# Understanding Esophageal Cancer



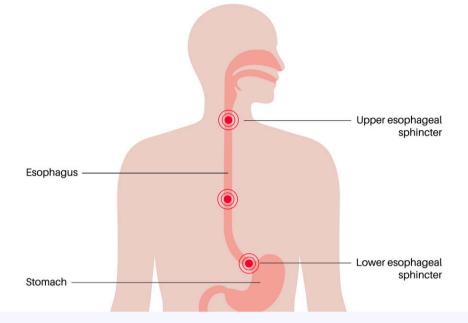


A cancer diagnosis is never easy. You are not alone if you or someone you care for has esophageal cancer. Over 22,000 people in the U.S. are diagnosed with esophageal cancer each year. People with an esophageal cancer diagnosis may experience many challenges during their cancer experience.

This fact sheet will provide an overview of esophageal cancer and treatment options. It will discuss ways to manage treatment side effects and how to speak with your care team. This resource has information about coping with mental health challenges. It also includes support for caregivers. At the end of this fact sheet, you will find additional resources.



Esophageal cancer is a type of cancer located in the cells lining your esophagus. The esophagus is the muscular tube that connects your throat to your stomach. Your esophagus transports food and liquid from your mouth through your digestive system.



# Esophageal cancer is categorized into two types: Adenocarcinoma and Squamous Cell Carcinoma.

**Adenocarcinoma** is the most common type of esophageal cancer in the US. This type of cancer occurs in the lower esophagus near your stomach. Squamous cells line the inside layer throughout your entire esophagus. **Squamous cell carcinomas** are typically found in the upper or middle areas of the esophagus. It can appear in other parts of the esophagus as well.

**Note:** These are the two main types of esophageal cancer. There are other rare forms of cancer and tumors that may occur in your esophagus. Talk with your healthcare team to learn more about your specific type of cancer.

# Common signs and symptoms of esophageal cancer may include:

DIFFICULTY OR PAIN WITH SWALLOWING

PAIN IN YOUR CHEST AFTER SWALLOWING

PERSISTENT ACID REFLUX

**CHRONIC COUGHING** 

**HICCUPS** 

VOICE HOARSENESS

You may also experience weight loss, indigestion, and heartburn. If you are experiencing any of these symptoms, reach out to your healthcare team.



For more resources and additional information about esophageal cancer, visit www.CancerSupportCommunity.org/Esophageal-Cancer

### **ESOPHAGEAL CANCER RISK FACTORS**

Risk factors are things that can increase a person's chance of developing a disease.

# Risk factors for esophageal cancer include: A person's age | Family history | Other behaviors and lifestyle factors

Your risk of developing esophageal cancer increases as you age. Esophageal cancer is most often diagnosed in people 55 years and older. Men and people designated male at birth are the most likely to develop esophageal cancer. Your racial identity may influence your risk of developing esophageal cancer. If you are a person of color, you may be at a higher risk of developing squamous cell carcinoma.

Your diet may impact your risk for developing cancer. A diet high in processed meat may increase your likelihood of developing cancer. Some examples of processed meats include sausages, bacon, ham, and hot dogs. Hot liquids, such as teas or coffee, may also increase your risk. Frequent alcohol consumption is considered a risk factor for esophageal cancer. It is important to prioritize nutritious, well-rounded diets to help reduce your risk of developing esophageal cancer.

# Other risk factors for<br/>esophageal cancer include:Image: Sophageal cancer include:<

### **TYPES OF ACID REFLUX & BARRETT'S ESOPHAGUS**

Long term acid reflux can damage the esophagus. This condition is called Barrett's Esophagus. Barrett's Esophagus is a common risk factor for esophageal cancer. There are two common types of acid reflux that lead to Barrett's Esophagus:

### **GERD (Gastroesophageal Reflux Disease)**

This is a condition where you may experience frequent acid reflux from the stomach. Acid reflux occurs when the lower area of the esophagus is not closing properly. This area is called the lower esophageal sphincter (LES). This allows acid in your stomach to rise into your esophagus. GERD can lead to pain, inflammation, indigestion, and swallowing difficulties.

