Gastrointestinal Stromal Tumor (GIST)

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. They can group together to form a tumor. Cancer cells can also invade (grow into) other tissues, something that normal cells can't 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.

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 always named (and treated) based on the place it started. For example, breast cancer that has spread to the liver is still called 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 is why people with cancer need treatment that is aimed at their particular kind of cancer.

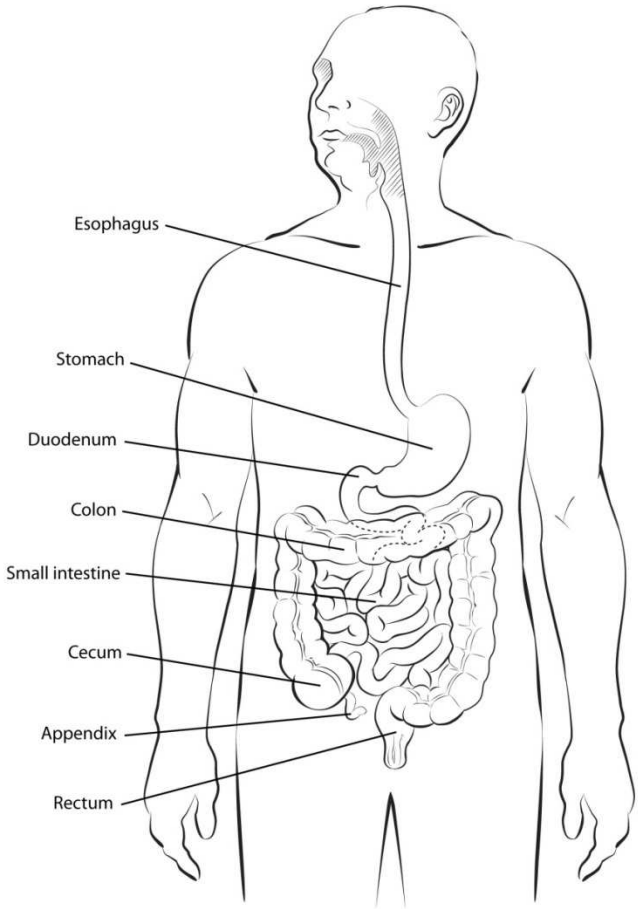
Not all tumors are cancerous. Tumors that aren't cancer are called *benign*. Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they can't grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body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

What are gastrointestinal stromal tumors?

To understand gastrointestinal stromal tumors, it helps to know something about the structure and function of the gastrointestinal system, also known as the *digestive system.*

The gastrointestinal system

The gastrointestinal (GI) system (or digestive system) processes food for energy and rids the body of solid waste. After food is chewed and swallowed, it enters the esophagus, a tube that carries food through the neck and chest to the stomach. The esophagus joins the stomach just beneath the diaphragm (the thin band of muscle below the lungs).



The stomach is a sac-like organ that holds food and helps the digestive process by secreting gastric juice. The food and gastric juices are mixed into a thick fluid called *chyme* that is then emptied into the small intestine. The small intestine continues breaking down the food and absorbs most of the nutrients into the bloodstream. This is the longest section of the GI tract, measuring more than 20 feet.

The small intestine joins the large intestine, the first part of which is the colon, a muscular tube about 5 feet long. The colon absorbs water and mineral nutrients from the remaining food matter. The waste left after this process goes into the rectum as stool (feces), where it is stored until it passes out of the body through the anus.

Gastrointestinal stromal tumors

Gastrointestinal stromal tumors (GISTs) are uncommon tumors of the GI tract. These tumors start in very early forms of special cells found in the wall of the GI tract, called the *interstitial cells of Cajal* (ICCs). ICCs are cells of the autonomic nervous system, the part of the nervous system that regulates body processes such as digesting food. ICCs are

sometimes called the “pacemakers” of the GI tract because they signal the muscles in the digestive system to contract to move food and liquid through the GI tract.

More than half of GISTs start in the stomach. Most of the others start in the small intestine, but GISTs can start anywhere along the GI tract. A small number of GISTs start outside the GI tract in nearby areas such as the omentum (an apron-like layer of fatty tissue that hangs over the organs in the abdomen) or the peritoneum (the layer of tissue that lines the organs and walls of the abdomen).

Not all GISTs are cancerous. Some are benign (not cancerous) and don’t grow into other areas or spread to other parts of the body. Doctors have ways to find out whether a GIST is benign or cancerous. These are discussed in the section, “How are gastrointestinal stromal tumors diagnosed?”

Other gastrointestinal tract cancers

It is important to understand that GISTs are not the same as other, more common types of GI tract cancers.

Cancers can occur anywhere in the GI tract − from the esophagus to the anus. Usually, these cancers start in glandular cells that line most of the GI tract. The cancers that develop in these cells are called *adenocarcinomas*. Most cancers of the GI tract, including those of the esophagus, stomach, colon, and rectum, are adenocarcinomas.

Some parts of the GI tract, like the upper part of the esophagus and the end of the anus, are lined with flat cells called *squamous cells*. These are the same type of cells found on the surface of the skin. Cancers starting in these cells are called *squamous cell carcinomas*.

The GI tract also has neuroendocrine cells. These cells have some features in common with nerve cells but other features in common with hormone-producing (endocrine) cells. Cancers that develop from these cells are called *neuroendocrine tumors*. These cancers are rare in the GI tract. Carcinoid tumors are an example of a neuroendocrine tumor found in the GI tract.

Other rare types of cancer in the GI tract include leiomyosarcomas (cancers of smooth muscle cells), angiosarcomas (cancers of blood vessel cells), and peripheral nerve sheath tumors (cancers of cells that support and protect nerves).

GISTs are different from these other GI tract cancers. They start in different types of cells, need different types of treatment, and have a different prognosis (outlook). This is why doctors need to figure out whether a person with a tumor in the GI tract has a GIST, some other type of cancer, or a non-cancerous condition.

What are the key statistics about gastrointestinal stromal tumors?

Gastrointestinal stromal tumors (GISTs) are not common, and the exact number of people diagnosed with these tumors each year is not known. Until the late 1990s, not much was known about these tumors (and doctors didn't have good ways of identifying them with lab tests), so many of them ended up being classified as other kinds of GI cancers.

Current estimates for the total number of GIST cases each year in the United States range from about 4,000 to about 5,000.

These tumors can start anywhere in the GI tract, but they occur most often in the stomach (about 60%) or the small intestine (about 30%). Most of the rest are found in the esophagus, colon, and rectum. A small number develop in the abdomen outside the GI tract.

Most people diagnosed with GIST are older than 50, but these tumors can occur in people at any age. They are slightly more common in men.

Survival statistics for GIST are discussed in the section, "Survival rates for gastrointestinal stromal tumors."

What are the risk factors for gastrointestinal stromal tumors?

A risk factor is anything that affects a person's chance of getting a disease like cancer. Different cancers have different risk factors. Some risk factors, like smoking, can be changed. Others, like a person's age or family history, can't be changed.

But risk factors don't tell us everything. Having a risk factor, or even several, does not mean that a person will get the disease. And many people who get the disease may have few or no known risk factors.

Currently, there are very few known risk factors for gastrointestinal stromal tumors (GISTs).

Being older

These tumors can occur in people of any age, but they are rare in people younger than 40 and are most common in people aged 50 to 80.

Genetic syndromes

Most GISTs are sporadic (not inherited) and have no clear cause. In rare cases, though, GISTs have been found in several members of the same family. These family members inherited a gene mutation that can lead to GISTs.

Familial gastrointestinal stromal tumor syndrome: This is a rare, inherited condition that leads to an increased risk of developing GISTs. People with this condition tend to develop GISTs at a younger age than when they usually occur. They are also more likely to have multiple GISTs.

Most often, this syndrome is caused by an abnormal *c-kit* gene passed from parent to child. The *c-kit* gene is the same gene that is mutated (changed) in most sporadic GISTs (see "Do we know what causes gastrointestinal stromal tumors?"). People who inherited this abnormal gene from a parent have it in all their cells while people with sporadic GISTs only have it in the cancer cells.

