

What to know when deciding about preventative stomach surgery

Experiences from those with hereditary
diffuse stomach cancer syndrome



Sinai
Health

Zane Cohen Centre
for Digestive Diseases

A guide from those with experience

This booklet was created to share experiences from individuals who were faced with the decision of having risk-reducing surgery to remove their stomach (gastrectomy) after learning they have a hereditary stomach cancer condition known as Hereditary Diffuse Gastric Cancer Syndrome (HDGC). These are their words and their experiences.

- 15 individuals were interviewed by the Zane Cohen Centre at Sinai Health (Toronto) – some had surgery, some did not.
- Their points of view vary – everyone is different!
- They wanted to share their answers to questions they wish they knew as they were considering this life-changing decision.

Booklet provided by: Zane Cohen Centre (Sinai Health)

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Background and definitions

There are several hereditary cancer conditions that increase the risk to develop stomach cancer, however, few would require having preventative (prophylactic) surgery to remove the entire stomach (total gastrectomy).



Cambridge protocol – a method for screening individuals at high risk of diffuse-type gastric cancer (see screening section for more details).

CDH1 – the name of the gene impacted in individuals with HDGC.

Diffuse-type gastric adenocarcinoma (DGC) – the type of stomach cancer the individuals with HDGC are at higher risk for. It grows silently under the stomach lining and can be hard to detect. An older term for this type of cancer is Linitis Plastica.

Dumping syndrome – see page 18

Hereditary Diffuse Gastric Cancer Syndrome (HDGC) – a hereditary cancer condition that increases the risk of diffuse-type stomach cancer which is very hard to screen for and prevent. Since the cancer is often very aggressive and hard to catch at an early, preventative stomach surgery may be recommended.

Lobular type breast cancer (LBC) - a specific type of breast cancer. The second most common cancer in individuals with a *CDH1* mutation.

Prophylactic total gastrectomy (PTG) – total removal of the stomach as a risk-reducing measure to prevent cancer.

Signet-ring cell carcinoma (SRC) – another term for DGC, referring to the way this cancer looks under a microscopic (like a signet-cell fraternity ring).

Stricture and dilation – see page 20

TPN – see page 15

Gathering information

We asked individuals with hereditary gastric cancer syndrome where they obtained information on surgery and screening. Their responses in no particular order:

- Internet research
- Reading articles
- Nutritionist/Dietitian
- Blogs
- Facebook groups
- Support groups online
- One-on-one peer support (set up by GC, or skyping/Zooming others)
- Primary care practitioner
- Surgeon (referred to by team, or finding outside surgeons who specialize in this)
- Genetic Counsellor
- Family members
- Family friends who were specialists (doctors)
- <https://www.nostomachforcancer.org/>
- Zane Cohen Centre – arrange peer support for individuals in their Registry

Sources of Support:

- Talking to family
- Talking to genetic counsellor
- Journal and blogging
- Talking to a psychiatrist

Gathering information - quotes

- The help and resources are out there, it's just a matter of looking them up and getting the information and whatever is going to help you feel better to make the right decision.
 - My mentor gave me all the heads up on everything she went through, her experiences, and that really helped me through doing this. I think a mentor is very important. Someone who has been through it.
 - The most helpful information was actually personal stories through the bloggers that were of the same age as me. It was helpful because we were the same age going through the same thing.
 - I'd already made the decision (to have surgery), but it was very good for me to visit someone who had just had the surgery. This was 6 weeks prior to me having my surgery to see that yes, there is a life after surgery. I was there to witness her eat her first few mouthfuls of Jell-O...and that was very good for me to witness.
 - My first thought was my children. To learn as much as I could about how it would impact them and wanting to prepare them with how to process the information.
 - I knew it had to be my decision, but I wanted somebody to give me some indication that if I have the surgery that it was the best thing for me. It was frustrating me (not getting direct advice).
 - Wish there was more therapist that specialize in this
-

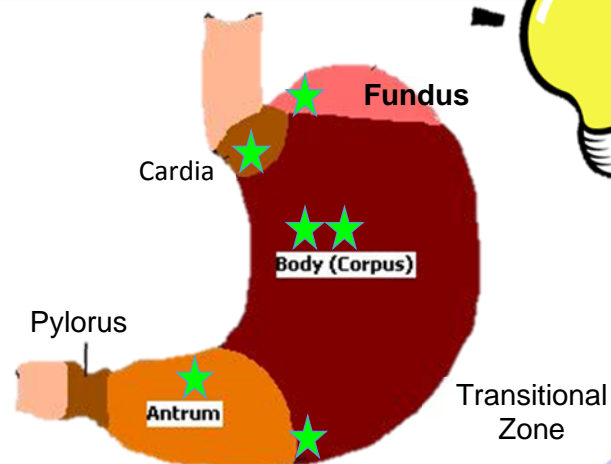
Trust in the screening - quote

This refers to screening the stomach using an upper scope called a gastroscopy done yearly, with random biopsies. This is done for individuals who chose not to have stomach surgery.

Did you know?

The Cambridge protocol refers to taking ~30 random biopsies in specific areas of the stomach (★), looking for microscopic cancer in individuals with hereditary diffuse gastric cancer syndrome.

Blair et al, *Lancet Onco*, 2020



- It didn't make me feel like I was Scott-free.
- It is kind of like searching for a needle in a haystack, but it gives me a little bit more piece of mind. I do it every 6 months because once a year wouldn't be enough for me.
- I know that gastroscopy isn't necessarily the be all and end all and it's the only thing that we've got now but I'd rather have the annual screening than making a serious decision like removing my stomach.
- I will remove my stomach if they find abnormal cells because then I feel, there you go it's a warning, if I have abnormal cells growing then how long will it be till I have cancer. I'm using it more like a warning system, I figure that if it doesn't catch it one year it'll catch it the next and what stage will the cancer be at when they catch it. It is a bit of a game, you're trying to buy time by going through these screenings and you're hoping that somehow some research might show some benefit.