### Laryngopharyngeal Reflux (LPR)

LPR is also known as silent reflux. Silent reflux occurs when the upper area of the esophagus is not closing properly. This area is called the upper esophageal sphincter (UES). This allows stomach acid to rise into the larynx (voice box) and pharynx (throat). With silent reflux, you may not experience the common symptoms related to GERD. Silent reflux is known to affect your voice, throat, and sinuses.

### **DIAGNOSES & STAGING**

There are many procedures that your healthcare team may use to diagnose esophageal cancer. Imaging tests allow your doctor to see the esophagus. These tests may include:

- CT Scan
- MRI
- PET Scan
- Barium Swallow Test
- Endoscopy

A Barium Swallow Test is used to see the upper part of the gastrointestinal (GI) tract. The mouth, esophagus, stomach, small intestines, large intestines, rectum and anus make up your GI tract. In this test, the doctor will ask you to swallow a chalky substance, called barium. Barium coats and highlights the organs in your GI tract. This allows your doctor to better see your organs during xrays.

Esophageal cancer is also diagnosed through a series of endoscopic procedures. An endoscopy is a nonsurgical procedure. Your doctor uses an endoscope to see your digestive tract. The endoscope is a thin tube with a camera and surgical tool attached to it. Some endoscopic procedures may include:

- Upper Endoscopy
- Endoscopic Ultrasound
- Bronchoscopy
- Thoracoscopy
- Laparoscopy

Your care team may also use lab and blood tests to diagnose esophageal cancer.

### **STAGING FOR ESOPHAGEAL**

Your care team will use a staging system to diagnose and treat your esophageal cancer. A cancer's "stage" is a measure of how far it has spread. Understanding your cancer's stage can help your care team select the best treatment option for you. Esophageal cancer is divided into four main stages. Each stage can be split into A and B, based on how much the cancer has spread. Stage I adenocarcinomas can be further classified into stage IC.

Visit **www.CancerSupportCommunity.org/Esophageal-Cancer** to learn more about staging.

| STAGE 0   | Abnormal cells have been identified in the lining of the inner esophagus.  |
|-----------|--|
| STAGE I   | The cancer has grown beyond the innermost layer of tissue in the wall of the esophagus.  |
| STAGE II  | The cancer has spread to the outer<br>wall of the esophagus. In stage II, the<br>cancer may begin spreading to<br>nearby lymph nodes.  |
| STAGE III | The cancer has spread into the thick<br>outer layer of the esophagus and may<br>have extended beyond the esophageal<br>wall. In late-stage III diagnoses, the<br>cancer may spread into to nearby<br>tissues or lymph nodes as well. |
| STAGE IV  | Stage 4 cancer is also known as<br>advanced cancer. In stage IV, the cancer<br>has spread to nearby and distant lymph<br>nodes. The cancer may have also spread<br>to other parts of the body, such as the<br>liver or lungs.        |

Many people are diagnosed with esophageal cancer at a later stage. It is important to communicate with your healthcare team when you first notice symptoms.

### **ESOPHAGEAL CANCER CARE TEAM**

Cancer treatment can be complex. You need a reliable healthcare team that aligns with your needs and goals. When choosing your team, it is important to feel that you can have honest and open conversations.

During appointments, share your concerns and ask questions. It is important to advocate for your needs throughout your treatment experience. This can be done by yourself or your caregiver(s). If you don't feel your team is addressing your concerns, consider getting a second opinion. Your care team should encourage seeking a second opinion. It is important for you to feel confident in your care team. Your care team may consist of the following specialists:

**Gastroenterologist:** A doctor who specializes in conditions affecting the digestive system. This includes all digestive system organs from your mouth to the anus.

**Medical Oncologist:** A doctor who diagnoses and treats all cancer types. This person creates your treatment plan(s) and educates you on your specific diagnosis. They will work with other healthcare professionals on your care team and coordinate follow-up care.

**Radiation Oncologist:** An oncologist that treats cancer using radiation therapy. This therapy uses high energy rays to target the specific area of your tumor. It can help with pain and damage cancer cells.

