



NATIONAL CANCER INSTITUTE

# HDGC

Hereditary Diffuse Gastric Cancer

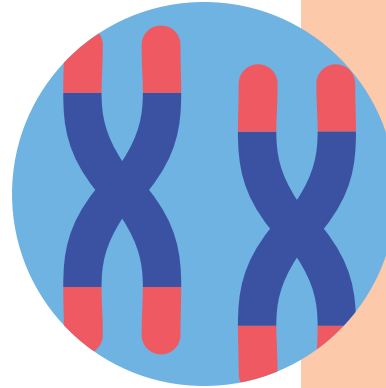




# What Is Hereditary Diffuse Gastric Cancer?

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**Hereditary Diffuse Gastric Cancer (HDGC)** is a rare cancer syndrome that leads to a higher-than-average risk of developing two types of cancer: diffuse gastric cancer (DGC) and lobular breast cancer (LBC).



**Diffuse gastric cancer** is a type of cancer that spreads within the lining of the stomach. Because it does not typically cause a bulky tumor to develop, it is more difficult to find and more likely to be found at a later stage when it can be very difficult to treat successfully.

## How Does a Person Get HDGC?

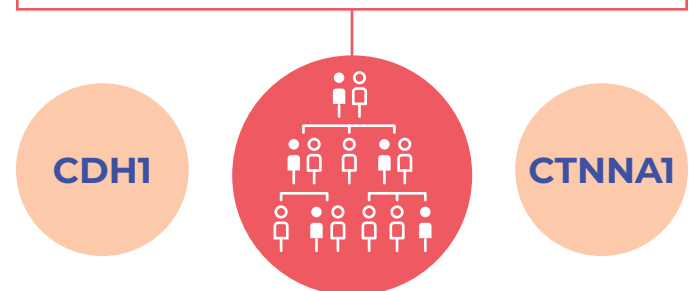
HDGC is inherited, meaning that the condition is passed down from a parent to a child. Most families with HDGC have a mutation\* (a change in the genetic code) in a gene called *CDH1*.

**When you have a parent with HDGC caused by a mutation\* in the *CDH1* gene, you have a 50 percent chance of also having that same mutation\*.**

In a small number of cases, HDGC is caused by a mutation\* in a different gene called *CTNNA1*.

For more information on genes and genetic testing, see "[Genetic Testing and HDGC](#)."

## INHERITANCE OF HDGC



**50% chance to pass mutation\* to children**

## What Should I Do If I Suspect My Family Has HDGC?

If you can, try to gather information on the types of cancer your family has experienced, pathology reports from doctors, the age of the family member at diagnosis and, if it applies, the age that they died. Tell this information to your doctor and request a referral to a genetic counselor.

## FAMILY HEALTH REPORT



TYPES OF  
CANCERS



PATHOLOGY  
REPORTS



AGE AT  
DIAGNOSIS

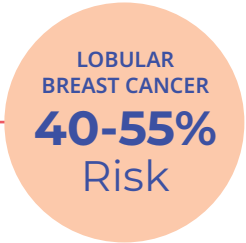
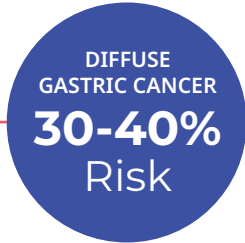


VISIT YOUR  
DOCTOR

**\*A mutation is also known as a pathogenic or likely pathogenic (PLP) variant.**

**What Does It Mean to Have HDGC?**

If you are diagnosed with HDGC syndrome, it does not necessarily mean that you have or will develop cancer — you just have a **higher risk**.



**Though It Can Be Difficult to Estimate Your Exact Risk of Cancer:**

With a *CDH1* mutation\*, it is generally accepted that the lifetime risk for **diffuse gastric cancer** is in the 30% to 40% range.

1

Women with a *CDH1* mutation\* have an estimated 40 to 55 percent risk of having **lobular breast cancer** in their lifetime.

2

People with a *CDH1* mutation\* and little or no family history of stomach cancer may have a lower risk of diffuse gastric cancer, but family history may not be a completely reliable factor in determining cancer risk.

3

*These cancers can affect adults of all age groups, with an average age of 47.*



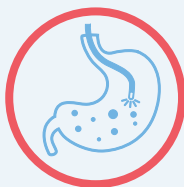
**Know Your Risk and Management Options**

Knowing that you are at a higher risk for certain cancers could save your life.

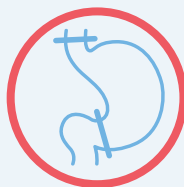
If You Are at Risk of Gastric Cancer Due to a *CDH1* Mutation\*, Consider Your Options.



**FIND A TEAM WITH  
HDGC EXPERTISE**



**SCREENING**



**TOTAL  
GASTRECTOMY**

**Find a team with *CDH1* and gastric cancer expertise:**

No matter what option you choose, a team with genetic counselors, gastroenterologists, surgical oncologists, pathologists and registered dietitians will be indispensable to help develop the care plan that is right for you.

**Screening:**

If you are diagnosed with a *CDH1* mutation\*, you should have an upper endoscopy (a procedure done to visually examine your upper digestive system) and stomach biopsies (the removal of samples of stomach tissue for examination).

**Total Gastrectomy:**

It is recommended that individuals who have a *CDH1* mutation\* and a family history of gastric cancer have a total gastrectomy, or removal of the stomach, to eliminate the risk of developing an advanced gastric cancer. This surgery is also referred to as a *risk reducing total gastrectomy*. Some people with a *CDH1* mutation\* are not able to have a gastrectomy or choose not to have the surgery. For these people, upper endoscopy every 6- 12 months is advised.

**\*A mutation is also known as a pathogenic or likely pathogenic (PLP) variant.**

## BREAST CANCER

If you are at risk of lobular breast cancer (LBC) due to a *CDH1* mutation\*, consider your options.



**FIND A TEAM  
FAMILIAR WITH  
HDGC AND LBC**



**SCREENING**



**BILATERAL  
MASTECTOMY**

### Find a team with *CDH1* and LBC expertise:

This may include breast oncologists, surgical oncologists and pathologists who can help you develop a care plan that is right for you.

