You have cancer!

Terrifying words when directed to you. Like being slugged in the gut with a baseball bat.[1]

- They were directed to me on January 23, 2023.
- Esophageal cancer. Stage 3B.
- A cancer that rattles even health care providers.

Why I'm writing this -

I'm trying to help you avoid what happened to me. An upper endoscopy (EGD) is the key.

An upper endoscopy is a procedure for your upper digestive tract like a colonoscopy is for your lower digestive tract.

We should insist on having an upper endoscopy in two circumstances:

1. When we have symptoms like swallowing difficulties, reflux, heart burn and/or GERD. Or, are on medication for them.
2. Without symptoms – for screening at least by the time you're having screening colonoscopies. Perhaps earlier depending upon your history, genetics or other considerations.

Let's call circumstance No. 1 a **Symptom** Upper Endoscopy and circumstance No. 2 a **Screening** Upper Endoscopy. Illustrations follow.

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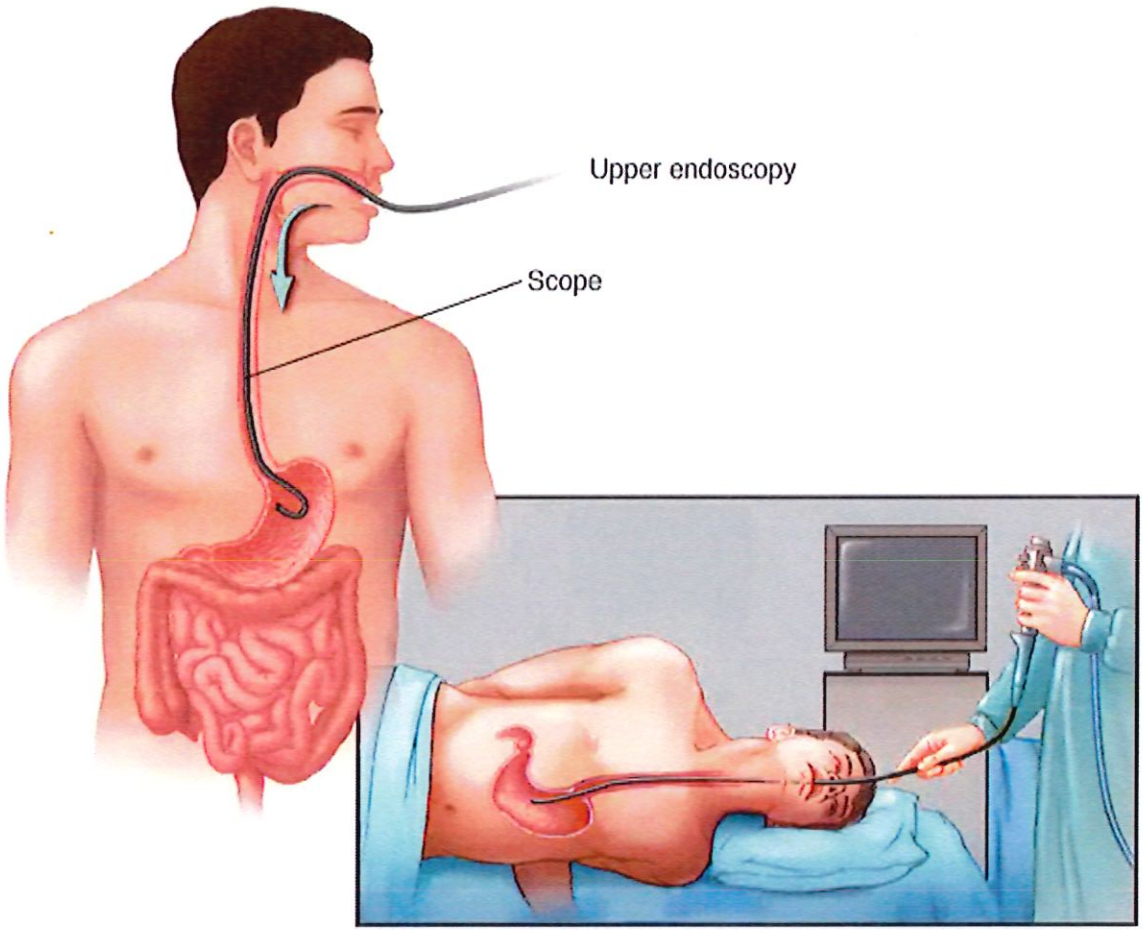
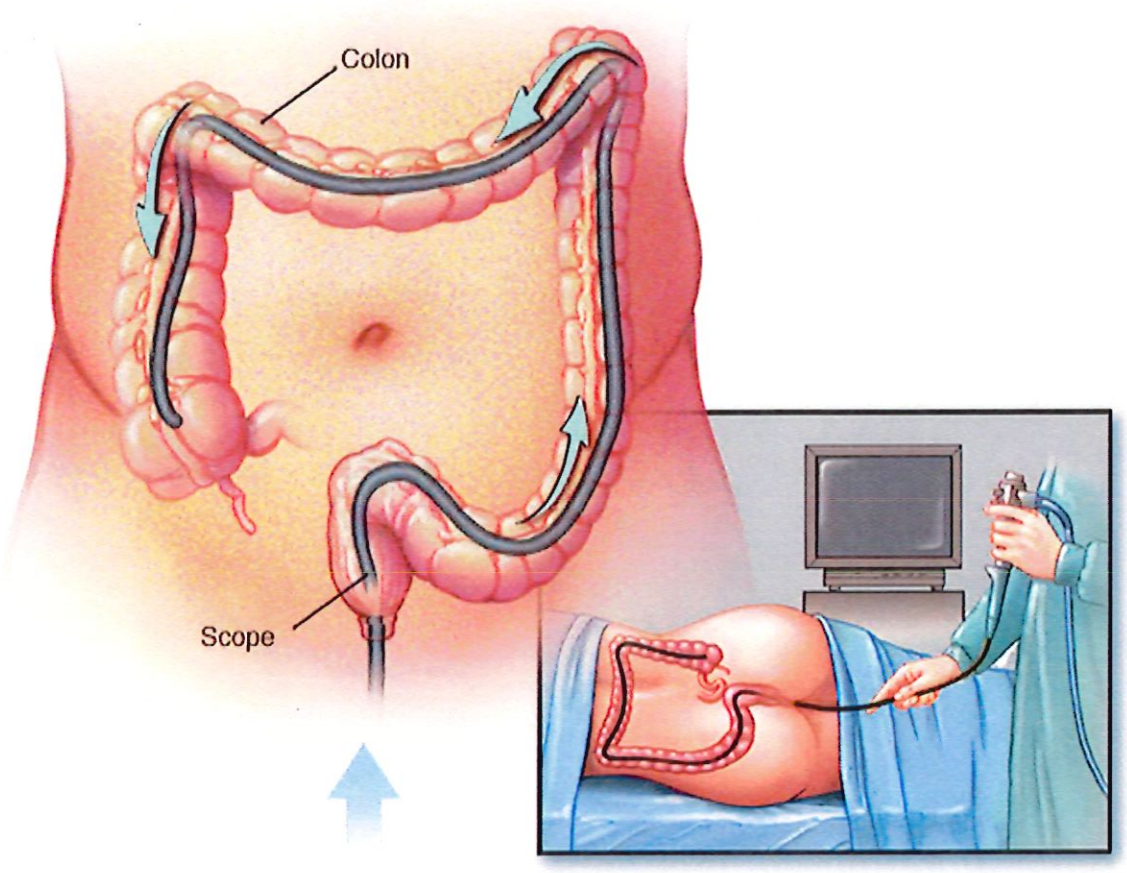
[1] I attended my own funeral many times when closing my eyes after hearing those words. What's worse? Your child or grandchild being told they have cancer. That would be indescribably worse.