Nurse Practitioner (NP), Physician's Assistant (PA), and Nurse (RN): These healthcare professionals will work alongside your oncologist. They provide education and additional care to patients experiencing cancer.

### **Registered Dietician:** A

Registered Dietician (RD) is trained to recommend foods and other ways to make sure your body gets the nutrients it needs. RDs can help you manage symptoms such as difficulty swallowing, nausea, taste changes, and dietary restrictions.

**Otolaryngologist (ENT):** A physician that specializes in caring for the ears, nose, and throat. They may work closely with your cancer care team to support your needs during and after treatment. They can also perform surgeries within the ears, nose, and throat. **Surgical Oncologist:** An oncologist who is trained to perform surgery to remove cancer tumors. A Thoracic Oncologist is a type of surgical oncologist. They specialize in performing esophagectomies. An esophagectomy is a type of surgery to remove some or all of the esophagus.

**Social Worker:** A Social Worker is trained to help you and your caregiver with any emotional and logistical needs. They can help you navigate appointments and find other support resources you need.

**Caregiver(s):** A person or group of people dedicated to assisting you during your cancer experience. A caregiver team can be made up of family members, friends, and/or other loved ones.

**Mental Health Therapist, Community and/or Spiritual Leader:** Cancer is a lot to deal with. Having someone to talk to can affect how you look at things. It may help you find or maintain the energy you need to get through treatment and take the best possible care of yourself. It is a good idea to seek support early on, so you have somewhere to turn when you need it.

### TREATMENT FOR ESOPHAGEAL CANCER

Your care team will consider your cancer's type, stage, and location when making your treatment plan. Your care team should also consider your general health and personal goals. Speak with your care team about your preferences and any questions you have about your treatment plan.

Here are some of the most common methods to treat esophageal cancer:

*Surgery* is the most common treatment for esophageal cancer.

**Esophagectomy (esoph-a-gec-to-my):** During this procedure all or part of your esophagus is removed. This is dependent upon the stage and location of the cancer. In advanced cases, nearby lymph nodes may be removed as well.

**Radiation** uses high energy rays to kill cancer cells in the esophagus. External-Beam Radiation Therapy and Internal Radiation Therapy may be recommended by your care team to treat esophageal cancer.

**Chemotherapy** uses drugs to damage cancer cells. Chemotherapy rarely treats esophageal cancer on its own. It is commonly given in combination with radiation therapy.

**Targeted Drug Therapy** uses drugs to target specific changes in cancer cells that help them grow, divide, and spread. Targeted therapy drugs are designed to be more precise. They fight cancer cells while causing less harm to other cells in the body.

*Immunotherapy* works with the body's immune system to find, attack, and kill cancer cells. These drugs help the immune system to better recognize and attack cancer cells

**Endoscopic Treatment** places an endoscope into your esophagus to treat cancer symptoms. This procedure may be used to treat areas of Barrett's Esophagus and early stages of esophageal cancer. **Clinical Trials** are research studies to test new treatments or learn how to use existing treatments better. They find new and better ways to prevent or treat esophageal cancer.

There are certain lifestyle changes that have to be made after an esophagectomy. Your surgical team will work closely with you to help you adapt to these changes. For example, you must lie at a 30-degree angle while sleeping following your surgery. It is not safe to lie flat after this procedure. While this surgery can impact some areas of life more than others, people who have this procedure can live well. Your care team will provide you with resources to adjust to your new normal and manage any side effects.

> **Palliative Care** is a type of supportive care for esophageal cancer patients. It addresses any physical, social, emotional, and spiritual concerns during treatment. The palliative care team anticipates and helps manage difficult symptoms, pain, and side effects.

It is important to advocate for yourself. You should feel included in all decisions throughout your cancer experience. Your care team should empower you to share your voice and opinions. This is called shared decision-making.

If you need help understanding your treatment plan or advocating for yourself, there are professionals available. Talk with a social worker, nurse, or nurse navigator. During treatment, open communication with your care team and support network is critical to your well-being.

