



(Packet created by Melissa Adams VanHouten & approved by administration)

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WELCOME MESSAGE AND SUMMARY OF RULES

(Established/Approved by Administration & Written by Melissa Adams VanHouten)

Welcome to the group! We are always looking for ways to improve your experience in our groups and to ensure that you have the support and information you need. To that end, we have created this "Gastroparesis Support Group New Members Packet" and included it in the files section of this group and all our subgroups. Despite its label, we hope all members (newly diagnosed and long-term) will find it beneficial. Please feel free to use what you wish and discard the portions with which you disagree or find less than helpful. (Please note that all suggestions are opinion only and cannot substitute for professional medical advice. In addition, this is not meant to be a complete list of all GP-related topics; it is simply a selection of issues we hope some will find useful.) We wish to help you navigate both the groups and the often confusing and complicated world of gastroparesis, and we hope you find our groups both informative and supportive.

We would also like to remind you of some of the basic rules and policies of our groups. If you see an inappropriate post or comment that violates our rules, you may click the pull-down arrow at the top of the post and select "Report to Admin" to report it. You may also tag an administrator by typing the administrator's name in the comments, or you may send one of us a PM with the name of the original poster and a brief description of the post. (Typing "administrator" in the comments will not tag us. You must type in and tag us by name. All administrators are listed in the pinned post in the "Featured" section of the group and can also be found in the "Members" section.) The best/easiest/quickest path is to hit the "Report" button, but all of these will work. Please refrain from commenting on the inappropriate post, as this often tends only to intensify the conflict.

We ask that you send us a private message if you have a problem, complaint, or dispute about group matters. Please do not take these arguments to the feed. We do not wish to drag the entire group through feud after feud. Everyone here is too tired and sick to constantly deal with these matters. We must focus on getting out information, answering questions, and supporting one another. Ultimately, any group will only be as good as its members decide it will be. Please be kind and respectful to one another.

Our rules (which vary slightly in some of our subgroups, but which can be found in brief in the "About" sections of all of our groups) are as follows:

- We wish for this group to be a source of support to all. Please remember that everyone here is looking for care, comfort, validation, and information that will help them get through the day. When responding to posts, try to keep in mind that people are struggling and doing their very best to get by. Your support and helpful comments are much appreciated, but we ask that you refrain from posting comments that are hurtful or off-topic. (If you have an issue that does not directly relate to the original post, consider creating your own, separate post.)

- Do your very best to avoid drama, confrontation, and actions that serve only to escalate a conflict. We exist to help others who are dealing with very difficult circumstances and situations. We have a “zero-tolerance” policy regarding bullying in any form. Please refrain from name-calling, personal insults, and intimidation of other members through posts or private messages. Any violation of this policy will result in removal of the post/comment and can result in immediate removal of the member without prior notice.
- No discussion of illegal activities will be allowed. Posts/comments regarding the use, promotion, distribution, transfer, or sale of illegal substances or the illegal sale or transfer of prescription medications are prohibited. They will be removed, and the member will be blocked from the group. We will strictly enforce all rules established by Facebook as well. Please see a complete list of Facebook’s community guidelines at <https://www.facebook.com/communitystandards>.
- With due consideration to the above statement, we also try not to prohibit members from posting whatever they feel the need to express, in whatever way they wish to express it. People cope in different ways. Our community should be a safe haven where people feel comfortable sharing their innermost concerns without the fear of negative repercussions and hurtful responses, and so, support and helpful comments should be all we see. We should be able to openly and honestly discuss anything in our lives that disturbs us, concerns us, keeps us from healing, fascinates us, or uplifts us. We should be able to be respectful of one another as well, even if we disagree. Minor disputes do not need to become wars.
- Currently, we have not banned the use of cursing in the group (though Facebook imposes certain limits to which we must adhere), but we do prohibit members from directing it at each other. This is a difficult issue, and we hope we can all be respectful of and sensitive to each other's beliefs without having to engage in censorship. We know this is upsetting to some members, but we hope you can understand that not everyone expresses their feelings in the same way or with the same language.
- We do NOT require that members place photos in the comment section; nor do we require "trigger" warnings. We do believe, however, that it is a kind and sensitive gesture to place disturbing images/pictures in the comments and/or post a trigger warning, and we encourage those who are willing to please do so. In addition, on occasion, at our discretion, we may remove a particularly upsetting photo and/or ask you to re-post with the image in the comments.
- Regarding the issue of religion in this group, as stated, we do not wish to be censors. No one is now nor has ever been banned from discussing faith, posting a prayer or a prayer request, remarking that they are atheist, or engaging in conversation about any religion or lack of religion; however, we will not permit attacks by group members on other group members or bullying in any fashion. No one should ever be harassed because of his/her belief OR non-belief. If you cannot reasonably discuss the issue raised in a post, then scroll by. Also, please remember that we are not primarily a religious group; we are a gastroparesis support group. We realize that faith, religion, and spirituality can be a huge

factor in people's lives and do not wish to ban all discussion of the topic, but we cannot turn this group into a religious vs non-religious battleground. No proselytizing is permitted. (Note: Our Christian group at <https://www.facebook.com/groups/GastroparesisSupport4Christians/> allows for in-depth discussion of religion and doctrine.)

- We take a similar stance on political issues. We do not require members to adhere to any particular political views, and membership in a political party is not a requirement for membership in THIS group. Likewise, no one is required to support any specific bills or policies. We permit discussion on broad policy issues regarding health care but only in a general, nonpolitical manner. We do not reject members based on their political views; nor do we wish for them to feel unwelcome. We have zero tolerance for name-calling or attacks on any person, party, or political figure. Those sorts of discussions are best saved for personal pages and political forums. We are a GASTROPARESIS support group and not a political debate club.
- We do not allow fundraising requests, requests for donations, goods, or money, advertising, promotions, discounts, contests, raffles, giveaways, gift exchanges, free samples, or any form of solicitation or sales in the group. We also ask that you refrain from posting links to outside groups and pages. Our feed quickly becomes overrun with such posts, and they will be removed. Do not harass, stalk, threaten, or target people in this group for fundraisers, "Go Fund Me" ads, and similar endeavors. Please refrain from targeting people in posts and through private messages. Engaging in such behavior will result in immediate removal from the group. If you wish to post a fundraiser, sales offer, or monetary request, or if you have a GP-related support group, Facebook community page, blog advertisement/link, work opportunity, or other sources you have started or from which you directly benefit and would like to share, you may post such personal advertisements in our community group at <https://www.facebook.com/groups/GPSupportGroupCommunityInfoPage/>. If you wish to send cards or small gifts to others in the community (with no expectation of reciprocation) or wish to connect via mail, text, or phone, please use either our community group (linked above) or our pen pals group at <https://www.facebook.com/groups/GastroparesisHome4Holidays/>.
- All "Watch Parties," reels, YouTube, and "Facebook Live" or personal videos must be ***pre-approved*** by an administrator. All unapproved events will be deleted. No TikToks.
- Blocking an administrator will result in automatic removal from the group. At times, it is necessary for us to comment on your posts and/or reach you via PM, and we cannot do so if we have been blocked. We must have minimal access to group members to maintain order in the group and facilitate appropriate and acceptable discussion.
- This is a closed group, and we take our members' privacy seriously. Please do not share anyone's personal information or posts outside of this group without the original poster's permission. Do not post screenshots from this group onto your personal page, and do not share them with other support groups unless you have express permission from the

original poster to do so. Likewise, do not post screenshots from any other closed group on this page. It is important to respect the privacy and trust of our members.

- We require those requesting membership to send their requests personally. We do not allow automatic "adds" to the group and ask that your family members and friends send their requests directly rather than being auto-added by you. This is not a reflection on you or your family members and friends; rather, it is an attempt to keep our group safe and secure. We must ensure that all accounts are legitimate, and we have a set of screening questions all potential members must answer before being admitted to the group. In addition, we must make certain your friends and family truly wish to join the group. We will gladly approve members once we know this is the case. We are sorry for any inconvenience this may cause you, but we want to make certain we are exercising caution and good judgment.

Above all else, we exist to help others who are dealing with troubling circumstances. There are difficult issues that arise in a group this large and diverse, and our goal is to be kind, supportive, and respectful of and sensitive to each other's beliefs without having to engage in censorship.

We share the horrors of this cruel disease, but we experience and cope with them in different ways. What other people deem an appropriate way to express their needs might not always match your own views. Likewise, people make various treatment choices, and what works for one might not work for another. While you are welcome to offer your own experiences (with life and with treatments), we will not permit you to dictate or judge the choices of others, as we recognize that we must be tolerant of diverse views, and there is no one superior approach which applies to all.

We also ask that you evaluate before posting whether your comment is designed to incite or to genuinely discuss an issue important in your life and that you keep all comments below the original post civil and non-argumentative. If you wish to answer the question posed in the original post, then do so, but do so in a respectful manner. You must agree to disagree and scroll by or hide posts you cannot tolerate. Further, please refrain from commenting if you cannot offer helpful advice or encouragement. Arguing and leaving hateful comments under a post does not create an atmosphere of support. This only further upsets the member who is struggling and has somehow managed to get up the courage to post about his/her issues in the manner s/he sees fit. We must be willing to peacefully disagree.

Ultimately, this group will stand or fall on the actions of its members. We, as administrators, can police the group only so much. It is up to all group members to maintain a welcoming and supportive atmosphere. We realize that not all members will agree with our rules and policies, but we ask that you respect them, and if you cannot do so, we will help you find a group that better suits your needs. It is unfortunate when someone leaves us and loses a potential source of support, but it is just as unfortunate when a group member does not feel comfortable posting. We wish to avoid both these situations when possible.

We want this group to be a welcoming and safe place for all to come and share their concerns, joys, heartaches, questions, and helpful information. We ask only that you are kind to one

another and that you do your very best to strengthen the bonds between us. Your cooperation is most appreciated!

If you need help or wish to speak with an administrator, please do not hesitate to tag or PM one of us. We are always glad to assist you if we can.

