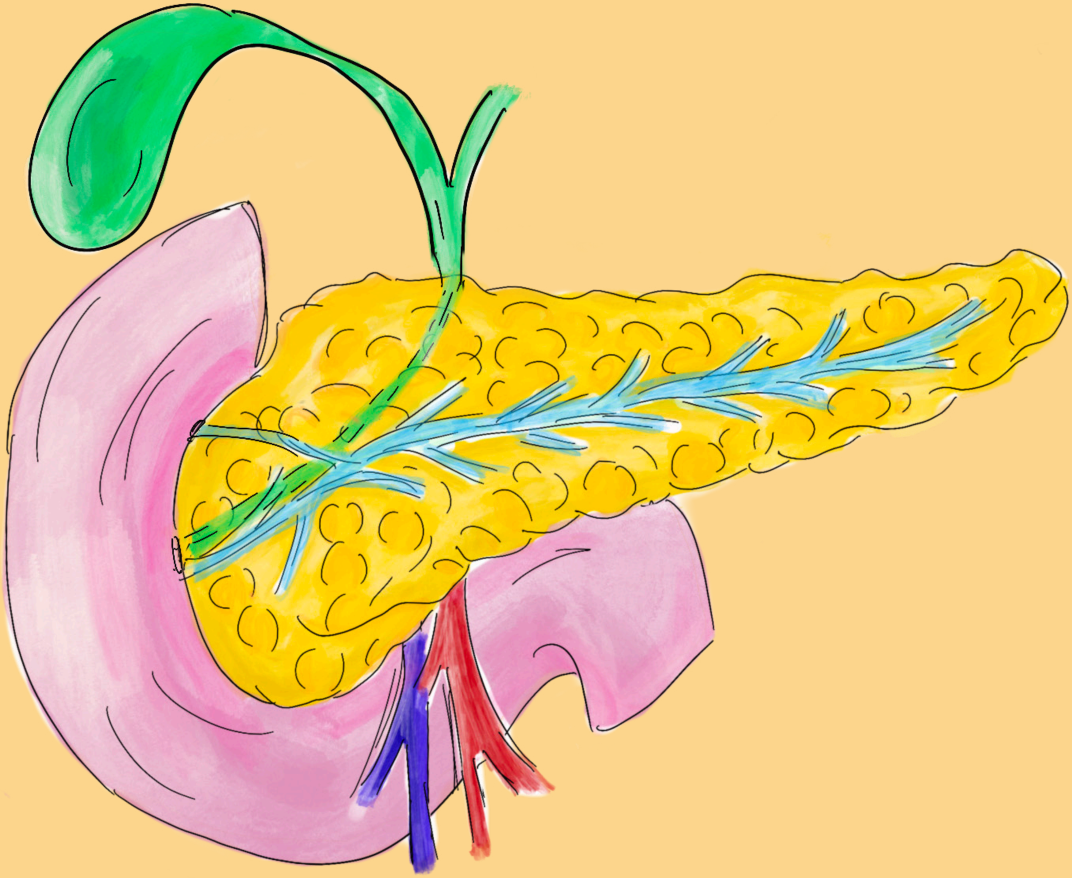
Pancreas Cancer

A patient-centered guide to diagnosis & treatment



Written and illustrated by Maria Baimas-George MD MPH

TerryBooks™

This book was written with help from:

XXXX

XX incredible hepatobiliary surgeons whose subject-matter expert review and edits of this material helped support the creation of this book.

Book Map

Before you begin reading - our DISCLAIMER

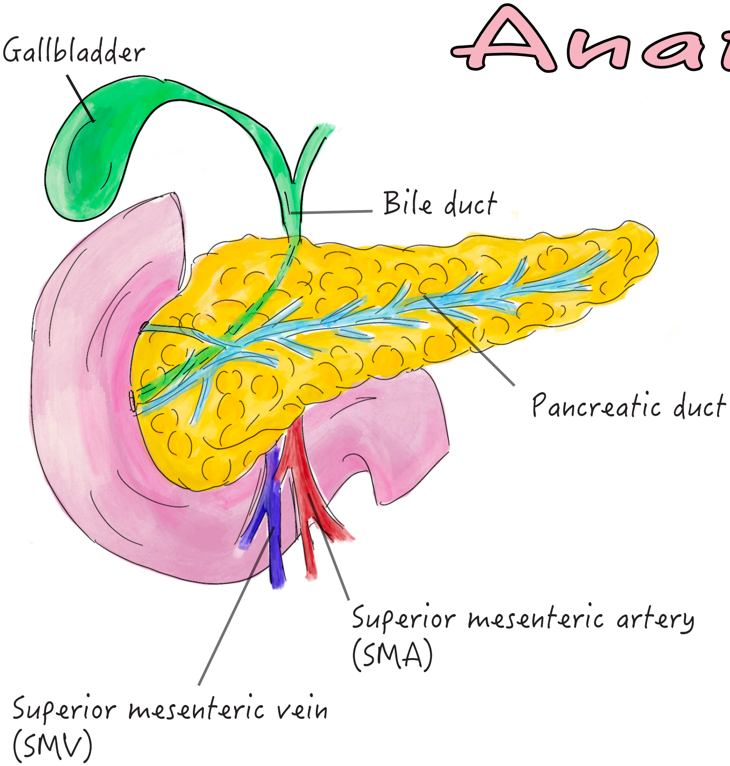
What this book will **not** do. It will **not** mince words. It will **not** blow smoke.
It won't focus on "beating cancer", "fighting the good fight",
or looking back on "what should have been done".
It is not a substitute for your doctors and healthcare team.
It does not include every bit of information available.

What this book will do. It will be **direct**. It will help you
understand a shocking, life-changing event. It will be a simple but
complete guide to your cancer, from finding (diagnosis) to treatment,
to long-term watching (surveillance) and supportive care.

It will be easy to read and understand,
so you can be an active partner in your care.
And it will give you the power to decide your path —your goals-
and come up with a plan that suits you!

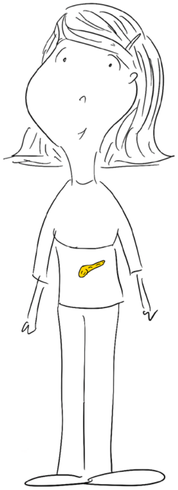
During this journey, remember to live in the present.
Find moments of joy, focus on quality of life.
Cherish time with loved ones.
When discouraged, don't forget there is hope through research.
Advancements leading to promising new treatments, and
increased survival rates. And remember to ask questions, seek second
opinions, and be active participants in your care.

Anatomy



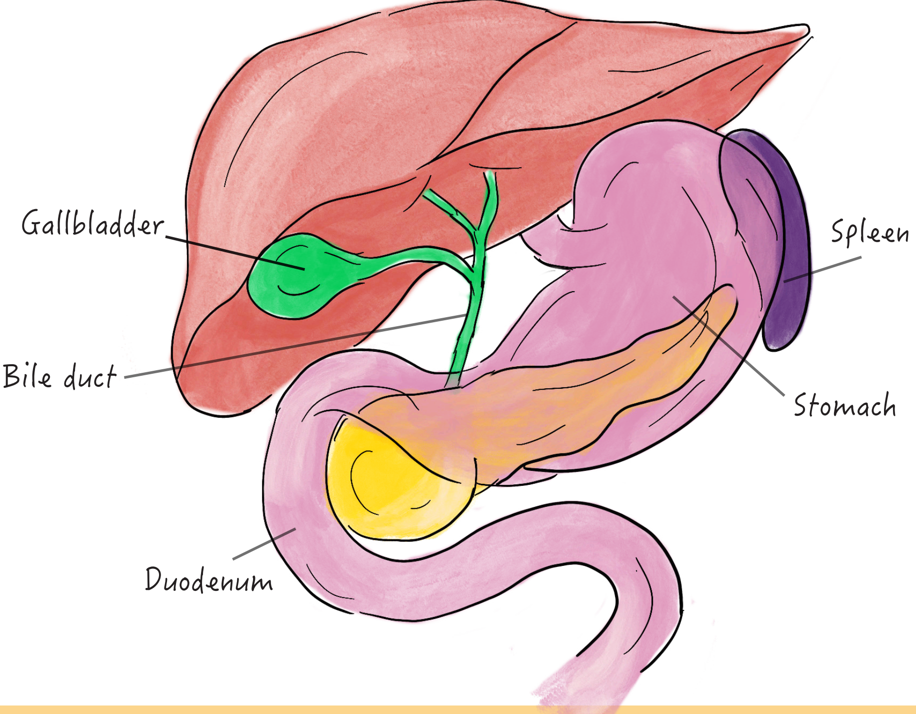
So first off, what is the pancreas?

The **pancreas** is an odd-shaped organ. Looks a little bit like a leaf or an ear of corn. It weighs less than a pound. And is flat and a dull, yellow color.

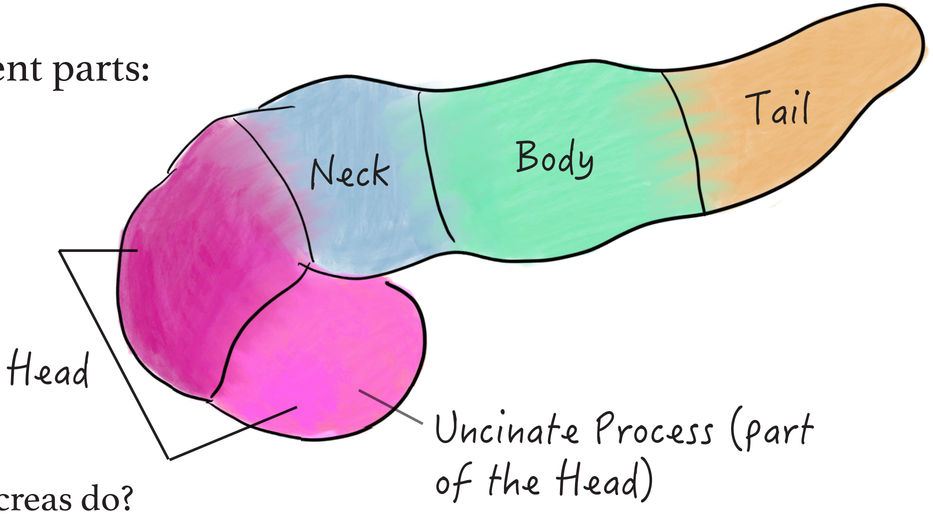


The pancreas sits in the upper left part of your abdomen (belly).

It is surrounded by a lot of different organs and major blood vessels.

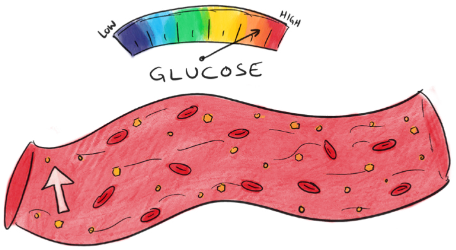


It has several different parts:



So, what does the pancreas do?

Well, it works in 2 systems of the body.



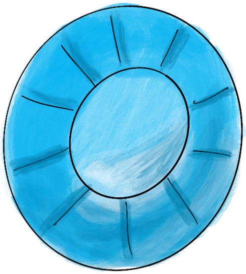
1) **The endocrine system** — creates hormones that are important for many things — like metabolism, growth, reproduction, stress, & blood sugar (**glucose**). The pancreas makes hormones (**insulin** & **glucagon**) to keep your blood sugar normal. Normal blood sugar is needed for the rest of your body - like the brain - to do their jobs.

2) **The exocrine system** — a series of glands that make different juices for your body. Like sweat, breast milk, and digestive juice. The pancreas makes **digestive juices** to break down food you eat. These juices travel in the **pancreatic duct** — a system of tubes. The pancreatic duct joins the **bile duct** (which travels from the liver) to empty into the first part of your small intestine (the **duodenum**). Here, the juices join with the food you eat to do their work.

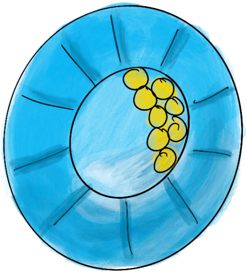
What is **pancreatic cancer**?

Pancreas cancer is cancer that begins in the pancreas. It begins when cells in your pancreas change (or **mutate**). They can become cancer cells.

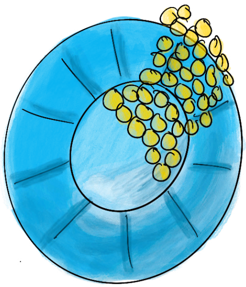
Cancer cell



Normal pancreas duct



Early Cancer



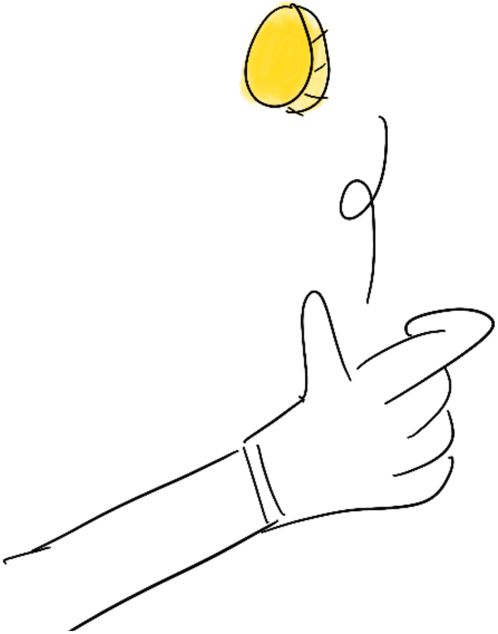
Invasive Cancer

There two main types of pancreatic cancer.

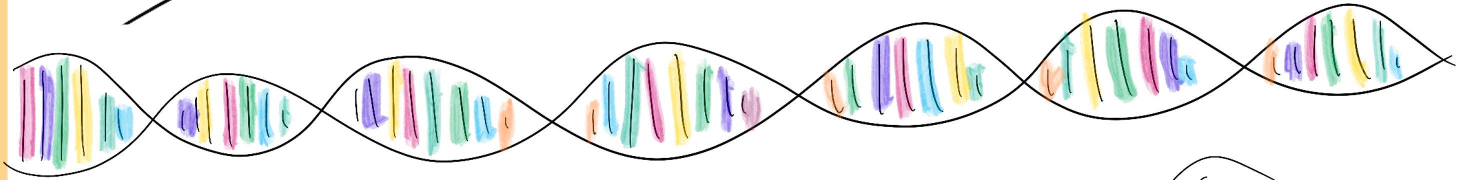
1) **Adenocarcinoma** – this is the most common type. It causes 80% of pancreas cancers. It comes from mutations in the pancreatic duct cells.
2) **Neuroendocrine tumors** – this tumor comes from mutations in the pancreatic endocrine cells. They are not always cancer. Sometimes they are benign.

This book is about **adenocarcinoma.**

Why does pancreas cancer happen?

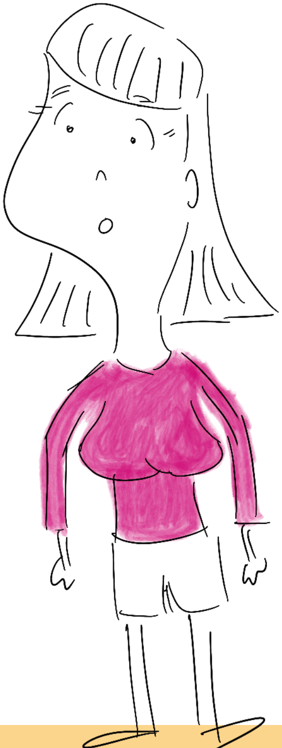


Pancreas cancer happens due to random **mutations**, or mistakes, in your DNA. Like a flip of a coin. We're not totally sure why these mistakes happen. So it is NOT your fault.



We do know there are some factors that can increase your chance of getting pancreas cancer. But remember, most of the time it is for unknown reasons.

- **unknown**
- smoking
- heavy drinking
- diabetes
- pancreatitis



Sometimes, it is due to **genes** (10%). If certain cancers are common in your family, we might test you for these genes. We'll discuss this in more detail on page XX.

Diagnosis

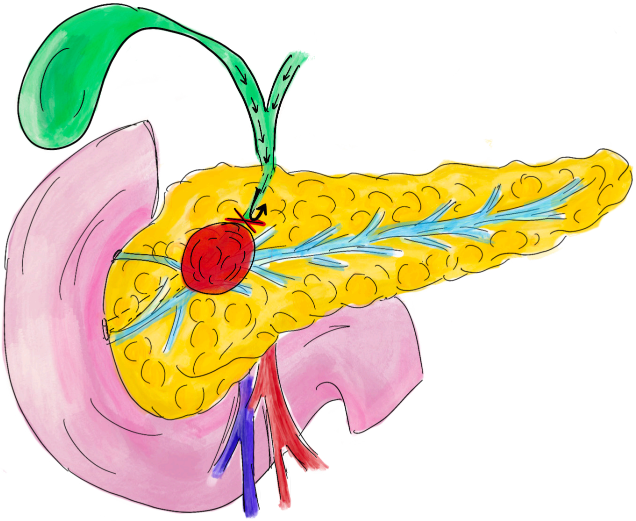
So how do we find (diagnose) it?

Sometimes pancreas cancer is found by accident. On imaging you may have of your abdomen that you needed for other reasons. Like after a car accident.

Most people with **early** pancreas cancer do not have signs or symptoms. That's why pancreas cancer is tricky. Because by the time it causes symptoms, it may have already spread to other organs.

Signs or symptoms of pancreas cancer may include:

1) Jaundice
2) Belly pain
3) Weight loss
4) Fatty stools (diarrhea!)
5) New diagnosis of diabetes



Jaundice is yellowing of the skin and eyes. It is caused by cancer blocking your bile duct. This causes bile to build up in the body. Your bilirubin lab number will be high. You may need special treatment with an **ERCP** (pg XX) to unblock your bile duct.

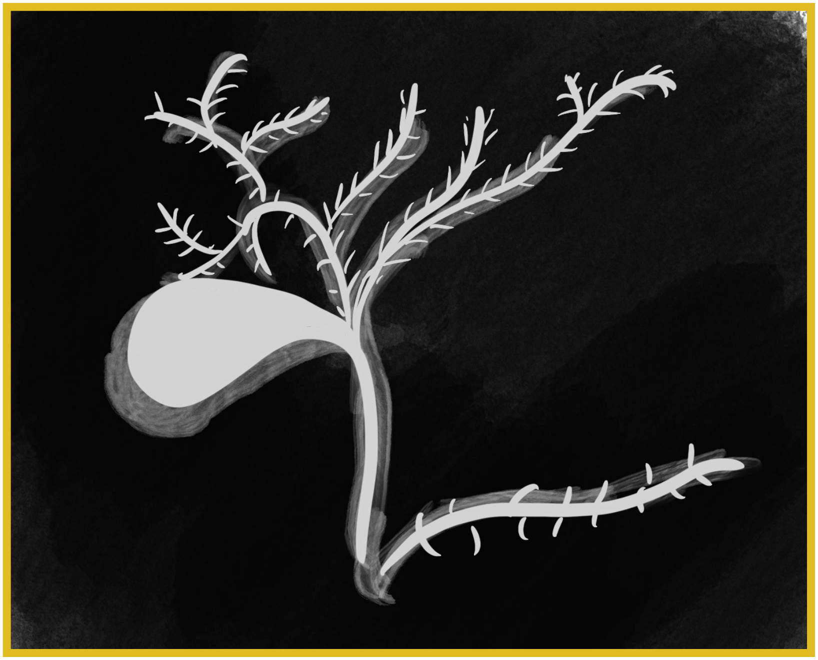
If you have these symptoms or there is a suspicion for cancer for another reason, you will get a CT or MRI scan.

CAT (CT) scan

This is imaging done of your pancreas. It will help confirm the diagnosis of pancreas cancer. It can also help stage the cancer. It can tell us:

- the cancer location
-if it involves major blood vessels
-if it has spread to other organs.