### Screening:

Recommended screening procedures include mammograms and MRIs of the breasts on a regular basis starting at age 30.

### Bilateral Mastectomy:

Having a bilateral mastectomy (surgery to remove both breasts) to decrease breast cancer risk may be an option.



## Other Risk Factors

Many factors can influence the risk of cancer.

Diet and nutrition guidelines that may reduce the risk of stomach cancer in the absence of a *CDH1* mutation\* include the following:

Keep in mind that diet and lifestyle recommendations to reduce the risk of stomach cancer *do not* guarantee cancer prevention.



Maintain a healthy weight



Keep physically active



Eat a variety of whole grains, vegetables, fruit (especially citrus fruits) and beans



Avoid salt-preserved and high-salt (high sodium) foods



Avoid sugar-sweetened beverages



Limit processed and red meat consumption



Limit your alcohol intake



Avoid tobacco

### A note about *CTNNA1*:

Our knowledge about *CTNNA1* cancer risk is limited. Therefore, individuals with a *CTNNA1* mutation\* are recommended to have yearly screening for gastric cancer and breast cancer. Gastrectomy and mastectomy may be options on a case-by-case basis.

**\*A mutation is also known as a pathogenic or likely pathogenic (PLP) variant.**

# Questions to Ask Your Surgeon

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Use this sheet to help guide the questions you ask your surgeon (or prospective surgeon) before total gastrectomy. Bring a pen and a notebook, to your appointment. You can fill in answers below each question and should feel free to add any other questions that you may want answered.



**What are some of the anticipated complications of this operation?**

**How many total gastrectomy operations do you perform each year?**

**Can I speak to other patients who have had this operation with you?**

**What will my follow-up with you be?** *(If the surgeon will not be your primary point of contact for follow-up after surgery, make sure to ask who will be responsible for your post-gastrectomy care.)*

**How long can I expect to be in the hospital?**

**Will I meet with a registered dietitian before surgery?** *(Meeting with a registered dietitian before surgery is as important as meeting with one after.)*

**Do you check margins in the operating room to confirm that all gastric tissue has been removed?** *(For patients with CDH1, this answer should be yes as recommended by an international group of experts.)*

**Do you routinely place a feeding tube during this operation?**

**How often do you observe esophageal strictures after this operation?** *(An esophageal stricture is an abnormal tightening or narrowing of the esophagus.)*

**What is your personal complication rate with this operation?** *(Most surgeons keep track of their own complications, or their hospital likely does, and they will be forthcoming about their own outcomes and how they manage them.)*



# Physical Health Tips to Prepare for Total Gastrectomy?

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## Physical Fitness

It is important that you are physically prepared for your surgery to help minimize the risk of complications after surgery and throughout your healing process.

### Physical fitness for surgery includes good heart and lung function.

Any medical conditions, including heart and lung problems, may pose a risk for complications after surgery and should be addressed with your health care team.

If you smoke, you need to quit smoking, especially since smoking is a significant risk factor for many kinds of cancer, including gastric cancer.

For at least one month before surgery, get 30 minutes of exercise every day, such as brisk walking, gardening, exercising at home or going to the gym, to promote good cardiovascular health.



## Weight

Even though you will lose weight after your total gastrectomy, most people should not gain weight before surgery. Being overweight or obese increases the risk of complications after surgery.

Talk to your dietitian and health care team about your weight goals before surgery and how to achieve those goals.

## Diet and Nutrition Tips to Prepare for Total Gastrectomy

- 1 Review "Diet and Nutrition After Gastrectomy: What You Should Know."** That packet describes the dietary and lifestyle changes you will have to make after surgery.
- 2 Practice eating slowly and concentrate on chewing your food well.** Chew your food until it is pureed before you swallow.
- 3 Eat smaller meals more often.** Start eating 5 or 6 small meals per day instead of 3 larger meals. You may need to adjust your home, work and/or school schedule to allow frequent meals.
- 4 Practice eating meals without drinking liquids.** Drink fluids 30 minutes before or 30 minutes after your meal.
- 5 Start reading nutrition labels for added sugars.** After gastrectomy, you will need to avoid added sugars to prevent side effects such as dumping syndrome (described in "Diet and Nutrition After Gastrectomy: What You Should Know"). Find products that do not have added sugar to replace any products you eat now that do have added sugar.

- 6 Learn which foods are high in protein.** Since you will feel full quickly, it is very important to have protein at every meal and snack so that you can meet your protein needs. Start having a high protein food with every meal and snack, such as a no sugar added protein drink, bar or yogurt.



- 7 Take good care of your teeth.** Since you will need to chew your food extra carefully after total gastrectomy, good oral hygiene is key. See your dentist for regular cleanings and make sure to address any known dental concerns *before* your surgery.
- 8 Talk to your dietitian about vitamin supplements before your surgery.** Tell your dietitian about any supplements you are currently taking. Depending on your supplements, lab results, past medical history and/or other factors, you may need to take specific vitamins before surgery to correct low vitamin levels.



# Physical Health After Total Gastrectomy

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You can expect your recovery from total gastrectomy to take many months — typically from 6 months to a year. Physical recovery from surgery (healing) alone takes 6 to 8 weeks. The first 3-6 months after total gastrectomy can also be the hardest emotionally and psychologically for the patient and their family, too.

Remember that recovery may not always feel steady; there will be both good days and bad days. Every patient's experience is different. Talk to your health care team about any concerns.

At six months post-surgery, most patients feel as though they have “turned the corner.” This is often associated with having incorporated the new diet and lifestyle habits into your daily routines and having those habits start to feel like second nature.

By one year post-surgery, most people feel as though they established their “new normal,” meaning the post-operative diet and lifestyle changes are now a part of their normal life.

## Weight Loss

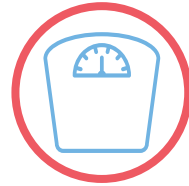
You can expect to lose weight rapidly during the first month after surgery. It typically takes about 6-12 months for you to reach a stable final weight.