### MANAGING TREATMENT SIDE EFFECTS

All treatment types may result in side effects. Side effects can vary from patient to patient. Some may last for a long time, even after treatment. These may require life-long attention. For example, an esophagectomy is a common treatment procedure for esophageal cancer. This type of treatment requires lifestyle changes and may lead to long term side effect management.

Learning about the side effects of treatment before you begin is important. The more you know the easier it will be to talk with your healthcare team to determine the best plan for you. Talk with your doctor about any possible side effects that may arise with each treatment option.

### Side effects of esophageal cancer treatment may include:

### **DIETARY & APPETITE CHANGES**

You will likely experience dietary changes when undergoing treatment for esophageal cancer. You may be advised to avoid rich, spicy, acidic, or greasy foods. Your care team may recommend limiting alcohol. You may need to eat at a slow pace and eat smaller, more frequent meals. Specific side effects may include:

- Loss of Appetite The decreased desire to eat.
- Weight Loss You may experience weight loss following treatment due to dietary changes and reduced stomach capacity.
- Dysphagia & Odynophagia Dysphagia is when you are having trouble swallowing. Odynophagia is when you are experiencing pain while swallowing.
- Nausea & Vomiting The feeling of discomfort in the stomach which may result in an urge to vomit.
- Dry Mouth or Thick Saliva A decreased amount of saliva in your mouth so that your mouth becomes very dry, and your saliva becomes thick.
- **Esophageal Strictures** Narrowing of the esophagus that may lead to difficulty swallowing.
- Painful Sores in the Mouth and Throat An ulcer in your mouth that may be red, white, or yellow.
- **Aspiration** When food or liquid enters your airways instead of the esophagus. This may cause coughing during or after eating, choking while eating, and regurgitation. Aspiration can occur at any point.

### LUNG ISSUES

Changes in your lung health are a top concern following an esophagectomy. Your care team may recommend rehabilitation for your lungs to prevent breathing problems.

### **VOCAL CHANGES**

Nerves may be damaged during surgery affecting the vocal cords.

### HEARTBURN

Gastric acid reflux is a common symptom after an esophagectomy. Gastric acid reflux leads to heartburn and discomfort.

### **CHANGES IN SLEEP PATTERNS**

Following an esophagectomy, you must sleep at a 30-degree angle. This prevents the contents of your stomach from traveling up the esophagus.

### **DUMPING SYNDROME**

This occurs when food moves too quickly from the stomach to the small intestines. This can cause other Gl side effects.

### **DIARRHEA/CONSTIPATION**

You may experience changes in bowel movements.

Speak with your care team about any side effects that you experience. They may recommend specific medications or lifestyle changes. Seeing a palliative care specialist can also help address side effects that arise during treatment.

### CAREGIVING FOR ESOPHAGEAL CANCER

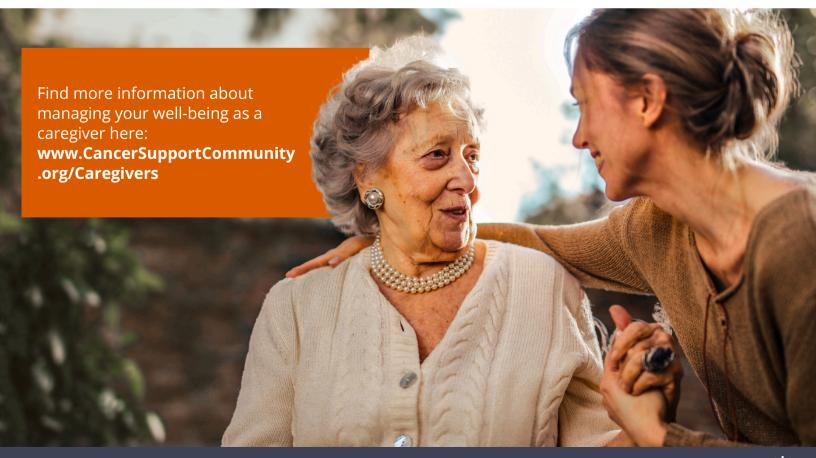
Caregivers play an essential role in the cancer experience. Your caregiver may take on various tasks and responsibilities. Caregivers support, advocate, and assist their loved one throughout the cancer experience.

