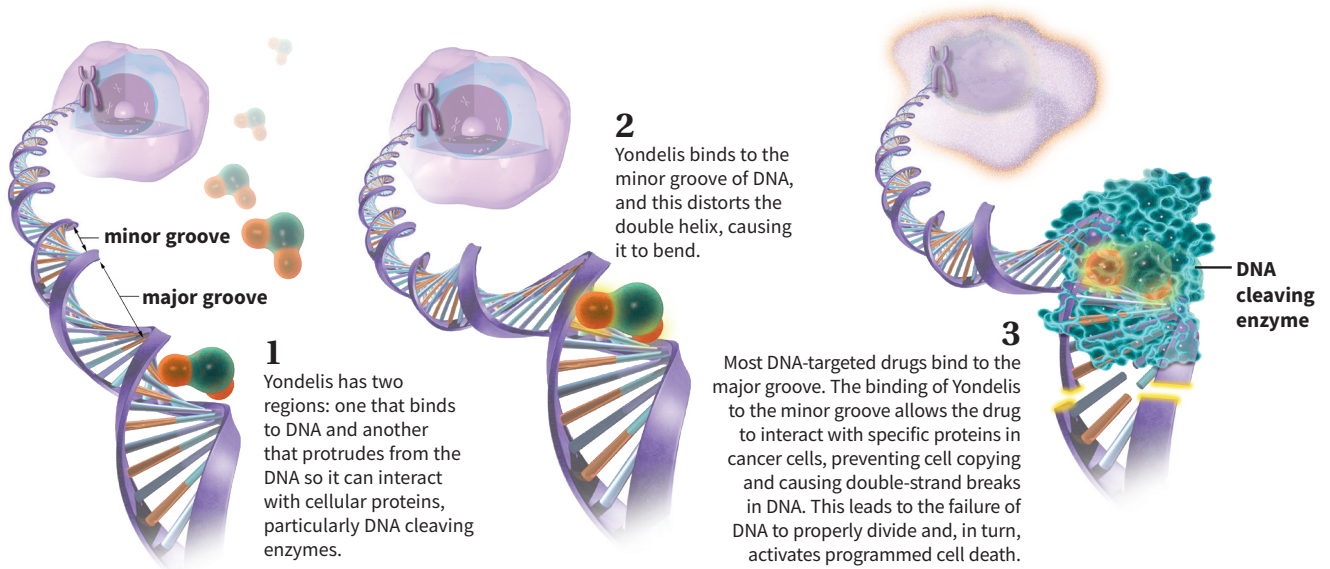
Antimetabolites interfere with DNA and RNA production. They are effective in a specific cycle of cell growth and are used against leukemias, lymphomas and cancers of the ovary, breast, gastrointestinal tract and lung.

Topoisomerase inhibitors interfere with enzymes that are important for accurate DNA replication. »

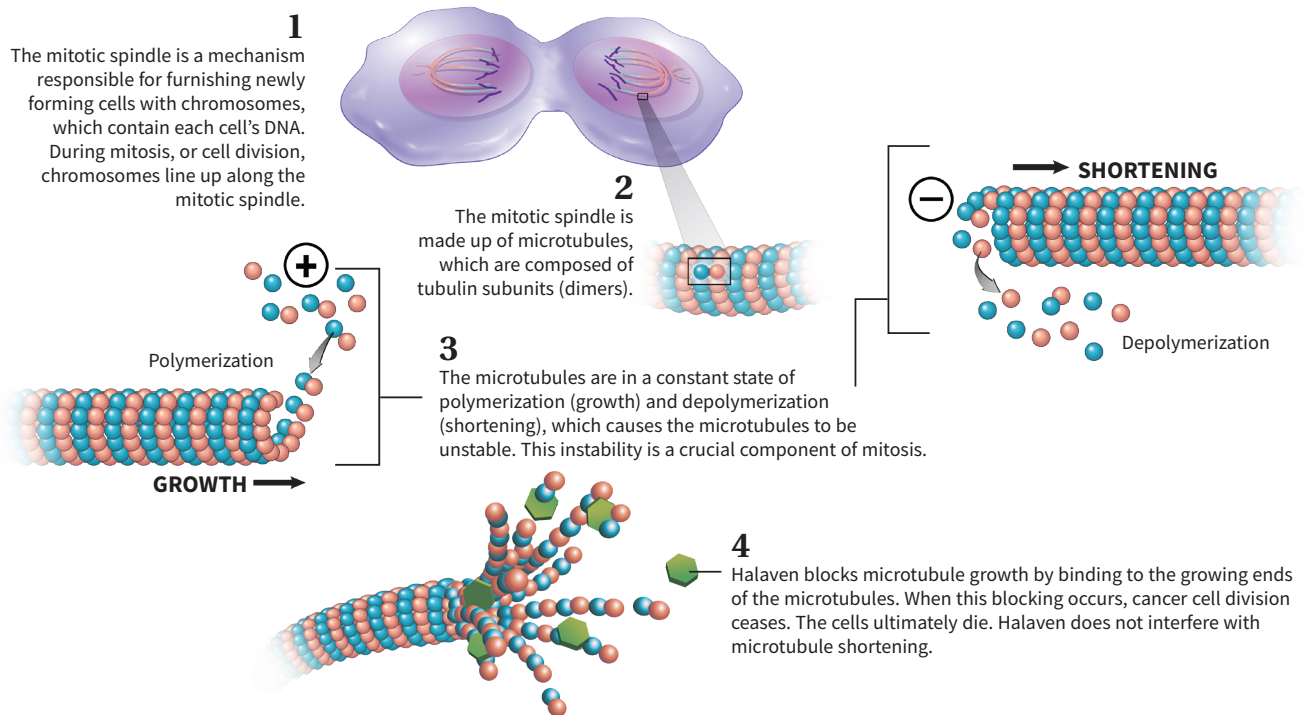
MARINE-DERIVED CANCER TREATMENTS

YONDELIS (trabectedin) and HALAVEN (eribulin) are the first chemotherapies originally derived from marine life, although they are now synthetically made. Both of these alkylating agents are approved for the treatment of liposarcoma, and Yondelis also for the treatment of leiomyosarcoma. These conditions are types of soft-tissue sarcoma, meaning that they are among at least 50 rare cancers that have individual characteristics but start in the body's connective tissues. Halaven is also approved for the treatment of breast cancer.

YONDELIS was originally made from sea squirts, or the marine organism *Ecteinascidia turbinata*. It works by stopping the abnormal multiplication of cancer cells within the body that would otherwise spread, destroying nearby tissues. It does this by binding to and damaging the DNA in cancer cells, causing the cells to die.



HALAVEN was derived from an antibiotic substance, halichondrin B, that is produced by a type of black sponge that lives along the coast of Japan. The drug works by stopping the process of cell division within cancer cells.



PART 3: CHOOSING TREATMENT

They are used to treat certain types of leukemia, as well as colorectal, gastrointestinal, lung, ovarian and other cancers.

Anthracyclines are anti-tumor antibiotics that interfere with enzymes involved in DNA replication. Anthracyclines treat a variety of tumors and work in all phases of the cell cycle. Because they can damage the heart muscle, anthracyclines have a lifetime dose limitation.

STEM CELL TRANSPLANTATION

Bone marrow, the spongy material inside the bone, is the natural home for hematopoietic stem cells (HSCs), the “parent cells” that develop into different types of blood cells. These stem cells can be retrieved from either the patient (called an autologous transplantation) or a donor (an allogeneic transplantation). Patients who provide their own HSCs have them removed from the bone marrow or the bloodstream prior to chemotherapy and/or radiation, and the cells are frozen for later use. In other cases, the HSCs come from a donor, who might be an identical twin, another close relative (often a sibling), an unrelated person or even an unrelated newborn. Patients with leukemia, myeloma, low-grade lymphoma, myelodysplastic syndromes and, less often, various other cancers, might be treated with stem cell transplantation.

High doses of radiation and/or chemotherapy have the unwanted side effect of damaging a patient’s bone marrow stem cells. Transplantation restores the patient’s bone marrow. Over time, the infused cells divide and mature into cells normally produced by healthy bone marrow, a process known as engraftment. When donor cells mount an immune attack on residual cancer cells, the effect is called graft-versus-tumor.

Graft-versus-host disease, or GVHD, can occur after allogeneic transplantation if the donor immune cells view the recipient’s body as foreign. The recipient’s immune system has largely been destroyed by conditioning treatment and cannot fight back. The donor immune cells can attack certain organs (most

often the skin, liver and gastrointestinal tract), which impairs the organs’ ability to function, while the required suppression of the immune system increases the chance of infection.

About one-third to one-half of patients who receive an allogeneic transplantation develop acute GVHD within 25 days (on average). Serious cases of uncontrolled GVHD, though uncommon, can be fatal.

HORMONE THERAPY

Hormone therapies interfere with the interaction of sex hormones (androgens and estrogens) and some types of cancer, particularly breast and prostate. Hormone therapy can be used alone or with other treatments.

Following surgery, women with breast cancer that is shown to be fueled by estrogen are treated with an estrogen blocker and/or drugs called aromatase inhibitors. These drugs are taken for at least five years. Aromatase inhibitors block an enzyme that converts androgens to estrogens in postmenopausal women.

Patients with prostate cancer could receive androgen-deprivation therapy to lower testosterone levels. Another group of drugs, known as anti-androgens, are sometimes helpful if other hormone therapies stop working. Removing the ovaries or testicles can also reduce the level of sex hormones.

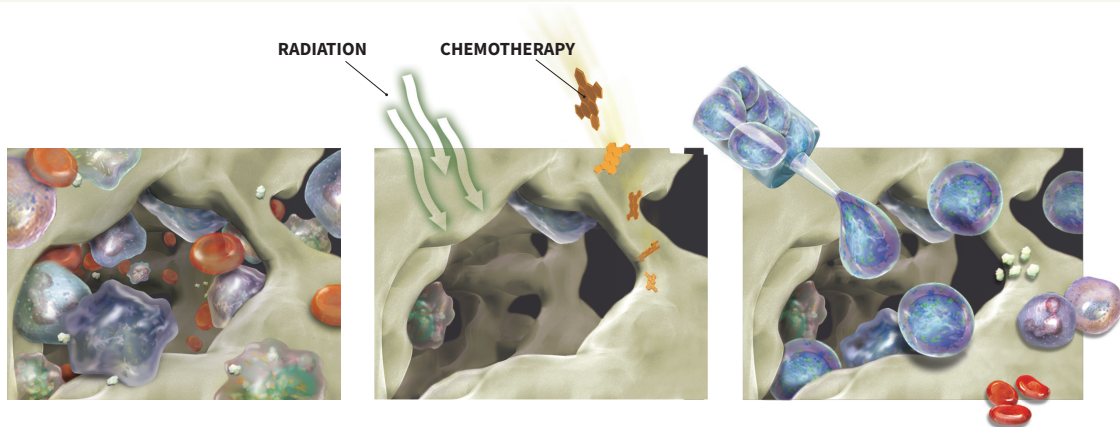
TARGETED THERAPY

Researchers have learned more about specific molecular changes responsible for cancer growth, resulting in new drugs called targeted therapies. These drugs target genes or proteins in the cell. However, many of these newer agents must be combined with traditional chemotherapy, and some carry their own side effects, such as rash, diarrhea, heart malfunction or high blood pressure.

Angiogenesis inhibitors prevent the formation of new blood vessels to the tumor (angiogenesis). Shutting down its blood supply shrinks the tumor, which needs nutrients and oxygen from blood to survive and grow. Most anti-angiogenic drugs target either a protein secreted by certain tumors to promote the growth of new blood vessels (called

STEM CELLS & TRANSPLANTATION

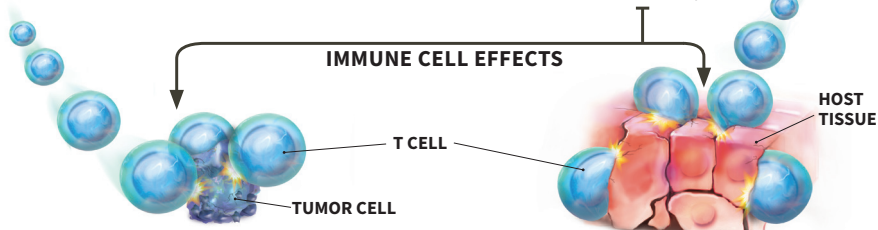
TO THE BONE AND BEYOND – Blood-forming (hematopoietic) stem cells can be harvested from the bone marrow, drawn from the circulating (peripheral) blood or taken from blood in a newborn’s umbilical cord and placenta.



Cancer cells in the bone marrow or blood can impede the immune system and disrupt blood function.

Radiation and chemotherapy destroy most rapidly dividing cells, yet residual malignant cells can lead to relapse.

Donor stem cells travel to the marrow, where they begin producing healthy blood cells that redevelop the immune system.



Graft-Versus-Tumor
The donor immune cells (the graft) attack any remaining cancer cells in the blood.

Graft-Versus-Host Disease (GVHD)
The donor immune cells (the graft) recognize the recipient’s (the host’s) tissues as “foreign” and attack those tissues.

vascular endothelial growth factor, or VEGF) or the VEGF receptors on blood vessel cells.

Kinase inhibitors block enzymes with a variety of functions, including angiogenesis, growth factor receptors and other aspects of cell signaling, and are used in treating many types of cancer.

Proteasome inhibitors treat multiple myeloma and mantle cell lymphoma by blocking multi-enzyme complexes called proteasomes. These molecules break down proteins involved in regulating cell processes relevant to cancer.

mTOR inhibitors block a key protein in cells that regulates cell growth and survival. These inhibitors block the translation of genes that regulate the cell cycle and

reduce levels of certain growth factors involved in the development of new blood vessels, such as VEGF. mTOR inhibitors are currently used for breast, kidney, neuroendocrine and other cancers.

PARP inhibitors block the activity of an enzyme that helps cancer cells repair their DNA when it’s damaged. This can cause the cells to die. Often, these drugs work well in cancers with inherited or acquired mutations to the BRCA genes, because these cancers already have DNA repair problems and the medications further interfere with that process. PARP inhibitors are used to treat breast, ovarian, pancreatic and prostate cancers.

Histone deacetylase inhibitors interfere with the activity of specific proteins to stop cancer cells from repairing their DNA when it’s damaged and change the way certain »

CANCER THERAPY'S MANY TARGETS

A VARIETY OF METHODS ARE NEEDED to attack the numerous ways cancer cells multiply, spread and survive, including those illustrated here. By combining agents that use different strategies, scientists are gaining ground on cancer.

It only takes a small percentage of cancer cells to break away from the tumor and invade other organs via the bloodstream or lymph system. Methods to block cell mobility and **ultimately prevent metastasis** are under way.

Proteins, such as VEGF, are secreted by cancer cells to signal blood vessel growth to the tumor. **Anti-angiogenic drugs block these proteins** and starve the tumor of nutrients.

DNA contains the cancer cell's instructions to multiply and resist death. Chemotherapy targets the DNA of these fast-growing cancer cells, **stopping proliferation** and causing cell death.

Hormones spur the growth of hormone-dependent breast, ovarian and prostate cancers. **Hormonal agents cut off the effect of hormones** on cancer cells by either lowering hormone levels or blocking receptors.

Growth factors signal the cell to continue multiplying at an abnormal rate. When targeted agents bind to these growth factors or their intended receptors, **the pathway is halted or turned off.**

genes express themselves. This harms the ability of cancer cells to function, preventing them from growing and multiplying. These drugs are approved to treat multiple myeloma and T-cell lymphoma.

Monoclonal antibodies are laboratory-manufactured versions of natural human antibodies, proteins made by the immune system to fight invaders such as cancer. Monoclonal antibodies are designed to seek out and bind to antigens, or markers, on the surfaces of cancer cells, thus stimulating the immune system to attack those cells. These drugs are approved to treat many cancer types, including breast, blood and colorectal.

Antibody-drug conjugates combine two kinds of drugs. One type are monoclonal antibodies, targeted immunotherapies that use natural

substances or engineered alternatives to boost the immune system and fight cancer. They have been approved by the Food and Drug Administration (FDA) for many types of cancer. Antibody-drug conjugates use a linker to attach one of these drugs to a potent chemotherapy agent. The antibody delivers the chemotherapy to cancer cells, and, once the drug is absorbed by the cells, the linker releases the chemotherapy. The FDA has approved this type of treatment for HER2-positive breast cancer and certain types of lymphoma. (See page 84 to learn more about immunotherapies.)

IMMUNOTHERAPY

Drugs that stimulate the body's immune system to attack cancer are known as immunotherapies. In the pages immediately ahead, we explore immunotherapy types including checkpoint inhibitors and chimeric antigen receptor (CAR)-T cell therapy.

WEARABLE DEVICES

Wearable therapeutic devices are newer techniques. One of them, Optune, is approved to treat the brain cancer glioblastoma. Designed to be worn 18 hours a day, the device uses tumor-treating electromagnetic fields to prevent cancer DNA from dividing and multiplying.

A product called Quell is for cancer pain. It wraps around the calf and sends low-frequency electricity to sensory nerves, causing the brain to block pain signals.

Other wearable devices include scalp cooling caps, worn for a period of time before, during and after chemotherapy infusions to help prevent hair loss. Additionally, devices that may detect certain types of cancer are being studied.

NEOADJUVANT AND ADJUVANT TREATMENTS ENHANCE PRIMARY THERAPY

It is becoming more common for patients with cancer to get neoadjuvant and adjuvant treatments, which are given before and/or after the main therapy. These therapies are used in cancers including breast, lung, bladder, colon and ovarian.

Neoadjuvant treatments are often given before surgery to shrink a tumor so it is easier to fully remove. In some cases, the amount of shrinkage affects subsequent treatment decisions. The goal of adjuvant treatment is to prevent recurrence or spread by killing any cancer cells that linger after the primary treatment, which in many cases is surgery.

A number of treatments can be used as neoadjuvant or adjuvant therapies, including chemotherapy, targeted drugs, radiation and hormone-blocking medications. Immunotherapy is available as an adjuvant therapy and is being studied as a potential neoadjuvant treatment.

These before-and-after treatments are given when scientific evidence shows that they are likely to improve health outcomes based on the cancer’s type and stage. They are typically given to patients whose cancer has grown past the very earliest stage, so there is a risk it could leave cells behind after primary treatment, but not to the metastatic stage, meaning it has reached distant parts of the body. Patients with cancers driven by mutations associated with a high risk of recurrence might also benefit from neoadjuvant and/or adjuvant treatments.

ADVICE FROM *a* SURVIVOR

EMILY WARD



“To get a grasp of my situation, I had to spend a lot of time doing my own research. I had to become an advocate for my own health, as most doctors in Maine had never heard of (mesothelioma) except for the legal commercials on TV.

I knew I didn’t want to sacrifice my quality of life for more time on this earth. I had to be the one to push for a lower dose on my pain medications. In a similar situation a few years later, after my third round of chemotherapy began to take a heavy toll, I had to speak up and ultimately decided to stop treatment. Thanks to the continued efforts and honest opinion of my current oncologist, I decided to begin treatment again, this time with (an) experimental immunotherapy drug.

I recently celebrated seven years as a mesothelioma survivor. I wholeheartedly believe that I would not have made it this long without the research I did. Patients need to ensure they understand and trust everything they are being fed by their health care team. It is every patient’s responsibility to become self-educated on what they can do to help beat their cancer, whether that’s making the decision to travel further away to receive treatment from a specialist or seeking the guidance of an outside advocacy group. Ultimately, patients should feel informed enough to choose and determine which options are right for them.”



SCAN THE QR CODE to read EMILY’S story.

Like primary treatments, these types of treatments can cause side effects, so patients should talk with a doctor about the types of therapies recommended, how much they are expected to lower risk of recurrence or cancer death, how they will affect daily life and for how long. **■**



LEARN MORE!

Online resources provided by the Cancer Research Institute can inform you about cancer immunotherapy.

Scan the QR code to read *CURE*'s article.



Delving Into Immunotherapy

Understanding how the immune system controls itself has led to impressive treatment gains

IMMUNOTHERAPY IS A RAPIDLY evolving strategy that enlists the body's own immune system to fight cancer. These treatments work by stimulating the production and activity of T cells and antibodies, which exist naturally in the body and have the ability to recognize and kill cancer cells.

Types of cancer that can be treated with immunotherapies approved by the Food and Drug Administration include melanoma, Hodgkin lymphoma, acute lymphoblastic leukemia, squamous cell carcinoma of the skin, and kidney, bladder, lung, prostate, breast, colorectal, liver, gastric, cervical, uterine, brain, pancreatic, esophageal and head and neck cancers. Immunotherapies are also being tested in other forms of cancer, including additional blood cancers.

Combinations of these drug types with each other, or with other anti-cancer therapies, may be more effective for some patients.

While immunotherapies don't cause the hair loss that comes with chemotherapy, they can spark nausea, rash, fever, chills, fatigue, diarrhea or even severe autoimmune reactions or endocrine hormone deficiencies. These drugs can also be very expensive.

So far, 20% to 30% of patients with immunotherapy-treatable cancers respond, and researchers are asking why, and figuring out how to make the most of the treatments. Some responses can be long-lasting or curative, so there is interest in refining this approach and expanding the number of patients and types of tumors that can be successfully treated. »

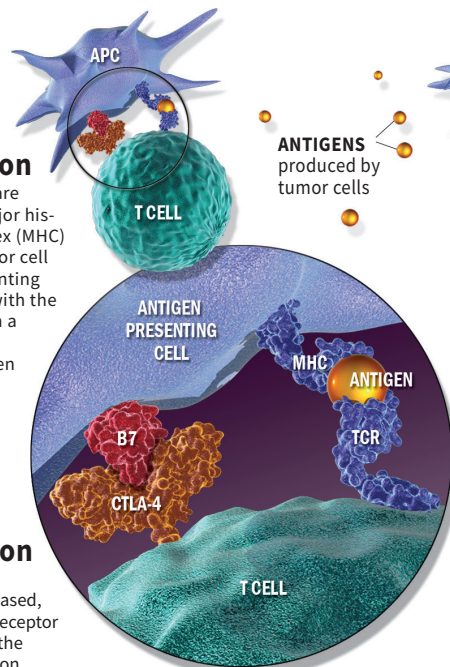
IMMUNOTHERAPY FOR LUNG AND OTHER CANCERS

IMMUNOTHERAPIES CALLED CHECKPOINT INHIBITORS are changing the landscape of treatment for lung, melanoma and other cancers. Several approved immunotherapies inhibit the PD-1/PD-L1 cell signaling pathway, and one inhibits the CTLA-4 pathway. All of these drugs work by taking the brakes off the immune system and boosting its power to fight cancer.

CTLA-4 Pathway

1 T-Cell Activation

Immune cells (T cells) are activated when the major histocompatibility complex (MHC) — a molecule on a tumor cell or on an antigen-presenting cell (APC) — interacts with the T-cell receptor (TCR) on a T cell. Specifically, the MHC presents an antigen to the TCR, telling it what it should be activated against.

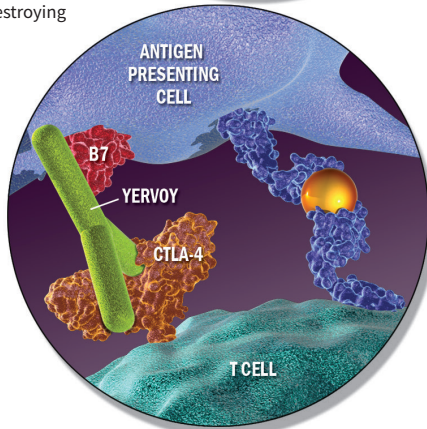


2 Immune Evasion

Immune cells can be downregulated, or decreased, when CTLA-4, a protein receptor on the T cell, binds with the protein B7. This interaction prevents T cells from destroying cancer cells.

3 Treatment

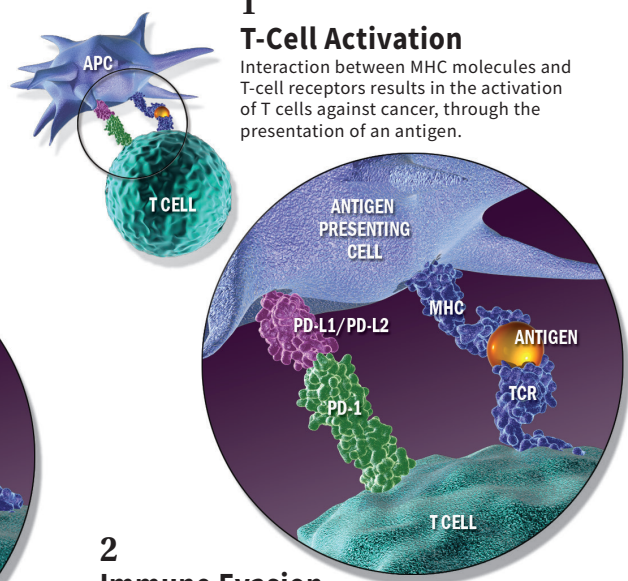
Blocking the interaction between CTLA-4 and B7 with a CTLA-4 inhibitor, like Yervoy (ipilimumab), allows the T cell to stay active, proliferate and attack the tumor.