Talk to your dietitian to get specific recommendations to help you avoid losing weight too quickly, to avoid losing too much weight or too much muscle mass, and to maintain a healthy weight long-term after gastrectomy.

## Lifestyle Modifications

For 8 weeks following surgery you will need to avoid heavy lifting (more than 10 pounds). It can take 6 months to a year for energy and stamina levels to return to pre-operation levels.

Lifelong, you will need to be able to eat small but frequent meals throughout the day (“[Diet and Nutrition After Gastrectomy: What You Should Know](#)”). Therefore, some people have had to adjust their work, home or school schedules, change careers/jobs or apply for special accommodations to meet their diet, nutrition and lifestyle needs after total gastrectomy.



## Bone Health

### Gastrectomy increases the risk of bone density loss.

**The causes of low bone density after total gastrectomy may include:**

- Decreased absorption of calcium, which is needed for healthy bones
- Decreased absorption of vitamin D which is needed for healthy bones
- Weight loss after total gastrectomy, which may also impact bone health

### There are guidelines for vitamin and mineral supplementation after gastrectomy.

**These guidelines recommend the following:**

- Take 1200-1500mg per day of elemental calcium in the form of calcium citrate.
- Take at least 3,000 international units of vitamin D daily.
- Consider having a bone density scan (dual-energy x-ray absorptiometry, or DEXA) two years post-operatively.

**To minimize the risk of bone density loss after total gastrectomy, follow these tips:**

- Talk to your dietitian about which calcium citrate and vitamin D supplements are best for you.
- Talk to your team about exercises and physical activities to keep your bones strong.
- Talk to your team about monitoring your bone density after total gastrectomy.

# Diet and Nutrition After Gastrectomy: What You Should Know

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## General Guidelines and Issues to be Aware of

### After total gastrectomy, your digestive system:

- Holds a smaller quantity of food
- Cannot grind food
- Cannot digest and absorb every nutrient in food effectively
- Will not send you the same signals to tell you to eat

### To compensate for these effects, you will need to:

- Eat smaller meals, having at least 6-8 small meals per day
- Avoid drinking a lot of fluids with your meals
- Chew your food very well
- Take the recommended vitamins every day
  - > See the section on vitamin supplements
  - > Also talk to your dietitian about your individual needs
- Have small meals every few hours even when you don't feel hungry.

## YOU WILL NEED TO:



Eat smaller meals & chew food well



Avoid drinking a lot of fluids with meals



Take your vitamins

## Side Effects to Expect After Total Gastrectomy

### Weight Loss:

Weight loss is fastest the first month after surgery. You can then expect gradual weight loss for 6-12 months after gastrectomy. This weight loss includes loss of both fat tissue and muscle mass.

- Speak with your dietitian to get specific recommendations to help you avoid losing weight too quickly, to avoid losing too much weight or too much muscle mass and to maintain a healthy weight long-term after gastrectomy.

### Early satiety, or feeling full quickly.

- > To get enough nutrition despite early satiety, you will need to eat high-calorie and high-protein foods every 1-2 hours until you are able to eat larger amounts.
- > You can find guidance on your meal plan in "[Diet and Nutrition After Gastrectomy: Your Plan.](#)"

- As your body adapts after surgery, you will gradually be able to increase portion sizes.

### Anorexia, or not feeling hungry.

After gastrectomy, your body does not have the usual signals to tell you to eat. Therefore, you may forget to eat or forget to eat often enough to meet your nutrition needs.



- > To make sure you get enough nutrition:
  - Eat on a schedule, rather than waiting until you feel hungry.
  - Set timers or other reminders to eat and drink throughout the day.
  - Try protein drinks.

### Nausea:

You may feel nauseous if you eat too much or don't chew your food well enough.

- Eat only small amounts of food, eat slowly and chew your food thoroughly before swallowing.
- If it has been more than two hours since your last meal or snack, nausea may be a hunger signal.



### Constipation:

You are more likely to become constipated if you do not drink enough fluids, and it can be difficult to drink enough fluids after surgery because you feel full quickly (early satiety).

- **To avoid constipation:**

- > Sip on fluids between your meals.
- > Aim for at least 64 ounces of fluid per day.
- > Choose unsweetened protein drinks for some of your small meals.
- > Take a short walk between meals and snacks.
- Talk to your dietitian about when it is safe to add high-fiber foods back into your diet. Talk to your dietitian and health-care team about medications if constipation continues.

### Bile Reflux:

Bile reflux is when bile, the digestive liquid produced by your liver, backs up into your esophagus (the tube between your mouth and the rest of your digestive tract).

- **To avoid bile reflux:**

- > Sleep with your head elevated at least 30 degrees, about 6 inches or more.
- > Stay upright for at least 30-60 minutes after eating.
- > Maintain good posture and avoid leaning forward at the waist.
- > Eat small meals throughout the day and chew your food well.
- > Avoid constipation.
- > If bile reflux continues despite taking these physical steps to avoid it, you may need medication. Talk your dietitian and health care team about your options.

### Dumping Syndrome:

Dumping syndrome happens when large amounts of food or undigested food pass too quickly into the small intestine.

**Symptoms of dumping syndrome can happen right after you eat (early dumping syndrome) or hours after eating (late dumping syndrome).**

## DUMPING SYNDROME

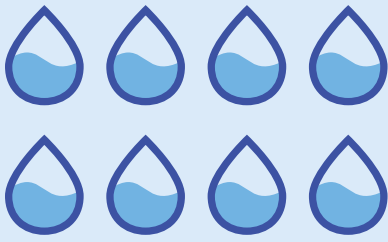
### Early Dumping Syndrome .

