

Gastroparesis: Common Concerns

This handout will provide you with information about the most common concerns gastroparesis patients have about their condition, and advice on how to cope with them.

Individuals with gastroparesis often share similar concerns about living with their illness.

Some of the most common concerns associated with gastroparesis include:

- understanding gastroparesis and what your future holds
- coping with social situations
- working with healthcare professionals

Understanding gastroparesis and what your future holds

The symptoms of gastroparesis can have a significant effect on how you perceive yourself. In particular, gastroparesis patients sometimes worry that others believe they are making their illness up. In many cases, it is difficult for doctors to discern a physical cause for gastroparesis and some patients interpret this as a sign that it is “all in their head” and therefore they should be able to control it. This belief can be confusing and very distressing for patients, family, and friends.

Just because there is no physical explanation for your symptoms, it does not mean that they do not exist or that you are somehow choosing to be sick. These symptoms are real, and can sometimes be quite severe and debilitating. While we may not understand what causes the symptoms, we do know that feelings of anxiety, depression, and distress can exacerbate gastroparesis symptoms. In many cases it can be helpful to learn ways to cope with these emotions in order to reduce symptom severity.

Gastroparesis symptoms can also change the activities that you are able to take part in, and how you imagine your future. As mentioned below, gastroparesis can alter social interactions, but it can also lead people to give up previously meaningful activities such as exercise and pursuing a healthy lifestyle. The symptoms can make it difficult to focus on anything else, and leave little energy to get through the day. It is no surprise that many patients find work/study life difficult at times, and may end up considering leaving work/study. Without the activities and interactions that they used to enjoy, patients sometimes feel that they have lost their sense of identity, and start to define themselves by their illness. This sort of thinking can lead to increased feelings of worthlessness, a lack of hope for the future, and the promotion of a vicious cycle.

How to manage:

- Learn about your condition. Become familiar with the content on gastroparesisclinic.org, and the many other information sheets that can be found online. You may also like to share these with your family and friends to help them understand gastroparesis.
- Complete the modules on gastroparesisclinic.org to learn about how your thoughts can influence your gastroparesis symptoms. Practice the techniques included in the modules that aim to manage your unhelpful thoughts and symptoms.

- It is true that gastroparesis symptoms can make it difficult to engage in some activities. However, by practicing relaxation and managing your unhelpful thoughts (in conjunction with any other treatments you are receiving) you may find that your symptoms are reduced, making it easier to take part in the activities that you enjoy. Sometimes the symptoms will still be too severe, and you may need to find new activities that are easier on your mind and body, and are able to be done in an environment that is comfortable for you. For example, you may swap a run for a gentle walk, or a night at the cinema for a DVD night at home with friends.
- Focus on your vision for the future and the goals you have set for yourself (see Module 1 of the intervention program for more information). If your symptoms are stopping you from achieving your goals in the way you had imagined, give some thought to breaking your goals down further, or find an alternative approach. For example, if one of your relationship goals was to go out with friends for dinner each week, you could arrange to have them all over for a cup of tea instead. This way you still get to meet up with your friends, but you are in a comfortable environment, and do not have to eat food. No matter how small, a step towards your vision for the future and goals in life is always worth celebrating.

Coping with social situations

Many people find that their social life is affected by gastroparesis symptoms. Social situations often revolve around food, which can become an issue when your digestive symptoms require you to alter what, when, and where you eat.

Individuals with gastroparesis report that their family and friends often feel uncomfortable if they choose not to eat at social gatherings, but also react badly if they do eat and then vomit as a result. Gastroparesis patients can also feel harshly judged by people around them who don't fully understand their illness, or their need to eat differently. Even amongst a group of people who are very understanding of the difficulties associated with gastroparesis, patients often feel set apart from others who are engaging in more readily accepted eating behavior.

Although people with gastroparesis still enjoy spending time with others, the pressure to conform to "normal" eating behavior can sometimes lead them to withdraw from socializing. It becomes safer to eat only at home, where they can easily access the bathroom if they need to vomit. By restricting social eating, patients greatly limit social interactions and can end up feeling isolated and unsupported.

How to manage:

- If possible, choose a meeting location that you are comfortable with. Maybe close to home, or somewhere that has a nearby and discreet bathroom. If you are able to eat solid food, try to meet at a café or restaurant where you are familiar with the menu and know what you can eat there.
- If you do not feel comfortable eating while you're out, suggest meeting for a cup of tea, at a juice bar, or at a park or museum.
- Allow time for relaxation before going out. As discussed on gastroparesisclinic.org, anxiety can make digestive issues worse. By setting aside time before going out to engage in breathing exercises, mindfulness, or guided imagery, you can help to stop any anxious thoughts from taking over and exacerbating your condition.
- Remember to monitor and challenge your unhelpful thoughts. For example, are you guessing what others are thinking and feeling without them telling you? What is the evidence for this? Is there another way you could interpret the situation? Replace your unhelpful thought by looking for positive alternatives.
- Focus on your goals. In Module 1 you are asked to establish a vision for your future, including some short and long term goals. When confronted with a social outing that is causing you distress, ask yourself if going

out will get you closer to achieving your vision for the future. Similarly, how will avoiding the outing affect your goals? Focus on what you want to achieve, and the steps you need to take in order to get there.

- Remember that the more you avoid social activities, the more fearful you will become of them. Do your best to connect with others, even if only for a short amount of time, in a setting that is comfortable for you.

Working with healthcare professionals

People with gastroparesis often express concerns about their experiences with healthcare professionals. Gastroparesis is not a common condition, and as a result some doctors may not have encountered gastroparesis before. This can lead some individuals who experience gastroparesis to feel uncertain, lost, and confused about their condition.

How to manage:

- Remember that gastroparesis is a rare condition. While general practitioners have a wealth of wide-ranging medical knowledge, they cannot possibly know everything about every health condition. It is likely that your general practitioner will need to investigate your condition, or refer you to a gastrointestinal specialist.
- Help us to better understand the relationship between gastroparesis and quality of life. Limited research has been conducted on gastroparesis, and as a result it is still not fully understood. By participating in the gastroparesisclinic.org intervention, you can help us to better understand the impact of the condition, and we can then share this information with the healthcare community.
- Throughout the modules of the gastroparesisclinic.org intervention, and in the advice section of the home page, we have provided tips on how to communicate with your healthcare team. We know that health professionals are very busy, which can sometimes make it difficult to get the information that you want from them. By reading through the communication tips, and preparing for your appointments (e.g. with a list of questions to ask), it will make it easier for you to get what you need from your meetings.

For more information on the common concerns associated with gastroparesis, please refer to:

Bennell, J., & Taylor, C. (2013). A loss of social eating: the experience of individuals living with gastroparesis. *Journal of Clinical Nursing*, 22(19-20), 2812-2821.

Bielefeldt, K., Raza, N., & Zickmund, S. L. (2009). Different faces of gastroparesis. *World Journal of Gastroenterology*, 15(48), 6052 - 6060.