MRCP



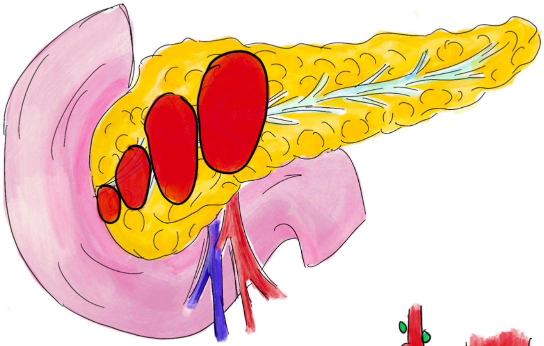
Magnetic resonance cholangiopancreatography (MRCP) is another type of imaging done of your pancreas to help confirm the diagnosis of pancreas cancer. It is a type of MRI that takes very clear pictures of the pancreas and bile ducts. It can also help stage the cancer.

-Not everyone will need a MRCP.

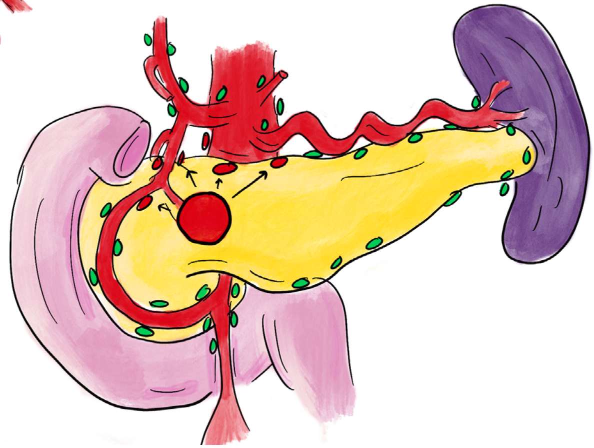
Staging

Next up – staging. Staging is a way to describe how much cancer is in the body. The official staging system for pancreas cancer is called TNM.

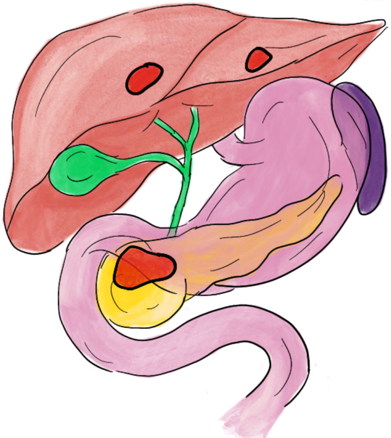
T = tumor size –
how big is the cancer?



N = lymph nodes –
do they have cancer cells in them?



M = metastasis –
has the cancer spread to distant parts of the body?



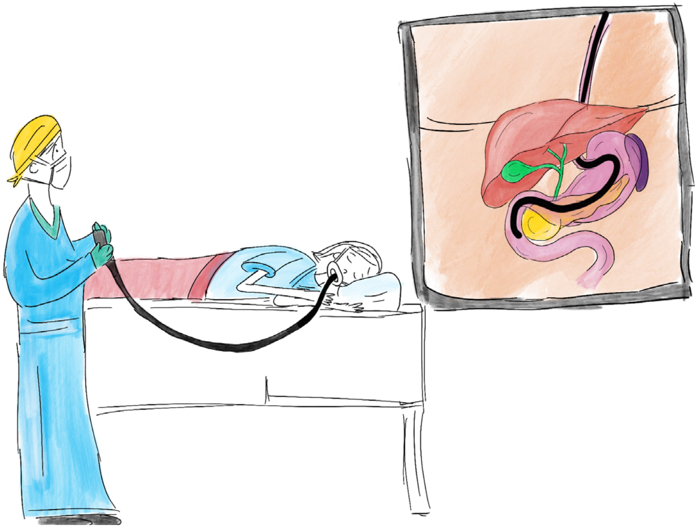
T N M are determined by a bunch of different tests including the CT scan and/or MRI scan. All information learned from these tests help determine the best treatment for you. **The main question is whether you have metastatic cancer or not.** **

These tests may include:
-Endoscopic ultrasound
-ERCP
-Labs
-Biopsy
-Genetics

Endoscopic Ultrasound

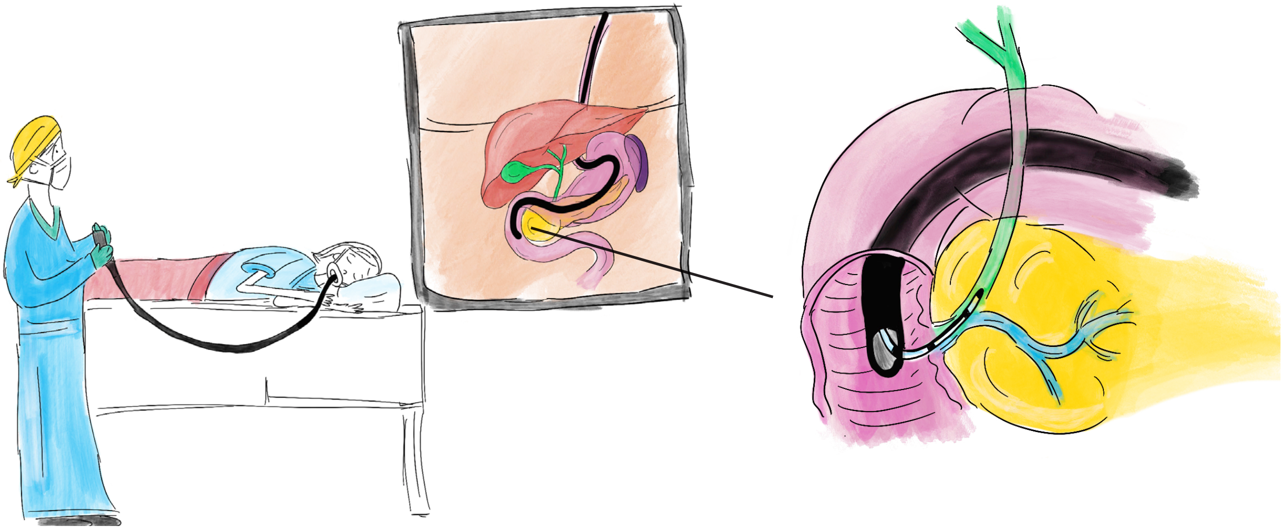
Endoscopic ultrasound (or EUS for short) is is a special type of ultrasound using an **endoscope**. An endoscope is a camera that goes in the mouth and is guided down to the pancreas. You will be asleep during this so it won't be uncomfortable.

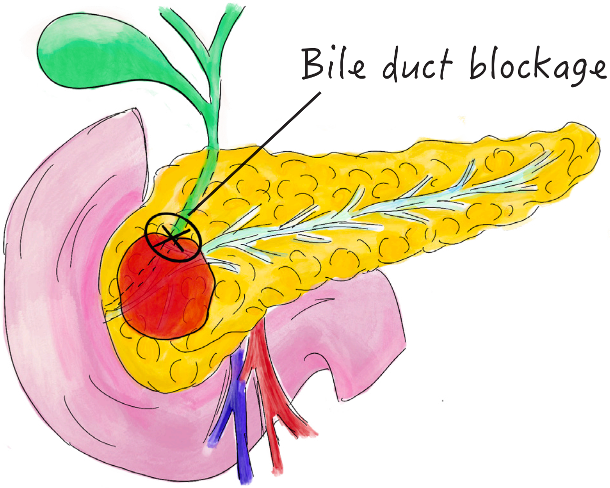
The EUS can tell us:
-the size of the tumor
-the location of the tumor
-if the lymph nodes are involved
-and to get a biopsy of the cancer

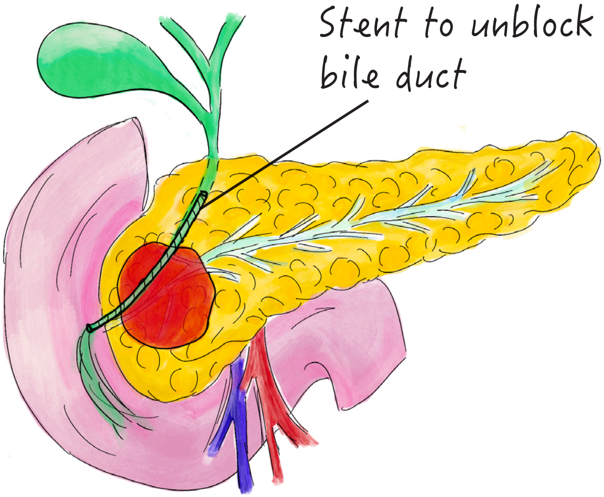


ERCP

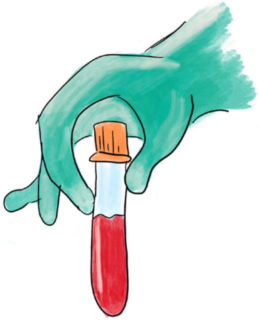
An ERCP is a special procedure that uses an endoscope and x-rays to see if the pancreas cancer is blocking your bile ducts (which causes jaundice). A small tube, called a **stent**, is placed in the bile duct to keep it open. This allows bile to flow again.





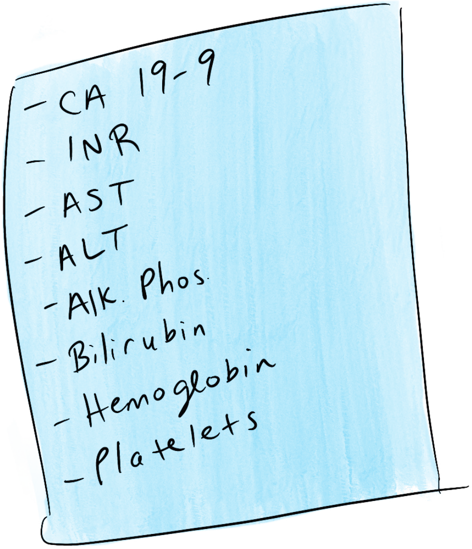


Labs



You will have labs drawn to look at your liver function – in particular your **bilirubin.**

High levels of bilirubin might mean the cancer is blocking your bile ducts or is in the liver.

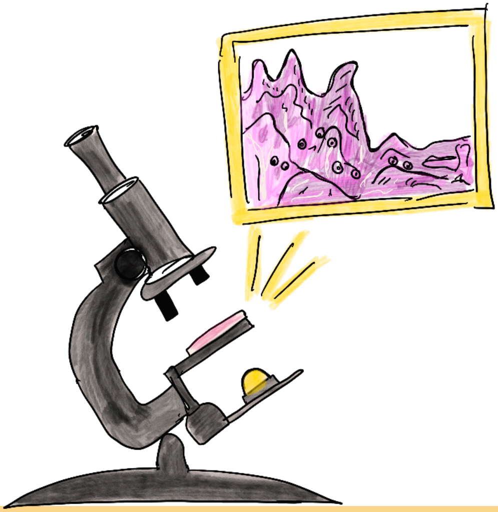


- CA 19-9
- INR
- AST
- ALT
- Alk. Phos.
- Bilirubin
- Hemoglobin
- Platelets

You will also get a special lab called the **Cancer antigen 19-9** (CA 19-9) level. This is because some pancreas cancer makes a protein called CA 19-9. So, measuring how much you have in your blood may be helpful.

Biopsy

Depending on the stage of your cancer, a **biopsy** may or may not be needed right away. If you are getting chemotherapy first, a biopsy is needed. Your doctors may get this with an endoscopic ultrasound. If you are getting surgery first, a biopsy may be taken at time of surgery.



Genetics

You may get tested for a gene mutation if you have a family history of pancreas cancer. Or other cancers.

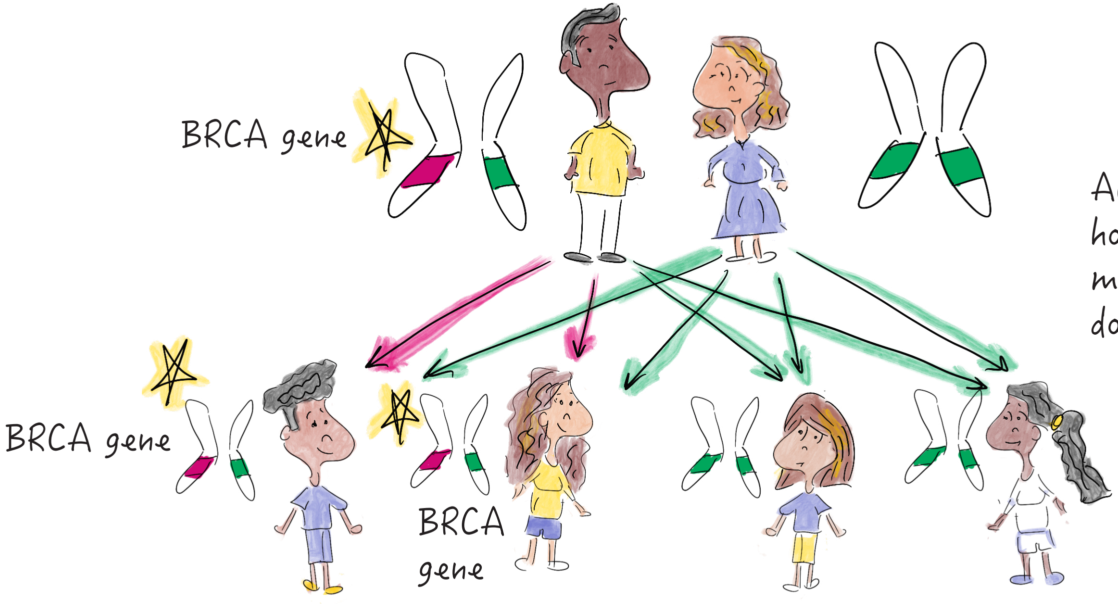
Most of the time (80%), we won't know the name of the gene (because we have yet to discover it!)
Sometimes (20%), we do know the name of the gene!

Common gene mutations we test for:

- BRCA1
- BRCA2
- ATM
- TP53
- CDKN2A
- MLH1
- MLH2
- MLH6
- TP53
- STK11

If you have a gene mutation, this can help guide treatment. We may suggest specific chemotherapy for you. Or clinical trials. Or immunotherapy.

***Immunotherapy** is a type of treatment that uses a person's own immune system to fight cancer.*

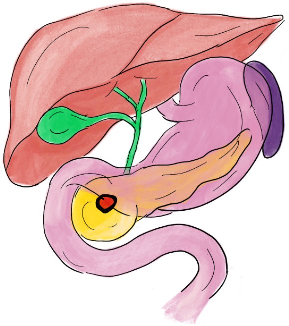


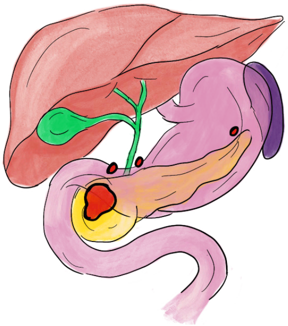
An example of how a BRCA gene may get passed down in a family

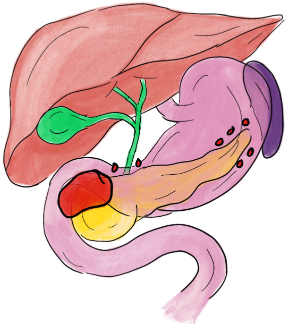
Cancer Stage

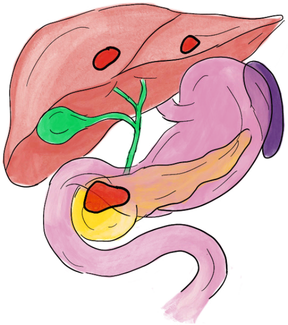
Treatment for pancreas cancer depends on the cancer **stage.**

There are four stages.









Stage 1
- Tumor only in pancreas
- Size < 4cm

Stage 2
- Tumor in pancreas & 1-3 lymph nodes
- Size > 4cm

Stage 3
- Tumor in pancreas
- Tumor also in nearby organs or more than 4 lymph nodes

Stage 4
- Tumor in distant organs

For treatment purposes, we use another staging system.

The cancer is divided into groups based on whether they can be **removed** with surgery. These groups are:

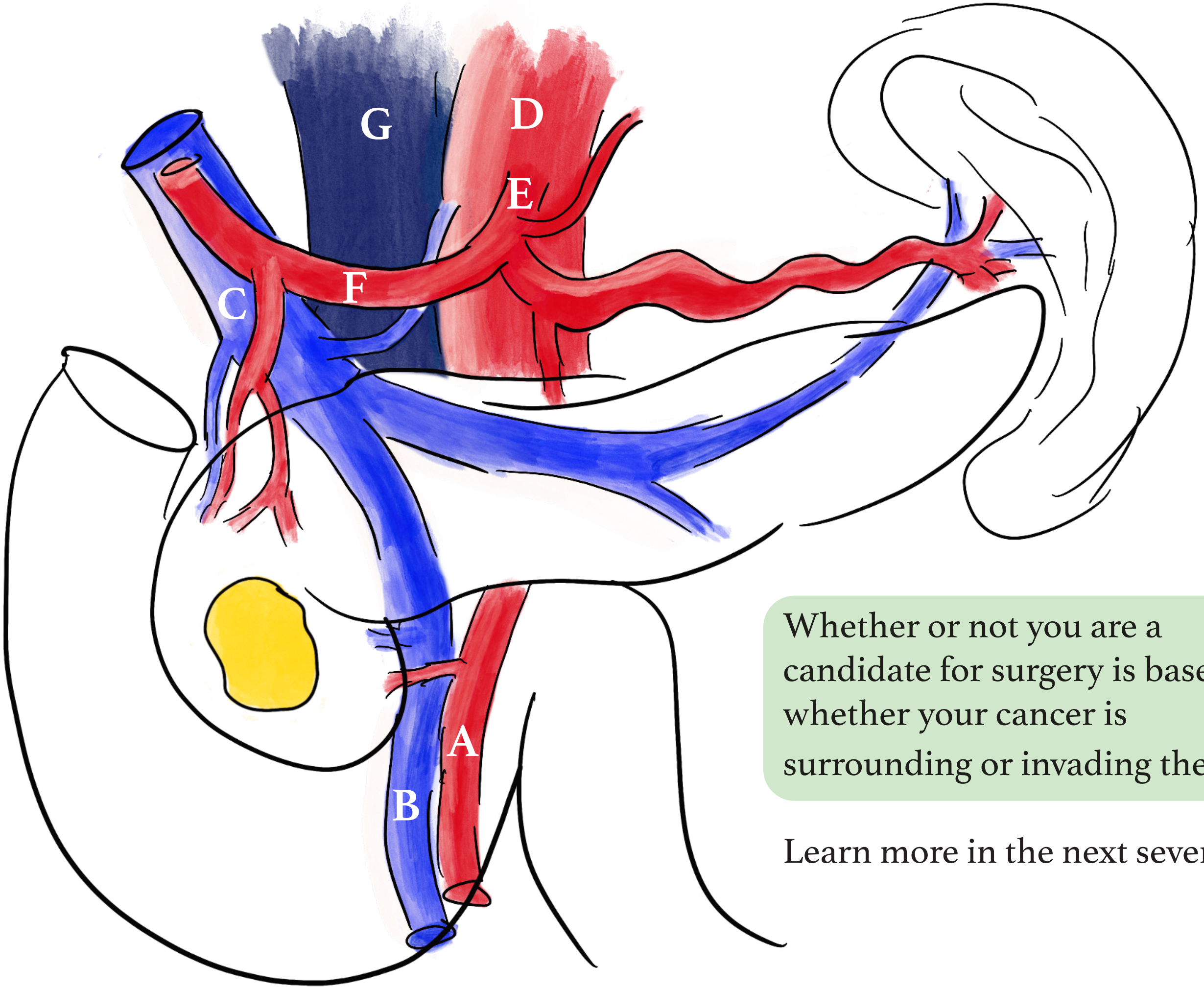
Resectable
Borderline resectable
Locally Advanced
Metastatic

