



# Small Intestine Cancer

## What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide to make new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out or dying cells or to repair injuries.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells continue to grow and form new, abnormal cells. In most cases, the cells form a tumor. Cancer cells can also grow into (invade) other tissues, something that normal cells cannot do. Growing out of control and invading other tissues are what makes a cell a cancer cell.

Cells become cancer cells because of damage to DNA. DNA is in every cell and directs all its actions. In a normal cell, when DNA is damaged the cell either repairs the damage or the cell dies. In cancer cells, the damaged DNA is not repaired, but the cell doesn't die like it should. Instead, this cell goes on making new cells that the body does not need. These new cells will all have the same damaged DNA as the first abnormal cell does.

People can inherit damaged DNA, but most often the DNA damage is caused by mistakes that happen while the normal cell is reproducing or by something in our environment. Sometimes the cause of the DNA damage is something obvious, like cigarette smoking. But often no clear cause is found.

In most cases the cancer cells form a tumor. Some cancers, like leukemia, rarely form tumors. Instead, these cancer cells involve the blood and blood-forming organs and circulate through other tissues where they grow.

Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors that replace normal tissue. This process is called *metastasis*. It happens when the cancer cells get into the bloodstream or lymph vessels of our body.

No matter where a cancer may spread, it is named (and treated) based on the place where it started. For example, breast cancer that has spread to the liver is still breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is still prostate cancer, not bone cancer.

Different types of cancer can behave very differently. They grow at different rates and respond to different treatments. That's why people with cancer need treatment that is aimed at their particular kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign*. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they can't invade other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

## What is a small intestine cancer?

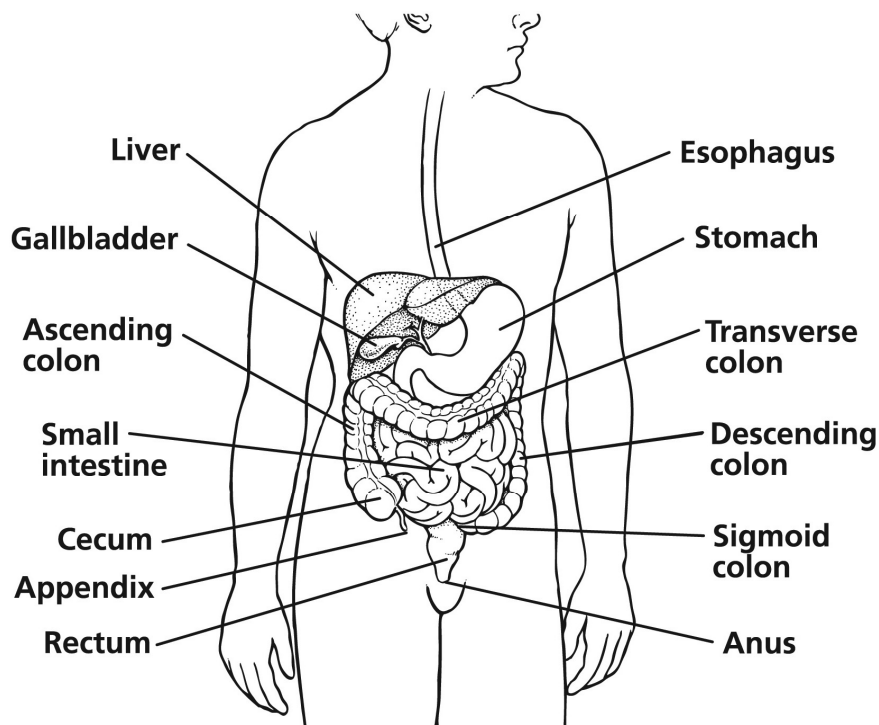
### The gastrointestinal (digestive) system

The digestive system processes food for energy and rids your body of solid waste. After you chew and swallow your food, it enters the *esophagus*. This is a tube-shaped organ that carries food to your stomach. The esophagus joins the *stomach* just beneath the breathing muscle under the lungs (the diaphragm)

The stomach is a sack-like organ that holds swallowed food and begins the digestive process by secreting gastric juice. The food and gastric juices are mixed into a thick fluid, which is then emptied into the small intestine. The *small intestine* continues breaking down the food and absorbs most of the nutrients. Even though it is called the small intestine, it is actually the longest section of the gastrointestinal (GI) tract. The small intestine is about 15 to 20 feet long. Because of its length, to fit in the abdomen, the small intestine has many loops.

The small intestine has 3 sections. The first section is the *duodenum*. It is short, only about 8 inches long. It is directly attached to the stomach and is where the stomach empties its contents. A short distance from where it attaches to the stomach, the pancreatic duct and bile duct attach to the duodenum. These discharge bile and pancreatic juices into the duodenum to further the digestive process. They attach at a site called the *ampulla of Vater*

The next 2 sections of the small intestine are the *jejunum* and *ileum*. These parts of the intestine are where all the nutrients in food are absorbed into the bloodstream. They make up most of the length of the small intestine with the ileum being slightly longer. The duodenum goes into the jejunum. The ileum comes after the jejunum and ends when it empties into the large intestine (*colon*). The *colon* is a muscular tube about 4 to 5 feet long. The *appendix* is found near the place the ileum meets the colon. The colon continues to absorb water and mineral nutrients from the food matter and serves as a storage place for waste. The waste left after this process goes into the rectum. From there it passes out of your body through the anus.



## Small intestine cancers

These major types make up about 60% to 70% of small intestine cancers.

- Carcinoid tumors,
- Sarcomas (including gastrointestinal stromal tumors),
- Lymphomas.

We have other documents that talk about these 3 types. This document is about the 4th type of small intestinal cancer – *adenocarcinoma*.

Adenocarcinomas make up about 30% to 40% of small intestine cancers. This type of cancer starts from the cells that line the intestine. Most experts think that cancer of the small intestine develops much like colorectal cancer. It first begins as a small benign outgrowth called a *polyp*. Over time, the polyp can change into a cancer. Most small intestinal cancers develop in the duodenum and the rest occur in the jejunum and ileum.