Thank you for everything you do to make this a welcoming and supportive group for all!

ANY SUGGESTIONS OFFERED IN THIS GROUP ARE OPINION ONLY AND CANNOT SUBSTITUTE FOR PROFESSIONAL MEDICAL ADVICE. PLEASE CONSULT YOUR PHYSICIAN BEFORE STOPPING, STARTING, OR ALTERING ANY MEDICATIONS.*

REGARDING SUICIDAL POSTS OR IMMEDIATE THREATS OF SELF-HARM:

We take these threats very seriously and will do whatever is within our power to prevent a death. Please note that we do not wish to discourage anyone from asking for help; in fact, we hope you do if you need support. The administrators and members of this group care and will do their best to offer support and assistance; however, we are not trained professionals, and we urge you to seek professional counseling and assistance outside this group as well if you are experiencing feelings of despair and hopelessness or are actively contemplating self-harm.

We understand people need support from the group when they are overwhelmed and feel as though they do not have the strength to continue. Venting and requesting support and encouragement is certainly welcome, as this is a support group; however, if you are genuinely experiencing suicidal thoughts or actively contemplating self-harm, PLEASE seek immediate assistance from your physician, the nearest emergency room, and/or one of the resources listed below. We, as administrators, do our best to oversee the group and we wish to help, but this group is not monitored at all times.

We also ask that group members contact an administrator (via PM) and/or tag us immediately in any suicide-related post so that we can easily find the information. We will do our best to contact the member, provide the Suicide Prevention Hotline number (1-800-273-TALK (8255) or 988), and offer any additional assistance we can. We ask that group members also use discretion in such situations. There is a difference between "wishing" to die and actively contemplating self-harm. When in doubt, please contact an administrator. If you are unable to reach an administrator and need immediate assistance, you may report a suicidal post to Facebook by completing the form at <https://www.facebook.com/help/contact/305410456169423/>. You will be given additional instructions upon completion of the form.

PLEASE NOTE: Mental health professionals are required by law to report all credible threats of intent to engage in self-harm, and while we are not trained mental health professionals, if the threat is imminent, we will, at our discretion, and upon belief of intent to self-harm, contact

Facebook and follow up with the Suicide Prevention Hotline and LOCAL POLICE when possible. We understand that such posts are sometimes merely attempts at expressing deep feelings and hurt, but we must address all such posts, and we must report and follow up for the safety of all concerned.

IF YOU DO NOT WISH FOR US TO IMPLEMENT FOLLOW-UP PROCEDURES, PLEASE ADD A NOTE THAT YOU WOULD NEVER HARM YOURSELF, OR YOU ARE "VENTING," OR SOMETHING OF THAT NATURE TO LET US KNOW YOU ARE IN NO IMMEDIATE DANGER; otherwise, we must report a dangerous situation.

Sources for help in suicide prevention:

- US/Canada Suicide Prevention Hotline: 1-800-273-TALK (8255) or 988
- US Crisis Text Line: Text 741741 or 988
- UK/Ireland (List of hotlines): <http://www.suicide.org/hotlines/international/united-kingdom-suicide-hotlines.html>
- Australia: <https://www.lifeline.org.au/> and Kids Helpline Australia: <https://kidshelpline.com.au/>
- You can view a list of suicide prevention hotlines in other countries at <http://www.suicide.org/international-suicide-hotlines.html> and <http://www.befrienders.org/> and <https://www.facebook.com/help/103883219702654/>
- Additional information provided by Facebook can be found at <https://www.facebook.com/help/594991777257121/#resources> and https://www.facebook.com/emotional_health

Please also note that we are held to the requirements of Facebook Community Standards and MUST remove posts that violate those standards.



DEFINITION OF A SUPPORT GROUP

Melissa Adams VanHouten

In this group, we believe in supporting the whole person and in creating an atmosphere conducive to addressing all aspects contributing to one's well-being. This includes everything that affects us physically, mentally, emotionally, and spiritually. We seek relationship-building and personal connection. We are a Gastroparesis support group, but GP touches every part of our lives, and, so, we are more than a "medical information only" board. If you are looking for that -- for medical information minus the human aspect -- this group is likely not a good fit for you. Here, we talk about our pets, our children, our difficult relationships, our employment, our celebrations, our hardships, our significant life milestones, and a whole host of other topics that are not directly related to GP, but which, nonetheless, impact our lives. And that will remain the case. This is the only "family" some people have, and we will not take that away from the members of this community.

Here is our definition of a support group and all it entails...

WHAT IS A SUPPORT GROUP?

A support group can serve many functions, but the most basic definition is "a group of people with common experiences who provide emotional and moral support for one another. " (Merriam-Webster Dictionary) When you "bear all or part of the weight of" another's burden, "give assistance to" one another, or "enable" others "to function or act," you have offered support. (Oxford Dictionary) That is what we do best in this group!

We are a fountain of information where people newly diagnosed or searching for answers can turn, of course, but we are far more than a "Question & Answer" board. We are a source of encouragement and a soft spot where all who are struggling can land. We are a safe place where members may freely express their fears, concerns, heartaches, and joys, and address any issues that affect their physical, mental, emotional, or spiritual well-being. We empower people not only by providing information but also by offering kind words and lifting each other up when it feels as if the whole world might be against us.

If you are looking for true support, then you have found your home.

But if you seek perfection – a "facts-only," atmosphere with little connection or emotion – or expect to never witness "venting," or "negative" emotions, then this group is likely not for you. We are not cold or sterile; nor do we lack emotional attachment. We are complex, flawed human beings who gather together as a community to try to sort out all the intricacies of this cruel illness and find a way to cope with its impact on our daily lives. We fail and we rise again. We have good days and bad. We express disappointment and delight. We rage and praise, cry and

laugh, and celebrate and mourn. We are real human beings doing the best we can to get through the long, painful days.

In this group, we welcome you to participate as much or as little as you are comfortable and ask only that you offer listening ears, open minds, understanding, and an attitude of helpfulness and gentleness.

We are thankful for all our fabulous members who give of their time, offer advice and expertise, and endeavor endlessly to offer genuine solace and reassurance to those in need. You are the very definition of a "support" group.



GASTROPARESIS: COMMON TERMS AND ACRONYMS

Melissa Adams VanHouten

Button Tube: A low-profile feeding tube that sits at skin level.

CIP (or CIPO): Chronic Intestinal Pseudo-Obstruction. Paralysis of the small bowel.

Colonic Inertia: A motility disorder in which fecal matter passes too slowly through the colon.

DTP: Digestive Tract Paralysis.

Dumping Syndrome: When undigested stomach contents move too quickly into the small intestine. Nutrients are not absorbed properly, and this can lead to malnutrition.

EDS: Ehlers-Danlos Syndrome. A group of connective tissue disorders.

Endoscopy/Scope: Procedure whereby a long, flexible tube with a camera is used to view the GI tract.

Enteral Feeding: Delivering food/nutrition directly to the stomach or small intestine.

Gastric Electrical Stimulator/Pacemaker/Pacer: A small neurostimulator that is placed in the abdomen to help control nausea and vomiting. It delivers electric pulses to the lower stomach.

GERD: Gastroesophageal Reflux Disease. A digestive disease characterized by acid reflux.

GES: Gastric Emptying Study. Measures the speed in which food empties from the stomach into the small intestine.

GI: Gastrointestinal. Also used to refer to one's gastroenterologist. Pertaining to the stomach and intestines.

G/J-Tube: Gastrojejunostomy Tube. A feeding tube that accesses both the stomach and the jejunum (middle part of the small intestine).

GP: Gastroparesis. Paralysis of the stomach; delayed emptying of the stomach.

G-Tube: Gastrostomy (or Gastric) Tube. An abdominal feeding tube that delivers nutrition directly to the stomach.

Idiopathic: Of unknown/uncertain cause.

Ileostomy: A surgical opening in the abdominal wall, designed to expel waste from the body, via a stoma. Waste is collected in a pouch.

J-Tube: Jejunostomy Tube. A feeding tube placed directly into the jejunum (middle part of the small intestine).

NG Tube: Nasogastric Tube. A feeding tube that is passed through the nostril, down into the stomach.

NJ Tube: Nasojejunal Tube. A feeding tube that is passed through the nostril, through the stomach, and down into the middle part of the small intestine (called the jejunum). It essentially bypasses the stomach.

NPO: Nothing by mouth.

PCP: Primary Care Physician.

PEG Tube: Percutaneous Endoscopic Gastrostomy Tube. It is a G-Tube that is placed endoscopically.

PEJ Tube: Percutaneous Endoscopic Jejunostomy Tube. It is a J-Tube that is placed endoscopically.

PICC Line: Peripherally Inserted Central Catheter. A catheter inserted through a vein in order to deliver nutrition and/or medications more easily and efficiently.

POTS: Postural Orthostatic Tachycardia Syndrome. A form of dysautonomia in which changes in body position result in an increased heart rate and accompanying problems.

SIB/SIBO: Small Intestinal Bacterial Overgrowth. Excessive bacteria in the small intestine.

Spoon Theory: Please see <http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>. This is a common explanation used by those with chronic illness to explain the amount of energy needed and used in a day. It is the reason some refer to us as “spoonies.”

Stoma: The opening in the body where the feeding tube passes through.

TPN: Total Parenteral Nutrition. Providing nutrition directly into the bloodstream. A central IV line is surgically placed for this method of providing nutrition.

For additional terms and acronyms, please also see: <https://www.agmdhope.org/common-terms-and-acronyms/>.

GETTING STARTED

Melissa Adams VanHouten

There are several organizations and sites that offer basic information regarding gastroparesis. You might consider beginning your search on our website, www.curegp.org, the IFFGD site at <https://www.iffgd.org/>, or the AGMD site at <http://www.agmdhope.org/>. For a more technical explanation of GP and a description of protocols, see <https://gi.org/guideline/management-of-gastroparesis/> and the recently updated version at https://journals.lww.com/ajg/fulltext/2022/08000/acg_clinical_guideline_gastroparesis.15.aspx.