PD-1/PD-L1 Pathway

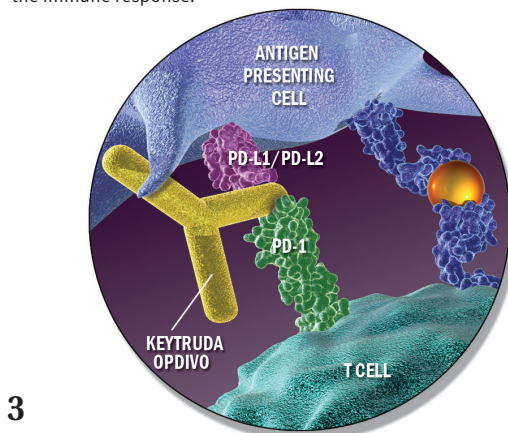
1 T-Cell Activation

Interaction between MHC molecules and T-cell receptors results in the activation of T cells against cancer, through the presentation of an antigen.



2 Immune Evasion

A protein on the T cell called PD-1 can bind with the ligands (molecules) PD-L1 and, to a lesser degree, PD-L2, dampening the immune response.



3 Treatment

Blocking PD-1 or PD-L1 with Keytruda (pembrolizumab), Opdivo (nivolumab), Tecentriq (atezolizumab), Imfinzi (durvalumab) or Bavencio (avelumab) allows the T cells to remain activated against the tumor.

PART 3: CHOOSING TREATMENT

CYTOKINES

Some cytokines, such as interleukins and interferons, which are found naturally in the body, can also be produced in the laboratory and given to patients to change the way their immune systems are regulated, potentially stimulating immune responses. These approved drugs are used to treat melanoma, kidney and bladder cancers, although they work only in a minority of those patients, and side effects can be severe.

IMMUNE CHECKPOINT INHIBITORS

While T cells have cancer-killing ability, they are normally held somewhat at bay by “inhibitory checkpoints” in the immune system. The job of these checkpoints is to keep the T cells from engaging in out-of-control activity. The problem with this system is that cancers can hide in the body by sending out the same signals as these checkpoints, along the cell-signaling pathways PD-1/PD-L1 or CTLA-4; this way, T cells don't recognize or fight them.

One group of immunotherapy drugs blocks this kind of signaling so that the checkpoints no longer have a hold over the activity of T cells. This frees up the T cells to fight cancer. However, in doing so, the immune cells also attack some normal tissue, causing a variety of side effects.

Checkpoint inhibitors have been approved for the treatment of a variety of solid tumor types, and continue to be tested in clinical trials. They are also approved to treat any cancer, regardless of type, that is considered microsatellite instability-high, meaning that cancer cells are unable to repair their own DNA when it's damaged.

MONOCLONAL ANTIBODIES

When the immune system is provoked by foreign cells and other substances, it reacts by activating T-cell lymphocytes (a type of white blood cell), which can directly kill foreign cells, and by stimulating B-cell lymphocytes to make proteins called antibodies. These antibodies are drawn to other proteins known as antigens, which sit perched on the outsides of cells; drawn like magnets, the antibodies attach to the antigens. Once in place, the antibodies call in the immune system to destroy the cells to which they are attached.

Monoclonal antibodies, which are designed to seek and destroy specific cancer-associated antigens, can be made in a lab and then given to patients. Some of these strictly target one type of antigen, but cannot always fight tumors on their own. Bispecific antibodies may be more effective, because they can bind to, and destroy, two different antigens present on one or many cells. One antibody enlists a T cell while the other targets a tumor, bringing the main partners of the immune process together.

ADOPTIVE T-CELL THERAPY

If a good immune response is already happening in a patient's body, adoptive T-cell therapy may improve it. In adoptive cell transfer, a sample of a patient's tumor is sent to a lab, where T cells inside the tumor are removed and stimulated to recognize a tumor surface protein and increase in number. Then, this larger group of T cells, known as tumor infiltrating lymphocytes, is returned to the patient intravenously. This experimental method has been shown to induce complete, durable regression of certain malignancies, including a number of blood cancers and melanoma.

CHIMERIC ANTIGEN RECEPTOR THERAPY

Like adoptive T-cell therapy, chimeric antigen receptor (CAR) therapy involves manipulating a patient's T cells in a lab. But in this case, the T cells are genetically modified to express a specific surface receptor, which prepares them to home in on, and attack, specific proteins on a particular kind of cancer cell. When the CAR T cells are infused into the patient's body, they can multiply and continue to eradicate tumors over time. Currently, there are two CAR-T cell therapies approved in the U.S. One is for advanced or recurrent acute lymphoblastic leukemia in children and young adults. The other is for certain types of advanced or recurrent non-Hodgkin lymphoma. Clinical trials have shown that this method can also have significant anti-tumor activity in neuroblastoma and chronic lymphocytic leukemia, and trials are exploring CAR-T cell therapy in an array of solid tumors and blood cancers that affect both children and adults.

CAR-T cell therapy is carried out in the hospital, where patients are monitored closely for side effects, »

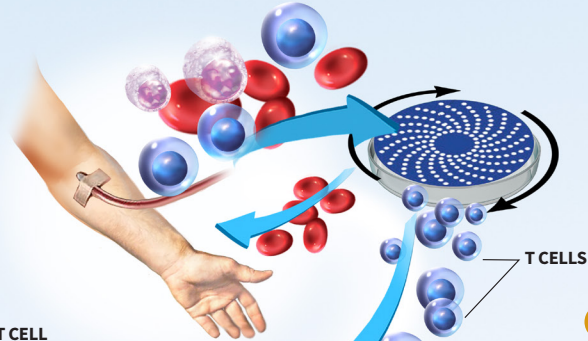
CAR-T CELL THERAPY

CHIMERIC ANTIGEN RECEPTOR (CAR)-T cell therapy is a form of immunotherapy. This laboratory-assisted method modifies a patient's own immune cells to fight cancer that has developed in the body.

The therapy involves removing a patient's T cells and "engineering" them to recognize and attack a cancer-specific antigen, or molecule, on the surface of cancer cells. A genetic sequence is inserted into the T cells, causing them to develop receptors capable of binding to the antigens on cancer cells. Binding triggers the T cells to destroy the malignant cells.

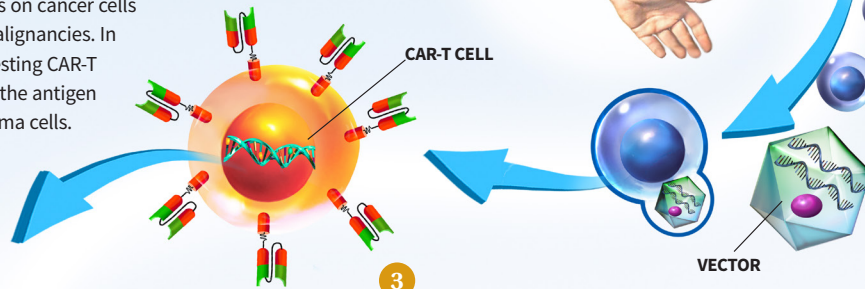
Two CAR-T cell therapies have been approved by the Food and Drug Administration: Kymriah (tisagenlecleucel) and Yescarta (axicabtagene ciloleucel) for acute lymphoblastic leukemia and non-Hodgkin lymphoma, respectively. These drugs target the antigen CD19 that sits on cancer cells associated with those malignancies. In addition, scientists are testing CAR-T cell therapies that target the antigen BCMA on multiple myeloma cells.

1 Doctors start CAR-T cell therapy by removing blood from a patient, separating and storing T cells, and returning the remainder of the blood to the patient's body.



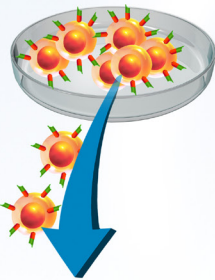
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Laboratory technicians insert a synthetic form of the desired T cell receptor-encoding gene sequence (known as a vector) into the T cells via an inactivated virus or another delivery method, such as a cationic polymer.



3

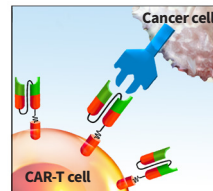
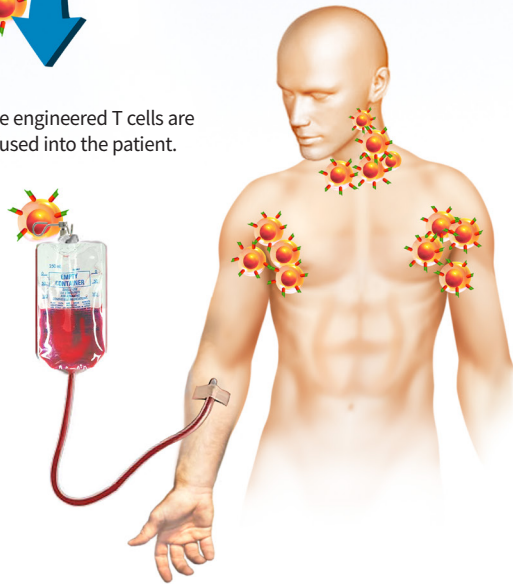
Inserting the vector causes the T cells to express receptors (CARs) on their surfaces, enabling them to find and fight the antigen associated with the patient's cancer.



4

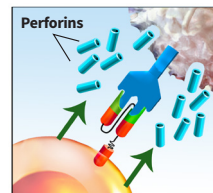
The "armed" T cells are multiplied in the lab into the hundreds of millions.

5 The engineered T cells are infused into the patient.



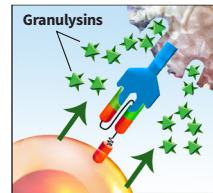
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The reinfused T cells do what they were trained to do: seek out cancer cells marked by a specific antigen, and lock onto that antigen wherever they find it. Binding activates the T cells so they can multiply.



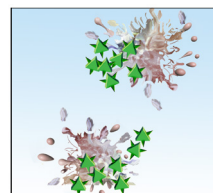
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The activated T cells release perforins, proteins that pierce the cancer cell membrane.



8

The T cells then release granuleysin, a substance that enters the cancer cell through the holes made by the perforins.



9

As a result of this attack, the cancer cells are destroyed. The engineered T cells continue to circulate in the patient's blood, prepared to attack any similar cancer cells that appear.

STAYING SAFE

When to Avoid Immunotherapy

SOME PATIENTS WITH CANCER may not be candidates for immunotherapy.

Despite all the fanfare about immunotherapies in cancer care, these drugs are not for everyone. Those with certain other conditions are not good candidates for the drugs, and should mention these concerns to their oncologists. Here are three potential contraindications to immunotherapy use, according to Marianne Davies, NP, an oncology nurse practitioner at the Smilow Cancer Hospital at Yale-New Haven and an assistant professor at the Yale School of Nursing:

▶ **Autoimmune Conditions.**

Because immunotherapy works by activating T cells to attack cancer, it can also inflame healthy tissues, meaning that patients with autoimmune conditions, such as lupus,

rheumatoid arthritis or Crohn disease, who already have hyperactive immune systems, are not appropriate for the therapy.

“It has the potential to have a significant increase in morbidity, perhaps even mortality, for those patients,” cautions Davies. Similarly, patients who have undergone a prior organ transplant or who have a history of liver damage would not be good candidates for the therapy.

▶ **Steroid Use.** Ongoing use of steroids to treat a health condition other than cancer is also contraindicated, since steroids may suppress the effects of immunotherapy. As a result, unless such patients can be tapered off the steroids, they are not considered good candidates for immunotherapy.

It’s true that steroids are sometimes transiently used in patients

who have been taking immunotherapy, to treat immune-related side effects. However, immunotherapy is often temporarily or permanently halted during the course of this steroid treatment.

In addition to steroids, patients should be monitored for all prescription and nonprescription medications, including vitamins and herbal supplements, to make sure those products are safe to take along with immunotherapy, and will not diminish the immunotherapy’s effectiveness.

▶ **Aggressive Disease.** Patients with a very high tumor burden or rapidly growing cancers may want to opt for chemotherapy or radiation — or, in the case of brain lesions, stereotactic radiosurgery — before moving on to immunotherapy, because these treatments work more quickly than immunotherapy.

particularly the immune system’s potential attack on healthy organs.

VACCINES

A host of vaccines, some approved and some experimental, also fall into the immunotherapy category. There are four main basic types:

- ▶ Vaccines that use an engineered **inactivated virus** to deliver an agent such as a cytokine that can cause the destruction of cancer cells.
- ▶ Vaccines that send **whole tumor cells** into the body with the goal of drawing the immune system’s attention to the foreign cells so it will fight

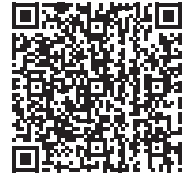
them — as well as the tumor cells already growing in the body.

- ▶ Infused **dendritic cell vaccines**, which are made uniquely for each patient using his or her own white blood cells, mixed with an agent that will help the body mount an immune response against cancer cells.
- ▶ **Peptide vaccines.** These include a small peptide (amino acid) sequence taken from a tumor-associated antigen. This is mixed with an agent that stimulates dendritic cells to process the peptide sequence; in turn, that causes the immune system to recognize and fight any antigens that contain the sequence. ■

**LEARN MORE!**

Patient enrollment in clinical trials that involve genomic testing is important in progressing research in their cancer types.

Scan the QR code to learn more.



Understanding Clinical Trials

What patients need to know to decide whether a clinical trial is right for them

CLINICAL TRIALS provide data that prove whether a new treatment is better than the standard therapy.

They could offer alternatives if patients have few treatment options or if they're seeking a treatment with the potential of being more beneficial than the standard treatment. Choosing a clinical trial might mean patients can find an option with fewer toxicities than the one being offered or one that is more convenient, such as an oral medication or one with a shorter treatment time. Although an increasing number of investigational cancer drugs are being approved by the Food and Drug Administration (FDA) each year, the process is still lengthy and complex. If patients can navigate the process, they might find a good option, but it's important to understand the phases involved in clinical trials and the potential benefit.

Phase 0 trials are the first to move a drug out of the laboratory and into people. Their goal is to determine how the body handles a specific drug. These trials are very small, including only 10 to 15 people, usually healthy individuals.

Phase 1 trials enroll a small number of patients with diverse tumor types to study side effects and establish a safe dosage for a potential treatment, usually by increasing the dose serially and observing for side effects. Phase 1 studies also evaluate how a new treatment should be given (for example, if a new drug is best taken orally or injected into the bloodstream or muscle), how often it should be administered and the most effective dose with the fewest or least severe side effects. Most patients who enter phase 1 trials have limited treatment options or do not improve with standard therapies. This phase is not designed to determine the effectiveness of the treatment.

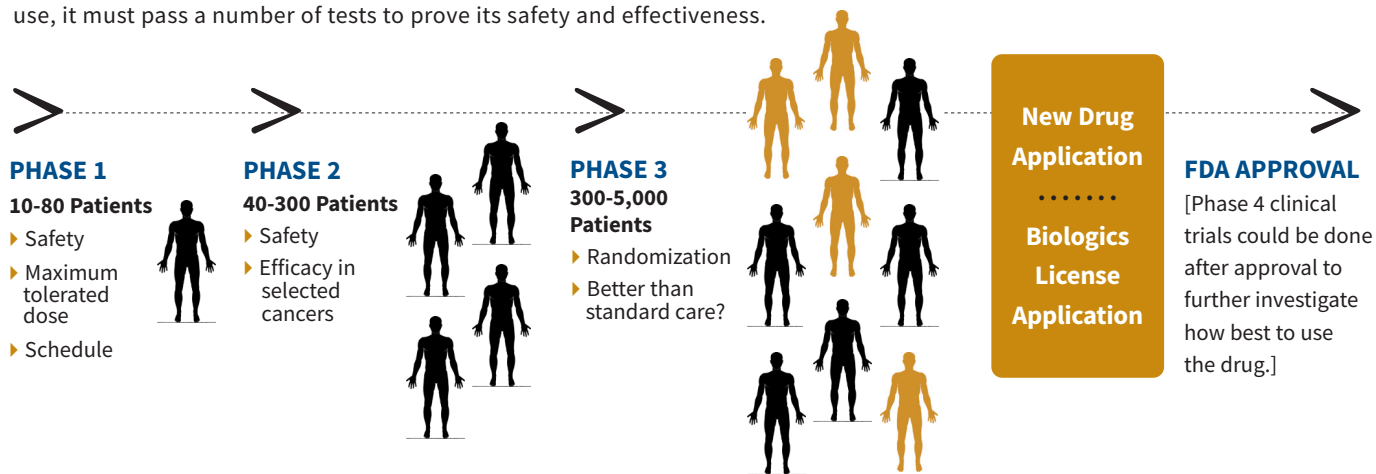
Phase 2 trials continue to test the safety of a treatment while beginning to evaluate how well it work, sometimes in combinations with approved drugs. These trials are usually limited to a specific cancer that showed benefit with the treatment in earlier trials.

Phase 3 trials compare the experimental drug, combination of drugs, regimen of radiation therapy or »

PART 3: CHOOSING TREATMENT

FROM THE LABORATORY TO THE CLINIC

Before a drug can be approved by the Food and Drug Administration for use, it must pass a number of tests to prove its safety and effectiveness.



surgical procedure with the current standard to determine if it is better. Enrollment is often in the hundreds to thousands across multiple locations. Typically, a participant is randomly assigned to the standard treatment or the new treatment (called randomization). Patients who are not randomized to the experimental treatment will receive identified standard treatments.

Phase 4 trials are sometimes referred to as real-world studies, because they illustrate how a drug works outside of a strictly regulated clinical trial. Some, but not all, of these trials occur after a drug has been approved by the FDA. Some goals of phase 4 trials are to learn more about a drug's effectiveness, safety and side-effect profile. These trials also help determine how the medication works when given alongside other treatments, how it compares to other therapies on the market and whether or not it is cost-effective. Phase 4 investigations are large, including several hundreds or thousands of patients.

COMPASSIONATE DRUG USE

Compassionate drug use is the use of a new, unapproved drug to treat a seriously ill patient when no other treatments are available.

Many people with life-threatening diseases can't find suitable clinical trials. This might be because they live too far from cancer research centers where the studies are being done, or because they're not eligible for some reason.

People who aren't in clinical trials might be able to get access to an unapproved drug from the company that makes it in two ways:

- ▶ Through expanded access programs (EAPs).
- ▶ Through "Right to Try" laws.

Expanded Access Programs (EAPs). In general, EAPs are for patients who meet all of these conditions:

- ▶ Have a serious and life-threatening condition.
- ▶ Are not eligible for any current clinical trial that's using the drug.
- ▶ Have no other comparable treatment options.
- ▶ Are likely to experience benefits that outweigh the risks involved.

The FDA approves or denies EAP requests based on available reports from the company sponsoring the drug in clinical trials, including safety information and data about how the drug may treat cancer. To learn more, see the FDA's information about EAPs at [tinyurl.com/y9wosc3](https://www.fda.gov/oc/ohrt/).

"Right to Try." "Right to try" came about when a federal law was passed in 2018 that allows patients another path to access unapproved drugs, without needing the review and approval of the FDA. "Right to try" laws do not replace EAPs, but provide another way to possibly be able to access unapproved drugs.

It's important to understand that "right to try" does not actually give patients the right to try any unapproved

drug. Instead, it gives them the right to request access to an unapproved drug from the company that makes it, without having to go through the FDA.

Bypassing the FDA does not necessarily mean that such access will be granted. To be eligible for “right to try,” a person must:

- ▶ Have a diagnosis of a life-threatening disease or condition.
- ▶ Have tried all approved treatment options for the disease or condition.
- ▶ Be certified by a doctor to be unable to participate in a clinical trial for the investigational drug.
- ▶ Give written informed consent that he or she understands the risks of taking the investigational drug.
- ▶ Receive permission from the maker of the drug and approval from the institutional review board of a plan to administer and monitor effects from the drug.

To learn more, see the FDA’s information about “right to try” at [fda.gov/patients/learn-about-expanded-access-and-other-treatment-options/right-try](https://www.fda.gov/patients/learn-about-expanded-access-and-other-treatment-options/right-try).

INFORMED CONSENT

Before enrolling in a clinical trial, patients are asked to sign an informed consent document that states they understand the purpose of the research, its risks and benefits, the study procedures and their rights as patients. Patients should keep a copy of the informed consent document with their medical records. No informed consent document can ask patients to waive their legal rights or release the trial’s research team, trial sponsor, drug manufacturer or institution from liability for negligence.

Patients are allowed time to discuss the informed consent documents with family, friends or their physicians and to ask follow-up questions of the research team. As the trial progresses, the research team will continue to provide information and updates. It is important to understand that because the treatment is experimental, the outcomes and side effects are not always foreseeable, although any predicted risks should be explained in detail beforehand.

COVERING THE COST

Patients should discuss the costs associated with the trial with the research team and ask what would be covered by insurance. In most trials, the therapy under investigation is provided at no cost to the participant. Routine costs, such

as hospital stays, outpatient appointments and tests done during a trial, are often covered by insurance or Medicare if the trial meets certain criteria.

A provision in the Affordable Care Act, effective in 2014, prohibits new health plans from denying coverage for routine care that the plan would otherwise provide just because a person with cancer is enrolled in a clinical trial. The law also prohibits insurers from dropping coverage because a person chooses to participate in a clinical trial. Patients considering a clinical trial might also want to calculate the cost of travel and lodging if the site of the trial is distant, especially if the trial extends over several weeks or months and frequent trips are needed. Some institutions and nonprofit organizations can help with certain expenses for travel and housing (visit [curetoday.com/journey](https://www.curetoday.com/journey)).

SEARCHING FOR A CLINICAL TRIAL

No single resource lists every clinical trial, but ClinicalTrials.gov is the most comprehensive and allows searching by tumor type, drug type, location and other factors. The process might involve searching the web, calling pharmaceutical companies or asking a doctor or cancer center for information. Patient advocacy groups can also help patients find appropriate trials.

Patients should begin with their oncologist, who not only can tell them if something is available locally, but also give them resources on what is happening in other parts of the country. Although it could be time-consuming to search for clinical trials at each location, patients will probably want to start with facilities closest to home. Those who are looking for a particular drug might want to contact the pharmaceutical company directly for the best information.

Fewer trial locations will be available for drugs in early-phase testing, so patients might have better luck with late-phase trials, which are conducted in multiple sites across the country.

Each trial has its own eligibility criteria and often has restrictions based on the type and stage of cancer, age of the patients, previous treatments received and current health status. Patients should have their medical histories accessible when searching for clinical trials because eligibility requirements could disqualify them from participating. Once they have found a number of trials for which they possibly qualify, patients should discuss them with their doctors and contact the study coordinators. ■

Is a Clinical Trial Right for Me?

A nurse discusses the pros and cons

ONCE PATIENTS ARE AWARE that clinical trials are an option for cancer treatment, many have questions about whether this might be the right path for them. Blanca Ledezma of UCLA Health in Santa Monica, California, a nurse practitioner who holds a master's degree in nursing, has some insights that can help patients decide. Here, she answers some top patient questions about the pros and cons of joining trials.

When and why should I consider joining a clinical trial?

Patients should ask about clinical trials as soon as they receive their diagnosis and are making their first treatment decisions. They should always know what trials are available to them and whether they want to take part. Perhaps there aren't any trials that are appropriate for them, but at least they've asked and providers know they are interested.

Some patients find it worthwhile to participate in trials because it means they will get a novel agent that could be more effective than standard care alone (Standard, or standard-of-care, treatment is approved by the Food and Drug Administration — the FDA — and widely recommended for use for patients with a particular condition). This may especially be of interest to patients with cancers for which there are few standard treatments or none

that are very effective. Patients may also feel good knowing they are contributing to research that could help others in the future.

How will I know if I'm eligible for a clinical trial?

For a trial to be appropriate for an individual, that patient must meet its eligibility requirements. These can include having a specific cancer or one that is associated with a certain genetic mutation, having cancer that is a certain stage, being within a specified age range, meeting a certain level of healthiness and ability to complete the daily activities of living, and having had or not had certain treatments in the past.

What kinds of drugs would I take in a clinical trial?

Trials can test targeted agents or immunotherapies, which are now available in numerous cancer types and are being tested in even more. They may also test chemotherapies, new classes of drugs, combinations of medications or medical devices.

These types of drugs work in different ways. For instance:

- ▶ Chemotherapy affects cells that are rapidly growing and dividing; this includes cancer cells but also some healthy cells.
- ▶ Targeted drugs home in on cells affected by



« Patients should ask their oncologists about clinical trials, but also research on their own or with the help of patient advocacy groups.

a specific genetic mutation that drives cancer. Typically, they stop the activity of cancer-causing proteins that are made by the body due to such mutations. This means that targeted drugs mainly affect cancer cells.

- ▶ Immunotherapy stimulates the body's own immune system to fight cancer.

Both targeted drugs and immunotherapies have changed the landscape quite significantly for certain disease types for which there wasn't much treatment to begin with. Now, we've been able to give patients more treatments, either alone or in combination with other therapies, that are personalized to their specific disease types, and they're doing better than they have in the past.

Unfortunately, none of these drugs are free from side effects. Chemotherapy can cause fatigue, nausea, vomiting, diarrhea, hair loss, mouth sores and low blood counts that can lead to infection. Targeted drugs can cause diarrhea, liver problems and rash and interfere with blood clotting and wound healing. Immunotherapies can cause fatigue, nausea, rash and, less often, problems in organs including the lungs, liver, kidneys, intestines and glands that make hormones.

Why is molecular profiling important prior to a clinical trial?

In standard treatment or clinical trials, molecular profiling of a patient's tumor is essential. Many targeted drugs and immunotherapies work by targeting a specific genetic mutation and counteracting its cancer-causing activity. Generally, these drugs won't work well, or at all, unless the cancer has these mutations, so it wouldn't make sense to give them without first testing tumor tissue or cancer cells found in blood to determine which genetic alterations are present.