A major site of cancer in the duodenum is the ampulla of Vater. But because this area is closely associated with the pancreas, it is treated like pancreatic cancer and discussed in our document called *Pancreatic Cancer*

# What are the key statistics about small intestine adenocarcinoma?

Cancers of the small intestine are rare. The American Cancer Society estimates for these cancers in the United States for 2015 are:

- About 9,410 people in the United States will be diagnosed with small intestine cancer (in about 3,140 of these the small intestine cancer will be adenocarcinoma).
- About 1,260 people will die of small intestine cancer.

This cancer is more common in African Americans than in whites in the United States.

# What are the risk factors for small intestine adenocarcinoma?

A *risk factor* is anything that changes your chance of getting a disease such as cancer. Different cancers have different risk factors. For example, exposing skin to strong sunlight is a risk factor for skin cancer. Smoking is a risk factor for many cancers. But risk factors don't tell us everything. Someone without any risk factors can develop cancer, and having a risk factor, or even several, does not mean that you will get the disease. Because small intestine adenocarcinoma is so uncommon, risk factors for this disease have been hard to study. Some of the known risk factors include:

## Sex

Small intestinal adenocarcinoma occurs slightly more often in men than in women.

## Age

Small intestinal adenocarcinoma becomes more common as people get older. The average age of people when they are diagnosed is about 60.

## Smoking and alcohol use

Some, but not all, studies have found an increased risk with either smoking or drinking alcohol.

## Celiac disease

For people with celiac disease, eating gluten (a protein that is found in wheat and other types of grain) causes the body to make antibodies that then attack the lining of the intestines. The damaged lining makes it hard to digest and absorb the nutrients from food, often leading to diarrhea and weight loss. People with celiac disease have an increased

risk of a certain kind of lymphoma of the intestine called *enteropathy-associated T-cell lymphoma*. They may also have an increased risk of small intestine adenocarcinoma. This disease is also known as *celiac sprue* and *gluten-sensitive enteropathy*.

## Colon cancer

Survivors of colon cancer have an increased risk of getting cancer of the small intestine. This could be due to shared risk factors.

## Crohns disease

Crohns disease is a condition in which the immune system attacks the gastrointestinal (GI) tract. This disease can affect any part of the GI tract, but it most often affects the lower part of the small intestine. People with this condition have a risk of small bowel adenocarcinoma that is much higher than normal. These cancers are most often seen in the ileum.

## Diet

One study has shown that a diet high in fiber may help lower the risk of small intestine cancer.

## Inherited causes

People with certain inherited conditions have a higher risk of small intestine adenocarcinoma.

### **Familial adenomatous polyposis (FAP)**

In this condition, many (even hundreds) of polyps develop in the colon and rectum. If the colon isn't removed, one or more of these polyps will become cancerous. Polyps in the stomach and the small intestine are also part of this syndrome, and they can lead to cancers in these areas. In FAP, most small intestine cancers are found in the duodenum. This condition is caused by an abnormal change (mutation) of the gene *APC* and is discussed more in our document called *Colorectal Cancer*.

### **Hereditary nonpolyposis colorectal cancer (HNPCC)**

Another name for HNPCC is *Lynch syndrome*. In most cases, this disorder is caused by a defect in either the gene *MLH1* or the gene *MSH2*, but at least 5 other genes can cause HNPCC: *MLH3*, *MSH6*, *TGBR2*, *PMS1*, and *PMS2*. An abnormal copy of any one of these genes reduces the body's ability to repair damage to its DNA. This results in an increased risk for cancer of the colon and small intestine, as well as a high risk of endometrial and ovarian cancer. People with this syndrome have up to a 4% chance of

developing small intestine cancer. This condition is also discussed in our document called *Colorectal Cancer*.

### **Peutz-Jeghers syndrome (PJS)**

People with this condition develop polyps in the stomach and intestines, as well as in other areas including the nose, the airways of the lungs, and the bladder. The polyps in the stomach and intestines are a special type called *hamartomas*. They can cause problems like bleeding or blockage of the intestines. People with PJS can also have dark freckle-like spots on the lips, inner cheeks and other areas. PJS can increase the risk of many types of cancer, including small intestine adenocarcinoma. This syndrome is caused by mutations in the gene *STK1*.

### **MUTYH-associated polyposis**

People with this syndrome develop colon polyps which will become cancerous if the colon is not removed. They also can get polyps in the small intestine and have an increased risk of small intestine cancer. Other cancers that can occur in people with this syndrome include cancers of the skin, ovary, and bladder. This syndrome is caused by mutations in the gene *MUTYH*.

### **Cystic fibrosis (CF)**

People with this condition have severe lung problems. Often, in someone with CF, the pancreas cannot make the enzymes that break food down so that it can be absorbed. People with CF have an increased risk of adenocarcinoma of the ileum. The gene that causes CF is called *CFTR*. A child must have 2 abnormal copies of this gene (one from each parent) to get this disease.

## **Do we know what causes small intestine adenocarcinoma?**

Very little is known about the causes of small intestine adenocarcinoma. In fact, many experts wonder why it's so rare. The small intestine is the longest structure in the gastrointestinal tract, yet it has only 2% or less of the adenocarcinomas.

Scientists have recognized some DNA changes in the small intestine adenocarcinoma cells that are probably responsible for their increased growth and abnormal spread. Many of these tumors show specific genetic abnormalities. But what causes these changes is not yet known.

One cause of these cancers is thought to be problems repairing DNA, the large molecule that contains our genetic material. Certain genes control substances called *enzymes* that are responsible for repairing DNA when it makes mistakes when reproducing itself. Some have compared this to a spell checker on a computer. Without these spell checker

enzymes, mistakes are not corrected and genetic mutations or changes are allowed to persist. These changes may produce abnormal substances that lead to cancer formation.

A second theory is that mutations take place naturally with aging and that some of these will lead to cancer formation.

## **Can small intestine adenocarcinoma be prevented?**

At this time, there is no known way to prevent most cases of small intestine adenocarcinoma. Since smoking may increase the risk of this cancer, not starting or quitting smoking may reduce the risk for this disease.

People with familial adenomatous polyposis (FAP) can have a very high risk of duodenal cancer. Doctors may suggest that these patients have surgery to remove the duodenum before cancer can develop. The procedure most often used is called a *pancreaticoduodenectomy*, a major operation that removes the duodenum, part of the pancreas, the gallbladder, the common bile duct, and part of the stomach. This surgery is most often done in patients with FAP who have many polyps in the duodenum and so are at a high risk of getting duodenal cancer. This procedure is discussed in more detail in the “Surgery for small intestine adenocarcinoma” section of this document.