- When I'm waiting for my screening results, it's agonizing and I just think, what if something comes back? Should I have (had surgery) earlier? Did I do this to myself? Then when (my results) come back normal, I go back to my normal level-headed opinion.
- The screening found my stomach looked a little different. Like the cells were changing. It pushed me towards deciding on surgery.
- I kind of looked forward to doing the yearly screening because it kind of gave me another year of feeling normal.
- It can be an insanely difficult decision to decide to go ahead with surgery or continue with surveillance. I felt the that sickening feeling for a long time when given my diagnosis, and while the fear is still there, I have learned to bury those feelings and have trained myself to try and live the normal life I was leading before hearing the news. I have decided, for now, to continue with surveillance every 6 months and will go from there.
- The surgery is the point of no return. Your lifestyle changes forever, and as much as you read that you can have a normal lifestyle - whose normal lifestyle? You know it changes people's lifestyle, e.g. the way you eat, how your body gets nutrients. Having your stomach removed is an extremely difficult decision and there's always the hope with technology, procedures might improve to where they can diagnose the cancer early. Removing your stomach is very barbaric compared to other types of surgery, so there may be some hope in a few years (that better screening will be developed).

Did you know?

Reasons given for declining/delaying surgery:

Lifestyle change, Disruption to family, Lack of information, Surgery-related concerns, Age (over 60 or under 35 years), Belief in screening, Fertility concerns, Life stress, Close relative with negative experience.

McGarragle et al. *Familial Cancer*, 2020)



Messages from those who chose NOT to have stomach surgery

- It's a very extreme surgery. My surgeon used the word "risk tolerance". My risk tolerance tells me to wait until 30-31 years old. I was also concerned about fertility. Determine your own risk – your age, support system, children, and family history?
 - I booked the (surgery) date and then I delayed it because I wasn't super prepared. My family said, "We can see that you are not committed yet and you have to be 100% positive and you're not, so don't do it yet."
 - Hope is very important. I remember, years ago, there was a higher probability of getting (cancer) and now those statistics are not as high as they used to be.
 - For the most part I have gotten back to living a normal and healthier life, but every so often, my brain reminds me that I still have this life- changing decision hanging over my head and it can get hard sometimes. For now, I am continuing with surveillance and praying for an advancement in science that can change the outcome in the future.
 - There are a lot of misconceptions and when (my friends) hear 'I'm going to get my entire stomach removed, they're like I'm sorry, what? You need a bag? Are they making you a new stomach? I've seen online that there's hundreds of people that are living the 'new normal'. They're living a different life, but it's by no means a lesser life. So that's what keeps me positive and what I keep in mind for the future.
 - I think that the age of when you discover this plays a key part. There is a huge difference discovering (the gene) in your late 50s versus your 20s. Are you going to worry about dying in your 40s? Or when you're in your late 50s, you may think if I make it to 80, I'll consider myself lucky.
-

Decision to HAVE surgery

I don't wake up in the morning anymore thinking: What am I going to be diagnosed with today?

I knew that if I did have it (a *CDH1* mutation) I would have the prophylactic gastrectomy because otherwise for me it would like a time bomb.

A random biopsy found cancer. I think it would've been really hard to get the stomach removed and then find out there was nothing there, but this helped me make my decision. It was a really weird moment you find out you have this cancer but it was a confirming moment for me. Like all of my "ifs" and "buts" were answered. It was like okay, let's do it, let's get it out. It was an easy decision at that point.

I was very scared having lost my relatives to cancer, and knowing that one was gone in almost three months. I didn't want to ever have to feel that because I had a stomachache, I'll think that it's cancer.

I just wanted to get it done and get it over with, and my mentor, seeing how well she was doing, I just decided that it was the right thing without having to think about the screening every 6 months. Thinking what if, what if?

I wanted to have the weight off my shoulders, I wouldn't have to deal with the consequences.

I was prepared to do yearly gastroscopies, but when they get a hit (finding cancer on endoscopy), I just had to do it (have the surgery).

I didn't really enjoy going through the testing process and I didn't want to have to keep doing that every 6 months or so or even every year and I think that was the turning point there.

I think just enjoying food and being able to eat normally and have full meals, so knowing that was not how my life was going to be anymore was pretty big. It was probably the biggest factor in me having second thoughts about the surgery. In the end, I just figured that if I did go through with surgery, then I would be able to have – not regular meals – but at least still eat and enjoy food in a different kind of way. More importantly, it would hopefully raise my chances to be around for my family for a lot longer. So the emotional impact was....there were a lot of thoughts about mortality, and what life might be like afterwards – and that was all hard stuff to think about because nobody really wants to think about that stuff. When you're making the decision, you're just trying to move forward, and you're not thinking about the bad stuff so much anymore. You're just trying to make the best of it.

I wanted to make sure my family doctor was well informed and knew how to care for me after the surgery. But after, when it came time to take out my staples – my doctor was always referring me back to the surgeon, and the surgeon said the family doctor should help me (like with a rash around the staples) That was a challenge. My family doctor had gastric bypass patients, but no patients who had total gastrectomy. You have to have a doctor who is willing to look into it and find things out, to educate him or herself.

What do the Researchers Say?

- Stomach surgery (PTG) is recommended for anyone with a *CDH1* mutation (or likely-mutation).
- Starting age 20. Not usually recommended after age 70.
- Finding microscopic signet-ring cell (SRC) during screening should not prompt a rush to surgery. It's not an unexpected finding in HDGC. - Gamble et al. *JAMA Surgery*, 2021

- PTG is recommended for *CDH1* carriers with a family history of diffuse-type gastric (stomach) cancer (DGC).
- For *CDH1* carriers with no family history of DGC, (i.e. breast cancer only or no cancer in family), there is still a risk of DGC. Recommend yearly screening, and consider PTG. Recommend PTG if a SRC is found during screening – Blair et al, *Lancet Oncology*, 2020

Main concerns before surgery



Risk of surgery

- Risk of surgery in general
- Waking up after surgery
- Pain management

How long will recovery take (when will I sit up, walk, lift things)

Did you know?