These groups mainly depends on whether the cancer is invading **major blood vessels.**

Blood Vessels

The major blood vessels are:

- A) Superior Mesenteric Artery (SMA)
- B) Superior Mesenteric Vein (SMV)
- C) Portal Vein (PV)
- D) Aorta
- E) Celiac Artery
- F) Hepatic Artery
- G) Inferior Vena Cava (IVC)



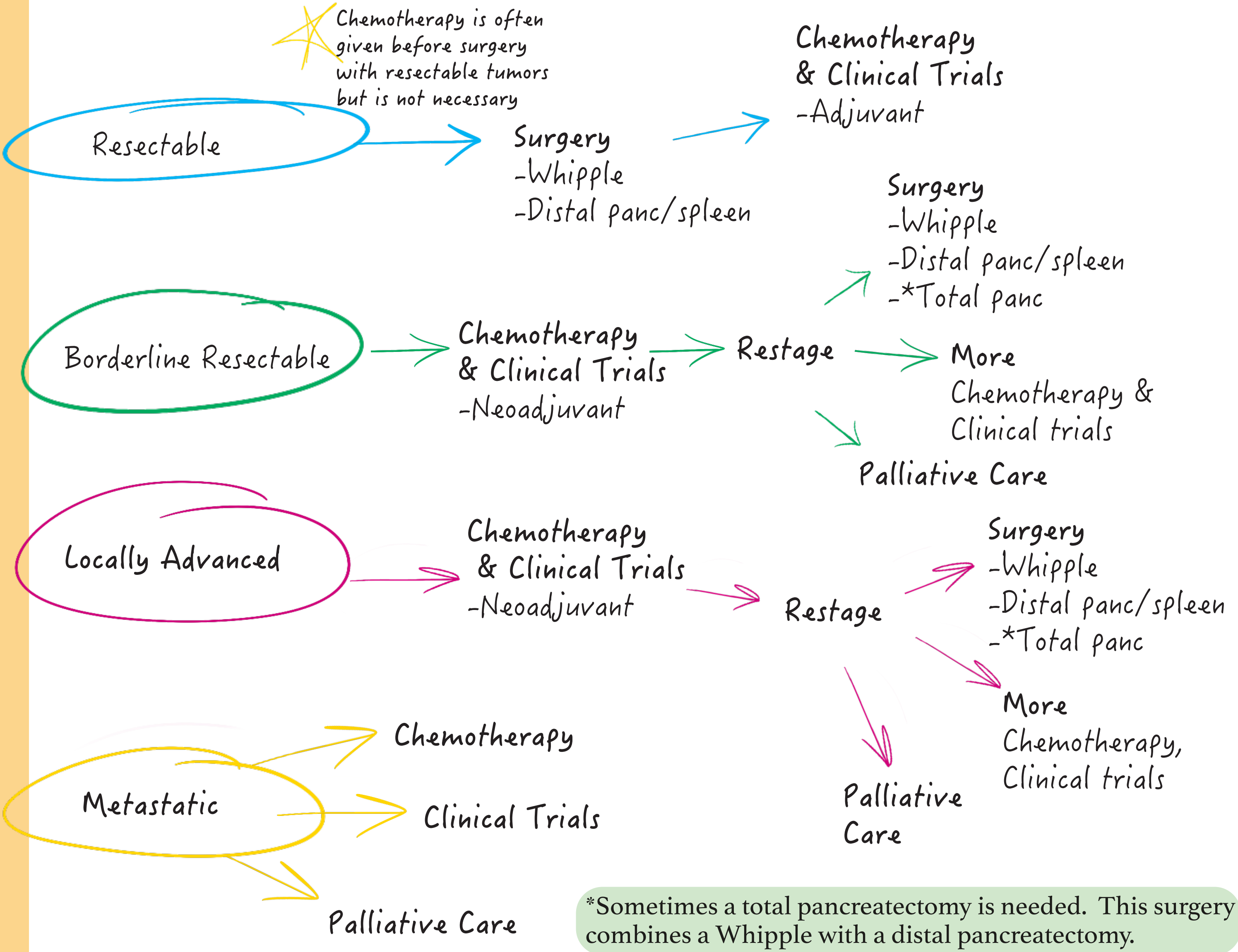
Whether or not you are a candidate for surgery is based on whether your cancer is surrounding or invading them.

Learn more in the next several pages.

Treatment

Treatment for pancreas cancer depends on these four cancer groups.

Below is the basic pathway treatment. However, treatment may vary based on your individual cancer, anatomy, and health.



Chemotherapy is often given before surgery with resectable tumors but is not necessary

Resectable

Surgery
-Whipple
-Distal panc/spleen

Chemotherapy & Clinical Trials
-Adjuvant

Borderline Resectable

Chemotherapy & Clinical Trials
-Neoadjuvant

Restage

Surgery
-Whipple
-Distal panc/spleen
-*Total panc

More Chemotherapy & Clinical trials

Palliative Care

Locally Advanced

Chemotherapy & Clinical Trials
-Neoadjuvant

Restage

Surgery
-Whipple
-Distal panc/spleen
-*Total panc

More Chemotherapy, Clinical trials

Palliative Care

Metastatic

Chemotherapy

Clinical Trials

Palliative Care

*Sometimes a total pancreatectomy is needed. This surgery combines a Whipple with a distal pancreatectomy.

Resectable Cancer

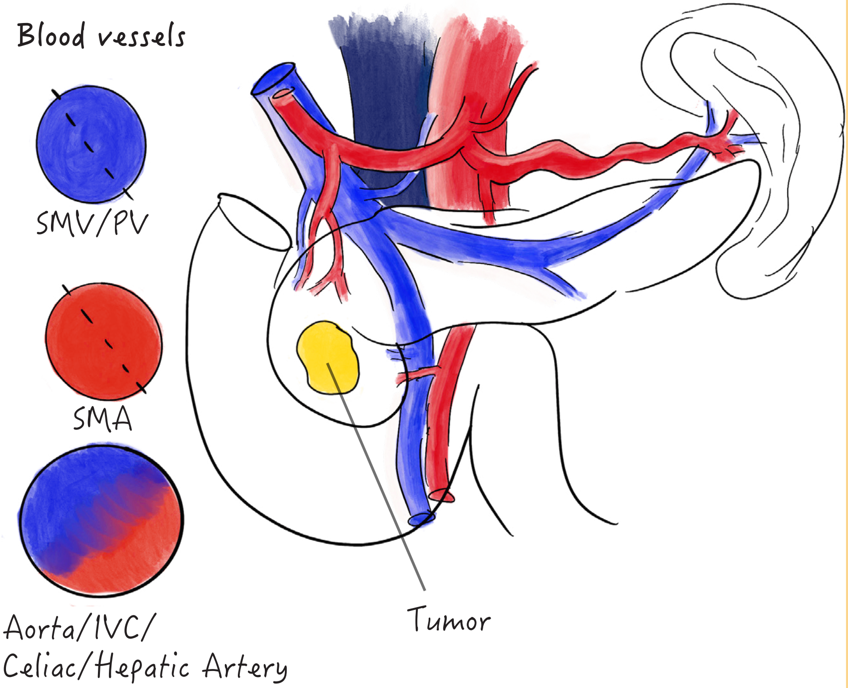
What is Resectable Cancer?

-Stage 1 or Stage 2 disease

-Tumor is limited to the pancreas and the organs nearby (like the small bowel, bile duct, stomach)

-Tumor does not surround/invade any major blood vessels

-No metastatic disease (M0)



Only 20% of patients (2 out of 10 people) will have resectable cancer.

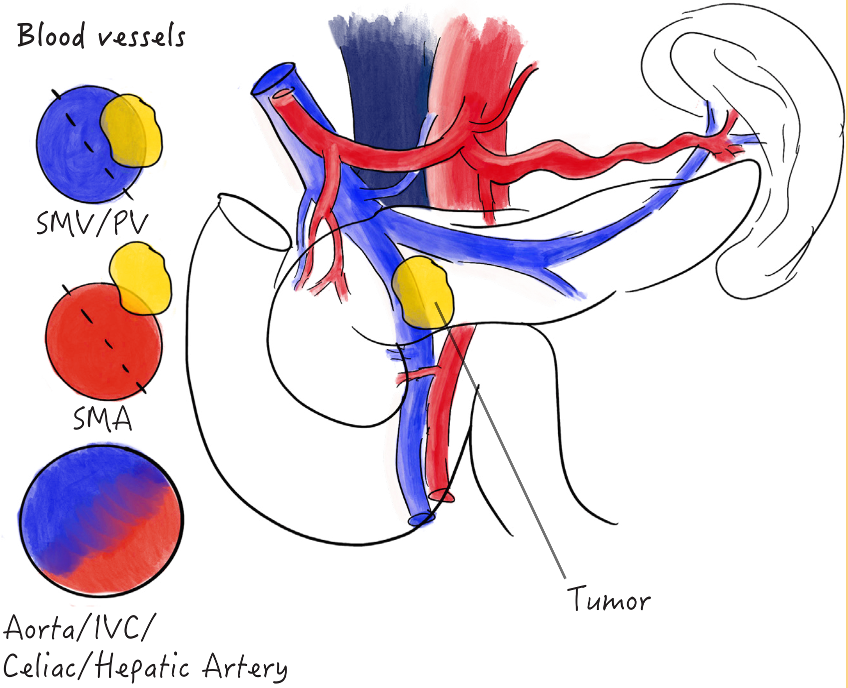
Treatment can be surgery first. Often, chemotherapy is given before surgery. But it is not necessary. The surgery is a big abdominal surgery. It will be either a **Whipple** (pg XX) or a **distal pancreatectomy with splenectomy** (pg XX). Which type of surgery depends on the cancer location. After surgery, you will need chemotherapy.

It is important to remember that some cancers might look resectable on imaging. But sometimes, once surgery has started, it becomes clear that the cancer is not resectable. That means that not all of the cancer can be removed. In this case, your surgeon will stop the surgery or has to leave some of the cancer behind and do a palliative surgery (pg XX).

Borderline Resectable Cancer

What is Borderline Resectable Cancer?

- Stage 3 disease
- Tumor is limited to the pancreas and the organs nearby (like the small bowel, bile duct, stomach)
- Tumor **does** surround or invade major blood vessels but resection is still possible
- No metastatic disease (M0)



Treatment is chemotherapy first. This is called **neoadjuvant** treatment. The goal is to decrease the size of the cancer, making surgery possible. You may also be put in a **clinical trial** (pg XX).

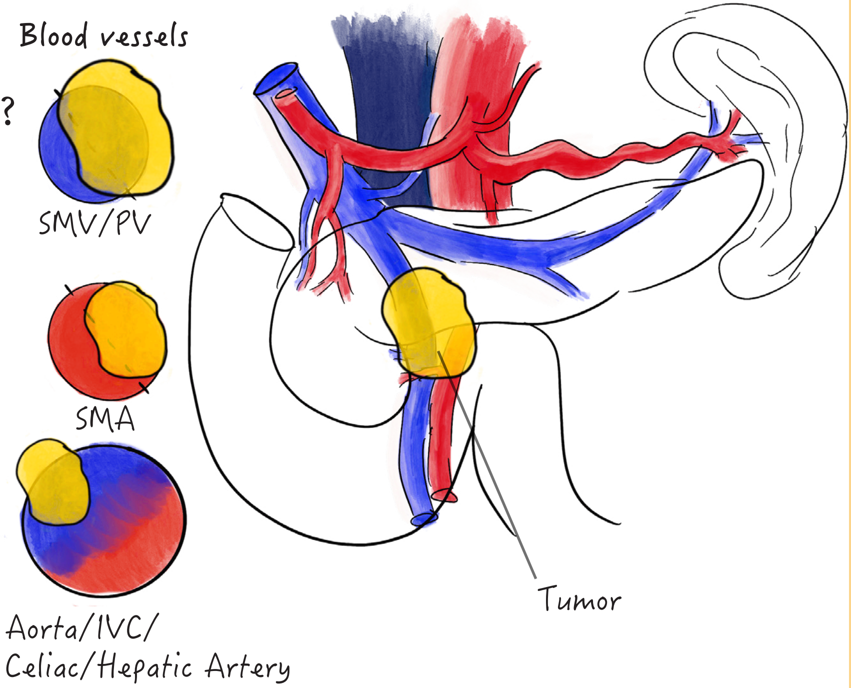
A course of chemo is 6 months. Once chemo is done, you will have a break to let the treatments kill cancer cells. After 3 to 6 weeks, your doctor will '**restage**' you. This means they will repeat your CT or MRI scans to see if the cancer is smaller.

If your cancer now looks resectable, you will have surgery. If not, you might get more chemo, clinical trials, or palliative care.

Locally Advanced Cancer

What is Locally Advanced Cancer?

- -Stage 3 disease
- -Tumor is limited to the pancreas and the organs nearby (like the small bowel, bile duct, stomach)
- -Tumor **does** surround or invade major arteries or having vein involvement that cannot be reconstructed***
- -No metastatic disease (M0)



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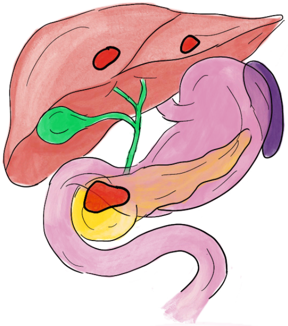
Metastatic Cancer

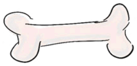


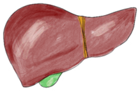
- Metastatic
  - Symptomatic (bleeding, obstruction)
    - Palliative Surgery or Procedures
      - Chemotherapy & Clinical Trials
    - Palliative Medical Care
  - Not symptomatic
    - Chemotherapy & Clinical Trials
    - Palliative Medical Care

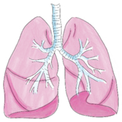
What is Metastatic Cancer?

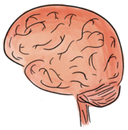
-Stage 4 disease

-The cancer has spread beyond the pancreas to distant organs (like the liver, lungs, bones, & brain)









If your metastatic disease starts off **symptomatic** - causing you problems - you may need a surgery to help you feel better before starting chemo (page XX).

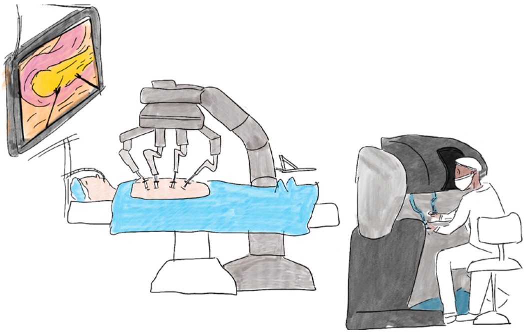
If you are not symptomatic, you may start with chemo and clinical trials. After this, you will be '**re-staged.**' Your treatment options will then depend on those restaging results. In very very rare cases, if there is limited metastatic disease or all the disease responds to treatment, surgery may be an option.

Surgery:

Big or little cuts (incisions)?

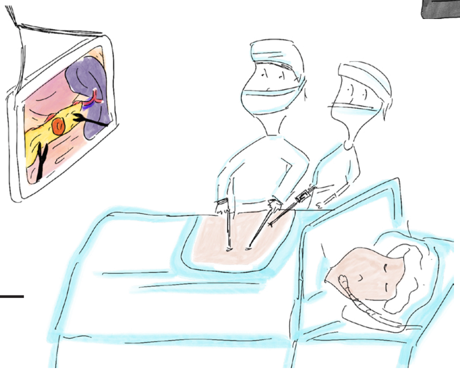
How do we do surgery? There are two main ways. *Minimally invasive* or *open*.

Minimally invasive (MIS) uses a camera and long tools that go in through small cuts. Your belly is filled with gas to expand the area and allow your surgeon to see inside better.

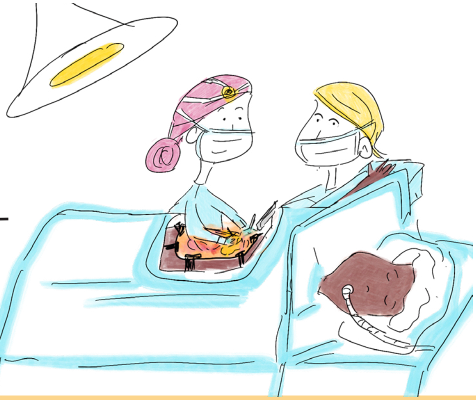


There are two types of MIS surgery:

1) **Robotic Surgery**: The surgeon may use a robot-like machine to remove tissue. You will have one bigger cut to remove the cancer from your body.

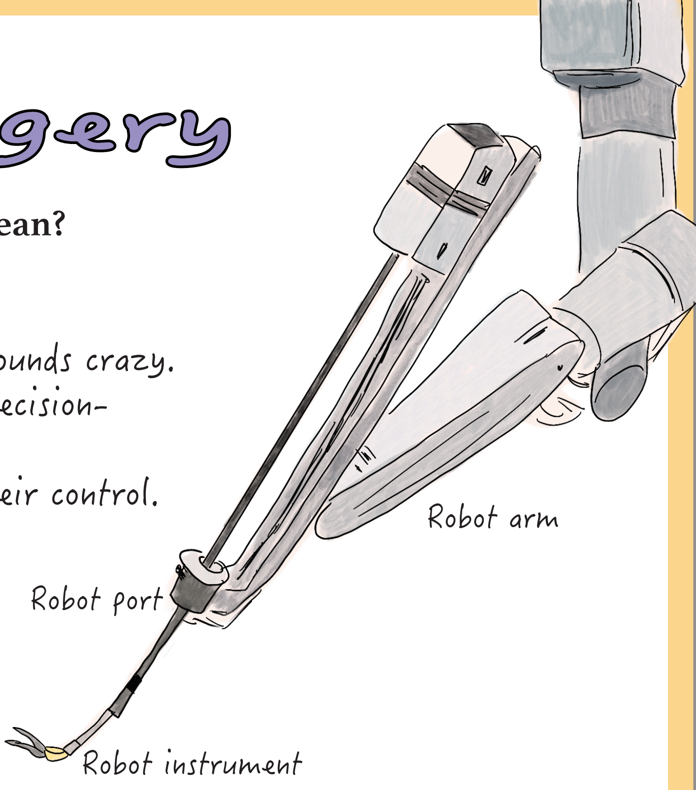


2) **Laparoscopic Surgery**: The surgeon may remove the tissue with tools and the camera to guide them. You will have one bigger cut to remove the cancer from your body.



Open surgery uses one big cut. Sometimes, we may start or combine with MIS surgery. But switch to open surgery while in the middle of surgery. We may do this for safety reasons. Or we may not be able to see enough with the camera. We may also do open surgery if you have a lot of scar tissue from other surgeries.

MIS Surgery



So, first - robotic surgery. What does that even mean?

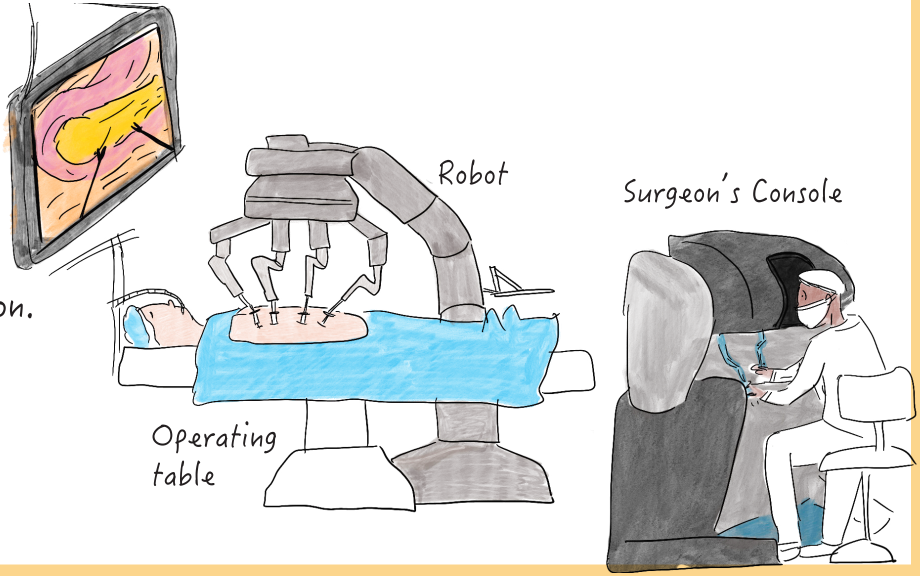
Robotic surgery is a type of MIS surgery.
Surgeons use robotic machines to do your surgery. Sounds crazy.
Your surgeon is still your surgeon. They do all the decision-making and operating. The robot simply helps them see better, move their hands better, and improve their control.

