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GUIDELINES  
FOR PATIENTS®

2024

# Small Bowel Adenocarcinoma



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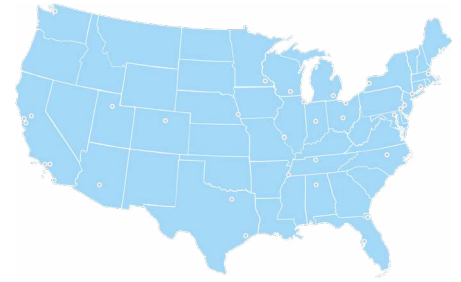
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# About the NCCN Guidelines for Patients®



Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).



Cancer care is always changing. NCCN develops evidence-based cancer care recommendations used by health care providers worldwide. These frequently updated recommendations are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). The NCCN Guidelines for Patients plainly explain these expert recommendations for people with cancer and caregivers.

**These NCCN Guidelines for Patients are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Small Bowel Adenocarcinoma, Version 3.2024 — April 30, 2024.**

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# 1

## About small bowel adenocarcinoma

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**Many small intestine (bowel) cancers are adenocarcinomas. These tumors start in mucus-making cells on the inner lining of the small bowel. Seeking treatment within a clinical trial is encouraged for these uncommon cancers.**

## The small bowel

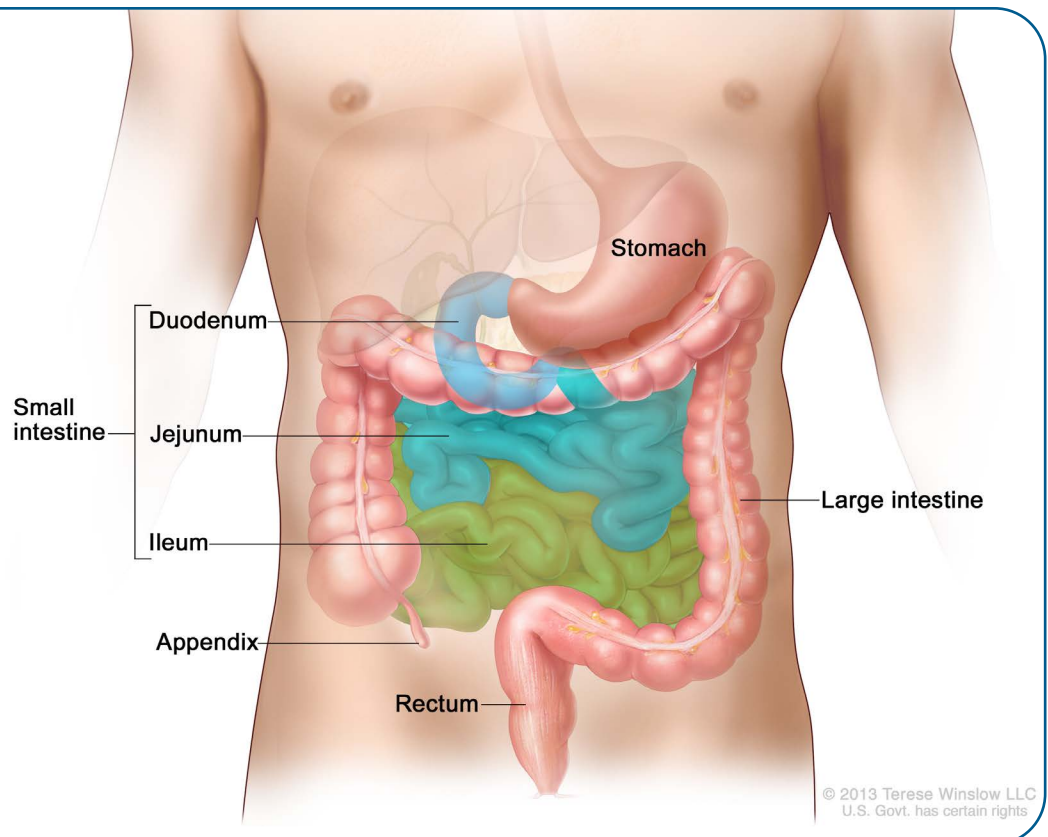
When food leaves your stomach, it enters the small bowel. The first part is the duodenum. More than half of all small bowel adenocarcinomas start here. These tumors can block food from passing between the stomach and the rest of the small bowel. This causes vomiting because the food doesn't have anywhere to go.

The rest of these cancers start in either the jejunum, or less often, in the ileum. Tumors that form in the lower sections of the small bowel may cause nausea, vomiting, constipation, cramping, and abdominal pain.

Gastrointestinal (GI) bleeding is also common in people with a small bowel adenocarcinoma.

### The small bowel

**Most small bowel adenocarcinomas start in the duodenum. The rest start in the jejunum, or less often, in the ileum.**



The loss of blood causes fatigue, weakness, pale skin, and other symptoms. This is called iron deficiency anemia.

If left untreated, the cancer cells will grow from the inner lining of the bowel, through the outer layers of the bowel wall and towards other organs and tissues in the abdomen. Cancer cells can also break off from the small bowel tumor and travel through lymph or blood to nearby lymph nodes or to more distant organs.

Small bowel adenocarcinoma can be hard to treat. The only way to cure it is to surgically remove it. But in about 1 in 3 people, the cancer will return after surgery. This is called relapse or recurrence.