The following are additional resources that might be helpful when searching for information regarding various aspects of gastroparesis:

Gastroparesis Explained

<https://curegp.org/gastroparesis-the-basics/>

<http://www.niddk.nih.gov/health-information/health-topics/digestive-diseases/gastroparesis/Pages/facts.aspx#1>

<https://rarediseases.org/rare-diseases/gastroparesis/>

<http://europepmc.org/article/PMC/3785986>

https://www.hopkinsmedicine.org/gastroenterology_hepatology/_pdfs/esophagus_stomach/gastroparesis.pdf

Gastroparesis Diets

<http://gicare.com/diets/gastroparesis-diet/>

<https://med.virginia.edu/ginutrition/wp-content/uploads/sites/199/2014/04/Gastroparesis-and-DM-02.23.17-1.pdf>

Digestive Disorders Organizations

Gastroparesis: Fighting for Change (GFFC) - <https://www.curegp.org/>

Association of Gastrointestinal Motility Disorders (AGMD) - <http://www.agmdhope.org/>

International Foundation for Gastrointestinal Disorders (IFFGD) - <http://www.iffgd.org/>

Gastroparesis Patient Association for Cures and Treatments - <http://www.g-pact.org/>

Digestive Disease National Coalition - <http://www.ddnc.org/>

Oley Foundation - <http://oley.org/>

American Neurogastroenterology and Motility Society (ANMS) - <https://motilitysociety.org/>

American Gastroenterological Association (AGA) - <https://www.gastro.org/>

American College of Gastroenterology (ACG) - <https://gi.org/>

Rome Foundation - <https://theromefoundation.org/>

Books

Gastroparesis: Pathophysiology, Clinical Presentation, Diagnosis and Treatment, by Richard Mccallum, Henry Parkman, John Clarke, and Braden Kuo

Comforting Your Uncomfortable Stomach, by Dr. Kenneth Koch, M.D., and Laura Dotson

Gastroparesis: A Roadmap for your Journey, by Chelsey M. McIntyre, PharmD

How to Live Well with Chronic Pain and Illness: A Mindful Guide, by Toni Bernhard

Real Life Diaries: Living with Gastroparesis, by Lynda Cheldelin Fell and Melissa Adams VanHouten

The Gastroparesis Cookbook: 102 Delicious, Nutritious Recipes for Gastroparesis Relief, by Karen Frazier

The Gastroparesis Healing Diet: A Guided Program for Promoting Gastric Relief, Reducing Symptoms and Feeling Great, by Tammy Chang

Living Well with Gastroparesis: Answers, Advice, Tips & Recipes for a Healthier, Happier Life, by Crystal Zaborowski, Saltreli, CHC

Blogs

<https://curegp.org/blog-melissa/>

<https://melissarvh.blogspot.com/>

<https://gastroparesiscrusader.weebly.com/>

<https://curegp.org/faces-of-gp/> (Collection of Personal Stories from the GP Community)

Clinical Trials

<https://www.clinicaltrials.gov/>

<https://www.centerwatch.com/>

<https://www.agmdhope.org/clinical-trials/>

<https://iffgd.org/research/clinical-trials-studies.html>

Pain

<http://patients.about.com/od/painkillerlegalsafety/a/Pain-Drugs-Drug-Seekers-Your-Doctor-And-The-Law.htm>

<http://theacpa.org/>

Weight Gain & Malnutrition

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8180181/>

http://www.huffingtonpost.com/dr-mark-hyman/malnutrition-obesity_b_1324760.html

<http://www.webmd.com/diet/ss/slideshow-weight-gain-shockers>

<http://www.womenshealthmag.com/weight-loss/what-is-starvation-mode>

Feeding Tubes & TPN

<https://apfed.org/>

<https://specialty.optum.com/find-care/support-complex-conditions/home-parenteral-nutrition.html>

<http://www.fvfiles.com/520883.pdf>

<http://oley.org/>

<https://www.childrensmn.org/references/pfs/homecare/gastrostomy-care-g-j-tube.pdf>

<https://gpresourcehub.weebly.com/parenteral-nutrition.html>

Disability

<https://www.disabilitysecrets.com/what-is-the-difference-between-ssdi-and-ssi.html>

<https://www.disabilitybenefitscenter.org/social-security-disabling-conditions/gastroparesis>

<http://www.disabilitysecrets.com/resources/disability/getting-social-security-disability-benefits-se>

<http://www.disabilitysecrets.com/topics/social-security-denials-and-appeals.htm>

<http://www.disabilitysecrets.com/tip8.html>

<http://allsup.com/>

<https://www.dol.gov/odep/topics/disability.htm>

<https://www.ssa.gov/pubs/EN-05-10029.pdf>

Coping

<http://www.psychologytoday.com/blog/turning-straw-gold/201207/what-those-chronic-pain-or-illness-do-want-hear>

<https://inspiringwomen.org/2023/01/18/coping-with-chronic-illness/>

<http://www.a-spiritual-journey-of-healing.com/7-stages-of-grief.html>

<https://aboutkidsgi.org/living-with-gi-disorders/talking-about-gi-disorders/helping-children-and-adolescents-cope-with-abdominal-pain/>

http://www.huffingtonpost.com/lottie-v-ryan/living-with-chronic-illness_b_5878410.html

<http://gastroparesisclinic.org/index.php>

<http://www.faithgateway.com/depression-fighting-dragons/>

<http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

<http://www.tonibernhard.com/>

Common Problems/Conditions

<https://iffgd.org/gi-disorders/>

<https://agmdhope.org/list-of-motility-disorders/>

<https://www.yahoo.com/health/how-your-body-signals-that-youre-vitamin-deficient-100516369838.html>

<http://www.med-health.net/Feels-Like-Something-Is-Stuck-in-My-Throat.html>

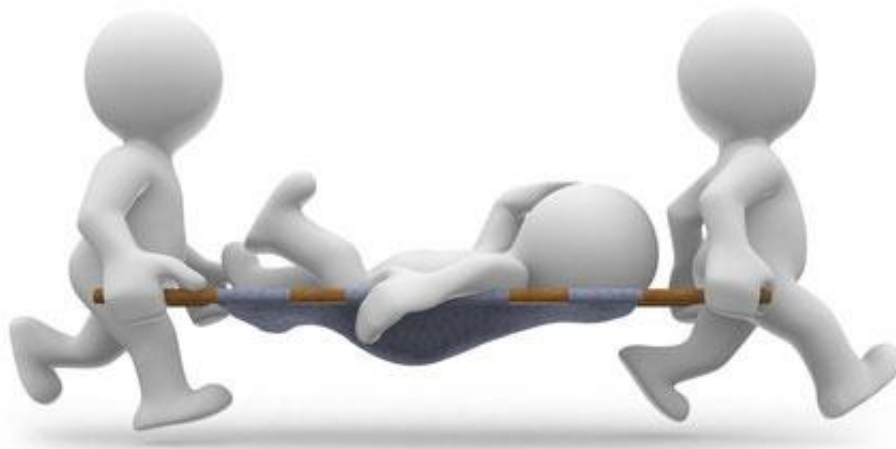
<https://www.siboinfo.com/>

<http://www.webmd.com/digestive-disorders/tc/difficulty-swallowing-dysphagia-overview>

Finding a Doctor

There are a few organizations that have made attempts at compiling lists, but because physicians constantly enter and exit the field and relocate to other states, lists are difficult to maintain and are often incomplete and outdated. The AGMD maintains a list of motility specialists at <https://www.agmdhope.org/locate-a-physician/>, and the IFFGD offers several lists at <https://iffgd.org/manage-your-health/your-healthcare-team/>. The ANMS list, though not completely up to date, is also a very good starting point: https://motilitysociety.com/wp-content/uploads/2021/11/current_registry.pdf. Motility specialists are quite helpful, but if you are open to seeing a gastroenterologist who does not necessarily specialize in Gastroparesis, you might search here: <http://www.castleconnolly.com/doctors/specialty/Gastroenterology.cfm>. And one final option is to post in our state groups for referrals. A list of all state groups, with links, can be found at <https://curegp.org/resources/>.

The AGMD also offers a list of neurogastroenterology and motility centers at <https://www.agmdhope.org/neurogastroenterology-and-motility-centers/>, a list of dietitians at <https://www.agmdhope.org/dietitians/>, and a list of other illness-related specialists at <https://www.agmdhope.org/locate-specialists/>.



LINKS TO VARIOUS GASTROPARESIS-RELATED RESOURCES

Melissa Adams VanHouten

Help with Medical/Prescription Costs

<https://www.mhanational.org/how-can-i-get-help-paying-my-prescriptions> (*START HERE*):
Links to federal, state, and local assistance programs as well as tips for cutting costs

<https://www.ssa.gov/benefits/medicare/prescriptionhelp/>: Information on the Medicare “Extra Help” program

https://www.needhelppayingbills.com/html/help_with_medical_bills.html: Tips and links to federal and state programs offering assistance with medical bills

<http://www.needymeds.org/index.htm>

<http://rxoutreach.org/>

<https://www.drugs.com/discount-card/>

<https://www.rxhope.com/home.aspx>

Individual drug manufacturers also frequently offer discounts and charitable program. Check individual sites for more information.

Help with Nutritional Supplements & Equipment

https://oley.org/page/Equipment_Exchange: Oley’s equipment supply and exchange program

<https://www.feedingtubeawareness.org/resources/>: Various feeding tube tips and assistance resources

<https://www.facebook.com/groups/MedicalSupplyExchange/>: Facebook-based medical supply and exchange group

<https://www.facebook.com/groups/MedicalNeedsExchange/>: Facebook-based medical supply and exchange group

<https://www.facebook.com/groups/GPACTSupplyDepot/>: Facebook-based medical supply and exchange group

Help with Dental Care

www.freedentalcare.us/

<https://dentallifeline.org/our-state-programs/>

Local dental schools

State Dental Association websites (for a list of assistance programs)

State Health Department

1-800-DENTIST (for low-cost recommendations in your area)

Help with Transportation

(Please note that these are not personal recommendations. They are merely suggestions for further research, and we would highly recommend scrutiny when seeking assistance from organizations offering these types of services.)