- > Symptoms of early dumping syndrome include:
  - Abdominal cramping
  - Urgent diarrhea
  - Bloating
  - Feeling faint or weak
  - Nausea

### Late Dumping Syndrome

- > Symptoms of late dumping syndrome can include:
  - Confusion
  - Cold Sensation
  - Sweating
  - Double vision
  - Drowsiness
  - Blurred vision
  - Weakness
  - Hunger
  - Dizziness
  - Nausea
  - Heat sensation
  - Fear/anxiety
  - Difficulty speaking
  - Tiredness
  - Palpitations
  - Shivering/trembling/shaking
  - Tingling in the lips
  - Difficulty concentrating

- To prevent both early and late dumping syndrome:
  - > Avoid foods and drinks with added sugars.
  - > Eat small meals often during the day.
  - > Eat protein at each meal and snack.
  - > Separate fluids from solid foods by at least 30 minutes.
  - > Chew food thoroughly.
  - > Avoid meals or snacks with large portions of carbohydrates (example: fruit, starch) and always eat carbohydrates with protein.
- To treat dumping syndrome:
  - > If you experience early dumping, sit upright in a chair or lie with the head of the bed at a 30-degree incline to slow the movement of food through your intestine. Eat or drink again as soon as possible to replace what your body did not fully absorb due to dumping.
  - > If you experience late dumping, eat or drink a carbohydrate with protein as soon as possible to correct your low blood sugar. Do not correct low blood sugar with simple sugars or added sugars.



**Sip Fluids  
Throughout  
the Day**

## Staying Hydrated After Total Gastrectomy

Since you will feel full quickly and cannot drink large amounts while eating solid foods, you need to sip fluids throughout the day to avoid dehydration.

Dehydration can lead to constipation, electrolyte imbalances, fatigue, dizziness, confusion and nausea. Chronic dehydration increases the risk of kidney stones.

**Talk to your dietitian about your fluid goal.**

**To avoid dehydration after gastrectomy:**

- Start sipping on fluids early in the day and sip continuously between meals.
- Keep a water bottle with you at all times.
- Don't wait until you feel thirsty to drink. If you are thirsty, you are already mildly dehydrated.
- Set a timer to remind yourself to drink.
- Use a food diary to track how much you are drinking.
- Avoid caffeinated beverages until you can meet your fluid needs every day.

Contact your health care team if you are unable to drink enough fluids to stay hydrated or if you experience severe dehydration.



## Alcohol after Total Gastrectomy

Alcoholic drinks increase the risk of dehydration. In addition, even small amounts of alcohol can cause intoxication and low blood sugar after a total gastrectomy.

Some studies suggest an increased risk of alcohol use disorder after gastrectomy. Be cautious with any alcohol intake.

## Vitamins and Minerals

You are a high risk for multiple vitamin and mineral deficiencies after total gastrectomy. Specially formulated vitamins, referred to as bariatric vitamins, result in fewer deficiencies than standard multivitamins.

Calcium citrate is the form of calcium that can be absorbed without stomach acid.

**Take the recommended bariatric multi-vitamin and calcium citrate supplements every day. Take the calcium citrate at least 2 hours apart from iron-containing supplements.**



You must take your multivitamin and calcium citrate every day to avoid problems associated with deficiencies, such as anemia, hair loss and low bone density. Talk to your dietitian about which specific bariatric formulated multivitamin and calcium citrate supplements are right for you.

## Dental Care After Total Gastrectomy

After a total gastrectomy, you need to chew every bite of food completely so that your intestines can absorb your food, and you need healthy teeth to do this!

**To make sure your teeth are healthy:**

**See your dentist before your total gastrectomy**

- See your dentist *every 6 months* after surgery.
- Brush, floss and use mouthwash often during the day.
- Take your vitamins every day to avoid any micronutrient deficiencies.



# Diet and Nutrition After Gastrectomy: Your Plan

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## PHASE 1

### FOR THE 6-8 WEEKS AFTER SURGERY

This is your body's recovery period. Your body needs foods that are high protein to help you heal and to slow weight loss. Your body also needs foods that are easy to digest as your intestine adjusts to digestion without a stomach.

#### General Guidelines

- Eat often. You need at least 6-8 small meals each day. These meals may only be about 1-2 ounces each (about the size of a shot glass).
- Choose high-calorie, high-protein foods and fluids. Make at least half of your plate protein.
- Eat slowly and relax while eating.
- Chew foods completely, into puree form, before swallowing. Drink fluids 30 minutes before or 30 minutes after eating, but not during your meals.
- Remain upright after eating to avoid bile reflux.
- Avoid foods high in insoluble fiber and gas-producing foods.
- Avoid foods and drinks with **added sugars**. Use the **Nutrition Facts label to find foods with no added sugars**.

**You may find it helpful to use a food diary or app to record what you are eating and drinking. Bring your food diary to follow-up appointments after surgery. Your dietitian will be able to help you identify foods and/or patterns that are causing any symptoms.**

## PHASE 2

Once your weight loss slows and you are tolerating phase 1 foods well, you can begin phase 2. Phase 2 will be your lifelong dietary plan for eating without a stomach.

Just like in **phase 1**, remember to:

- Eat at least 6-8 small meals each day.
- Eat slowly and relax while eating.
- Chew foods completely before swallowing.
- Drink liquids or soup 30 minutes before or 30 minutes after eating.
- Limit liquids to 1/4-1/2 cup with meals.
- Eat protein at every meal and snack.
- Avoid added sugars.
- Avoid alcohol.
- Use a food diary as needed if you experience any discomfort after eating.
- Talk to your dietitian about your specific calorie and protein needs and how to meet those needs.

In **phase 2** you can:

- Begin to add higher fiber foods.
- Include well-tolerated fruit, vegetables, whole grains, beans, nuts and other whole, plant-based foods in your meals every day.
- Make sure you balance higher fiber, lower calorie foods (such as fruits and vegetables) with higher calorie, high-protein foods as needed to avoid losing too much weight, avoid foods and drinks with added sugars.