## Who gets small bowel adenocarcinoma?

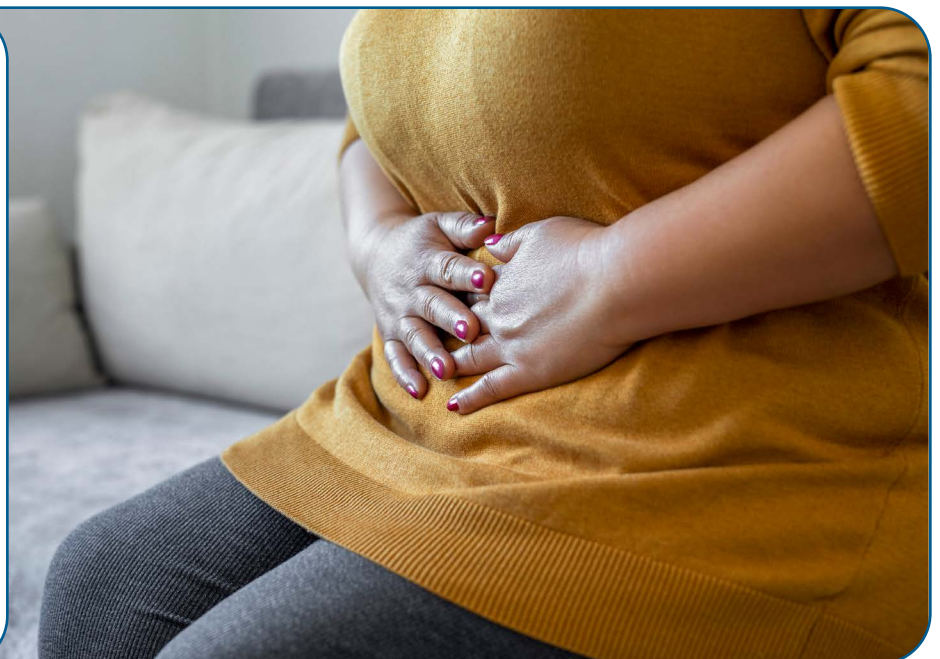
Compared to large bowel (colorectal) cancers, small bowel adenocarcinoma tends to be diagnosed at an earlier age, and at a later stage. This is partly because there isn't a good way to screen for it, even for people at high risk. The cancer is usually found because the tumor causes problems and symptoms as it grows.

A risk factor is something that increases your risk of developing a health problem. Risk factors for small bowel adenocarcinoma are similar to those for colorectal cancer. They include lifestyle factors, inflammatory bowel disease (IBD), and certain hereditary cancer syndromes.

### Lifestyle factors

Because small bowel cancer is so rare, there isn't much data on lifestyle factors that may

**Inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease, may raise the risk of cancer in the lower sections of the small bowel. People with celiac disease may also be at higher risk of small bowel adenocarcinoma.**





increase the risk of developing it. Drinking alcohol, using tobacco, and certain eating habits may increase the risk of this cancer. Food and diet-related risk factors include not getting enough fiber, eating a lot of red or processed meats, and drinking sugary drinks.

### **Inflammatory bowel disease and celiac disease**

Inflammatory bowel disease (IBD) is a group of health problems that cause long-term swelling and damage in the digestive tract. Ulcerative colitis and Crohn's disease are types of IBD.

There is a known link between IBD and large bowel (colorectal) cancer. Research suggests that IBD also increases the risk of cancer in the lower sections of the small bowel, especially the ileum.

People with celiac disease may also be at increased risk of small bowel adenocarcinoma. In people with this condition, eating gluten (a protein in certain grains) causes an immune reaction. Symptoms can include diarrhea, bloating, and gas. The link between celiac disease and small bowel cancer isn't well understood.

### **Hereditary cancer syndromes**

Some rare conditions that affect families increase the risk of small bowel cancer. These hereditary conditions include Lynch syndrome, Peutz-Jeghers syndrome, and familial adenomatous polyposis. These rare conditions are discussed more in the next chapter.

## Key points

- ▶ Many small intestine (bowel) cancers are adenocarcinomas. These tumors start in mucus-making cells on the inner lining of the small bowel. Most form in the first part of the small bowel, called the duodenum.
- ▶ People with an inflammatory bowel disease (IBD) or one of several hereditary cancer syndromes are at higher risk of small bowel adenocarcinoma. Drinking alcohol, using tobacco, and certain eating habits may also increase the chance of developing this cancer.
- ▶ Most small bowel adenocarcinomas are found because they cause problems as they grow. Symptoms can include nausea, vomiting, abdominal pain, cramping, constipation, weakness, fatigue, and shortness of breath.
- ▶ Seeking treatment within a clinical trial is encouraged for these uncommon cancers.

# 2

## Testing

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**This chapter discusses testing for small bowel adenocarcinoma and other steps needed to create your treatment plan. All small bowel adenocarcinomas should be tested for a feature called mismatch repair deficiency.**

## Imaging

Imaging tests can show areas of cancer inside the body. A radiologist interprets the images and conveys the results to your oncologist. Your care team will tell you how to prepare for your scans.

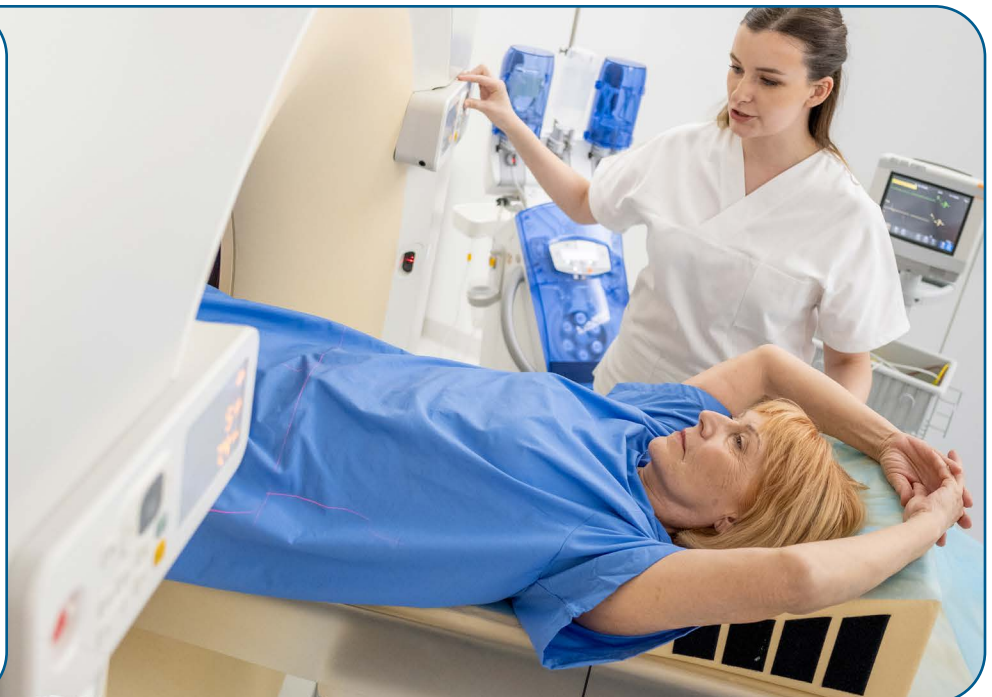
### Computed tomography

Computed tomography (CT) is the main imaging test used to learn the extent of small bowel cancer in the body. CT scans of your chest, abdomen, and pelvis are recommended. This is roughly the area from your shoulders to your groin.