Upper endoscopy

During an upper endoscopy, a healthcare professional inserts a thin, flexible tube equipped with a light and camera down the throat and into the esophagus. The tiny camera provides a view of the esophagus, stomach and the beginning of the small intestine, called the duodenum.



Colonoscopy

During a colonoscopy, the healthcare professional puts a colonoscope into the rectum to check the entire colon.

My experience -

I was treated at Mayo Clinic by highly skilled doctors who specialize in this cancer. I owe them my life.

Starting in March of 2023, I had two months of FLOT chemotherapy; essentially a "poison" that attacks healthy cells as well as cancer cells (so leaves life-long side effects). After that, I had 25 radiation sessions (with three more chemo infusions).

Then on August 3rd, I had an esophagectomy. Mayo Clinic says it's a "big surgery." It sure is.

My esophagus and surrounding tissue was removed. My stomach was "reconfigured" and pulled up through my diaphragm to be my new esophagus. An eight-hour surgery. Eleven days in the hospital. Several weeks recovery. Even if successful, as mine was, this "big" surgery results in huge life changes.[2]

An illustration of this surgery from Mayo Clinic is on the next page. You can learn more on the Mayo website or via Google. I encourage you to look.

[2] I've had three follow up surveillance ct scans since my 2023 surgery. No evidence of cancer. A miracle, literally. That's what my doctors say. I'm extraordinarily fortunate, thankful, and grateful.

What Typically Happens During Surgery

- You are admitted to the hospital the morning of surgery.
- A small tube, called an intravenous (IV) catheter, is put into one of your veins. You receive fluid and medication through the IV.
- General anesthesia is given in the operating or procedure room.
- A tube is guided into your airway, and a ventilator is used to help you breathe during surgery.

During this surgery, parts of your esophagus and stomach are removed. The parts that stay typically are connected. The decision about where to connect your digestive tract depends on your condition. See Figures 7 and 8.

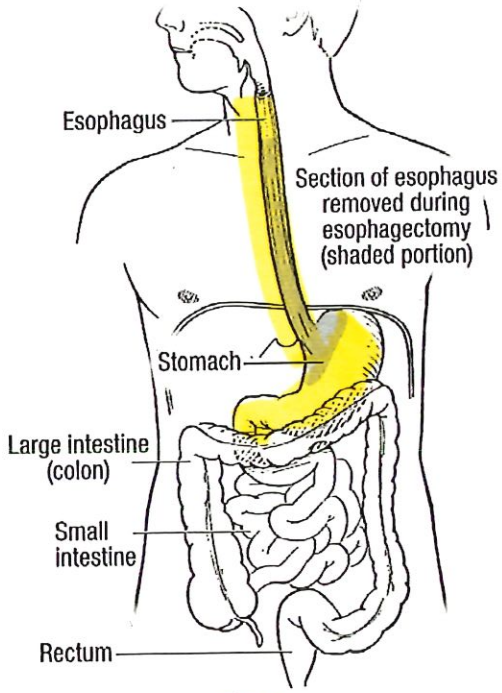


Figure 7. Before esophagectomy

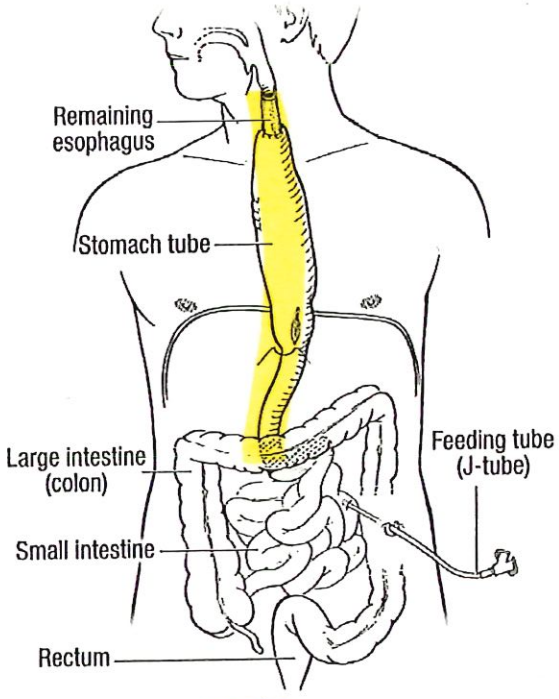


Figure 8. After esophagectomy

Your family and friends

While you are in surgery, your family and friends can wait in your hospital room or in the waiting room. If they leave the waiting area, they should tell a person at the desk or a member of the nursing staff where they can be reached. They should ask a member of the care team how and when surgery updates are provided.

Side effects –

Briefly on side effects from treatment –

> I have permanent chemo-caused peripheral neuropathy in my hands and feet; worse in my feet. Pain, numbness, cold, swelling. All day every day. Medication helps.
>
> Learning to eat and drink with my reconstructed digestive system which means much smaller portions many more times a day. Easy to state, hard to get right. Really hard.
>
> > When you don't get it right – eat or drink too much - a "bad" feeling overtakes you. It eventually goes away.[3]

I won't address emotional side effects. You've observed those with family and friends.

There are worse things -

As terrifying as esophageal cancer is, there's worse. A terminal cancer diagnosis where no treatment will stave off death. Terminal neurologic diseases such as ALS. Heart attacks. Strokes. Addiction. And so on.