In standard treatment, having this genetic information can help doctors decide which therapies to give and the order in which to administer them to maximize the options available.

When there are no FDA-approved treatments that target certain mutations, clinical trials of novel drugs can be especially helpful, although the efficacy of such medications can never be certain until these studies have been concluded.

Because knowing all a tumor's treatable mutations is so crucial in terms of picking therapies, it's very important at diagnosis for patients to wait until all molecular test results have come back before choosing a course of treatment. »

PART 3: CHOOSING TREATMENT

If I join a trial, is it possible I will get a placebo instead of real medicine?

In trials for patients with metastatic cancer, participants would never get just placebo but would always get some treatment — in many cases the current standard of care. Giving these patients nothing would be unethical.

If it's a trial of an adjuvant drug (given after the primary treatment) for earlier-stage disease, and it's not standard practice to give any therapy after the main treatment for a particular cancer, in that case there is a possibility that a treatment arm may consist of placebo alone.

How can I know if a trial drug will work for me?

Once patients are found to be eligible to take a drug, the only way to know if it is going to work is by trying it and that's true in standard-of-care therapy and in clinical trials. The difference is that we have data from studies of standard-of-care drugs and know, based on this data, that a treatment has been shown to have a certain efficacy for a particular disease type. In a clinical trial, we're trying to develop (those) data so we can have more treatment options for patients.

Like standard-of-care patients, those in studies are followed with scans to evaluate their response to treatment.

How can I weigh the pros and cons of enrolling in a trial?

Trials are something many patients are open to because they gain access to a new novel agent that is not otherwise available to them. They get the added benefit of being followed very closely.

On the other hand, some patients may say, "I'm working and trying to maintain normalcy, and that doesn't work for me," because being in a trial generally requires a greater time commitment than getting standard treatment. We always have to consider the patient, their current situation, their desires and their current physical state.

We inform patients that trials are voluntary and

that we don't want to make them feel pressured to enter or stay in a trial. At the end of the day, they should do what they feel is the best decision for them.

How can I learn about clinical trials that might be right for me?

First, it's important that patients educate and empower themselves and really understand their disease and the available treatment options. Providers will have a detailed discussion with patients regarding treatment options, including standard of care and possibly clinical trials. If patients have further questions regarding treatment options, they should contact their oncologists.

Patient advocacy groups can be of benefit in providing information about available treatments, as long as they're reputable organizations such as the American Cancer Society, *CancerCare*, Cancer Support Community and disease-specific groups including the American Lung Association, the Prostate Cancer Foundation, the Multiple Myeloma Research Foundation and the Cholangiocarcinoma Foundation. Some patients may want to seek a second opinion to make sure they're aware of all their options. Clinical treatment guidelines written by the National Comprehensive Cancer Network (nccn.org/patients/guidelines/cancers.aspx) specifically for patients can also be helpful in spelling out what standard treatment should consist of.

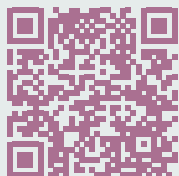
Those who want to learn about clinical trial options can ask their doctors, nurse navigators or other members of their health care teams for suggestions about trials that may be appropriate for them. Some practices run trials and can enroll patients; others don't offer trials, but may refer patients to other institutions that do.

To search on their own for trials, patients can go to **ClinicalTrials.gov** and search by disease type and/or drug type. Some patient advocacy groups have searchable online databases of clinical trials, and some offer navigators at no cost who can help patients find trials. ■

new



Clinical Trial CORNER



Responding to the needs of our readers, we are proud to announce the launch of the new Clinical Trial Corner resource on curetoday.com. There you'll find the latest news on clinical trial availability and enrollments.

Visit curetoday.com to stay up-to-date on clinical trials.
curetoday.com/clinical-trial-corner



LEARN MORE!

CURE® frequently explores insurance issues related to cancer care. **Stay informed by subscribing to *CURE*® magazine and visiting curetoday.com.**



Handling Insurance Matters

Strategies can help patients get the most out of their health care coverage

Adapted with permission of the American Cancer Society

IT IS IMPORTANT to have and keep good medical insurance. Many patients have private insurance through employee group plans or individual plans. It's essential for patients to become familiar with their individual insurance plans and their provisions to know what they will have to pay for themselves.

This information can be found in the Summary of Benefits and Coverage that can be obtained from the patient's insurance administrator at work or from the company that sold the individual policy. Individual policies can

be purchased in each state's insurance marketplace without regard to preexisting conditions.

Another option to consider is supplemental insurance, which pays a fixed amount for each day a patient is hospitalized. There is usually a limit on the total number of hospital inpatient days covered in a calendar year. Supplemental policies are often used to pay for medical expenses not covered by the insurance plan or other expenses that might come up during an illness. However, they are really helpful only if patients already have health insurance coverage to cover the

bulk of their health care costs. The money from this type of policy can be used however a policyholder wishes. It is often used for the other expenses that families face when one member is ill.

KEEPING RECORDS OF HEALTH INSURANCE AND MEDICAL CARE

Keeping accurate records of medical bills, insurance claims and payments will help families manage their resources and reduce stress. It is also important for those who wish to take advantage of the deductions available in filing itemized tax returns. The Internal Revenue Service ([irs.gov](https://www.irs.gov)) can provide information and free publications regarding tax exemptions for cancer treatment expenses.

RECORDS TO KEEP:

- ▶ Medical bills from all health care providers.
- ▶ Claims filed.
- ▶ Reimbursements and explanations of benefits.
- ▶ Dates, names and outcomes of contacts made with insurers and others.
- ▶ Nonreimbursed or outstanding medical costs and copayments.
- ▶ Meals, lodging and travel expenses, including gas.
- ▶ Cellphone or telephone expenses related to medical or other types of care, including psychosocial.
- ▶ Admissions, clinic visits, laboratory work, diagnostic tests, procedures and treatments.
- ▶ Drugs given and prescriptions filled.

TIPS FOR KEEPING RECORDS:

- ▶ Decide who will keep the records or how the task will be shared.
- ▶ Seek the help of a relative or friend. This may be especially important for people who live alone.
- ▶ Set up a file system in a file cabinet, drawer, box or three-ring binder.

ADVICE FROM *a* SURVIVOR

BONNIE ANNIS



“Don’t be afraid to appeal a decision by your insurance company not to pay for something you feel you need. I did that when my insurance company deemed my lymphedema recirculation pump ‘medically unnecessary.’ I felt it unfair to have to defend myself to the insurance company. As survivors, we’ve already had to fight in a battle we didn’t choose. Breast cancer is a financial burden, and as a victim of this dreaded disease, I relied on insurance to cover the exorbitant costs. To be forced to fight for rights to medical equipment doesn’t make sense. Shouldn’t doctors decide what’s best for patients instead of insurance companies?”



SCAN THE QR CODE to read BONNIE’S story.

- ▶ Check all bills and explanations of benefits for accuracy.
- ▶ Review bills promptly after receiving them.
- ▶ Save and file all bills, payment receipts, records of checks and proof of online payments.
- ▶ Keep a daily log of events and expenses; a calendar with space for writing is useful.
- ▶ Maintain a list of phone numbers for cancer care team members and other contacts. »

PART 3: CHOOSING TREATMENT



📌 Patients should become familiar with what their health insurance plans cover.

HANDLING A CLAIM DENIAL OR REFUSAL TO COVER A PRESCRIBED SERVICE

It is not unusual for particular claims to be denied or for insurers to say they will not cover a test, procedure or service ordered by a patient's doctor. If this occurs, it is important to have a working relationship with a case manager who can discuss the situation.

First, patients should ask their doctors to write a letter explaining or justifying what has been done or requested. Patients then should resubmit the claim with a copy of the denial letter and the doctor's explanation. Sometimes the test or service will need to be coded differently.

If challenging the denial in this way is not successful, then patients might need to:

- ▶ Postpone payment until the matter is resolved.
- ▶ Resubmit the claim and request a review.
- ▶ Ask to speak with a supervisor who has the authority to reverse a decision.
- ▶ Seek help from the consumer services division of the state insurance department or commission.
- ▶ Consider taking legal action.

Patients should keep originals of correspondence. The cancer care team or doctor's office staff might help make copies if needed. Also, patients should keep a record of dates, names and conversations they have about the denial.

FOR THOSE WHO ARE UNINSURED

Patients who are uninsured may qualify for financial help to buy a health plan sold on their state's health insurance marketplace. If their income is below a certain level, they may be eligible for coverage through Medicaid (eligibility varies by state). Some states have chosen to broaden access to Medicaid coverage under the health care law. Patients can search for plans at [healthcare.gov](https://www.healthcare.gov) from Nov. 1 to Dec. 15 each year, or outside that window if they have experienced a major life event such as job loss.

Those who are uninsured can also talk to hospital social workers, who may be able to help find funding for treatment.

For more information or help with insurance, visit [cancer.org](https://www.cancer.org) or call 800-227-2345. 📺

PART FOUR

During Treatment

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SCAN THE QR CODE TO
LEARN MORE!

CURE® asked an expert about
scalp cooling to prevent hair
loss during chemotherapy.



Coping With Side Effects

Treatment side effects have their own management strategies

TREATMENT FOR CANCER could include many options. Surgery, chemotherapy, hormone therapy, biologic and targeted therapies, radiation therapy — or any combination of these — can cause side effects that range from mild to severe, depending on the treatment and individual reactions. In the past, suffering from treatment side effects was an accepted part of the cancer experience, but today there are many ways to ease or even prevent most of them.

NAUSEA AND VOMITING

Treatment-related nausea and vomiting can develop at any time. The body releases the chemical serotonin in response to several types of chemotherapy. When serotonin binds

to certain receptors in the brain, patients can experience nausea. Many anti-nausea drugs (antiemetics) work by blocking and shutting down these serotonin receptors.

Chemotherapy can also cause nausea and vomiting by stimulating NK-1 receptors in the brain. NK-1 receptor inhibitors help prevent acute and delayed nausea and vomiting.

Steroids are also used to prevent nausea. Side effects can include jitteriness, but the doses used typically do not cause the effects of long-term steroid use, such as swelling and immune suppression.

A recent study showed that nausea and vomiting are no longer the side effects that cause the most concern for patients undergoing chemotherapy, due to the effective

medications that are available to prevent and treat these problems.

Patients worry more about sleep loss and the effects of their illness on loved ones, the study showed.

HAIR LOSS

Because chemotherapy kills rapidly dividing cells, it can affect hair follicles, resulting in hair loss. The degree, pattern and timing of hair loss vary among patients, as do changes that occur during hair regrowth. Some drugs, particularly certain chemotherapies, can cause profound hair loss, whereas targeted agents that are aimed directly at cancer cells usually won't cause any. Patients should ask their doctors about what degree of hair loss to expect with treatment.

It's normal for patients to feel distressed about losing their hair, which usually begins about two weeks after their first treatment. The scalp can become sensitive to washing, combing or brushing during the time when the hair is falling out. Facial hair, such as nasal hair, eyelashes and eyebrows, can also fall out, as well as hair on the arms, legs and pubic area.

Patients who experience hair loss should do whatever feels comfortable, whether it's wearing scarves, caps, hairpieces or wigs, or simply leaving the head bare. If thinking about wearing a wig or a hairpiece, patients should buy it before treatment or at the start of treatment, so the wig shop can match their hair color and texture. Many cities have professional stylists who will cut a wig or hairpiece to a patient's preference.

Patients should ask their doctors for a prescription for the wig because it might be covered by their health insurance. Hair should begin to grow back a few weeks after treatment ends.

Those who are very upset by the prospect of losing their hair, or who want to keep their illness private by preserving their usual appearance, can consider using scalp cooling

ADVICE FROM *a* SURVIVOR

BARBARA TAKO



“When dealing with side effects of treatment, it’s important to learn to pay attention to your body and communicate what you’re experiencing to your doctors. Make sure to accept help when you need it, and be gentle with yourself — don’t try to do too much in a day. Feel free to cry, and also to give yourself mental hugs and reassurances. Don’t do cancer alone — consider joining a support group or even seeing a psychotherapist when facing challenging times. Other coping tools that have worked for me include journaling, guided imagery, meditation and connecting with nature.”



SCAN THE QR CODE to read BARBARA'S story.

caps. Also known as scalp hypothermia or cold cap therapy, this technique involves cooling the scalp for a period of time before, during and after each chemotherapy treatment. This is thought to lessen the amount of drugs reaching the hair follicles, helping to prevent or reduce hair loss. The technique seems to work best in patients whose chemotherapy regimens do not include an anthracycline, such as doxorubicin.

The DigniCap Scalp Cooling System is approved for the reduction of hair loss during »

PART 4: DURING TREATMENT

chemotherapy for patients with solid tumors. The Paxman Scalp Cooling System is approved to prevent hair loss in patients with solid tumors who are undergoing chemotherapy. Both can be purchased by hospitals, which can provide them to interested patients. DigniCap includes a cap attached to an automatic cooling system. It is becoming more widely available and its cost to each patient — \$1,500 to \$3,000 for the duration of chemotherapy — may be at least partially covered by insurance. Those interested can ask about availability at the facilities where they receive treatment.

For approximately \$450 per month, its website states, patients who have any kinds of solid tumors can rent Penguin Cold Caps and bring them to chemotherapy appointments. The cheapest option — a few hundred dollars — is to buy several Elasto-Gel caps online, a cooler or two and some dry ice, and have a friend come to infusion appointments to help change the caps every 30 minutes before, during and after treatment.

Some experts worry that cooling the head during treatment leaves open the possibility that cancer will spread to the scalp, but other oncologists say this is unlikely.

Patients considering scalp cooling should confer with their doctors about whether it makes sense for them.

LYMPHEDEMA

Lymphedema is swelling that can occur due to a buildup of lymph fluid, a clear liquid that moves through the body carrying proteins, water, salts and white blood cells.

Lymphedema can be caused by the removal of lymph nodes during cancer surgery, or by radiation, infection or the cancer itself. Where it occurs depends on the location of treatment. Lymphedema most often affects the arms or legs, but, alternatively, it could affect the face, abdomen, neck or genitals.

Lymphedema is treatable through techniques such as specialized massage or the use of compression garments to help keep it under control.

It's a good idea to ask your medical team, before treatment, whether you are at risk, and what you — and they — can do to help prevent lymphedema. One method is to use presurgical or other techniques that guide doctors in removing as few crucial lymph nodes as possible.

NEUROPATHY

Patients taking mitotic inhibitors, such as taxanes and vinca alkaloids, platinum-containing agents or proteasome inhibitors, could develop neuropathy in the hands and feet. This nerve damage can develop weeks, months or years after treatment and typically involves the fingers and toes, or the entire hand and foot. Symptoms may resolve completely, although it can take a few weeks to many months or even a couple of years as the nerves slowly heal. Some drugs can cause permanent neuropathy, and in rare cases, can also injure the auditory nerves, causing hearing loss.

Sensory neuropathy, the more common type, can cause pain, numbness, tingling or loss of sensation because it affects the nerves needed for touch, temperature and pain. Motor neuropathy results in a disruption of signals to the muscles and can lead to muscle weakness, clumsiness, balance problems and foot drop, a condition in which the front part of the foot is difficult to lift.

Patients who develop neuropathy during chemotherapy should tell their doctors immediately. There may be things that can be done to help keep it from worsening and prevent permanent damage. Neuropathy may be treated with anticonvulsants or antidepressants because of their effects on certain chemical signals. A compounding pharmacy can prepare a topical cream that might reduce the severity of side effects. Also available topically is an anesthetic patch, which can be applied to intact skin in the »

CANCER PAIN AT ITS SOURCE

A SIGNIFICANT NUMBER OF PATIENTS experience cancer-related pain during or after treatment. Pain can be caused by cancer or its treatment but can often be relieved with an array of treatment strategies.

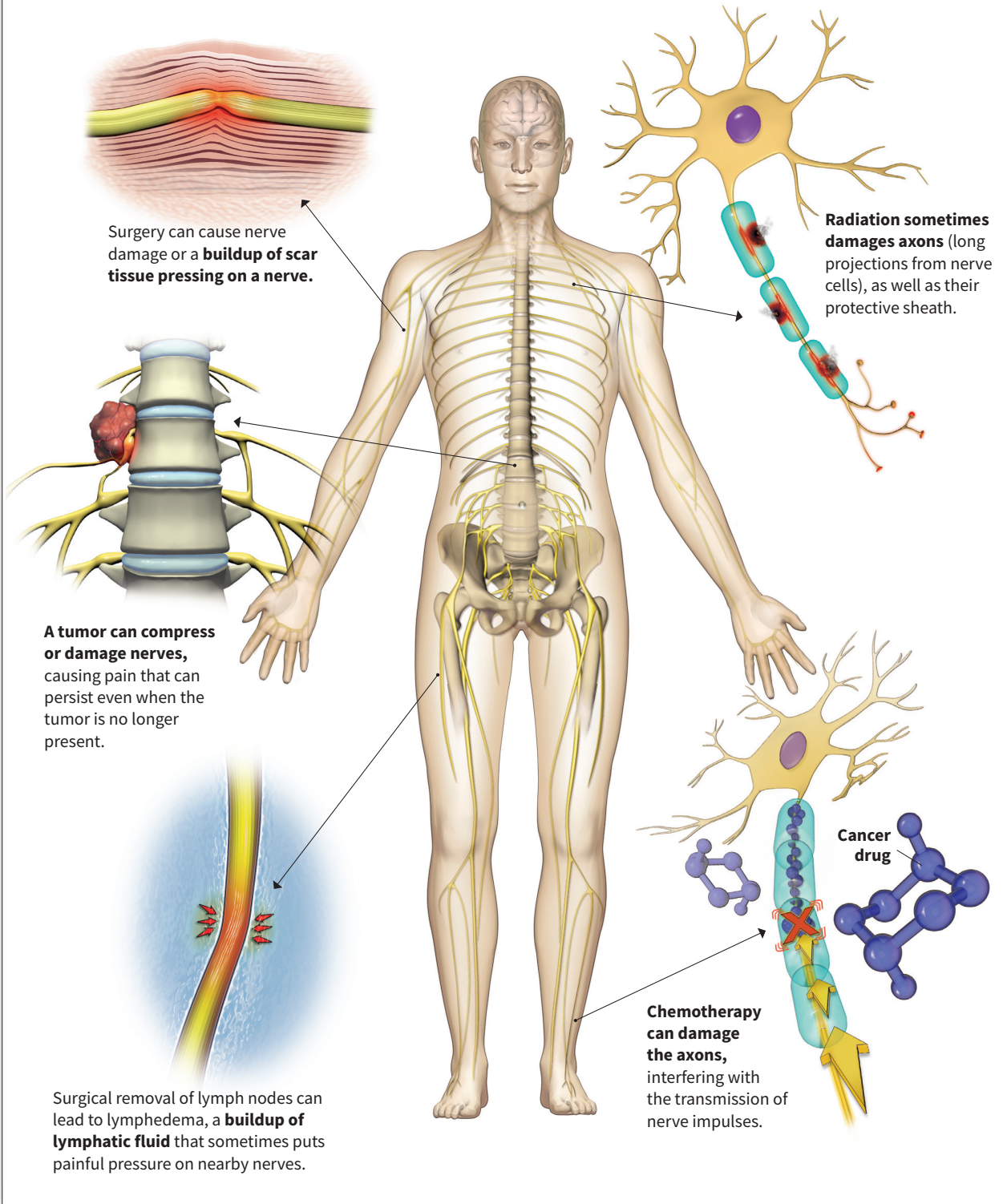


ILLUSTRATION BY ERIN MOORE

PART 4: DURING TREATMENT

area with the most pain. In some cases, a change in the dose or type of anti-cancer drug might be necessary.

CANCER PAIN

Management strategies are available for patients who experience cancer-related pain during and after treatment. Many cancer centers have pain and palliative care specialists. With the help of a doctor or pain specialist, patients can develop a personal pain management plan that might include relief strategies for long-term (chronic) and short-term (acute) pain, as well as brief, severe flare-ups called breakthrough pain.

Patients with cancer who experience pain might need around-the-clock medication to prevent the pain rather than waiting to relieve it once it occurs. Long-acting medications continuously given or metabolized slowly in the body may be best for cancer-related chronic pain and can be combined with short-acting medication for acute and breakthrough pain.

Although morphine is not used for all types of pain, and has side effects that can include constipation, drowsiness, itchiness, urinary retention and nausea, it may be the best choice for patients with cancer pain. Medications are also available to relieve symptoms caused by opioids. Because constipation is a common side effect of opioids, stool softeners and laxatives should be taken regularly. It might take time to reach a balance of pain relief and manageable side effects by gradually adjusting doses or trying different opioids. Many side effects improve once the body adjusts to the medication.

Pain relief patches that are applied to the skin for continuous release of medication over several days might be more convenient than oral medication, especially if patients have trouble swallowing. For example, narcotic patches can deliver opioids continuously through the skin for up to 72 hours. Some versions of the pain patch include a potent semisynthetic opioid

that has milder side effects. Narcotics are also used for breakthrough pain and may be available in various formulations: as a lozenge, an effervescent tablet that is held between the cheek and gum, a mouth spray, a nasal spray and a dissolvable film placed on the inner cheek. For some less-common situations, pain specialists could use nerve blocks or drugs delivered to the spinal fluid.

Patients who are worried about becoming addicted or have other concerns about taking pain medication should talk to their doctors or a pain specialist. Although the fear of addiction is common, very few patients become addicted to pain medication when it is taken properly. If patients have trouble getting the pain control they need, they should work with their treatment teams to get relief that works. In complicated cases where pain control is difficult to achieve, a pain specialist might be needed.

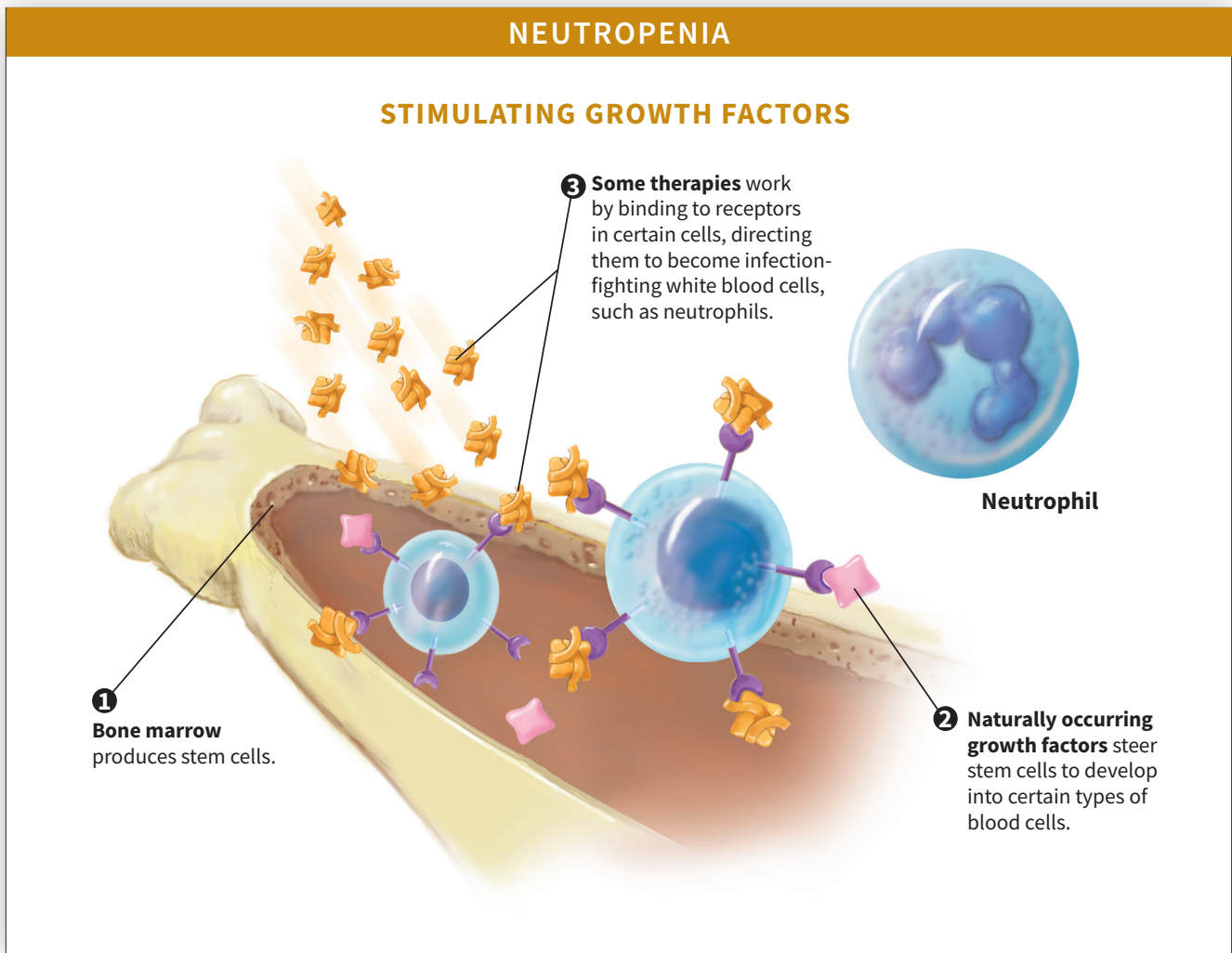
There have been few studies within the United States exploring the potential medical benefits of marijuana, or cannabis. The prescription, possession or sale of the substance is legal in some states but not in others. Where cannabis is legal for medical use, each state may have its own rules about which patients are eligible.