The median surgery time is 199 minutes (225 minutes for laparoscopic, 220 minutes for the robotic, and 174 minutes for the open approach).

The median length of stay was 7 days

(Study was done at Memorial Sloan Kettering Cancer Centre in New York, US
Strong et al. *Annals of Surgery*, 266; 6, 2017)



Important Notice

Ask your doctor

This booklet cannot replace a discussion with your doctor about the risks and benefits of surgery. Here are some questions you may want to ask: 1) *What is your experience with prophylactic total gastrectomy?* 2) *What type of surgery do you offer: Open-surgery, laparoscopic (key-hole surgery), robotic-assisted TG?* 3) *What are the risks and benefits of those surgeries?* 4) *What has been your experience with patient's recovery after?*

Main concerns before surgery

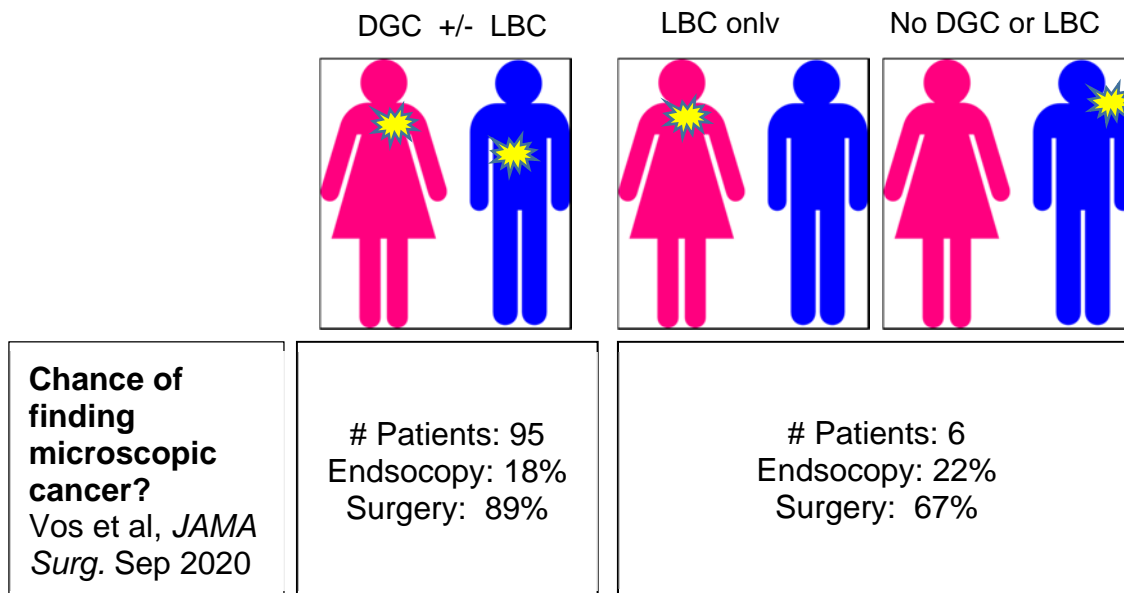
Risk of cancer

- What is the risk of stomach cancer after surgery?
- What if they find cancer/waited too long for surgery?



Did you know?

Not all families with *CDH1* mutations causing HDGC have a history of diffuse stomach cancer (**DGC**). Some families *only* have lobular-type breast cancer (**LBC**), which is the second most common cancer in HDGC. Some have neither DGC nor LBC. **Does the chance of finding microscopic stomach cancer during screening or after surgery, differ based on family history?**



Main concerns before surgery

Lifestyle changes

- How it would impact my eating – how am I going to eat, what am I going to eat?
- Will I need to have things soft and mushy before I eat it?
- How often will I eat?
- Do I need to be two steps from the bathroom?
- How it would impact socially?
- How it would affect regular activities, i.e. physical activities such as running?
- Will I have very low energy? For how long?
- How will it impact my ability to take medication/B12 shots?

**See section on
pregnancy after surgery**

Timing of surgery

- Timeline (i.e. when to do the surgery - for young person)?
- When to have children (pre or post-surgery)?
- What are long term effects having surgery in your twenties (i.e. is there higher risk for osteoporosis)?
- Are there any studies looking at long term outcomes?
- Should I be in good shape before surgery to help recovery later?
- I have concerns being away from young child/not being able to lift or have energy for young children
- Who is going to care for me/my children in the beginning of my recovery?

What did you eat right before surgery?

- Chicken wings
- Big steak, potato chips
- Steak and baked potato
- Big steak dinner
- I went for the best steak I could find

Do you
sense a
theme?

- I wish I had ice cream – tons of ice cream. I can't eat ice cream anymore.
- I became lactose-intolerant after surgery, so lactose would have been my meal.
- I didn't really have like a blowout meal or anything like that, but I'm fine now I can eat anything at all so I don't feel like I missed out.
- I went to Vegas and ate anything that I wanted and I drank anything that I wanted.



Did you know?

2-4 weeks after surgery, the most common symptoms were: pain (75%), fatigue (88%), trouble sleeping (75%), shortness of breath (63%), and appetite loss (63%).

(Muir, Aronson et al. *J. Gastrointest Surg.* 2016)



On very rare occasions, patients may not be able to tolerate food by mouth in the weeks following surgery and may be temporarily placed on **total parenteral nutrition (TPN)**. TPN is an alternative way to get nutrients by giving fluids intravenously (through a flexible tube into the vein), in an effort to bypass the digestive tract.