I'm lucky – I have a fighting chance!

[3] This side effect has its own side effects. Here are two examples: (1) terrible abdominal pain often with no identifiable cause which has landed me in the ER multiple times; and (2) the development of a "large" hernia because my colon decided to join my reconfigured stomach above my diaphragm and eventually pinch off my new esophagus (conduit) so I could not drink a thimble of water or eat one bite. A recent emergency surgery brought the colon down below my diaphragm where I hope it stays.

Good happens –

Good comes from cancer if you look for it.

- You experience extraordinary support from family and friends.
- You prove you're tougher than you think. Much tougher.
- You focus.
- Your priorities are radically reordered.
- You become more grateful and express it better.
- You are compelled to help others, especially cancer patients.
- You smile more and develop a higher hugging quotient.
- You read more books to your grandkids, spend more time with them at the park. On walks.
- You fish more. Not better, just more.

More good news -

You can avoid what happened to me.

Symptom Upper Endoscopy

I had symptoms for years so should have had a **Symptom** Upper Endoscopy long before I did.

My symptoms included intermittent swallowing difficulty, intense heart burn, and nasty reflux. The heart burn and reflux were moderated by omeprazole which I took for years (another sign of

potential trouble). There are other symptoms easily found on the Mayo website or by Google search. I encourage you to look.

Why didn't I have a **Symptom** upper endoscopy much earlier?

I had no idea I should, and no one told me I should.

Screening Upper Endoscopy

I started having screening colonoscopies many years ago (my dad died of colon cancer) so perhaps should have had **Screening** Upper Endoscopies at the same time.

Why didn't I have a **Screening** Upper Endoscopy when I had Screening Colonoscopies? Great question.

Again, I had no idea I should and nobody told me I should.

Our society doesn't recommend or even address Screening Upper Endoscopies; yet, as we know, it vigorously recommends screening colonoscopies with timelines and follow up based upon results.

Why the difference?

I don't know. I do know that fewer die each year of esophageal cancer than colon cancer so perhaps someone has decided that implementing Screening Upper Endoscopies is a cost society should not incur.

A dangerous cost-based conclusion because:

1. With esophageal cancer, like colon cancer, if you wait for symptoms before having diagnostic procedures, you're likely to find yourself in deep trouble with late-stage cancer facing far more aggressive treatment and a significantly lower survival rate.

2. The esophagus, like the colon, can harbor disease not yet presenting symptoms. **Silent killers**.

3. So, if screening for the lower end of the digestive tract is appropriate - and society deems it is - then perhaps screening for the upper end should be viewed the same way. Why not?

4. **Screening** upper endoscopies will save lives just like screening colonoscopies do. No doubt about it.

   Waiting for symptoms to appear is a very bad idea.

Advocate for yourself -

Ask your doctor:

1. Why does society recommend screening colonoscopies before symptoms appear?

2. Isn't it true that waiting for symptoms to appear in the upper end of the digestive tract (esophagus) is as dangerous as waiting for symptoms to appear in the lower end (colon)?

3. Isn't it also true that finding problems in the upper digestive tract (esophagus) before symptoms with a **Screening** Upper Endoscopy is as beneficial as finding problems in the lower digestive tract (colon) before symptoms with a screening colonoscopy?

4. What medical science justifies approaching **Screening** Upper Endoscopies differently from Screening Colonoscopies.

5. Isn't it also true that Stage 3 or 4 esophageal cancer is as dangerous and life-threatening as a Stage 3 or 4 colon cancer.

6. Can you have a **Screening** Upper Endoscopy the same time as your colonoscopy? Yes. Do one end, then the other.

It's Simple -

> **Early diagnosis is obviously your best shot at living, keeping treatment to a minimum, and surviving treatment with a decent quality of life.**

If you have symptoms, please talk with your doctor about a **Symptom** Upper Endoscopy.

Otherwise, discuss with your doctor scheduling a **Screening** Upper Endoscopy.

Again, my laymen's bottom line is this:

> **A Screening Upper Endoscopy should be valued and implemented equally with the Screening Colonoscopy.**
>
> **Setting aside the issue of cost, I believe there's no medical reason for treating them differently.**
>
> **Stage 3 or 4 esophageal cancer is as dangerous and life-threatening as Stage 3 or 4 colon cancer.**

I hope this was worth your time. If others might benefit from reading it, please forward to them. I'm happy to talk with whomever whenever.

Gary

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