A study whose results were published recently showed that one-quarter of patients with cancer who responded to a survey about marijuana reported using the substance to quell pain, nausea, stress or depression about their illness, or to stimulate appetite. The patients surveyed lived in a state in which medical marijuana was legal.

If you are considering using marijuana to ease side effects of your cancer or its treatments, speak confidentially with your doctor about the pros and cons, so that you can make an informed decision.

ANEMIA

Patients whose levels of red blood cells (RBCs) drop significantly can develop fatigue, shortness



of breath, heart palpitations and disorientation — all symptoms of anemia. RBCs are made from stem cells in the bone marrow and carry oxygen to the body's tissues. Certain cancers, such as leukemia, lymphoma and myeloma, crowd out or suppress the production of healthy RBCs. Chemotherapy and radiation can damage the stem cells that make RBCs.

In some patients, low levels of RBCs or low hemoglobin levels — a measure of the ability of RBCs to carry oxygen — can be treated with genetically engineered erythropoietin (EPO), a protein produced normally in the kidneys. Certain drugs that act like natural EPO decrease the likelihood of a transfusion, but patients could still need one if their RBC levels dip dangerously low.

Because of serious side effects, the Food and Drug Administration does not recommend these drugs for treating anemia in patients who are not receiving chemotherapy or for those receiving chemotherapy as a curative treatment. It's also recommended that they only be used with a goal of avoiding transfusions or severe anemia, rather than to try to get RBCs to a normal level.

NEUTROPENIA

Neutropenia, a shortage of the white blood cells called neutrophils, can make patients prone to infection, which may cause fever, fatigue and body aches. Fast-growing neutrophils are quickly killed off by chemotherapy and radiation. Neutropenia can result »

PART 4: DURING TREATMENT

in delayed treatment and dose reduction to allow the body to make more neutrophils. Drugs that activate granulocyte colony-stimulating factors (particles in the body that signal white blood cells to grow) are effective at reducing neutropenia, but they can produce a side effect of bone pain. Patients who develop neutropenia are advised to take special precautions to prevent infection until their white blood cell counts improve, including frequent hand washing, avoiding people who are sick and not eating raw fruits and vegetables. Patients who develop fever or display signs of infection during chemotherapy should notify their doctors immediately.

FATIGUE

Most patients experience mild to severe fatigue at some point during treatment. Fatigue caused by anemia and low thyroid function can be treated. When those causes are ruled out, the patient's medical team will look for other approaches. Fatigue can worsen if patients have pain, are distressed or have sleep problems. Exercise, such as walking, has been found to improve fatigue.

IMMUNE-RELATED SIDE EFFECTS

Immunotherapies, particularly those known as checkpoint inhibitors, hold a lot of promise as treatments for a variety of cancers. While these drugs are generally known for being easier to tolerate than chemotherapies, they are associated with a unique array of side effects. These reactions arise from inflammation caused by the stepped-up immune system harming some normal tissue.

Immune-related side effects can include fatigue, headache, weakness, diarrhea, abdominal pain, constipation, skin rashes, itchiness, shortness of breath, cough, low blood pressure, high blood pressure, joint pain, hepatitis, inflammation of the liver, or hormonal problems such as an overactive or underactive thyroid or underactive pituitary gland.

These are most often treated with steroids, in some cases combined with temporary or permanent interruption of the immunotherapy. Imodium (loperamide) can treat milder diarrhea.

Hormonal imbalances caused by immunotherapy may end up being permanent, meaning that those affected will need to take hormone supplements indefinitely.

A more severe autoimmune reaction, which may occur in people who take CAR-T cell therapies, is called cytokine release syndrome, and arises from the immune system attacking healthy organs while it attacks cancer cells.


This can cause side effects including serious heart and breathing problems, as well as brain issues such as confusion or the inability to understand speech.

Steroids can be used to treat cytokine release syndrome induced by CAR-T cell therapy, and approved to treat severe cases is Actemra (tocilizumab), a monoclonal antibody that suppresses the immune system.

Sometimes, immunotherapy needs to be delayed or stopped because of side effects. Patients may worry about having to stop treatment, but they should be open with their care teams about side effects as soon as they occur. This can help doctors and others on the team to control side effects before they become severe.

OTHER SIDE EFFECTS

All patients undergoing treatment are unique — as are the side effects they experience. Additional possible side effects include rash, cognitive dysfunction (also called chemo brain), mouth sores (oral mucositis), diarrhea, insomnia and low platelet counts (thrombocytopenia).

Patients should ask their doctors about solutions for side effects they believe are associated with treatment — both physical and psychological. Also, they should ask for a name and phone number of a person to contact after hours should they experience these side effects. 

MANAGING DISCOMFORT

Supportive Care Improves Quality of Life

PATIENTS EXPERIENCING SIDE EFFECTS before, during or after treatment for cancer should ask their medical teams for supportive care, also known as palliative care.

This kind of care is for anyone at any stage of the cancer journey whose quality of life has been lowered by physical or emotional side effects of the disease or its treatment. The goal of supportive care, which is given separately from medical, surgical and radiotherapy treatments, is to make patients more comfortable. It can be provided by physicians, nurse practitioners/physician assistants, counselors, psychologists, physical therapists, nutritionists, acupuncturists, massage therapists, artists and others focused on a holistic approach to managing symptoms. In some cases, this care can improve patients' health outcomes.

Supportive care includes the following:

- ▶ Medication for pain.
- ▶ Physical therapy to build strength or address debilitation from the disease or its treatments.
- ▶ Talking with a counselor or psychologist about emotional distress.

- ▶ Meeting with a hospital chaplain to discuss spiritual distress.
- ▶ Consulting a nutritionist or dietitian regarding significant changes in weight related to cancer or its treatments.
- ▶ Integrative medicine techniques, such as acupuncture, oncologic massage, tai chi, qi gong, yoga, meditation, cooking, art therapy and music therapy.
- ▶ Advance care planning, such as writing a living will and designating a medical power of attorney to make decisions, if ever needed.

The American Society of Clinical Oncology recommends supportive care for all patients with advanced cancer, but this care is voluntary, and patients can choose which services they want and which they don't.

Patients should ask their care teams early on for supportive care. If the hospital does not provide it, patients can ask for referrals.

For the vast majority of patients, health insurance covers supportive care visits, although some integrative therapies, such as acupuncture, may not be covered.





LEARN MORE!

Those treated for bladder cancer or prostate cancer may experience sexual side effects. **CURE® offers more information.** Scan the QR code to learn more.



Understanding & Managing Long-Term & Late Effects

When deciding on treatment, patients should also consider the risk of future health problems

FOR MOST PATIENTS, the actual treatment for cancer will be short-lived. Generally, the longer the cancer experience — from the first suspicious symptom to the final treatment appointment — the longer the time needed to recover from the physical and emotional ripple effects.

The post-treatment picture can vary substantially, depending on the type of cancer and treatment, and the long-term prognosis. For example, some cancer types might require ongoing treatment or follow-up surgery, such as reconstructive procedures, leaving the patient cancer-free, but not free of cancer's effects.

Some patients have lingering physical and emotional effects that began during treatment

and continue afterward. Called long-term effects, these can include pain, neuropathy (nerve damage), lymphedema (swelling of the extremities), anxiety, sleep disturbances, cognitive dysfunction and fatigue.

Others might have issues related to cancer or its treatment that emerge months or years after treatment has ended. These so-called late effects include such issues as secondary cancers, infertility and heart, bone or lung problems.

While both adult and pediatric cancer survivors experience late effects, more is known about survivors of pediatric cancer because researchers have gathered long-term survival data for those cancer types for more than 20

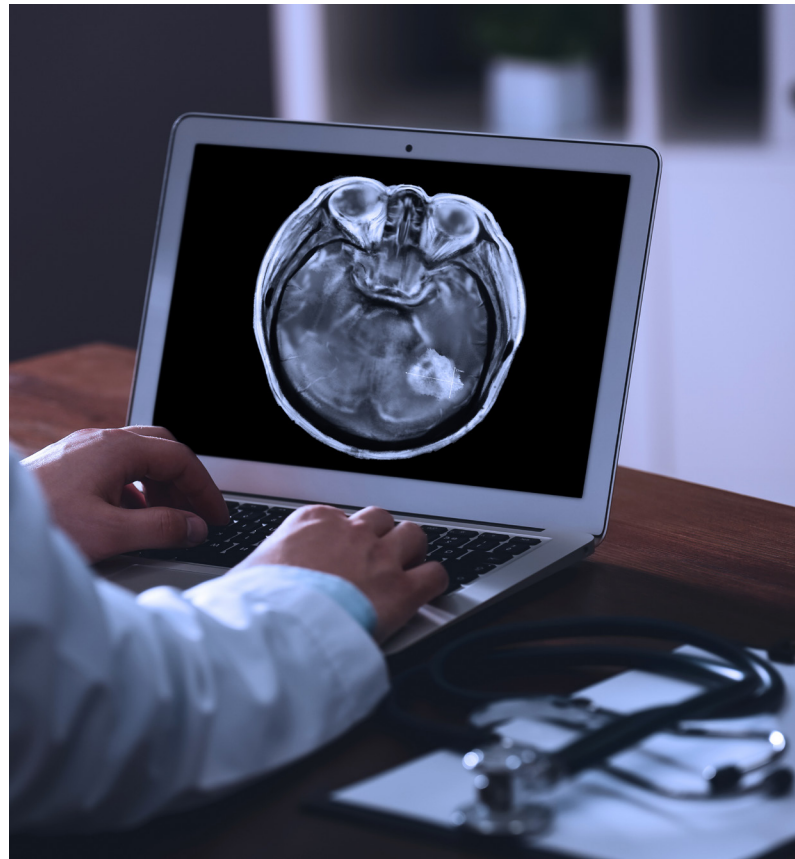
years. Research into late effects experienced by adult survivors is complicated by the fact that as people age, they develop other medical problems, or comorbidities, making it more difficult to determine if the problems are related to prior cancer treatment, aging or an interaction between the two.

Examples of late effects are that one class of medications, known as anthracyclines, as well as the drug Herceptin (trastuzumab) for HER2-positive breast cancer, can cause damage to the heart.

These are some other problems that can occur:

- ▶ High blood pressure caused by drugs that target the vascular endothelial growth factor (VEGF).
- ▶ Lung damage from chemotherapy and/or radiation therapy to the chest.
- ▶ Osteoporosis or joint pain due to chemotherapy, steroids or hormonal therapy.
- ▶ Brain, spinal cord and nerve damage manifesting as hearing loss or increased risk of stroke, due to chemotherapy or radiation.
- ▶ Dental problems due to chemotherapy, bone-protective drugs or radiation.
- ▶ Vision problems due to steroids or some targeted therapies.
- ▶ Digestive disturbances due to chemotherapy, radiation or surgery.
- ▶ Lymphedema, a pooling of liquid in limbs or other body parts due to surgery or radiation to the lymph nodes
- ▶ Peripheral neuropathy, nerve damage in the hands and feet from chemotherapy, which can cause numbness, weakness or pain

The damage is usually dose-dependent: The more of a drug a patient has, the more likely he or she will have a problem. Radiation presents another heart risk, since beams aimed at the chest to fight lymphoma, breast or other cancers can also reach the heart and lungs. Radiation can weaken or scar the heart muscle or damage



its valves. It also can accelerate coronary artery disease, creating rough spots in the lining of the arteries where fatty plaque can accumulate.

MENTAL CHANGES

Foggy, unfocused thinking before, during or after chemotherapy, sometimes lasting months or years, is often referred to as “chemo brain.”

Chemo brain can involve trouble with memory, focus, details, common words and multitasking. High doses of chemotherapy are particularly associated with the problem, although other risk factors include lack of sleep, depression, anxiety, stress, medications, pain and its treatments, older age and other health conditions.

Treatments for chemo brain can include psychostimulant medications and memory and attention training.

Other ways to help counteract chemo brain include keeping a daily planner, doing word »

PART 4: DURING TREATMENT

puzzles, getting enough sleep, getting physical exercise, eating vegetables, following routines and avoiding multitasking.

Accepting your new normal and explaining it to friends and relatives can help, too.

SEXUAL SIDE EFFECTS

Some cancers and their treatments can have a significant effect on both sexuality and fertility, and knowing about these possibilities in advance can help patients and their doctors prepare for and choose therapies.

In addition to fear and worry, treatments can interfere with sexual activity. Patients may feel nauseated or fatigued from treatment, or may have physical problems or pain that interferes with sex due to treatment or its effects on hormones. They also may feel sensitive about changes in their bodies caused by surgery or other treatment.

Communication with your partner and choosing alternative forms of closeness can be important in supporting a sexual relationship in the face of these challenges.

In men, some treatments may cause erection or ejaculation problems. Some men experiencing these effects may benefit from supplements, medications or other treatments recommended by their doctors. Before getting therapy for cancer, men should talk to their doctors about the treatment's anticipated effects on their fertility, and ask if they should consider preserving sperm if they want to father children after treatment.

For women, surgery and other treatments can affect physical appearance and sexual function. For example, hormonal changes may cause menstrual cycles to decrease or stop, and this can result in vaginal dryness and pain during sexual activity. Lubricants and other treatments or procedures should be discussed as options for these problems.

Because some treatments can cause problems with fertility, women who may want to have children after treatment should talk to their doctors

about options for preserving their eggs. (See Page 36 for details.)

SECONDARY CANCERS

If cancer returns, it is considered a recurrence of the primary cancer. When a survivor receives a diagnosis of a new primary, it might not be connected to treatment for the first diagnosis, or it might be a secondary cancer — one caused (or whose risk could have been increased) by treatment for the initial cancer.

A second cancer can occur for a variety of reasons, most unrelated to past cancer treatment. For example, it is well known that breast cancer survivors with BRCA mutations are at higher risk for ovarian and other cancers, and current or former smokers who have survived other cancers have an increased risk of lung cancer.

Researchers know that many patients who received a secondary cancer diagnosis experienced high doses of radiation to certain areas of the body or particular types of chemotherapy. For example, radiation is known to be a risk factor for breast cancer in women who had radiation to the chest area.

Researchers have also concluded that some late effects tend to occur within a specific time period. For example, leukemia and other blood cancers caused by some chemotherapy drugs tend to develop within several years of treatment. By contrast, the risk of developing a new solid tumor continues to increase even 10 years after therapy.

Some survivors of breast cancer who underwent mastectomy and then reconstruction using textured breast implants have developed a blood cancer called breast implant-associated anaplastic large cell lymphoma (BIA-ALCL). A specific product line associated with this condition has been recalled, but patients planning reconstruction should receive a written warning from their plastic surgeons spelling out the risks associated with implants, and should confirm that these doctors are familiar with BIA-ALCL and how to treat it. ■

**LEARN MORE!**

CURE® shares recipes that can be part of a healthy diet for patients and survivors affected by cancer.



Scan the QR code.

Getting Proper Nutrition

Maintaining a healthy diet, including proper hydration, is important

M **MAINTAINING A HEALTHY DIET is important during treatment.** Patients might think loading up on vitamins instead will help fight the cancer or reduce some negative side effects of treatment. Unfortunately, certain dietary supplements do more harm than good, as some can actually interfere with drugs used for cancer treatment. In fact, many oncologists discourage patients from using any supplements during treatment. Therefore, patients who are trying to balance their nutritional needs during treatment should consult their doctors before using dietary supplements.

LOSING OR GAINING WEIGHT

Weight loss or gain is a common side effect, depending on the cancer type or its treatment. Fatigue and decreased physical activity can also contribute. Increasing consumption of vegetables and fresh fruits can help patients to cope with weight fluctuations. With approval from their doctors, patients can exercise to help with fatigue, weight maintenance, anxiety and mobility. Some gyms and cancer centers have programs designed for patients with cancer, and many oncology practices have a dietitian with oncology experience on staff. »

A HEALTHFUL DIET

During cancer treatment, you might need to change your diet to help keep up your strength and cope with side effects that can make it difficult for you to meet your nutritional needs. Your health care team can refer you to a dietitian who can help individualize your eating plan based on your specific needs.

Having frequent small meals might make eating easier if you don't feel well, and can help keep your energy up.

Those who are finding it difficult to tolerate nutritious foods should eat whatever is most appealing to them.

Special diets can be helpful for people with specific cancers, or who are undergoing certain treatments; ask your care team to advise you.

Finally, take care to avoid fad diets and eating plans you might learn about from friends or on the internet, especially any promoted by those with money-making interests. Talk to your health care team about the best eating plan for you during treatment.

STAYING HYDRATED


Water is the most important substance in a patient's diet. Dehydration occurs when the body takes in less fluid than it releases. It happens quickly when a patient has diarrhea, vomiting or fever with sweating.

Patients might not have the desire or energy to eat or drink, so when they do feel thirsty, they are probably already dehydrated. Symptoms include little or dark-colored urine, fatigue, sunken eyes

and skin that remains raised if pinched (called decreased or poor skin turgor). Signs of severe dehydration, such as low blood pressure, rapid heartbeat, dizziness and confusion, could require immediate intravenous fluids.

Proper hydration can help ease common side effects, such as constipation and fatigue, as well as rare but serious ones, such as kidney damage. Because the kidneys filter waste, chemicals and excess compounds from the blood, intravenous fluids are given during some types of treatment, and patients might be told to drink water before and after therapy to flush toxins through the kidneys and bladder quickly.

Patients with compromised immune systems can stay hydrated by drinking water. Tap water may be OK if it is from a municipal water supply. If water is from a private well, it is best for patients with cancer to have it tested and, if contaminants are found, to install a filter that removes those specific pollutants. If it comes from other sources, patients should boil and cool their water before drinking it, use distilled water or choose bottled brands that specify on their labels that it was cleaned using reverse osmosis.

Sometimes it's hard to take in enough water to help avoid dehydration. Other ways to get fluids include broth, sports drinks, juice, gelatin, ice chips and Popsicles. Patients should talk with their cancer teams if they have concerns. Good hydration is one way patients can stay as healthy as possible and feel better during and after treatment. 

NUTRITION TIPS

Eating Well During Therapy



GOOD NUTRITION CAN BE A STRONG ALLY during cancer treatment. Below are tips patients should consider.

WEIGHT MANAGEMENT

- ▶ **Eat nutrient-dense foods first** so as not to get full too quickly on other things.
- ▶ **Keep indulgent foods** on hand for when absolutely nothing else will do.
- ▶ **Add powdered milk to liquid milk.** Sprinkle grated cheese in soups and on vegetables.

LACK OF ENERGY

- ▶ **Ask for help** with food shopping and meal preparation.
- ▶ **Eat off disposable plates** and use plastic utensils to reduce clean-up time.
- ▶ **Try finger foods.** Cheese, avocado sandwiches, and bananas with peanut butter can be quick and satisfying.

NAUSEA

- ▶ **Take anti-nausea medication** as directed.
- ▶ **Cold foods** are often better tolerated.
- ▶ **Make sure food preparation areas** are properly ventilated. Some odors can worsen nausea.

MOUTH SORES

- ▶ **Choose soft textures** and moisten solid foods with sauces or gravies.
- ▶ **Stay away from** acidic, spicy and salty items, as well as tobacco and alcohol, as they can irritate mouth sores.
- ▶ **Take pain medication** before meals or as prescribed.

To learn more about nutrition during the cancer journey, watch CURE Connections® at curetoday.com/cure-connections/nutrition/jtcc-nutritional-advice.



LEARN MORE!

A **CURE**® advisory board member and oncology exercise expert shares information on why physical activity is important and what it should consist of.

Scan the QR code to read more.



Staying Active

Exercising during cancer treatment can give patients a boost

M

MANY PATIENTS WONDER if they can — or should — exercise during cancer treatment. In a recent report by the American Cancer Society, a group of experts in nutrition, physical activity and cancer survivorship evaluated the scientific evidence and concluded that exercise is not only safe during cancer treatment, but also can improve quality of life in many ways. An American College of Sports Medicine roundtable on exercise guidelines for cancer survivors also concluded that exercise during cancer treatment is safe and can improve physical functioning, quality of life and cancer-related fatigue. In fact, for those living disease-free or with stable disease, physical activity might even help prolong life.

The bottom line: Avoid inactivity. Experts say any kind of activity helps. Studies show a significant benefit from simply walking three to five hours a week at an average pace. Walking is easy,

cost-free and can be done just about any time, anywhere. Patients should use good judgment when beginning or continuing to exercise, make sure to warm up and stretch, and always discuss their plans with their doctors before starting.

MENTAL BENEFITS

Some of the most important benefits of activity can be psychological. Being active offers a sense of self-control and helps with body image, self-esteem, anxiety and depression during treatment. Because exercise boosts endorphins, it's recommended for healthy people who have mild to moderate depression and is known to decrease mild depression. It has the same effect in those undergoing cancer treatment.

PHYSICAL BENEFITS

Exercise conveys a range of physical benefits, too. It helps combat fatigue, control weight gain

PREPARING TO EXERCISE

What to Know Before Beginning an Exercise Program

NEARLY EVERYONE CAN DO some type of activity. But it's important that patients keep in mind a few general precautions before exercising during cancer treatment.

Patients who were already active might have to slow down a bit during treatment and perhaps not exercise as intensely as before.

They should assess how they feel and avoid pushing themselves. It's important for patients to communicate with their health care providers about their planned physical activities.

People who were sedentary before diagnosis should start exercising slowly, adding more intensity and frequency as they are able. Patients should consider how active they were before treatment and adjust accordingly.

Side effects of treatment can determine the most appropriate type of exercise. For example, someone with neuropathy could have numb toes, which would make riding a stationary bike a better choice than walking on a treadmill. Patients experiencing lymphedema have long been discouraged from upper body strength training or vigorous



activity, but a number of clinical trials have shown that not only are these activities safe for these

individuals, they might actually reduce the incidence and severity of lymphedema. Patients must talk to their doctors to determine what is safe.

Patients who are undergoing frequent chemotherapy treatments could have lower immune function and should avoid working out in public places, such as gyms. People who are having skin

reactions from radiation treatments and those with open wounds or catheters should avoid swimming.

An upper body port placement might necessitate temporarily avoiding upper body strength training. Patients with advanced disease who experience limitations due to bone metastases should discuss exercise with their health care providers and generally use pain or discomfort as a guide for what type of activity to avoid.

and could help reduce the chance of recurrence of certain cancers. Other side effects of treatment that could be favorably influenced by exercise include nausea, deconditioning of the heart and lungs and loss of muscle mass and bone strength. Studies show that exercise could help reduce the overall risk for breast, colon and other types of cancer, too. To learn more about how exercise can help, visit the American Cancer Society's website at [cancer.org/healthy/eat-healthy-get-active.html](https://www.cancer.org/healthy/eat-healthy-get-active.html).

OVERCOMING BARRIERS

While there are plenty of reasons to exercise, some patients might need guidance and motivation in the beginning if exercising is new.

One challenge is learning how to deal with treatment-related physical limitations. Talk to your care team about physical fitness programs that will fit in best with your overall treatment plan. **■**



Find organizations that can offer you financial assistance. Visit the resources section of our Cancer Guide at curetoday.com/journey.

Managing Financial Matters

Organization and help are crucial in handling finances during treatment

A DIAGNOSIS OF CANCER affects more than patients' health — it also affects their money.

For patients coping with cancer, simultaneously dealing with financial issues, and possibly debt, can be difficult and draining.

Cancer Support Community, which can be found at CancerSupportCommunity.org/cost, can help patients make educated, shared decisions with their health care professionals about which treatments to choose. In a meeting with Cancer Support Community experts, patients can explore that issue via the Open to Options® treatment decision model (CancerSupportCommunity.org/make-treatment-decision-right-you). Through this process, they can identify their goals in seeking therapy and consider treatment benefits in relation to their goals and concerns such as side effects and cost of care.

Such meetings are free and can take place over the phone or in person; to set up an appointment, call the organization's help line at 888-793-9355.

Once treatment decisions have been made, there are ways to lessen the financial burden.

Ask friends and loved ones for help. Have someone open and organize bills into categories, such as medical, household, credit card statements, taxes and so on. Also, they can look for any benefit checks and help get them deposited quickly.

Rank the bills in order of priority. For most people, health insurance premiums, food, medicines and utilities will be near the top of the list.

Negotiate for smaller payments. Often, creditors will work with patients. Most creditors prefer that people in debt make small payments rather than pay nothing at all.

Work out a payment plan. Organizations such as Clearpoint Credit Counseling Solutions (800-750-2227), which offers most counseling and education services for free, can help patients negotiate a payment plan to satisfy their creditors.

Talk with an oncology social worker.

These specialists can help with financial issues and might be able to point out sources of financial aid.

Ask the hospital about financial counseling. Some hospitals offer free financial counseling to patients.

Consider crowdfunding. Companies such as GoFundMe and others will do most of the work for you when it comes to raising funds online to help with your medical or everyday expenses. Some of these companies will keep a small percentage of donated funds as payment for their service.

Look for organizations that might offer you financial assistance. These can include nonprofit organizations and pharmaceutical companies. For a listing of groups that may be able to help, visit curetoday.com/journey.

MAKE A FINANCIAL PLAN

A sound plan means always preparing for the worst while hoping it never happens. When patients are going into treatment, it's good to plan for:

- ▶ The highest out-of-pocket medical expenses.
- ▶ Travel costs.
- ▶ The greatest number of hospital stays.
- ▶ High prescription drug costs.
- ▶ Experimental therapy not covered by insurance.



- ▶ Home health care costs.
- ▶ A disruption in work schedule.
- ▶ Home services, such as cooking or cleaning.

Some of these costs can be difficult to estimate. Patients might want to discuss them with their doctors so they can plan accurately.