<http://www.angelflight.com/>: Air transportation

<https://palservices.org/>: Air transportation

<https://mercymedical.org/>: Air and ground transportation

<https://angelwheels.org/>: Ground transportation only

<https://www.tsa.gov/travel/special-procedures>: TSA medical information and travel assistance

Help with Housing, Utilities, and Other General Living Expenses

https://www.hud.gov/topics/housing_choice_voucher_program_section_8: Section 8 housing options

<https://howtogeton.wordpress.com/2017/07/30/housing-tips-for-spoonies/>: General tips and links to low-income housing programs

https://www.needhelppayingbills.com/html/low_income_assistance_programs.html: Offers links to federal and state low income assistance programs, including housing, utilities, job training, education, legal advice, and medical care programs

<https://howtogeton.wordpress.com/2017/01/31/how-to-be-poor-in-america/>: General resource article offering tips and resources for finding free or low-cost transportation, medical, food, housing, and other assistance programs

<http://www.operationwearehere.com/financialassistance.html>: General assistance resources, mostly benefitting military members and families

<http://www.211.org/>: Enter your location, and you will be connected to various assistance programs in your local area

Help with Holiday Gifts or Holiday-Related Expenses

<https://helpingamericansfindhelp.org/christmas-assistance-help/>: List of Christmas assistance programs, organized by state

<https://www.makeuseof.com/tag/7-top-charities-that-offer-online-christmas-help-for-low-income-families/>: Top 7 holidays assistance programs

https://charity.lovetoknow.com/Charity_Christmas_Assistance: List of social service organizations and nonprofits offering holiday assistance to needy families

https://www.needhelppayingbills.com/html/christmas_assistance_programs.html: List of state resources, broken down by county

<https://militarybenefits.info/christmas-programs-for-military-families-in-need/>: Holiday assistance programs for military families

Local churches, clubs, neighborhood associations, and civic organizations can also provide help.

Miscellaneous Requests

If you have additional needs not addressed above, wish to share a fundraiser, donation request, “Go Fund Me” campaign, work-from-home opportunity, or giveaway, you are welcome to post these requests in our Community Group at

<https://www.facebook.com/groups/GPSupportGroupCommunityInfoPage/>.

TESTS TO DIAGNOSE GASTROPARESIS

Melissa Adams VanHouten

There are several tests which may be performed to help diagnose gastroparesis. The following is a list of some of the common methods used. Please note that no assessment method is foolproof, and your physician should evaluate results in conjunction with your symptoms and medical history. Test results can also vary from day to day and can be affected by many factors; results are a snapshot of a moment in time and must be viewed in this light:

Gastric Emptying Study/Scintigraphy (GES): This test is considered the “gold standard” by which to diagnose gastroparesis. The patient ingests a small amount of radioactive material (that has been added to foods and/or liquids) and then a nuclear medicine technician, using a gamma camera, traces that material as it passes through the stomach and enters the intestines. Images of the substance’s progression are taken at regular intervals. (See <http://motilitysociety.org/wp-content/uploads/2016/11/Gastric-Emptying-Patient-Information-AMS-8-15-2005.pdf> for additional information regarding preparation for the test; <http://snmmi.files.cms-plus.com/docs/Guideline%20for%20Adult%20Gastric%20Emptying.pdf> for information regarding preferred procedure and methods of testing; and chart below for information regarding interpretation of results.)

Wireless Capsule Monitoring/Smart Pill: This is an ingestible electronic device in capsule form which measures pressure, pH level, and temperature as it travels through the digestive tract. This information is then sent to a receiver, downloaded, and analyzed by a technician. Doctors use this information to evaluate progress through the digestive tract. (Please be aware that this test is not available in all locations and is not covered by some insurance companies. For additional information, see https://www.hopkinsmedicine.org/gastroenterology_hepatology/docs/patient_info/Smart_Pill_Info.pdf.)

Gastric Emptying Breath Test (GEBT): This test measures the rate at which food moves from the stomach into the small intestines. The patient fasts overnight and is then given a non-radioactive food containing a specific type of carbon which can be measured through a series of breath samples given at regular intervals. (For additional information, see <https://www.uspharmacist.com/article/diagnostic-spotlight-gastric-emptying-breath-test>.)

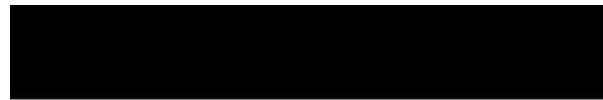
Upper Gastrointestinal Endoscopy: This procedure is used to get a visual of your esophagus, stomach, and duodenum. Once sedated, the doctor places a long, thin, flexible tube with a camera attached which is maneuvered down the esophagus and into the stomach. The doctor is able to get a more accurate picture of inflammation, stomach contractions, blockages, bezoars, and/or undigested food. (See <https://www.niddk.nih.gov/health-information/diagnostic-tests/upper-gi-endoscopy> for additional information.)

Upper GI Series/Barium: For this procedure, the patient is instructed to drink a chalky liquid (Barium) and then must undergo a series of x-rays. This can sometimes highlight undigested food, blockages, and tumors. (For additional information, see <https://www.niddk.nih.gov/health-information/diagnostic-tests/upper-gi-series>.)

Electrogastrogram (EGG): For this test, electrodes are placed on the abdomen and stomach to monitor and record electrical activity or rhythm in the stomach. An irregular pattern may indicate improper function of the stomach muscles. (For additional information, see <https://www.medicinenet.com/electrogastrogram/index.htm>.)

Antroduodenal Manometry: This is the test where a catheter is placed through the nose and then passed down the throat and into the stomach and small intestines to record muscle activity and muscle contractions. Abnormal patterns may indicate a motility disorder. (Additional information can be found at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3714419/>.)

For a list of additional associated tests, please see: <https://www.agmdhope.org/common-tests/>



Severity of Gastroparesis

	Mild	Moderate	Severe
Retention at 4 hours	10-15%	16-35%	>35%
Homogenised food	Rare	Sometime	Routine
Nutritional supplements	Rare	By mouth	Jejunal tube
Non-pharmacologic treatment	No	No	Yes

N Eng J Med 2007;356:820-829




TABLE 2
Normal Limits for Gastric Retention

Time point	Lower limit (a lower value suggests abnormally rapid gastric emptying)	Upper limit (a greater value suggests abnormally delayed gastric emptying)
0.5 h	70%	
1.0 h	30%	90%
2.0 h		60%
3.0 h		30%
4.0 h		10%

Data are from *Am J Gastroenterol.* 2007;102:1-11.

Please note: Rates above are for a standard 4-hour Gastric Emptying Scintigraphy. Retention greater than 10% is considered delayed emptying. Results (in conjunction with symptoms and medical history) should be further evaluated by your physician.

A SAMPLING OF MEDICATIONS AND TREATMENTS FOR GASTROPARESIS

Melissa Adams VanHouten

According to the National Institutes of Health (NIH), an estimated 5 million people or more live with gastroparesis; yet, this illness is still little-known to the public and often misunderstood by healthcare professionals who impact our care. This lack of knowledge can lead to under-diagnosis and/or delayed diagnosis and treatment.

There are variations in symptoms and levels of severity of gastroparesis, and individuals respond differently to the available treatment approaches. In general, patients struggle to maintain nutrition levels and are at risk of malnutrition and/or dehydration due to their inability to ingest and absorb nutrients. There is no scientifically known cure for gastroparesis, and, so, treatments tend to focus on symptom control and may gradually progress to greater levels of intervention, based on how well or poorly one responds to each step in the treatment plan. Treatments may include:

- Dietary Changes
- Medications
- Alternative and Complementary Therapies
- Tube Feedings or TPN
- Gastric Stimulator and/or Other Surgical Interventions

Though it would be difficult to list all possible treatments, as they numerous and varied, a few treatment approaches are listed below. This information ***does not substitute for proper professional medical advice. Please consult your physicians before starting, stopping, or altering any medications or treatments.***

Dietary Changes: The basic GP diet calls for small, frequent, low-fat, low-fiber, high-protein foods and liquids (at tolerable levels) which are easier to digest. Many diet plans call for a 3-step process, beginning with a liquid-only diet and then progressing to soft-foods (low-residue, low-fat), and eventually, a maintenance diet (which adds just a bit more fat as well as some well-cooked, easy to chew foods).

In reality, many find the basic diet plan difficult to follow, as tolerances vary, and it must be tailored to fit individual needs. In short, what works for one might not work for another, so it is largely a process of trial and error. To complicate this further, many of us find that our food tolerances can change from day-to-day and over time. So, what works for us one day might not work the next. Some find they get “stuck” on one “step” in the diet or that they move up and down the steps rather than steadily progressing. Others find that, though they follow the plan precisely, they have little to no tolerance of the recommended foods and liquids and cannot maintain adequate hydration and nutrition levels.

We recommend keeping a food journal which notes your daily intake and any reactions, intolerances, or worsening symptoms you experience. This might assist you in finding patterns over time. Further, we suggest “testing the waters” by slowly and gradually adding one or two liquids/foods, in small amounts. Be mindful of the guidelines and note what works for others, but

do not be surprised if your tolerances differ from those of others, and be willing to tailor the diet plan to suit your individual needs. You must do what works best for you!

If you find you are not maintaining adequate hydration and nutrition levels, consider asking your doctor for a referral to a dietitian or speak with your provider about the possibility of other methods of supplementation.

Medications: Typically, patients will be presented medications intended to lessen their specific symptoms. Prokinetics (such as Domperidone, Metoclopramide, and Erythromycin), designed to help the stomach empty, are commonly offered as are antiemetics (such as Zofran, Phenergan, Tigan, and Compazine), to help with nausea and vomiting. Depending on symptoms, patients might also be offered antidiarrheal, constipation, and/or pain control medications. Low-dose antidepressants are also somewhat common, as they are thought to help with pain in some cases. Botox is a less common approach, and although the scientific literature is mixed and not plentiful, some find this approach helpful. (Please note that some physicians will not offer Botox treatments and many insurance companies will not cover it for these reasons.)

