





# I have a *Tumor* ... I Was Referred to a *Surgeon* ...

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#### So Many Questions

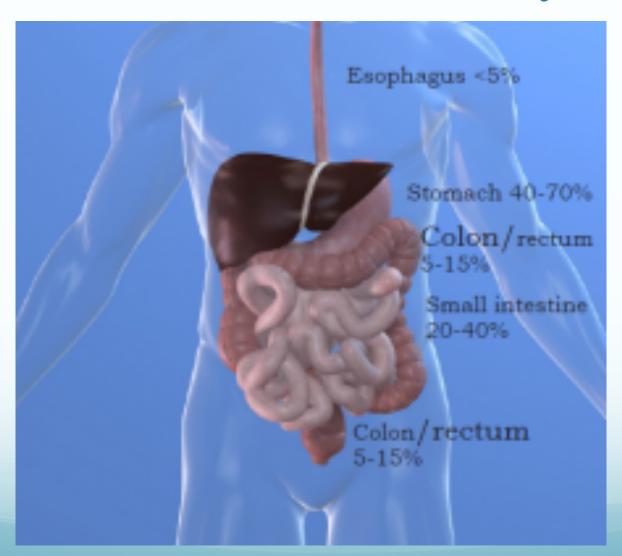
- Do I need surgery?
- Who is eligible for surgery?
- Where exactly is the stomach/small intestine anyway?
- What is it like? How big will the incision(s) be? How long will it take?
- What are the risks?
- What can I do before surgery to make it the best possible outcome?
- What is recovery like? How long will I be in the hospital? Will I be in pain?
- What are some potential long terms effects of surgery?
- What treatment will I need after surgery and when will it start?
- What if I can't have surgery?

#### Do I Need Surgery?

• In GIST treatment today, surgery may be the first step – perhaps the only step - toward a cure.

• Sometimes surgery is undertaken for *palliation* if surgical cure is not possible

#### Where Is this GIST Anyway?



### How Will the Surgeon Determine If and When I Can Have Surgery? And Which Procedure?

- Imaging CT and/or MRI scans of the abdomen, PET scan
  - Where is the tumor located?
  - Does the primary tumor touch or invade other organs?
  - Is there metastatic disease? Most commonly found in liver, also lungs, bone, other sites.

• Endoscopic procedures – EGD, EUS – for biopsy, assessment of other organ involvement

#### "Locally Advanced Disease"

- Makes surgery technically challenging as well as decreasing the chances of completely removing the tumor.
- In some cases chemotherapy and/or radiation may come *before* surgery, to 'downstage' the tumor and make complete removal by surgery possible, safer, less extensive.

#### What is Surgery Like?

- Most GIST surgery can be performed using minimally invasive techniques (laparoscopy, robotic).
- Sometimes a small tumor can be removed endoscopically.
- Open surgery means either an incision up-and-down in the middle of the upper abdomen, or across the abdomen below the ribs. The size of the incision is related to tumor extent, complexity of operation, patient body habitus.
- Length of surgery can be 1 hr, 3 hrs, or more—"as long as it takes".

#### What Are the Risks of Surgery?

- Bleeding possibly requiring a blood transfusion.
- Organ / anastomotic leak.
- "Ileus" or delay in function of gut.
- Infection.
- Venous thrombosis or blood clots.
- Death.

### What Can I Do Before Surgery to Ensure the Best Possible Outcome?

- Try to eat a diet rich in protein, low in fact. Frequent small meals may be easier. Nutritional shakes (e.g. Ensure, Glucerna) are helpful for some patients.
- It's never too late to quit smoking!
- Keep active even two or three 15 minute walks a day can decrease the risk of blood clots.

### How Long Will I Be In the Hospital? What Will That Be Like?

• "Typical" hospital stay for small gastric wedge resection is overnight; more complex procedures could be 3-5 days.

(As long as you need to be.)

• Immediately after surgery will be transferred to a monitored nursing unit (recovery room), transfer to regular nursing floor when stable.

#### Hospital Continued...

- You *may* have one or more drains tubes coming out of the abdomen with fluid collecting in a little bag.
- These are temporary.
- They help us "spy" for complications such as leaks.
- They are removed "at the bedside" when we are reasonably sure there is no leak or infection, in the hospital or even in the office.
- If there is a leak, very, very often these drains control the leakage until it heals on its own.
- Usually the day after surgery you will be allowed sips of clear liquids, to test if your stomach is "ready" for food.

#### Hospital Continued...

- It is not uncommon to experience nausea or even vomit. This usually means your gut has not recovered enough to handle food.
- This is called "ileus" and is not dangerous.
- Generally this resolves on its own and does not require any additional medication.

#### When Can I Leave the Hospital?

When you are ready.

• Eating "enough", pain controlled with oral pain meds.

#### What Will Those First Days at Home Be Like?

- Probably similar to the hospital but in your own bed!
- Frequent small meals, maybe Ensure or other nutrition drink.
- Expect to feel tired and need to rest frequently.
- Do try to walk at least short distances several times a day.
- Feel free to call the office with questions or concerns –
  particularly for things such a fever, increased pain, vomiting, or
  changes in the incision or drains.

#### Possible Long Term Effects

• For gastric "wedge resections" or most small bowel resections, anatomy is not drastically altered so long term sequelae are rare.

• For "anatomic resections" anatomy can be substantially modified and life-altering changes may occur.

#### Anatomic Gastrectomy Long Term Effects

- Distal gastrectomy lower portion of stomach is removed, including *pylorus*, a valve that regulates the rate of food passage from stomach to intestine
  - Initially stomach capacity feels reduced, but over time the stomach will "stretch" and eating will become more normal
  - "Dumping syndrome" may occur where high-sugar meal moves into intestine too quickly (no pylorus) symptoms may include nausea, vomiting, flushing, sweating, diarrhea, dizziness, rapid heart rate
  - Vitamin B12 and iron deficiency can lead to anemia (low blood count) and this should be monitored periodically to assess for need for supplementation

#### Anatomic Gastrectomy Long Term Effects

- Subtotal or total gastrectomy most of or the entire stomach is removed, for large tumors or those close to the top of the stomach
  - Eating will never feel the same frequent small meals will be necessary
  - "Dumping syndrome" may also occur
  - Vitamin B12 and iron deficiency can lead to anemia (low blood count) and this should be monitored periodically to assess for need for supplementation
  - Sometimes temporary feeding tube is necessary until you become accustomed to eating the new way

## When Do I See the Surgeon Again? What About the "Biopsy" Report?

- You will come in for a check-up within two weeks of discharge. Frequency of follow-ups after that will be determined by your individual situation.
- The pathology report may be ready before you leave the hospital. If not, your surgeon will discuss it with you when you return to the office.

## Will I Need Chemotherapy? When Do I Start That?

- Some GISTs are aggressive and you may be referred for "adjuvant" (after surgery) medication to decrease the risk of recurrence, even if the entire tumor was removed.
- You will be referred to a medical oncologist for a discussion on the best treatment plan for you, based on your overall health and you individual tumor.
- You will start that when you have sufficiently recovered from surgery; ie., you are eating better, wounds have healed, drains are out. This is typically 4 to 8 weeks after surgery.

## What If ... I Can't Have Surgery? What Do I Do?

- Your surgeon will refer you to a medical oncologist to discuss your options based on your individual situation. This may include chemotherapy, clinical trials, radiation, or even an informed choice to have no treatment.
- A palliative care specialist may also be recommended based on your individual situation.

#### My Advice

- Get the big picture, the whole plan.
- Surgery, chemo, radiation, staging, prognosis it can be overwhelming.

• But then take it one day at a time.