Gastroparesis Patient Survey Results

June 2010

Please Note: This is not a scientific study. It is based on self-reported data from 143 people living with gastroparesis. It is for informational purposes only and is in no way intended as medical advice. Opinions given by survey respondents are solely their own.
Sex: Male: 9%  Female: 91%

How old were you when you were diagnosed?

- Younger than 20: 27.6%
- 20-29: 20.4%
- 30-39: 15.1%
- 40-49: 3.3%
- 50-59: 7.9%
- 60 or older: 25.7%

How long have you had Gastroparesis?

- Less than 1 year: 26.3%
- 1-2 years: 26.3%
- 3-5 years: 24.3%
- More than 5 years: 23.7%
Other Responses:

- Not sure (3)
- Autonomic Dysfunction/Neuropathy (3)
- Autoimmune Condition (2)
- Congenital Defect
- Thoracic spine fractures (possibly)
- Scleroderma
- MSA
- Spinal syrinx
- Along with Chronic Intestinal Pseudo-obstruction
- Hypothyroidism
- Narcotic pain medication
- Severe Anorexia Nervosa
Other Responses:

- Diarrhea (4)
- Dizziness (4)
- Fatigue (3)
- Weakness (2)
- Interstitial Cystitis
- Esophageal spasms
- Constant backache (from constipation)
- Aversion to Food
- Weight Loss
- Alternating constipation and diarrhea
- Depression
- Burning in chest that radiates down left arm
- Malnutrition
- Excessive acid production
- Burping
- Low Blood Pressure
- Fast resting heartbeat

"I answered these for how my GP was at its worst. Through some changes in diet and lifestyle, I no longer have these ‘often,’ most now occur rarely or never."
Other Responses:

- Balanced nutrition/proper diet (3)
  - “I can almost completely manage my GP with diet.”
  - “Regular amounts of fats, zero fiber (fiber = polysaccharides - sits in gut and ferments due to slow digestion), zero sugar, and vegetable juicing stopped my symptoms.”

- Supplements (3)
  - “Multi vitamins & B-12 sublingual. I believe they help. I can’t say for sure but I will keep taking them.”
  - “Nutritional supplement for weight gain, very helpful. (Now at maintenance.)”

- Erythromycin (2)
- Unable to exercise (2)
- Meditation/Breathing Exercises (2)
- Zantac
- Cisapride
- Tramadol
- Abdominal massage
- Tube feeding
- “Many years after diagnosis, discovered true food allergies. Avoiding those foods has made a tremendous difference, although I am still on meds, I no longer have daily, multiple episodes of projectile vomiting constantly.”
- “Acupuncture significantly helps symptoms such as headache, nausea, fatigue, abdominal pain; it has not got my stomach to work again though.”
Effectiveness of Treatment Options vs. Type of Gastroparesis

- Idiopathic
- Diabetic
- Post-Surgical
- Post-Viral
- Average

Bar chart showing various treatment options and their effectiveness for different types of gastroparesis.
Other Responses:

- Lack of awareness among physicians (3)
  - “It took 30 years to get a diagnosis!”
  - “Lack of info in the UK – it’s nowhere near as widely recognized over here!”
  - “Coming across doctors who don’t believe me or understand.”
- Fatigue (2)
- Anxiety/Fear (2)
  - “Becoming ill made me phobic about leaving my environment (home or work) and about traveling. I am just now coming out of it.”
- Inability to manage pain (2)
- Feeling Alone (2)
- Poor development (in children)
- Depression
- Accusations of eating disorders
- Body Image
- Side Effects of Medications
- Loss of Family
- Coping with the understanding that you "have this and it may never go away"
- Lack of understanding among general population
- “Basically, gastroparesis has negatively impacted every part of my life - a successful career as well as my role as wife, mother, child, friend, etc.”
What are the staples of your diet?