Huh? How does that work?

Robotic surgery is performed through tiny cuts. Ports are placed through these cuts into the belly. The robot instruments go through these ports. And then the surgeon moves the robot arms & instruments from a special computer desk called a console. The console sits in the operating room right next to the operating table.

What's the difference between robotic and open surgery?

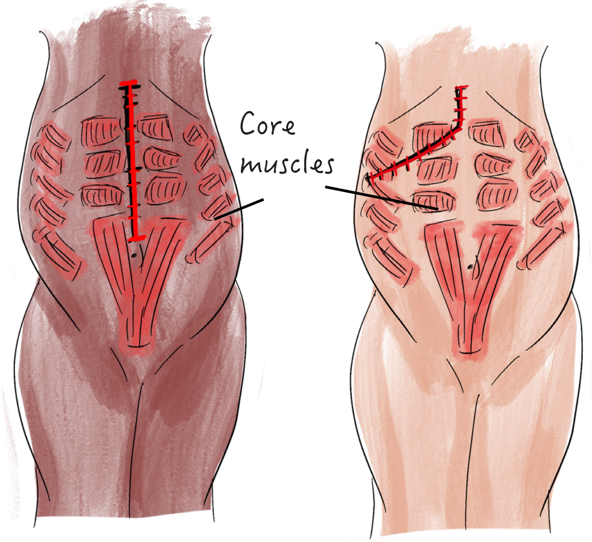
Robotic surgery has many advantages. It lets surgeons perform difficult surgeries with more control, flexibility, and precision. The robotic camera lets the surgeon see everything in high-def and 3D. It also can zoom in up to TEN times! So they can see better.



So what's so special about MIS pancreas surgery?

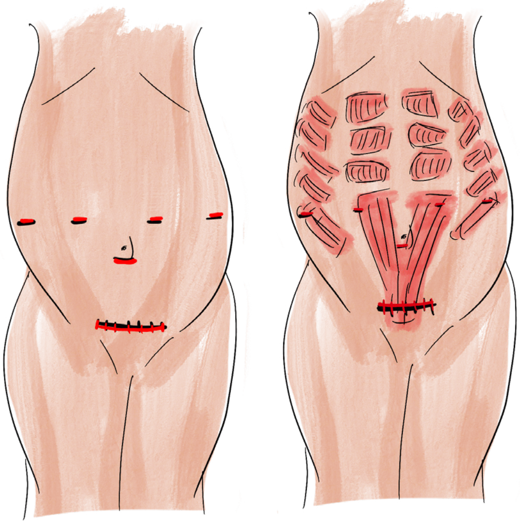
In an open pancreas surgery, surgery is done through one large cut. This cut is opened so the surgeon can see and operate. It's a big cut either straight down your belly or right under your right ribs. In both cases, it cuts through your core muscles. Core muscles are used for nearly everything you do. Breathing. Sitting up. Moving around. So after an open surgery like this, it is a longer recovery. It may hurt more to take deep breaths and move around. And it may be more time before you feel ready to get back to normal life.

Open surgery cuts



Now with minimally invasive surgery - both robotic and laparoscopic - the surgery is done through tiny cuts. So your core muscles are not hurt. There is one bigger cut that is made. This cut is to remove the cancer from your belly without hurting it. Surgery does not happen through this big cut. So it does not get stretched or pulled apart.

MIS surgery cuts



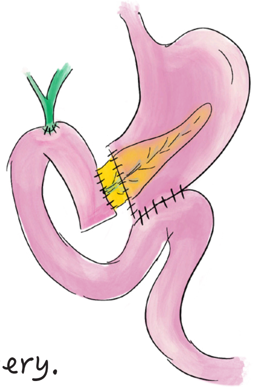
What about after surgery?

People who have MIS surgery get out of the hospital faster. Often in XX days! They also have less pain. Because of the smaller cuts! They also return to normal activity sooner (usually in 4 weeks instead of 4 to 6 weeks).

Why doesn't everyone have MIS surgery for pancreas cancer then?

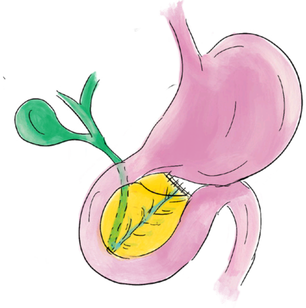
Pancreas surgery is very difficult. Doing it with MIS is even more difficult. So it may be too challenging for you and your type of cancer. It also might not be offered by your surgeon. **In general...**

If you are having a Whipple surgery:



-Very few surgeons offer a **laparoscopic** approach.
Because laparoscopy is the hardest way to do a Whipple surgery.
So it is very unlikely you will be offered this.
-More surgeons offer a **robotic** approach.
Because robotic surgery is also a very hard way to do a Whipple Surgery.
But it is easier than laparoscopy so more surgeons offer this approach.
-All surgeons offer an **open** approach. This is the most common way a Whipple is done.

If you are having a Distal Pancreatectomy surgery:



-Many surgeons offer a **laparoscopic** approach.
-Many surgeons offer a **robotic** approach.
-All surgeons offer an **open** approach.

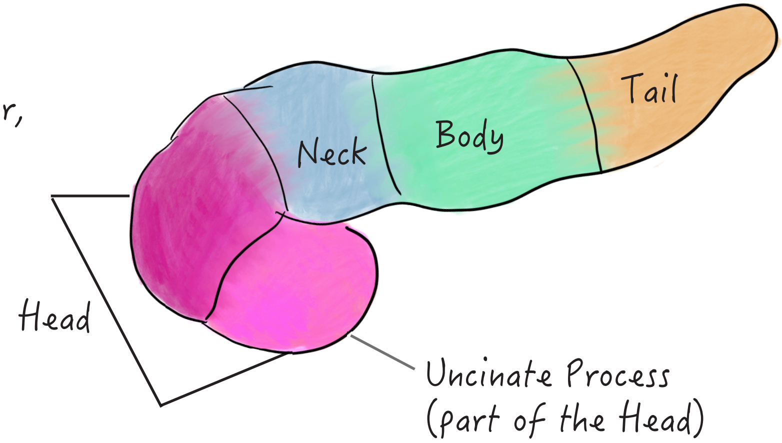
Sometimes, your surgeon is skilled in MIS surgery.
But recommends an open surgery for you. Why?

Not all cancers and patients are candidates for MIS surgery.
And not all surgeons and centers offer MIS surgery.

Open surgery is often safer for:
-cancers that involve the blood vessels
-older, frail patients
-patients that cannot tolerate MIS surgery

Discuss with your surgeon which type of surgery they offer and which is best for you!

Surgery



So, what will your surgery consist of?

During surgery we will remove your cancer, its blood supply, and lymph nodes.

It is one of two surgeries:

- Pancreaticoduodenectomy ('Whipple')
- Distal pancreatectomy with or without splenectomy ('Distal Panc')

Which surgery you need is based off of the cancer's location:

1) Cancer in the head, uncinate process or neck --> **Whipple Surgery.**
2) Cancer in the body or tail --> **Distal Pancreatectomy.**

Can surgery be cancelled?

Yes. CT scans and other imaging you have before surgery only give so much information. They are not perfect. Sometimes the cancer is more advanced - or has invaded more places then imaging shows. And surgery is not possible. In order to find out, we will:

1) before we start the cancer surgery, we peek around your belly with a camera through tiny incisions or through one small bigger incision. This is a '**diagnostic laparoscopy /laparotomy.**' We are looking to see if the cancer is metastatic - or has spread to more distant areas in your body. Like your liver. If it has, we will not move forward with the big cancer surgery. You may still get a palliative surgery (pg XX).

2) If it isn't metastatic, we will continue with the cancer surgery as planned. However, as we continue to operate, we may find that the cancer is more locally advanced then we thought. And surgery is not possible. If so, we will stop surgery and talk to your family.

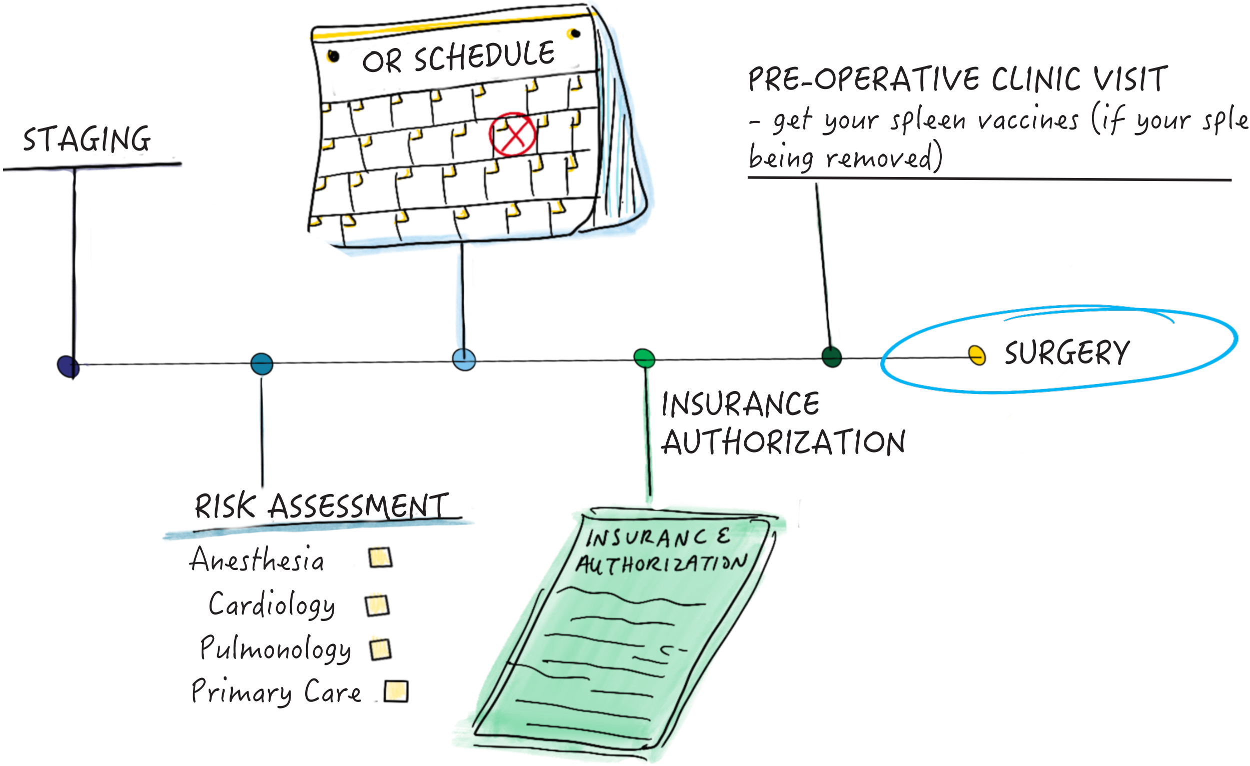
When will it happen?

So, when is surgery?

Just like you, we want to treat or remove it as soon as we can. But we need to be safe. Don't forget, your cancer took many years to grow. It will not spread over weeks while we complete testing and plan surgery. **You need the following to happen BEFORE surgery:**

1) If you had chemotherapy, wait 6 to 8 weeks after finishing and then complete the steps in the diagram below!

2) If you do not need chemotherapy before surgery, just complete the steps below!



Whipple Surgery

For cancers in: the head, uncinate process, or neck of the pancreas

What's removed: Head, uncinate process & neck of the pancreas, duodenum, gallbladder, part of stomach, part of bile duct

What's connected: Three connections ('**anastomoses**') are made.

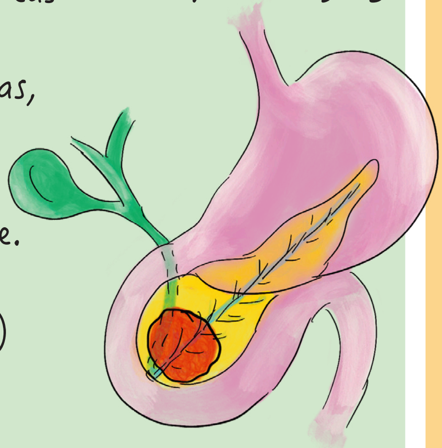
1) Bile duct to small intestine – 'Hepaticojejunostomy' (A)
2) Pancreas to small intestine – 'Pancreaticojejunostomy' (B)
3) Stomach to the small intestine – 'Gastrojejunostomy' (C)

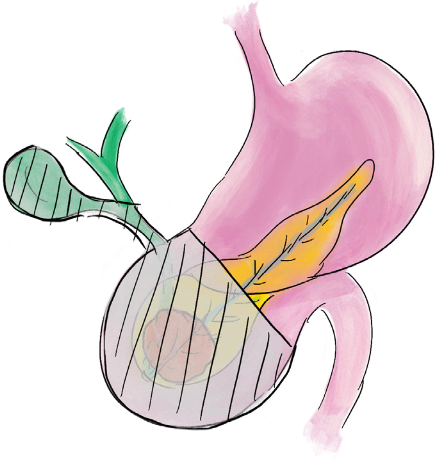
Surgery time (most often): Between 4-6 hours (but see page XX for details).

Surgery type (most often): Open surgery.

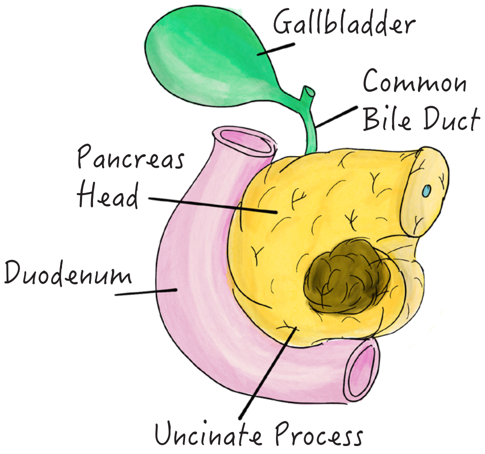
Drains: Sometimes 1 or 2 drains are left – by the connections to the pancreas & liver

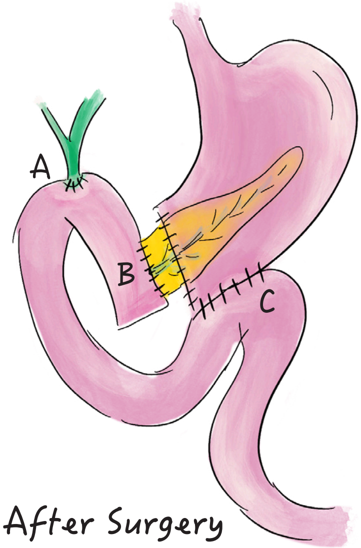
Before Surgery



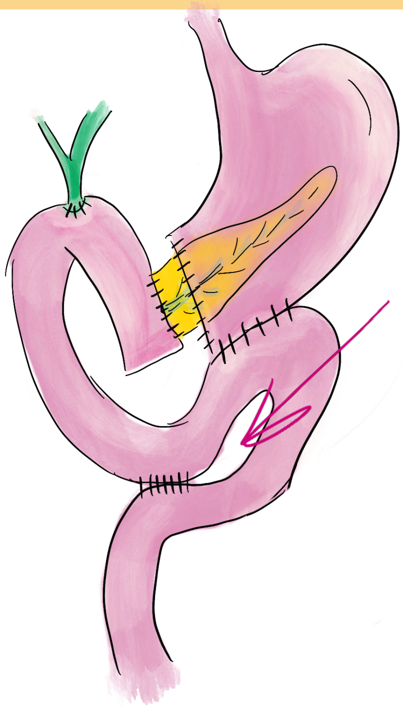


What's removed





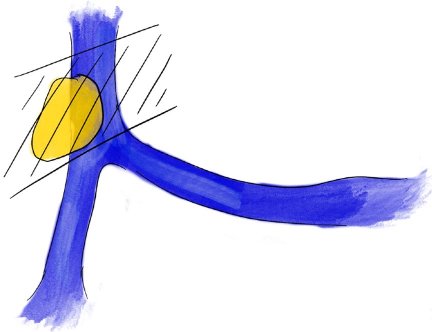
After Surgery



Some surgeons will give you one extra connection.

This is called a '**Braun enteroenterostomy**'. It is a connection between two loops of small bowel.

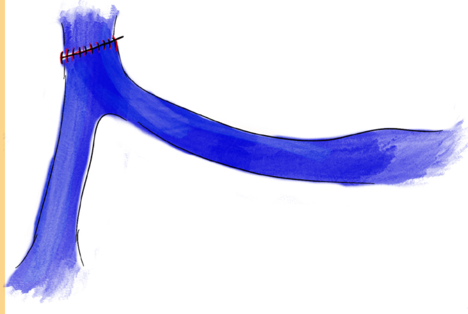
It may help lower your risk of delayed gastric emptying (see the next page!)

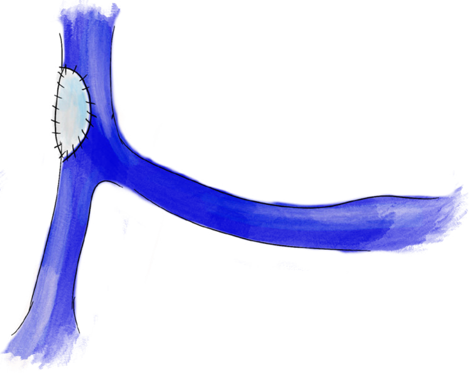


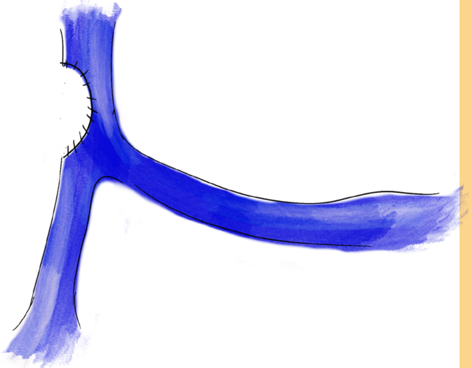
Sometimes your cancer might be invading the portal vein or the superior mesenteric vein.

In this case, you may need that piece of the vein - that has the cancer in it - cut out.

After the cancer and vein piece is removed, the vein is rebuilt. This can done several different ways. See pics below!

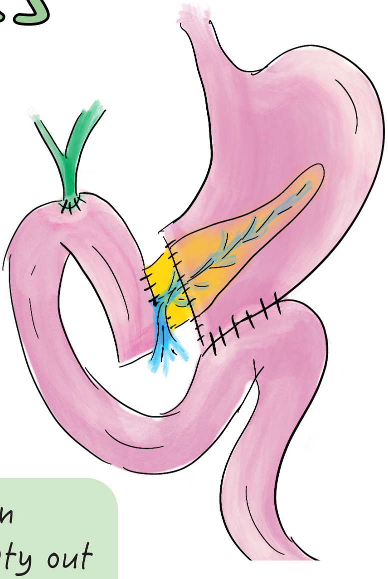




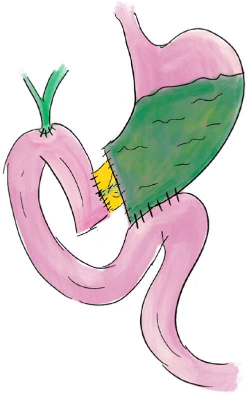


Some Surgery Risks

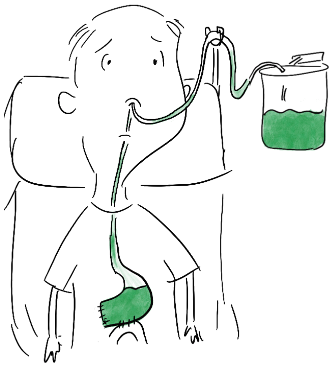
Short term risks:



Anastomotic leak: This is when bile, stomach juices or pancreas juices leak from the surgery connections that are made. Sometimes you may need a drain and antibiotics. You may also need IV nutrition (TPN) while you heal.