A substance called contrast is usually used to make the pictures clearer. It may be injected into your vein and/or mixed with a liquid to drink. If you've had an allergic reaction to contrast in the past, you may be given or asked to take a steroid and an antihistamine medication (like Benadryl) before the scan.

During the scan you will lie face-up on a table that moves through a short tunnel-like machine. You will be able to hear and talk to the technician at all times.

**CT with contrast is the main imaging test used to determine the extent of small bowel cancer in the body. CT scans of your chest, abdomen, and pelvis are recommended if a small bowel cancer is suspected.**



## MRI

Magnetic resonance imaging (MRI) isn't used often to plan treatment for small bowel cancer. Your doctor may order an MRI of the abdomen and pelvis if you can't have the contrast used for computed tomography, or if CT images were unclear.

If you do need an MRI, the scanning process takes longer compared to CT. You may need to hold your breath for brief periods of time. The tunnel is longer and may be more narrow. Tell your team if you get nervous in small spaces. You may be given a sedative (medicine) to help you relax.

MRI doesn't use radiation and is safe for most people. Those with certain heart monitors, pacemakers, or some types of surgical clips generally can't have MRI scanning.

## Endoscopy procedures

Endoscopy is an important tool in the diagnosis of small bowel adenocarcinoma. It allows your provider to see inside the small bowel and remove tissue samples for testing (a biopsy).

Endoscopy involves inserting a thin, tube-shaped tool called a scope into the body. The scope is guided through a natural opening, usually the mouth. One end of the scope has a small light and camera lens.

Types of endoscopy that may be used for small bowel adenocarcinoma are described next.

### EGD

An esophagogastroduodenoscopy (EGD) is recommended for suspected tumors in the first part of the small bowel, the duodenum. EGD allows your provider to look for signs of cancer or other issues, such as enlarged blood vessels or ulcers. While you are sedated, an endoscope is guided down your throat, through the esophagus and stomach, and into the duodenum.

If it's unclear whether the tumor is in the small bowel or in a connecting organ (such as the head of the pancreas), endoscopic ultrasound (EUS) may be used during EGD. It can also be used if the extent of the cancer is unclear based on other imaging, or to biopsy areas outside the bowel (like nearby lymph nodes).

EGD usually takes less than an hour. You can go home the same day. Your throat may feel sore or swollen afterward.

### Balloon enteroscopy

Over time, inflammatory bowel disease (IBD) can cause scar tissue to form in the lining of the bowel. This causes the bowel to narrow in certain areas, called strictures. Balloon enteroscopy can be helpful when there are strictures.

Using a long thin tube (enteroscope) with a high-resolution camera at the tip, your gastroenterologist guides the scope either down your throat or up your anus to reach the small bowel. Small balloons attached to the scope inflate and deflate. This allows your provider to see and biopsy areas that would otherwise be blocked.

### Capsule endoscopy

When a problem in the small bowel is suspected but can't be seen using imaging or other types of endoscopy, capsule endoscopy may be helpful.

This involves swallowing a capsule with a tiny camera inside. While the capsule travels through your digestive tract, the camera takes thousands of pictures and transmits them to a device. The device turns the pictures into a video that your provider can view.

## Biopsy and tissue testing

The tissue samples and lymph nodes removed during endoscopy are sent to a lab for testing. An expert called a pathologist determines the cancer type and other details about the cancer. All small bowel adenocarcinomas should be tested for DNA mismatch repair (MMR) testing, described next.

### Mismatch repair testing

This feature of some cancers is a type of biomarker. Biomarkers are targetable changes of a cancer that can help guide your treatment. Testing involves analyzing a piece of the tumor (removed during a biopsy or surgery) in a lab.

Depending on the method used, an abnormal result is called either mismatch repair deficiency (dMMR) or microsatellite instability-high (MSI-H). Tumors that don't have these changes are referred to as mismatch repair proficient (pMMR) or microsatellite stable (MSS).

Compared to colorectal cancers, dMMR is more common in small bowel adenocarcinomas. This means that inherited problems with the MMR genes are also more likely. If the cancer is dMMR/MSI-H, you will also be tested for Lynch syndrome.

## Family health history

Most small bowel adenocarcinomas occur for unknown reasons. But some people are born with a gene mutation that makes them more likely to get bowel cancer and other cancers. Those born with Lynch syndrome, for example, are at high risk of developing bowel, endometrial, and ovarian cancers.

Lynch syndrome is caused by inherited mutations of genes that fix damaged DNA, called mismatch repair (MMR) genes. All small bowel adenocarcinomas should be tested for problems with the MMR genes. If the cancer is dMMR/MSI-H, you will also be tested for Lynch syndrome.

Peutz-Jeghers syndrome is a condition that causes polyps to form in the middle and lower sections of the small bowel (the jejunum and ileum). Small bowel adenocarcinoma can start in these polyps, putting those with this syndrome at risk.

Familial adenomatous polyposis (FAP) is a rare inherited cancer syndrome that causes hundreds to thousands of polyps to form in the colon and rectum, and rarely in the small bowel. The polyps start as benign growths, but over time can become invasive cancers.

If your provider thinks you may have an inherited syndrome, they will refer you to a genetic counselor. This expert can talk with you and your family about getting tested for syndromes related to small bowel adenocarcinoma. If they determine that testing is appropriate, they can order a blood or saliva test to see if you have an inherited gene mutation.

## Blood tests

Blood tests alone can't confirm small bowel adenocarcinoma, but abnormal results may suggest a problem.

### General health

A complete blood count (CBC) measures the number of white blood cells, red blood cells, and platelets in a blood sample. White blood cells help you fight infection. Red blood cells carry oxygen throughout the body. Platelets help wounds heal by forming blood clots.

A chemistry profile, also known as a comprehensive metabolic panel (CMP), is a group of tests that shows how well your kidneys, liver, and other organs are working.