Add Higher  
Fiber  
Foods



# Taking Medications After Total Gastrectomy

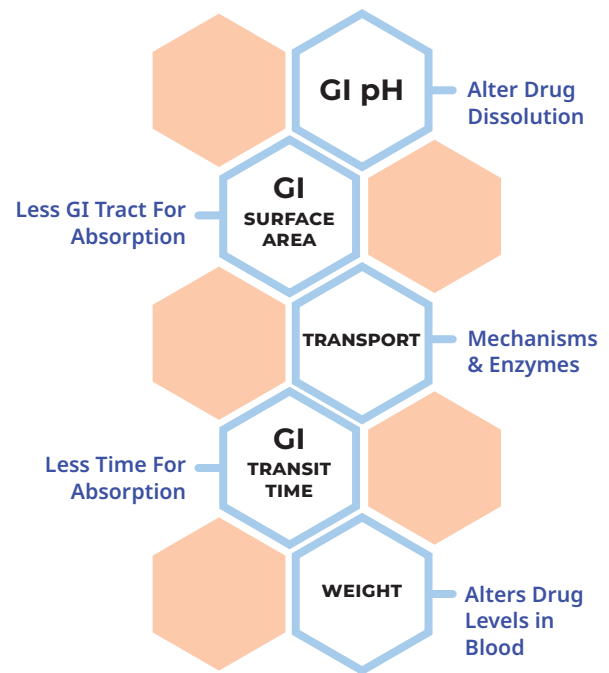
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**HDGC**

## Factors That Alter Drug Absorption

Total gastrectomy can significantly alter drug absorption. Remember to discuss any medications you may take with your pharmacist and your healthcare team.

### After gastrectomy you have:

- A higher gastrointestinal (GI) pH, which may alter how drugs dissolve
- A smaller GI surface area, which means less opportunity for medications to be absorbed into your body
- Fewer transport mechanisms and enzymes to digest medications
- Faster GI transit time, and therefore less time to absorb medications
- Likely weight loss, which alters drug concentration levels in your bloodstream



## General Recommendations to Follow After Total Gastrectomy

- Review your medication history with a clinical pharmacist and your healthcare team before surgery.
- You and your team may consider alternate forms of medications, such as transdermal (through the skin), sublingual (under the tongue), or intranasal (through the nose), when there are concerns with oral absorption.
- You may be able to crush some medications or open capsules to help them dissolve and help your body absorb them better.
  - > Always check with your pharmacist or healthcare team before crushing or opening any medications.

## Liquid medications may contain sugar, which may increase the risk of dumping syndrome

- > Discuss these medications with your pharmacist or dietitian first.



## Try to Avoid



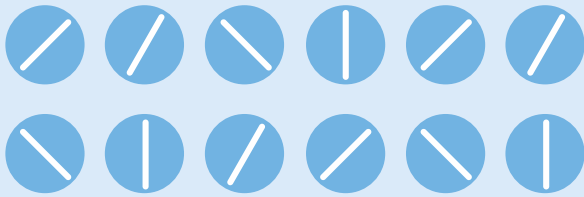
- Timed or controlled-release medications, including those labeled ER, XR, or CR
- Medications that cause gastrointestinal irritation or require a highly acidic environment for optimal absorption

## Avoid Medications with these Labels

ER

XR

CR



## Pain Medications After Your Gastrectomy

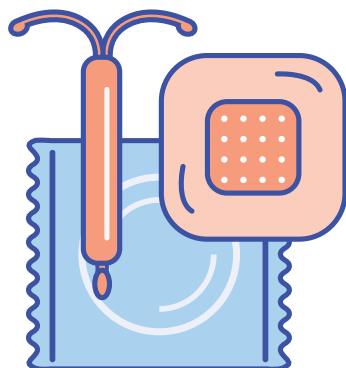
- Your pain management medications after surgery may come in multiple forms, including epidurals, intravenous and oral medications
- Short-term use of oral opioids may be used as prescribed by a doctor for pain as needed
- Immediate-release acetaminophen tablets may be used as needed
- Moderate amounts of Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), such as, ibuprofen and naproxen, may be used if needed for short periods.



## Contraception

- After a total gastrectomy, you will want to **avoid oral contraceptives (“the pill”)** containing estrogens or progesterone due to decreased absorption (and therefore decreased efficacy).
- Discuss alternative forms of contraception, such as intrauterine or implantable devices, with your healthcare team and/or OB-GYN **before** gastrectomy.

**Discuss alternative forms of contraception**



## Medications for Bile Reflux

Bile reflux occurs when digestive liquid produced in your liver backs up into the esophagus.

- Bile reflux is not the same as acid reflux
  - > Therefore, you should avoid typical drugs used to treat acid reflux, such as proton pump inhibitors (e.g., Omeprazole, pantoprazole) and Histamine2 blockers (e.g., Famotidine).
- Your treatment for bile reflux will include lifestyle and diet changes as well as medications such as sucralfate
  - > If diet and lifestyle changes do not help your bile reflux, talk to your pharmacist or healthcare team for more information about possible alternative medications.

## Chronic Medications

- Your weight is expected to rapidly drop after total gastrectomy and reach a new stable baseline between 6 and 12 months after surgery
  - > Some medications, such as those used to treat hypertension and diabetes, or medications that are dosed based on weight, will likely require dose adjustments based on your new baseline weight.

**Close follow-up with a primary care physician is crucial during this period.**

- You should review your medication list with your gastrectomy care team and clinical pharmacist prior to surgery and in any follow-up appointments.



# Pregnancy After Total Gastrectomy

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## Preimplantation Genetic Testing (PGT)

PGT is to screen embryos for genetic conditions to reduce the risk of passing on the condition to children. The PGT process involves in vitro fertilization (IVF). For more on PGT, see "[Genetic Testing and HDGC](#)."

## Nutrition before Pregnancy

Good nutrition is important for fertility and for a healthy pregnancy. Good nutrition is also needed to prevent micronutrient deficiencies, to reach a healthy weight before pregnancy, to support healthy pregnancy weight gain, and to support fetal growth and development. See "[Diet and Nutrition After Gastrectomy: What You Should Know](#)" for more details on nutrition after total gastrectomy.

### Calorie and Macronutrient Intake

Talk to your dietitian and health care team about your calorie goals during pregnancy.

Post-gastrectomy symptoms, such as early satiety (feeling full quickly), lack of hunger cues and changes in nutrient absorption can make it difficult to eat enough to gain the necessary weight for a healthy pregnancy after total gastrectomy. Additional pregnancy symptoms, such as nausea, may make it even harder to gain weight.