TO START A FINANCIAL PLAN, PATIENTS SHOULD TAKE FOUR STEPS

1. Estimate their expenses.
2. Identify sources of income and benefits.
3. Manage their savings and investments.
4. Plan their estates.

Tackling financial issues can be a challenge for anyone. Cancer treatments sometimes leave patients little energy to think about money matters. If it's more difficult to address some topics than others, they should take on the easier ones first.

Being in treatment can mean added expenses that might be high. At the same time, patients' incomes can go down if their work hours are reduced or they are unable to work.

Patients should make budgets using numbers that are based on the maximum out-of-pocket expenses for their existing health care plans, plus something for charges above and beyond the covered expenses. [📄](#)



LEARN MORE!

Newer cancer therapies easily cost upward to \$100,000. Why so much? Who sets the prices and what can patients do if they can't afford them?

Scan the QR code to learn more.



Financial Lifelines

People struggling with medical bills can turn to pharmaceutical and nonprofit programs

WHAT HAS COME TO be known as financial toxicity is considered a side effect of cancer treatment in America. Patients can wind up in debt or even bankrupt due to the costs of treatment, hospital stays and follow-up testing, which may continue to add up over a long period.

To make matters worse, doctors often don't broach this subject with their patients.

That's why it's important that patients ask their doctors about the costs of the treatments offered and any cheaper alternatives. If expensive therapy is necessary but difficult to afford, patients do have organizations they can turn to for help.

NONPROFIT ORGANIZATIONS

By providing either guidance or direct funding, many nonprofit organizations and government

agencies help patients navigate the economic pitfalls of cancer care.

A good place to start: the American Cancer Society, which has a website section dedicated to information about financial programs and resources. The organization also suggests ways to afford prescriptions and handle hard-to-pay medical bills. To learn more, call 800-227-2345 or visit [cancer.org/treatment/finding-and-paying-for-treatment.html](https://www.cancer.org/treatment/finding-and-paying-for-treatment.html).

The National Cancer Institute maintains an alphabetical list of more than 100 organizations that may be able to offer financial support. Searches can also be done by cancer type or type of assistance needed. For more information, call 800-422-6237 or visit supportorgs.cancer.gov/home.aspx?js=1.



The National Comprehensive Cancer Network offers free assistance through its Virtual Reimbursement Resource Room. A patient can sort through information by cancer type or explore reimbursement programs. The entire guide can be downloaded, and the network also offers the Reimbursement Resource App for smartphones and tablets. Learn more at nccn.org/business-policy/business/virtual-reimbursement-resource-room-and-app, or call 215-690-0300.

The Cancer Financial Assistance Coalition, a 15-member consortium, makes it easy to quickly search for aid using a series of check boxes and drop-down menus. The site also offers an overview of cancer costs and a tutorial on taking control of finances. Visit cancerfac.org for more information.

NeedyMeds provides information on assistance programs from more than 400 companies and data on more than 4,000 medications. The extensive site, which offers drug discount cards, rebates and coupons, can point a person to local and national financial resources based on diagnosis. For assistance, call 800-503-6897, email info@needymeds.org or visit needymeds.org.

Don't forget to check out our list of useful resources online at curetoday.com/journey, which includes many organizations that provide such aid.

PHARMACEUTICAL COMPANIES

Drugmakers can sometimes step in when medication price tags present a challenge. Pharmaceutical companies operate hundreds of programs that provide financial help in the form of free or discounted medication and, together, help a surprisingly large percentage of patients.

Often, these programs aim to help those who are uninsured or underinsured. Most programs also have income eligibility limits, but these may be set quite high, so even patients who are financially well-off may be eligible. Patients can apply through the mail, via fax or online, and sometimes doctors' offices will help.

Pharmaceutical companies also offer copay assistance programs that discount the price of their drugs and are open to people who have health insurance. Although many copay programs are not available to those on Medicare, it's worth checking with drugmakers to find out for sure. »

PART 4: DURING TREATMENT

Some pharmaceutical companies even offer counselors who guide patients in finding other sources of financial help. Counselors also can assist patients in appealing insurance company decisions to not pay for care.


To find a pharmaceutical program, go to the website of the company that makes your drug and search for patient assistance programs, or call the company. Another option: Visit the website of the Partnership for Prescription Assistance (medicineassistancetool.org), run by the Pharmaceutical Research and Manufacturers of America, to access a searchable database of most of these programs.

Visit curetoday.com/journey, for a list of resources.

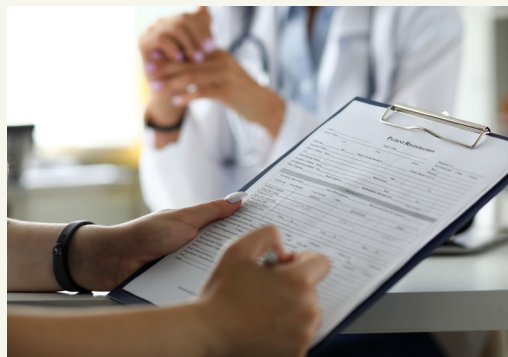
CONSERVING FUNDS

Making informed decisions about care with both cost and effectiveness in mind can also help patients avoid debt.

Ask yourself and your care team if a treatment is warranted and if there is a similarly effective but more affordable alternative. It's also important to consider whether options are supported by scientific evidence and expert recommendations. The National Comprehensive Cancer Network issues clinical guidelines that spell out what treatments are called for in different types and stages of cancer (nccn.org/patients/guidelines/cancers.aspx). In addition, tests and procedures that duplicate recent care — and associated costs — might not be necessary.

The American Society of Clinical Oncology has a Choosing Wisely campaign to guide patients in making cost/benefit decisions about treatment. A list of treatments and practices that patients and their doctors should question or avoid can be found here: choosingwisely.org/societies/american-society-of-clinical-oncology. 

ASSISTANCE PROGRAMS



Help for Patients

THE COSTS OF CANCER TREATMENT can become overwhelming, even for patients who have medical insurance. Patient assistance programs are offered by various companies, nonprofit organizations and government agencies to help patients with little or no insurance get access to drugs and money for other treatment-related expenses.

A patient interested in enrolling in an assistance program must first gather information, usually from the doctor or care team. In most cases, the patient will need to fill out an application from the drug manufacturer. A doctor must be involved in the process because the physician writes the prescription for the medication.

Many patient assistance applications will require proof of income, including tax returns, Social Security income, interest and retirement income, to prove financial burden and meet income requirements. In addition to many state governments, numerous organizations provide information on patient assistance programs. For listings, visit curetoday.com/journey.

PART FIVE

After Treatment

Handling Fear of Recurrence · 122

Developing a Survivorship Care Plan · 124

For related articles, visit
curetoday.com



LEARN MORE!

What's the most respectful language to use when discussing cancer and survivorship? **Scan the QR code** to read **CURE**'s exploration of this issue.



Handling Fear of Recurrence

The uncertainty that cancer might return can be managed

PATIENTS UNDERGOING TREATMENT often worry about whether therapy will cure their disease. But a different kind of worry — fear of the cancer returning — often emerges at the completion of therapy when the medical team is no longer present.

Although fear of recurrence might never go away, it should diminish over time, especially if a patient has a positive experience living as a survivor and a well person. Managing fear is essential when external stimuli, known as triggers, feed anxiety. Some common triggers include a relative or friend receiving a cancer diagnosis, aches and pains previously associated with cancer, media coverage of cancer and follow-up medical appointments. Having to revisit those emotions during medical appointments can sometimes lead survivors to avoid necessary follow-up testing. For others, fear becomes part of an action plan, motivating

survivors to seriously look at maintaining a proper diet and healthy lifestyle.

Helpful coping strategies include using calming self-statements, imagery and distraction; talking to family, friends, doctors or nurses about the fear; or writing in a journal, which provides a setting for a personal monologue to explore issues behind the fear and ways to overcome it. Other tips follow.

Acknowledge the fear, anger or sadness. Survivors should accept that sometimes they will worry about cancer returning, and the best thing to do is acknowledge their feelings and talk with someone who will listen and not judge.

Live life to the fullest. Around the time of a check-up, survivors should pursue activities that provide a distraction so they have something else to focus on.

Exercise. Survivors should find an exercise they enjoy that will take their mind off fear. Exercise can also help reduce stress.

Learn the actual signs of recurrence. Being informed about the potential warning signs of recurrence and the potential risk of it can help ease concerns.

Get a check-up. If fear of recurrence is overwhelming, survivors should talk with their doctors about blood work or other tests that could alleviate their fears.

Sometimes people become so fearful that they fall into despair. Symptoms of fear that can indicate a need for mental health care include excessive anger and irritability, difficulty with concentration and problem solving, and physical symptoms, such as muscle tension, dry mouth, trembling, shaking or restlessness.

Changes in appetite or sleep can also be important symptoms that indicate a need for help. Some people find that medication is appropriate in helping them get through the most stressful periods. ■

ADVICE FROM *a* SURVIVOR

SAMIRA RAJABI



“The thing about being in constant fear of recurrence is that it is remarkably hard to stop paying attention.

Recovery brought with it a fear of being well, a fear that, if I returned to my life, the way I wanted to live it, that one day it would all collapse out from under me. I was afraid to get better at the risk my symptoms would reoccur. Every time I feel a drip out of my nose, a surge of a headache, the ringing in my ears, I must remind myself that it doesn't necessarily mean I am sick again. I also must remind myself, as my mother once did, that even if it did mean I would be sick again, with hope, with a continued devotion to my life and those I love, everything would be OK.”



SCAN THE QR CODE to read SAMIRA'S story.

FUTURE RISK

Predicting Recurrence

DOCTORS CAN'T PRECISELY PREDICT if cancer will recur, but depending on the type, stage and other factors, a strategy to monitor for recurrence can be put in place when treatment ends.

Typically, patients who had complete surgical removal of their tumor or those with early-stage, nonaggressive tumors are less likely to have a recurrence. For most cancers, the risk of recurrence declines over time, but every cancer type has a different pattern.

Patients should establish a regular schedule of follow-up visits with doctors and have an idea of the kind of testing that should be done to check for recurrence. This might include blood tests or imaging. A newer and more sensitive technique for finding a very small number of lingering cancer cells, and thus detecting a recurrence early or even preventing it, is liquid biopsy. These tests check the blood for traces of DNA shed by tumors. In clinical trials, the

tests can find DNA that would otherwise be undetectable. Liquid biopsies are not widely used yet, but are a promising strategy in a number of cancer types, including breast.

After treatment for cancer, adjuvant (postsurgical) therapy with drugs or radiation can help some patients lower their risk of recurrence. In addition, frequent exercise and a healthy diet that includes plenty of fruits and vegetables could help lower recurrence risk in many cancers.



LEARN MORE!

A nurse describes two kinds of survivorship care plans in *CURE*®'s article. **Scan the QR code.**



Developing a Survivorship Care Plan

It's never too soon to prepare for life after cancer

MANY PATIENTS are overwhelmed when they learn they have cancer, and studies show it's difficult for them to absorb information about their diagnosis. Then, as they focus on getting through treatment, they might not think to ask their health care teams about life beyond cancer.

The time after initial treatment ends has become recognized as its own, distinct phase of the cancer experience, and those who study cancer survivors have suggested a strategy for the ongoing clinical care of cancer survivors. At the heart of this strategy is a survivorship care plan (SCP), a document

that includes details not only about the patient's diagnosis and treatment, but also essential information needed for long-term follow-up care.

The SCP should officially switch a patient to a general physician who will provide primary care and routine disease screenings. Designed for discussion at the end of treatment, the SCP should include summaries of key diagnostic and staging results, treatments and dosages received and the potential late effects of those treatments. It should prompt discussion about recurrent and new cancers; genetic implications; possible long-term and »

cure[®] Extraordinary HEALER[®]2022



Do you know an **Extraordinary Oncology Nurse?**

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CURE[®] is now accepting essay nominations for the 2022 Extraordinary Healer[®] Award for Oncology Nursing!

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Maria Lim, B.S.N., RN, OCN, BMTCN
Winner of 2021 Extraordinary Healer Award

Submit your essay today!
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curetoday.com/EH22



late effects; explanations of legal rights affecting employment and insurance; recommendations for nutrition, exercise, lifestyle changes and rehabilitation; and referrals for psychological and support assessments.

WHO'S IN CHARGE?

With today's complicated health care system, ever-changing insurance coverage and multiple specialists, it's hard to keep up with medical history and long-term follow-up appointments, not to mention the standard medical needs associated with aging. More oncologists are connecting with patients' primary care physicians after treatment because they will be assuming the survivor's care after a set period of follow-up by the oncologist.

But many primary care doctors are not fully versed in the follow-up requirements for patients whose medical histories include cancer. Therefore, patients should be prepared to inform their primary care doctors about their unique needs or find physicians willing to collaborate with their oncologists to better understand those needs.

WHERE AND WHEN TO BEGIN?

It's never too soon to start gathering the information that will become part of the SCP. A number of organizations offer plans that can be accessed online.

- ▶ The Abramson Cancer Center of the University of Pennsylvania (oncolink.org/oncopilot)
- ▶ American Society of Clinical Oncology (cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans)
- ▶ LIVESTRONG (tinyurl.com/j6rrllm)

Many SCPs are designed for use by health care professionals, but some are templates that can be adapted by patients.

At appointments with health care providers, patients should ask for relevant information or



explanations of anything they do not clearly understand about their diagnosis and treatment. They might have to ask for copies of pathology reports and treatment drugs and dosages. They should ask health care personnel to translate medical terminology into understandable language.

After the SCP is completed, patients might want to make copies and have them available for other health care providers and family members.

As time progresses, patients should ask for updates to their SCPs at follow-up oncology appointments. A patient should be specific about any facts that are needed to complete the SCP, and question members of the health care team about decisions today that could have lingering effects long into the future. In addition, patients should:

- ▶ Be sure their family members understand any genetic implications cancer has for their lives.
- ▶ Ask if new information should be added, especially concerning late effects of drugs or radiation that were part of treatment and any associated tests or surveillance measures that are needed.
- ▶ Ask if any new information is available that could change plans for surveillance or prevention of cancer recurrence. 📌

PART SIX

Caregiving

Taking on a New Role · 128

Practicing Self-Care · 131

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LEARN MORE!

Caregivers of patients with cancer may face financial toxicity and stress — with little time to take care of themselves. **Scan the QR code** to learn more.



Taking on a New Role

Notes on navigating the challenging territory of caregiving

BECOMING A CAREGIVER is one of the most important — and loving — things someone can do. While each individual's cancer experience is unique, there are some caregiving tips that apply to nearly everyone.

Talk about it. It's important that caregivers take some time to process what's happening. They should talk to the patient about the decisions that will need to be made, including second opinions, treatments and where to be treated.

Listen and learn. During appointments, caregivers should take notes or, with the doctor's permission, record the session. Unless the caregiver has permission from the patient to pursue a dialogue with the

doctor, the patient should lead the conversation. Once the treatment plan has been determined by the medical team, the patient and caregiver should get the plan in writing and ask questions about any points that are unclear.

Be realistic about what's ahead. Treatment can be emotionally and physically taxing, so caregivers shouldn't minimize what they or their loved ones are going through. Patients react differently to treatments, and the toll can be cumulative. Patients might feel fine at the outset of treatment, but could feel worse before starting to feel better.

Perform simple acts of kindness. Small gestures can make a big difference. »

R E S E A R C H S T U D Y

Do you have a patient with myelofibrosis?

We are conducting three research studies to evaluate an investigational medication (called navitoclax) in patients with myelofibrosis. The primary objective of this program is to evaluate the effect of navitoclax (in some cases, in combination with ruxolitinib) on reducing spleen volume in patients with myelofibrosis. Patients may continue on study as long as they are receiving benefit. We need help from the local medical community to help us identify qualified study participants.

LOCATIONS WORLDWIDE

If you would like to speak with a Principal Investigator conducting one of the AbbVie myelofibrosis studies in your area, please contact us today.

AbbvieResearchStudies.com

Navitoclax, an investigational medication, is under clinical development and is not approved by regulatory health agencies.
Safety and efficacy have not been established.

abbvie

Discuss legal and financial issues. Most patients want to take care of important affairs, such as wills, living wills and medical power of attorney. Caregivers should consider reviewing financial details, such as bank accounts, tax documents, stocks, bonds, mutual funds, retirement accounts, CDs and contact information for financial advisers.

Allow patients to express feelings. Caregivers should make sure patients feel safe and comfortable expressing how they feel, and

remind them that there's no need to be upbeat all the time. Caregivers should also be prepared for patient mood swings, which can be a side effect of treatment.

Call a family meeting. Friends and family, regardless of distance, might want to be involved in the patient's care. Caregivers should organize a family meeting, even if it's just by phone, to discuss who will do what. It's important for the patient to be involved, too. ■

GET ORGANIZED

Creating a Notebook

THE AMOUNT OF PAPER generated by a cancer diagnosis can quickly become overwhelming. Below are ways caregivers can keep cancer information organized and accessible.

- ▶ **CREATE A SUMMARY** with cancer diagnosis details, the official treatment regimen and any other regularly needed information, such as important phone numbers, names and other health issues. Be sure to list all the medications taken at home, and include other details, such as nutritional supplements the patient takes.
- ▶ **KEEP A CALENDAR** for appointments.
- ▶ **DOCUMENT THE PROCEDURES AND TREATMENTS** given and planned, including possible side effects.

- ▶ **WRITE LISTS OF QUESTIONS** for appointments. Store extra paper for taking notes.
- ▶ **KEEP SECTIONS FOR EACH DOCTOR**, as well as for pathology, radiology and lab reports.
- ▶ **ORGANIZE INFORMATION** into simple categories, such as treatment options, side effects and clinical trials.
- ▶ **FILE ALL EXPLANATIONS OF BENEFITS**, bills and other correspondence with the insurance company in one section. Take notes, including names and dates, of any conversations with insurance companies.

Various cancer nonprofit agencies, such as the LIVESTRONG Foundation and the American Cancer Society, offer free resources for patients and caregivers. Caregivers should visit cancer.org/caregivers to find a guide that discusses how to handle specific side effects and symptoms, as well as information on nutrition for patients with cancer, pain control and choosing home care or hospice services. Downloadable worksheets that cover treatment, financial and practical issues are provided at caregiverslibrary.org; click on the link for checklists and forms.

**LEARN MORE!**

Caring for a loved one who has cancer can be an all-encompassing experience. One woman who helped her adult daughter through a cancer journey discusses what she faced in a blog for **CURE**®.



Practicing Self-Care

How and why caregivers should care for themselves

IN THE CHAOS AND INTENSITY that surrounds a new cancer diagnosis, everyone tends to focus all of their care and concern on the patient. While caregivers often brush aside their own needs, experts warn that such selfless devotion can backfire. The constant stress of providing care can make caregivers more vulnerable to getting sick or burned out. Caregivers should look at their stress levels and try to prevent burnout before it happens. Following are some ways to prevent burnout.

Reach out. Caring for someone full time can lead to feelings of panic, despair and isolation. After the initial crisis of diagnosis and treatment, there's often a lingering worry that the

cancer could return. Caregivers should reach out to friends, family, online chat groups and support organizations to help reduce feelings of isolation.


Support groups for cancer patients and caregivers can be located through local hospitals or the American Cancer Society. It makes a big difference for caregivers to know they're not alone in their experiences or feelings. They should try exercise, meditation and other stress reduction techniques, too. If nothing seems to help, it might be time to consult a therapist or doctor.

Accept help. If friends or neighbors ask what they can do to help, caregivers should tell them. By keeping a to-do list ready, caregivers »

can let others know exactly what is needed when asked. If friends or relatives are not available to step in for a few hours, caregivers might want to hire someone or find adult day care. The U.S. Administration on Aging offers a national database of eldercare providers at eldercare.acl.gov.

Get some sleep. To overcome insomnia, experts suggest things like staying on a regular sleep schedule, keeping the bedroom quiet and using guided imagery and relaxation techniques. Cutting back on late-afternoon caffeine and adding mild to moderate exercise can also help caregivers sleep better. Alcohol can interfere with sleep as its effects wear off, so try warm milk or a soothing herbal noncaffeinated tea instead. Sometimes it helps to write down any worries and “release” them for the day before heading to bed. If all else fails, it could be time to talk with a doctor.

Stay healthy. With everything they have to do in a day, caregivers often neglect basic health maintenance. Some simple things to strive for include eating regular meals that are rich in fruits and vegetables, staying hydrated and exercising, even if it’s just a brisk 15-minute walk each day. Caregivers should line up help so they can keep regular appointments for their own dental cleanings, health screenings and annual checkups, too.

Find meaning. Caregivers who can take their experience with cancer and learn from it might have less depression and anxiety. Through caregiving, many people find more meaning in life and are able to focus on their highest priorities. Caregivers can work on personal growth by meditating, starting journals, talking with counselors or leaning on their spiritual communities. 

GET HELP

Setting Up a Caregiver Team

ASSEMBLING A CREW of helpful friends and family members is key. Caregivers should start by making a list of tasks they’ll need help with and then think of all the family members, friends, neighbors or fellow congregants at their houses of worship who could be reliable sources of support. It might be helpful to identify a family member or friend who can take the lead in organizing what needs to get done, and choosing who will do it. Here are some tips for getting needed support.

CALL FOR HELP. If a caregiver is in the thick of doctors’ visits and is feeling overwhelmed, the laundry should be the last thing on the to-do list. Caregivers shouldn’t be afraid to ask for help. Often friends and family members want to help but don’t know what to offer. Most friends would gladly deliver a meal, do household chores or provide transportation.

SEEK EMOTIONAL SUPPORT. This can often come from established cancer organizations, such as the **Cancer Support Community** (Helpline at 888-793-9355; CancerSupportCommunity.org). Support groups can help caregivers avoid feelings of isolation and allow them to share their experiences, as well as their collective wisdom, with other members. There are also online support communities for caregivers, such as those hosted by **Inspire** (Inspire.com), where caregivers can connect with each other and share their concerns and resources in a supportive, online space.

USE TECHNOLOGY. To update friends and extended family, caregivers should consider setting up a website. They’ll receive support and inspiration by encouraging visitors to post messages and volunteer for tasks, and they’ll be able to keep others in the loop. Sites such as **the Cancer Support Community’s MyLifeLine** service (MyLifeLine.org), **CaringBridge** (CaringBridge.org) and **Lotsa Helping Hands** (LotsaHelpingHands.com) make it easy to create a free website that will help connect friends and family. If the caregiver isn’t web-savvy, friends or family members might be willing to serve as webmasters.

PART SEVEN

Toolbox

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For related articles, visit
curetoday.com

Useful Resources

LEARN MORE!

Knitted Knockers provides free knitted breast prostheses for women who have undergone mastectomy. Learn more at curetoday.com/link/115.



PEOPLE WITH CANCER and their families often need assistance coping with the emotional and practical aspects of the disease. Those providing Spanish-language content are marked with an “S.”

GENERAL INFORMATION AND SUPPORT

American Cancer Society

800-227-2345; cancer.org **S**
Offers a variety of services to patients and their families and provides printed materials, a glossary and information about cancer; can provide information on programs that may help patients get drugs at substantially lower costs or for free, depending on their financial circumstances and insurance plans.

American Society of Clinical Oncology

571-483-1780; 888-651-3038;
contactus@cancer.net;
cancer.net **S**
Presents timely, comprehensive, oncologist-approved information to help patients and families make informed health care decisions.

CancerCare

800-813-4673; info@cancercares.org;
cancercares.org **S**
Leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer.

Cancer Hope Network

877-467-3638; 877-HOPENET;
info@cancerhopenetwork.org;
cancerhopenetwork.org **S**
Matches patients with cancer and family members with trained volunteer cancer survivors who have recovered from a similar cancer experience.

Cancer Research Institute

800-992-2623; info@cancerresearch.org;
cancerresearch.org
Works with global network of researchers, supporters, patients and advocates to fund research while promoting awareness, and share up-to-date immunotherapy information.

Cancer Support Community

888-793-9355;
help@cancersupportcommunity.org;
cancersupportcommunity.org
A global nonprofit network of 175 locations, including CSC and Gilda’s Club affiliates, hospitals and other health care partnerships that, together with its toll-free helpline, education materials and digital services, deliver more than \$50 million in free services to patients and their loved ones each year.

Coping University

866-725-7877; copinguniversity.com
Offers free video seminars on how to cope with the distress of medical challenges.

I Had Cancer

212-994-5270; feedback@ihadcancer.com;
ihadcancer.com
Empowers anyone who has been affected by cancer to take control of life before, during and after a diagnosis; provides tools that connect community members with each other and trusted resources for answers, support and inspiration at any point of the cancer journey.

Imerman Angels

877-463-7626; info@imermanangels.org;
imermanangels.org **S**
Provides personalized connections that enable one-on-one support among cancer fighters, survivors and caregivers.

Livestrong

855-220-7777; livestrong@livestrong.org;
livestrong.org
Helps people with cancer through education, public health and research.

National Cancer Institute

800-422-6237; NCIinfo@nih.gov;
cancer.gov **S**
Provides comprehensive information about cancer and clinical trials and links to cancer centers. Offers free clinics that advise

people with brain, spinal cord and rare cancers, and gastrointestinal stromal tumor.

National Center for Complementary and Integrative Health

888-644-6226; info@nc.nih.gov;
nc.nih.gov/tools/contact.htm **S**
Provides the latest news, research, events and clinical trials involving complementary medicine.

Triage Cancer

424-258-4628; info@triagecancer.org;
triagecancer.org
Provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials and resources.