Alternative and Complementary Therapies: Some patients find therapies such as acupuncture, acupressure, hypnosis, aromatherapy, essential oils, and chiropractic care helpful in controlling symptoms. Some also prefer a “natural” approach consisting of herbs, vitamins, and supplements preferable or complementary to traditional medicinal approaches. Scientific evidence is scant, and we caution that, though this approach might be helpful for some, “natural” does not always mean “harmless.” We caution our members to research these approaches as you would traditional therapies and to consult your physicians regarding proper dosage and use.

Tube Feedings and TPN: Some patients progress to the point where they require supplemental nutrition provided by tube or intravenous feedings. This can be temporary or long-term, and may vary in type, depending on medical necessity. There are risks (such as infections) and benefits associated with each form of care, and if you find you are not maintaining adequate hydration and nutrition levels, we recommend you consider asking your doctor about this approach.

Gastric Electrical Stimulator and Other Surgical Interventions: While the stimulator (or pacer, as it is commonly known) can be helpful in some cases (especially in the case of diabetic GP accompanied by nausea and/or vomiting), please note that it is FDA-approved only under the Humanitarian Use exemption to treat nausea and vomiting. Your physician must obtain approval through this program before using this treatment. Please also be aware that because of these restrictions, many insurance companies consider the stimulator experimental and will not cover the cost. Additional surgeries offered may include pyloroplasty, G-POEM/POP, gastric bypass, and partial or total gastrectomy. Surgical intervention is generally considered only after other less-invasive treatments have failed. We recommend you research these options and consult your physician if you believe these therapies might benefit you.

Note: Gastroparesis can be but is not necessarily progressive. Some patients improve over time, while others find their condition worsens. Some note little to no change in their symptoms or severity level over time. Many patients experience fluctuations between (sometimes lengthy) symptom-free, remission-like periods and symptom-heavy flares.

Progression depends largely on the cause and on how well one responds to dietary changes and available treatments. In some cases, treating the underlying cause (such as Diabetes), can lead to significant symptom improvement. In other cases (such as post-viral gastroparesis or gastroparesis brought on by medications), the scientific literature indicates the condition can (but not necessarily will) resolve itself over time.

Regardless of severity level, cause, or pattern, there is no scientifically known cure for gastroparesis and no one treatment which benefits all. Progression and effectiveness of treatments are highly individualized.

For a good discussion of treatment options, see: <https://rarediseases.org/rare-diseases/gastroparesis/>, <https://www.niddk.nih.gov/health-information/digestive-diseases/gastroparesis/treatment>, https://journals.lww.com/ajg/Fulltext/2013/01000/Clinical_Guideline_Management_of_Gastroparesis.8.aspx, and https://journals.lww.com/ajg/fulltext/2022/08000/acg_clinical_guideline_gastroparesis.15.aspx (recently updated guidelines).

For information regarding the causes and complications of Gastroparesis, please visit: <https://curegp.org/gastroparesis-the-basics/>.

For a partial summary of medications/treatments, mechanisms of action, and potential risks/side effects, see: <https://med.emory.edu/departments/medicine/documents/allamneni-aga-refractory-gastroparesis.pdf>. (Chart from this publication included on following page.)

For a partial summary, discussion, and chart of common antiemetics, see: <https://www.amboss.com/us/knowledge/Antiemetics/>

Medications for Medically Refractory Gastroparesis				
	Drug and or Class	Mechanism / Efficacy	Dosing	Adverse effects / Cons
Medications for Nausea and Vomiting	Domperidone	- Dopamine D2-receptor antagonist - Does not readily cross the blood brain barrier, fewer central side effects than Metoclopramide - 68% had an improvement in symptom scores	- Recommended starting dose 10mg TID ; escalation to 20mg QID has been reported, but should be avoided for CV safety	- QT prolongation and ventricular tachycardia are risks - Availability in the US is only through an FDA investigational drug application
	5-HT3 antagonists (Ondansetron & Granisetron)	- Block serotonin receptors in the chemoreceptor trigger zone and inhibit vagal afferents - Similar efficacy between Ondansetron & Granisetron - Transdermal Granisetron decreases symptom scores by 50% in patients with refractory gastroparesis symptoms	- Ondansetron – 4-8mg BID – TID - Granisetron – 1mg BID - Granisetron patch - 34.3 mg patch weekly	- Selection can be determined by price, availability, and mode of delivery
	Neurokinin (NK-1) receptor antagonists (aprepitant, tradipitant, casopitant, rolapitant)	- Block substance P in critical areas involved in nausea and vomiting - Appear to improve nausea/vomiting in up to 1/3 of patients	- Aprepitant 80mg qd	- Symptoms improved regardless of presence or absence of gastroparesis
	Phenothiazine antipsychotics (e.g., prochlorperazine, chlorpromazine)	- Reduce nausea and vomiting by inhibiting dopamine receptors in the brain	- Prochlorperazine 5-10mg BID - Chlorpromazine 10-25 mg TID or QID	- Have not been studied in gastroparesis or compared prospectively to other antiemetics
Medications to Accelerate Gastric Emptying	Erythromycin	- Macrolide antibiotic, accelerates gastric emptying by binding to motilin receptors	- Intravenously in hospitalized patients (3 mg/kg every 8 hours), or PO in outpatients (50-100 mg QID (AC and qhs))	- Tachyphylaxis limits effectiveness - Higher oral doses may cause early satiation and pain, and may exacerbate nausea and vomiting - QT prolongation, risk of cardiac arrhythmia
	5-HT4 receptor agonists (Cisapride, Velusetrag, Prucalopride)	- Cisapride – appeared effective - Velusetrag – accelerated gastric emptying in phase 2 RCT - Prucalopride – accelerated gastric emptying and improved symptoms	- Velusetrag experimental - dosing not yet approved - Prucalopride 2mg qd	- Cisapride off market due to adverse cardiac effects - Other agents not yet approved for gastroparesis

Medications for Medically Refractory Gastroparesis (cont.)				
	Drug and/or Class	Mechanism / Efficacy	Dosing	Adverse effects / Cons
Medications for Visceral Pain	TCA (Nortriptyline, Amitriptyline, Imipramine)	- Noradrenaline reuptake inhibition is considered the main mechanism for controlling visceral pain - Per NORIG trial, no improvement in GCSI score on Nortriptyline over placebo - Greatest benefit in patients with functional dyspepsia overlap	- Amitriptyline 25-100 mg/qd - Imipramine 25-100 mg/qd - Desipramine 25-75 mg/qd - Nortriptyline 25-100 mg/qd	- Does not improve gastric emptying - Evidence in functional dyspepsia but not gastroparesis
	SNRI (Duloxetine)	- Improved diabetic polyneuropathic pain	- 60-120 mg/day	- Can worsen nausea or constipation in higher doses
	Pregabalin	- Inhibits release of excitatory neurotransmitter for anti-nociceptive and anticonvulsant effects - Pooled data from seven RCTs indicates reduction in pain	- 100-300 mg/day in divided doses	- Adverse effects - dizziness, somnolence, weight gain and peripheral edema

Gastric Electrical Stimulation

- Precise mechanism unknown; does not increase gastric emptying, rather modulates the gastric pacemaker and interstitial cells of Cajal
- Does improve refractory nausea & vomiting
- Option for gastroparesis patients with refractory/intractable nausea and vomiting who have failed standard therapy, are not on opioids, and do not have abdominal pain as the predominant symptom

Pylorus directed therapies

- Abnormalities of pyloric tone and pressure (e.g. “pylorospasm”), and dyscoordination between antral contractions and pyloric relaxation, may impair gastric emptying, and contribute to symptoms
- Pylorus directed therapies include:**
- **Intrapyloric botulinum injection** - available data argues against use of botulinum toxin in refractory gastroparesis, except in clinical trials
 - **Transpyloric stent placement** – should be considered investigational, lack of data
 - **Gastric per oral myotomy (GPOEM)** - Two separate multi-center trials noted improvement in symptoms and reduction in gastric emptying times.
 - Studies suggest a reduction in post-procedure GCSI scores and improved gastric emptying
 - Should only be performed at tertiary care centers using a team approach of experts

*AGA Clinical Guideline: Update on Management of Medically Refractory Gastroparesis, by Chaitanya Allamneni, MD: <https://med.emory.edu/departments/medicine/documents/allamneni-aga-refractory-gastroparesis.pdf>. Note that only medications for refractory GP are included.

A NOTE REGARDING DOMPERIDONE

Melissa Adams VanHouten

According to the FDA, there is only one pharmacy (inside or outside the U.S.) whereby U.S. patients may legally obtain Domperidone: Dougherty's Pharmacy in Dallas, Texas. You can find Dougherty's on the web at <http://www.doughertys.com/> or reach them via telephone at (214) 373-5300. The FDA has stressed that this is the ONLY legal method for obtaining Domperidone available to U.S. residents.

It is a common misconception (even among doctors) that Domperidone may legally be obtained outside the U.S., but this is not the case. U.S. residents seeking to obtain Domperidone outside the U.S. technically do so in violation of regulations and run the risk of having their Domperidone confiscated at the border. This can and has occurred. In this case, the patient does not receive his/her Domperidone, nor does s/he receive reimbursement for the order.

It is also a common misconception that Domperidone may be obtained through compound pharmacies in the U.S. Again, this is a violation of FDA regulations. Compounding pharmacies are prohibited from making and distributing Domperidone and do so at risk of being fined. The FDA fines these pharmacies and orders them to cease production/distribution once they have been made aware. Many patients have found that local compounding pharmacies which once filled/refilled their prescriptions for Domperidone have now been banned from this practice. When this happens, the patient is left with no recourse and no access to the medication.