In a few cases, a change in a different gene, the *PDGFRA* gene, causes this genetic syndrome. Defects in the *PDGFRA* gene are found in about 5% to 10% of sporadic GISTs.

Sometimes people with familial GIST syndrome also have skin spots like those seen in patients with neurofibromatosis (discussed below). Before tests for the *c-kit* and *PDGFRA* genes became available, some of these people were mistakenly thought to have neurofibromatosis.

Neurofibromatosis type 1 (or von Recklinghausen disease): This disease is caused by a defect in the *NF1* gene. This gene change may be inherited from a parent, but in some cases it occurs before birth, without being inherited.

People affected by this syndrome often have many benign tumors that form in nerves (called neurofibromas), starting at an early age. These tumors form under the skin and in other parts of the body. These people also have a certain type of tan or brown spots on the skin (called *café au lait spots*).

People with this condition have a higher risk of GISTs, as well as some other types of cancer.

Carney-Stratakis syndrome: People with this rare, inherited condition have an increased risk of GISTs (most often in the stomach), as well as nerve tumors called *paragangliomas*. GISTs often develop when these people are in their teens or 20s. They are also more likely to have more than one GIST.

This syndrome is caused by a change in one of the succinate dehydrogenase (*SDH*) genes, which is passed from parent to child.

Do we know what causes gastrointestinal stromal tumors?

We do not know exactly what causes most gastrointestinal stromal tumors (GISTs). But in recent years, scientists have made great progress in learning how certain changes in DNA can cause normal cells to become cancerous. DNA is the chemical in each of our cells that makes up our *genes* – the instructions for how our cells function. We usually

look like our parents because they are the source of our DNA. But DNA affects more than just how we look.

Some genes control when cells grow and divide into new cells. Certain genes that help cells grow and divide are called *oncogenes*. Others that slow down cell division or cause cells to die at the right time are called *tumor suppressor genes*. Cancers can be caused by DNA changes that turn on oncogenes or turn off tumor suppressor genes.

A few families have gastrointestinal stromal tumors (GISTs) caused by a DNA mutation passed down from parent to child. But most DNA mutations related to GISTs are not inherited. These changes occur for no apparent reason, and are called *acquired* or *sporadic*.

The cancer cells of most patients with GIST have a change in an oncogene called *c-kit*. The *c-kit* gene is found in all cells of the body. It directs the cell to make a protein called KIT, which causes the cell to grow and divide. Usually the *c-kit* gene in interstitial cells of Cajal (ICCs) is inactive. It is only active if there is a need for more (ICCs. In most GISTs the *c-kit* gene is mutated and is always active. This may explain why the cancer forms. The cells are always growing and dividing. In some families that have many members with GISTs, doctors have found inherited mutations of the *c-kit* gene.

In about 5% to 10% of GISTs, the cancer cells have mutation in a different gene called *PDGFRA*, which causes the cell to make too much of a different protein (also called PDGFRA). This has the same effect on the cell as does KIT.

Most GISTs have changes in either the *c-kit* or the *PDGFRA* gene, but not both. A small number of GISTs do not have changes in either of these genes. Researchers are still trying to determine what gene changes lead to these cancers.

The gene changes that lead to most GISTs are now understood, but it’s still not clear what might cause these changes. There are no known lifestyle-related or environmental causes of GIST. Some might have causes that haven’t been found yet, but many of these changes may just be random events that sometimes happen inside cells that unfortunately lead to cancer.

As doctors have learned more about the gene and protein changes common in GIST cells, they have been able to use this information to help diagnose and treat these cancers. (See the section called “Targeted therapy for gastrointestinal stromal tumors.”)

Can gastrointestinal stromal tumors be prevented?

The risk of many types of cancer can be reduced with certain lifestyle changes (such as maintaining a healthy weight or quitting smoking), but the only known risk factors for gastrointestinal stromal tumors (GISTs) − age and certain rare, genetic syndromes – cannot be changed. At this time we do not know of any way to protect against these cancers.

Can gastrointestinal stromal tumors be found early?

Screening is testing for diseases like cancer in people who do not have any symptoms. Screening tests can find some types of cancer early, when treatment is most likely to be effective. But at this time, no effective screening tests have been found for rare tumors like gastrointestinal stromal tumors (GISTs), so routine testing of people without any symptoms is not recommended.

Still, some GISTs may be found early by chance. Sometimes they are seen on an exam for another problem, like during colonoscopy to look for colon cancer. Rarely, a GIST may be seen when an imaging test, like a computed tomography (CT) scan or barium study, is done for another reason. GISTs may also be found incidentally (unexpectedly) during abdominal surgery for another problem.

Signs and symptoms of gastrointestinal stromal tumors

Most gastrointestinal stromal tumors (GISTs) occur in the stomach or small intestine. These tumors might not cause any symptoms unless they are in a certain location or grow to a certain size. Small tumors might not cause any symptoms and may be found accidentally when the doctor is looking for some other problem. These tumors are often benign.

Blood loss

GISTs are often found because they cause bleeding into the gastrointestinal (GI) tract. Signs and symptoms of this bleeding depend on how fast it occurs. Brisk bleeding into the stomach or small intestines can make bowel movements black and tarry. Brisk bleeding into the stomach can also cause a person to vomit blood. When the blood is thrown up it may be partially digested and so look like coffee grounds. Bleeding from the esophagus can also cause the person to throw up blood. Brisk bleeding into the large intestines is likely to turn the stool red with visible blood.

If the bleeding is slow, it often doesn’t cause the person to throw up blood or have a change in their stool. Over time, though, slow bleeding can lead to low red blood cell counts (anemia), and make a person feel tired and weak.

Bleeding from the GI tract can be very serious. If you have any of these signs and symptoms you should see your doctor right away.

Other possible symptoms of GISTs

- Abdominal (belly) discomfort or pain

- A mass or swelling in the abdomen
- Nausea, vomiting
- Feeling full after eating only a small amount of food
- Loss of appetite
- Weight loss
- Problems swallowing (for tumors in the esophagus)

Sometimes the tumor grows large enough to block the passage of food through the stomach or intestine. This is called an *obstruction*, and it causes severe abdominal pain and vomiting. It can even cause a hole (*perforation*) to develop. Emergency surgery is often needed to treat the blockage.

Although many of the symptoms of GIST (like belly pain and nausea) can be caused by things other than cancer, if you have these symptoms, especially if they last for more than a few days, you should see your doctor.

How are gastrointestinal stromal tumors diagnosed?

Gastrointestinal stromal tumors (GISTs) are often found because a person is having signs or symptoms. Others are found during exams or tests for other problems. If cancer is suspected, you will need further tests to confirm the diagnosis.

Medical history and physical exam

The doctor will ask you questions about your medical history, including your symptoms (eating problems, pain, bleeding, etc.), possible risk factors, family history, and other medical conditions.

Your doctor will give you a thorough physical exam to get more information about the possible signs of a GIST, like a mass in the abdomen, or other health problems.

If there is a reason to suspect that you may have a GIST (or other type of GI tumor), the doctor will use imaging tests or endoscopy exams to help find out if it is cancer or something else. If it is a GIST, further tests will be done to help determine the extent (stage) of the cancer.

Imaging tests

Imaging tests use x-rays, magnetic fields, or radioactive substances to create pictures of the inside of the body. Imaging tests may be done for a number of reasons, including:

- To help find out if a suspicious area might be cancer

- To learn how far cancer has spread
- To help determine if treatment has been effective
- To look for signs that the cancer has come back

Most patients who have or may have cancer will have one or more of these tests.

Barium x-rays

Barium x-rays are not used as much today as in the past. In many cases they are being replaced by endoscopy – where the doctor actually looks into your colon or stomach with a narrow fiber-optic scope (see below).