Delayed Gastric Emptying: This is very common after a Whipple Surgery. Your food won't empty out of your stomach into your small intestine as quickly as normal. Food stays in your stomach longer. This can make you feel nauseous. It can also make you vomit. It most often goes away about 4 to 12 weeks after surgery. You may need a nasogastric tube (NG Tube) to help drain the stomach. You may also need a feeding tube to get good nutrition while you heal.



Chyle leak: This is a leak from lymph vessels in your body. Chyle is fluid your body makes when you eat fat. It will look like cloudy or 'milky' fluid. You may need to be on a low-fat diet. You may also need to stop eating and get IV nutrition (TPN).

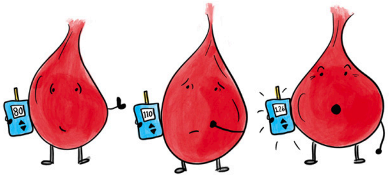
Bleeding: After surgery, bleeding can happen. This can be from blood vessels that are injured during surgery. Like the gastroduodenal artery (the GDA). You may need a special radiology scan (called an angiogram) with embolization (blocking) of the bleeding vessel. Sometimes you will need to go back to the operating room.

Infection - We will give you antibiotics before surgery to help lower this risk.

Other short term risks include: blood clots, kidney or liver problems, & heart problems

Long term risks:

Weight loss: EVERYONE loses weight. Don't worry. You will regain some of your weight as you start to take in more food!



Diabetes: This is more likely to happen if you have a family history of diabetes or have pre-diabetes. The pancreas is in charge of making and releasing insulin. Insulin controls your blood sugar. So removing part of your pancreas can impact your blood sugar level.

Pancreatic enzyme insufficiency: The pancreas is in charge of making and releasing digestive enzmes. These enzymes help break down the food you eat. So removing part of your pancreas can impact this. If this occurs, you may need pancreatic enzyme replacement therapy. These are just pills you take when you eat food.

Death: 1-2%. Risk of death from surgery or a complication after surgery is a small but real risk. At most high volume centers, it is 1 or 2 people out of a 100.

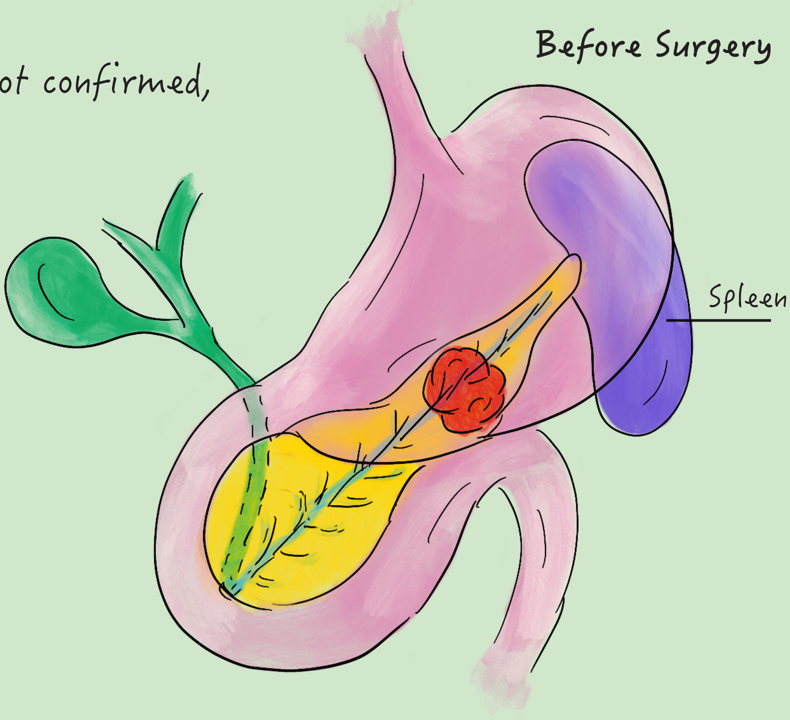
Distal Pancreatectomy Surgery

For cancers in: the body & tail of the pancreas

What's removed: the body & tail of the pancreas, the spleen

What's connected: nothing. There are no connections (or anastomoses) made.

The spleen: is always removed if your tumor is cancer or suspected to be cancer.
Rarely, when a cancer diagnosis is not confirmed, we may consider leaving the spleen.



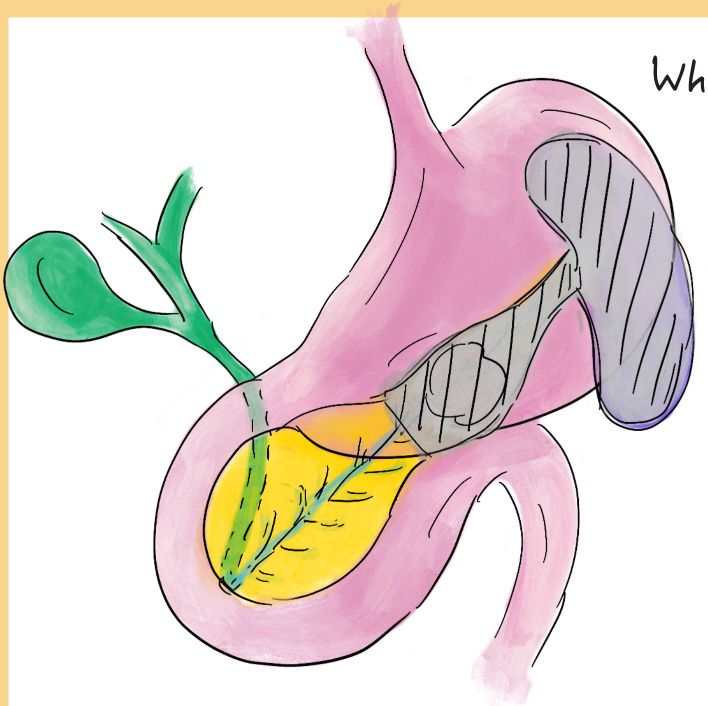
Spleen vaccines: you will need to get spleen vaccines about 2 weeks before surgery if

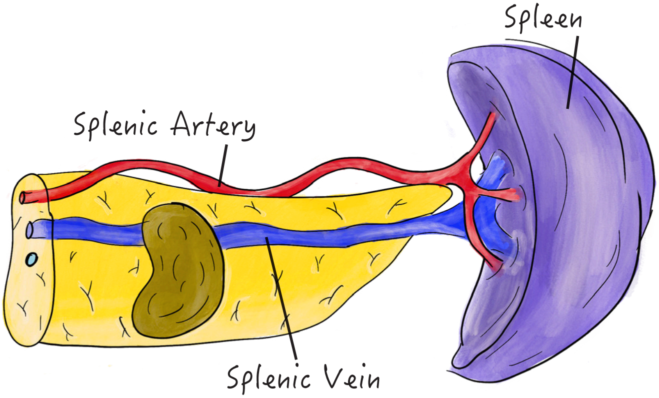
Surgery time (most often): between 3-4 hours (but see page XX for details).

Surgery type (most often): MIS (laparoscopic or robotic)

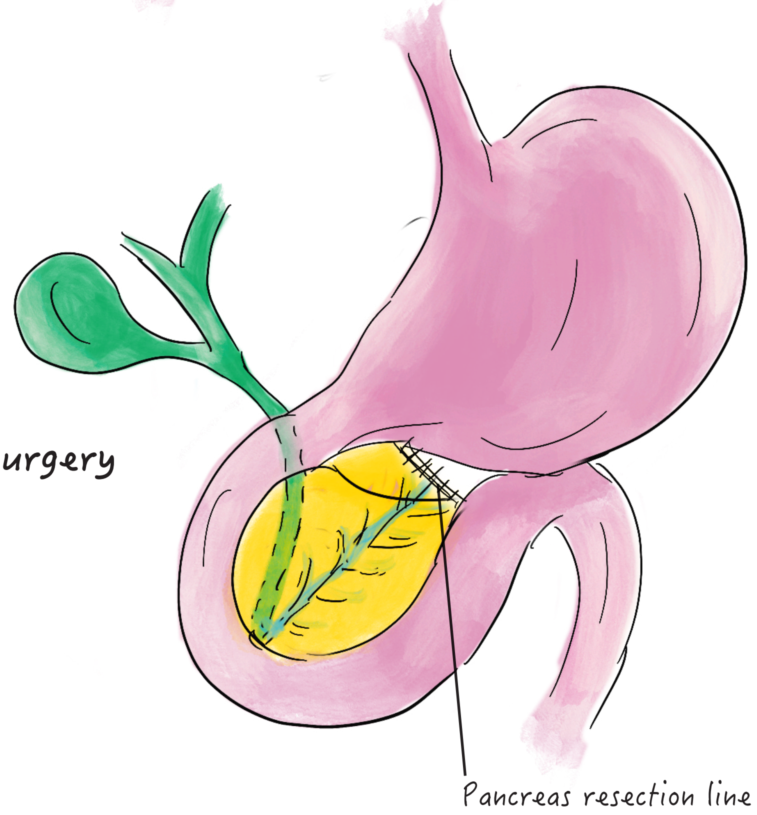
Drains: sometimes 1 or 2 drains are left at the pancreas resection line

What's removed



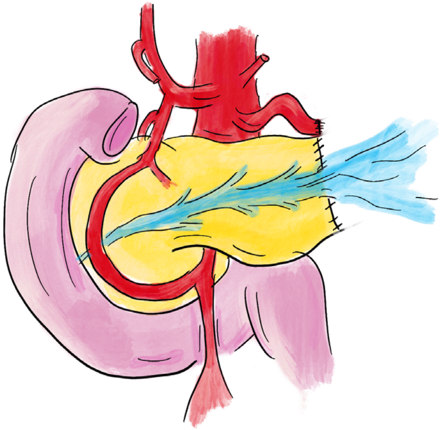


After Surgery



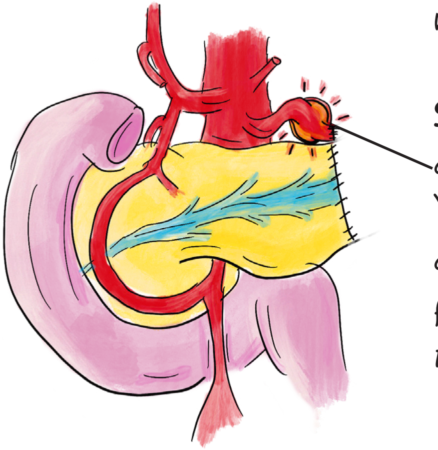
Some Surgery Risks

Short term risks:



Pancreas fistula (leak): 30% risk - or 3 in 10 people. This is a leak at the cut end of the pancreas. This causes pancreas juices to leak into the belly - instead of staying within the pancreas and bowel. It happens if the pancreas stitches or staples do not heal properly. You may need another drain from a radiology doctor, an ERCP (pg XX), or another surgery. You may also need IV nutrition while you heal.

Bleeding: 3% risk - or 3 in 100 people. After surgery, bleeding can happen. This can be from blood vessels that are injured during sugery. Like the splenic artery or the gastroduodenal artery (the GDA). You may need a special radiology scan (called an angiogram) with embolization (blocking) of the bleeding vessel. Sometimes you will need to go back to the operating room.



Splenic artery pseudoaneursym: This is a rare problem after surgery. The splenic artery forms an aneurysm. You may need a special radiology scan (called an angiogram) with embolization (blocking) of the pseudoaneurysm. Sometimes you will need to go back to the operating room.

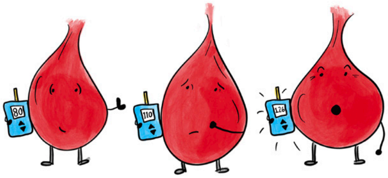
Infection - We will give you antibiotics before surgery to help lower this risk.

Other short term risks include: blood clots, kidney or liver problems, & heart problems

Long term risks:

Weight loss: 100% This is very common. Don't worry. You will regain some of your weight as you start to take in more food!

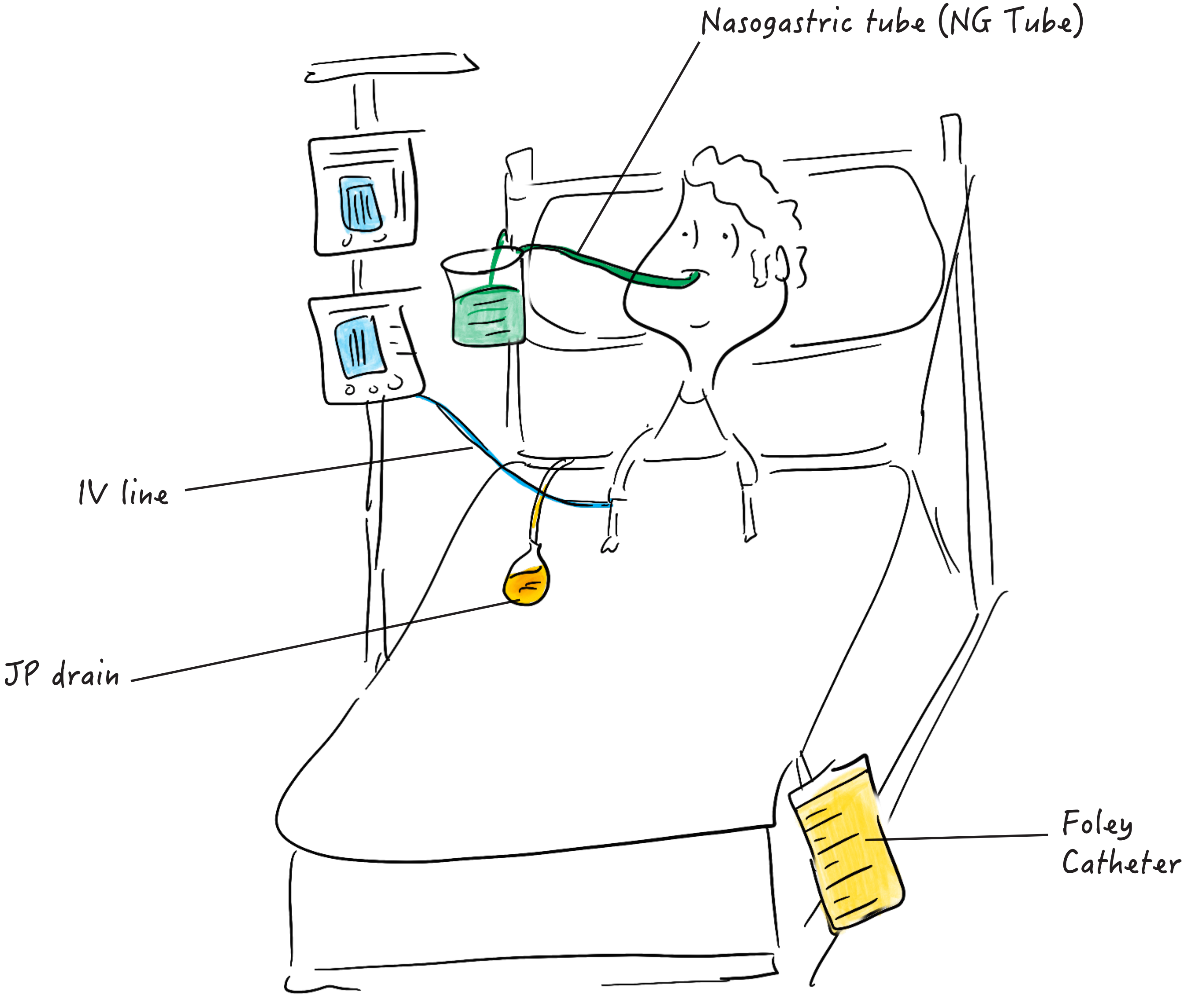
Diabetes: This is more likely to happen if you have a family history of diabetes or have pre-diabetes. If you didn't have diabetes before surgery, your risk of having diabetes is 33% (or 1 in 3 people). The pancreas is in charge of making and releasing insulin. Insulin controls your blood sugar. So removing part of your pancreas can impact your blood sugar level.



Pancreatic enzyme insufficiency: If you were not on pancreas enzymes before surgery, your risk of needing them after surgery is 33% (or 1 in 3 people). The pancreas is in charge of making and releasing digestive enzmes. These enzymes help break down the food you eat. So removing part of your pancreas can impact this. If this occurs, you may need pancreatic enzyme replacement therapy. These are just pills you take when you eat food.

Death: 1-2%. Risk of death from surgery or a complication after surgery is a small but real risk. At most high volume centers, it is 1 or 2 people out of a 100.

Surgery Tubes



1. **Nasogastric tube** – this tube goes from your nose into your stomach. It helps keep the stomach empty. You may have this tube after surgery. If you do, you'll most likely have this for several days before its removed. Sometimes it will need to be replaced if you have an ileus or DGE (pg XX).

2. **IV lines** – you will have a few IVs. We use these to watch your blood pressure and give you medicines. You may have a large one in your neck. This is the "**central venous line**".

3. **Foley catheter** – A bladder catheter is placed in you when you are asleep in the OR. This tube goes into your bladder and collects your urine. This one most often comes out a couple of days after surgery once you start walking. Sometimes it needs to be replaced (most often in older men with prostate problems).

4. **EKG leads**- these are stickers on your chest that watch your heart rate and rhythm. (P.S. these can hurt to remove if you have a hairy chest...prepare yourself!)

5. **Oxygen saturation probe**- a sticker that wraps around your finger that measures oxygen.

6. **JP drain** – this is a surgical drain. Most people get a couple of these. They drain fluid from around your pancreas while you are healing. They also alert your team to bleeding or pancreas duct (or other connection) leaks. Your team will send labs from the drain. If the lab levels are high, you may have surgery connection leaks. Learn more on page XX. Sometimes these drains are removed before you leave the hospital. Sometimes you may go home with a JP drain. Don't worry, your nurse will teach you how to take care of it!

7. **Pancreas External Stent** - this is a small tube that is placed inside the pancreas duct and out through the skin. Not everyone will need one of these. It is usually used if you have a 'soft' pancreas. A soft pancreas is at higher risk for a pancreas leak. This tube can help prevent leaks. It will stay in place for 6 to 8 weeks. And then will be removed in clinic.