SPECIAL POPULATIONS AFFECTED BY CANCER

ADOLESCENTS AND YOUNG ADULTS (AGES 15 TO 39)

Livestrong Fertility

855-844-7777; livestrong@livestrong.org;
livestrong.org/fertility
Educates patients who have cancer about fertility issues; division of LIVESTRONG.

Stupid Cancer

212-619-1040; contact@stupidcancer.org;
stupidcancer.org
Empowers young adults with cancer through programs, support, education and awareness.

Teen Cancer America

310-208-0400; info@teencanceramerica.org;
teencanceramerica.org
Partners with hospitals throughout the United States to develop specialized facilities and services for teens and young adults with cancer; builds teen-friendly environments; develops standards for age-targeted care; improves collaboration between pediatric and adult specialists; supports dedicated research to improve outcomes and survival rates.

Young Survival Coalition

877-972-1011; info@youngsurvival.org; youngsurvival.org **S**

Dedicated to the critical issues unique to young women and breast cancer; works with survivors, caregivers, and the medical, research, advocacy and legislative communities to increase the quality and length of life for women diagnosed with breast cancer at age 40 and younger.

AMPUTEES

Limbs for Life Foundation

888-235-5462; admin@limbsforlife.org; limbsforlife.org

Dedicated to providing fully functional prosthetic care to individuals who cannot afford it and raising awareness of the challenges facing amputees.

CAREGIVERS

Family Caregiver Alliance

800-445-8106; info@caregiver.org; caregiver.org **S**

Offers information and advice, discussion groups and a navigator to help find local resources and services.

National Alliance for Caregiving

202-918-1013; info@caregiving.org; caregiving.org

Provides support for family caregivers and the professionals who help them; raises awareness of family caregiving issues.

CHILDREN'S CANCERS

Alex's Lemonade Stand Foundation

866-333-1213; info@alexslimonade.org; alexslimonade.org

Offers support for siblings of patients, helps fund travel for care and offers parent-to-parent network; emerged from the front-yard lemonade stand of cancer patient Alexandra "Alex" Scott (1996-2004), evolving into a national fundraising movement that has raised more than \$120 million and funded over 550 pediatric cancer research projects nationally.

American Childhood Cancer Organization

855-858-2226; staff@acco.org; acco.org

Dedicated to easing the lives of families dealing with childhood cancers and their long-term side effects; works toward giving these children the benefit of one more miracle cure; offers resources, peer support, local groups and a list of organizations that can provide financial assistance with treatments.

Chai Lifeline

212-465-1300; 877-CHAI-LIFE; info@chailifeline.org; chailifeline.org

Finds ways to bring joy to the lives of young, seriously ill patients and their families through creative, innovative and effective family-centered programs and activities and services that are free, including a camp, community services, counseling, crisis intervention, educational assistance, hospital services and trips.

Children's Wish Foundation International

800-323-WISH; info@childrenswish.org; childrenswish.org

Grants wishes for seriously ill children and young adults.

Clayton Dabney for Kids with Cancer

214-361-2600 in Dallas; 713-471-8358 in Houston; Lauren.lee@claytondabney.org; claytondabney.org

Helps low-income families with children in the last stages of terminal cancer to create everlasting memories; provides last wishes, gifts, special events, family travel and financial assistance with household expenses; arranges aid through the parents and remains anonymous to the child.

Compassion Can't Wait

310-276-7111; info@compassioncantwait.org; compassioncantwait.org

Responds within 24 hours of a hospital social worker's request to provide essentials such as food, transportation, utilities, medications and rent or mortgage payments so that a single parent who lacks resources can stay at the bedside of a child with a catastrophic illness; pays for wishes, such as a wig for a teenager returning to school after chemotherapy or a plane ticket for a grandparent to visit.

Dream Factory

502-561-3001; dreamfactoryinc.org
Grants wishes to children with life-threatening or chronic illnesses or disorders.

First Hand Foundation

816-201-1569; firsthandfoundation@cerner.com; firsthandfoundation.org

Provides funding for individual children with health-related needs when insurance and other financial resources have been exhausted; pays for items including medical treatment, equipment such as wheelchairs or prostheses, expenses associated with traveling for treatment and vehicle modifications such as lifts or ramps.

Hugs for Brady Foundation

908-334-7740; sherrie@hugsforbrady.org; hugsforbrady.org

Dedicated to helping children with childhood cancers in every way possible, including defraying the costs of treatment.

InsureKidsNow.gov

877-KIDS-NOW; insurekidsnow.gov **S**

Helps income-eligible parents get free or low-cost health and dental insurance for their children.

Locks of Love

888-896-1588; locksoflove.org; info@locksoflove.org

Accepts donations of hair and provides hairpieces to financially disadvantaged children under age 21 suffering from long-term medical hair loss from any diagnosis.

Make-A-Wish

800-722-WISH; mawfa@wish.org; wish.org **S**

Grants wishes for children diagnosed with a critical illness.

Mattie Miracle Cancer Foundation

703-625-6030; pbrown@mattiemiracle.com; mattiemiracle.com

Dedicated to increasing childhood cancer awareness, education, advocacy, research and psychosocial support services to children, their families and medical personnel; offers support throughout the cancer treatment journey, ensuring access to quality psychosocial and mental health care and enabling children to cope with cancer so they can lead happy and productive lives.

The National Children's Cancer Society

314-241-1600; communications@thencs.org; thencs.org

Provides information and support before and after treatment, as well as financial assistance and partial college scholarships.

Ronald McDonald House Charities

630-623-7048; rmhc.org; info@rmhc.org

Offers families of children with serious illnesses temporary housing near site of treatment; provides rooms inside hospitals so families can rest and regroup; sends out care mobiles to give children access to health care; offers grants to nonprofit organizations that help ill children.

A Special Wish Foundation Inc.

800-488-9474; info@aspecialwishfoundation.org; aspecialwishfoundation.org

Gifts items, trips or meetings with personal heroes to people under age 21 who have life-threatening illnesses.

Sunshine Foundation

215-396-4770; info@sunshinefoundation.org; sunshinefoundation.org
Grants wishes for seriously or chronically ill, physically challenged or abused children whose families cannot afford to fulfill their requests.

FACING HOMELESSNESS

Catholic Charities USA

703-549-1390; webmaster@catholiccharitiesusa.org; catholiccharitiesusa.org
Works to ease homelessness, among many other services for people in need.

Family Promise

908-273-1100; info@familypromise.org; Familypromise.org
Helps people find temporary housing to avoid homelessness.

Members of Congress

202-224-3121; house.gov/representatives/find-your-representative
Provide navigators who help people get what they need from federal programs, including Medicaid, and may be able to assist people who are sick in finding resources.

National Health Care for the Homeless Council

615-226-2292; council@nhhc.org; nhhc.org/directory/
Offers searchable directory listing sites in a handful of states that will provide free temporary housing to patients undergoing or recovering from medical treatment.

INHERITED CANCERS OR PREDISPOSITIONS TO CANCER

Facing Our Risk of Cancer Empowered (FORCE)

866-288-7475; info@facingourrisk.org; facingourrisk.org **S**
Provides support, education and programs to help those facing hereditary breast and ovarian cancer know their health care options.

Proactive Genes

609-716-7777; info@proactivegenes.com; proactivegenes.com
Provides support, insights and resources to help families start a conversation about health history.

Sharsheret

866-474-2774; info@sharsheret.org; Sharsheret.org
National non-profit organization improves the lives of Jewish women and families living with or at increased genetic risk for breast or ovarian cancer through personalized support and saves lives through educational outreach.

LGBTQ

National LGBT Cancer Network

212-675-2633; info@cancer-network.org; cancer-network.org
Addresses the needs of LGBT cancer survivors and those at risk by educating members of the LGBT community about their increased cancer risks and the importance of screening/early detection; trains health care providers to offer culturally competent and safe treatment to LGBT people; advocates for LGBT inclusion in cancer research, media and mainstream cancer organizations; supports LGBT cancer survivors through free online support services.

MILITARY/VETERANS

Fisher House

888-294-8560; info@fisherhouse.org; fisherhouse.org
Offers comfort homes worldwide where military personnel and veterans can stay for free when they need to be near a loved one in a military or veterans hospital.

PREGNANT WOMEN

Hope for Two: The Pregnant With Cancer Network

800-743-4471; info@hopefortwo.org; hopefortwo.org
Connects women worldwide who are pregnant and have cancer with other women who have been pregnant with the same type of cancer and can lend support, offer hope and share their experiences through phone and email conversation.

SURVIVORS

National Coalition for Cancer Survivorship

877-NCCS-YES; info@canceradvocacy.org; canceradvocacy.org **S**
Nation's oldest survivor-led advocacy organization; redefines survivorship from the time of diagnosis through the balance of life early on; serves as authority on the full spectrum of survivorship issues; advocates to improve cancer-related public policy and empower cancer survivors with education and resources.

WOMEN

Cancer Recovery Foundation

717-545-7600; info@cancerrecovery.org; cancerrecovery.org
Provides grants up to \$250 maximum per family per year to help pay for rent and utilities for women with breast, cervical, endometrial, ovarian, uterine, stomach, esophageal, pancreatic or lung cancers.

WORKING ADULTS

Cancer and Careers

646-929-8032; cancerandcareers@cew.org; cancerandcareers.org **S**
Provides a workbook, educational resources and support for cancer patients about working through treatment and returning to work.

PREVENTION

Prevent Cancer Foundation

800-227-2732; 703-836-4412; pcf@preventcancer.org; preventcancer.org **S**
One of the nation's leading voluntary health organizations and the only U.S. nonprofit groups focused solely on cancer prevention and early detection; fulfills its mission through research, education, outreach and advocacy.

CLINICAL TRIALS

ClinicalTrials.gov

888-346-3656; ClinicalTrials.gov **S**
Offers information for locating federally and privately supported clinical trials for a wide range of diseases and conditions, including cancer.

FINANCIAL HELP

ASSISTANCE FOR THE UNINSURED

Blink Health

844-265-6444; 833-794-1293 to order medicines; info@blinkhealth.com; blinkhealth.com
Can help patients save up to 95% on prescriptions through more than 57,000 participating pharmacies nationwide. Patients pay one negotiated price for a medication. Pay online, pick up at a local pharmacy. Open to anyone, but individuals who are uninsured or have high deductibles or expensive copays may benefit most.

Medicaid

877-267-2323; medicaid.gov@cms.hhs.gov; medicaid.gov
Offers programs that may be able to help those who can't afford insurance or care — contact local or state department of social services or welfare office.

Medicine Assistance Tool

571-350-8643; medicineassistancetool.org **S**
Helps qualifying patients who don't have prescription drug coverage get their medicines for free or nearly free. This search engine run by Pharmaceutical Research and Manufacturers of America connects patients with patient assistance programs run by pharmaceutical companies.

Veterans Benefits Administration

800-827-1000; benefits.va.gov
May be able to help those who have served in the military and their dependents.

HELP FOR OLDER AND DISABLED PATIENTS

BenefitsCheckUp

812-567-2324; 800-794-6559; agentchuckg@gmail.com; benefitscheck-up.org **S**

National Council on Aging program; aims to help patients over 55 pay for prescription drugs, health care and other needs.

Medicare

800-633-4227; medicare.gov; medicare.gov/Pubs/pdf/11931-Cancer-Treatment-Services.pdf **S**

May be able to offer assistance or information; can explain what services and equipment it covers under its plans.

Medicare Rights Center

800-333-4114; info@medicarerights.org; medicarerights.org

National, nonprofit consumer service organization; works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives.

FINANCIAL HELP FOR ADOLESCENTS AND YOUNG ADULTS

Cameron Siemers Foundation for Hope

949-412-4922; jennie@cameronsiemers.org; cameronsiemers.org

Supports young adults with life-threatening illnesses; awards at least four life grants a year of up to \$5,000 to help young adults undertake projects that make a difference in their lives and their communities.

Cancer for College

760-599-5096; info@cancerforcollege.org; cancerforcollege.org

Provides low-income, high-achieving students who have survived cancer with college scholarships of up to \$5,000, along with professional mentorship services.

Cancer Survivors' Fund

281-437-7142; csf@cancersurvivorsfund.org; cancersurvivorsfund.org

Provides college scholarships for young survivors of cancer, prosthetic limbs to disadvantaged young adults, counseling and emotional support.

The Samfund

617-938-3484; info@thesamfund.org; thesamfund.org

Provides financial support to young adult cancer survivors who are trying to pay medical bills; has helped patients pay for rent, car insurance and gym memberships; has given over \$1.6 million in grant funding.

NONPROFIT FUNDING FOR CANCER CARE AND LIVING EXPENSES

The Assistance Fund

855-845-3663; info@tafcares.org; tafcares.org

Manages 40 funds that can help patients with cancer and other serious diseases to pay for their medications.

Benefits.gov

800-333-4636; benefits.gov **S**

Online resource to find out about possible government assistance.

Cancer Financial Assistance Coalition

cancerfac.org

Composed of 14 organizations that help provide support.

Cancer Information Service

800-422-6237; cancer.gov/contact **S**

Run by the federal government; can suggest organizations that offer advice on financial aid.

Family Reach

Boston office: 857-233-2764; New Jersey office: 973-394-1411; info@familyreach.org; familyreach.org

Helps patients with cancer financially through a network of social workers; offers a financial handbook at familyreach.org/financial-edu.

Friends of Man

303-798-2342; friendsofman.org

Provides medical equipment for various populations in need, including children, the elderly and the disabled.

Good Days

877-968-7233; admin@mygooddays.org; mygooddays.org

Provides financial assistance to patients who can't afford medication; helps with travel costs.

The HealthWell Foundation

800-675-8416; support@healthwellfoundation.org; healthwellfoundation.org **S**

Provides financial assistance for medical treatment to insured patients living with chronic and life-altering illnesses.

Hill-Burton Program

877-464-4772 in Maryland; hrsa.gov/get-health-care/affordable/hill-burton/index.html

Pays for some eligible patients' use of hospitals built with the help of federal funding; these hospitals must treat lower-income patients. Provides hotline to the Department of Health and Human Services.

NeedyMeds

800-503-6897; info@needymeds.org; needymeds.org **S**

Maintains a website of free information on programs that help individuals who cannot afford medications and health care costs; provides a free drug discount card that offers up to 80% savings at thousands of pharmacies nationwide.

Patient Access Network Foundation

800-394-0161; info@panfoundation.org; panfoundation.org/index.php/en/contact

Helps underinsured people with life-threatening, chronic and rare diseases get the medications and treatment they need by paying for their out-of-pocket costs and advocating for improved access and affordability.

Patient Advocate Foundation

800-532-5274; help@patientadvocate.org; patientadvocate.org, copays.org **S**

Offers free copay relief programs; acts as a liaison between patients and their insurers, employers and creditors to help resolve insurance, job retention and debt crisis issues related to their illnesses.

Rx Outreach

888-796-1234; questions@rxoutreach.org; rxoutreach.org **S**

Nonprofit, mail-order pharmacy; helps patients save money on medications and carries many cancer drugs.

Social Security Administration

800-772-1213; ssa.gov/applyfordisability **S**

Offers disability payments to those who qualify.

Zichron Shlome Refuah Fund

718-438-9355; zsrff.org

Helps people with cancer with funding for medical expenses, dream fulfillment, wigs, vitamins, living expenses, housekeeping, retreats, transportation, summer camps, plane tickets and insurance.

HELP IN SPECIFIC GEOGRAPHIC REGIONS

Kelly Anne Dolan Memorial Fund

215-643-0763; pdolan@dolanfund.org; dolanfund.org

Lightens the burdens and lifts the spirits of families caring for children with serious illnesses, disabilities, and injuries while respecting the pride and dignity of families in need; provides financial assistance for needs not covered by insurance; offers Family Fun Day programs, noncash items and financial management education to families living or seeking treatment in Pennsylvania, New Jersey, and Delaware; advocates for

and provides education and information on other resources and education to families nationwide.

FINANCIAL HELP: BLOOD CANCERS

Be the Match

888-999-6743; patientinfo@nmdp.org; bethematch.org/patients-and-families/support-for-you-and-your-family/one-on-one-support **S**

Manages the largest and most diverse marrow registry in the world; matches patients with donors to save lives through bone marrow transplant; offers counseling and financial grants to patients and support to caregivers.

The Bone Marrow & Cancer Foundation Lifeline Fund

800-365-1336; bmf@bonemarrow.org; bonemarrow.org/support-and-financial-aid/financial-assistance/lifeline-fund Offers post-transplant grants for copays, transportation, gas and housing or medicine and medical costs that insurance doesn't pay; transplant team member must apply: patientgrants@nmdp.org.

Children's Leukemia Research Association

212-491-1200; 516-222-1924; info@childrensleukemia.org; childrensleukemia.org/patient-aid-summary Allows adults and children with any kind of leukemia — except those receiving Medicaid benefits — to apply, without proof of income, for copay assistance programs until group's annual funding is exhausted; maximum of \$1,500 per patient.

Help Hope Live

800-642-8399; info@helphopelive.org; helphopelive.org Supports community-based fundraising for people with unmet medical and related expenses due to cell and organ transplants or catastrophic injuries and illnesses.

Leukemia & Lymphoma Society

800-955-4572; lls.org/support/financial-support **S** Provides limited financial assistance to patients with leukemia, lymphoma, multiple myeloma or myelodysplastic syndromes who have demonstrated financial need.

Lymphoma Research Foundation

800-500-9976; helpline@lymphoma.org; lymphoma.org/resources/supportservices/financialsupport **S**

Gives limited funds to patients with lymphoma who are uninsured, or insured but having difficulty covering their medical and related expenses, through Patient Aid Grant Program; allows reapplication every six months for \$500 grants.

Patient Services Incorporated

800-366-7741; psidevelopment@uneeedpsi.org; patientservicesinc.org Provides financial assistance to patients with specific diseases including acute myelogenous leukemia, acute lymphocytic leukemia, B-cell lymphoma and chronic granulocytic leukemia.

The Shannon Mosher Memorial Foundation

678-377-7036; shannonmosherfoundation@aol.com; shannonmosherfoundation.org/patientassistance.html Offers financial assistance to patients with leukemia via reimbursements for expenses not covered by health insurance.

FINANCIAL HELP: BRAIN CANCER

The Darren Daulton Foundation

DarrenDaultonFoundation@gmail.com; Darrendaultonfoundation.org Provides grants to patients with cancer, tumors or injuries to the brain who are receiving treatment and experiencing financial hardship; pays directly to companies to which accepted recipients owe money.

Friends4Michael Foundation

617-657-9630; kwinmarriott@friends4michael.org; friends4michael.org Gives grants of up to \$500 per family per year for nonmedical costs generated by a diagnosis of a pediatric primary brain tumor — a social worker must apply on the family's behalf.

Glenn Garcelon Foundation

503-969-7651; ggf@glenngarcelonfoundation.org; glenngarcelonfoundation.org Gives small grants to help with medical and living costs for patients and families affected by brain tumors.

Matthew Larson Foundation for Pediatric Brain Tumors

201-410-2751; info@ironmatt.org; ironmatt.org/familyassistance Financially helps families of patients with brain tumors who are age 21 or younger and are receiving treatment — a social worker must apply on the family's behalf.

Mission4Maureen

440-840-6497; info@mission4maureen.org; mission4maureen.org/apply-today Offers grants to help patients with brain tumors and their families pay living expenses.

Owen Lea Foundation

540-446-6871; owenleafoundation.org/assistance Helps cover what insurance doesn't, along with nonmedical costs of treatment and living expenses, for those affected by neuroblastoma.

Pediatric Brain Tumor Foundation Scholarship Program

800-253-6530; familysupport@curethekids.org; curethekids.org/family-resources/scholarships Pays \$500 in any given year to a school to defray tuition for a student who was younger than 19 when diagnosed with a primary central nervous system tumor in the brain or spinal cord.

Smiles for Sophie Forever

info@smilesforsophieforever.org; smilesforsophieforever.org/WhoWeveHelped/ApplyforaGrant.aspx Gives up to \$1,000 per year to families of children who have brain cancer.

Thompson-Mason Brain Cancer Foundation

606-207-0293; info@braincancerhelp.org; braincancerhelp.org Helps patients with brain cancer with medical and nonmedical expenses, paid directly to service vendors; allows reapplication every six months.

FINANCIAL HELP: BREAST CANCER

American Breast Cancer Foundation

410-730-5105; info@abcf.org; abcf.org **S** Provides financial assistance for breast cancer screenings and diagnostic tests for uninsured and underserved individuals, regardless of age or gender.

The Donna Foundation

877-236-6626; thedonnafoundation.org; breastcancermarathon.com Provides financial assistance for the critical needs of those living with breast cancer; offers emotional support to individuals living with breast cancer; funds groundbreaking breast cancer research; helps develop and maintain Mayo Clinic's Breast Cancer Translational Genomics Program.

Driving Miss Darby Foundation

Drivingmissdarby.org/assistance; info@drivingmissdarby.org Helps patients pay for expenses incurred as a result of participation in a breast cancer clinical trial at a state-licensed facility.

My Hope Chest

727-488-0320; info@myhopechest.org; myhopechest.org/patients/patient-application **S** Funds breast reconstruction for uninsured or underinsured women who have undergone mastectomy and are under age 65.

The Pink Daisy Project

425-643-8148; pinkdaisyproject.com/need-help.html; info@pinkdaisyproject.com Provides short-term help through gift cards for groceries, restaurants and gas for women under age 45 who are within three months of treatment for breast cancer or reconstruction.

The Pink Fund

877-234-7465; info@thepinkfund.org; pinkfund.org/get-help Gives up to \$3,000, over as many as three months, for help with living expenses to those with breast cancer who have lost income during treatment.

Sisters Network Inc.

866-781-1808; infonet@sistersnetworkinc.org; sistersnetworkinc.org/programs.html National African American survivorship organization; helps pay for utilities, rent or mortgage, and medical accessories for women being treated for breast cancer.

United Breast Cancer Foundation

877-822-4287; info@ubcf.org; ubcf.org/programs/program-application-index Provides a variety of grants to those being treated for breast cancer or who are within three to 10 years of remission: Individual grant is (for medical, insurance, travel and living expenses), holistic care (for integrative therapies such as nutritional services and mind/body treatments) and breast reconstruction; gives grants to all who are eligible (having a household income of up to 2 1/2 times the federal poverty level); requires pay-it-forward contribution of \$25 or \$50.

FINANCIAL HELP: COLORECTAL CANCERS Meredith's Miracles Colon Cancer Foundation

765-722-0302; info@merediths-miracles.org; merediths-miracles.org Provides assistance with daily living expenses such as past-due rent, utility bills and car repairs for patients with colon cancer under age 40 so that they can focus on their health; requires referral by a medical professional.

FERTILITY PRESERVATION AID

Fertile Action

Fertileaction.org/learning-center/fertility-preservation; info@fertileaction.org Gives grants to reduce the costs of egg or embryo freezing by 55% to 95%.

The Samfund

617-938-3484; info@thesamfund.org; thesamfund.org/get-help/grants Gives scholarships to young adult survivors of cancer for disease-related costs, including family-building expenses: up to \$1,000 toward the storage of eggs, embryos or sperm (option A) or up to \$4,000 toward fertility preservation procedures, from testing to in vitro fertilization, surrogacy or adoption (option B).

Team Maggie's Dream

678-977-5755; Teammaggiesdream.org/grants; mary@teammaggiesdream.org Assists men or women with cancer who need help paying for fertility preservation expenses, including copays, transportation and storage of frozen eggs or sperm and have been denied coverage by their health insurers; allows applications for grants before starting treatment for cancer.

FINANCIAL HELP: GASTROINTESTINAL STROMAL TUMOR

GIST Support International

215-340-9374; gistsupport.org/about-gist-support-international/financial-assistance; gsi@gistsupport.org Offers a second-opinion fund that will help pay for related expenses, such as travel, meals, parking and lodging for patients traveling to consult another specialist.

FINANCIAL HELP: KIDNEY CANCER

American Kidney Fund

800-638-8299; helpline@kidneyfund.org; kidneyfund.org/financial-assistance/information-for-patients **S** Offers multiple grant funds for patients experiencing kidney failure, including those who have kidney cancer.

FINANCIAL HELP: LIVER CANCER

American Liver Foundation

800-465-4837; info@liverfoundation.org; liverfoundation.org/resource-center/ **S** In partnership with NeedyMeds, offers a free drug discount that is accepted at more than 63,000 pharmacies and can be printed from the organization's website; card can't be combined with payments made by health insurance but is available to patients regardless of their insurance, income or residency requirements and can be used instead of insurance.

FINANCIAL HELP: PANCREATIC CANCER

Hirshberg Foundation for Pancreatic Cancer Research

310-473-5121; info@pancreatic.org; pancreatic.org/patients-caregivers/financial-aid Offers limited assistance with treatment, transportation, pain medication, home care and child care costs; administered through CancerCare at the above phone number.

National Pancreatic Cancer Foundation

800-859-6723; info@npcf.us; npcf.us Gives grants to help pay living expenses of patients undergoing treatment for pancreatic cancer; offers in-person and online support groups, patient advocacy programs and awareness efforts.

FINANCIAL HELP: RARE CANCERS

National Organization for Rare Disorders

800-999-6673; orphan@rarediseases.org; rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs-2/ Offers information and resources for patients, as well as funding to help with insurance and copays, testing, travel assistance and more.

FINANCIAL HELP: SARCOMA

Kylee's Dancing Angels

Kyleesdancingangels.org/find-your-happy-place; allanwebster1018@gmail.com Funds activities, trips or wishes for people with sarcoma.