## **Can small intestine adenocarcinoma be found early?**

If a person is predisposed genetically to develop small intestine adenocarcinoma, tests such as endoscopy can be done to find it early. These tests are discussed in detail in the next section. If someone with a genetic predisposition has symptoms of small intestinal adenocarcinoma (see the next section), they should be tested immediately.

## **Signs and symptoms of small intestine adenocarcinoma**

The symptoms of small bowel tumors are often vague. In one study, it took more than 6 months from the time of the first symptom until the diagnosis was made. The most common symptoms are:

- Pain in the belly (abdomen)
- Weight loss (without trying)
- Weakness and fatigue
- Low red blood cell counts (anemia)

Often, the first symptom is pain in the stomach area. This pain may start or get worse after you eat. As the tumor gets larger, it can start to block the passage of digested food. This can lead to increased pain – it may be more intense and last longer. The tumor can cause a condition called *obstruction*. When this happens, the intestine is completely blocked and nothing can move through. This leads to pain with severe nausea and vomiting.

Rarely, a cancer will cause a hole to form in the wall of the intestine (*perforation*). This hole lets the contents of the intestine spill into the abdominal cavity. Symptoms of perforation include sudden severe pain, nausea, and vomiting.

Sometimes a tumor will start bleeding into the intestine. If the bleeding is slow, it could lead to a low red blood cell count (anemia) over time. Symptoms of anemia include weakness and fatigue. If the bleeding is rapid, the stool can become black and tarry from digested blood and the patient may feel lightheaded or even pass out.

These problems are more often caused by things other than cancer. Still, you should have them checked by your doctor to find the cause.

## How is small intestine adenocarcinoma diagnosed?

If there is a reason to suspect you have a small intestinal cancer, the doctor will use one or more methods to find out if the disease is really present.

### Medical history and physical exam

When a doctor takes your medical history, you will be asked questions about your symptoms and risk factors. The doctor will specifically ask about symptoms that could be caused by a mass in the intestines and examine you, concentrating on your abdomen looking for any swelling or sounds of the bowel trying to overcome a blockage.

### Blood tests

If your doctor suspects an intestine cancer, he or she will likely order some blood tests, such as:

- A complete blood count (CBC), which measures red blood cells, white blood cells, and platelets. Small intestine cancer often causes a low red blood cell count (anemia)
- Blood chemistry tests to look for signs that a cancer has spread to the liver



## Imaging tests

### Barium x-rays

For these studies, a liquid containing barium (also called a *contrast liquid*) is swallowed to coat the lining of an area in the intestines or stomach, and then x-rays are taken. The barium helps outline abnormalities in the esophagus, stomach, and intestines, making them more visible. These x-rays are most often used to look at the upper or lower parts of the digestive system, and can help find tumors there. They are least helpful in finding small intestine tumors. Barium studies were used more often before endoscopy was available.

- **Upper GI series:** This test is a way to look at the upper part of the digestive tract. The patient drinks a white, chalky solution containing barium and then x-rays are taken. The barium coats the surface of the esophagus, stomach, and first part of the small intestine so that abnormalities show up on x-ray. To look for problems in the rest of the small intestine, more x-rays can be taken over the next few hours as the barium passes through the intestines. This is called a *small bowel follow-through*. This test often gives good pictures of the first part of the small intestine (the duodenum), but the rest of the small intestine may be hard to see in detail.
- **Enteroclysis:** This procedure gives more detailed pictures of the small intestine than the upper GI with small bowel follow-through. A tube is passed from the nose or mouth through the stomach and into the small intestine. Then, barium is sent through the tube directly into the small intestine. X-rays are taken as the contrast moves through the small intestine.
- **Barium enema:** This is a way to look at the large intestine. Before this test, the bowel needs to be cleaned out. This is done by using strong laxatives and enemas the night before and the morning of the exam. For this test, the barium solution is given into the large intestine through the anus (like an enema). For better pictures, air can be injected into the intestine through a tube. This is called *air contrast*. This procedure is meant to be used to look at the large intestine, but sometimes the last part of the small intestine can be seen as well.

### Computed tomography

A computed tomography (CT or CAT) scan is an x-ray procedure that makes detailed cross-sectional images of your body. Instead of taking one picture, like a conventional x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these pictures into an image of a slice of your body. The machine takes pictures of multiple slices of the part of your body that is being studied.

A CT scanner has been described as a large donut, with a narrow table in the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

CT scans are often used in people with abdominal pain to try to find the source of the problem. Although small intestine tumors may not be seen well by CT, these scans are good at showing some of the problems that these tumors can cause (like obstruction or perforation). CT scans can also help find areas of cancer spread.

Before the test, you may be asked to drink 1 or 2 pints of a contrast liquid. This helps outline the intestine so that certain areas will not be mistaken for tumors. You may also get an IV (intravenous) line through which a different kind of contrast dye is injected. This helps better outline structures in your body.

The injection can cause some flushing (redness and warm feeling that may last hours to days). A few people are allergic to the dye and get hives. Rarely, more serious reactions like trouble breathing and low blood pressure can occur. Medicine can be given to prevent and treat allergic reactions. Be sure to tell the doctor if you are allergic to shellfish or have ever reacted to any contrast material used for x-rays.

CT scans can also be used to guide a biopsy needle precisely into an abnormal area that could be cancer spread. For this procedure, called a *CT-guided needle biopsy*, the patient remains on the CT scanning table, while a radiologist moves a biopsy needle toward the location of the mass/tumor. CT scans are repeated until the doctors are confident that the needle is within the mass. A *fine-needle biopsy* sample (tiny fragment of tissue) or a *core-needle biopsy* sample (a thin cylinder of tissue about ½-inch long and less than 1/8-inch in diameter) is removed and looked at under a microscope.

## Endoscopy

### Upper endoscopy

Upper endoscopy (also called *esophagogastroduodenoscopy* or *EGD*) is used to look at the esophagus, stomach and duodenum (the first part of the small intestine). This test uses an endoscope – a flexible lighted tube with a video camera on the end. The endoscope goes in through the mouth, and then passes through the throat and the esophagus into the stomach and then into the first part of the small intestine. This allows the doctor to see clearly any masses in the lining of the digestive organs. If abnormalities are found, small pieces of tissue can be removed through the endoscope (biopsy) and looked at under a microscope to see if cancer is present.