For these tests, a chalky solution containing barium is used to coat the inner lining of the esophagus, stomach, and intestines. This makes abnormalities of the lining easier to see on x-ray. These tests are sometimes used to diagnose GI tumors, but they can miss some small intestine tumors.

You will probably have to fast starting the night before the test. If the colon is being examined, you might need to take laxatives and/or enemas to clean out the bowel the night before or the morning of the exam.

Barium swallow: This test is often the first test done if someone is having a problem swallowing. For this test, you drink a liquid containing barium to coat the inner lining of the esophagus, A series of x-rays is then taken over the next few minutes.

Upper GI series: This test is similar to the barium swallow except that x-rays are taken after the barium has time to coat the stomach and the first part of the small intestine. 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*.

Enteroclysis: This test is another way to look at the small intestine. A thin tube is passed through the mouth or nose, down your esophagus, and through your stomach into the start of the small intestine. Barium is sent through the tube, along with a substance that creates more air in the intestines, causing them to expand. Then x-rays are taken of the intestines. This test can give better images of the small intestine than a small bowel follow through, but it is also more uncomfortable.

Barium enema: This test (also known as a *lower GI series*) is used to look at the inner surface of the large intestine. For this test, the barium solution is given through a small, flexible tube inserted in the anus while the patient is lying on the x-ray table. When the colon is about half full of barium, the patient rolls over so the barium spreads throughout the colon. For a regular barium enema, x-rays are then taken. After the barium is put in the colon, air may be blown in to help push the barium toward the wall of the colon and better coat the inner surface. Then x-rays are taken. This is called an *air-contrast barium enema* or *double-contrast barium enema*.

Computed tomography (CT) scan

The CT scan is an x-ray test that produces detailed, cross-sectional images of your body. Instead of taking one picture, like a standard x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these into images of slices of the part of your body that is being studied. Unlike a regular x-ray, a CT scan creates detailed images of the soft tissues in the body.

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.

Before the test, you may be asked to drink 1 to 2 pints of an oral contrast liquid. This helps outline your digestive tract so that certain areas are not mistaken for tumors. You may also receive an intravenous (IV) line so that a different kind of contrast dye can be injected. This helps better outline blood vessels in your body.

Some people are allergic to the dye and get hives, a flushed feeling, or, rarely, more serious reactions like trouble breathing and low blood pressure. Medicines can be given to help prevent or treat allergic reactions, so be sure to let the doctor know before the scan about any allergies or previous reactions you have had to contrast material used for x-rays.

CT scans take longer than regular x-rays. The test is painless, but you may find it uncomfortable to hold still in certain positions for minutes at a time.

CT scans can be useful in patients with GISTs to find the location and size of a tumor, as well as to see if it has spread into the abdomen or the liver.

In some cases, CT scans can also be used to guide a biopsy needle precisely into a suspected cancer. However, this can be risky if the tumor might be a GIST (because of the risk of bleeding and a possible increased risk of tumor spread), so these types of biopsies are usually done only if the result might affect the decision on treatment. (See the biopsy information below.)

Magnetic resonance imaging (MRI) scan

MRI scans use radio waves and strong magnets instead of x-rays. The energy from the radio waves is absorbed and then released in a pattern formed by the type of tissue and by certain diseases. A computer translates the pattern into a very detailed image of parts of the body. A contrast material might be injected just as with CT scans, but is used less often.

MRI scans are a little more uncomfortable than CT scans. They take longer – often up to an hour. You have to lie inside a narrow tube, which is confining and can upset some people with a fear of enclosed spaces (claustrophobia). Newer, more open MRI machines can help with this, although the images may not be as sharp in some cases. The machine

also makes buzzing and clicking noises that some people might find disturbing. Some places will provide earplugs to help block this noise out.

MRI scans can sometimes be useful in people with GISTs to help find the extent of the cancer in the abdomen, but usually CT scans are enough. MRIs can also be used to look for cancer that has come back (recurrence) or spread (metastasis) to distant organs, particularly in the brain or spine.

Positron emission tomography (PET) scan

For a PET scan, a radioactive substance (usually a type of sugar related to glucose, known as *FDG)* is injected into the blood. The amount of radioactivity used is very low. Because cancer cells in the body grow quickly, they absorb large amounts of the radioactive sugar. After about an hour, you will be moved onto a table in the PET scanner. You lie on the table for about 30 minutes while a special camera creates a picture of areas of radioactivity in your body.

PET scan images are not finely detailed like CT or MRI images, but a PET scan can look for possible areas of cancer spread in all areas of the body at once. Some newer machines are able to perform both a PET and CT scan at the same time (PET/CT scan). This lets the doctor see areas that “light up” on the PET scan in more detail.

PET scans can be useful for looking at GISTs, especially if the results of CT or MRI scans aren’t clear. This test also can be used to look for possible areas of cancer spread to help determine if surgery is an option.

PET scans can also be helpful in finding out if a drug treatment is working, as they can give an answer quicker than CT or MRI scans. The scan is usually obtained about 4 weeks after starting the medicine. If the drug is working, the tumor will stop taking up the radioactive sugar. If the tumor still takes up the sugar, your doctor may decide to change your drug treatment.

Endoscopy

For these tests, the doctor puts a flexible lighted tube (endoscope) with a tiny video camera on the end into the body. The camera sends pictures to a video screen, so that the doctor can clearly see any masses (tumors) in the lining of the digestive tract. If abnormal areas are found, small pieces can be biopsied (removed) through the endoscope. The biopsy samples can be looked at under the microscope to find out if they contain cancer and if so, what kind of cancer it is.

GIST tumors are often below the inner lining (mucosa) of the GI tract. This makes them harder to see with endoscopy than more common GI tract tumors, which typically start in the mucosa. The doctor may see only a bulge under the normally smooth surface if a GIST is present. GISTs that are below the mucosa are also harder to biopsy through the endoscope. This is one reason only about half of GISTs are diagnosed before surgery.

If the tumor breaks through the inner lining of the GI tract and is easy to see on endoscopy, there is a greater chance that the GIST is cancerous (malignant).

Upper endoscopy

For this procedure, patients are usually given medicines through an intravenous (IV) line to sedate them (make them sleepy). Then an endoscope is passed through the mouth to look at the inner lining of the esophagus, stomach, and first part of the small intestine. Biopsy samples may be taken from any abnormal areas.

Upper endoscopy can be done in a hospital, in an outpatient surgery center, or in a doctor's office. It usually takes 10 to 20 minutes, but it might take longer if a tumor is seen or if biopsy samples are taken. If medicine is given to make you sleepy for the procedure, you will need someone you know to drive you home (not just a cab).

This test is also known as EGD (short for esophagogastroduodenoscopy).

Colonoscopy (lower endoscopy)

For this test, a type of endoscope known as a *colonoscope* is inserted through the anus and up into the colon. This lets the doctor look at the lining of the entire rectum and colon and to take biopsy samples from any abnormal areas.

To get a good look at the inside of the colon, it must be empty and cleaned out before the test. This often means drinking a large amount of a liquid laxative the evening before and spending much of the night in the bathroom. Sometimes more liquid needs to be drunk or enemas are used the morning of the procedure to make sure the bowels are empty.

You will be given intravenous (IV) medicine to make you feel relaxed and sleepy during the procedure. A colonoscopy can be done in a hospital, in an outpatient surgery center, or in a doctor's office. It usually takes 15 to 30 minutes, but it can take longer if a tumor is seen and/or a biopsy taken. Because medicine is given to make you sleepy for the procedure, you will need someone you know to drive you home (not just a cab).

Capsule endoscopy

Unfortunately, neither upper nor lower endoscopy can reach all areas of the small intestine. Capsule endoscopy is one way to look at the small intestine.

This procedure does not actually use an endoscope. Instead, the patient swallows a capsule (about the size of a large vitamin pill) that contains a light source 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 intestine (usually over about 8 hours), it takes thousands of pictures. These images are transmitted electronically to a device worn around the person's waist. The pictures can then be downloaded onto a computer, where the doctor can view them as a video. The capsule passes out of the body during a normal bowel movement and is discarded.