Sarcoma Alliance

415-381-7236; sarcomaalliance.org/resources/financial-assistance; info@sarcomaalliance.org **S** Gives up to \$500 to help fund travel, phone bills and consultations for those who want second opinions about sarcoma treatment.

FINANCIAL HELP: SKIN CANCERS

Miles Against Melanoma

573-280-7012; milesagainstmelanoma@gmail.com; milesagainstmelanoma.com/family-assistance-program Helps pay medical or insurance related bills of patients whose melanoma has reached stage 3 or 4 through Family Assistance Program; pays grants — typically, \$700 to \$1,000 — directly to the service vendor billing the patient.

FINANCIAL HELP: STOMACH CANCER

Stomach Cancer Relief Network

888-252-8866; info@scrnet.org; scrnet.org Offers one-time grants to patients or their caregivers for any financial needs.

FINANCIAL ASSISTANCE FROM DRUGMAKERS

Amgen Safety Net Foundation

888-762-6436; amgensafetynetfoundation.com **S**

Helps qualifying uninsured patients access Amgen medicines at no cost if they meet certain requirements, such as being a resident of the United States or its territories and not having other financial support options.

AstraZeneca

800-292-6363; azandmeapp.com/ **S**

Helps those who do not have prescription insurance, are ineligible for any federal or state programs and have an income at or below \$30,000 for an individual, \$40,000 for a couple, \$50,000 for a family of three or \$60,000 for a family of four.

Bristol Myers Squibb Access Support

800-861-0048; BMSAccessSupport.com

BMS Access Support helps patients understand and navigate insurance coverage for cancer treatment or appeal payer decisions to decline coverage; can refer patients to independent charitable foundations that may be able to provide financial support, including the Bristol Myers Squibb Patient Assistance Foundation, a charitable organization that provides free medicine to eligible uninsured patients who have an established financial hardship.

BMS copay program helps eligible, commercially insured patients who have been prescribed Opdivo or Yervoy with copays or co-insurance costs.

Dendreon

877-336-3736; corporate.communications@dendreon.com; dendreononcall.com/enrollment

Offers financial assistance for patients who have commercial insurance; provides medication such as Provenge free of cost for those patients who are uninsured or rendered uninsured; has reimbursement coordinator to provide program information to patients and their providers and assist with the application process. Those interested must submit an enrollment form, which can be found on the website.

Ferring Reproductive Health Heart Beat Program

888-347-3415; 877-252-0553 in Arkansas, Massachusetts and New Jersey; ferringfertility.com/patient-resources

In partnership with Walgreens Pharmacy, offers free fertility medications to women with cancer who want to undergo fertility preservation treatments; has no financial requirements or forms, but patients must

not have had chemotherapy within the previous six months.

Genentech

877-436-3683; info@genentech-access.com; genentech-access.com/patient/biooncology.html **S**

Genentech BioOncology Access Solutions offers assistance based on the medicine a patient is taking, such as Avastin or Herceptin.

Janssen Ortho LLC

877-CAREPATH; janssencarepath.com; janssenprescriptionassistance.com

Offers two assistance programs, Janssen Ortho CarePath for individuals with insurance and Janssen Prescription Assistance for uninsured patients, which provide information on affordability programs and up-to-date information about independent foundations that may have available funding to help minimize medication costs.

Lilly

800-545-6962; lillycares.com

Lilly Cares Foundation Patient Assistance Program assists qualifying patients who have been prescribed Lilly medications get them for free if they meet the criteria.

Merck & Co.

855-257-3932; merckaccessprogram.com; merckaccessprogram-keytruda.com/hcc/the-merck-patient-assistance-program (for Keytruda)

Merck Patient Assistance Program may provide free Keytruda to U.S. patients who do not have insurance coverage, whose insurance does not cover the drug or who otherwise cannot afford to pay if they meet certain financial and medical criteria.

Merck Access Program provides reimbursement support for some patients prescribed Keytruda, helping them understand and navigate their insurance coverage for the drug; can help answer questions about insurance coverage, prior authorization, insurance appeals and direct patient assistance, including copay support for eligible patients; can offer information about independent copay assistance foundations to which Merck donates, which provide financial assistance to eligible patients who cannot afford their cost-sharing obligations (each independent foundation has its own eligibility criteria and application process).

Novartis Pharmaceuticals Corporation

888-669-6682; patientassistancenow.com/index.jsp

Novartis Oncology's Patient Assistance NOW

program helps users find assistance by searching by drug name.

Pfizer Inc.

844-989-PATH; pfizerrxpathways.com **S**

Pfizer RxPathways may be able to provide eligible patients with assistance programs that offer insurance support, copay help and medicines for free or at a savings.

RxAssist

rxassist.org; info@rxassist.org

Gives information about pharmaceutical patient assistance programs, in one place.

Tolmar Pharmaceuticals

877-354-4273; info@tolmar.com;

eligard.com/getting-started-on-eligard Patient assistance program helps qualified patients who are uninsured or underinsured to pay for Eligard (leuprolide acetate) to treat prostate cancer.

FREE SERVICES

BEAUTY SERVICES

Look Good Feel Better

800-395-5665; info@lookgoodfeelbetter.org; lookgoodfeelbetter.org/programs/men **S**

Helps with appearance-related side effects of cancer and its treatments — hair loss from chemotherapy; brittle nails; rough, flaky or discolored skin; sores and scars; offers complimentary group, individual and online lessons on skin care and cosmetics, nail care, wigs and turbans, accessories and styling to help men and women with cancer regain their self-esteem.

CAMPS AND ADVENTURE PROGRAMS

FOR CHILDREN

Believe in Tomorrow National Children's Foundation

410-744-1032; info@believeintomorrow.org; believeintomorrow.org

Premier provider of overnight accommodations for families of children receiving treatment at the Johns Hopkins Children's Center in Baltimore; developed the concept for pediatric respite housing and is the leading provider in the United States; operates beach and mountain respite properties year-round, allowing families with critically ill children the opportunity to get away, relax and reconnect in the midst of a child's treatment and recovery.

Camp Good Days and Special Times

800-785-2135; 585-624-5555; info@campgooddays.org; campgooddays.org

Provides free camp services for children who have cancer, have a parent or sibling with cancer, or lost a parent or sibling to cancer; also offers weekend adult retreats.

Camp Quality USA

501-249-2145; laura.vaughn@campqualityusa.org; Campqualityusa.org
Serves children with cancer and their families. Week-long overnight summer camps in 13 states. Offers teen weekends, family overnights and sibling retreats year round.

Camp Happy Days (South Carolina)

843-571-4336; cindy@camphappydays.com; camphappydays.org/programs
Free year-round programs to children diagnosed with cancer and their families.

Camp Kesem (nationwide)

253-736-3821; support@campkesem.org; campkesem.org
Supports children affected by a parent's cancer at no cost to families.

Camp Magical Moments (Idaho)

208-483-4345; heatherolsen@campmagicalmoments.org; campmagicalmoments.org
Offers children with cancer and their families a place of retreat.

Camp Rap-A-Hope (Alabama)

251-476-9880; info@rapahope.org; camprapahope.org
Free year-round programs including summer camp and weekend and daylong programs to children diagnosed with cancer and their families.

Camp Sunrise and Sidekicks (Arizona)

480-382-8564; info@swkcf.org; swkindscancerfoundation.org
Programs for children who have or had cancer and their siblings.

Camp Sunshine (Maine)

207-655-3800; info@campsunshine.org; campsunshine.org
Free programs to provide respite and support to families affected by life-threatening childhood illness.

Dream Street Foundation

424-333-1371; dreamstreetca@gmail.com; Dreamstreetfoundation.org
Provides camping programs for children and young adults with chronic and life-threatening illnesses.

Give Kids the World Village

800-995-5437; 407-396-1114; dream@gktw.org; gktw.org
An 84-acre, nonprofit resort in Central Florida; provides weeklong, free vacations to children with critical illnesses and their families, including stays in fully furnished villas, transportation, tickets to theme parks, meals, daily entertainment and much more.

The Hole in the Wall Gang Camp

203-772-0522; 860-429-3444; info@holeinthewallgang.org; holeinthewallgang.org
Founded by actor Paul Newman in 1988; helps seriously ill children celebrate fun and friendship for free.

FOR ADOLESCENTS/YOUNG ADULTS AND ADULTS

Camp Mak-A-Dream (Montana)

406-549-5987; 406-288-3030; info@campdream.org; campdream.org
Free to cancer survivors between ages 18 and 40; offers activities such as swimming, horseback riding, field sports, pottery, weaving and jewelry making; also offers adult retreats.

Epic Experience

855-650-9907; info@epicexperience.org; epicexperience.org
Free weeklong outdoor adventure experiences for cancer patients and survivors ages 18 and over.

First Descents

303-945-2490; info@firstdescents.org; firstdescents.org
Provides outdoor adventures of up to a week, at no charge, for young adults ages 18 to 39 affected by cancer.

Me-One Foundation (California)

916-784-2267; info@me-onefoundation.org; me-onefoundation.org
Gives adult cancer patients and their loved ones a no-cost weekend retreat at the Mission Springs Camp and Conference Center in Scotts Valley, California.

Project Koru

904-441-0495; info@projectkoru.org; projectkoru.org
Brings the healing power of community and the outdoors for cancer survivors, who can participate in surfing, stand-up paddling, outrigger canoeing and snowboarding.

Heart of Passion, Inc.

504-982-3588; president@heartofpassion.org; heartofpassion.org
Provides Red Carpet Day retreats for children with cancer. Retreats occur in Georgia, Louisiana and North Carolina.

True North Treks

info@truenorthtreks.org; Truenorthtreks.org
Free backpacking and canoeing adventures in the wilderness for young adults affected by cancer and their caregivers.

FOR WOMEN WITH BREAST CANCER

Casting for Recovery (nationwide)

888-553-3500; info@castingforrecovery.org; castingforrecovery.org
Combines breast cancer education and support with fly fishing experiences.

Little Pink Houses of Hope (North Carolina)

336-213-4733; info@littlepink.org; littlepink.org
Provides weeklong vacation retreats for patients with breast cancer and their families.

Team Survivor Northwest (Washington)

206-732-8350; executivedirector@teamsurvivornw.org; teamsurvivornw.org
Empowers women who have received a cancer diagnosis through fitness, health and wellness services.

FOR MEN WITH CANCER

Reel Recovery (nationwide)

800-699-4490; info@reelrecovery.org; reelrecovery.org
Helps men in cancer recovery through fly-fishing experiences.

RETREATS

Harmony Hill Healing Retreat (Washington)

360-898-2363; info@harmonyhill.org; harmonyhill.org
Retreat center focusing on wellness for those affected by cancer.

Smith Center for Healing and the Arts (Washington, D.C.)

202-483-8600; outreach@smithcenter.org; smithcenter.org
Offers retreats and arts-based programs for adults living with cancer and their caregivers.

COMMUNICATION

CaringBridge

651-789-2300; customer-care@caringbridge.org; caringbridge.org
Lets patients post updates to private groups they create; offers emotional support.

Lotsa Helping Hands

info+contactus@lotsahelpinghands.com; lotsahelpinghands.com
Simplifies the process of organizing help — family and friends sign up to make meals, give rides to medical appointments, or stop by to say hi.

EXERCISE

Livestrong at the YMCA

855-220-7777; livestrong.org/what-we-do/program/livestrong-at-the-ymca
Offers free programs around the country.

HATS, HEADWEAR AND WIGS

Breast Friends Hat Project

503-598-8048; mail@breastfriends.org;
breastfriends.org/request-a-hat
Sends free humorous caps to U.S.-based patients receiving chemotherapy for breast, ovarian or gynecologic cancers and experiencing hair loss.

EBeauty Community

ebeauty@ebeauty.com; ebeauty.com
National wig exchange program supporting women living with cancer.

Heavenly Hats

920-362-2668; anthony@heavenlyhats.com;
heavenlyhats.org/hat-request
Provides a new hat to anyone who loses their hair due to illness or treatment.

Hope Scarves

502-333-9715; hello@hopescarves.org;
hopescarves.org/about-us/contact
Provides a free head scarf to any patient in treatment for cancer, along with the story of the person who wore it previously. Patients are encouraged to return the scarves when they no longer need them, along with their stories.

Susan G. Komen

877-GO-KOMEN; ww5.komen.org/affiliates.aspx **S**
Free wigs distributed in some areas — call local chapter to see if they offer wigs.

Wigs & Wishes by Martino Cartier

856-582-6600; info@wigsandwishes.org;
wigsandwishes.org/contact-us.php
Distributes free wigs to women who have lost hair due to cancer treatment and grants wishes for children with cancer.

Wigs for Kids

440-333-4433; wigsforkids.org
Provides free, handmade wigs — individually made to look just like children's real hair — to children with hair loss.

HOME CLEANING SERVICES

Cleaning For A Reason

877-337-3348; info@cleaningforareason.org;
cleaningforareason.org
Works with maid services around the country to arrange for free house cleanings for those affected by cancer.

HOUSING WHEN TRAVELING FOR TREATMENT

American Cancer Society Hope Lodge

800-227-2345; cancer.org/hopelodge **S**
Offers free housing to patients and their families traveling for treatment; has more than 30 lodges throughout the United States.

Joe's House

877-563-7468; info@joeshouse.org;
joeshouse.org
Lists thousands of places to stay across the country near hospitals and treatments centers that offer a discount for traveling patients and their loved ones.

Hotel Keys of Hope

800-804-3724; 800-227-2345; extendedstay-america.com/acs-partnership **S**
Donates or deeply discounts hotel rooms to provide lodging for people with cancer and their families who need to travel for treatment; works to support the American Cancer Society's Hope Lodge program.

LEGAL ISSUES

Cancer Legal Resource Center

866-843-2572; CLRC@drlcenter.org; thedrlc.org/cancer **S**
Provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, health care professionals, employers and others coping with cancer.

CancerLinc

804-562-0371; info@cancerlinc.org; cancerlinc.org
Large network of attorneys offering legal assistance to patients with cancer and their families who live or receive treatment in the Greater Richmond, Virginia, area.

Know Cancer

knowcancer@knowcancer.org; knowcancer.com/cancer-lawyers
Online community provides social and professional support to people affected by cancer; offers information about free or low-cost legal help.

LawHelp.org

info@probono.net; lawhelp.org **S**
May direct individuals to free or discounted legal advice.

Legal Aid Societies

Offer help to those lacking financial resources in many communities or counties.

Legal Services Corporation

202-295-1500; info@lsc.gov; lsc.gov **S**
Helps connect low-income people with legal aid services.

National Cancer Legal Services Network

nclsn.org
Can point people toward free or discounted legal help.

Patient Advocate Foundation

800-532-5274; help@patientadvocate.org;
patientadvocate.org **S**
Provides education, legal counseling and referrals to survivors concerning managed care, insurance, financial issues, job discrimination and debt crisis matters.

Your Local Bar Association

May offer a short, discounted discussion with a lawyer.

TRANSPORTATION

AeroAngel

303-817-7355; info@aeroangel.org;
aeroangel.org
Provides free, lifesaving flights for very sick children.

Air Care Alliance

888-260-9707; info@aircarealliance.org;
aircarealliance.org
Allows patients who must travel for cancer care to reach out to all charitable organizations offering free air transportation at once or specific member organizations.

Air Charity Network

877-621-7177; info@mercymail.org;
aircharitynetwork.org
Provides air transportation to patients traveling for treatment.

American Cancer Society's Road to Recovery

800-227-2345; cancer.org/treatment/support-programs-and-services/road-to-recovery.html **S**
Refers patients to volunteers or local organizations, including Lyft, that can drive them to medical appointments.

Angel Flight

918-749-8992; angel@angelflight.com;
Angelflight.com
Organization of pilots, volunteers and friends that serve the heartland area of Oklahoma, Texas, Arkansas, Missouri and Kansas; arranges free air transportation for any legitimate, charitable, medically related need; available to individuals and health care organizations; will arrange transportation of people who are financially distressed or in a time-critical, nonemergency situation due to their medical condition.

Children's Flight of Hope

919-466-8593; missions@cfoh.org;
childrensflightofhope.org

Provides air transportation for children in need of specialized medical care.

Corporate Angel Network

914-328-1313; info@corpangelnetwork.org;
corpangelnetwork.org

Provides air transportation to patients traveling for treatment, matching patients with empty seats on corporate and private planes.

Lifeline Pilots

800-822-7972; missions@lifelinepilots.org;
lifelinepilots.org

Provides free air transportation to patients traveling for treatment.

Patient Travel Referral Program of Mercy Medical Angels

757-318-9174; info@mercymedical.org;
patienttravel.org

Provides information about all forms of charitable, long-distance medically related transportation; provides referrals to all appropriate sources of help available in the national charitable medical transportation network; aims to ensure that no financially underserved patient is denied access to distant specialized medical evaluation, diagnosis or treatment for lack of a means of long-distance medical transportation.

Uber Health

support@health.uber.com **S**

Provides transportation to and from doctors' appointments that is free to patients with cancer but must be paid for by the participating treating facility, which arranges the rides.

RESOURCES BY CANCER TYPE

BLADDER CANCER

American Bladder Cancer Society

888-413-2344; 413-684-2344; cdkinsell@bladdercancersupport.org; bladdercancersupport.org **S**

Provides information about bladder cancer.

Bladder Cancer Advocacy Network

888-901-2226; info@bcan.org; bcan.org

Aims to improve public awareness of the disease and increase research directed toward the diagnosis, treatment and cure of bladder cancer.

Bladder Cancer WebCafe

Blcwebcafe.org

Provides support for people affected by bladder cancer through blogs, a survivor art gallery, facts about treatment options, patient survival guides, survivor stories, an email discussion group and more.

BLOOD CANCERS

Aplastic Anemia and MDS International Foundation

800-747-2820; 301-279-7202; help@aamds.org; aamds.org **S**

World's leading nonprofit health organization dedicated to patients afflicted with bone marrow failure disease; offers information, conferences, a patient helpline and support networks.

Be the Match

888-999-6743; patientinfo@nmdp.org;
bethematch.org **S**

Community of donors, volunteers, health care professionals and researchers; helps patients get lifesaving marrow or umbilical cord blood transplant through Be The Match Registry, operated by the National Marrow Donor Program, the world's largest and most diverse donor registry; lists more than 13.5 million potential marrow donors and more than 225,000 cord blood units; offers information about transplant and clinical trials, telephone counseling, financial grants, support groups and caregiver support.

CLL Society

support@cllsociety.org; cllsociety.org

Patient-centric, physician-curated nonprofit organization focused on patient education, support and research; explains the rapidly changing therapeutic landscape and the importance of clinical trials; supports and builds patient networks; engages in research and educates both providers and patients; offers conferences, support groups, the Expert Access, no-cost second opinion program and many more programs and services for patients with CLL and their caregivers.

Cutaneous Lymphoma Foundation

248-644-9014; info@clfoundation.org;
clfoundation.org **S**

Dedicated to supporting every person affected by cutaneous lymphoma by promoting awareness and education, advancing patient care and fostering research for the best possible outcomes; aims to ensure that each person with cutaneous lymphoma gets the best care possible.

Hairy Cell Leukemia Foundation

224-355-7201; info@hairycellleukemia.org;
hairycellleukemia.org

Offers a range of support for those affected by hairy cell leukemia, including evidence-based disease information, a list of leading centers that treat the condition, an ask-an-expert program, forums and webinars, an online community, information about clinical trials and a patient data registry designed to help researchers advance treatment.

International Myeloma Foundation

818-487-7455; themif@myeloma.org;
myeloma.org **S**

Provides a toll-free hotline, seminars, educational materials and 150 support groups for patients and their families; offers a list of organizations that provide financial aid to people with myeloma.

International Waldenstrom's Macroglobulinemia Foundation

941-927-4963; office@iwmf.com; iwmf.com/about-us/contact-us **S**

Aims to support everyone affected by Waldenstrom's macroglobulinemia and advance the search for a cure by offering mutual support and encouragement to the Waldenstrom's macroglobulinemia community and others with an interest in the disease, providing information and educational programs that address patients' concerns, and promoting and supporting research leading to better treatments and, ultimately, a cure.

Leukemia & Lymphoma Society

800-955-4572, lls.org **S**

Provides financial aid for specified treatment expenses and transportation, family support groups, a professionally supervised peer support program, referrals and school re-entry materials.

Lymphoma Research Foundation

800-500-9976; helpline@lymphoma.org;
lymphoma.org **S**

Nation's largest nonprofit organization; devoted exclusively to funding innovative lymphoma research and providing people with lymphoma and health care professionals with up-to-date information about this type of cancer; aims to eradicate lymphoma and serve those touched by this disease.

Multiple Myeloma Research Foundation

888-841-6673; 203-229-0464; info@themmrf.org;
themmrf.org/contact-us **S**

Pursues innovative means that accelerate the development of next-generation multiple myeloma treatments to extend the lives of patients and lead to a cure; committed to funding research and educating and supporting people with myeloma, their family members, caregivers and health care professionals about the disease and today's most promising treatment options.

BRAIN TUMORS

A Kids' Brain Tumor Cure PLGA Foundation

800-253-6530; contact@akidsbraintumor-cure.org;
akidsbraintumorcure.org

Aims to accelerate the pace of research for the most common forms of pediatric brain

cancer; acts as a central resource and portal for patients, families, medical personnel and nonprofit organizations seeking information about these diseases.

American Brain Tumor Association

800-886-2282; 773-577-8750; info@abta.org; abta.org

Offers free publications, educational programs, support group lists, physician lists, a pen pal program and social service consultations by telephone.

Brain Tumour Survivor

Btsurvivor.com

Online bulletin board of discussion groups with topics including treatment, trial data, personal stories and useful websites.

Children's Brain Tumor Foundation

212-448-9494; info@cbtf.org; cbtf.org **S**

Founded in 1988 by parents, physicians and friends; improves the treatment, quality of life and long-term outlook for children with brain and spinal cord tumors through research, support, education and advocacy on behalf of families and survivors.

EndBrainCancer Initiative

425-795-8489;

WeCare@endbraincancer.org;

endbraincancer.org/contact

Dedicated to helping patients with brain cancer and their caregivers access information, resources and rapid treatment.

Greg's Mission

612-437-5903; gregsmmission.org;

greg.cantwell@gregsmmission.org

Provides support, education, resources, awareness and hope to patients who have brain tumors, especially glioblastoma multiforme; aims to ensure that patients know about all treatment options prior to surgery so they can make informed choices.

Musella Foundation for Brain Tumor Research & Information

888-295-4740; musella@virtualtrials.org;

virtualtrials.com

Offers a copy assistance program, information, online support groups and a Brain Tumor Virtual Trial that is studying patients, the treatments they received and their outcomes to help determine best treatments.

National Brain Tumor Society

617-924-9997, questions@braintumor.org;

braintumor.org **S**

Provides information on how to cope with brain tumors.

Tug McGraw Foundation 707-947-7124;

info@tugmcgraw.org; tugmcgraw.org

Aims to enhance the quality of life for kids and adults diagnosed with brain tumors and provide vital support for their families through fundraising, education and collaboration; facilitates programs focusing on the physical, cognitive, social and spiritual components of brain-related trauma and tumors; supports research into traumatic brain injury and post-traumatic stress disorder, which helps the nation's ill and injured service members.

BREAST CANCER

Breastcancer.org

610-642-6550; breastcancer.org **S**

Helps women and their loved ones make sense of the complex medical and personal information about breast health and breast cancer so that they can make the best decisions for their lives.

Breast Cancer Support

Bcsupport.org; bcsurvivors@gmail.com

Offers meeting-place and discussion boards for survivors seeking support, information and someone with the same diagnosis; topics include surgery, chemotherapy, recurrence, genetics, young survivors, children with cancer and men with breast cancer.

BreastCancerTrials.org

888-282-7099; help-desk@bctrials.org;

Breastcancertrials.org

Helps match women who have breast cancer with clinical trials for which they might be eligible.

Bright Pink

312-787-4412; brightpink@brightpink.org;

brightpink.org **S**

Only national nonprofit organization focused on prevention and early detection of breast and ovarian cancer in young women; Women's Health Provider Education Initiative centers around a proprietary, research-based lecture, offering the opportunity to educate the next generation of women's health care providers on how best to identify and manage risk among their patients.

The Donna Foundation

877-236-6626, info@thedonnafoundation/

org; thedonnafoundation.org, breastcancer-marathon.com

Provides financial assistance for the critical needs of those living with breast cancer; offers emotional support to individuals living with breast cancer; funds groundbreaking breast cancer research; helps develop and maintain Mayo Clinic's Breast Cancer Translational Genomics Program.

The IBC Network Foundation

theibcnetwork.org; hello@theibcnetwork.org

Funds research regarding inflammatory breast cancer; provides an avenue to network proactive education to both the general population and the medical community regarding inflammatory breast cancer and its treatments.

Living Beyond Breast Cancer

855-807-6386; 610-645-4567; mail@lbcc.org; lbcc.org/about-lbcc/contact-us **S**

Connects people with trusted breast cancer information and a community of support; provides services such as national conferences, Breast Cancer 360, the Guide to Understanding Breast Cancer series and a toll-free helpline at little or no cost.

Male Breast Cancer Coalition

913-362-2196; mmpeggy@gmail.com;

Malebreastcancercoalition.org

Offers support through an online community, information about male breast self-exam, an annual male breast cancer conference, a video series about male breast cancer, survivor stories and a resources list.

