

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 life-style 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.



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.