Caregiving for a loved one with esophageal cancer may require unique types of care. For example, caregivers may need to assist their loved one with dietary needs. Some caregivers have feelings of anxiousness and uncertainty when assisting their loved one with a feeding tube. Caregivers may feel nervous because this type of medical care may be completely new to them. It is not uncommon for caregivers to notice changes in their own relationship with food.

Treatment for this type of cancer may involve moving to a different location to receive care. Caregivers play a major part in helping with this transition. They may need to organize travel, lodging, and appointments with the care team. Caregivers may feel responsible for helping their loved one adjust to a "new normal". Relocation may bring feelings of loneliness and isolation for both you and your loved one.

The cancer experience can bring up a lot of stress and emotions for caregivers. Your caregiver may feel like they have too much going on between caregiving and other roles. They may experience feelings of grief, sadness, or even anger.

Your caregiver is not alone in feeling the emotional effects of this role. It is important for them to take care of themselves during this time. This includes both their physical and mental health. Taking care of their needs and wellness will help them better support you during this experience.





# MENTAL HEALTH & EMOTIONAL WELL-BEING

Navigating life with cancer can be difficult and may look different for everyone. Treatment side effects can impact your physical and mental health.

Mental health refers to your overall emotional, psychological, and social well-being. After a cancer diagnosis, you and your caregiver may experience many emotions. Some include:

Anxiety An emotion characterized by feelings of dread, apprehensive uneasiness, stress, and nervousness.

Depression A mood disorder A negative resulting in persistent feelings of sadness.

**Overall distress** emotional response to internal and external stressors and life events.

### Fear of recurrence

The fear of cancer returning or progressing can lead to anxiety, depression, and overall distress.

While some degree of distress is normal, it is important to know when it is time to ask for help. No level of distress or anxiety is too small to ask for help. Talk to your care team about how you are feeling so that they can connect you with a mental health professional.

Learn more about coping with mental health concerns during your cancer diagnosis: www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

### **GETTING SUPPORT**

Life may feel very different after an esophageal cancer diagnosis for both you and your loved ones. It helps to have support before, during, and after treatment. The type of support may look different as your needs change. Often, after treatment a flood of emotions may occur. Talking with people who understand your experience can help you cope and feel in control. A good support system can also help you with practical things. This support system may include a partner, friend, or other family member. This could be staying physically active, eating well, and maintaining your overall health. There are many places to turn to for practical and emotional support. Meeting with a social worker can be a good resource to start with.

Adjusting to this "new normal" may feel challenging. It is important to know that what you and your loved ones are feeling is normal. Although your life may look different, there are people and resources to support you at every step.

### CANCER SUPPORT HELPLINE

If you need help finding resources or want help getting information about cancer, call CSC's toll-free Cancer Support Helpline® at **888-793-9355.** 

It is staffed by community navigators and resource specialists who can assist you Monday – Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.

# **ESOPHAGEAL CANCER RESOURCES**

**Esophageal Cancer - Cancer Support Community** 888-793-9355 <u>www.CancerSupportCommunity.org/Esophageal-Cancer</u>

**Esophageal Cancer Education Foundation** 732-385-7461 <u>www.FightEC.org</u>

**EC Aware** 1-800-601-0613 <u>www.ECAware.org</u>

Esophageal Cancer Action Network 410-358-3226 www.ECAN.org

**Esophagus Cancer - American Cancer Society** 800-227-2345 <u>www.Cancer.org/Cancer/Types/Esophagus-Cancer.html</u> **Cancer Support Helpline**® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

**Open to Options**® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer**® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of nearly 196 locations, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more:

www.CancerSupportCommunity.org/Find-Location-Near-You **Cancer Experience Registry**® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org. MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org. **Grassroots Network** — Make sure your voice is heard by federal and state policy

makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Beco me-Advocate.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Esophageal-Cancer** For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org** 

## Frankly Speaking About Cancer: Esophageal Cancer Program Partner



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