### Tumor markers

Cancer antigen 19-9 (CA 19-9) and carcinoembryonic antigen (CEA) are proteins normally made by digestive organs. They can be detected and measured in blood. People with small bowel adenocarcinoma tend to have more than normal.

When caused by cancer, high levels at diagnosis often mean a higher cancer stage. Your care team will take these levels into account when planning treatment. Levels may be checked to see if they are changing.

Tumor marker levels can't be used alone to diagnose small bowel adenocarcinoma, for a few reasons. High levels can be caused by other health conditions. Some people with small bowel cancer have normal levels. And, some people don't make CA 19-9 naturally.

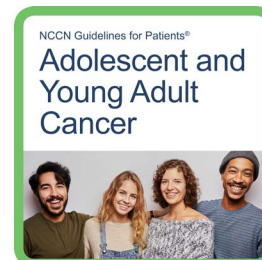
## Key points

- ▶ CT is used to see the extent of small bowel cancer in the body. If you can't have the contrast agent for CT or if the images are unclear, MRI may be used to view the abdomen and pelvis.
- ▶ Endoscopy allows your provider to see and biopsy the small bowel using a thin tube with a lens for viewing. EGD is recommended for suspected cancers in the duodenum. Endoscopic ultrasound may be used to confirm the location or extent of the cancer, or to guide biopsies of areas outside the bowel.
- ▶ Balloon enteroscopy may be used when the bowel is too narrow to access with a scope. Capsule endoscopy may be helpful if other imaging and endoscopy procedures can't find the problem.
- ▶ Biopsies or other tumor tissue tests are needed to diagnose small bowel adenocarcinoma. All small bowel adenocarcinomas should be tested for mismatch repair deficiency (dMMR). If the cancer has this biomarker, the next step is to test your blood or saliva for inherited changes in the MMR genes. These are the gene changes that cause Lynch syndrome.
- ▶ Small bowel adenocarcinoma is linked with other rare hereditary cancer syndromes. Depending on your family health history, your provider may refer you to a genetic counselor for guidance and possibly genetic testing.

### Fertility and family planning

If you want the option of having children after treatment or are unsure, tell your care team. Your doctor will discuss any fertility-related risks of your treatment plan with you. You may be referred for counseling about your fertility preservation options.

For more information, see the *NCCN Guidelines for Patients for Adolescent and Young Adult Cancer* at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.





# 3

## Treatment

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**When possible, small bowel adenocarcinoma that is contained within the small bowel is treated with surgery. Chemotherapy may follow. Metastatic cancer is usually treated with systemic therapy.**

### Non-metastatic (stage 1, 2, and 3) cancer

A cancer that can be safely removed with surgery (resection) is called resectable. Resection is recommended for non-metastatic small bowel adenocarcinoma when possible. The surgeon will also remove all nearby lymph nodes. If you aren't a candidate for surgery, see page 17.

#### Whipple procedure

Most small bowel adenocarcinomas start in the duodenum. A Whipple procedure is often recommended, especially if the cancer has grown into any part of the pancreas or common bile duct. This surgery, also called pancreaticoduodenectomy, removes:

- ▶ Part of the small bowel, pancreas, and common bile duct
- ▶ The gallbladder
- ▶ Nearby lymph nodes
- ▶ Sometimes part of the stomach and parts of blood vessels

Reconstruction starts with attaching the pancreas and bile duct to the middle part of the small bowel (the jejunum). Then, either the stomach or duodenum is attached farther down on the jejunum. Blood vessels may need reconstruction.

#### Segmentectomy

This type of surgery is recommended for cancers in the middle or last parts of the small bowel. It is also used for cancers in the duodenum that don't require a Whipple procedure.

Your surgeon will remove the tumor and 5 to 10 centimeters (about 2 to 4 inches) of normal-looking tissue on either side of it. They will also remove lymph nodes closest to the tumor and any others nearby that look suspicious.

#### Staging

The tissue and lymph nodes removed during surgery are sent to a lab for testing. A pathologist assesses how far the cancer has grown within the bowel wall and assigns the cancer a stage of I (1), II (2), or III (3). This process is called surgical staging. The stage is used to determine whether chemotherapy is needed.

##### Stage 1

Observation is recommended for all cancers found to be stage 1. In staging terms, these cancers are written as T1 or T2, N0, M0. Surveillance will begin.

### Stage 2

For stage 2 cancers, treatment after surgery depends on the mismatch repair (MMR) status of the cancer and whether there are high-risk features. In staging terms, stage 2 cancers are written as T3 or T4, N0, M0.

Observation is recommended for dMMR or MSI-H stage 2 cancers. The benefit of chemotherapy after surgery is less clear for pMMR or MSS stage 2 cancers. These may be observed or treated with chemotherapy.

### Stage 3

If cancer cells are found in any lymph nodes removed during surgery, the cancer is stage 3. Chemotherapy is recommended after surgery for all stage 3 cancers. Radiation therapy may be used in addition to chemotherapy.

### More about chemotherapy

If chemotherapy is planned after surgery, your options may include 1 or more of the regimens listed below. The individual medicines in these regimens are listed in **Guide 1**.

- 5-FU/LV
- Capecitabine
- FOLFOX
- CAPEOX

Chemotherapy is given in cycles of treatment days followed by days of rest. This allows your body to recover between cycles. Cycles vary in length depending on which drugs are used.

Any regimen that has “OX” in the name includes the drug oxaliplatin. Oxaliplatin can

#### Guide 1 Chemotherapy regimens

<b>FOLFOX</b>	Leucovorin calcium (folic acid) + fluorouracil + oxaliplatin
<b>CAPEOX</b>	Capecitabine + oxaliplatin
<b>FOLFIRI</b>	Leucovorin calcium + fluorouracil + irinotecan
<b>FOLFIRINOX</b>	Leucovorin calcium + fluorouracil + irinotecan + oxaliplatin
<b>5-FU/LV</b>	Fluorouracil + leucovorin calcium
<b>Capecitabine</b>	Capecitabine

cause potentially permanent nerve damage (called neuropathy) in the fingers and toes. Symptoms include numbness, cramping, tingling, or pain in these areas.

Any regimen that has “IRI” in the name contains the drug irinotecan. Irinotecan tends to cause abdominal cramping, nausea, diarrhea, and hair loss.