Recovery – months 1 to 12 post-surgery

*These patients had open surgery

- Difficulty eating
- Weight loss
- Vomiting after eating certain foods
- Low energy levels
- Pressure from family (telling you to eat)
- Stricture (and waiting for them to be dilated, losing weight with any delay)



Did you know?

Weight loss is impacted by pre-surgery weight. Two years after surgery:

Obese weight pre-surgery: 28% loss

Overweight pre-surgery: 18% loss

Normal weight pre-surgery: 14% loss

(Vos et al. *JAMA Surgery*. 2020)

- Right after surgery, you're just fully hooked up to every machine possible. It's very eerie. I wish someone warned me about that.
- I didn't wake up every morning with that anxiety of wondering "what am I going to be diagnosed with and what are the results going to be?"
- Helpful booklet - *Art of Eating Without a Stomach*. Most dietitians give info about being lactose free and higher fat, but this book was more specific for no stomach.
- After the surgery, I didn't have a lot of pain, but I struggled with trying to walk again. I was so weak.
- The first couple of days are brutal. And then the first week is brutal, but then I think after the 6-7th day, we started to see the light.
- I didn't have much pain around the midsection and the stomach area, but what was killer was the shoulder (from the way I was positioned during surgery).

- I was up walking the second day – they had me up walking, and I didn't have anything to eat until the 6th or 7th day. They fed me some ice chips on the 6th or 7th day, but nothing before that.
 - I had a 14 inch incision from left to right, through all my belly muscles, so I couldn't sit up and I felt like I couldn't push myself up off the bed. It took 8 weeks before I felt like I could sit up and not feel any pain or anything straining from my abdomen.
 - The people who worked at the hospital were bringing meals for me. I thought that they were going to give me a special diet, but I was just getting regular hospital food. I don't think they knew what to do with me because it was kind of a rarer surgery. The doctor told them I could eat stuff, but they didn't necessarily explain to them what my requirements were and they didn't have any advice to give me, as to how much to eat or how slowly I should eat. I just kind of had to gauge that myself.
 - I'm just kind of figuring out what's good and what's not good and what volume, but my biggest worry is the weight loss and I step on the scale and go 'oh my god I lost another pound or another two pounds'. I probably shouldn't be doing that but it's the only factual thing I can see. (1 month out)
 - I had my surgery in June, and in September I started most of the activities I was doing before. I won't say I was 100% but I was able to go for a very short walk, and I did a lot of sleeping.
 - I found that I couldn't drink water for the first three or four months.
 - I like a lot of soups that I pack in with my proteins that are like beans, lentils, chick peas you know things like that. I can eat a bit of chicken, shrimp or fish. (6 months post-surgery).
 - I was back to work in 6 weeks.
 - At 8 months – I don't enjoy food anymore, I have yet to sit and have a meal and say wow. Before I could sit with a good glass of wine, or a plate of pasta or really amazing steak, now it's like "oh it's time to eat". I should eat something, because you know it's the afternoon and I haven't eaten one thing and I don't want to pass out.
-

- Food was such an emotional, passionate, thing. Finding recipes and restaurants and wine bars and it's nothing like that anymore and socially I don't get invited out as much anymore.
 - I found the dietitians in my area, they know how to tell people how to eat post bariatric surgery but those people want to lose weight and we want to gain weight. She's like "well did you try ensure or any of that?" and I said, "I did and it was awful, it's so processed that it made me feel very ill." I know some other people can drink it but I can't drink it, there's too much in it, I think.
 - The first month was really hard just in terms of slowing down how much I would eat. I would start to feel sick 20-30 minutes after I ate. Some things wouldn't go down very easily, they'd get stuck in my throat, so I would have to chew really well and swallow little bits at a time. When I found foods that I could eat pretty easily like eggs, I would eat too much of them really quickly. All of a sudden, half an hour later, I would have the worst nausea and stomach ache of my life (because of dumping syndrome). Trying to figure out that pace, that frequency and how quickly I could eat and how much I could eat. That took a whole year.
-



Dumping syndrome – symptoms caused because food and liquid rush into the small bowel too quickly, leading to abdominal pain, vomiting, diarrhea, bloating, dizziness and cold sweats. During late dumping syndrome, sugar from the food can cause a quick rise in blood sugar resulting in a release of insulin that can quickly lead to low blood sugar (or hypoglycemia). This may cause weakness, fatigue, cold sweats and rapid heartbeat.

Recovery – 12 months after surgery

Most people said they felt they were at their new normal by this point.

Still dealing with:

- Core weakness
 - Low energy (B12 shots)
-

- You lose weight but eventually stabilize at your new normal weight.
 - Muscle loss in first year, also wanted to eat at home a lot so I knew what was in the food, and I was near a bathroom.
 - It's going to take a little while for your body to adjust and for it to know exactly what you can and can't eat. There were foods that I might be able to eat today and be fine and if I eat it two days from now, I may not feel the same, I may have dumping syndrome.
 - It took about a year, a little bit more maybe before I can eat as much as I did before. I eat slower, but my meals are normal size.
 - I would say within a year I was feeling really good, although I still can't eat a whole lot in one sitting.
 - I kept soda crackers and Ritz crackers beside my bed. I'd eat probably 10 of those during the night because I had a little bit of heartburn. That's long gone now, but some maybe food didn't agree with me and it would come back to haunt me maybe 8 hours later, so I would just eat the Ritz crackers and it would go away.
-

Recovery – after the first year

I had 7 strictures and dilations in first year..... It was in the **second year** when I was starting to feel normal. I had learned if you eat this, you'll pay for it for an hour or so. You're going to run to the bathroom or you're going to be in pain for an hour, depending on what it was. It was by the second year when things started to get back to normal.

I wake up every day now just thinking "okay I'm going to see how I can eat."