This test requires no sedation – the patient can just continue normal daily activities as the capsule travels through the GI tract. This technique is fairly new, and the best ways to use it are still being studied. One disadvantage is that any abnormal areas seen can't be biopsied during the test.

Double balloon enteroscopy (endoscopy)

This is another way to look at the small intestine. The small intestine is too long and has too many curves to be examined well with regular endoscopy. This method gets around these problems by using a special endoscope that is made of 2 tubes, one inside the other.

The patient is given intravenous (IV) medicine to relax them, or even general anesthesia (so that they are asleep). The endoscope is then inserted either through the mouth or the anus, depending on if there is a specific part of the small intestine to be examined.

Once in the small intestine, the inner tube, which has the camera on the end, is advanced forward about a foot as the doctor looks at the lining of the intestine. Then a balloon on the end of the endoscope is inflated to anchor it. The outer tube is then pushed forward to near the end of the inner tube and is anchored in place with a second balloon. The first balloon is deflated and the endoscope is advanced again. This process is repeated over and over, letting the doctor see the intestine a foot at a time. The test can take hours to complete.

This test may be done along with capsule endoscopy. The main advantage of this test over capsule endoscopy is that the doctor can take a biopsy if something abnormal is seen. Like other forms of endoscopy, because you are given medicine to make you sleepy for the procedure, someone you know will need to drive you home (not just a cab).

Endoscopic ultrasound

This is a type of imaging test that uses an endoscope. Ultrasound uses sound waves to take pictures of parts of the body. For most ultrasound exams, a wand-like probe (called a *transducer*) is placed on the skin. The probe gives off sound waves and detects the pattern of echoes that come back.

For an endoscopic ultrasound, the ultrasound probe is on the tip of an endoscope. This allows the probe to be placed very close to (or on top of) a tumor in the wall of the digestive tract. Like a regular ultrasound, the probe gives off sound waves and then detects the echoes that bounce back. A computer then translates the pattern of echoes into an image of the area being looked at.

Endoscopic ultrasound can be used to find the precise location of the GIST and to determine its size. It is useful in finding out how deeply a tumor has grown into the wall of the digestive tract. The test can also help show if the tumor has spread to nearby lymph nodes or has started growing into other tissues nearby. In some cases it may be used to help guide a biopsy (see below).

This procedure is usually done under sedation (medicine is given to make the patient sleepy). Because of this, the patient needs to have someone they know drive them home (not just a cab).

Biopsy

Even if a mass is found on an imaging test such as a barium x-ray or CT scan, these tests cannot tell if the mass is a GIST, some other type of tumor (benign or cancerous), or some other condition (like an infection). The only way to know what it is for sure is to remove cells from the abnormal area. This procedure is called a *biopsy*. The cells are then sent to a lab, where a doctor called a *pathologist* looks at them under a microscope and does other tests on them.

GISTs are often fragile tumors that tend to break apart and bleed easily. If the doctor suspects a tumor may be a GIST, biopsies must be done carefully and are usually done only if they will help determine treatment options, because of concerns the biopsy might cause bleeding or possibly increase the risk of cancer spreading.

There are several ways to biopsy a GI tract tumor.

Endoscopic biopsy

Biopsy samples can be obtained through an endoscope. When a tumor is found, the doctor can insert biopsy forceps (pincers or tongs) through the tube to take a small sample of the tumor.

Even though the sample will be very small, doctors can often make an accurate diagnosis. However, with GISTs, sometimes the biopsy forceps can’t go deep enough to reach the cancer because the tumor is underneath the lining of the intestine or stomach.

Bleeding from a GIST after a biopsy is rare, but it can be a serious problem. If this occurs, doctors can sometimes inject drugs into the tumor through the endoscope to constrict blood vessels and stop the bleeding.

Fine needle aspiration (FNA) biopsy

In some patients, a biopsy is done with a thin, hollow needle. The most common way to do this is during an endoscopic ultrasound. The doctor uses the ultrasound image to guide a needle on the tip of the endoscope into the tumor. Less commonly, the doctor may place a needle through the skin and into the tumor while guided by an imaging test such as a CT scan.

Surgical biopsy

If a sample can’t be obtained from an endoscopic or FNA biopsy or if the result of a biopsy wouldn’t affect treatment options, your doctor might recommend waiting until surgery to remove the tumor to get a sample of it.

If the surgery is done through a large cut (incision) in the abdomen, it is called a *laparotomy*. In some cases, the tumor may be sampled (or small tumors can be removed) using a thin lighted tube that allows the surgeon to see inside the belly through a small incision called a *laparoscope*. The surgeon can use long, thin surgical instruments that are passed through other small incisions in the abdomen. This is known as *laparoscopic* or *keyhole surgery*.

Testing the biopsy sample

Once a tumor sample is obtained, a pathologist looks at it under a microscope. The pathologist may suspect that a tumor is a GIST, but often can't be sure without further tests.

For a special test called *immunohistochemistry*, a part of the sample is treated with man-made antibodies that will attach only to the KIT protein (also called *CD117*). The antibodies cause color changes if the KIT protein is present, which can be seen under a microscope. Most GIST cells have this protein, but cells of most other types of cancer do not, so this test can help determine whether a GI tumor is a GIST or not. If the tumor cells do not contain KIT, they will be checked to see if they have too much of the PDGFRA protein. This is found in about 5% to 10% of GISTs.

If the doctor is still unsure if the tumor is a GIST, other tests might be done on the biopsy sample to look for mutations in the *c-kit* or *PDGFRA* genes themselves.

If a GIST is diagnosed, the doctor will also look at the cancer cells in the sample to see how many of them are actively dividing into new cells. This is known as the *mitotic rate*. A low mitotic rate means the cancer cells are growing and dividing slowly, while a high rate means they are growing quickly. The mitotic rate is an important part of the stage of the cancer (see "How are gastrointestinal stromal tumors staged?").

Blood tests

Your doctor may order some blood tests if he or she thinks you may have a GIST. There are no blood tests that can tell if a person has a GIST. These tumors do not release any known substances in the blood that can be used to diagnose a GIST or to measure its response to treatment.

However, blood tests can sometimes point to a possible tumor (or to its spread). For example, a complete blood count (or CBC) can tell if you have a low red blood cell count (are anemic). Some people with GIST may become anemic because of bleeding from the tumor. Abnormal liver function tests may mean that the GIST has spread to your liver.

Blood tests are also done to check your overall health before you have surgery or while you get other treatments such as targeted therapy.

How are gastrointestinal stromal tumors staged?

The stage of a cancer describes how far the cancer has spread. For many cancers, the stage is an important factor in selecting treatments and in predicting a person's prognosis (outlook). To help stage the tumor, doctors use the results of physical exams and imaging, endoscopy, or other tests, such as those described in "How are gastrointestinal stromal tumors diagnosed?"

AJCC TNM staging system

Doctors use a staging system to describe the extent of spread of most types of cancer, including gastrointestinal stromal tumors (GISTs). The most common system used is the TNM system of the American Joint Committee on Cancer (AJCC). This system is based on 4 key pieces of information:

- **T** describes the size of the primary **tumor**, measured in centimeters (cm).
- **N** describes whether the cancer has spread to nearby (regional) lymph **nodes** (this is very rare for GISTs).
- **M** indicates whether the cancer has **metastasized** (spread) to other organs of the body. If a GIST does spread, most often it is within the abdomen, such as to the liver. Less often, it may spread to the lungs and bones.
- The **mitotic rate** is a measure of how fast the cancer cells are growing and dividing. It is described as either low or high. A low mitotic rate predicts a better outcome.

Numbers or letters appear after T, N, and M to provide more details about each of these factors:

- The numbers 0 through 4 indicate increasing severity.
- The letter X means "cannot be assessed" because the information is not available.