Metaplastic Breast Cancer Global Alliance

732-536-7395; 321-405-4194; admin@

mpbcalliance.org; mpbcalliance.org

By raising awareness and funding research, seeks to re-invigorate research that leads to targeted treatments for this rare type of breast cancer that is often resistant to chemotherapy. Offers information about metaplastic breast cancer, treatments, doctors who treat the disease, genomic testing, second opinions, clinical trials and more.

Metastatic Breast Cancer Network

888-500-0370; mbcn@mbcn.org;

mbcn.org/contact-us

National, independent, nonprofit, patient advocacy group dedicated to the unique concerns of the women and men living with metastatic breast cancer.

MetAvivor

818-860-1226; info@metavivor.org;

metavivor.org

Dedicated to the fight of women and men living with stage 4 metastatic breast cancer; provides support programs and works to raise awareness of the disease; sole US organization dedicated to awarding annual grants for stage 4 breast cancer research, using 100% of donations.

National Breast Cancer Foundation, Inc.

972-248-9200; Nationalbreastcancer.org **S**

Increases awareness through education and provides nurturing support services to patients and survivors, as well as mammograms for patients in need; hosts retreats

for patients with metastatic breast cancer; gives tips for navigating the workplace with breast cancer.

Share Cancer Support

844-275-7427; jgolden@sharecancersupport.org; sharecancersupport.org **S**
 Nationwide community founded in 1976; provides peer-led support, information and the benefit of experience to women diagnosed with breast and ovarian cancers and their caregivers; free services include a peer-staffed helpline, support groups, and educational programs and webinars on both the treatment of cancer and living with the disease

Susan G. Komen

561-514-3020; info@komensouthflorida.org; helpline@komen.org; komen.org **S**
 Provides breast health and breast cancer educational materials and a list of patient resources.

Susan G. Komen Central and South Jersey

609-896-1201; info@komenncsnj.org; komenncsnj.org
 Provides information about breast cancer, hosts local events and supports breast health services for women who would not otherwise have access.

Susan G. Komen Florida

561-514-3020; info@komenflorida.org; komenflorida.org
 Provides information about breast cancer, a list of resources for patients, reduces barriers to care, holds fundraising events and gives research grants.

Susan G. Komen Greater New York City

212-560-9590; info@komennyc.org; komennyc.org
 Offers patient navigation and case management that help individuals get screening and treatment, supports programs that provide services including transportation, financial assistance, meals, legal assistance and the elimination of barriers to clinical trials. Offers education and outreach programs that directly link women to screening.

Susan G. Komen Miami/Ft. Lauderdale

954-909-0454; info@komiemiaftl.org; komiemiaftl.org **S**
 Saves lives by meeting the most critical needs in its community and investing in breakthrough research to prevent and cure breast cancer. Provides education about breast cancer, holds fundraising events and grants money to researchers.

Tigerlily Foundation

888-580-6253; transformation@tigerlilyfoundation.org; tigerlilyfoundation.org
 Educates, advocates for, empowers and supports young women before, during and after breast cancer. Offers a wealth of educational materials online.

Twisted Pink

502-890-2662; info@twistedpink.org; twistedpink.org
 Seeks to extend lives and improve quality of life by funding research into metastatic breast cancer. Offers an online book about metastatic breast cancer, a free app for storing medical information, a clinical trials finder and a list of resources.

Young Survival Coalition

877-972-1011; info@youngsurvival.org; youngsurvival.org **S**
 International network of breast cancer survivors and supporters dedicated to the issues of women under 40 who are diagnosed with breast cancer.

COLORECTAL CANCER

Colon Cancer Coalition
 952-378-1237; info@coloncancercoalition.org; coloncancercoalition.org
 Empowers local communities to promote prevention and early detection of colon cancer by raising awareness about the importance of screening. Provides educational materials about the disease online.

The Colon Club

info@colonclub.com; colonclub.com
 Connects young adults diagnosed with colorectal cancer so they never have to feel alone. Educates young adults and others about the risk factors, genetic precursors and symptoms of colorectal cancer and encourages them to demand a colonoscopy when appropriate.

Colorectal Cancer Alliance

877-422-2030; info@ccalliance.org; ccalliance.org **S**
 Organization dedicated to championing prevention, funding cutting-edge research and providing patient support services.

Fight Colorectal Cancer

877-427-2111; 703-548-1225; answer@fightcrc.org; fightcolorectalcancer.org
 Provides patient support and advocates for research and legislation to improve screening, diagnosis and treatment of colorectal cancer.

GASTROINTESTINAL CANCERS ESOPHAGEAL CANCER

Esophageal Cancer Awareness Association

800-601-0613; info@ecaware.org; ecaware.org **S**
 Provides educational materials about esophageal cancer and its treatments, guidance for survivors and online communities for survivors and for caregivers.

GI Cancers Alliance

646-598-2001; contact@gicancersalliance.org; gicancersalliance.org
 Raises awareness, provides education and advocates to prevent, treat and cure gastrointestinal cancers through a collaboration between advocacy groups, industry and institutional partners. Provides educational materials about specific GI cancer types and recommends advocacy groups that can help people with those conditions.

GIST Support International

215-340-9374; gsi@gistsupport.org; gistsupport.org
 Offers information about gastrointestinal stromal tumor, a patient community, summits and financial aid to help patients afford to seek second opinions about their treatment.

GYNECOLOGIC CANCER

Foundation for Women's Cancer

312-578-1439; FWCinfo@sgo.org; foundationforwomenscancer.org/contact-us **S**
 Provides education about and awareness of gynecologic cancers.

National Ovarian Cancer Coalition

888-682-7426; nocc@ovarian.org; ovarian.org/connect/contact-us **S**
 Provides support, education and hope for women with ovarian cancer and their families.

Ovarian Cancer Research Alliance

866-399-6262; info@ocrahope.org; ocrhope.org/about/contact
 Funds research, works with government to help prioritize the fight against ovarian cancer, and supports women and their families throughout their journeys with the disease.

Share Cancer Support

844-275-7427; jgolden@sharecancersupport.org; sharecancersupport.org **S**
 Nationwide community founded in 1976; provides peer-led support, information and the benefit of experience to women diagnosed with breast and ovarian cancers and their caregivers; free services include a peer-staffed

helpline, support groups and educational programs and webinars on both the treatment of cancer and living with the disease.

HEAD AND NECK CANCER

Head and Neck Cancer Alliance

866-792-4622; 866-916-5107 helpline; info@headandneck.org; headandneck.org/contact-us

Provides resources, education and support for patients; includes a discussion forum and clinical trial information.

The Oral Cancer Foundation

949-723-4400; info@oralcancerfoundation.org; oralcancerfoundation.org

Aims to contribute to the reduction of suffering, permanent physical damage and disfigurement, and death caused by oral cancer through increased public and professional awareness, prevention through lifestyle changes, early detection initiatives, education, improved treatment modalities and sponsorship of research; offers educational materials and listings of patient resources.

Support for People With Oral and Head and Neck Cancer

800-377-0928; info@spohnc.org; spohnc.org/contact-us

Provides education resources and publications to support patients with oral and head and neck cancer and their families.

KIDNEY CANCER

Kidney Cancer Association

800-850-9132; office@kidneycancer.org; kidneycancer.org

Offers information about the diagnosis and treatment of kidney cancer, sponsors support groups and provides physician referral information.

LIVER CANCER

Blue Faery

818-636-5624; info@bluefaery.org; bluefaery.org

Aims to prevent, treat and cure primary liver cancer — specifically, hepatocellular carcinoma — through research, education and advocacy; offers education, one-on-one support and help finding clinical trials.

Cholangiocarcinoma Foundation

888-936-6731; info@cholangiocarcinoma-foundation.org; cholangiocarcinoma.org

Aims to find a cure and improve the quality of life for those affected by cholangiocarcinoma, a rare fatal cancer that originates from the cells in the lining of the bile ducts; offers education, a patient registry, discussion boards, help finding clinical trials and an annual conference for patients.

Fibrolamellar Cancer Foundation

203-862-3196; info@fibrofoundation.org; fibrofoundation.org

Founded in 2008 by Tucker Davis, when he received diagnosis of fibrolamellar hepatocellular carcinoma, and three friends; supports research in hopes of finding a cure; offers a patient registry, closed Facebook group and an annual gathering.

Global Liver Institute

info@globalliver.org; globalliver.org

Aims to improve the lives of individuals and families affected by liver disease by promoting innovation, encouraging collaboration and scaling optimal approaches to help eradicate liver diseases; seeks patients willing to share their stories.

Yes

877-937-7478; info@sayyestohope.org; beatlivercancer.org

Provides education and support, including a friend for the journey, teleconferences and a newsletter.

LUNG CANCER

American Lung Association

800-586-4872; info@lung.org; lung.org/lung-cancer

Committed to defeating lung cancer and supporting those affected. Offers credible information and resources online, informs about clinical trials and provides lung cancer experts patients can speak with. Offers a LUNG FORCE community for in-person support through walks, expos and more. At LUNGFORCE.org, patients can share their stories and find local events.

Free to Breathe

844-835-4325; info@lung.org; lungcancer-researchfoundation.org

Partnership of lung cancer survivors, advocates, researchers, health care professionals and industry leaders united in the belief that every person with lung cancer deserves a cure; aims to double lung cancer survival by 2022; provides education and connection to resources through free lung cancer support line.

Go2 Foundation for Lung Cancer

800-298-2436; info@go2foundation.org; go2foundation.org

Dedicated to saving, extending and improving the lives of those vulnerable, at risk and diagnosed with lung cancer. Works to end stigma, increase public and private research funding and ensure access to care. Offers a help line, clinical trial finder, mentorship by survivors, edu-

cational webcasts and written materials and resource lists.

Lung Cancer Foundation of America

323-741-4713; lcfa@lcfamerica.org; lcfamerica.org

Raises awareness and research money to benefit those with lung cancer. Provides educational materials about the disease, a searchable database of clinical trials and an opportunity to share patient stories.

Lung Cancer Research Foundation

844-835-4325; 212-588-1580; 608-833-7905; info@lcrf.org; lungcancerresearchfoundation.org

Funds research, raises awareness, offers educational programs and hosts community events nationwide through the Free to Breathe Events program.

LUNGevity

844-360-5864; 312-407-6100; info@lungevity.org; lungevity.org/about-us/contact-us

Provides support, community and education to patients and survivors of lung cancer.

Upstage Lung Cancer

617-835-9722; info@upstagelungcancer.org; upstagelungcancer.org

Through the performing arts, raises money for research and to advocate for early detection in lung cancer, with a goal of increasing detection and diagnosis rates. Promotes awareness, advances understanding and works to remove the social stigma of lung cancer. The first cancer charity to exclusively use music and the performing arts to accomplish our mission.

NEUROENDOCRINE TUMORS

Healing NET

615-369-6463; info@thehealingnet.org; thehealingnet.org

Raises awareness about neuroendocrine tumors and supports patients by providing educational information, a clinical trials matching service, a list of resources and more.

Neuroendocrine Tumor Research Foundation

617-946-1780; info@netrf.org; netrf.org

Funds research to discover cures and more effective treatments for carcinoid, pancreatic and related neuroendocrine cancers; directs donations to fund breakthrough scientific research of neuroendocrine cancers to achieve rapid discovery of cures; has awarded over \$12 million in large-scale, multi-year research grants to leading scientists at renowned research institutions and funded research at seven of the top 10 U.S. cancer centers; com-

mitted to supporting patients, families, friends, and caregivers affected by neuroendocrine tumors.

PANCREATIC CANCER

The National Pancreas Foundation

866-726-2737; info@pancreasfoundation.org; pancreasfoundation.org

Only foundation dedicated to patients with all forms of pancreas disease, including pancreatic cancer; developing national patient registry for individuals suffering the isolating and debilitating conditions associated with pancreatic disease; provides physician education, patient educational resources and funds research grants; designates and works with foundation's Centers of Excellence; offers patient education materials, nutrition advice, a patient support community and a clinical trials resource center; has 24 chapters.

National Pancreatic Cancer Foundation

800-859-6723; info@npcf.us; npcf.us
Offers in-person and online support groups, patient advocacy programs and awareness efforts; gives grants to patients undergoing treatment for pancreatic cancer to help pay living expenses.

Pancreatic Cancer Action Network

877-272-6226; info@pancan.org; pancan.org/contact-us **S**
Provides information about support networks, clinical trials and reimbursement for care.

PROSTATE CANCER

Fans for the Cure

888-301-4414; info@fans4thecure.org; fans4thecure.org
Offers educational seminars, awareness events, PSA screenings and medical referrals to professional organizations and the general public. Supports prostate cancer research and serves as an advocacy partner for the Metastatic Prostate Cancer Research Project being conducted by the Broad Institute of MIT and Harvard and the Dana-Farber Cancer Institute.

National Alliance of State Prostate Cancer Coalitions (NASPCC)

877-627-7228; info@naspcc.org; naspcc.org
Network of state coalitions and groups and individuals interested in forming state coalitions. Support men and families by developing and advocating for policies that support patient education and multidisciplinary care.

Prostate Cancer Foundation

800-757-2873; info@pcf.org; pcf.org/contact-us **S**
Connects patients and loved ones to the latest developments, best practices and news from the prostate cancer treatment pipeline.

Prostate Cancer Research Institute

310-743-2116; help@pcri.org; pcri.org
Helps patients and caregivers research treatment options using resources designed by a multidisciplinary team of patients, advocates and leading medical doctors; aims to help patients, through education about the disease, have more productive interactions with their medical professionals and get better individualized care.

Prostate Conditions Education Council

866-477-6788; info@prostateconditions.org; prostateconditions.org
Offers information about prostate cancer and other prostate conditions, early detection and treatment options. Also conducts prostate cancer screenings and research.

Uromigos

[Twitter.com/uromigos?lang=en](https://twitter.com/uromigos?lang=en); kidneycancer.org/podcasts
A collaboration between specialists in genitourinary oncology who, through Twitter, share their opinions on trends and developments in their field. Participants are Brian Rini, M.D., of Vanderbilt-Ingram Cancer Center; Thomas Powles, M.D., M.B.B.S., M.R.C.P., of Barts Cancer Institute; Silke Gillissen, M.D., of the University of Manchester; David F. McDermott, M.D., of Beth Israel Deaconess Medical Center; Christopher Sweeney, M.B.B.S., of Dana-Farber Cancer Institute; Srikala Sridhar, M.D., M.S.c, FRCPC, of Princess Margaret Cancer Centre; Laurence Albiges, M.D., Ph.D., of Gustave Roussy Institute; and Cristina Suárez Rodríguez, M.D., of Hospital Quirón Barcelona.

Us Too International Prostate Cancer Education and Support Network

800-808-7866; ustoo@ustoo.org; ustoo.org/contact-US-TOO **S**
Educates patients about prostate cancer, offers support groups and provides information about treatment.

Zero: The End of Prostate Cancer

844-244-1309; 202-463-9455; info@zerocancer.org; zerocancer.org
Lobbies for programs that help men at risk of or living with prostate cancer, provides men and families with educational resources and funds research to improve

early detection options. Offers a wealth of information online about the disease and treatment, as well as information for survivors and caregivers and a list of resources that can provide support, including financial.

SARCOMA

National Leiomyosarcoma Foundation

annie@nlmsf.org; nlmsf.org **S**
Provides patient education opportunities and support through patient/family/caregiver educational programs, collaborating with cancer research centers; provides patient advocacy on legislative issues and initiatives that advance awareness of leiomyosarcoma and research efforts; promotes and funds leiomyosarcoma research in support of accelerating treatment advancements and breakthroughs.

Sarcoma Alliance

415-381-7236; info@sarcomaalliance.org; sarcomaalliance.org/about/contact **S**
Provides education, support and guidance in finding medical providers, treatment options and more

Sarcoma Foundation of America

301-253-8687; info@curesarcoma.org; curesarcoma.org
Advocates for patients with sarcoma by funding research and increasing awareness about the disease; raises money to fund grants for sarcoma research; conducts education and advocacy efforts on behalf of patients with sarcoma.

SKIN CANCER

Aim at Melanoma Foundation

833-236-3635; engageus@AIMatMelanoma.org; AIMatMelanoma.org
Globally engaged and locally invested in advancing the battle against melanoma through groundbreaking research, legislative reform, education, and patient and caregiver support; helps patients speak with an oncology nurse or search for clinical trials or a melanoma specialist.

Melanoma Research Foundation

800-673-1290; info@melanoma.org; melanoma.org
Largest independent organization devoted to melanoma; committed to the support of medical research and educating patients about prevention, diagnosis and the treatment of melanoma.

Skin Cancer Foundation

212-725-5176; dnaranjo@skincancer.org; skincancer.org **S**

Raises awareness of and educates people about skin cancer, prevention methods and early detection.

STOMACH CANCER

Debbie's Dream Foundation: Curing Stomach Cancer

855-475-1200; Admin@debbiesdream.org; debbiesdream.org/contact-us

Promotes education and support for people with stomach cancer.

Esophageal Cancer Awareness Association

800-601-0613; info@ecaware.org; ecaware.org

Helps patients, caregivers, survivors, family members and anyone at risk of developing the disease; aims to create a community of survivors, patients and caregivers that together can provide support and information and increase awareness about the disease.

Hope for Stomach Cancer

424-239-9943; hope@stocan.org; stocan.org

Provides resources to patients, caregivers and loved ones; promotes early detection and prevention to the general and medical communities; creates and facilitates programs that enable those affected by stomach cancer to take actionable steps to live the best possible life through each phase of the disease.

No Stomach for Cancer

608-692-5141; info@nostomachforcancer.org; nostomachforcancer.org

Supports research and aims to unite the caring power of people worldwide affected by stomach cancer; focuses on advancing awareness and education about stomach cancer, including hereditary diffuse gastric cancer; provides a support network for affected families; supports research for screening, early detection, treatment and prevention of stomach cancer.

TESTICULAR CANCER

Testicular Cancer Awareness Foundation


testicularcancerawarenessfoundation.org; info@testescancer.org

Dedicated to the fight against testicular cancer through awareness and outreach, promoting the importance of monthly self-exams for early detection, support and guidance to patients and families, a resource for the medical community, providing financial assistance to those in need and continuing to save lives.

THYROID CANCER

ThyCa: Thyroid Cancer Survivors' Association Inc.

877-588-7904; thyca@thyca.org; thyca.org/about-us **S**

Provides support and education for thyroid cancer survivors. 

Cancer Terms

Adenocarcinoma: Cancer that starts in the glandular tissue, such as in the ducts or lobules of the breast or in the gland cells of the prostate.

Adjuvant therapy: Treatment used in addition to the main treatment. It usually refers to treatment given after surgery to increase the chances of curing the disease or keeping it in check.

Angiogenesis: The formation of new blood vessels. Some cancer treatments work by blocking angiogenesis, thus preventing blood from reaching the tumor.

Antigen: A substance that can cause the body's immune system to respond. This response often involves making antibodies. For example, the immune system's response to antigens that are part of bacteria and viruses helps people resist infections. Certain cancer cells have antigens that can be found by lab tests. They are important in cancer diagnosis and in watching response to treatment. Other cancer cell antigens play a role in immune reactions that could help the body resist cancer.

Benign tumor: An abnormal growth that is not cancer and does not invade into nearby tissues or spread to other areas of the body.

Biopsy: The removal of a sample of tissue to see whether cancer cells are present.

Brachytherapy: Internal radiation treatment given by placing a radioactive source directly into the tumor or close to it.

CAR-T cell therapy: Chimeric antigen receptor (CAR)-T cell therapy is a form of immunotherapy. To give this treatment, doctors remove immune cells known as T cells from a patient and engineer them in a lab to home in on a specific enzyme associated with the patient's cancer cells. The engineered cells are multiplied in the lab and then infused into the patient's body, where they are expected to not only recognize and fight the cancer, but also continue to multiply and stand watch against the disease indefinitely.

Carcinoma: A malignant tumor that begins in the lining layer (epithelial cells) of organs.

Chemotherapy: Treatment with drugs to inhibit cancer cell division. Chemotherapy is often used with surgery or radiation to treat cancer when the cancer has spread, when it has come back (recurred) or when there is a strong chance it could recur.

Clinical trials: Research studies that test new drugs or treatments and compare them with current standard treatments. Before a new treatment is used on people, it is studied in the lab. If lab studies suggest the treatment works, it is tested on human volunteers. These human studies are called clinical trials.

Cytokine: A protein made by certain cells that affect the immune system and can stimulate immunity or slow it down.

Cytokine release syndrome: This severe potential side effect, also known as a cytokine storm, occurs when immunotherapy stimulates a patient's immune cells so thoroughly that they quickly release many proteins known as cytokines. The immune system then wages an attack on both cancerous and healthy tissues. Symptoms include fever, nausea, headache, rash, low blood cell counts and changes in the brain that cause confusion or seizures.

DNA (deoxyribonucleic acid): The genetic "blueprint" found in the nucleus of each cell. DNA holds genetic information for proteins involved in cell structure, growth and function.

Enzyme: A protein that starts, helps or speeds up the rate of chemical reactions in living cells.

Gene: A segment of DNA that contains information on hereditary characteristics, such as hair color, eye color and height, as well as susceptibility to certain diseases.

Genetic testing: Tests performed to determine whether a person has certain gene changes known to increase the risk of cancer or other diseases.

Genomic testing: Assessing genomic changes in the tumor that are acquired, not inherited, and may be treatable with specific targeted therapies. These tests can be done via tumor biopsy or blood testing known as liquid biopsy.

Growth factors: Naturally occurring proteins that help cells grow and divide. Some cancer cells are too sensitive to growth factors, which helps them grow quickly.

Hereditary cancer syndrome: Conditions associated with cancers that occur in several family members because of an inherited, mutated gene.

Hormone therapy: Treatment with drugs that interfere with hormone production or hormone action, or the surgical removal of hormone-producing glands. Hormone therapy can help kill or slow the growth of cancer cells that depend on hormones to grow.

Immunotherapy: Treatments that promote or support the body's immune system response to a disease such as cancer.

Leukemia: Cancer of the blood or blood-forming organs. People with leukemia often have a noticeable increase in white blood cells (leukocytes).

Liquid biopsy: This blood test finds tumor cells, or DNA pieces from tumor cells, that are circulating in the blood. It can detect minimal amounts of cancer that cannot be seen on scans and help guide a recurrence-preventing treatment plan or track its effectiveness. A series of these tests over time can assist in monitoring the molecular changes occurring within a tumor, providing a research tool to aid in developing more effective cancer drugs. This remains investigational for most tumor types.

Localized (or local) cancer: A cancer that is confined to the organ where it started; that is, it has not spread to distant parts of the body.

Lymph nodes: Small bean-shaped collections of immune system tissue, such as lymphocytes, found along lymphatic vessels. They remove cell waste, germs and other harmful substances from the lymph. They help fight infections and also have a role in fighting cancer, although cancers sometimes spread through the lymph system.

Lymphoma: A cancer of the immune system cells called lymphocytes (a type of white blood cell). It often affects the lymphatic system, a network of thin vessels and nodes throughout the body. The two main types of lymphoma are Hodgkin and non-Hodgkin.

Malignant: Cancerous cells that can invade nearby tissues or spread (metastasize) to distant areas of the body.

Metastasis: The spread of cancer cells to one or more sites elsewhere in the body, often by way of the lymph system or bloodstream. Regional metastasis is cancer that has spread to the lymph nodes, tissues or organs close to the primary site. Distant metastasis is cancer that has spread to organs or tissues that are farther away (such as when prostate cancer spreads to the bones, lungs or liver).

Mutation: A change in the DNA of a cell. Cancer is thought to be due to changes in a cell's DNA. Most mutations happen after the person is born.

Neoadjuvant therapy: Systemic and/or radiation treatment given before the main treatment.

Palliative treatment: Treatment that relieves symptoms, such as pain, but is not expected to cure the disease. Its main purpose is to improve the patient's quality of life.

Pathologist: A doctor who specializes in diagnosis and classification of diseases by lab tests such as examining tissue under a microscope. The pathologist determines the specifics of a diagnosis.

Radiation therapy: Treatment with high-energy rays (ionizing energy, such as X-rays) or particles to kill or shrink cancer cells. The radiation can come from outside of the body (external radiation) or from radioactive materials placed directly in or near the tumor (brachytherapy or internal radiation).

Recurrence: The return of cancer after treatment. Local recurrence means that the cancer has come back in the same location as the original cancer. Regional recurrence means that the cancer has come back after treatment in the nearby tissues or lymph nodes near the primary site. Distant recurrence occurs when cancer comes back in distant organs or tissues after treatment.

Remission: Complete or partial disappearance of the signs and symptoms of cancer in response to treatment. A remission might not be a cure.

Sarcoma: A malignant tumor that starts in connective tissues, such as cartilage, fat, muscle or bone.

Standard therapy: The most commonly used and widely accepted form of treatment that has been tested and proven.

Stem cell transplantation: A procedure used to restock stem cells in the bone marrow when they have been destroyed by chemotherapy, radiation or disease. Stem cells can be the patient's own (autologous) or can come from someone else (allogeneic). Bone marrow transplantations were the first method for replacing stem cells.

Targeted therapy: Treatment to attack the part of cancer cells that make them different from normal cells. Targeted agents tend to have different side effects than conventional chemotherapy drugs.

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EXPECT PROGRESS

Introducing the
MMRF CureCloud[®], the first
research study with at-home
genomic testing for multiple
myeloma patients.

Our groundbreaking research study, the MMRF CureCloud, will help accelerate research with the ultimate goal of identifying smarter treatment options for each and every multiple myeloma patient. Joining the study is free, can help inform your discussions with your doctor, and can make a difference for the entire myeloma community.

Visit MMRFCureCloud.org to learn more