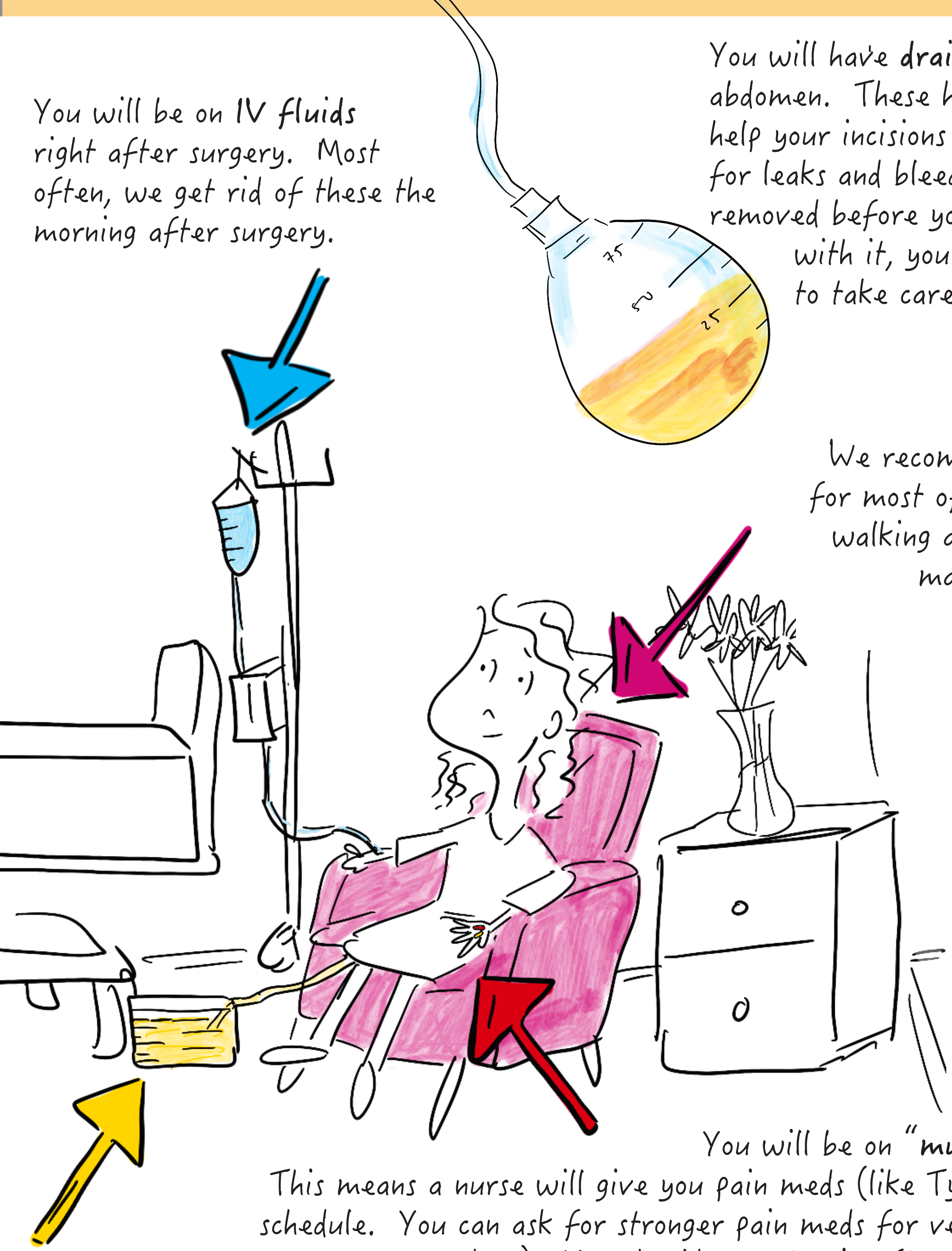
8. **Feeding tube** - Learn more on page XX.

Your Hospital Stay

You will be given ice chips after surgery. After a couple days, you will start on a **clear liquid diet**. Pick one thing from your tray and snack on it all day. After you start farting, you will be given more food.

Your surgery cuts (**incisions**) may be covered in purple glue or small tape. You can shower and let the water run over them. But, no soaking in a bathtub.

Foley bag - A bladder catheter is placed in you when you are asleep in the OR. We remove this a couple of days after surgery. Sometimes it needs to be replaced (most often in older men with prostate problems).



You will be on **IV fluids** right after surgery. Most often, we get rid of these the morning after surgery.

You will have **drains** coming out of your abdomen. These help drain extra fluid to help your incisions heal. And help monitor for leaks and bleeding. Usually they are removed before you go home. If you go home with it, your nurse will show you how to take care of it.

We recommend you **sit** in the chair for most of the day when you are not walking around. But in particular, make sure you eat all meals sitting up!

You will be on "**multimodal pain medicines.**" This means a nurse will give you pain meds (like Tylenol and gabapentin) on a schedule. You can ask for stronger pain meds for very bad pain (like tramadol or oxycodone). You should expect pain after surgery, even while taking multimodal pain meds.

A typical hospital day

You'll walk at least 3 times.
Feel free to walk more.
Keep in mind, walking is one of the only things that helps our bowels wake up!

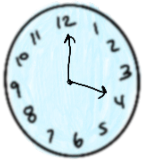
The surgery team will make their rounds early (often before 7:00AM). They'll ask about your pain and if you have a sick stomach or are throwing up. They will also ask how your bowels are working (gas or poop). They'll look at your cuts, too.

A couple of tips:

-Write down any questions you have. That way when your team shows up, you'll remember them!

-Feel free to call your family on the phone when your surgery team makes their rounds so they can hear the plan for the day.

-Bring books, laptop, walking shoes/slippers and cozy clothes to wear (sweatpants, t-shirts).



You may work with physical therapy. They usually come by once every day or every several days.

Your nurse will help you get into a chair. And help you use the bathroom.

Make sure you eat all meals in a chair sitting up!

Nutrition

Right after surgery, we will not let you eat or drink. After a little bit (most likely a couple of days), you may start having sips of liquids.

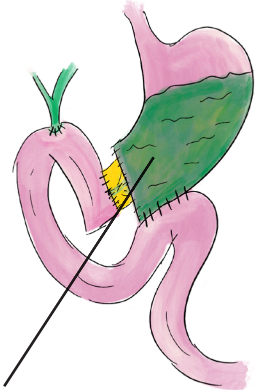
Keep in mind, people are not all the same. Some may need longer. Food often tastes funny (like cardboard!) for a few weeks after a big surgery Don't worry! Your tastebuds will return!

When you start eating, pick **one** thing from your tray and snack on it all day. You had a big surgery so it takes time for your bowels to wake up.

When your stomach (called '**delayed gastric emptying**') or bowels are not working (called an '**ileus**'), your stomach will act like a clogged sink.

The more you eat and drink, the faster it fills up.
This makes you feel bloated and sick.

There are 3 ways to help your stomach & bowels wake up:



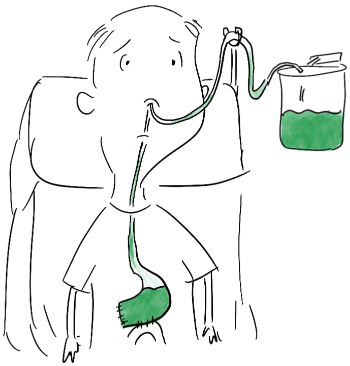
DGE after a Whipple

1) Walk often
2) Limit how many narcotic pain meds you take
   (these help the pain but make it hard to poop!).
3) Time. You just need to wait (which can be the hardest part).

These are signs that your stomach or bowels are not working yet:

1) burping
2) hiccuping
3) sick stomach (nausea)
4) throwing up
5) feeling bloated.

If you have bad nausea and are throwing up, you may get a **nasogastric tube** (NGT). This is a tube that goes into your nose and down to your stomach.

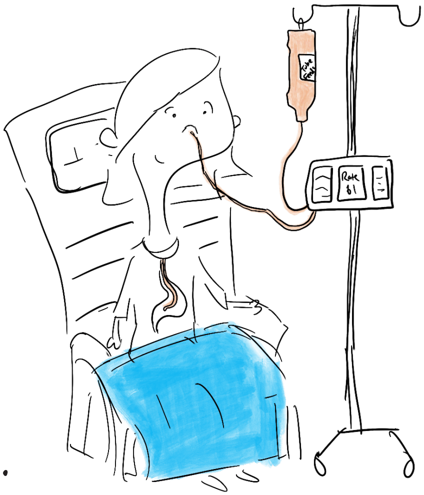


It pulls out the fluid in your stomach (empties the clogged sink!). This will help you until your stomach or bowels start working again.

You need lots of nutrition to heal. So, if you can't eat or drink for days, we may give you extra nutrition.

This extra nutrition might be:

1) IV nutrition called **TPN**
2) tube feeds that are sent into your bowel through a tube in your nose (**Dobhoff tube**)
3) tube feeds that are sent into your bowel (and go around your stomach) through a feeding tube (**GJ tube**)

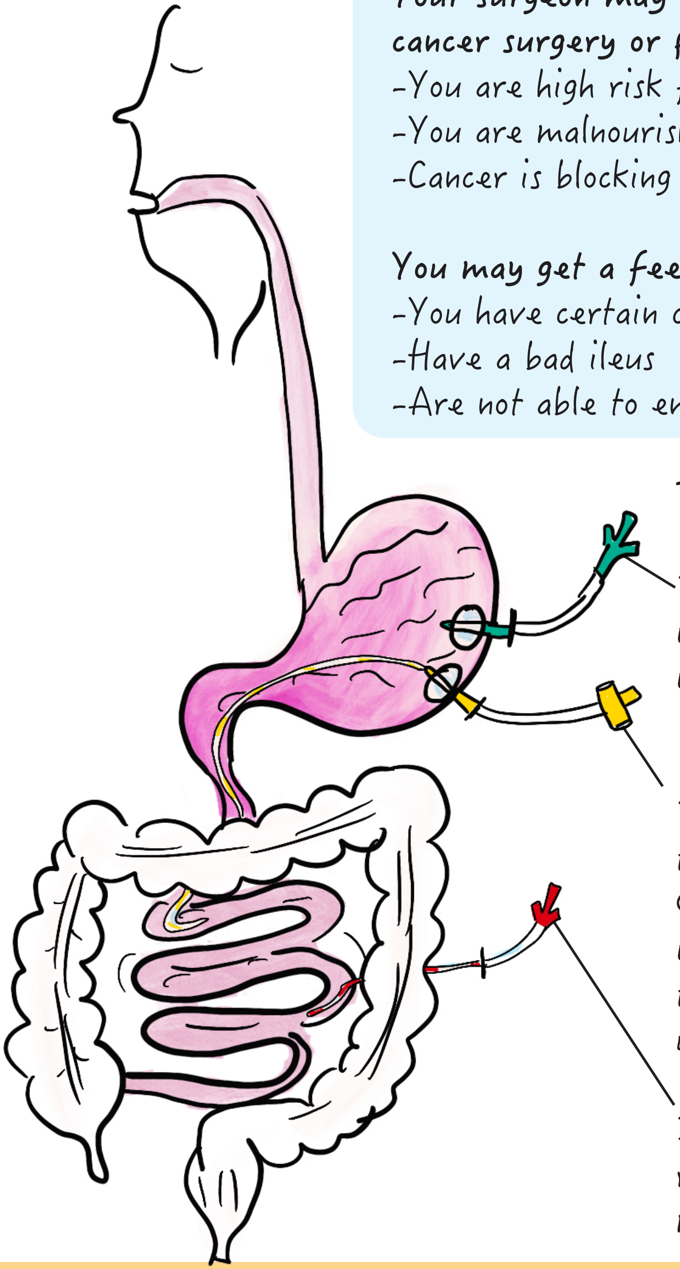


Check out the next page to learn about feeding tubes.

Feeding Tubes

Your surgeon may plan to give you a feeding tube during your cancer surgery or palliative surgery if:
-You are high risk for delayed gastric emptying (DGE) or an ileus
-You are malnourished before surgery
-Cancer is blocking your stomach or bowels

You may get a feeding tube after surgery (by a GI doctor) if:
-You have certain complications after surgery, like DGE
-Have a bad ileus
-Are not able to enough to heal



There are 3 main types of feeding tubes:

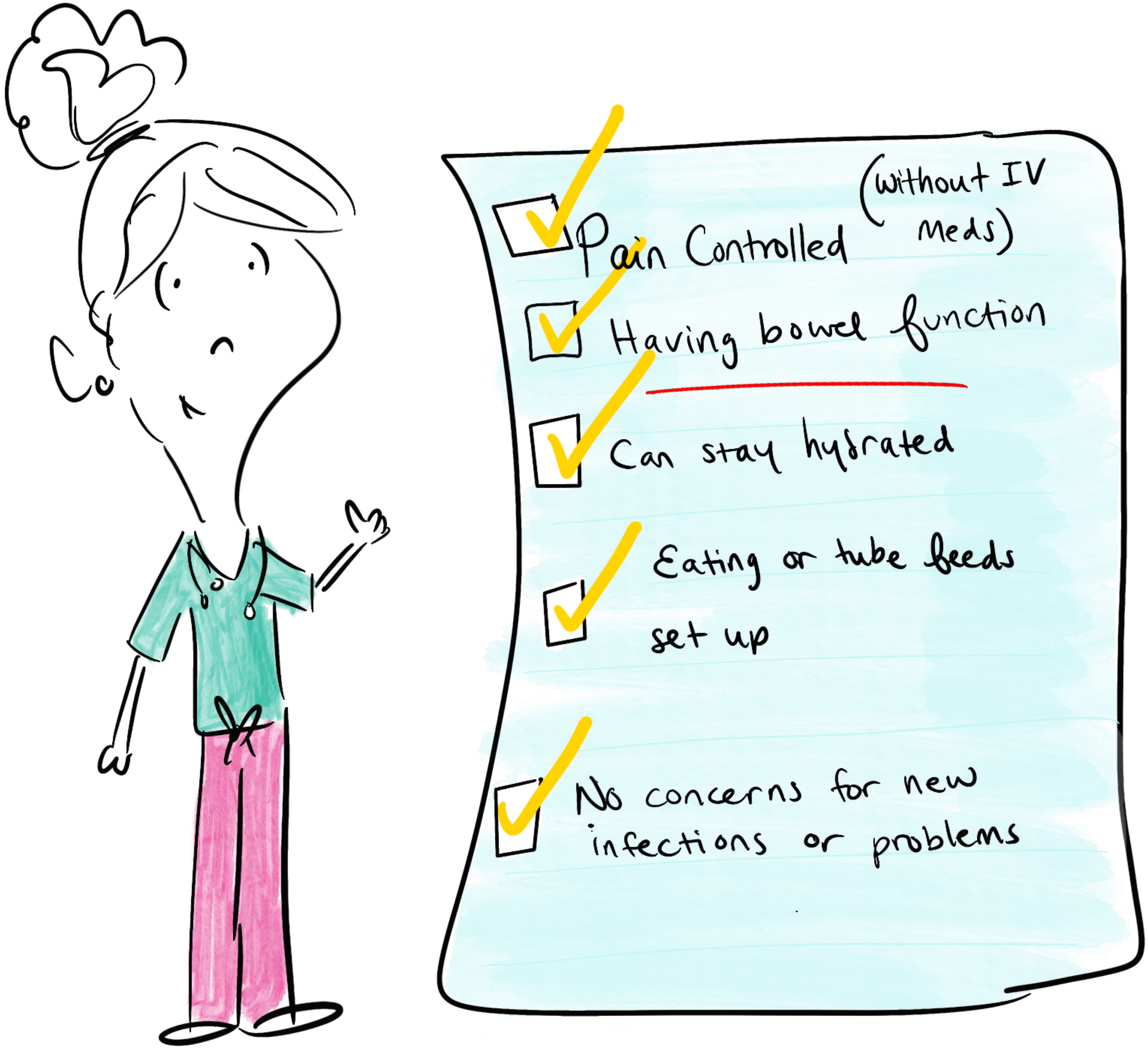
1) **Gastrostomy tube (G-tube)** - this tube goes into the stomach. It helps empty the stomach when its blocked. So you can use it when you feel sick.

2) **Gastrojejunostomy tube (GJ tube)** - This is the main type of tube we use. It has 2 'limbs'. One goes in the stomach and one goes in the small intestine. The stomach tube (G-limb) can empty the stomach. The small intestine tube (J-limb) is used for medicines & tube feeds.

3) **Jejunostomy tube (J-tube)** - this tube goes right into the small intestines. It is used for giving medicines & tube feeds.

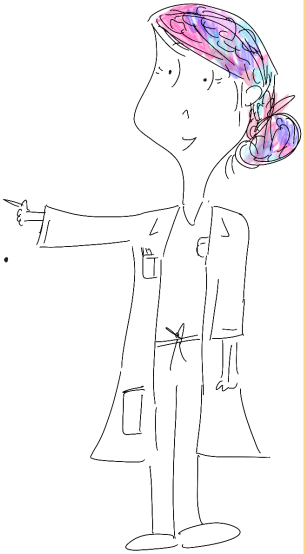
Discharge Rules

Here are some general discharge rules before you can leave the hospital. You may have others too! Ask your surgeon!



- ☑ Pain Controlled (without IV Meds)
- ☑ Having bowel function
- ☑ Can stay hydrated
- ☑ Eating or tube feeds set up
- ☑ No concerns for new infections or problems

Discharge Instructions



-Okay to shower. Do not soak in a bathtub, pool, ocean, etc. for 4 weeks

-Okay for water and soap to run over your incisions. No scrubbing. And no lotions or ointments.

-If you have staples, your staples will be removed in clinic in several weeks.

-If you have surgical glue, it will fall off on its own in a few weeks. Don't pick it off.

-Do not lift anything heavier than 10 pounds (gallon of milk) for 6 weeks.

-Do not drive for 2 weeks or if you are still taking pain medicines.

-Try to be out of bed for 8 hours every day. And walk at least 4 times a day. Take the stairs too!

-Eat small, frequent meals. High protein foods are best! Drink protein shakes 2 to 3 times per day!

-Keep doing deep breathing exercises. This helps prevent lung infections (pneumonia)

-You will be called, or talked to in clinic, about your pathology results.

Call your doctor if you have:

- -Fever > 101 F
- -Shaking chills
- -Worsening pain, nausea, or vomiting
- -No pooping or farting for > 24 hours
- -Increased redness, drainage, or swelling from your surgical cuts
- -Dehydration (dry mouth, dry skin, peeing more often, extra fast heart beat, dizziness, lightheadedness, headache)

Discharge Medicines

Pain medicines:

- Continue to use over the counter tylenol & ibuprofen around the clock (alternate every 3 hours!)
- Use the prescribed narcotic ONLY for breakthrough pain
- Try to take these meds with food. This lessens your stomach's irritation.
- Narcotic pain meds are constipating. Drink lots of water. And take over the counter stool softeners like Colace or Senna as needed.
- Don't take more than 3,000 mg of tylenol in one day from all sources (Remember - Norco, Vicodin, and Percocet all contain tylenol).

Acid blocker:

- If you had a Whipple, you will be on a proton pump inhibitor (a type of acid blocker) for the rest of your life. This medicine helps decrease acid in your stomach. So there is less of a chance for an stomach ulcer to form.

Pancreas Enzymes:

- If you have pancreas insufficiency (see page XX) after surgery, you may need to start taking pancreas enzymes. Take with meals or however your team told you to take them!

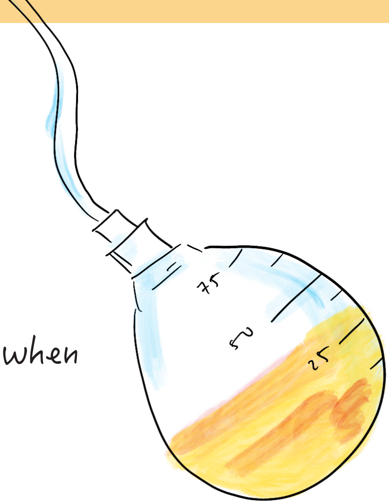
Diabetes meds:

- Restart your diabetes meds from home, unless instructed otherwise.
- Or start taking your new diabetes meds if you have new diabetes after surgery.
- Please take your blood sugar before and after meals when you are home.
- If your blood sugar is too high or low, call the team that prescribes your diabetes meds.

Blood thinners:

- Due to the increased risk of blood clot associated with your pancreas cancer and surgery, you are going home with an injectable medication called **Lovenox**. This is a blood thinner.
- A nurse will show you or your caregiver how to give these shots.
- You will continue this for a total of 28 days, beginning with the date of surgery.

Drain Care



If you are going home with a drain….

-Change the bandage over the drain whenever it is wet or dirty.

-There is a stitch keeping the drain in place. It will be removed when the drain is removed.

-Call the doctor if you have a lot of drainage around the drain.

-Do not have the shower directly hit your drain site until **2 days** after the drain is removed.

-Empty the drain at least 2 times everyday or more. And record the amounts! (see next page)

-Wash your hands before and after emptying the drain.