Most patients having this test are given medicine to make them sleepy. If this is the case, they will need someone to take them home (not just a cab).

This test is helpful in looking at the first part of the small intestine. Other tests, such as capsule endoscopy and double-balloon enteroscopy, are needed to look at the rest of the small intestine.

## Capsule endoscopy

This procedure does not actually use an endoscope. Instead, the patient swallows a capsule (about the size of a large vitamin pill) that has a light and a very small camera. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels through the small intestine (usually over a period of about 8 hours), it takes thousands of pictures. The camera sends the images to a device the person wears around the waist while going on with normal daily activities. The pictures can then be downloaded onto a computer, where the doctor can look at them as a video. The capsule passes out of the body during a normal bowel movement and is flushed away.

## Double-balloon enteroscopy (endoscopy)

Regular upper endoscopy cannot look very far into the small intestine because it is too long (20 feet) and has too many curves. This method gets around these problems by using a special endoscope that is made up of 2 tubes, one inside the other. The procedure can start like a regular upper endoscopy, with the endoscope going in through the mouth, down the throat and esophagus, and through the stomach into the small intestine. Then the inner tube, which is an endoscope, goes forward a small distance, and then a balloon at its end is inflated to anchor it. Then the outer tube goes forward to near the end of the inner tube and it is then anchored in place with a balloon. This process is repeated over and over, letting the doctor see the intestine a foot at a time. An advantage of this over capsule endoscopy is that the doctor will be able to biopsy anything abnormal.

Another way of doing this is to go through the colon to get to the small intestine, so that it starts out like a regular colonoscopy. If that is done, the patient has to clean out the colon the night before the procedure. This is most often done by drinking a large amount (2 to 4 quarts) of a liquid laxative solution, which results in spending much of the evening in the bathroom.

Using either approach, this procedure is done after the patient is given drugs to make him or her sleepy (sedation) or even asleep (general anesthesia), so he or she will need someone to take them home (not just a cab).

## Biopsy

Procedures such as endoscopy and imaging tests can find areas that look like cancer, but the only way to know for certain is to do a *biopsy*. In a biopsy, a piece of the abnormal area is removed and examined under a microscope.

There are several ways to take a sample of an intestinal tumor. One way is through the endoscope. When a tumor is found, the doctor can use biopsy forceps (pincers or tongs) through the tube to take a small sample of the tumor. The specimen the doctor takes will be very small, but doctors can usually make an accurate diagnosis. Bleeding after a biopsy is a rare but potentially serious problem. If bleeding becomes a problem, doctors can sometimes inject drugs that constrict blood vessels through the endoscope into the tumor to stop the bleeding.

In some patients, surgery is needed to biopsy a tumor in the intestines. This may be done if the tumor cannot be reached with an endoscope.

Sometimes CT scans or other imaging tests are used to guide a needle to biopsy tumors in other organs (like the liver) to see if they are cancer.

## How is small intestine adenocarcinoma staged?

Staging is a process that tells the doctor how widespread your cancer may be when you are first diagnosed. It will show if the cancer has spread and how far. The treatment and outlook for small intestine cancer depends, to a large extent, on its stage. For early stage cancer, surgery may be all that is needed. For more advanced cancer, other treatments, such as chemotherapy or radiation therapy, may be required. Please be sure to ask your doctor to explain your cancer's stage so you can make the best choice about your treatment.

The staging system used is that of the American Joint Committee on Cancer (AJCC). It is also called the TNM system. Stages are described using the number 0 (zero) and the Roman numerals I through IV.

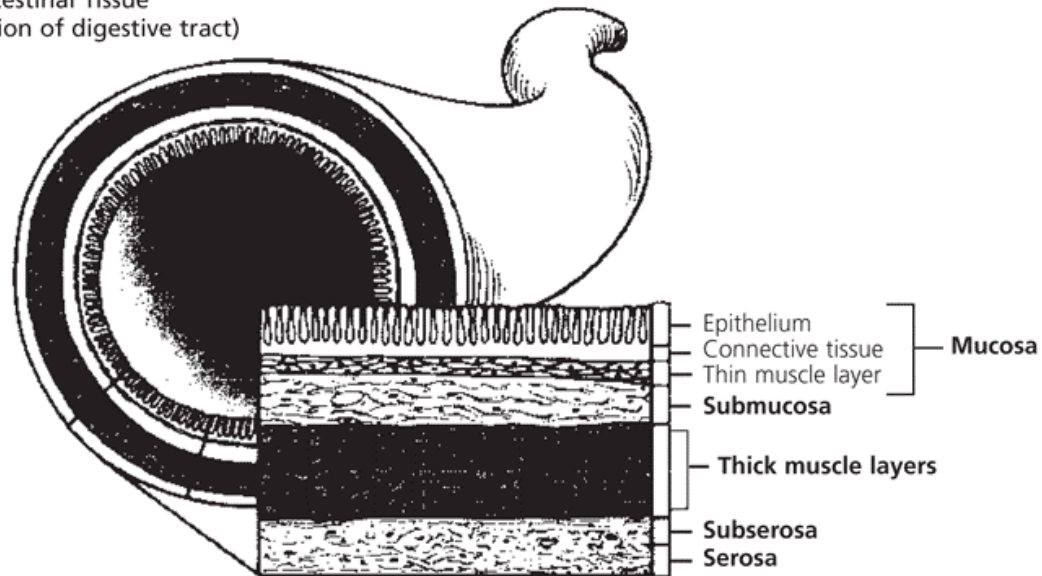
This staging system describes the spread of the cancer in relation to the layers of the wall of the small intestine. Because for most patients, this stage is unknown until after surgery, most doctors wait until then to decide on the cancer's stage. The stages described below are called *pathologic stages*. The pathologic stage is determined by the findings of the pathologist from looking at the cancer and other actual tissue that has been removed.

The AJCC/TNM System describes the extent of the primary tumor (T), the absence or presence of metastasis to nearby lymph nodes (N), and the absence or presence of distant metastasis (M).