It's almost my **3 year anniversary** since my gastrectomy and I feel like my third year is my best – every year I get better. I can actually eat sweets now. It was a fear before to eat sweets but I can eat sweets. I think I got to a point where I was like "just screw it, I'm going to try everything and whatever happens, happens". Sometimes I paid for it but I can eat a cookie now and be okay. I think maybe that has led to the weight gain.

After **3 years**, I'm doing very good in terms of maintaining but I have to eat every 2-3 hours. Within the last week I've even told myself "maybe I can get away with not eating every 3 hours" but if I don't I start to feel the effects of not eating, I start to feel tired, sometimes I get a headache.

After **3 years** - If I eat sugar right before I go to bed, like a cookie or something, I usually wake up fairly early the next morning. I think it's because of your blood sugar and the way your body digests it must tank really hard and it wakes you up and then I'm wide awake.

It's been almost **4 years** since my surgery for my stomach and I'm still finding that I have trouble eating some foods, I still can't drink milk. Some foods like meats and chicken I guess there's more substance to them so they take longer to digest and the digestion causes discomfort.

At **4 years** - You can eat whatever you like, it's just that some foods you have to eat minimally and just once in a while. And it's just an adjustment phase where you learn to eat over again and you learn what goes and what doesn't.



A stricture is a narrowing in the esophagus (swallowing tube connected to the small bowel after stomach removal) caused by inflammation or scar tissue after surgery. **Dilation** is a medical procedure, often using an upper scope under sedation, to stretch the narrowing, making it easier for food go down.

By year 4, you're more accepting of everything that's gone on but you're never 100% back to your original energy levels.

When I exercise my energy level is significantly better and my eating is also better. It seems kind of counterintuitive because you want to maintain your calories but I've noticed that as soon as I exercise I have significantly better energy. (**4 years** after surgery)

5 years later, there is nothing that I can't eat. Whether it's ice cream, a cinnamon bun, or fatty food, if I have it slowly enough, then I'm totally fine eating it. It's just a matter of me controlling how much and how quickly I'm eating it. Stuff that's really fibrous or raw vegetables – particularly carrots – that kind of stuff is the hardest for me to eat. It doesn't make me feel sick, it's just a potential to get stuck in my throat if I don't chew it into a teeny tiny little bit of mush. The biggest change in terms of my overall diet is that I snack more now. I'll go to a restaurant and I'll only have a third of it and take the rest of it home and have it for lunch the next day.

I'd consider myself, I'd say 99% recovered. It was a journey, like it's been over **5 years** for me now. So I went from being sick at every meal and to now maybe getting sick once a month – and it's my own fault, because you end up trying to go back to old habits, and you can't eat the way you used to. You got to be able to chew your food well, or it gets stuck. Other than that, I feel great. I've put weight back on. I don't think I'll ever be the size that I was before, but I feel healthy. I'm full of energy. I can't sit still.

5 years later: "It's been a long process. I'm still down 35 pounds, because of all the weight loss, I've lost all my muscles in my legs. I have a hard time walking long-distance. I received a handicap pass to deal with the muscular-skeletal problems. I still have quite a bit of dumping. I probably vomit once every couple of weeks, sometimes twice a week. I struggle with eating. If I don't eat, I feel sick, and if I do eat, I feel sick. So it's like a Catch-22. I'm damned if I do and I'm damned if I don't."

I just recently started getting **hunger pains**. Yep, before it was just kind of an empty feeling, but now I'm feeling those hunger pains – 'pangs' I guess you call them, that I used to have when I had my

Post-surgery: self-image

- I had lost a lot of weight and I had that nice scar on my stomach. So, I had all these reminders of the surgery and why I had the surgery. It did get me down a bit.
 - With my height and build, I really looked anorexic and it wasn't easy to get the weight back on. Even when I started eating normally, it was hard to get any weight back on. That was hard to deal with. It was nice to lose a few pounds, but I didn't want to lose that much. I felt like my clothes were hanging off me. Even though I lost weight, which is always nice to do, I didn't feel good about it.
 - I didn't feel as strong. I felt pretty weak and that was difficult to accept, that I was a strong person and now I'm not because I lost so much muscle.
 - Right after surgery, it was stressful because I had lifting restrictions and I couldn't go back to work. I was off work and I had a really hard time. I was a career-a-holic and was really career-focused and after surgery it was really hard to sit at home for 3.5 months before I could get back.
 - In the last few months, we went to Florida, and I bought myself a bikini. I said to my husband, 'you know, I've been afraid to wear one in the past.'
 - I'm still about 10 pounds overweight, but I'm sure the surgery has kept me from over-eating. If anything, it's probably made me a little bit happier with my overall physical appearance.
 - After losing 100 lbs – excess skin can be an issue.
 - It is easier to lose weight now than it was before, and I think I am at a healthy weight. I lost about 40lbs, and I was carrying extra weight before the surgery. Just buying new clothes was an issue in the first year.
-

Eating and drinking after surgery



I can still eat ice cream but not to the same extent. I was like a two bowl kind of guy before, now I'll have a reasonable amount. It took me a good 2 years before I could eat it.

At **3 years**, I can eat **ice cream**, just not very much, maybe a spoonful or two. I can eat more now than I could a year ago. A year ago, I would have one spoonful and be in a lot of pain.

After **3 years**, I **can't eat very much ice cream**. I can still eat about a cup full of ice cream and I know what's going to happen. I'll get a kiddie scoop, and I try to pick ice cream with nuts or protein in it – a pistachio ice cream.



Caesars are good because eating anything with tomato in it is good and I think it's because of the acidity in the tomato. Anything I ever make that has tomato in it I can eat a lot of. And ground beef, pasta sauce, chili are all really good. I can eat a lot of chili. And burritos, or burrito salad without the wrap, that's really good too. Those are like my easiest digested food. Very high protein diet, less carbs I think is the key.