Here is a link to the FDA's website regarding how to obtain Domperidone:

<https://www.fda.gov/drugs/investigational-new-drug-ind-application/how-request-domperidone-expanded-access-use>

Their website instructs, in part, "Patients 12 years of age and older with certain gastrointestinal (GI) conditions may be able to receive treatment with Domperidone through an expanded access investigational new drug application (IND). These conditions include gastroesophageal reflux disease with upper GI symptoms, gastroparesis, and chronic constipation. Patients who are eligible to receive Domperidone have generally failed standard therapies. Expanded access INDs facilitate access to investigational drugs (such as Domperidone) for patients with serious diseases or conditions for which there is no comparable or satisfactory alternative therapy to diagnose, monitor, or treat the patient's disease or condition. In addition to other applicable requirements, an IND must be in effect prior to the importation, interstate shipment, and administration of Domperidone."

*Please note that we seek to provide you with the most accurate and up-to-date information possible, but we cannot and will not try to direct your behavior. Your choices are your own. If you have any further questions, we advise you to call the FDA directly at 1-888-463-6332.

For the most recent research on Domperidone, please see

<https://www.practiceupdate.com/c/54e9eb34-7d9c-4f0e-bad8-35ddf668d182> and https://journals.lww.com/jcge/Citation/2019/10000/Effect_of_Chronic_Domperidone_Use_on_Q_T_Interval_.14.aspx.

INSURANCE ISSUES

Melissa Adams VanHouten

It can be very tough when insurance denies medications, tests, and procedures we need to help us cope with our illness. I am no expert in this area, but I will offer my opinions and recommendations for you to pursue or dismiss as you please. I hope you will find something useful here!

When your insurance denies coverage, you have the right to appeal, and I recommend that you first follow your insurance company's appeals process for its duration. Your insurance company must give you a reason for denial, and it is crucial to address this when you appeal. You are essentially arguing your case and must know the facts to be able to do so. To begin with, it will be helpful to contact your insurance and inquire as to what constitutes medical necessity in your particular case. Request an explanation of this in writing. Also, ask for the names of everyone who was involved in researching your case at the insurance company and making the decision to deny it.

Once you have this information, you can proceed with the appeals process. If you have an urgent need for approval, you may ask for an expedited appeal. (Requirements for this vary. Check with your insurance company for further information.) Your doctor can assist you with your appeal by writing a letter declaring medical necessity for the medication, procedure, test, etc. you are seeking. Encourage your doctor to include notes demonstrating how you responded to inferior treatments and his opinion as to why the treatment in question would benefit you. (If s/he is unwilling to cooperate, you might wish to consider finding a new doctor.) You should include this letter every time you appeal. You should also clearly state your reason for appealing and include studies and other pertinent writings which provide evidence of the benefits of the given treatment. In addition, you might consider contacting the drug company/manufacturer for help with your appeal. Many have patient assistance programs and will be glad to assist. If you are employed, contact the HR department. They are often willing to intervene on your behalf as well.

Send all letters via certified mail and request a return receipt. (Keep copies for your own files as well.) Follow up to make certain your correspondence was received and is being addressed in a timely manner. Document (in writing) any contact (telephone or written) you have with your insurance company. Take note of the date, the name of the person addressing your issue, and what was discussed. Keep a timeline.

It might also be helpful to file an appeal with your state's insurance division (links at <https://eapps.naic.org/cis/fileComplaintMap.do>) and let your insurance company know that you have done so. Send a letter to both your insurance company and your state's insurance division to let them know everything you have endured and every step you have taken to correct this and to try to get proper treatment.

If your coverage is repeatedly denied, you may request an external appeal, which will be overseen by an independent third party. If, after reviewing all pertinent documents and evidence, the external party decides in your favor, your insurance company must comply. You will receive

coverage at this point. If the third party does not find in your favor, there are still a few additional steps you might consider.

First, you may decide to consult an attorney. You might also consider contacting your state congressional representatives for assistance. (This is a long shot, but it might be worth a chance.) You may file a claim with your state's Department of Insurance as well.

As a patient, you have rights. Not all decisions will be made in your favor, and all of the above methods might ultimately fail, but at least can rest assured that you have exhausted all options. Insurance denials are a significant impediment to quality care, so it is best to know your rights and options!

Here are a few links you might find helpful:

Check patient rights for your state here: <http://coveragerights.org/>

Internal Insurance Appeals: <https://www.healthcare.gov/appeal-insurance-company-decision/internal-appeals/>

External Reviews for Insurance: <https://www.healthcare.gov/appeal-insurance-company-decision/external-review/>

File a complaint with your state's Dept. of Insurance:
<https://eapps.naic.org/cis/fileComplaintMap.do>

Health Insurance



ADVOCATING FOR YOURSELF WHILE HOSPITALIZED

Melissa Adams VanHouten

1. Know your rights as a patient. You have a right to basic information regarding your care, informed consent, and high quality care. You have the right to be treated with respect. You have a right to make decisions about your own care – including the option to refuse treatments. You have the right to designate a healthcare representative to act on your behalf. And you have a right to object to improper care.
2. Speak up when you have a question, ask for additional information when little is provided, and object when you disagree. It is perfectly proper to inquire about all medications and treatments you are receiving, their intended purposes, alternative treatments, and risks. It is also acceptable to suggest medications or treatments you would prefer and to ask for the reasons they have been denied.
3. Make certain you let your medical staff know of all medications you have recently taken so that no unintended negative interactions occur. Keep staff informed of any changes in your condition or reactions to medications.
4. If you believe your rights have been violated, speak up, document (in writing) all incidents, who was involved, the time and date, and any steps made toward resolution by you, your health representative, or the hospital staff. Take statements from witnesses, if available, as well. Ask for a copy of your hospital's statement of patient rights and note violations.
5. Report incidents and complaints to the charge nurse and all nursing supervisors up the chain of command. If your issue involves a physician, ask the hospital to direct you to his immediate supervisor and pursue the chain of command from there. If all else fails, ask to speak with the hospital CEO.
6. Request a patient advocate or hospital ombudsman. Though they are employed by the hospital, in theory, they are required to act in accordance with patient rights and address all violations. They can also advise you regarding who to contact should things go awry.
7. Request a different nurse or physician. Essentially, this means “firing” the existing personnel. Not all hospitals take kindly to this, but many will readily comply to avoid further issues. (You may ask for a transfer to a different facility as well, but the alternate facility is not required to accept you and insurance may refuse coverage. You are also free to walk out the door at any time, but if you do so against medical advice, you will likely release your current hospital from liability. You might also check with your insurance company as to whether BOTH hospital stays will be covered should you leave AMA.)
8. Address the situation until it is resolved. Do not give up. Complain – but in a courteous manner – until you have exhausted all options.
9. Follow up in writing with the hospital (and/or your physicians) when you have received sub-standard care. Document all incidents and issue a written response to the hospital after you are

released. Clearly state the nature of your complaints and what you believe could have been done to remedy the situation. Some hospitals welcome such feedback and use it to make changes, but even if this is not the case, you can take a measure of satisfaction in knowing that you have addressed the situation to the best of your ability.

10. File complaints when necessary and proper. File complaints about improper care with your state's Department of Health: <http://empoweredpatientcoalition.org/report-a-medical-event/report-a-hospital-or-facility/state-health-departments-health-licensing/>. File complaints about your physician with your state's Medical Board: <http://fsm.org/state-medical-boards/contacts>.

DEMAND BETTER!



EXPECT MORE!

MAKING THE MOST OF YOUR DOCTOR VISITS

Melissa Adams VanHouten

Questions to Ask Your Doctor:

- * Do you specialize in my condition?
- * How quickly will I be seen should I need an appointment?
- * What is my diagnosis and how did you conclude this? Could this be something else? Do you know the cause? Would you please explain my condition to me?
- * What is my prognosis?
- * How will this affect my daily life?
- * What are my treatment options – medications, procedures, and alternative therapies? What are the side effects and risks of these? Which do you recommend given my personal circumstances?
- * What tests will be ordered? What do you hope to conclude from these tests? What are the risks and limitations of these tests? What are the costs associated with these tests? How and when will I receive the results?
- * What are your treatment goals for me? How will we evaluate my progress toward these goals?
- * What should I do if my symptoms worsen? Under what circumstances should I contact your office? When should I seek immediate help from an urgent care center or the ER?
- * What informational and support resources are available to me?
- * Should I seek a second opinion or be referred to other specialists?

Questions Your Doctor Might Ask You:

- * What brings you here today? What would you like me to do for you today?
- * What are your most bothersome symptoms? How did they start? How long have you been experiencing them? How severe are they? Have they become worse over time? Have you been able to identify any triggers or patterns regarding the onset of these symptoms? Where is the location of these symptoms?
- * Tell me about your family medical history. Has anyone else in your family experienced something similar or do they have other significant health issues?

* Do you have any other health problems? Surgeries? Hospitalizations? Have you seen any other doctors or had any tests related to your current illness?

*Are you now or have you ever taken any prescription or OTC medications? Do you take any vitamins or supplements?

* Tell me about your lifestyle choices. Do you exercise, eat healthy, smoke, drink, etc.? Have you ever struggled with depression or mental or emotional issues?

* What are your goals for treatment?

* Do you have any other questions for me today?

Tips for Making Your Doctor's Visit a Success:

* Make certain the doctor has received all your medical records before your appointment. Maintaining good home records will help your visits go smoothly, too. Keep a list of all medications (including OTC and vitamins/supplements) as well as dosage and date you began taking them. Track and record all significant medical visits, tests, and procedures. Consider keeping a diary of symptoms and how symptoms are affected by various medications, foods, activities, etc. Bring all pertinent records and information in an easy-to-read form to all doctor visits – just in case. Also, consider bringing a list of ALL current medical providers and their contact information.