### T categories for small intestine adenocarcinoma

T categories of small intestine cancer describe the extent of spread through the layers that form its wall.

Normal Intestinal Tissue  
(Cross section of digestive tract)



These layers, from the inner to the outer, include the lining (*mucosa*), the fibrous tissue beneath this muscle layer (*submucosa*), a thick layer of muscle that contracts to force the contents of the intestines along (*muscularis propria*), and the thin outermost layers of connective tissue (*subserosa* and *serosa*) that cover the small intestine. The serosa is also known as the *visceral peritoneum*.

**Tx:** No description of the tumor's spread is possible because of incomplete information.

**Tis:** The cancer is only in the epithelium (the top layer of cells of the mucosa) – it has not grown into the deeper tissue layers. This is the earliest stage and is also known as *carcinoma in situ* (CIS).

**T1:** Is split into 2 groups

- **T1a:** The cancer has grown from the top layer of cells of the mucosa and into the layer of connective tissue below (the lamina propria).
- **T1b:** The cancer has grown through the mucosa and into the submucosa

**T2:** The cancer has grown through the mucosa and submucosa into the muscularis propria.

**T3:** The cancer has grown through the inner layers of the intestine wall (mucosa, submucosa, and muscularis propria) into the subserosa. It has not started to grow into any nearby organs or tissues.

**T4:** The cancer has grown through the entire wall of the small intestine (including the serosa). It may be growing into nearby tissues or organs.

## N categories for small intestine adenocarcinoma

N categories indicate whether or not the cancer has spread to nearby lymph nodes.

**Nx:** No information about lymph node involvement is available (often because no lymph nodes have been removed).

**N0:** Lymph nodes near the tumor were checked and do not contain cancer.

**N1:** Cancer cells found in 1 to 3 nearby lymph nodes.

**N2:** Cancer cells are found in 4 or more nearby lymph nodes

## M categories for small intestine adenocarcinoma

**M** categories indicate whether or not the cancer has spread to distant organs, such as the liver, lungs, or distant lymph nodes.

**M0:** No cancer has been found in other organs or tissues.

**M1:** Cancer has been found in other organs or tissues.

## Stage grouping

The T, N, and M categories are combined (in a process called *stage grouping*) to determine the stage. The stage is expressed in Roman numerals from stage I (the least advanced stage) to stage IV (the most advanced stage). The following guide illustrates how TNM categories are grouped together into stages:

### **Stage 0: Tis, N0, M0**

The cancer is in the earliest stage. It has not grown beyond the top layer of cells of the mucosa of the small intestine. This stage is also known as *carcinoma in situ*.

### **Stage I: T1 or T2, N0, M0**

The cancer has grown from the top layer of cells of the mucosa and into deeper layers such as the lamina propria (T1a), the submucosa (T1b), *or* the muscularis propria (T2). It has not spread into nearby lymph nodes (N0) or distant sites (M0).

### **Stage IIA: T3 or T4, N0, M0**

The cancer has grown through most of the wall of the small intestine and into the subserosa (T3 or T4). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).

### **Stage IIB: T4, N0, M0**

The cancer has grown through the wall of the intestine and into the serosa or into nearby tissues or organs (T4). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).

### **Stage IIIA: Any T, N1, M0**

The cancer has spread to 1 to 3 nearby lymph nodes (N1) but not to distant sites (M0).

### **Stage IIIB: Any T, N2, M0**

The cancer has spread to 4 or more nearby lymph nodes (N2) but not to distant sites (M0).

### **Stage IV: Any T, Any N, M1**

The cancer has spread to distant sites such as the liver, lung, peritoneum (the membrane lining the abdominal cavity), or ovary.

## **Survival rates of small intestine adenocarcinoma, by stage**

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some patients with cancer may want to know the survival statistics for people in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you decide that you don't want to read them, skip to the next section.

The 5-year survival rate is the percentage of patients who live at least 5 years after their cancer is diagnosed. Of course, many people live much longer than 5 years (and many are cured). Also, people with small intestine cancer can die of other things. The numbers below, known as observed survival, don't take that into account.

In order to get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Improvements in treatment since then may result in a more favorable outlook for people being diagnosed with small intestine cancer now.

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they cannot predict what will happen in any particular person's case. Many other factors may affect a person's outlook, such as their age, general health, the grade of the cancer, and how well the cancer responds to treatment. Your doctor can tell you how the numbers below may apply to your particular situation.

The numbers below were published in 2010 in the 7<sup>th</sup> edition of the AJCC Staging Manual. They come from the National Cancer Data Base, and are based on people diagnosed with small intestine adenocarcinoma between 1998 and 2002.

<b>Stage</b>	<b>5-year observed survival</b>
Stage I	55%

Stage IIA	49%
Stage IIB	35%
Stage IIIA	31%
Stage IIIB	18%
Stage IV	5%

## How is small intestine adenocarcinoma treated?

*This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.*

*The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.*

*Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.*

### General treatment information

Depending on the type and stage of your cancer, you may need more than one type of treatment. Doctors on your cancer treatment team may include:

- A surgeon: a doctor who uses surgery to treat cancers or other problems
- A surgical oncologist: a doctor who treats cancer with surgery
- A radiation oncologist: a doctor who uses radiation to treat cancer
- A medical oncologist: a doctor who uses chemotherapy and other medicines to treat cancer
- A gastroenterologist: a doctor that specializes in diseases and problems of the digestive tract

Many other specialists may be involved in your care as well, including nurse practitioners, nurses, psychologists, social workers, rehabilitation specialists, and other health professionals.

After the small intestine cancer is found and staged, the cancer care team will suggest one or more treatment plans. Choosing a treatment plan is an important decision. It is also important for you to take time and think about all of your choices.



The main types of treatment used for small intestine adenocarcinoma are:

- Surgery
- Chemotherapy
- Radiation therapy

The main factors in selecting treatment options for small intestine adenocarcinoma are the size and location of the tumor, whether it has spread to lymph nodes, liver, bones, or other organs, whether there are any other serious medical conditions, and whether the tumor is causing bothersome symptoms. It's often a good idea to get a second opinion. A second opinion may give you more information and help you feel more confident about the treatment plan chosen.

The next few sections describe the different types of treatment for small intestine adenocarcinoma. This is followed by a discussion of the most common treatment options based on the extent of the cancer.