If regimens containing oxaliplatin or irinotecan are expected to be too harsh, your doctor may recommend 5-FU/leucovorin or capecitabine alone. These regimens also have side effects. Capecitabine can cause hand-foot syndrome. Symptoms include redness, swelling, and pain on the palms of the hands, bottoms of the feet, or both. Sometimes blisters appear.

#### What if I can't have surgery?

If you aren't a candidate for surgery, treatment with chemotherapy is recommended. Recommended regimens include:

- FOLFOX
- CAPEOX
- 5-FU/LV
- Capecitabine
- FOLFIRINOX

If chemotherapy works well, surgery may become an option. If the cancer stays unresectable, your doctor may recommend chemoradiation next. Otherwise, continuing chemotherapy or switching to a different systemic therapy is recommended.

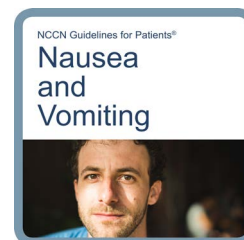
Tumors growing in or around the bowel can block stool from moving and leaving the body.

## Chemotherapy side effects

Systemic therapy kills both cancer cells and healthy cells. The damage to healthy cells can cause hair loss, cracked skin, mouth sores, and other side effects.

Managing side effects is a shared effort between you and your care team. It is important to speak up about bothersome side effects, such as nausea and vomiting. Ask about your options for managing or relieving the effects of treatment.

More information on supportive care is available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



In this case, the bowel needs to be unblocked before starting systemic therapy. This is done using one of several surgical techniques. Or, a mesh metal tube with a stent may be used for duodenal tumors.

## Surveillance

After surgery (and chemotherapy, if given), surveillance testing is done to:

- Check for late side effects of treatment
- Check for cancer recurrence
- Check for new areas of cancer growth

Surveillance after treatment for small bowel adenocarcinoma includes:

- Physical exams
- Carcinoembryonic antigen (CEA) and/or CA 19-9 blood tests
- Computed tomography (CT) scans of the chest, abdomen, and pelvis

The recommended schedule is shown in **Guide 2**.

People who have inflammatory bowel disease (IBD) or a familial cancer syndrome (like Lynch syndrome) are at high risk of forming more small bowel adenocarcinomas. More intensive surveillance may be needed and might include endoscopy of the small bowel.

In addition to surveillance testing, a range of other care is important for cancer survivors. For more information, see *Chapter 4: Survivorship*.

### Guide 2

#### Surveillance after surgery

**Physical exam and blood tests (CEA and CA 19-9)**

**First 2 years:** Every 3 to 6 months

**Next 3 years:** Every 6 months

**Computed tomography (CT) of chest, abdomen, and pelvis**

**First 2 years:** Every 6 to 12 months

**Next 3 to 5 years:** Once a year

## Metastatic (stage 4) cancer

Metastasis is the spread of cancer cells through lymph or blood to other organs in the body. About 1 in 3 people diagnosed with small bowel adenocarcinoma has stage 4 cancer. This means that the cancer had already spread to the liver, abdominal lining, lungs, or other organs by the time it was found.

Surgery to resect areas of metastatic spread (metastasectomy) is rarely an option. Most people receive treatment with systemic therapy. Biomarker testing helps guide the choice of systemic therapy.



**Supportive care is available for everyone with cancer. It isn't meant to treat the cancer, but rather to help with symptoms and make you more comfortable.**

## Biomarker testing

Biomarkers are features of a cancer that may be targetable. They are often non-inherited mutations (changes) in the tumor's genes.

When possible, biomarker testing is performed on a piece of tumor tissue removed during a biopsy or surgery. If this isn't an option, a sample of your blood can be tested instead.

Testing for many biomarkers at one time is called next-generation sequencing (NGS). This method can find rare biomarkers for which targeted treatments may be available.

All metastatic small bowel adenocarcinomas should be tested for the following biomarkers:

- Mismatch repair deficiency/microsatellite instability-high (dMMR/MSI-H)
- *BRAF* mutations
- HER2 gene amplifications

NGS can find other other rare biomarkers, including:

- *POLE/POLD1* mutations
- *RET* gene fusions
- *NTRK* gene fusions

## Systemic therapy

Surgery is rarely an option for treating metastatic small bowel adenocarcinoma. Most people receive treatment with systemic therapy. The regimen you receive first is called first-line therapy.

For cancers with the dMMR/MSI-H or *POLE/POLD1* biomarkers, checkpoint inhibitor immunotherapy is recommended as first-line therapy. Immunotherapy increases the activity of parts of your immune system. This helps your body find and destroy cancer cells.

Assuming you haven't had treatment with a checkpoint inhibitor, currently recommended options include:

- Nivolumab (Opdivo)
- Nivolumab + ipilimumab (Yervoy)
- Pembrolizumab (Keytruda)
- Dostarlimab-gxly (Jemperli)

Chemotherapy is recommended as first-line therapy for most other stage 4 cancers. If you've had recent treatment with FOLFOX or CAPEOX, you shouldn't have more chemotherapy that includes oxaliplatin. It can cause serious nerve damage.

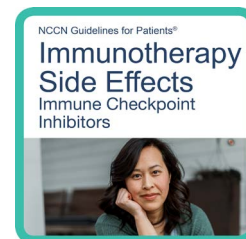
Your options for systemic therapy will depend, in part, on whether the cancer has any biomarkers. Targeted therapies available for cancers with specific biomarkers are listed on the next page in **Guide 3**.

Options for chemotherapy may include irinotecan-based chemotherapy, docetaxel, or paclitaxel.

## Immunotherapy side effects

Immune checkpoint inhibitors have unique side effects. Unlike other cancer treatments, the side effects of immunotherapy occur because the immune system is attacking healthy cells. Learning about possible side effects can help you notice reactions early and report them to your care team.

More information on the side effects of immune checkpoint inhibitors is available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app.