-Call if you have bleeding, severe pain, swelling, redness around the drain site, or fever.

-If your drain fluid suddenly becomes bloody, call or go to the hospital immediately.

Help! The drain….

-does not stay compressed. The drain should never look round and smooth (like an apple). Unless the plug is open as you empty the drain. If it does look round and smooth, it is either full, the plug is open, or there is a leak. Try emptying and re-closing the bulb. If it still becomes round and smooth, call your doctors office. This is NOT an emergency. Call during daytime hours.

-stopped draining or is leaking around the drain, onto the bandage. The drainage should slowly decrease over time. But, if it suddenly stops or starts leaking, it may be clogged. If there is an obvious blockage in the tubing, you may try to gently dislodge the blockage by squeezing and "milking" the tube. Don't pull on the drain as this will hurt. If you are unable to dislodge the blockage or you do not see any obvious blockage, call your doctors office. This is NOT an emergency. Call during daytime hours.

To empty the drain: open the plug and carefully pour the contents into a measuring cup. Squeeze the bulb and close the plug. The drain should look like it does while squeezing it (like it has a dent in it). Record the total daily drainage amount in the chart below. Bring this book with you to your follow-up clinic visit.

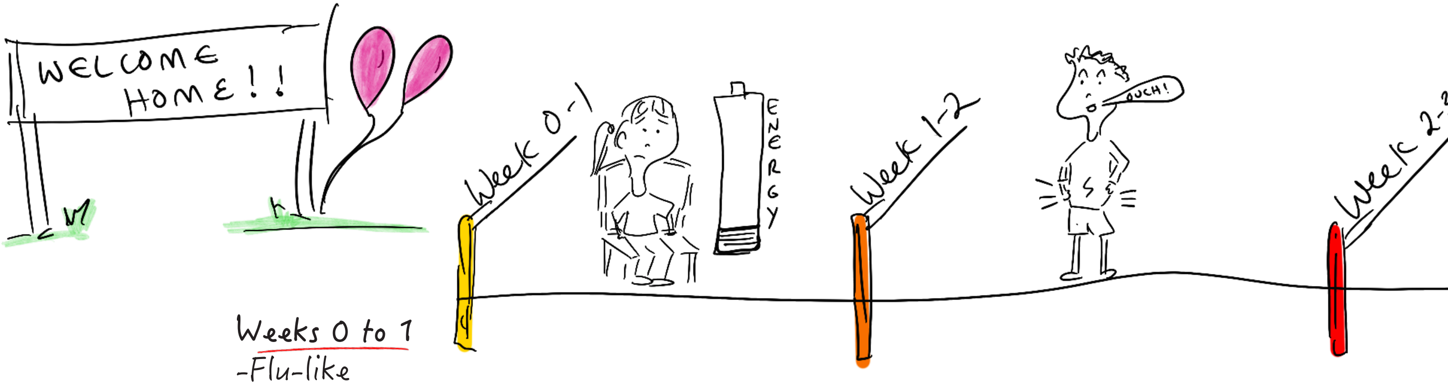
	Sun.	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	
Week 1								
Drain A								AM
								PM
Drain B								AM
								PM
Week 2								
Drain A								AM
								PM
Drain B								AM
								PM
Week 3								
Drain A								AM
								PM
Drain B								AM
								PM

After Surgery:

Now you're home! What will your recovery be like? Here's what we often see. Yours could be a little different. Use this as a guide. And remember, any complications from surgery will delay this timeline.

Weeks 1 to 2

- Flu-like
- Tired
- Chore to do anything
- Not hungry; food doesn't taste good
- Sharp pains in your surgery cuts
- Will worry about these pains — that's normal
- No driving
- Walk
- Shower
- No lifting more than 10 pounds
- No bathing/swimming



Weeks 0 to 1

- Flu-like
- Tired
- Chore to do anything
- Not hungry; food doesn't taste good
- Sharp pains in your surgery cuts
- Will worry about these pains — that's normal
- No driving
- Walk
- Shower
- No lifting more than 10 pounds
- No bathing/swimming

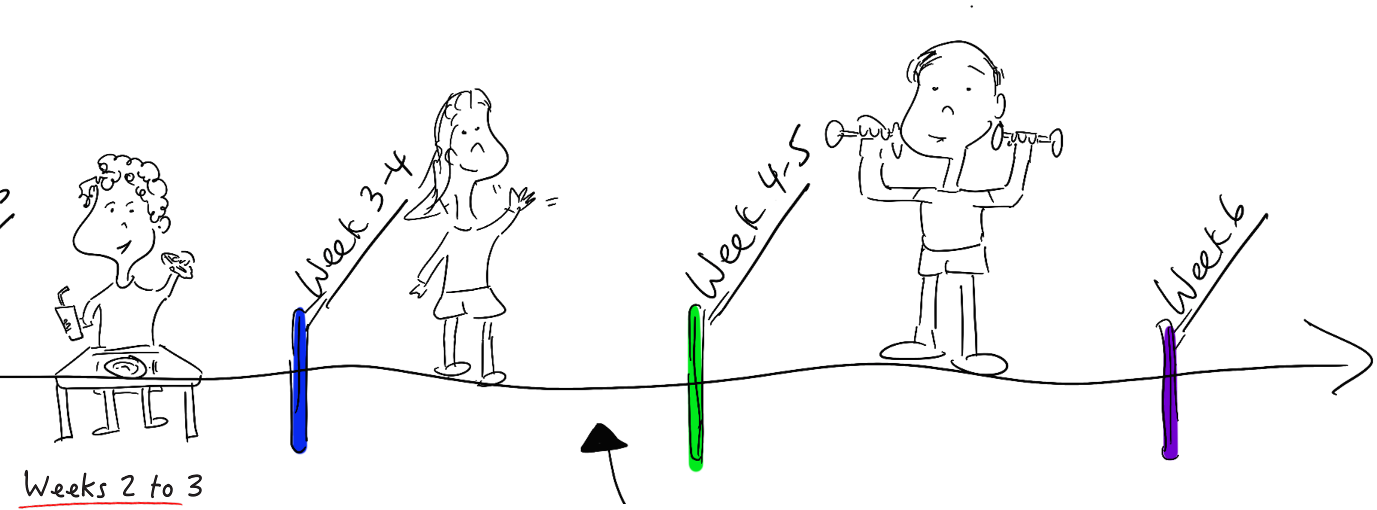
Your Recovery at Home

Weeks 3 to 4

- Follow-up (post-op) visit
- In most cases, pain is gone
- Eating even more
- Energy should be 60% to 70% of normal

Weeks 6 to 8

- Energy, activity, eating and drinking all back to normal
- You may still have some cramps and belly pain, but it should start getting better

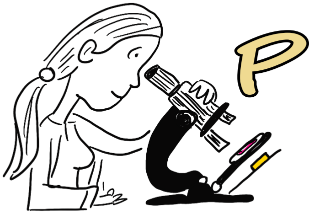


Weeks 2 to 3

- Most pain is gone
- Surgery cuts may still feel tight
- Start to feel hungry again
- Still feel some sharp pains in belly — but improving
- Can take a bath and swim
- Can drive if not taking pain meds

Post-op Visit

- No more limits on lifting
- Eat any food you want



Pathology Report

Learn how to understand your path report!

TUMOR

Tumor Site

Histologic Type
Histologic Grade
Does your cancer look like normal cells?
G1 (best) --> G2 --> G3 (worst)

Tumor Size

Tumor Extent – This is your T-Stage

Macroscopic Tumor Perforation
Lymphovascular Invasion
Perineural Invasion
High risk features

Treatment Effect – If you had neoadjuvant chemorads, did it damage your cancer (did it work?)

MARGINS

Margin Status for Invasive Carcinoma

Closest Margin(s) to Invasive Carcinoma

Distance from Invasive Carcinoma to Closest Margin →

Margin Status for Non-Invasive Tumor

REGIONAL LYMPH NODES

This is your N-Stage

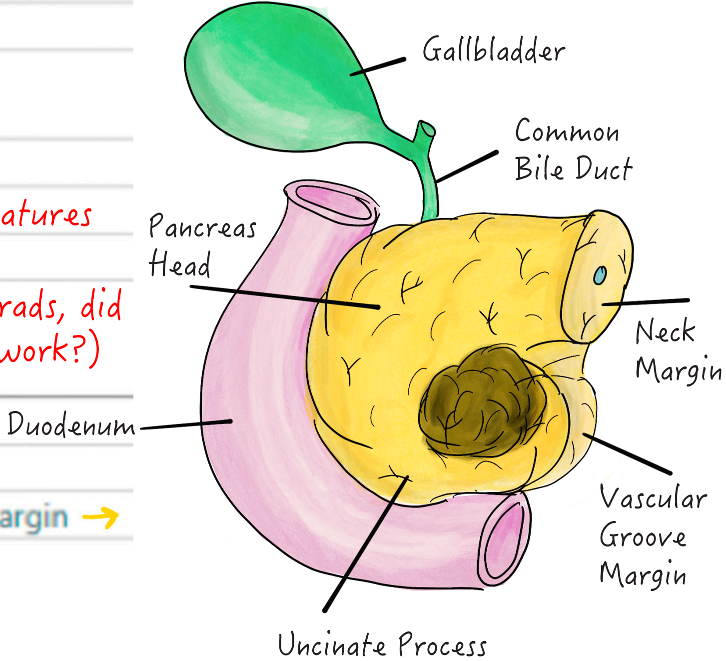
Regional Lymph Node Status

Number of Lymph Nodes with Tumor

Number of Lymph Nodes Examined – How many lymph nodes were removed with the surgery and do they have cancer in them

Tumor Deposits

Number of Tumor Deposits



Whipple specimen

Chemotherapy

We give chemotherapy to destroy cancer cells not ONLY in your pancreas and lymph nodes, but also in other parts of your body. Whether we can see them on imaging or not.

So who gets chemotherapy??
- Most people do
- Some get it before surgery (neoadjuvant)
- Some get it after surgery (adjuvant)
- And then some only get chemotherapy (and don't have surgery).

What's involved with chemotherapy?
First, you will be referred to medical oncology. They will discuss options with you. If you are going to have surgery, you will be on chemotherapy for **6 months** total. This can be split into some before and some after surgery. If you are not a candidate for surgery, you will have chemo on and off for the rest of your life.

What is the timing of the chemo if you have surgery first?
You will usually wait **6 to 8 weeks** after surgery to heal. And then start your chemo.

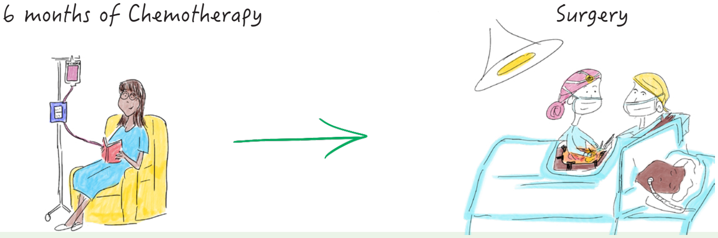
Usually your chemotherapy is some combination of the following medicines:
1) Gemcitabine (Gemzar)
2) 5-Fluorouracil (5-FU) or Capecitabine (Xeloda)
3) Oxaliplatin (Eloxatin)
4) Irinotecan (Camptosar)

Not all chemotherapy medicines work for all patients. Some patients might not be healthy enough to tolerate certain regimens.

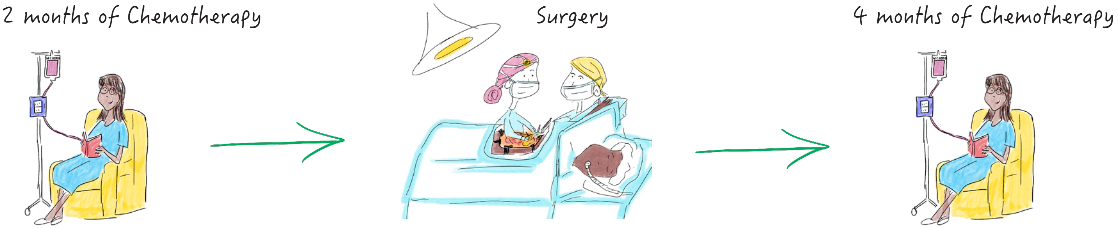
Any side effects?
There are different side effects for each different chemotherapy medicine. Ask your doctor what side effects you might have.

Chemo Timing

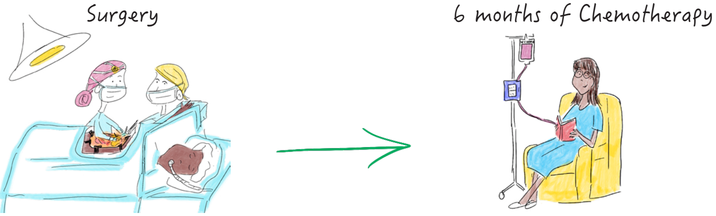
If you need surgery, the timing of your chemotherapy can be given one of three ways:



All 6 months of your chemo are given before surgery. After, we 'restage' you to see if you are still a surgery candidate (pg XX).



Part of your chemo is given BEFORE possible surgery. After, we 'restage' you to decide if you are a surgery candidate or not. After surgery, you will get the rest of the chemo. For example: 2 months of chemo before surgery & 4 months of chemo after surgery.

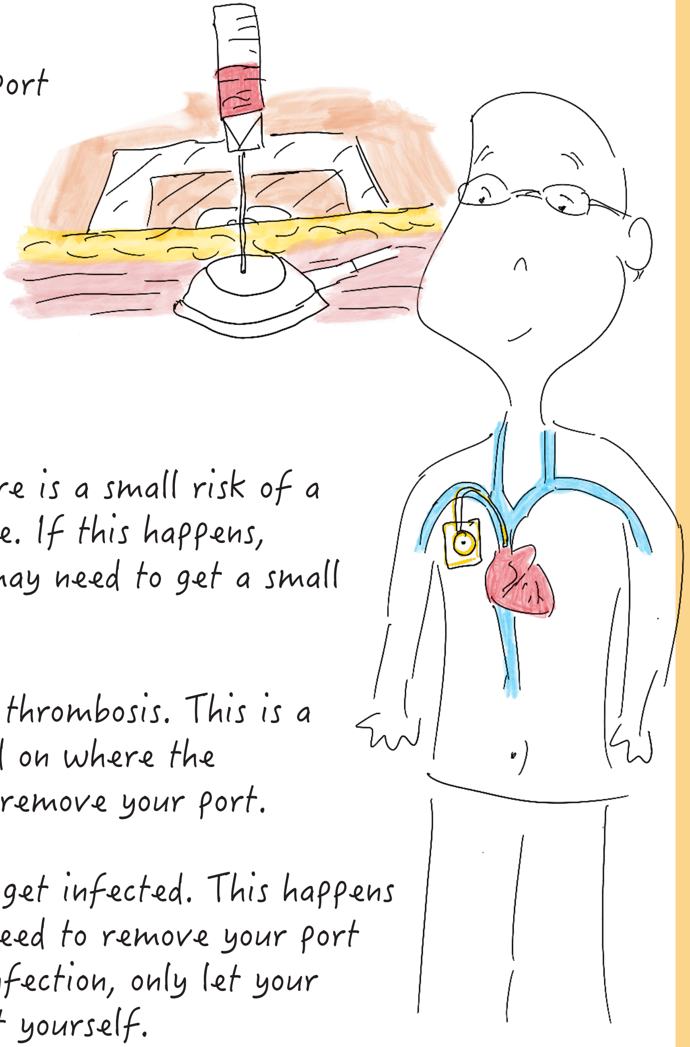


All of your chemo is given AFTER surgery. Sometimes this is planned. Other times, your pathology results after surgery show that you would benefit from more treatment.

Port Placement

We suggest you get a port for your chemo. Chemotherapy drugs can hurt small blood vessels. Also, it hurts to get poked with needles each time you need chemo or other medicines. A port lets chemo go straight into the large vein near your heart.

Procedure details:



- -Either a surgeon or a radiologist will put in your port
- -This is an outpatient procedure.
- -Stop eating after midnight the night before.
- -Putting the port takes about 30 minutes.
- -You can shower the day after but no baths or swimming for 5 days.

Some of the procedure risks:

Pneumothorax (a collapsed or flattened lung): There is a small risk of a pneumothorax. This happens in 1 out of 100 people. If this happens, doctors will do x-rays and watch you closely. You may need to get a small chest tube to help your lung fill up with air again.

Thrombosis (a blood clot): There is a small risk of thrombosis. This is a clot in either your port or your blood vessels. Based on where the clot is, you may need medicine or we may need to remove your port.

Infection: There is a small risk that your port can get infected. This happens in 5 out of 100 people. If this happens, we may need to remove your port and you may need antibiotics. To stay safe from infection, only let your chemo staff place a needle in your port. Don't do it yourself.

Restaging

What's restaging?

After you finish a treatment, we 'restage' you. Like after a period of chemo. This means you get a new CT scan or MRI scan. Your doctors also look at the trend in your CA 19-9 lab tests. It is to see if the treatment is working. Your next treatment options depend on these restaging results.

- If the treatment **is not** working, your doctors may need to switch your chemo medicines, consider other treatments, put you in research trials, and/or talk about comfort care.

- If the treatment is working, your doctors might continue that treatment or consider if surgery is an option.

When do you get restaged?

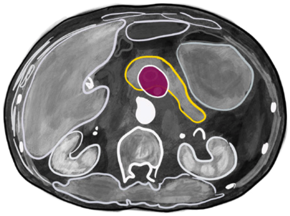
1) If you HAVE had surgery:
  - You will be watched after surgery with scans to see if your cancer comes back (pg XX). This is called cancer surveillance.

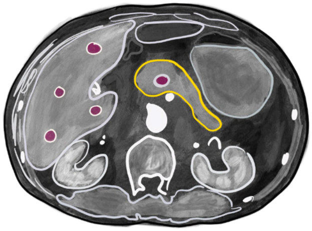
2) If you HAVE NOT had surgery:
  - After you finish ALL of your chemo
  - After you finish SOME of your chemo

3) If your disease is metastatic:
  - Periodically as you undergo chemo

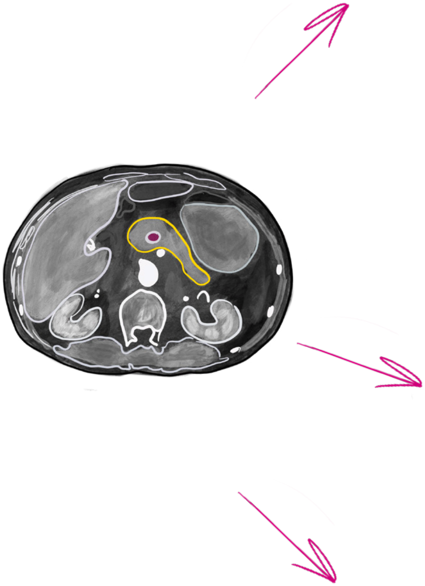
The restaging scans could show 3 things:

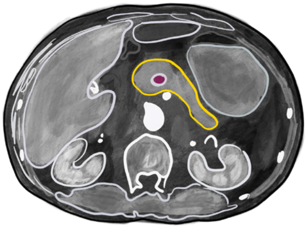
1) Your cancer has grown
2) Your cancer is the same or smaller.
3) Your cancer is gone.





a. Your cancer grows.
This could mean your cancer has grown bigger around the pancreas. Or has grown to other areas of your body. Like your liver. In these cases, surgery is usually not an option. You may need more chemo, other types of treatment (like immunotherapy or targeted therapy), do a research trial, or think about comfort care. Comfort care means you stop treatment and focus on comfort during your remaining time (see page XX). You will talk to your cancer doctor about this.





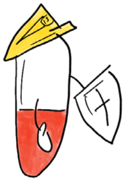
b. Your cancer is the same or smaller.
The chemo is working. If surgery is an option, you'll get surgery next. If you've already had surgery, you will continue with more chemo or other types of therapies.

c. Your cancer is gone. If you haven't had surgery yet, it's time! If you already had surgery, you will be closely watched (surveillance – pg XX).