## Surgery for small intestine adenocarcinoma

Surgery is the main treatment for small intestine cancer and it's often the only treatment. At this time, surgery is the only treatment that can cure a cancer of the small intestine. The type of operation will depend on a number of factors, including the size and location of the tumor, and whether the patient has any serious diseases of other organs.

### **Resection**

Usually this surgery is done through a cut made in the abdomen. This operation removes the piece of intestine that has the tumor and some of the normal tissue on either side of the tumor. The 2 cut ends of intestine are then sewn back together. Some nearby tissue containing lymph nodes will also be removed. After surgery, it can take a few days before the patient can eat and drink normally. Removing a small piece of intestine usually doesn't cause long-term problems with eating or bowel movements.

### **Pancreaticoduodenectomy (Whipple procedure)**

This operation is used to treat cancers of the duodenum, although it is more often used to treat pancreatic cancer. It removes the duodenum, part of the pancreas, nearby lymph nodes and part of the stomach. The gallbladder and part of the common bile duct are removed and the remaining bile duct is attached to the small intestine so that bile from the liver can continue to enter the small intestine.

This is a complex operation that requires a lot of skill and experience. It carries a relatively high risk of complications that could even be fatal. When the operation is done in small hospitals or by doctors with less experience, more than 15% of patients may die as a result of surgical complications. In contrast, when this operation is done in cancer centers by surgeons experienced in the procedure, less than 5% of patients die as a direct

result of complications from surgery. In general, people having this type of surgery do better when it is done at a hospital that does at least 20 of these procedures a year. Still, even in the best hands, many patients suffer complications from the surgery. These can include:

- Leaking from the various connections that the surgeon has to make
- Infections
- Bleeding
- Trouble with the stomach emptying itself after eating

Most, if not all, patients who have this surgery lose a lot of weight.

### **Palliative surgery**

If the cancer cannot be completely removed because it has spread too far in the abdomen, the surgeon may do an operation to help improve some of the symptoms that the cancer is causing. This is known as *palliative surgery*. Often, these operations are done to relieve a blocked intestine, to decrease pain, nausea, and vomiting, and allow the patient to eat normally for some time. If possible, the surgeon will remove enough of the tumor and nearby intestine to allow digested food to pass through.

Sometimes, the surgeon will leave the tumor in place and route the normal small intestine around the tumor so that any blockage is relieved or prevented.

In very advanced situations, a fairly rigid tube (called a *stent*) is passed through the blocked area and left in place so digested food can pass. If this can't be done, a tube may be placed in the stomach to drain it and decrease problems with nausea and vomiting.

For more general information about surgery, please see our document called *A Guide to Cancer Surgery*.

### **Chemotherapy for small intestine adenocarcinoma**

Chemotherapy (chemo) uses anti-cancer drugs that are injected into a vein or a muscle or taken by mouth to kill cancer cells. Because these drugs enter the bloodstream and can reach cancer cells anywhere in the body, this treatment can be useful for cancers that have metastasized (spread). But small intestine adenocarcinoma does not seem to be very sensitive to chemotherapy. This is why chemo is not often part of the main treatment for this cancer. Instead, it may be used when the cancer has spread to other organs.

When chemo is given after the tumor is removed with surgery, it's called *adjuvant* treatment. In this setting, the chemo is meant to get rid of the cancer cells that are left after surgery (but that are too small to see). This lowers the chance that the cancer will come back later. Adjuvant chemo is often used for colon cancer, but it is not known if it works as well for small intestine cancer.

Some of the chemo drugs that can be used include:

- Capecitabine (Xeloda<sup>®</sup>)
- 5-fluorouracil (5-FU)
- Oxaliplatin
- Irinotecan (Camptosar<sup>®</sup>, CPT-11)

5-FU is often given with a vitamin-like drug called leucovorin, which helps it work better.

Because small intestine cancer is rare, only a small number of patients have been treated with chemo. This makes it hard to know which drugs work best. Some of the drug combinations that seem to work in advanced small intestine cancer include

- Capecitabine and oxaliplatin (called CAPOX)
- 5-FU and leucovorin with oxaliplatin (FOLFOX)
- 5-FU and leucovorin with irinotecan (FOLFIRI).

Oncologists often use combinations that are used to treat colon or stomach cancer.

## **Side effects**

Chemo drugs kill cancer cells but also damage some normal cells, causing some side effects. Your health care team will pay careful attention to try and avoid or lessen side effects. These depend on the type of drugs, amount taken, and length of treatment. Common temporary side effects might include

- Nausea and vomiting
- Loss of appetite
- Loss of hair
- Mouth sores.
- Diarrhea

Chemotherapy can also damage the blood-producing cells of the bone marrow, so you may have low blood cell counts. This can lead to:

- An increased risk of infection (caused by a shortage of white blood cells)
- Bleeding or bruising after minor cuts or injuries (caused by a shortage of blood platelets)
- Fatigue (tiredness) or shortness of breath (caused by low red blood cell counts)

Along with these, some other side effects can be seen with certain medicines, for example:

**Hand-foot syndrome** can occur during treatment with capecitabine or 5-FU (when given as an infusion). This starts out as redness in the hands and feet, which can then progress to pain and sensitivity in the palms and soles. If it worsens, blistering or skin peeling can occur, sometimes leading to open, painful sores. There is no specific treatment, although some creams may help. These symptoms gradually get better when the drug is stopped or the dose is decreased. The best way to prevent severe hand-foot syndrome is to tell your doctor when symptoms first come up, so that the drug dose can be changed.

**Neuropathy** (painful nerve damage) is a common side effect of oxaliplatin. Symptoms include numbness, tingling, and even pain in the hands and feet. It can also cause patients to have intense sensitivity to hot and cold in the throat and esophagus (the tube connecting the throat to the stomach). This can cause problems (such as pain) swallowing liquids. If you will be getting oxaliplatin, ask your doctor about side effects beforehand, and let him or her know right away if you develop numbness and tingling or other side effects. More information about neuropathy can be found in our document *Peripheral Neuropathy Caused by Chemotherapy*.