* Make a written list of questions and/or topics you would like to discuss with your doctor in advance of your visit. Prioritize them so that your most important concerns are addressed. Consider the purpose of each visit and keep questions aligned with this goal if possible. What are the top symptoms you would like addressed? What quality of life goals do you hope to achieve? Your time with your doctor is limited and you will want to make the most of it. This will help you more clearly communicate your needs and goals and will help you remember those subjects you wish to address when you are rushed, flustered, or under stress. Be realistic about what and how much you can accomplish in one visit. Be aware that follow-up visits may (and likely will) be necessary. (Please note that some physicians will allow you to request lengthier visits if this is prudent. Check with office staff to see if this option is available.)

* Consider bringing a spouse, relative, or friend with you to help you communicate your desires and process all information given at the time of the visit. Another “ear” and a different perspective is often helpful. If you must go alone, consider making an audio or video recording of the visit (if permissible) or taking written notes. At the end of the visit, review with your doctor what you believe to be the main points of the visit and do not leave without understanding what your next steps should be. Make certain you understand your treatment plan and know how to properly take any medications you have been prescribed. Also, note the names of any specialist/referrals and make certain you know who will be scheduling the appointments and when they will be scheduled. Make sure you understand all lab orders and what you will need to do to prepare for any labs/tests. You might also wish to ask about the procedure and

requirements for seeking help in-between office visits should the need arise. Do not be afraid to ask questions if you do not understand or voice objections if you do not agree with the treatment plan/goals. Your doctor should partner with you to establish a care plan that is mutually acceptable.

* Research your illness as much as possible prior to your visit – not to self-diagnose but to interact on a more level playing field. The more you know in advance, the better you will be able to evaluate the treatment options your doctor recommends and the better able you will be to formulate relevant questions. Respected science-based medical sites are a good place to begin your research, but patient and support groups can also provide you with good information. If you have done research on your own, bring a summary of this and/or links to (reputable) sites with the information you have found. Discuss with your physician whether your research is pertinent to your circumstances. There should be collaboration between you and your physician, and the more you know, the better you will be able to participate in your own care.

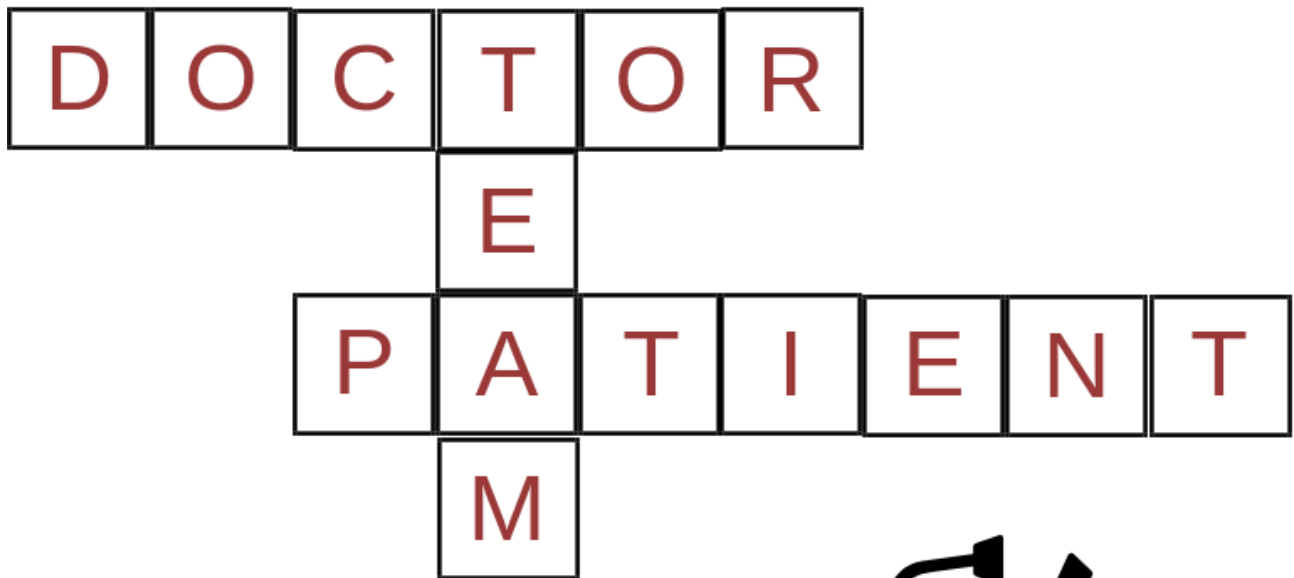
* When speaking to your doctor (and his staff), be polite, but assertive. Make eye contact and speak clearly and loudly enough to be heard. Be direct. Make certain you express your needs and goals, but try to do so in a calm, rational manner. This will make a far better impression and will set the tone for a mutually respectful visit. Remember: You have a right to be treated with dignity.

* Ask questions when you do not understand. There is no need to be embarrassed. This is a stressful time, and we are often faced with difficult terms and concepts with which we are unfamiliar. It is better to leave the appointment with a clear plan and a good understanding of your options than to walk away confused and uncertain about how you should proceed. Also, ask your doctor why he believes you need a certain test or treatment and why he believes a certain approach will best meet your individual needs. The tone of office visits should be conversational in nature and not a unilateral presentation by either party.

* When evaluating your tests, labs, and treatment options, consider the benefits and drawbacks of each as well as the risks. How will they diminish or better your quality of life? How difficult will it be to take the medication or follow the protocol your physician suggests? Will any of the options get you closer to your own physical or social goals? Be honest with your doctor about your lifestyle, your ability/willingness to follow suggested treatments, and your ability to pay for further testing and medications. Discuss alternatives when necessary.

* Request a copy of your medical records and an after-visit summary (if available) at the time of your doctor visit. If you do not have a copy of past records, request a copy of these from all providers as well. If your medical providers make available a medical portal, consider taking advantage of this service. You will be able to use these tools to review your recommendations, upcoming appointments and tests, and lab results. Many portals have a feature that allows you to message the doctor (or his office administrator) directly, and some even offer an online option for prescription refill requests. Combine all pertinent records in one location if possible. Review records for errors and request corrections where appropriate.

* Do not be afraid to ask for a second opinion or for referrals when appropriate. Consider finding a new doctor who is a better fit if you are not satisfied with your care and cannot resolve your care issues.



CHRONIC ILLNESS: OH, THE STRESS OF IT ALL!

Melissa Adams VanHouten

Everyone must deal with stress from time to time, and that is not necessarily a bad thing. Stress can actually be beneficial when it is short-term and low-level. It can boost your energy and memory, act as a motivator, and even enhance your physical strength. But those of us with chronic illness often battle prolonged stress, with few or no breaks, and this can be quite detrimental to our health. There is a growing body of evidence that indicates this type of stress can lead to serious health issues such as heart disease, migraines, stomach problems, high blood pressure, and depression. In order to avoid, or at least minimize these possible risks and effects, it is important to know how to recognize and manage potentially harmful stress.

Coping with stress can be particularly difficult for those of us living with chronic illness because of its long-term and serious nature. It comes with additional stressors that most other people do not face, and there is rarely a respite from these. Diagnosis is often accompanied by fear, confusion, and disbelief. Some of us experience apprehension because we feel we have not been given a proper initial explanation of our condition or enough information to manage it effectively. Conversely, there is commonly an overload of information to process regarding our numerous medications and the complex medical routines we must follow. We are often shocked by the overwhelmingly difficult lifestyle changes required of us. Upon initial diagnosis, many of us are confused and upset about the nature of our illness, its causes, its symptoms, our prospects for treatments or a cure, and the measures that will be required of us to accommodate the effects of our illness. We fear what the future holds.

There are other complications that concern us as well. It can be difficult to find a doctor who can (or will) treat us, and we must sometimes interact with several different physicians who manage our care. On occasion, we receive conflicting advice and recommendations from the medical professionals providing for our treatment. In times of medical crisis, we face decisions about whether it is appropriate to treat our illness at home, see our doctor, or perhaps visit the emergency room. Many of us struggle to find medications and treatments that work for us and must determine this through trial and error. Once we find helpful medications and treatments, we may face difficulty in gaining access to them and at times must battle with insurance companies who deny us coverage or physicians who hesitate to prescribe them. It can all be pretty overwhelming.

In addition to the hardship of dealing with the day-to-day management of the actual symptoms themselves, there are long-term concerns. Severe symptoms can eventually interfere with one's social life and even jeopardize one's career. Friends and family members may have unrealistic expectations about what a chronically ill person is capable of, and often, we ourselves have these same unrealistic expectations. We are regularly too sick to participate in social activities, and we feel much guilt over our withdrawal from social functions and gatherings we once found enjoyable. We may begin to feel increasingly cut off and isolated from the friends and family members we once knew. If serious enough, symptoms can result in missed days of work and eventual unemployment, which can lead to monetary woes. The loneliness, seclusion, and financial strain associated with these factors act as additional stressors and make it all the more difficult for those of us who are chronically ill to cope.

Indeed, life with chronic illness can be burdensome and stressful. Nonetheless, there are methods of averting or minimizing many of the factors that contribute to our stress. For starters, we can make an effort to prevent stress from occurring in the first place by educating ourselves. Searching the Internet, reading articles, asking questions of our doctors, and seeking out others with the same condition helps provide us with insight into our illness. It minimizes the fear of the unknown that accompanies our diagnosis and gives us an idea of what to expect in terms of symptoms, treatments, possible complications, and prognosis. It helps us recognize what is “normal” for our condition and what is cause for concern and aids us in preparing for what might be coming down the road.

We can also do our best to maintain a healthy lifestyle. (I am not suggesting we can attain perfect health; I am simply recommending doing whatever we can to be as healthy *as possible* given the limitations of our illnesses.) This might mean taking vitamins and supplements, exercising, making the most nutritious food/drink choices possible, getting adequate rest, and taking our medications as recommended.