### Guide 3 Biomarker-based systemic therapy

Biomarker	Available targeted therapies
<b>dMMR/MSI-H or <i>POLE/POLD1</i> mutation</b>	<ul style="list-style-type: none"> <li>• Dostarlimab-gxly (Jemperli)</li> <li>• Nivolumab (Opdivo)</li> <li>• Nivolumab + ipilimumab (Yervoy)</li> <li>• Pembrolizumab (Keytruda)</li> </ul>
<b><i>BRAF</i> V600E mutation</b>	Dabrafenib (Tafinlar) + trametinib (Mekinist)
<b>Tumor mutational burden-high (TMB-H)</b>	Pembrolizumab (Keytruda)
<b><i>NTRK</i> gene fusion</b>	<ul style="list-style-type: none"> <li>• Entrectinib (Rozlytrek)</li> <li>• Larotrectinib (Vitrakvi)</li> </ul>
<b><i>RET</i> gene fusion</b>	Selpercatinib (Retevmo)
<b>HER2 gene amplification</b>	Fam-trastuzumab deruxtecan-nxki (Enhertu)

## Clinical trials

A clinical trial is a type of medical research study. After being developed and tested in a laboratory, potential new ways of fighting cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

### Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- **Phase 1** trials study the safety and side effects of an investigational drug or treatment approach.
- **Phase 2** trials study how well the drug or approach works against a specific type of cancer.
- **Phase 3** trials test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase 4** trials study the long-term safety and benefit of an FDA-approved treatment.

### Who can enroll?

Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or



## Finding a clinical trial

### In the United States

NCCN Cancer Centers  
[NCCN.org/cancercenters](https://www.nccn.org/cancercenters)

The National Cancer Institute (NCI)  
[cancer.gov/about-cancer/treatment/clinical-trials/search](https://www.cancer.gov/about-cancer/treatment/clinical-trials/search)

### Worldwide

The U.S. National Library of Medicine  
 (NLM)  
[clinicaltrials.gov](https://clinicaltrials.gov)

### Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)  
 1.800.4.CANCER (1.800.422.6237)  
[cancer.gov/contact](https://www.cancer.gov/contact)

general health. These requirements ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

### Informed consent

Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also



provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss with family, friends, or others you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

### Start the conversation

Don't wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment team if you meet the requirements. Try not to be discouraged if you cannot join. New clinical trials are always becoming available.

### Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

### Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. You may, however, have costs indirectly related to the trial, such as the cost of transportation or child care due to extra appointments. During the trial, you will continue to receive standard cancer care. This care is billed to—and often covered by—insurance. You are responsible for copays and any costs for this care that are not covered by your insurance.

## Key points

- When possible, resection is recommended for non-metastatic small bowel adenocarcinoma. Chemotherapy may follow. A Whipple procedure is often used for tumors in the duodenum. Segmentectomy is often used for tumors in the jejunum or ileum.
- After surgery, observation is recommended for all stage 1 cancers. Chemotherapy is recommended for all stage 3 cancers. For stage 2 cancers, this depends on mismatch repair (MMR) status. Observation is recommended for stage 2 dMMR/MSI-H cancers. Stage 2 pMMR/MSS cancers tumors may be observed or treated with chemotherapy.
- All stage 4 (metastatic) adenocarcinomas should be tested for dMMR/MSI-H, *BRAF* mutations, and HER2 amplifications. Next-generation sequencing (NGS) can find other biomarkers such as TMB-H, *POLE/POLD1* mutations, *RET* fusions, and *NTRK* fusions.
- Surgery is rarely an option for treating metastatic small bowel adenocarcinoma. Most people start systemic therapy. For cancers with the dMMR/MSI-H or *POLE/POLD1* biomarkers, immunotherapy is recommended as first-line therapy.
- Supportive care is available for everyone with cancer to help with symptoms and make you feel more comfortable.
- Clinical trials provide access to investigational treatments that may, in time, be approved by the FDA.

# 4

## Survivorship

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**Survivorship focuses on the physical, emotional, and financial issues faced by cancer survivors. Managing the long-term side effects of cancer and its treatment, staying connected with your primary care provider, and living a healthy lifestyle are important parts of survivorship.**

## Your primary care provider

After finishing cancer treatment, your oncologist and primary care provider should work together to make sure you get the follow-up care you need. Ask your oncologist for a written survivorship care plan. Ideally, the plan should include:

- A summary of your cancer treatment history
- A description of possible late- and long-term side effects
- Recommendations for monitoring for the return of cancer
- Clear roles and responsibilities for your providers
- Recommendations on your overall health and well-being

## Paying for care

Cancer survivors face a unique financial burden. Paying for doctor visits, tests, and treatments can become unmanageable, especially for those with little or no health insurance. You may also have costs not directly related to treatment, such as travel expenses and the cost of childcare or missed work.

The term financial toxicity is used to describe the problems patients face related to the cost of medical care. Financial toxicity can affect your quality of life and access to needed health care. If you need help paying for your cancer care, financial assistance may be available. Talk with a patient navigator, your treatment team's social worker, and your hospital's financial services department.

## Help with side effects

Cancer survivors may experience both short- and long-term health effects of cancer and its treatment. The effects depend in part on the treatment(s) received. Surgery, anti-cancer medicines, and radiation therapy all have unique potential side effects.

### Nerve damage

The chemotherapy drug oxaliplatin can damage nerves in your fingers and toes. Symptoms include numbness, cramping, tingling, and pain in these areas. If you have painful nerve damage, duloxetine (Cymbalta) or a gabapentinoid (gabapentin or pregabalin) may help. If the pain is persistent, talk to your doctor about seeing a pain management specialist.

Methods that may help with numbness, cramping, and tingling include acupuncture, heat, ice, and balanced physical activity.

### Healthy habits

It is important to keep up with other aspects of your health after cancer treatment. Steps you can take to help prevent other health problems and to improve your quality of life are described next.

### Cancer screening

Get screened for other types of cancer, such as breast, prostate, and skin cancer. Your primary care provider can tell you what cancer screening tests you should have based on your age and risk level.

### Other health care

Get other recommended health care for your age, such as blood pressure screening, dental care, hepatitis C screening, and immunizations (like the flu shot).

### Quit smoking

If you smoke or vape, tell your care team. They can help you find ways to quit that works for you.

### Diet and exercise

Try to exercise for at least 150 minutes per week. This will help you stay at a healthy weight.

Eat a diet rich in plant-based foods. If you have confirmed celiac disease, avoid foods that contain gluten. Alcohol may increase the risk of certain cancers. Drink little to no alcohol.