T categories for GIST

TX: The primary (main) tumor cannot be assessed.

T0: No signs of a primary tumor.

T1: The tumor is 2 cm or less across (about 4/5 of an inch).

T2: The tumor is larger than 2 cm across but not larger than 5 cm (about 2 inches).

T3: The tumor is larger than 5 cm across but not larger than 10 cm (about 4 inches).

T4: The tumor is larger than 10 cm across.

N categories for GIST

NX: Regional (nearby) lymph nodes cannot be assessed.

N0: The cancer has not spread to nearby lymph nodes.

N1: The cancer has spread to nearby lymph nodes.

M categories for GIST

M0: The cancer has not spread (metastasized) to distant organs or sites.

M1: The cancer has spread to distant organs or sites (like the liver or the lungs).

Stage grouping

Once the T, N, and M categories have been determined, this information is combined, along with the mitotic rate, in a process called *stage grouping*. The overall stage is expressed in Roman numerals from I (the least advanced) to IV (the most advanced). The stage grouping depends on where the tumor starts.

GIST that starts in the stomach or the omentum*

*The omentum is an apron-like layer of fatty tissue that hangs over the organs in the abdomen

Stage IA: T1 or T2, N0, M0, low mitotic rate: The tumor is no larger than 5 cm across (T1 or T2). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage IB: T3, N0, M0, low mitotic rate: The tumor is larger than 5 cm but not larger than 10 cm across (T3). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage II: One of the following applies:

- **T1 or T2, N0, M0**, **high mitotic rate:** The tumor is no larger than 5 cm across (T1 or T2). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is high.
- **T4, N0, M0, low mitotic rate:** The tumor is larger than 10 cm across (T4). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage IIIA: T3, N0, M0, high mitotic rate: The tumor is larger than 5 cm but not larger than 10 cm across (T3). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is high.

Stage IIIB: T4, N0, M0, high mitotic rate: The tumor is larger than 10 cm across (T4). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is high.

Stage IV: One of the following applies:

- **Any T, N1, M0, any mitotic rate:** The tumor can be any size (any T) and the cancer has spread to nearby lymph nodes (N1). It has not spread to distant sites (M0). The tumor can have any mitotic rate.
- **Any T, any N, M1, any mitotic rate:** The tumor can be any size (any T) and it may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites, such as the liver or the lungs (M1). The tumor can have any mitotic rate.

GIST of the small intestine, esophagus, colon, rectum, or peritoneum**

**The peritoneum is a layer of tissue that lines the organs and walls of the abdomen.

Tumors in these locations are more likely to grow quickly than GISTs that start in the stomach.

Stage I: T1 or T2, N0, M0, low mitotic rate: The tumor is no larger than 5 cm across (T1 or T2). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage II: T3, N0, M0, low mitotic rate: The tumor is larger than 5 cm but not larger than 10 cm across (T3). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage IIIA: One of the following applies:

- **T1, N0, M0, high mitotic rate:** The tumor is no larger than 2 cm across (T1). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is high.
- **T4, N0, M0, low mitotic rate:** The tumor is larger than 10 cm across (T4). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is low.

Stage IIIB: T2 to T4, N0, M0, high mitotic rate: The tumor is larger than 2 cm across (T2 to T4). The cancer has not spread to nearby lymph nodes (N0) or distant sites (M0). The mitotic rate is high.

Stage IV: One of the following applies:

- **Any T, N1, M0, any mitotic rate:** The tumor can be any size (any T) and the cancer has spread to nearby lymph nodes (N1). It has not spread to distant sites (M0). The tumor can have any mitotic rate.

- **Any T, any N, M1, any mitotic rate:** The tumor can be any size (any T) and it may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites, such as the liver or the lungs (M1). The tumor can have any mitotic rate.

Resectable versus unresectable tumors

The AJCC staging system provides a detailed summary of how far a GIST has spread. But for treatment purposes, doctors are often more concerned about whether the tumor can be removed (resected) completely with surgery.

Whether or not a tumor is resectable depends on its size and location, whether it has spread to other parts of the body, and if a person is healthy enough for surgery. Tumors that can clearly be removed are defined as *resectable*, while those that can't be removed completely (because they have spread or for other reasons) are described as *unresectable*. In some cases, doctors may describe a tumor as *marginally resectable* if it's not clear if it can be removed completely.

If a tumor is considered unresectable or marginally resectable when it is first found, treatments such as targeted therapy may be used first to try to shrink the tumor enough to make it resectable.

Survival rates for gastrointestinal stromal tumors

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some people want to know the survival statistics for people in similar situations, while others might not find the numbers helpful, or might even not want to know them. If you do not want to read about the survival statistics for gastrointestinal stromal tumors (GISTs) given in the next few paragraphs, skip to the next section.

It is very hard to get accurate numbers on survival rates for GISTs. Part of this is because these tumors are not common. In the past, they were often classified as other types of cancers, which made the numbers available for study even smaller. Treatment has also changed dramatically in recent years now that newer, targeted therapy drugs are being used. The survival rates below are based on people treated many years ago, largely before these newer treatments were used, so people being treated for GISTs today are likely to have a better outlook.

The 5-year survival rate refers to the percentage of patients who live *at least 5 years* after their cancer is diagnosed. Five-year rates are used as a standard way of discussing prognosis. Of course, many people live much longer than 5 years. Five-year *relative* survival rates, such as the numbers below, assume that some people will die of other causes and compare the observed survival with that expected for people without the cancer. This is a more accurate way to describe the chances of dying from a particular type and stage of cancer.

The rates below are based on the stage of the cancer *when the person was first diagnosed*. When looking at survival rates, it's important to understand that the stage of a cancer

does not change over time, even if the cancer progresses. A cancer that comes back or spreads is still referred to by the stage it was given when it was first found and diagnosed, but more information is added to explain the current extent of the cancer. (And of course, the treatment plan is adjusted based on the change in cancer status.)

Based on people diagnosed between 2003 and 2009 the overall relative 5-year survival rate of people diagnosed with a malignant GIST was estimated to be about 76%.

- If the tumor was confined to the organ where it started, the 5-year relative survival was 91%.
- If it had grown into nearby tissue (or spread to nearby lymph nodes) when it was first diagnosed, the 5-year relative survival was around 74%.
- If it had spread to distant sites when it was first diagnosed, the 5-year relative survival was 48%.

How are gastrointestinal stromal tumors 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

Once a gastrointestinal stromal tumor (GIST) is found and staged, your cancer care team will discuss your treatment options with you. In determining these options, important factors include the tumor characteristics (such as its size, location, growth rate, and whether it has spread) and your overall health.

The main types of treatment used for GISTs include:

- Surgery
- Targeted therapy drugs

Other treatments, such as chemotherapy and radiation therapy, are used much less often.

Based on your treatment options, you might have different types of doctors on your treatment team including:

- A surgical oncologist: a doctor who treats cancer with surgery.

- A medical oncologist: a doctor who treats cancer with medicines.
- A gastroenterologist: a doctor who specializes in treatment of diseases of the digestive system.
- A radiation oncologist: a doctor who treats cancer with radiation therapy.

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

It is important to discuss all treatment options as well as their possible side effects with your doctors to help make the decision that best fits your needs. If you have time, it is often a good idea to seek a second opinion. A second opinion can provide more information and help you feel confident about your chosen treatment plan.

The next few sections describe the different types of treatment for GIST. This is followed by a discussion of the most common treatment options based on the extent of the cancer. The section called “Additional resources for gastrointestinal stromal tumor” has a list of other documents on the different types of cancer treatments and their side effects.

Surgery for gastrointestinal stromal tumor

The main treatment for a gastrointestinal stromal tumor (GIST) that hasn’t spread is usually surgery. The goal of the surgery is to remove all of the cancer.

If the tumor is small, it often can be removed along with a small area of normal tissue around it. This is done through a cut (incision) in the skin, but the exact type of surgery depends on where the tumor is. Unlike many other cancers, GIST almost never spreads to the lymph nodes, so removing nearby lymph nodes is usually not needed.