Oatmeal is really good for me to eat, (3 years)



I can't eat a lot of bread and bagels. I think within **the third year** I could eat a little bit more but I'm a little bit **afraid of white bread**, I won't eat a lot of white bread.

I do eat a lot of eggs. Start my day everyday with an egg.

I can chew bagels but not toast. I can eat scrambled

I had a piece of toast, and I usually just have peanut butter, but I felt I'm going to try jam. Oh my gosh, did I ever have dumping after. I just broke out wet and I was just shaking like a leaf!



Eating and drinking after surgery

Carrots are fine when they are boiled because they get really soft, but if raw, I never get past that kind of hard crunchy phase. I have targets in my head about how many calories I can have in a certain amount of time, and how much fat content I can have or oil content because those are things that can cause dumping syndrome for me. And with all those things in my head now, it's just kind of normal for me to sit down and know how much I can eat, and how much like how quickly I should be able to eat. All that to reach **my new normal took probably about a year.**

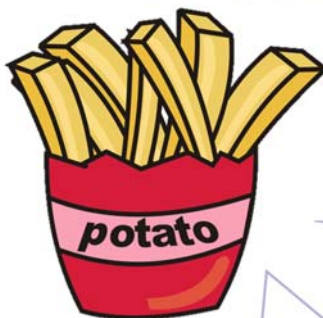
I eat a lot of chicken, turkey and fish. Anything that's dry, sometimes the chicken can be dry, it's very hard to get it down. But for the most part it's not too bad.



Some foods, especially if too dense or firm, make me vomit. But after I vomit, I try again and it seems to go down better.

I can't tolerate anything **greasy**. (Over **3 years** after surgery)

Junk food is easy, a honey dip doughnut at Tim Horton's goes down really easily.



Fried food makes me nauseous – A year after surgery – I can eat French fries, just not a lot.

I eat potato chips every night.

Drinking - water

I have trouble drinking water, and I cannot take a pill. So anything that is prescribed to me has to be in liquid form because I cannot get a pill down with water. It comes right back up.

Fizzy drinks gets stuck at the base of my throat, actually one time it cut off my air passage, and I couldn't breathe. With water it comes right back up



Water from the tap is the worst. Filtered water is better. Bottled water is better than that. Refined water is the best. It's like if you pour water into a glass tube, you get bubbles but those bubbles make its way to the top. That's exactly what happens in your stomach. You can feel the water stop halfway down, and you have to wait for that bubble to make its way to the top before you can take in anymore water. I think it has something to do with surface tension, you have to break surface tension by cutting your water with juice which somehow it goes down and then you can gulp it.

Probably the most difficult was drinking. I used to drink a lot of water. I can't guzzle water, I have to sip it. I always kind of relate it to if you're filling up a bottle with a funnel. You have to stop and let it drain a little or it will overflow right. If I drink too much, I choke. You have to wait, I feel like my esophagus is tightening. I have to sip, and then let it go down. Then sip some more.

After **3 years**, I **can't drink water regularly**, I have to sip it - I can't chug it. Unless it's bottled water and it's really cold. Sometimes I've tried to do a couple big gulps and sometimes it doesn't come back but sometimes it does. It tastes like you're drinking molasses, like it goes down really slow and it gets stuck sometimes. It's very weird, but filtered water is better.

After **3 years**, tap **water is not really great**, bottled water is a lot better. Like the more filtered it is, the better it goes down. But most of the time I cut my water with juice. Either orange juice, or this summer I was drinking cold herbal tea and I cut it with a bit of lemonade so it was like refreshing.

Drinking - other

Sucking an ice cube is helpful to get more liquid.

Coffee is like the easiest thing ever.

Wine is way easier than water. White wine is the best. I have one glass and I'm tanked. And then it goes away in an hour or half an hour and you do it again. **Same with coffee,** wine and coffee are the easiest things to drink. I really like coffee.

Wine is great!

A beer or two before supper really increases my appetite.



Tricks for eating and drinking

- It's trial and error and accepting that every day is not the same. Some days are better than others.
 - I'm just slowly teaching myself which foods give me discomfort. ... just keeping track of what you eat and keeping track of what bothers you and you either have to avoid that food or take it in small doses.
 - It's just a learning process and the more you learn, keeps you healthier. You're not just healthier physically, but also mentally because you're focusing on yourself and on your health. You start to feel better about yourself. You're paying more attention than you did in other surgeries or before you had been diagnosed. Those are the positive things about it.
 - You have to know what you can digest – what goes down and what doesn't because I've had quite a few times where I've had the meats and I had to vomit right afterwards.
 - I like the machines that make fried food but with little oil. I enjoyed a couple of French fries the other night out of it. Usually I can eat one French fry, but I think I ate four that night. You can do chicken wings, fries, all different things in it and it only uses a tablespoon of vegetable oil.
 - I usually snack on chips and stuff like that because they go down really easily. It's the perfect snack food because it doesn't get cold, it just sits there. I can have one. I can have like one chip every 3 minutes. The one thing I have found is that the more processed the food is, the easier it goes down. Which I know is bad from a dietary perspective, but fibrous things are always really hard for me.
 - I try to eat every 2 hours. Even from the variety point of view, you don't want to keep eating yogurt, you don't want to keep eating eggs (1 month post op)
 - Meal sharing with friend or spouse at a restaurant.
-

What happens when food doesn't agree with you?