See "[Diet and Nutrition After Gastrectomy: Your Plan](#)" for tips on getting more calories and protein. Talk to your dietitian if you have trouble getting enough nutrition to meet your weight goals.

### Micronutrients

Total gastrectomy increases the risk of multiple vitamin and mineral deficiencies. These vitamins and minerals are not only important for your overall health, they are also very important for fetal growth and development.

Specially formulated vitamins, referred to as bariatric vitamins, result in fewer deficiencies than standard multivitamins after a total gastrectomy. Prenatal formulations of bariatric



**Pregnancy Prevention**  
Your body may not absorb oral forms of contraception (e.g., "the pill") after total gastrectomy, which means oral contraceptives may not prevent pregnancy. If you do not want to become pregnant, discuss other forms of contraception, such as intrauterine devices or implanted devices, with your healthcare team and OB/GYN.

multivitamins are also available to help meet the unique nutrition needs during pregnancy after total gastrectomy.

**Note:** Standard prenatal multivitamins *do not* meet the micronutrient needs of an individual during pregnancy after total gastrectomy.

Available guidelines recommend a specialist obstetric service to monitor micronutrient levels and supplementation during pregnancy. Talk to your dietitian, obstetrician and/or health care team about which specific prenatal multivitamin meets your needs and how to monitor your vitamin and mineral levels during pregnancy.

### Weight

Because your weight will drop and may not stabilize until 6-12 months after total gastrectomy, current guidelines recommend waiting at least that long, or until weight is stable, before trying to become pregnant.

Recommendations for weight gain during pregnancy are available here: [Weight Gain During Pregnancy from the CDC](#). Talk to your healthcare team about your specific weight goal prior to and during pregnancy.



# Mental Health in Your Total Gastrectomy Journey

PATIENT RESOURCES  
**HDGC**



## The Pre-Operative Experience

Whether you move forward with total gastrectomy (TG) or ongoing surveillance, stress may arise in the decision-making process. It's likely that you will be given a lot of information during this time from members of the medical team, friends and family.

**Ultimately, the decision is yours — and that can be scary!**

### Here Are Some Tips for Decision Making:

- 1 Gather data.** Talk to the experts! Find a team with experience and knowledge in hereditary diffuse gastric cancer (HDGC) and total gastrectomy. Allow your knowledgeable team to give you information, pros and cons about all of your options.
- 2 Find resources.** Websites and or social media communities can be a great place to hear about other individual's experiences that may be similar to yours. These communities can point you to patient resources such as those provided by non-profit organizations and the National Cancer Institute's [Center for Cancer Research](#).
- 3 Talk with friends and family.** Your friends and family are and will continue to be a key part of your support system throughout this journey. Be open with them about your preferences and communication styles. Do you want their opinion? Do you want their unconditional support? Speak up and let them know what you want or need.
- 4 Connect with your values.** Values are the directions we want to go in life. Values remain even in the presence of pain, anxiety, fear and stress. When making a tough decision, let your values (not your fear) guide you.



## The Post-Operative Experience

If you decide to have a total gastrectomy, there are some challenges that lie ahead. Your lifestyle will change drastically and that can be tough, especially in the post-operative stages thoughts like, "Will other people notice?" You might find it beneficial to think of how you will answer questions that others may have — if you want to answer them at all — ahead of time.

### Here Are Some Challenges to be Aware of:



#### Relearning how and what to eat

You will receive a new set of dietary instructions from your team. A sample of a post-gastrectomy diet can be found in "[Diet and Nutrition After Gastrectomy: Your Plan](#)." These guidelines set you up for the best possible outcome after your TG. But everything you know about food and eating might change. Keep an open mind and ask questions!

Eating used to be second nature. You'll be working against all your old habits to shift your new feeding schedule. Sometimes forgetfulness will be your biggest challenge. You may want to try making sticky notes and placing them in frequently visited places around your house (like mirrors or door frames) as reminders!



#### The comparison game

No two total gastrectomy journeys are the same. You may find comfort in an online community or with family who have gone through TG. However, our minds are so good at evaluating and we might get hooked on "The Comparison Game." Notice your mind's "shoulds" (for example, "I *should* be farther in my journey by now" or "I *shouldn't* be having this difficulty") and remind yourself that your experience is yours and yours alone, not anyone else's.

> *continued next page*

## Challenges to be Aware of:

### Eating as a social activity

Birthday parties, special occasions, and simple family nights in often involve meals. Early in your post-operative journey, restaurant menus will probably pose difficulty for finding meals that fit within your dietary guidelines. Nevertheless, you can learn to enjoy the time out and this time spent with loved ones even if you aren't eating the same things as others at the table.

Proper planning like looking at the menu ahead of time or eating before the activity may alleviate the discomfort during the outings. It's normal for your mind to have thoughts like, *"Will other people notice?"* You might find it beneficial to think of how you will answer questions that others may have — if you want to answer them at all — ahead of time.

### Pain and physical discomfort

Some people experience pain in their post-operative period. This pain might take the form of bile reflux, abdominal discomfort or nausea. It's important to maintain your eating, drinking and medication regimen even in the presence of discomfort.

You will be challenged at first with thoughts like *"I can't eat right now"* or *"I'll take my vitamins when the bile reflux goes away."* These are normal and you can anticipate that they will show up! We can practice not taking our minds so seriously. While our minds are often trying to protect us, they're not always the most helpful voice!

### Treatment adherence

Adherence to medical regimens often decreases as time moves on. Keep this in mind as a potential challenge when you start feeling better. Make notes, create reminders and get in touch with your values so you continue to adhere to your medical team's guidelines.

**It's important to maintain your eating, drinking and medication regimen even in the presence of discomfort.**

## Long-Term Follow Up

Deciding to have a total gastrectomy is a decision that will change your life and how you live it.

### Here are some situations to be aware of as you continue to lead your life long-term after TG.

#### Change in identity

Some people experience a shift in their sense of identity post-TG. It's possible that your body will change how it looks or your priorities and sense of career will shift. Some people even switch jobs to fit their new lifestyle. This is normal! Use this as a time for flexibility and sense of exploration.