Most frequent responses:
- Potatoes
- Boost/Ensure/Carnation Instant Breakfast/Orgain
- Bread/English Muffin/Toast
- Crackers/Pretzels
- Smoothies
- Cereal
- Soup
- Baby Food Fruits/Applesauce
- Rice
- Cheese
- Nut Butters (peanut/almond)
- Chicken
- Hot Cereal (cream of wheat, cream of rice, oatmeal, quinoa)
- Low-fat or fat-free dairy products
  - Milk
  - Cottage cheese
  - Yogurt
- Fish (salmon; white fish; tuna fish)
- Bananas
- Waffles/Pancakes
- Jell-o
- Pudding
- Cooked Veggies (spinach, carrots, squash, yams, sweet potatoes)
- Ice cream/frozen yogurt
- Eggs/Egg Whites/Egg Beaters

Other responses:
- Rely primarily on tube feedings (8)
- Starches /Carbohydrates (6)
- Step 3” Gastroparesis Diet [low fat/low fiber] (4)
- Soy milk (4)
- Popsicles (4)
- Cereal bars/granola bars (3)
- Soft foods (3)
- Almond Milk (3)
- Chocolate (2)
- Coffee (2)
- Biscuits (2)
- Pop-Tarts (2)
- Protein Bars (2)
- Pork (lean/ground) (2)
- Well cooked ground beef (2)
• Small portions of “regular” food (2)
• “Meat, cheese and lactose-free milk”
• “Now that I have the gastric stimulator, I am able to eat anything I want.”
• “Whatever I feel like eating.”
• “Things that are easy to digest; avoid anything raw, acidic, or fried.”
• “Protein, almond flour, eggs, coconut milk, almond butter for baking breads”
• “When bad I ate baby food and drank liquids. Now I am eating normally and long may it continue.”
• “I eat just about everything. I’m thinking of eliminating broccoli because I’m afraid of bezoars.”
• Cantaloupe and honeydew, any melons really.
• Low-fat cold cuts
• Slim-Fast
• Resource 2.0
• Isopure
• Tomato juice
• Marshmallows
• Popcorn
• Ginger ale
Additional Comments

Advice

- Continue to push your doctors for the latest treatment options. Be your own advocate! And most importantly take care of yourself when symptoms are bad.

- Study the internet for any and all information you can find. Take questions to your doctor and ask if you can try treatments you read about. If he isn't taking you seriously, change docs.

- Don't give up. When you feel all is lost, there is always a reason to keep going and to keep striving. Living is the best reason to keep on keepin' on.

- If any medications are prescribed, get a second opinion. If anyone tells you it's "in your head," run like mad!

- Keep your hydration up.

- It takes courage and strength to face our diagnosis but we will overcome. We are not alone... we must fight to survive!!! Thanks to sites like this that makes us live for a new beginning. Lots of love and hope to all......

- Continue to educate yourself about GP. Educate your doctors so they can help you and others.

- Get your nutrition!

- Go to the Mayo Clinic and learn how to breathe correctly.

- Find the actual cause, as the gastroparesis is often a symptom in itself.

- Trust your "gut". Don't let anyone tell you that you are not really sick! Believe in how you feel and don't stop until you get answers!

- Keep going until someone listens to you. You're not crazy. Find a doctor that will help/listen. Seek support. Get as educated as you can about this.

- Get a family member to go to appointments with you to help fight for what you want. Keep a log of everything you do as this will help to let the doctors know what is going on and help you to remember as well.

- Please at least try food allergy testing by an allergist. You may be surprised at what is uncovered.

- It is definitely a misunderstood disease which one has to "learn" to adjust to according to each and every day. Don't "expect" too much of others that don't "understand". Make the best of each day and learn to pace yourself.

- Try to find something you enjoy in each day.

- A good attitude and a healthy dose of humor helps keep the balance.

- I recently learned that the birth control "pill" may not be as effective on someone with GP because of the way the body absorbs things.
My advice is for kids with GP (I’m 15 and have been sick since I was 11) to stay positive. Ask your doctor if there are any other kids in the same situation to talk to. I found a girl a little older than I am and it is very helpful to have someone to relate to. We find it’s very therapeutic.

Questions

- Are there other kinds of conditions commonly associated with Gastroparesis? I also have IBS & GERD.
- How do you know when it’s time for a feeding tube? Does anybody else have a dilated huge stretched stomach?

Personal Experiences/Thoughts

- After two years I have been able to manage almost 100% of my symptoms through diet. It took trial and error, but I feel like I live an almost normal life...without chocolate chip cookies, french fries or bacon!

- Although my gp is officially considered "idiopathic," it began following many GYN surgeries. At that time I was also diagnosed with chronic pancreatitis, chronic intestinal pseudo obstruction, severe small bowel dysmotility, severe bacterial overgrowth, all making life very limited. I appreciate the effort you have made to conduct this survey.