- I eat it and then about 5-10 minutes after, it starts with fatigue and sometimes a rapid heartbeat and it feels like your heart is pounding out of your chest and then you get hot and usually with the hot you're fatigued. Then you feel really foggy-brained and sometimes if you overdo it you feel nauseous.
 - Usually I go to sleep, like I just pass out. Like the heat is to a point that if I lay down and close my eyes I fall asleep. I sleep it off and feel fine.
 - Things feel like a constriction in my throat where I couldn't have another bite because I felt like everything was locked up in my esophagus. That happens to me sometimes – I'd say once a month – it doesn't really bother me anymore. Sometimes it goes away in a couple of minutes or a couple of hours it will go away, but I don't really panic or feel weird about it at all anymore. It was about at that one-year mark that I started feeling more comfortable with that and not really worrying about it. If I have my neck turned and I swallow that creates a turn and a constriction in my esophagus, so now, when I eat, I don't turn my neck much when I'm talking to people.
 - I break out into a sweat if I have chocolate or sweets. I just feel lousy and I have to lie down.
 - 15 minutes and put a cold cloth on your head, and then you're fine.
 - I felt awkward socially for a bit. With food not staying down. I always knew within the first five minutes of eating and you're in a social setting – whether it's a restaurant or, you know, with friends – I found that really difficult. A bit awkward.
-

Typical day of eating

2 weeks after surgery - Breakfast: ¼ c. cereal w/ milk, coffee, juice, Snack: yogurt, Lunch: ½ bowl soup, ¼ banana, ½ slice bread, Snack: Boost, tea, Snack: Tomato juice, Dinner: ½ c. Ham fried rice, Snack: ½ slice bread, Snack: Boost

Two weeks post-surgery – “Breakfast: 1 cheese string and half bowl cereal, Morning snack: 1 protein bar, Lunch: Kraft dinner, Snack: Freezy, Dinner: 1 hot dog, 10 veggie crackers, Snack: ½ freezv”

~3 weeks after surgery - Breakfast: 1 c. almond milk and ½ scoop protein powder, Morning snacks every 40 min: 1 slice watermelon, ½ slice rye bread and liverwurst, Lunch: 6 cashews, coffee w/cream, Snack: 5 crackers + hummus, Snack: 1 slice goat cheese and ham, Dinner: ¼ pear, 1 c. soup, Snack: 1 Tbsp. Tapioca pudding.

~3 weeks after surgery - Breakfast: English muffin w/ ham and butter, Snack: cereal bar and orange juice, Lunch: Wonton soup and pudding, Dinner: Chicken wrap and veggies, Snack: Chips and juice.

6 months post-surgery – Breakfast: 1 bowl oatmeal, 6 oz. café latte, Snack: 1 large bagel sandwich w meat and veggies, Snack: Ice cream cone, Lunch: ½ pita w beef and tomato, coleslaw, Dinner: ½ beer and 1 rib, Snack: 2 chicken balls and sauce

6 months post-surgery – Breakfast: 1 banana and coffee, Lunch: Sandwich and coffee, Dinner: Lasagna and ½ glass coke, Snack: 1/3 package chips, Snack: Hot chocolate and yogurt

6 months post-surgery – Breakfast: 3 slices bacon, 2 egg whites, ½ c. potato, 1 c. orange juice, Snack: coffee w/milk and sugar, Lunch: 1 ½ c. Baked beans, Snack: 2 c. Chips, Dinner: ½ chicken breast, 1 ½ c. potatoes, ¼ c. beans and parmesan cheese, 4 Tbsp. tzatziki, Snack: 1 c. pudding and whipped cream, Snack: 3 cookies and small Shirley Temple.

1 year post-surgery – Breakfast: ½ c. oatmeal, Snack: 1 oz. cheese and 2 crackers, Lunch: Noodles and veggies, soup, Snack: ¼ peanuts, Snack: 3 pieces of chocolate, Dinner: Pasta and sauce, Snack: Veggies and Dip.

1 year post-surgery – Breakfast: 1 ½ c. cereal w/milk, 1 c. juice, Snack: coffee w/milk and sugar, Snack: 2 pcs. toast w/butter, Lunch: ½ chicken breast, potatoes, Snack: Instant breakfast drink, Dinner: Pasta and sauce

I'll get up and have a banana and maybe some other fruit like berries and then maybe some cereal with milk and coffee, and then a little later I may have some toast, and lunch, I might be able to have soup and a sandwich. I just cannot have a large volume, similar to before, maybe just smaller portions. I might have an apple and cheese in the afternoon, and at night I may have popcorn and chocolate, dark chocolate. **{2 yrs. post}**

I'll get up in the morning before I go to work and I'll toast a bagel with peanut butter. Or I'll take leftovers from last night's supper and I eat all the time at work so right now I eat potato chips and some yogurt and nuts. I'll have a good breakfast and on weekends, it's a bigger breakfast. And then for lunchtime, I'll have a sandwich and some fruit, or a salad from the kitchen here. And then dinner is a big dinner for me. I eat quite a bit of meat and fish – salad and garlic bread – things like that. Oh, another thing is avocados – I eat one a day. I can't get enough avocados. I also snack on pistachios during the day. **(over 3 years later)**

I eat an egg every morning, not scrambled, but like an omelet with vegetables and cheese on it. Then I snack every couple of hours. I get power bars, crackers and cheese. I'm a grazer, so a little sandwich or half a sandwich for lunch. And then supper, I eat a normal supper, but very, very small portions. I can only eat two ounces of meat. And then I snack in the evening – potato chips. **(over 3 years)**

4 yrs. later - I eat everything, no one would know, 3 meals a day. It's just that I don't have carbonated beverages, sweets or refined carbohydrates like white bread. I only eat rye bread. It just makes me feel sleepy, that's all.