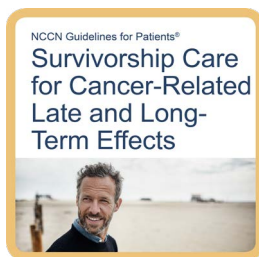
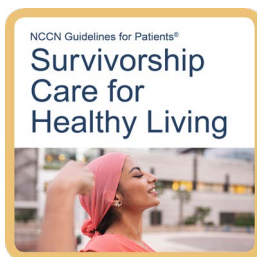
**Experts recommend that cancer survivors eat a diet rich in plant-based foods such as vegetables, fruits, and whole grains.**



## More information

For more information on cancer survivorship, the following are available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) and on the [NCCN Patient Guides for Cancer](#) app:

- › *Survivorship Care for Healthy Living*
- › *Survivorship Care for Cancer-Related Late and Long-Term Effects*



These resources address many topics relevant to cancer survivors, including:

- › Anxiety, depression, and distress
- › Fatigue
- › Pain
- › Sexual health
- › Sleep problems
- › Healthy lifestyles
- › Immunizations
- › Employment, insurance, and disability concerns

# 5

## Making treatment decisions

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**It's important to be comfortable with the cancer treatment you choose. This choice starts with having an open and honest conversation with your doctor.**

### It's your choice

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What is important to you may not be important to someone else. Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor.

If you take the time to build a relationship with your doctor, it will help you feel supported when considering options and making treatment decisions.

### Second opinion

It is normal to want to start treatment as soon as possible. While cancer should not be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it's a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

### Support groups

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. If your hospital or community doesn't have support groups for people with cancer, check out the websites listed in this book.

### Questions to ask

Possible questions to ask your doctors are listed on the following pages. Feel free to use these or come up with your own.







## Questions about stage 4 small bowel adenocarcinoma

1. Where has the cancer spread?
2. Am I a candidate for surgery? If not, is it possible that I'll become a candidate?
3. Which systemic therapy regimen do you recommend for me? Why?
4. How will you know if systemic therapy is working? What if it stops working?
5. Does my cancer have any biomarkers? How does this affect my options?
6. What is my prognosis?
7. What can be done to prevent or relieve the side effects of treatment?
8. Am I a candidate for a clinical trial? Do you know of one I can join?

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## Resources

**CancerCare**

[Cancercares.org](https://cancercares.org)

**Cancer Hope Network**

[Cancerhopenetwork.org](https://cancerhopenetwork.org)

**Colorectal Cancer Alliance**

[Ccalliance.org](https://ccalliance.org)

**Imerman Angels**

[Imermanangels.org](https://imermanangels.org)

**Love Your Buns**

[Loveyourbuns.org](https://loveyourbuns.org)

**National Coalition for Cancer Survivorship**

[canceradvocacy.org](https://canceradvocacy.org)

**Triage Cancer**

[Triagecancer.org](https://triagecancer.org)

**U.S. National Library of Medicine Clinical Trials Database**

[clinicaltrials.gov](https://clinicaltrials.gov)



Take our survey and help make the NCCN Guidelines for Patients better for everyone!

[NCCN.org/patients/comments](https://nccn.org/patients/comments)



## Words to know

### **adenocarcinoma**

A common type of small bowel cancer. Starts in mucus-making cells that line the small bowel.

### **adenoma**

The most common type of bowel polyp and the most likely to form cancer cells. Also called adenomatous polyp.

### **biomarker**

A targetable feature of a cancer that can help guide treatment.

### **carcinoembryonic antigen (CEA)**

A protein that gets released by some tumors and can be detected in blood.

### **duodenum**

The first part of the small bowel. Most small bowel cancers start in the duodenum.

### **familial adenomatous polyposis (FAP)**

An inherited medical condition that increases the risk of bowel cancer.

### **inflammatory bowel disease (IBD)**

A group of health conditions that cause long-term swelling in the digestive tract.

### **jejunum**

The middle part of the small bowel.

### **large intestine (bowel)**

A long tube-shaped organ that forms the last part of the digestive system. Includes the colon, rectum, and anus.

### **lymph node**

Small groups of special disease-fighting cells located throughout the body.

### **metastasis**

The spread of cancer cells from the first (primary) tumor to a distant site.

### **mismatch repair deficiency (dMMR)/ microsatellite instability-high (MSI-H)**

A biomarker (feature) of some bowel cancers that is used to guide treatment. All small bowel adenocarcinomas should be tested for this biomarker.

### **mismatch repair proficient (pMMR)/ microsatellite stable (MSS)**

Describes cancers without the mismatch repair deficiency (dMMR)/microsatellite instability-high (MSI-H) biomarker.

### **pathologist**

A doctor who specializes in testing cells and tissue to find disease.

### **polyp**

An overgrowth of cells on the inner lining of the bowel wall.

### **recurrence**

The return of cancer after a cancer-free period.

### **resectable**

Describes a cancer that can be safely removed using surgery.

### **supportive care**

Treatment for the symptoms or health conditions caused by cancer or cancer treatment.

### **surgical margin**

The normal tissue around the edge of a tumor removed during surgery.

**systemic therapy**

The use of medicines that enter the bloodstream. Chemotherapy, targeted therapy, and immunotherapy are examples.

**unresectable**

Describes a cancer that cannot be safely removed using surgery.

**Whipple procedure**

Surgery to remove the head of the pancreas and parts of other nearby organs. Also called pancreaticoduodenectomy.

**Let us know what you think!**

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

[NCCN.org/patients/response](https://www.nccn.org/patients/response)

# NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Small Bowel Adenocarcinoma, Version 3.2024. It was adapted, reviewed, and published with help from the following people:

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For disclosures, visit  
[NCCN.org/disclosures](https://www.nccn.org/disclosures).