**Diarrhea** is a common side effect with many of these drugs, but can be particularly bad with irinotecan. It needs to be treated right away – at the first loose stool – to prevent severe dehydration. This often means taking drugs like loperamide (Imodium<sup>®</sup>). If you are on a chemo drug that is likely to cause diarrhea, your doctor will give you instructions on what drugs to take and how often to take them to control this symptom.

Most side effects are short-term and tend to go away after treatment is finished. Some, such as hand and foot numbness, may persist for a long-time. There are often ways to lessen these side effects. For example, drugs can be given to help prevent or reduce nausea and vomiting. Do not hesitate to discuss any questions about side effects with the cancer care team.

You should report any side effects or changes you notice while getting chemo to your medical team so that they can be treated promptly. In some cases, the doses of the chemo drugs may need to be reduced or treatment may need to be delayed or stopped to prevent the effects from getting worse.

If you'd like more information on a drug used in your treatment or a specific drug mentioned in this section, see our Guide to Cancer Drugs , or call us with the names of the medicines you're taking.

For more information about chemo and its side effects, see our document *A Guide to Chemotherapy*.

## Radiation therapy for small intestine adenocarcinoma

Radiation therapy uses high-energy radiation to kill cancer cells. Radiation therapy may be an option for those whose cancer cannot be removed with surgery and is causing symptoms – for example if a particular spot is painful because of the cancer.

*External-beam radiation therapy* is the type of radiation used most often for most types of gastrointestinal cancer. It is like having a regular x-ray except it takes longer and uses much higher amounts of radiation. Patients typically have treatments 5 days a week for several weeks. Radiation therapy is used primarily to treat pain from cancer that has spread to the bones or other parts of the body.

The main side effects of radiation therapy to the stomach and intestines include

- Fatigue (tiredness)
- Nausea and vomiting
- Diarrhea
- Skin changes in the area where the radiation beams passed through, which range from mild redness to blistering and peeling

More information about radiation therapy can be found in our document *Understanding Radiation Therapy: A Guide for Patients and Families*.

## Clinical trials for small intestine adenocarcinoma

You may have had to make a lot of decisions since you've been told you have cancer. One of the most important decisions you will make is choosing which treatment is best for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your medical needs. You can reach this service at 1-800-303-5691 or on our website at [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials). You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials website at [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials).

You must meet requirements to take part in any clinical trial. If you do qualify for a clinical trial, you decide whether or not to enter (enroll) in it.

Clinical trials are one way to get state-of-the-art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

You can get a lot more information on clinical trials in our document called *Clinical Trials: What You Need to Know*. You can read it on our website or call us to have it sent to you.

# Complementary and alternative therapies for small intestine adenocarcinoma

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to Internet groups and websites might offer ideas for what could help you. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

## What exactly are complementary and alternative therapies?

Not everyone uses these terms the same way, and they are used to refer to many different methods, so it can be confusing. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

**Complementary methods:** Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help you feel better. Some methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few have even been found harmful.

**Alternative treatments:** Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may pose danger, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

## Finding out more

It's easy to see why people with cancer think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most of these alternative methods have not been tested and proven to work in treating cancer.

As you consider your options, here are 3 important steps you can take:

- Look for “red flags” that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a “secret” that requires you to visit certain providers or travel to another country?
- Talk to your doctor or nurse about any method you are thinking about using.
- Contact us at 1-800-227-2345 to learn more about complementary and alternative methods in general and to find out about the specific methods you are looking at. You

can also check them out on the *Complementary and Alternative Medicine* page of our website.

## **The choice is yours**

Decisions about how to treat or manage your cancer are always yours to make. If you want to use a non-standard treatment, learn all you can about the method and talk to your doctor about it. With good information and the support of your health care team, you may be able to safely use the methods that can help you while avoiding those that could be harmful.

## **Treatment choices for small intestine adenocarcinoma, based on tumor spread**

How your small intestine cancer is treated depends mainly on whether or not the cancer can be removed completely with surgery. Cancers that can be removed completely are called *resectable*, while those that cannot are called *unresectable*.

### **Resectable cancers**

Resectable cancers are treated with surgery to remove the cancer and some healthy surrounding tissue. If the cancer is in the first part of the small intestine, a Whipple procedure (or pancreaticoduodenectomy) is done. If the cancer is in another part of the small intestine, a resection is done.

If the cancer had grown through the wall of the intestine or spread to nearby lymph nodes, the doctor may recommend chemotherapy or radiation therapy to try to kill any cancer cells that may have been left behind but were too small to see. The hope is that this treatment will help keep the cancer from coming back (recurrence). This works for colon cancer, but has not yet been shown to help patients with small intestine cancer live longer.

### **Unresectable cancers**

A small intestine cancer may be unresectable if it has grown into nearby tissues or if it has spread to other organs and tissues. Sometimes patients with unresectable cancers still have surgery to treat blocked intestines. This can improve symptoms like nausea, vomiting, and abdominal pain.

Otherwise, these patients are treated with chemotherapy. Radiation therapy can be used to treat cancer that has spread to the brain or bones (especially the spine). Because there is no generally accepted standard treatment for these advanced cancers, taking part in a clinical trial is also a good option.

## More treatment information for small intestine adenocarcinoma

For more details on treatment options – including some that are not addressed in this document – the National Comprehensive Cancer Network (NCCN) and the National Cancer Institute (NCI) are good sources of information.

The NCI provides treatment guidelines via its telephone information center (1-800-4-CANCER) and its website ([www.cancer.gov](http://www.cancer.gov)). Detailed guidelines intended for use by cancer care professionals are also available on this website.

## What should you ask your doctor about small intestine adenocarcinoma?

It's important to have honest, open discussions with your cancer care team. They want to answer all of your questions, no matter how trivial you might think they are. For instance, consider these questions:

- What is the stage of my cancer and what does that mean for me?
- Will I need other tests before we consider treatment options?
- How much experience do you have treating this type of cancer?
- What are my treatment choices?
- What do you recommend and why?
- What is the goal of the treatment?
- Based on what you've learned about my cancer, what is my prognosis?
- What risks or side effects are there to the treatments you suggest?
- How will treatment affect my daily activities?
- What are the chances my cancer will come back with these treatment plans?
- What should I do to be ready for treatment?
- What type of follow-up might I need after treatment?

Along with these sample questions, you might write down some of your own. For instance, you might want more information about recovery time so you can plan your work schedule. Or you might want to ask about second opinions or clinical trials.