As soon as I get up I eat either oatmeal or 2 eggs. I eat breakfast in the morning and around 10:30 I eat my second breakfast so like leftovers. I eat lunch around 12 and it's similar to what a thin person would eat for lunch. Then I eat again around 2. Then I eat again after work. I eat every 2 hours. I eat 2 dinners – one around normal dinner time and then whatever I don't finish around 8 or 9. I eat everything twice. So I think I get my regular calories I just have to eat it divided up. I eat lots of snacks like granola bars, bananas. Early on I did a lot of protein shakes but I don't do them so much anymore. **(4 years)**

I usually have oatmeal. I don't tolerate milk but I can put it in my coffee, and sometimes I can put it in my oatmeal and cereal - some days it's fine, other days it makes me nauseous. I started using almond milk and it doesn't bother me at all. So, for breakfast, I can do oatmeal with almond milk, dry cereal or peanut butter toast maybe a banana. I will have a granola bar or nuts. I have a normal lunch with a snack in the afternoon. I find that in the nighttime it's worse, I am always hungry. I eat my dinner and an hour or two after, I get hungry. **(6 years)**

Pregnancy after gastrectomy



These were common themes shared by women who had pregnancy after their surgery:

- Able to tolerate a larger variety of foods than pre-pregnancy
- Felt almost like themselves prior to their total gastrectomy
- Could eat more sweets and not have dumping
- Back to their pre-pregnancy weight within a few months of delivery
- Many were able to breastfeed (some could go longer than a year)
- Most were followed by a high risk ob/gyn team
- A few needed IV iron infusions during their last trimesters
- Babies born a healthy and normal weight (if anything, the babies were born on the larger side).

Did you know?

One study looked at 7 pregnancies in 4 women with PTG, **All had healthy babies**

- Women may have specific nutritional requirements
- Should be followed by an obstetrician and a nutritionist
- Young women should continue taking vitamins so there won't be a deficiency when pregnancy occurs.

(Kaurah et al. *Familial Cancer*. 2010)



I wish I knew this before I had surgery...

- I put on about 10 pounds before I went into surgery, and I'm really glad I did.
 - I didn't start going back to the gym until, within the first year. I ran a 5k 8 months after surgery. I ran/walked it. It was challenging but I just decided I had a goal and I did that.
 - For me, this is my biggest message, to anyone who is considering/given the choice to get the surgery done, get it done. It's just a matter of time before that cancer shows up. I know that for a lot of people even though they have the gene it's not 100% that they will get the cancer but why play Russian roulette with your life? The lifestyle you want to live for the rest of your life is not to wake up with anxiety everyday over "am I going to have the cancer today? Is it going to be too late?" That's not a way to live.
 - A lot of people think where does your food go now that you don't have a stomach? Well it goes through my digestive system like yours. People ask do you have to be by a bathroom all the time? Well no, once things are normal, you go to the bathroom once or twice a day, it is like before I got my stomach removed, it's the same thing. I had all these questions; "when I eat, what happens to my food? How does it get digested?" Well it still gets digested pretty much the same way, just a little bit faster, I eat and then a half hour later I get hungry again. I do get hungrier more often.
 - Know that you can live a long healthy life without your stomach. You still go to the bathroom in the same as everyone else. I think people would like to know that for sure.
 - It's definitely very important for folks to understand that even though things aren't the same as what they would be – what they were before – they can still get back to a place where life feels normal. It's just a new normal for them – something they get used to in their daily lives.
-

- I think it would be good to have handouts with the list of foods that you can have after surgery so you can know what to buy prior to surgery so you can have it ready for after. Like eggs, oatmeal, a lot of smoothie recipes that would be good because you can load those with tons of calories and they go down easy. And not to feel discouraged, just give yourself some time. I remember early on, I used to read all the labels and look for whatever had sugar and I would avoid those foods because I was afraid of sugar because I was afraid of dumping. Which I only had once in the 3 years. I wouldn't wish that on my worst enemy. I thought I was dying. I think a lot of what I get is called reactive hypoglycemia. You could get a lot from talking to people but also from social media. People have questions like "I'm about to go into surgery what should I eat?" and lots of people will reply. I find there's a common trend with what people say is good for them.
 - I've heard other people say that they can't really burp anymore, but for me, it actually helps me if I have something stuck in my throat. I can still do it on command if it's something I want to. I asked the doctor about throwing up prior to the surgery because I know the stomach has a big part when you throw up. She said "you'll still be able to throw up", but I haven't been able to throw up since the surgery. So when I get really sick, I get super nauseous and I start to get really dizzy, I start to get sweaty and stuff, and then if it gets bad enough, I just pass out because I just don't throw up. My sister throws up all the time [after her surgery], but I can't.
 - You hear different things from different people, so some people are going to say 'Oh, I can't eat this food' or 'Having a tricky time keeping weight on'. I still can pretty much eat everything. It's important for people to know that there's a spectrum of possible results once the surgery is completed - there's a good chance that you could go back to eating everything you loved, and not having any trouble keeping weight on. Or there's a chance that you could have a whole lot of troubles. There's kind of a big spectrum of possibilities on how the surgery goes for each individual person.
 - This is not a life sentence. Your life still changes but other than that it's pretty good. There's a lot of people who have it a lot worse than you do. For me it's the attitude, if you get the attitude then you'll be okay.
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- I'd tell people is that it's really hard, and there will be times right afterwards where you will wonder if you did the right thing because you're not feeling good, or you're having a really hard time adjusting to your new way of eating – things like that. But at the same time, as time goes on, there's a sense of pride that just comes along with having been able to go through something that was so hard and so difficult.
 - For people who don't have insurance, they need to have some stuff in place because they potentially could be recovering for two years. They may not recover the same way and I think it's just a good thing to have.
 - I wish the hospital gave more instruction when you are getting discharged. Because I was alone a lot and not sure who was there to help – my family doctor, my surgeon. Would be good to speak to all your team before the surgery to come up with plans.
 - You've got to be all in, with a very positive attitude that you are doing something bigger than what you are doing for yourself, like this is not for me, the bigger thing is for my kids. I don't want to see my kids go through things that I saw my brother go through.
 - Just having a support person whose gone through it because my wife, or my friends don't understand what it feels like, even now when you eat a big meal and you're exhausted and you need to go lie down, they don't get it as much as someone whose going through the same thing.
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