Other Treatments

There are other treatments besides chemotherapy and surgery that can be used for pancreas cancer.

Usually these ‘second-line’ treatments are used if:
- you stop responding to chemo
- you need more treatment after 6 months of chemo
- you can’t have chemo
- your cancer comes back after surgery
- you have metastatic cancer
- you have a positive margin after surgery



Immunotherapy is a type of treatment that makes your own immune system fight your cancer. Your immune system protects you from getting sick. It fights ‘bad guys’ like viruses and bacteria. Cancer often hides from the immune system. Immunotherapy works by ‘exciting’ your immune system. It stimulates it to find cancer cells and fight them.

The immunotherapy medicines we currently have only work for certain types of pancreas cancer. Right now, we use immunotherapy for patients with ‘mismatch repair deficiencies’ with metastatic pancreas cancer.

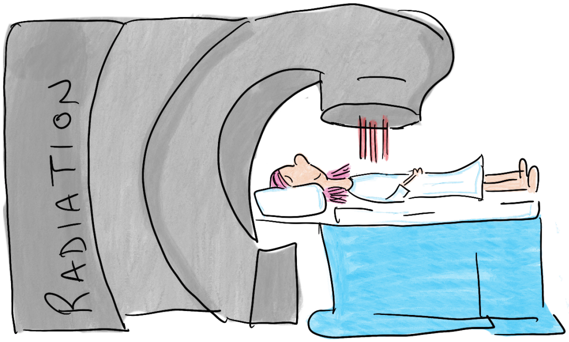
Targeted therapy is a type of treatment that targets how the cancer cells grow, divide, and spread. Most targeted therapy is called small-molecule drugs or monoclonal antibodies. These work by finding cancer cells when they grow, divide, or spread. Once they find them, they can mark them for destruction.

It is mainly used for patients with advanced cancer that cannot be removed by surgery who have not yet prior chemo.

Radiation are high power x-rays that aim at your pancreas to destroy the cancer cells. We give radiation to destroy cancer cells in your pancreas and the nearby lymph nodes.

Who usually gets radiation?

- -People who need more treatment after 6 months of chemotherapy
- -People who have bad pain or bleeding
- -People who can't have chemotherapy
- -Positive margins after surgery



What's involved with radiation?

First, you will be referred to radiation oncology. They will discuss options with you. Most often they will use stereotactic body radiation therapy (SBRT). Usually you will be on radiation for 5 to 6 weeks. It is may also be given with chemotherapy. This is called '**chemoradiation.**'

What is palliative radiation therapy?

This is radiation therapy that can help with pain and stop bleeding. It is a part of palliative care.

Any side effects?

It may cause skin changes like a sunburn, or you may notice other changes in skin color or feel. It may help to massage your skin with lotion or cream a few times a day.

Clinical research trials may be recommended by your doctor. These are ongoing tests for experimental treatments. It might be for new medicines. Or new combinations of medicines. Trials test if these are safe and effective for pancreas cancer. Clinical trials advance progress in finding cures. They are how research moves forward. Consider participating in a trial if your doctor recommends it. Patients who participate in clinical trials have better outcomes and give you opportunity to receive a promising new treatment.

Cancer Surveillance

What is cancer surveillance?

Cancer surveillance is watching for cancer to come back after it is removed with surgery. This is with imaging scans, lab tests, and doctor visits.

When does cancer surveillance start?

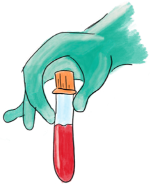
It starts when you are done with surgery and chemotherapy. Your surgeon and chemo doctor will watch you for XX years after surgery. They will check you to see if the cancer comes back.

How often will you need to see them?

Your visits will be every 3 to 6 months for the first 1 to 2 years. After 1 to 2 years, your visits will be every 6 months. These will go on until it's been 5 years since your surgery.

And what is included in these visits?

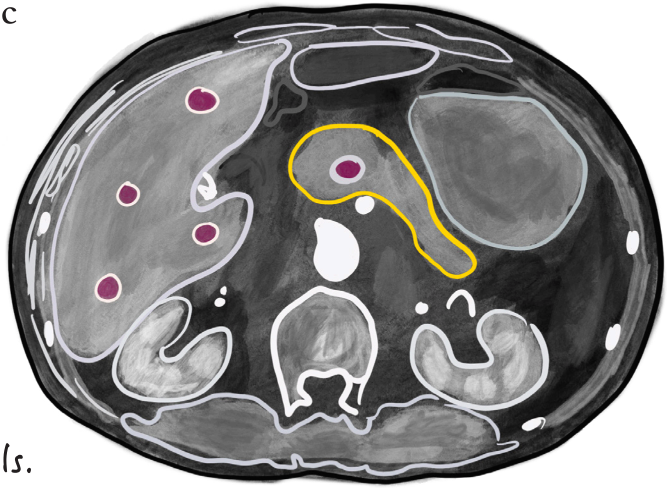
1) Testing for CA 19-9 level - This is a tumor marker that can be a sign of cancer
2) Physical exam
3) Periodic CT scans - These are more often in the first 2 years. These will be scans of your chest, belly, and pelvis.



These are all standard for all stages of pancreas cancer.
Details may change based on:

1) Your cancer stage
2) Your cancer doctor's orders
3) The results of scans and other screening tests

Metastatic Cancer



If your staging CT scans show you have metastatic cancer, this is stage 4 cancer.

It means your cancer has spread outside of the pancreas. Most often, it goes to the liver or to the lungs.

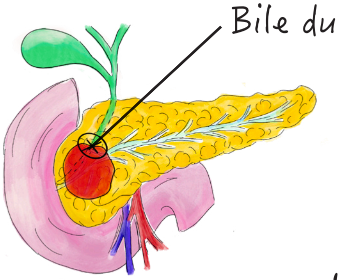
A **medical oncologist** (cancer doctor) will be the main person in charge of your care.

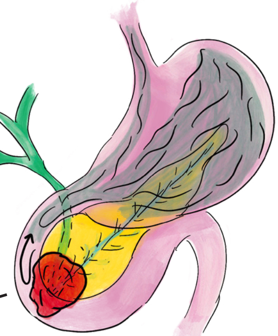
Treatment will be **chemotherapy and clinical trials.** After this, you will be re-staged. Your next treatment options depend on those restaging results.

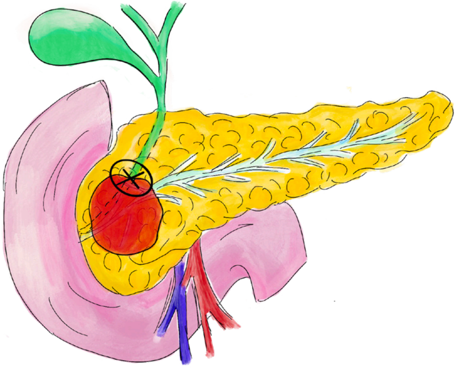
If your metastatic disease starts of **symptomatic** - causing you problems - you may need surgery or a procedure to help you feel better before starting chemotherapy.

We may do these procedures or surgeries to help ease your symptoms so we can:
1) get you to chemo quickly
2) help improve your quality of life

These problems could be if:
- cancer is blocking your bile duct
- cancer is blocking your bowels
- you have bad pain

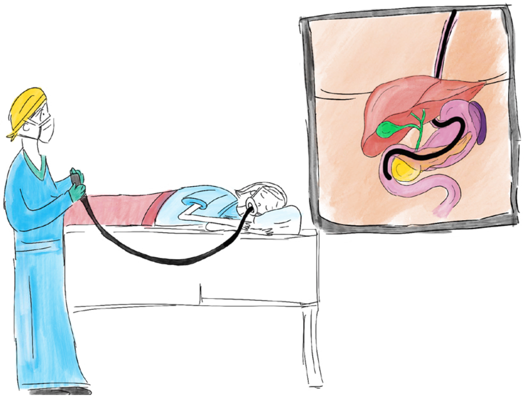


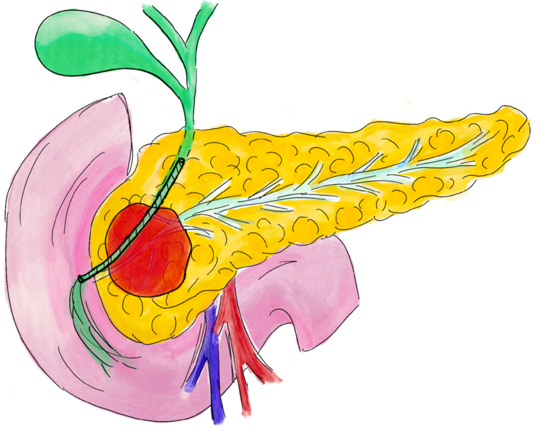




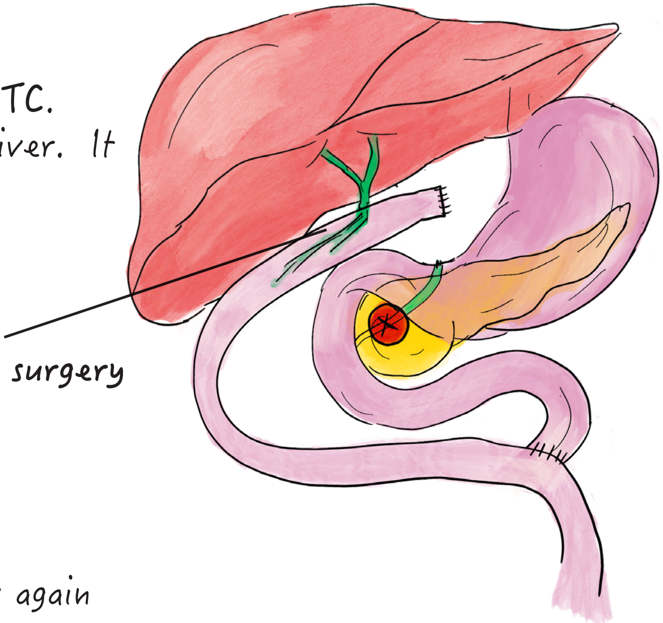
For cancer blocking your bile duct:

- You will have an **ERCP** to try and unblock it. A metal stent will be placed.





- If an ERCP does not work, you may need a **PTC**. This places a drain into a bile duct inside the liver. It diverts bile away from the cancer blockage.

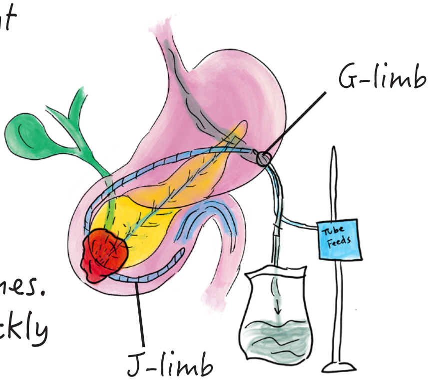


If an ERCP & PTC don't work, you may need surgery

- Surgery is called a **biliary bypass**
- A piece of intestine connects to the bile duct above the pancreas and the blockage
- This lets bile flow into your intestines again

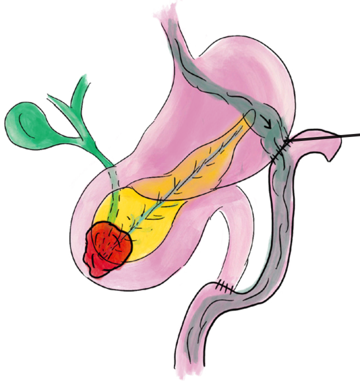
For cancer blocking your stomach or intestines:

- You may need a feeding tube, bypass surgery, or stent placement



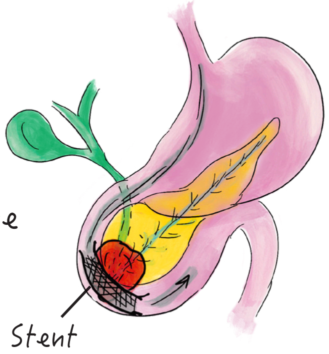
1) **Feeding tube**

- A tube is placed into the stomach through the skin (G-limb) and into the small intestine through the skin (J-limb)
- The G-tube lets you empty your stomach when you feel sick.
- The J-tube lets you feed your intestines and take your medicines.
- This helps ease your symptoms so we can get you to chemo quickly or help you feel better.



2) **Bypass surgery**

- We connect the middle of the small intestines to the stomach
- This lets food go around the cancer blockage so you can eat



3) **Stent placement**

- A hollow tube is placed into your duodenum to stop the blockage
- This requires expert training so not all hospitals offer it.

For cancer causing bad pain:

- If pain medicines are not controlling your pain, your doctor may suggest **celiac plexus block.**
- A needle is used to inject numbing medicine around your celiac plexus - which is a bundle of nerves in your belly. This nerve block can help improve your pain.
- It is an outpatient procedure with a radiology doctor.
- It lasts about 3 - 6 months. You may need to repeat this procedure.

Palliative Care

There may come a time when doctors tell you that your colon cancer is 'incurable.' It can't be cured. That doesn't mean untreatable but does mean you will die from your cancer. The care you receive from this point onwards is called Palliative Care.

Palliative care is care when your cancer can't be cured.
Palliative care focuses on your comfort and quality of life.

Doctors may still give you chemo to give you more time. If treatment stops working, or it's making you feel worse and much sicker, then you might meet with a palliative care doctor.

Sometimes, palliative care will involve your surgeon.
If your cancer is causing a blockage or symptoms that make you suffer, surgery might be a good choice. It might help improve your quality of life. Your surgeon will explain what choices you have. They will make sure your final choice fits with your goals and wishes.

Palliative care is all about your goals.

The talks you have about your care should be about the balance between:
1) time of life left,
and 2) quality of life.

We strongly suggest you talk openly with your family about your wishes.

Commonly Asked ???s

So, when is surgery? Just like you, we want to treat or remove it as soon as possible. But we need to be safe. Don't forget, your cancer took years to grow. It will not spread over a period of weeks while we do testing and plan your surgery. (see page XX). Further, if you have chemotherapy and/or radiation before surgery, you need to wait anywhere from 4 to 12 weeks before your body will be strong enough for surgery.

After surgery, when will I get my pathology results? Depends on the hospital you are at. It most often takes 5 to 10 business days (which can seem like forever).

When do I show up for surgery? You may need to show up 2 hours before or when your hospital pre-op center calls you in.

How long is the hospital stay after pancreas cancer surgery? Most patients stay for 1 to 2 weeks. But this depends on your recovery and any complications that arise.

How is chemotherapy given for pancreas cancer? Chemotherapy can be given through an intravenous (IV) infusion or, in some cases, as an oral medication. It is typically administered in cycles with rest periods in between to allow the body to recover.

What are the side effects of chemotherapy for pancreas cancer? Side effects depend on which drugs you get. They may include fatigue, nausea, vomiting, diarrhea, loss of appetite, hair loss, low blood cell counts, and increased risk of infections.

What should I eat during chemotherapy for pancreas cancer? A diet with high-protein foods, healthy fats, and easy-to-digest carbohydrates is best! This helps your energy levels. Also small, frequent meals, staying hydrated, and avoiding processed foods or excessive sugar.

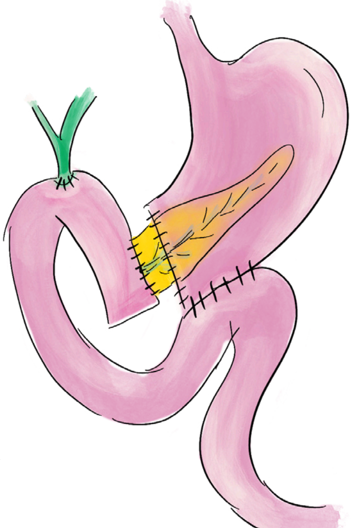
Are there new treatments being developed for pancreas cancer? Yes! There is lots of ongoing research into targeted therapies, immunotherapy, and personalized medicine based on tumor genes.

I want to know more. What sources do you suggest? Not Google. We trust these websites to give you good info:

- www.cancer.gov (National Cancer Institute)
- www.pancan.org (Pancreatic Cancer Action Network)
- www.nccn.org (National Comprehensive Cancer Network)

Doctor Words

Anastomosis — another name for a surgical connection. Like the connection that attaches your pancreas to bowel after we remove your cancer (page XX).



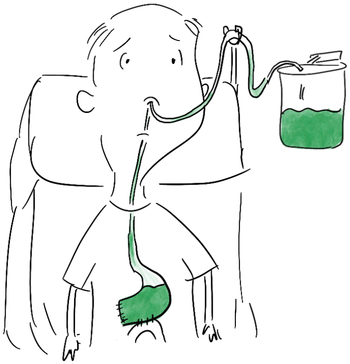
Hepaticojejunostomy (HJ) - an anastomosis after a Whipple. It connects the bile duct to the small intestine.

Pancreaticojejunostomy (PJ) - an anastomosis after a Whipple. It connects the pancreas to the small intestine.

Gastrojejunostomy (GJ) - an anastomosis after a Whipple. It connects the stomach to the small intestine.

Abscess — an infection pocket that can happen after surgery. Sometimes from an anastomosis leak. Based on the size, it may need a drain and/or antibiotics.

Ileus - when your bowels fall asleep and are not working after surgery. This can take a few days to clear up and some patients get a nasogastric tube. The only things you can do to help this are to walk, walk, walk and only use small amounts of narcotic pain meds.

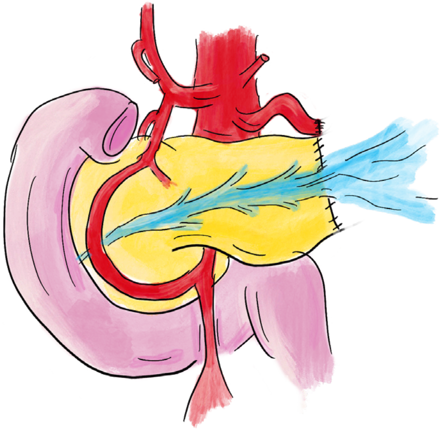


Nasogastric tube (NG tube) - For bad nausea and vomiting, some patients get a **nasogastric tube**. This is a tube that goes into your nose down to your stomach. It sucks out the liquid in your stomach until your bowels start working.

ERAS® (Enhanced Recovery After Surgery) - the method we use to manage your hospital care. It includes all the things on pages XX. Research shows that the "ERAS" method gets you out of the hospital faster, with fewer problems too!

Recurrence — when your cancer comes back

No Evidence of Disease (NED) — when your cancer is not detectable or seen on labs or imaging tests. If you remain 'NED' for XX years, we consider your cancer cured.

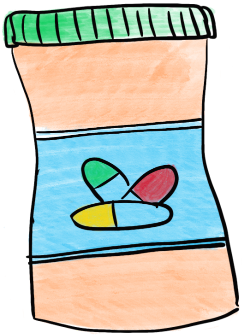


Pancreas Fistula - a leak at the cut end of the pancreas. This causes pancreas juices to leak into the belly - instead of staying within the pancreas and bowel.

Pancreas enzymes - the pancreas normally releases enzymes that help you digest you food.

Pancreatic enzyme insufficiency - this happens after pancreas surgery. After removing a piece of the pancreas, the remaining pancreas does not make enough enzymes & digestive juices to break food down properly. This can cause diarrhea, bloating, weight loss, and greasy poops. Treatment is with enzyme replacement pills.

Immunotherapy - a type of treatment that makes your own immune system fight your cancer.



Targeted therapy - another type of treatment that targets how the cancer cells grow, divide, and spread.

Meet the Author:

Dr. Maria Baimas-George

Maria Baimas-George MD MPH is an abdominal transplant surgeon. Inspired by her patients and mentors, she writes and illustrates books explaining medical and surgical conditions for patients and their loved ones. Her goal is to create books that provide useful information to help with understanding and to offer comfort and hope. You can find her book series at **www.StrengthOfMyScars.com**.

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