For some small cancers, “keyhole” (laparoscopic) surgery is an option. Instead of making a large incision in the skin to remove the tumor, the surgeon makes several small ones. Through one incision, the doctor inserts a thin lighted tube (with a tiny video camera) called a laparoscope. This allows him or her to see inside the belly. He or she then uses long, thin surgical tools to remove the tumor through the other incisions. Because the incisions are small, patients usually recover more quickly from this type of surgery than from traditional surgery that requires an incision several inches long.

If the tumor is large or growing into other organs, the surgeon could still try to remove it entirely. To do this, the doctor might have to remove parts of organs (such as sections of the intestines). The surgeon might also remove GISTs that have spread elsewhere in the abdomen, such as the liver (see the next section).

Another treatment for tumors that are large or have grown into nearby areas is to first give the patient the drug imatinib (see the “Targeted therapy for gastrointestinal stromal tumor” section) to try to shrink the tumor to make it easier to remove with surgery.

No matter what type of surgery is done, it is very important that it is done carefully by a surgeon with experience treating GISTs. GISTs are often delicate tumors, and surgeons

must be careful not to open the lining that surrounds them (known as the *capsule*), because it might increase the risk of spreading the cancer. GISTs also tend to have a lot of blood vessels, so your surgeon will be careful to control any bleeding from the tumor.

For more information about surgery, see our document *Understanding Cancer Surgery: A Guide for Patients and Families*.

Ablation and embolization to treat gastrointestinal stromal tumors

Treatments such as ablation and embolization are often used to treat cancers that start in the liver, but they can also be used to treat areas of cancer spread in the liver.

Ablation

Ablation can be used to destroy tumors in the liver caused by the spread of gastrointestinal stromal tumor (GIST). This technique can be used if there are a few small tumors in the liver. Because ablation often destroys some of the normal tissue around the tumor, it might not be a good choice for treating tumors near major blood vessels, the diaphragm (the muscle under the lungs), or major ducts in the liver.

Usually, you will not need to stay in the hospital for this type of treatment. Often, ablation can be done without surgery by inserting a needle or probe into the tumor through the skin. The needle or probe is guided into place with ultrasound or CT scanning. Sometimes, though, to be sure the treatment is aimed at the right place, it is done during surgery.

There are several types of ablation:

- Radiofrequency ablation (RFA), which uses high-energy radio waves to heat the tumor and destroy cancer cells.
- Ethanol (alcohol) ablation, where concentrated alcohol is injected directly into the tumor to kill cancer cells.
- Microwave thermotherapy, where microwaves transmitted through a probe placed in the tumor are used to heat and destroy the cancer cells.
- Cryosurgery (cryotherapy), which destroys a tumor by freezing it using a thin metal probe. This method sometimes requires general anesthesia (where you are deeply asleep and not able to feel pain).

Possible side effects after ablation therapy include abdominal pain, infection in the liver, and bleeding into the chest cavity or abdomen. Serious complications are uncommon, but they can happen.

Embolization

Embolization is a procedure that injects substances to try to block or reduce the blood flow to cancer cells in the liver.

The liver is unusual in that it has 2 blood supplies. Most normal liver cells are fed by branches of the portal vein, whereas cancer cells in the liver are usually fed by branches of the hepatic artery. Blocking the branch of the hepatic artery feeding the tumor helps kill off the cancer cells, but it leaves most of the healthy liver cells unharmed because they get their blood supply from the portal vein.

Embolization does reduce some of the blood supply to the normal liver tissue, so it may not be a good option for some patients whose liver has been damaged by diseases such as hepatitis or cirrhosis.

The main type of embolization used to treat gastrointestinal stromal tumors that have spread to the liver is arterial embolization (also known as *trans-arterial embolization* or TAE). In this procedure a catheter (a thin, flexible tube) is put into an artery through a small cut in the inner thigh and threaded up into the hepatic artery in the liver. A dye is usually injected into the bloodstream at this time to help the doctor monitor the path of the catheter via angiography, a special type of x-ray. Once the catheter is in place, small particles are injected into the artery to plug it up.

Typically, you will not have to stay in the hospital for this treatment.

Possible complications after embolization include abdominal pain, fever, nausea, infection in the liver, gallbladder inflammation, and blood clots in the main blood vessels of the liver. Because healthy liver tissue can be affected, there is a risk that liver function will get worse after embolization. This risk is higher if a large branch of the hepatic artery is embolized. Serious complications are not common, but they are possible.

Targeted therapy for gastrointestinal stromal tumor

Some drugs are able to target the gene changes in gastrointestinal stromal tumor (GIST) cells that have been found in recent years. These drugs work differently from standard chemotherapy (chemo) drugs. Targeted drugs are very helpful in treating GISTs, while standard chemo drugs are usually not effective.

All of these drugs are pills, taken once a day.

Imatinib (Gleevec®)

This drug is used to treat most patients with GIST at some point. It targets both the KIT protein and the PDGFRA protein, blocking their ability to make tumor cells grow and divide. GIST cells often have too much of these proteins.

Overall, about 2 out of 3 tumors shrink by at least half when treated with imatinib. Some other tumors shrink less or at least stop growing for a time. A small number of tumors are not helped by this treatment.

If a GIST has been completely removed by surgery, many doctors recommend you take imatinib for at least a year afterward to lower the risk of the cancer coming back. (This is known as *adjuvant therapy*.) Many doctors now recommend at least 3 years of imatinib after surgery for patients who are at a higher risk of their tumors returning (based on their tumor's size, location, and growth rate).

For larger tumors that may be hard to remove surgically, imatinib may be used first to try to shrink the tumor and make surgery more successful. (This is known as *neoadjuvant therapy*.) It is often given again after surgery as well.

Imatinib is also usually the treatment of choice for advanced GISTs that have spread too far to be removed by surgery. It doesn't seem to cure these patients, but it can often shrink or slow their tumors' growth for several years, helping them live longer and feel better. If the drug stops working and the tumor starts growing again, raising the dose of imatinib may help stop the growth for some time, but higher doses have more side effects.

Side effects can include mild stomach upset, diarrhea, muscle pain, and skin rashes. The stomach upset is lessened if the drug is taken with food. Imatinib can also make people retain fluid. Often this causes some swelling in the face (around the eyes) or in the ankles. Rarely the drug causes more severe problems, with fluid building up in the lungs or in the abdomen. It can also affect heart function in some people.

One other concern when using this drug to treat large GISTs is that these tumors often have a lot of fragile blood vessels. If imatinib causes the tumor to shrink quickly, it may lead to internal bleeding. For this reason, doctors watch patients carefully when they first start taking this drug.

Sunitinib (Sutent®)

This drug can be useful in treating GIST when imatinib doesn't work or when patients can't take imatinib because of its side effects (see previous section). Sunitinib targets the KIT and PDGFRA proteins (as well as several other proteins that imatinib does not target).

Sunitinib helps some patients, usually by slowing the growth of the tumor. It can also shrink tumors in a small number of patients. More importantly, patients getting the drug may live longer.

The most common side effects of sunitinib are fatigue, diarrhea, mouth irritation, and skin and hair color changes. More serious side effects can include high blood pressure, increased risk of bleeding, swelling, heart problems, and serious liver problems.

Regorafenib (Stivarga®)

Regorafenib is given to patients to treat GIST after imatinib and sunitinib stop working for them. It targets many proteins, including KIT and PDGFRA.

In studies, regorafenib has slowed tumor growth and even shrunk some tumors. So far, though, it's not clear if it helps patients live longer.

Common side effects include diarrhea, fatigue, high blood pressure, mouth irritation, hair loss, loss of appetite, and problems with redness, pain, or even blistering of the palms of the hands and soles of the feet (called *hand-foot syndrome*).

More information about the kinds of drugs considered targeted therapy can be found in our document *Targeted Therapy*. 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.