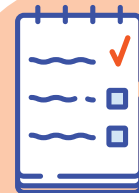
#### Difficult emotions

As post-operative life starts to settle down and your lifestyle changes turn into habits, sometimes new emotional experiences step in. Survivor's guilt may be one of them. Survivor's guilt is common experience among cancer survivors. It is a particular type of guilt experienced by those who have survived a life-threatening situation, like HDGC, when others have not.

Unique to certain types of diseases, HDGC has a hereditary component. If you have a child or grandchild who also carries the gene, you may experience guilt or feelings of fault. This is a reminder of the love you have for them and their health. Practice compassion (see next page) for these totally normal human emotions!

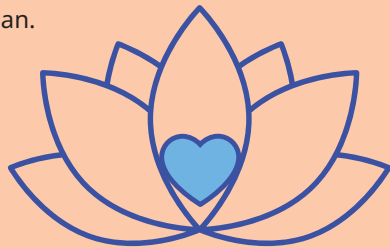
### And remember, prioritizing your health journey is a great opportunity to lead by example for your loved ones.

Create  
Reminders  
to Adhere to Your  
Medical Team's  
Guidelines



## Mental Health Tips and Tricks

- 1 Connect with values.** Why are you here? There's something in your values that is igniting the way. Whether it's health, family or vitality, our values are the most powerful tool we have to overcome challenges and life's curve balls. A periodic check in with your values can enhance your ability to stay on track even when life gets tough.
- 2 Watch your mind chatter.** Your mind will hand you all sorts of interesting thoughts. Expect it! *"I can't do this."* *"I wish this was easier."* *"I don't want this."* The funny thing about thoughts is ... they're just thoughts. We can pay attention to them when they are useful, and we can notice and acknowledge them when they're not. Imagine you're on a hillside watching a stream below. The stream holds all sorts of objects: sticks, animals, leaves. What these objects have in common is that they all come and go. So, imagine our thoughts like the leaves. Watch them. Notice them. And repeat!
- 3 Self-compassion is your new best friend.** This is hard! You can harness the power of self-compassion to recognize this incredible challenge you're in. Take pauses throughout the day to notice your thoughts, feelings and physical sensations and to hold yourself and your experience with compassion, warmth and love (just as you would for a loved one). The experience you are having may be unique to you, but the challenge is human.



## Conclusions

Mental health is an important part of this journey. Being an active observer of your own experience can help you decide when it's time to seek assistance. Acute distress is not a prerequisite for mental health treatment. Starting early can help you foster skills for later in the journey if you experience challenges. There's no time like the present!

## When to Seek Assistance

Think of mental health assistance like going to the gym: when you preemptively work out your muscles, you're prepared when you have to rearrange heavy furniture in your home. Mental health is the same way. And just like it's never too late to start working out, any time is a great time to seek help. If you notice your mood change (like anxiety or sadness) or even if you're feeling stress or pain, it's normal! Let a mental health professional (like a counselor, therapist, social worker, psychologist, etc.) help guide you toward your best valued life.

**You're still in the driver's seat of life, but mental health professionals can be great passengers holding a map!**

### How to Seek Assistance

Finding a mental health professional can seem like a daunting task. Here's how!

- 1.** Your medical team is your best resource. They may be able to provide you with in-house mental health services or refer you to a community-based practitioner that fits your insurance or financial needs.
- 2.** Use your friends and family as referrals. If you know someone who sees a therapist, ask them to connect you! Even if that person isn't the right fit, they'll likely know someone who is.
- 3.** Take to the internet! Psychologytoday.com and contextuallscience.org are great places to start the internet search. You can sort by insurance, location and specialty.

Therapy should be a good fit between the individual, therapist and approach. Don't be afraid to ask questions, like "What will therapy together look like?" or "What approach do you typically take?" Therapists vary in educational background, theoretical approach and areas of expertise.

**It's ok to try out different therapists. Search until you find the right one for you.**

# Genetic Testing and HDGC

PATIENT RESOURCES  
**HDGC**

## BACKGROUND



### What Are Genes?

Genes are a biological material that provide instructions for how our bodies look and function. Genes are made up of a chemical called deoxyribonucleic acid, or DNA.

### What Are Gene Variants?

DNA is made up of four building-block chemicals, labeled with the letters A, T, C and G. These letters of DNA need to be in a particular order for genes to work properly. Gene variants, or mutations, occur when the letters are out of order, added or missing.

**A gene variant that contributes to the development of a disease is known as a *pathogenic or likely pathogenic variant (PLP)***

### What is Genetic Testing?

Genetic testing is a type of medical test that looks at the order of the letters in your DNA to determine what gene variants you carry. This may help determine any diseases or disease risks that you have.

### What is a Genetic Counselor?

Genetic counselors have training in medical genetics and counseling to guide patients as they look for more information about how inherited diseases might affect them or their relatives.

A genetic counselor will help guide you through the process of getting a genetic test and interpreting its results. The National Society of Genetic Counselor's website has a tool for finding a genetic counselor that you can access [here](#).



Genetic Testing



Gene Variants



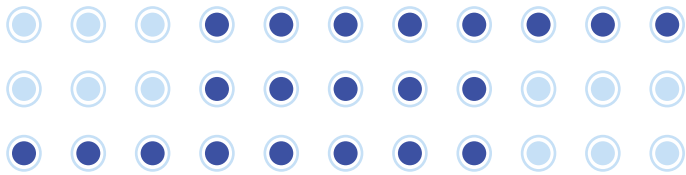
Genetic Counselor

You may also be able to meet with a doctor, nurse or physician assistant who specializes in cancer genetics, if that resource is available in your hospital or cancer center.

Refer to "[Questions to Ask Your Genetic Counseling Provider](#)" for some questions you may want to ask your genetic counselor before having any genetic tests.

## Who Would Benefit From Genetic Testing?

You may benefit from genetic testing if you have been diagnosed with diffuse gastric cancer (DGC). If you have not had cancer but you have a blood relative (parent, sibling, grandparent, aunt, uncle or cousin) that has been diagnosed with diffuse gastric cancer, then you may benefit from genetic testing. Having cases of intestinal gastric cancer and other types of cancers in the family, like breast cancer, can also be a reason to seek genetic testing.