- Sticking to a liquid diet really helps. Three flax seed oil caps really help. Miralax really helps. Drinking lots of liquids really helps.

- Stress management worked wonders for me. I had a milder form/case of GP and was able to feel better over about a year with reducing stress and changing my diet.

- From a chemistry standpoint, it makes sense to stop all sugar/starch intake because it ferments in our guts, furthering the debilitation by Candida overgrowth.

- I was told to avoid chocolate, tea, and coffee. These foods were making me very sick. Thank you for doing this survey. I wish you had included tube feedings and TPN in your treatment question.

- Don’t take Reglan, especially if you are prone to depression. The allergy symptoms are also awful, and the steroids...it’s just a disaster waiting to happen.

- Having the PEG to drain/vent is somewhat helpful. Using suction with it is helpful. The j-tube and TPN have saved my life.

- I try not to take any meds that I can do without, that’s me. I do stay with liquids as much as possible, it helps with pain management. I also have colonic inertia, so my colon doesn't work, so with liquids it helps everything work a little better. You just have to figure out what works best for you and stick to it as best you can till that step goes bad and then figure it out again.....

- Botox is a new thing and it worked for me for a while...so I would recommend anyone to try it.

- I have found that you have to be your own advocate. I have taken to keeping a journal in which I record my weight every morning, when and what medications I take, what I eat, and what symptoms I experience and their severity. It sounds time-consuming, but it wasn’t so bad once I got into the habit of keeping it.

- I’m tired of fighting doctors that don’t think that GP causes pain!!
• I don't think people appreciate how big this is. How it affects you emotionally as well as physically. I'm known now for being flakey: happy then crying for no apparent reason. I hate not having control of my own life.

• I had it for over four years without knowing what it was. When I finally was diagnosed I actually began to feel better (most of the time). I hope I can continue to teach for a couple more years so I can retire at full retirement. Good luck and much love to all my co-sufferers.

• Lack of info in the UK has been my biggest problem. ALL my internet searches lead me to America. I am starting up a website to post all the links over here - it would have helped me SOOOO much to have this to hand when I was diagnosed. My own hospital had never even heard of it!!! I've been referred to the nearest one that does which is 250 miles away.

• I need help with what to eat and managing pain!

• I control my stress with the help of medications and have noticed that my symptoms are slightly less.

• Had gastric stimulator implanted 8 weeks ago, but still waiting for it to work.

• Gin-gins candies from the Ginger people seem to help. Daily Activia yogurt plus and acidophilus pearl with a morning cup of strong coffee helps with the constipation due to lack of fiber. Drinking sips of water between each bite of food helps. Fingers crossed the Botox seems to be working and making eating and living easier.

• Gastroparesis sucks. I've come to accept this. Focusing on the little wins has helped me a lot. Making it through a whole movie at the theater with the girlfriend while enjoying it and not feeling sick for instance... It sounds like a little win, but still being able to do something like that can mean a lot to your self esteem. Don't let yourself rot. Get out and do things! For me, I've found the best treatment has been Domperidone (I know many of you may be unable to get this, and I pray that changes soon. I'm lucky enough to live near the Canadian border.) Four times a day at a dosage of 20-10-10-20. Marijuana in small amounts at the beginning of the day for nausea (this has helped me TREMENDOUSLY believe it or not, nothing else has helped with the nausea and vomiting more, this may or may not be the case for others.), exercise, exercise, exercise (I at first like I never had the energy for this because of the significant hit to my caloric intake, but after forcing myself to do it, it made huge overall improvements.), lots of water (dehydration is one of my biggest problems at the moment). I'm 5'9", in 4 months I went from 160lbs to 125lbs. It took me almost 7 or 8 months to figure out what works for me. Following my little routine I am slowly gaining weight. About a pound a week, although there are definite ups and downs. And I am generally experiencing a much better quality of life as opposed to 6 months ago without this regiment.

• Have your last food at least three hours before bedtime. I have found the new Metamucil soluble fiber to be effective and easy to tolerate.

• Not a lot of general understanding of this in the mainstream media.

• This is a horrible disease.

• Good to recognize moments as just moments. I rarely have good or bad days, just good or bad moments.

• Believe it won't last forever - I have had two major episodes and pray I will have no more.

• I'll be praying for some kind of breakthrough of relief for us all.