Chemotherapy for gastrointestinal stromal tumor

Chemotherapy (chemo) is the use of drugs to treat cancer. Often, these drugs are injected into a vein (IV) or given by mouth. They enter the bloodstream and reach throughout the body, making this treatment potentially useful for cancers that have spread beyond the organ they started in.

Any drug used to treat cancer can be considered chemo – even the targeted therapy drugs discussed earlier. But the term *chemo* is often used to describe certain drugs that work by attacking quickly growing cells anywhere in the body, which includes cancer cells. Before targeted therapy drugs like imatinib (Gleevec) were found to be helpful in treating gastrointestinal stromal tumors (GISTs), traditional chemo drugs were used. GISTs rarely shrank in response to these drugs, so this type of treatment is rarely used now that targeted drugs are available. Because traditional chemo has not worked well against GISTs, no standard chemo regimens are recommended. Patients considering chemo may want to consider participating in a clinical trial.

Chemo drugs attack cells that are dividing quickly, which is why they work against cancer cells. But other cells in the body, such as those in the bone marrow (where new blood cells are made), the lining of the mouth and intestines, and the hair follicles, also divide quickly. These cells can also be affected by chemo, which can lead to side effects. Side effects depend on the specific drugs used, their dose, and the length of treatment. Common side effects of chemo include:

- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Diarrhea
- Hair loss
- An increased chance of infection (from a shortage of white blood cells)
- Problems with bleeding or bruising (from a shortage of blood platelets)

- Fatigue or shortness of breath (from low red blood cell counts)

Along with the risks above, some chemo drugs can cause other side effects. Most side effects improve once treatment is stopped, but some can last a long time. Let your health care team know if you have side effects, so they can be treated. There are ways to prevent or treat many of the side effects of chemotherapy. For example, many drugs can help prevent or treat nausea and vomiting.

For more information about chemotherapy, see our document *A Guide to Chemotherapy*. 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.

Radiation therapy for gastrointestinal stromal tumor

Radiation therapy is the use of high-energy x-rays (or particles) to kill cancer cells. Radiation is not very effective in treating gastrointestinal stromal tumors (GISTs), so it is not used often. But it can be used to relieve symptoms like bone pain.

Before your treatment starts, the radiation team will take careful measurements to determine the correct angles for aiming the radiation beams and the proper dose of radiation. Radiation therapy is much like getting an x-ray, but the radiation is much stronger. The procedure itself is painless. The treatment lasts only a few minutes, although the setup time – getting you into place for treatment – usually takes longer. You might get radiation treatment for several days in a row.

Depending on where the radiation therapy is aimed, side effects may include:

- Skin changes – ranging from redness to blistering and peeling
- Nausea and vomiting
- Diarrhea
- Fatigue
- Low blood counts

Most side effects go away a short while after treatment ends, although fatigue and skin changes may take longer to resolve. Talk with your doctor about the possible side effects and the ways to reduce or relieve them.

More information on radiation therapy can be found in the Radiation section of our website, or in our document *Understanding Radiation Therapy: A Guide for Patients and Families*

Clinical trials for gastrointestinal stromal tumor

You might have had to make a lot of decisions since you've been told you have a gastrointestinal stromal tumor **(gas**-tro-in-**TEST**-uh-nul **stro**-muhl **too**-mer). 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. 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.

You must meet requirements to take part in any clinical trial. If you do qualify, it's up to you 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*.

Complementary and alternative therapies for gastrointestinal stromal tumor

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 might 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 could 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 read about them 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 gastrointestinal stromal tumor based on tumor spread

Treatment for gastrointestinal stromal tumors (GISTs) depends on the size of the tumor, where it is, how far it has spread, and how quickly it is growing. The main treatment is

surgery to remove the tumor when possible, but targeted therapies and other treatments may also help in some situations.

Localized, smaller (resectable) tumors

Surgery is the main treatment for most small tumors. For tumors that are small and are not growing quickly, this is often the only treatment needed.

The chance that a GIST will come back after surgery is higher if the tumor is larger or did not start in the stomach, or if the cancer cells are dividing quickly (have a high mitotic rate). If the doctor thinks that the cancer has an intermediate or high risk of growing back based on these factors, adjuvant treatment with the targeted drug imatinib (Gleevec) is typically recommended for at least a year after surgery. For tumors that are highly likely to come back, many doctors now recommend giving patients at least 3 years of imatinib.

For some very small tumors (less than 2 cm across) that are found incidentally and are not causing any symptoms, another option may be just to watch the tumor carefully with endoscopy once or twice a year. If it is not growing, you might not need further treatment.

Localized, larger (marginally resectable) tumors

Tumors that are larger or in certain places may be harder to remove completely and might require more extensive surgery that could cause health problems later on. Because of this, once a biopsy is done to confirm the tumor is a GIST, treatment with imatinib is usually started. It is continued at least until the tumor stops shrinking.

If the tumor shrinks enough, surgery might be done if the doctor thinks he or she can remove the remaining tumor safely. The patient might continue to take imatinib after surgery to lower the chance that the cancer will come back.

If the tumor doesn’t shrink enough to make surgery possible, imatinib is often continued as long as it seems to help. If it is no longer working or if the side effects are too severe, sunitinib (Sutent) may be tried instead. If sunitinib is no longer working, the targeted drug regorafenib (Stivarga) may help some patients.

Tumors that are not removable or have spread to distant sites (unresectable tumors)

Treatment options for GISTs that cannot be removed with surgery (are unresectable) or have spread (metastasized) depends on where they have spread and how extensive the spread is.

For most of these tumors, imatinib is the preferred first treatment option. It is continued as long as the tumor doesn’t grow (and the patient can tolerate the side effects of the drug). If the tumor starts to grow again, it may respond to increasing the dose of imatinib. If the tumor continues to grow or the side effects from imatinib are too severe, a switch to

sunitinib may be helpful. If sunitinib is no longer working, regorafenib may help some patients.

If the tumor shrinks enough with targeted therapy, surgery may then be an option for some patients. This might be followed by more targeted therapy if it is still effective.

If the cancer has spread to only 1 or 2 sites in the abdomen (such as the liver), the surgeon may advise removing the main tumor and trying to remove these other tumors as well. If this is the case, be sure to talk with your doctor about what the goals of treatment are (whether it is to try to cure the cancer, to help you live longer, or to prevent or reduce symptoms), as well as its possible benefits and risks. Usually this should be considered only for tumors that are slow growing or those causing local complications such as uncontrollable bleeding.

Other options to treat cancers that have spread to the liver include ablation and embolization. These treatments may include radiofrequency ablation (RFA; using electric currents to heat the tumor), or ethanol ablation (injecting concentrated alcohol into the tumor).

For ablation, a probe or needle is inserted through the skin and guided to the tumor by CT (computed tomography) scans or ultrasound images, then the tumor is destroyed by heat, cold, or an injection of alcohol.

For embolization material is injected into large blood vessels feeding the tumor to block blood flow and kill cancer cells. These treatments can shrink the tumors in the liver, but are not expected to cure the cancer.

Cancers that are no longer responding to the targeted drugs discussed above can be hard to treat. Some doctors may recommend trying other targeted drugs, such as sorafenib (Nexavar®), dasatinib (Sprycel®), or nilotinib (Tasigna®), although it's not yet clear how helpful these drugs are. Standard chemotherapy drugs are usually not very effective. Taking part in a clinical trial of a newer treatment may be a good option for some people.

Recurrent tumors

When a cancer comes back after treatment, it is called *recurrent*. If the cancer comes back (recurs) in or near the place it started, it is called a *local recurrence*. If it recurs at other sites (like the lungs or liver) it is called a *distant recurrence*. Treatment options for GISTs that recur after treatment depend on the location and extent of the recurrence.

For most recurrences, treatment with imatinib is probably the best way to shrink any tumors, as long as it is still effective and the patient can tolerate taking it. If the starting dose of imatinib does not work, the dose can be increased. Another option is to try sunitinib or regorafenib.