## Genetic Testing for Hereditary Gastric Cancer

Diffuse gastric cancer can run in families if there is a pathogenic or likely pathogenic (PLP) variant in the *CDH1* or *CTNNA1* gene. There are other genes that are known to increase the risk of developing intestinal gastric cancer. These genes are *APC*, *BMP1A*, *EPCAM*, *MLH1*, *MSH2*, *MSH6*, *PMS2*, *SMAD4*, *STK11* and *TP53*. There is also early evidence to suggest that the genes *ATM*, *BRCA1*, *BRCA2*, *CHEK2* and *PALB2* may increase the risk of gastric cancer.

**If you or a close blood relative have been diagnosed with gastric cancer then genetic testing may be right for you.**

Gene panel testing involves testing for more than one gene at the same time. All genetic testing is performed on a blood, cheek swab or saliva sample to look for gene variants.



### Legal Protections Against Genetic Discrimination

#### The Genetic Information

**Nondiscrimination Act (GINA) was signed into federal law in 2008. GINA prohibits health insurers and most employers from discrimination against individuals based on genetic information, including the results of genetic tests and family history information. More information about GINA can be found by visiting [www.ginahelp.org](http://www.ginahelp.org).**

## I'VE DONE GENETIC TESTING AND HAVE A *CDH1* PLP VARIANT. NOW WHAT?

If you have a PLP variant, you'll want to consider your cancer risk management options. Information on your options can be found in "**What is Hereditary Diffuse Gastric Cancer (HDGC)**." In addition, it is important to consider what this means for your family members. Though everyone has two copies of the *CDH1* gene, one from their father and one from their mother, it only takes one PLP variant in *CDH1* for an individual to be at risk for cancer. This type of genetic inheritance is called an *autosomal dominant pattern*. This pattern means that parents, children and siblings of an individual with a *CDH1* variant have a 50 percent chance of having that same variant in their genes.

See "**Speaking With Your Family**" for some recommendations on how to discuss your genetic testing results with family members. Any relative 18 years old or older is eligible for genetic testing. Anyone considering genetic testing should receive appropriate education and counseling.

### Reproductive options for individuals with a pathogenic variant in *CDH1*

If you are considering having children, you may be wondering if there are ways to avoid passing a PLP gene variant on to your children. Prior to becoming pregnant, it is recommended to meet with a genetic counselor who specializes in fertility to discuss prenatal diagnoses, the use of a donor or preimplantation genetic testing.

**Preimplantation genetic testing (PGT)** allows people who carry a PLP gene variant to have children without that variant. The PGT process begins with in vitro fertilization (IVF).

It is important to keep in mind that PGT can be an emotional and costly process that requires a commitment of time. Decisions around having children can be complex for individuals and couples. For information and support surrounding these issues, please visit <https://sharinghealthygenes.com/>.

# CTNNA1 Gene Variants and Diffuse Gastric Cancer

PATIENT RESOURCES  
HDGC



## CTNNA1 – Patient Guideline

*CTNNA1* is an established Hereditary Diffuse Gastric Cancer (HDGC) susceptibility gene. It codes for the alpha catenin protein. Like E-cadherin, alpha catenin is a cell adhesion protein. *CTNNA1* pathogenic variants (formerly called mutations) are much rarer than *CDH1* pathogenic variants. For example, in a study of 147 families with features suggestive of HDGC, only two carried a pathogenic variant.

The risk of DGC associated with *CTNNA1* has recently been estimated at around 50% by age 80. It means that half of individuals with a pathogenic variant are estimated to develop DGC. These estimates should be treated with caution as they were based on only thirteen families, and families with a strong history of DGC were overrepresented. Therefore the actual risk might be lower.

Management of *CTNNA1* variant carriers should be based on what is done for *CDH1*, perhaps with less emphasis on prophylactic gastrectomy, given the limited data available. Carriers should be offered annual screening gastroscopy by an expert. Prophylactic gastrectomy is discussed on a case-by-case basis, depending on the endoscopy findings and the patient's wishes.

In *CTNNA1* families, genetic testing can be performed from the age of 18. Diffuse Gastric Cancer before the age of 18 has not been reported in *CTNNA1* Pathogenic Variant carriers, and there is, therefore, no reason to test earlier.

*CTNNA1* is not considered a lobular breast cancer susceptibility gene at this stage. However, this could change given the biological plausibility of an association and preliminary data emerging from international collaborations.

## Hereditary Diffuse Gastric Cancer

- Most often caused by *CDH1* mutations
- *CTNNA1* mutations also lead to HDGC
- *CTNNA1* gene codes for alpha catenin protein
- Both *CDH1* and *CTNNA1* should be tested for in families with suspected HDGC

### CTNNA1 gene variants (i.e., mutations)

- *CTNNA1* variants are an infrequent cause of HDGC
  - > In 147 families with HDGC, only 2 had *CTNNA1* variants
- Genetic testing guidelines should be similar to *CDH1*

### Cancer risk due to CTNNA1

- Estimated lifetime risk of DGC is 50%
  - > This estimate should be treated with caution
  - > Estimate was based on 13 families with a strong family history of DGC
- *CTNNA1* has not been linked to lobular breast cancer risk at this time

### Clinical Trials and Registries

- It is important for affected individuals share family cancer information and to participate in a clinical trial or registry.

### Clinical management of CTNNA1

- Current management is similar to that for *CDH1*
  - > However, limited data are available
- Endoscopic screening and annual surveillance at an expert center are recommended
- Prophylactic total gastrectomy should be considered on a case-by-case basis
  - > This may be based on family history, individual wishes, and endoscopy findings

### Pathologic findings

- Individuals with *CTNNA1* pathogenic variants can harbor microscopic signet ring cells in their stomachs
- As with *CDH1*, the significance of this finding and the biological behavior of these cells is not fully understood

### Centers of Excellence (Finding an Expert)

- Find an expert or clinical trial by going to:
  - > [clinicaltrials.gov](http://clinicaltrials.gov)
  - > Search the web for stomach cancer advocacy organizations





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