# NCCN Cancer Centers

**Abramson Cancer Center**  
at the University of Pennsylvania  
Philadelphia, Pennsylvania  
800.789.7366 • [pennmedicine.org/cancer](https://pennmedicine.org/cancer)

**Case Comprehensive Cancer Center/  
University Hospitals Seidman Cancer Center and  
Cleveland Clinic Taussig Cancer Institute**  
Cleveland, Ohio  
UH Seidman Cancer Center  
800.641.2422 • [uhhospitals.org/services/cancer-services](https://uhhospitals.org/services/cancer-services)  
CC Taussig Cancer Institute  
866.223.8100 • [my.clevelandclinic.org/departments/cancer](https://my.clevelandclinic.org/departments/cancer)  
Case CCC  
216.844.8797 • [case.edu/cancer](https://case.edu/cancer)

**City of Hope National Medical Center**  
Duarte, California  
800.826.4673 • [cityofhope.org](https://cityofhope.org)

**Dana-Farber/Brigham and Women's Cancer Center |  
Mass General Cancer Center**  
Boston, Massachusetts  
877.442.3324 • [youhaveus.org](https://youhaveus.org)  
617.726.5130 • [massgeneral.org/cancer-center](https://massgeneral.org/cancer-center)

**Duke Cancer Institute**  
Durham, North Carolina  
888.275.3853 • [dukecancerinstitute.org](https://dukecancerinstitute.org)

**Fox Chase Cancer Center**  
Philadelphia, Pennsylvania  
888.369.2427 • [foxchase.org](https://foxchase.org)

**Fred & Pamela Buffett Cancer Center**  
Omaha, Nebraska  
402.559.5600 • [unmc.edu/cancercenter](https://unmc.edu/cancercenter)

**Fred Hutchinson Cancer Center**  
Seattle, Washington  
206.667.5000 • [fredhutch.org](https://fredhutch.org)

**Huntsman Cancer Institute at the University of Utah**  
Salt Lake City, Utah  
800.824.2073 • [healthcare.utah.edu/huntsmancancerinstitute](https://healthcare.utah.edu/huntsmancancerinstitute)

**Indiana University Melvin and Bren Simon  
Comprehensive Cancer Center**  
Indianapolis, Indiana  
888.600.4822 • [www.cancer.iu.edu](https://www.cancer.iu.edu)

**Mayo Clinic Comprehensive Cancer Center**  
Phoenix/Scottsdale, Arizona  
Jacksonville, Florida  
Rochester, Minnesota  
480.301.8000 • Arizona  
904.953.0853 • Florida  
507.538.3270 • Minnesota  
[mayoclinic.org/cancercenter](https://mayoclinic.org/cancercenter)

**Memorial Sloan Kettering Cancer Center**  
New York, New York  
800.525.2225 • [mskcc.org](https://mskcc.org)

**Moffitt Cancer Center**  
Tampa, Florida  
888.663.3488 • [moffitt.org](https://moffitt.org)

**O'Neal Comprehensive Cancer Center at UAB**  
Birmingham, Alabama  
800.822.0933 • [uab.edu/onealcancercenter](https://uab.edu/onealcancercenter)

**Robert H. Lurie Comprehensive Cancer Center  
of Northwestern University**  
Chicago, Illinois  
866.587.4322 • [cancer.northwestern.edu](https://cancer.northwestern.edu)

**Roswell Park Comprehensive Cancer Center**  
Buffalo, New York  
877.275.7724 • [roswellpark.org](https://roswellpark.org)

**Siteman Cancer Center at Barnes-Jewish Hospital  
and Washington University School of Medicine**  
St. Louis, Missouri  
800.600.3606 • [siteman.wustl.edu](https://siteman.wustl.edu)

**St. Jude Children's Research Hospital/  
The University of Tennessee Health Science Center**  
Memphis, Tennessee  
866.278.5833 • [stjude.org](https://stjude.org)  
901.448.5500 • [uthsc.edu](https://uthsc.edu)

**Stanford Cancer Institute**  
Stanford, California  
877.668.7535 • [cancer.stanford.edu](https://cancer.stanford.edu)

**The Ohio State University Comprehensive Cancer Center -  
James Cancer Hospital and Solove Research Institute**  
Columbus, Ohio  
800.293.5066 • [cancer.osu.edu](https://cancer.osu.edu)

**The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins**  
Baltimore, Maryland  
410.955.8964  
[www.hopkinskimmelcancercenter.org](https://www.hopkinskimmelcancercenter.org)

**The UChicago Medicine Comprehensive Cancer Center**  
Chicago, Illinois  
773.702.1000 • [uchicagomedicine.org/cancer](https://uchicagomedicine.org/cancer)

**The University of Texas MD Anderson Cancer Center**  
Houston, Texas  
844.269.5922 • [mdanderson.org](https://mdanderson.org)

**UC Davis Comprehensive Cancer Center**  
Sacramento, California  
916.734.5959 • 800.770.9261  
[health.ucdavis.edu/cancer](https://health.ucdavis.edu/cancer)

### UC San Diego Moores Cancer Center

*La Jolla, California*

858.822.6100 • [cancer.ucsd.edu](http://cancer.ucsd.edu)

### UCLA Jonsson Comprehensive Cancer Center

*Los Angeles, California*

310.825.5268 • [uclahealth.org/cancer](http://uclahealth.org/cancer)

### UCSF Helen Diller Family Comprehensive Cancer Center

*San Francisco, California*

800.689.8273 • [cancer.ucsf.edu](http://cancer.ucsf.edu)

### University of Colorado Cancer Center

*Aurora, Colorado*

720.848.0300 • [coloradocancercenter.org](http://coloradocancercenter.org)

### University of Michigan Rogel Cancer Center

*Ann Arbor, Michigan*

800.865.1125 • [rogelcancercenter.org](http://rogelcancercenter.org)

### University of Wisconsin Carbone Cancer Center

*Madison, Wisconsin*

608.265.1700 • [uwhealth.org/cancer](http://uwhealth.org/cancer)

### UT Southwestern Simmons Comprehensive Cancer Center

*Dallas, Texas*

214.648.3111 • [utsouthwestern.edu/simmons](http://utsouthwestern.edu/simmons)

### Vanderbilt-Ingram Cancer Center

*Nashville, Tennessee*

877.936.8422 • [vicc.org](http://vicc.org)

### Yale Cancer Center/Smilow Cancer Hospital

*New Haven, Connecticut*

855.4.SMILOW • [yalecancercenter.org](http://yalecancercenter.org)



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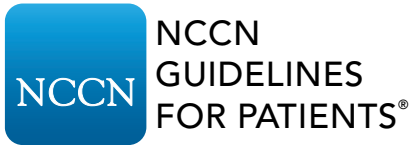
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