If the cancer comes back as a single, well defined tumor, removing or destroying the tumor may be an option. Doctors are still not certain if removing GISTs that come back after treatment helps people live longer. Some studies have found that it does, but other

studies disagree. You should discuss the risks and benefits of this treatment with your doctor and family.

Because these cancers are often hard to treat, patients may want to consider taking part in clinical trials of newer treatments as well.

More treatment information about gastrointestinal stromal tumor

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 NCCN, made up of experts from many of the nation's leading cancer centers, develops cancer treatment guidelines for doctors to use when treating patients. These are available on the NCCN website (www.nccn.org). (Information on gastrointestinal stromal tumors (GISTs) is found in the NCCN Soft Tissue Sarcoma guideline.)

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

What should you ask your doctor about gastrointestinal stromal tumors?

As you cope with cancer and cancer treatment, we encourage you to talk openly with your doctor, nurse, and cancer care team. You should feel free to ask any question that's on your mind, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them. Nurses, social workers, and other members of the treatment team may also be able to answer many of your questions. You can find more information about communicating with your health care team in our document *Talking With Your Doctor*.

- Where is my tumor located? How big is it?
- How likely is this tumor to grow or spread quickly?
- Has my tumor spread beyond where it started?
- What is the stage of my cancer, and what does that mean?
- Will I need other tests before we can decide on treatment?
- Will I need to see other doctors ?
- How much experience do you have treating this type of cancer?
- What are my treatment choices ?

- What do you recommend? Why?
- What's the goal of the treatment?
- What are the chances my cancer can be cured with treatment?
- How quickly do we need to decide on treatment?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What risks or side effects I should expect? How long are they likely to last?
- How will treatment affect my daily activities?
- What will we do if the treatment doesn't work or if the cancer recurs?
- Will my insurance plan pay for the cost of all of the recommended treatments?
- What type of follow-up will I need after treatment?
- Where can I find more information and support?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about second opinions or about clinical trials for which you may qualify.

What happens after treatment for gastrointestinal stromal tumors?

For some people with a gastrointestinal stromal tumor (GIST), 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's called a *recurrence*.) This is a very common concern for 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, *Living With Uncertainty: The Fear of Cancer Recurrence*, gives more detailed information on this. It can be read online, or call us to have a free copy sent to you.

For other people, the GIST may never go away completely. These people may get regular treatments with targeted therapy or other therapies to help keep the cancer in check. Learning to live with cancer as more of a chronic disease can be difficult and very stressful. It has its own type of uncertainty. Our document, *When Cancer Doesn't Go Away*, has more about this.

Follow-up care

Whether you have completed treatment or are still being treated, your doctors will still want to watch you closely. It is very important to go to all follow-up appointments. During these visits, your doctors will ask about symptoms, physically exam you, and may order blood tests or imaging tests like CT scans. Follow-up is needed to check for signs of cancer recurrence or spread, as well as possible side effects of certain treatments. This is the time for you to ask your health care team any questions you need answered and to discuss any concerns you might have.

Because of the risk that a GIST may come back after treatment, most doctors recommend follow-up visits and imaging tests like CT scans every 3 to 6 months for at least several years after treatment. If you are still being treated with imatinib (or any other drug), you will also need to have CT scans to make sure that the drug is still working

Almost any cancer treatment can have side effects. Some may last for a few weeks to several months, but others can last the rest of your life. Don't hesitate to tell your cancer care team about any symptoms or side effects that bother you so they can help you manage them.

If cancer does recur, treatment will depend on the location of the cancer and what treatments you've had before. For more information on how recurrent cancer is treated, see the section, "Treatment choices based on tumor spread." For more general information on dealing with a recurrence, you may also want to see the document, *When Your Cancer Comes Back: Cancer Recurrence*. You can get this by calling us at 1-800-227-2345, or you can read it online.

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 this information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored on a CD, DVD, etc.
- If you had surgery, a copy of your operative report(s)
- If you stayed in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home
- If you had targeted therapy or chemotherapy, a list of the drugs, drug doses, and when you took them

- If you had radiation therapy, a summary of the type and dose of radiation and when and where it was given

It is also important to keep 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.

Lifestyle changes after gastrointestinal stromal tumor

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

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 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 at 1-800-227-2345. A 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. You can get more

information in our document *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*.

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 often 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. An older person who has never exercised will not be able to take on the same amount of exercise as a 20-year-old who plays tennis twice a week. If you haven't been active 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 activity 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 is 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 and other treatment side effects, please see the can be found in our documents, please see *Fatigue in People With Cancer* and *Anemia in People With Cancer*. The "Additional resources" section has a list of other documents on symptoms and side effects.

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 a gastrointestinal stromal tumor affect your emotional health?

During and after treatment, you may find yourself overcome with many different emotions. This happens to a lot of people.

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 relationships with those around you. Unexpected issues may also cause concern. For instance, you may see your health care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or 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 is not 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. You can also read our document *Distress in People with Cancer* or see the "Emotional Side Effects" section of our website for more information.

If treatment for gastrointestinal stromal tumor is no longer working

If cancer keeps growing or comes back after one kind of treatment, it may be possible to try another treatment plan that might still cure the cancer, or at least shrink the tumors 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, including treatment side effects. 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 may 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 treatment might have about a 1 in 100 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, it is important that you 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 and supportive 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. But this is not the same as treatment to try to cure the cancer.

You can learn more about the changes that occur when curative treatment stops working, and about planning ahead for yourself and your family, in our documents *Nearing the End of Life* and *Advanced Directives* You can read them online or call us at 1-800-227-2345 to have free copies mailed to you.

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 document called *Hospice Care*.

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 gastrointestinal stromal tumor research and treatment?

There has been a great deal of progress in recent years, especially in treating gastrointestinal stromal tumors (GISTs). As researchers have come to understand the genetic changes that cause these tumors, they’ve been able to use newer treatments to target these changes.

Doctors know targeted treatments like imatinib (Gleevec) and sunitinib (Sutent) often work, but they still aren’t sure exactly how and when to give them to make them most effective. Should they be given after surgery to all patients, even those with very small tumors? How long should drug treatment be continued? Would sunitinib be as effective as imatinib if it was given first? These questions are now being studied in clinical trials.

Other drugs that target the KIT or PDGFRA proteins are also being studied for use against GISTs. Some of these, such as sorafenib (Nexavar), nilotinib (Tasigna), and dasatinib (Sprycel) have helped some patients in early studies, but it isn’t clear which one, if any, would be the best one to use after the standard targeted drugs stopped working.

Other drugs being studied, like BIIB021, are aimed at different targets involved with cancer, such as heat shock proteins.

People with GISTs that are no longer responding to standard treatments may want to ask their doctor about clinical trials of these newer targeted therapies.

Additional resources for gastrointestinal stromal tumor

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

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

Understanding Cancer Surgery: A Guide for Patients and Families (also in Spanish)

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

A Guide to Chemotherapy (also in Spanish)

Targeted Therapy

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)

Anemia in People With Cancer

Fatigue in People With Cancer

Sexuality for the Man With Cancer (also in Spanish)

Sexuality for the Woman With Cancer (also in Spanish)

Books

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 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:

GIST Support International (GSI)
Phone number: 215-340-9374
Website: www.gistsupport.org

> Provides education and support to GIST patients and their families and friends, including brochures, newsletters, books, DVDs, and a listserve chat community

National Cancer Institute (NCI)
Toll-free number: 1-800-4-CANCER (1-800-422-6237)
TYY: 1-800-332-8615
Website: 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
Toll-free number: 1-888-650-9127
Website: www.canceradvocacy.org

> Call 1-877-NCCS-YES (622-7937) for publications on many topics and Cancer Survivor Toolbox® orders. The Cancer Survival Toolbox is 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 anytime, day or night, for information and support. Call us at 1-**800-227-2345** or visit www.cancer.org.

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