# What happens after treatment for small intestine adenocarcinoma?

For some people with small intestine cancer, treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. When cancer comes back after treatment, it is called *recurrence*. This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to live with this uncertainty and are leading full lives. Our document called *Living with Uncertainty: The Fear of Cancer Recurrence* gives more detailed information on this. You can read it online, or we can send a free copy to you.

For other people, the cancer may never go away completely. They may get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful. It has its own type of uncertainty. Our document called *When Cancer Doesn't Go Away* talks more about this.

## Follow-up care

When treatment ends, your doctors will still want to watch you closely. It's very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you may have and may do exams and lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

It is important to keep your health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Should your cancer return, our document called *When Your Cancer Comes Back: Cancer Recurrence* can give you information on how to manage and cope with this phase of your treatment.

## Seeing a new doctor

At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It's important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have the following information handy:

- A copy of your pathology report(s) from any biopsies or surgeries

- If you had surgery, a copy of your operative report(s)
- If you were in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home
- If you had radiation, a copy of the treatment summary
- Copies of any x-rays or other imaging studies (these can be put on a DVD)
- If you had chemotherapy, a list of your drugs, drug doses, and when you took them

The doctor may want copies of this information for his records, but always keep copies for yourself.

## Lifestyle changes after having small intestine adenocarcinoma

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society for information and support. This tobacco cessation and coaching service can help increase your chances of quitting for good.

### **Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

Our document, *Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families* has more of our nutrition information.

## **Rest, fatigue, and exercise**

Extreme tiredness, called *fatigue*, is very common in people treated for cancer. This is not a normal tiredness, but a “bone-weary” exhaustion that doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. A person who has never exercised will not be able to take on the same amount of exercise as someone who plays tennis twice a week. If you haven’t exercised in a few years, you will have to start slowly – maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. It’s OK to rest when you need to. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. For more information on dealing with fatigue see *Fatigue in People With Cancer* and *Anemia in People With Cancer*.

Keep in mind exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

## How does having small intestine adenocarcinoma affect your emotional health?

When treatment ends, you may find yourself overcome with many different emotions. This happens to a lot of people. You may have been going through so much during treatment that you could only focus on getting through each day. Now it may feel like a lot of other issues are catching up with you.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, as you feel better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It isn't necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren't sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

## If treatment for small intestine adenocarcinoma stops working

If cancer keeps growing or comes back after one kind of treatment, it is possible that another treatment plan might still cure the cancer, or at least shrink it enough to help you live longer and feel better. But when a person has tried many different treatments and the cancer has not gotten any better, the cancer tends to become resistant to all treatment. If this happens, it's important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer – when you have been through many medical treatments and nothing's working anymore. Your doctor may offer you new options, but at some point you might need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and

side effects. In many cases, your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more chemo or radiation might have about a 1% chance of working. Some people are still tempted to try this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called *palliative care* or *supportive care*.

## Palliative care

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose - the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

## Hospice care

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more about hospice in our documents called *Hospice Care* and *Nearing the End of Life*. They can be read online, or call us to have free copies mailed to you.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends – times that are filled with happiness and meaning. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

# What's new in small intestine adenocarcinoma research and treatment?

There is always research going on in the field of gastrointestinal (GI) cancer. Scientists look for the causes of these cancers, as well as ways to prevent, and treat GI cancers. Small intestine adenocarcinoma is studied less often than some of the other GI cancers because it is so rare. Still, some recent studies have looked at the best way to treat this cancer with chemotherapy. Other studies are looking to see if drugs known as targeted therapy drugs could be helpful. One drug being studied in small intestine cancer, bevacizumab (Avastin<sup>®</sup>), is already used to treat colon cancer.

Also, studies of patients with colon cancer other GI cancers may prove useful for people with small intestine adenocarcinoma. These studies involve early detection, drug treatment, surgical methods, and understanding the cause of these cancers.

Most small intestine cancers look very similar to colon cancers under a microscope, but detailed studies of the chromosomes and DNA in their cancer cells have found some differences. Researchers hope that these results, as well as other research into the molecular changes in small intestine adenocarcinomas will eventually lead to more effective treatments.

## Additional resources for small intestine adenocarcinomas

### More information from your American Cancer Society

The following related information may also be helpful to you. These materials can be read on our website or ordered from our toll-free number, 1-800-227-2345.

#### **Dealing with diagnosis and treatment**

Health Professionals Associated With Cancer Care

Talking With Your Doctor (also in Spanish)

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families (also in Spanish)

A Message of Hope: Coping With Cancer in Everyday Life (also in Spanish)

#### **Family and caregiver concerns**

Talking With Friends and Relatives About Your Cancer (also in Spanish)

Helping Children When A Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

What It Takes to Be a Caregiver

### **Insurance and financial issues**

In Treatment: Financial Guidance for Cancer Survivors and Their Families (also in Spanish)

Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

### **More on cancer treatments**

A Guide to Cancer Surgery (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

Clinical Trials: What You Need to Know

### **Cancer treatment side effects**

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also in Spanish)

Distress in People With Cancer

Anxiety, Fear, and Depression

Nausea and Vomiting

Guide to Controlling Cancer Pain (also in Spanish)

Pain Diary

Peripheral Neuropathy Caused by Chemotherapy

Anemia in People With Cancer

Fatigue in People With Cancer

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at [cancer.org/bookstore](http://cancer.org/bookstore) to find out about costs or to place an order.

### **National organizations and websites\***

Along with the American Cancer Society, other sources of information and support include:

### **National Cancer Institute (NCI)**

Toll-free number: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Website: [www.cancer.gov](http://www.cancer.gov)

Their “Cancer Information Service” offers a wide variety of free, accurate, up-to-date information about cancer to patients, their families, and the general public; also can help people find clinical trials in their area.

### **National Coalition for Cancer Survivorship (NCCS)**

Toll-free number: 1-888-650-9127

Website: [www.canceradvocacy.org](http://www.canceradvocacy.org)

Has publications on many cancer-related topics; also offers the Cancer Survival Toolbox – a free program that teaches skills that can help people with cancer meet the challenges of their illness.

*\*Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us any time, day or night, for information and support. Call us at **1-800-227-2345** or visit [www.cancer.org](http://www.cancer.org).

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