In addition, we can work toward strong mental health. Rather than expecting “perfect” lives, we can focus on the good we have and be grateful for the small, joyful moments. Likewise, we can learn to manage the circumstances in our lives that can be governed and adapt to the ones beyond our command. (We may not be able to attend courses on a college campus, for example, but perhaps we can take online classes. Maybe we cannot make it to the movie theater, but we can view videos in the comfort of our own homes.) We can also forgive ourselves for our perceived shortcomings and pardon others for not acknowledging our limitations. We cannot control missing an event due to illness, but we can refuse to feel guilty and accept that we cannot “will” ourselves to be well. Our illnesses are real, and they come with genuine physical limitations.

Finally, we can learn to recognize the signs of harmful stress (i.e., mental confusion, anxiety, worry, depression, fatigue, altered sleep patterns) and seek help when we feel discouraged and defeated by joining support groups; talking to trusted friends, family members, and neighbors; or pursuing professional counseling. We can engage in pleasurable activities – such as reading, writing, listening to music, playing board games, etc. – that momentarily distract us from our debilitating symptoms. We can read encouraging books or practice relaxation techniques like yoga and meditation. We can ask loved ones for assistance or consider employing home helpers/aides to lend a hand with household chores or other tasks we have difficulty completing. Perhaps we can identify government and charitable programs (for prescription aid, low-income housing, reduced-cost medical care, and the like) that might ease our financial burdens.

We may not be able to entirely avoid the stress that results from our complicated and sometimes overwhelming circumstances, but we can learn to manage it. As chronic illness warriors, we face a constant, daunting battle against stress – but it is not one we must necessarily lose.

NAVIGATING THE HOLIDAYS

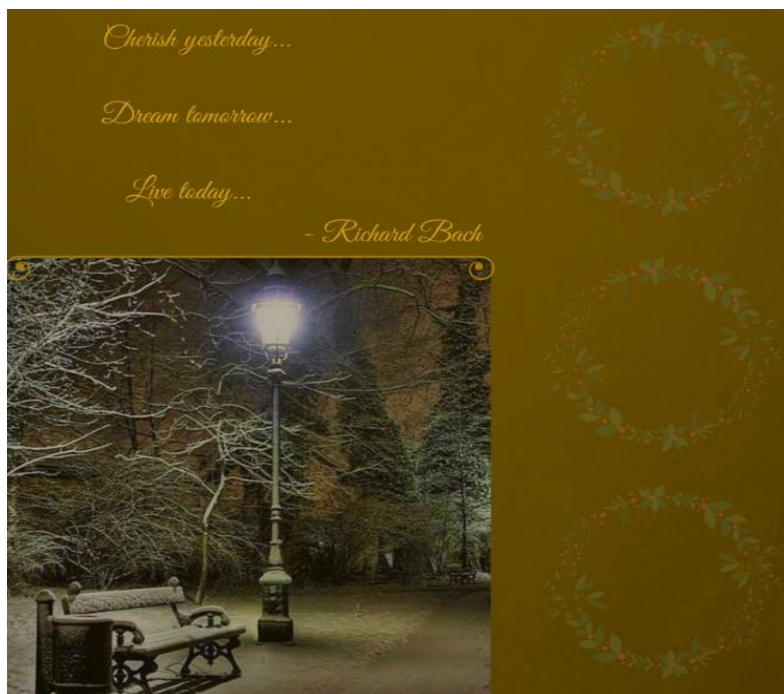
Melissa Adams VanHouten

The holiday season can be a physically, emotionally, and financially challenging time of year for both those diagnosed with gastroparesis and their loved ones. We long to connect but are faced with additional burdens and obstacles that often make it difficult to celebrate in familiar and traditional ways. And while no one can promise that the holidays will be the same as they were in pre-diagnosis times, we can help you have the best possible holidays moving forward.

You are welcome, of course, to post in our groups for tips, tricks, advice, and support during the difficult moments. You might find our Holidays and Pen Pals subgroup particularly helpful, as many there participate in voluntary card and small gift exchanges. There are sometimes giveaways as well. You can find this group at <https://www.facebook.com/groups/GastroparesisHome4Holidays>.

We have also compiled a grouping of blogs you might find useful:

- *"The Most Wonderful Time of the Year"... with Gastroparesis?:* <https://melissarvh.blogspot.com/2016/11/the-most-wonderful-time-of-year-with.html>
- *Feast Your Eyes on a Gastroparesis Holiday:* <https://melissarvh.blogspot.com/2016/11/feast-your-eyes-on-gastroparesis-holiday.html>
- *Managing the Financial Burden of the Holidays:* <https://melissarvh.blogspot.com/2017/12/managing-financial-burden-of-holidays.html>
- *Gastroparesis: Surviving Thanksgiving:* <https://melissarvh.blogspot.com/2016/11/gastroparesis-surviving-thanksgiving.html>
- *Happy Halloween:* <https://melissarvh.blogspot.com/2016/10/happy-halloween.html>



DENTAL CARE

Melissa Adams VanHouten

Due to frequent vomiting and poor nutrition, many Gastroparesis patients struggle with swollen gums, mouth sores, extreme sensitivity to hot and cold foods/liquids, eroded enamel, cavities, infections, and tooth loss. Vomiting causes gastric acid to travel to the mouth, where it erodes the protective tooth enamel and leads to decay. Permanent damage can occur within 6 months of the onset of vomiting. In addition, many are unable to meet proper nutritional requirements, and this lack of essential vitamins and nutrients leads to swollen gums and/or periodontal disease (gingivitis).

What can be done to slow the decay and lessen the damage? You might take several steps:

*Do not brush immediately after vomiting. This will further embed the acid in your teeth and gums and cause additional damage. Wait at least 30 minutes before brushing.

*Rinse your mouth with water only or with a mixture of baking soda and water. (Baking soda helps neutralize the acid.)

*Keep your mouth moist. Dry mouth increases your risk of gingivitis, tooth decay, and infection.

*Ask your dentist about a prescription toothpaste (such as CliniPro 5000, PreviDent, or GC MI Paste Plus). These pastes contain a greater percentage of fluoride and can help prevent decay. You might also consider having a protective sealant (such as PermaSeal or Durafinish) applied.

*Up your vitamin and nutrient intake when/if possible. Add probiotics, calcium, iron, folate, Vitamins B12, C, and D, and Omega 3 to your routine.

*For swollen gums, use saltwater rinses, cold compresses, and numbing agents if necessary. For hot/cold sensitivity, try a desensitizing toothpaste.

*Do not brush your teeth too hard, use an extra-soft toothbrush, slant your toothbrush at a 45-degree angle, and avoid acidic drinks and foods.

*Practice routine dental care. Brush, floss, and visit your dentist regularly.

If you cannot afford dental care, here is a list of sources you might consult for financial assistance:

*www.freedentalcare.us/

* <https://dentallifeline.org/our-state-programs/>

*Local dental schools

*State Dental Association websites (for a list of assistance programs)

*State Health Department

*1-800-DENTIST (for low-cost recommendations in your area)

Please also see: https://www.agmdhope.org/magazine/winter_2019_agmd_beacon_journal-final/#page=35

We hope this information helps you!



LINKS TO GASTROPARESIS SUPPORT GROUPS

Melissa Adams VanHouten

In an attempt to better serve several segments of our community, we have created numerous groups. You may join at any time. This is our way of creating “subgroups” of sorts to better serve your needs:

Gastroparesis Support Group

(<https://www.facebook.com/groups/GastroparesisSupportGroup/>): This is our main and largest group with more than 44,000 members. There is a wealth of information and support here for those who are comfortable in the larger groups.

GP Support Group Community Information Page

(<https://www.facebook.com/groups/GPSupportGroupCommunityInfoPage/>): Please post your GP-related fundraisers, blogs, community pages, group links, articles, and other such information pertinent to the Gastroparesis community at large. We would love to share the resources available in our GP community!

Gastroparesis Support Group for Christians

(<https://www.facebook.com/groups/GastroparesisSupport4Christians/>): This group is open to all those who have been affected by gastroparesis or other gastrointestinal issues. We seek to support each other spiritually through encouragement and prayer. If you would like to grow spiritually, please join us. We would love to have you!

Gastroparesis: Hospice & Palliative Care

(<https://www.facebook.com/groups/GPHospAndPallCare/>): This group is for those with Gastroparesis who are in a hospice or palliative care program. We hope you find this to be a place where you can gain and share information and resources, and we encourage you to discuss your stories and experiences. We would like for this group to be a source of support for those dealing with the unique aspects of advanced illness -- a setting which offers comfort, dignity, and nonjudgmental understanding while addressing physical, emotional, and spiritual needs.

Gastroparesis: Home for the Holidays & Pen Pals Group

(<https://www.facebook.com/groups/GastroparesisHome4Holidays/>): Are you "Home for the Holidays" due to Gastroparesis and its effects? Need company or assistance or wish to provide it to others? Looking for a pen pal? We invite you to celebrate holidays, birthdays, and all other significant events online with us. We hope to add a little cheer and make a few new friends. We will be working on projects (call lists, card exchanges, chats, sharing stories, etc.) to make it a little easier for those who struggle with the pressures, expectations, sadness, and loneliness that sometimes accompany the holidays and other significant milestones. It can be tough to cope with a limiting chronic illness, but you don't have to do it alone!

GP Book Nook, Movies, Blogs, and Crafts

(<https://www.facebook.com/groups/GPSupportGroupBooksAndHobbies/>): The Gastroparesis community shares many hobbies and interests. We are creative people! Please share your talents, time, and activities with us!

GP Support Group for Loved Ones

(<https://www.facebook.com/groups/GPSupport4LovedOnes/>): This group is for family, friends, and all loved ones of those who have been diagnosed with Gastroparesis or similar motility disorders. It is our hope that we can offer support and companionship to all those seeking to better understand and cope with this diagnosis.

GP Support Group Recipes & Nutritional Information

(<https://www.facebook.com/groups/GPSupportGroupRecipes/>): We invite you to share your GP-friendly recipes, diet recommendations, and nutritional information in this group. We would love for you to post your recipes and help others navigate the complicated world of nutrition while living with GP!

GP Support Group for Diabetic Gastroparesis

(<https://www.facebook.com/groups/GPSupportGroup4DiabeticGastroparesis/>): This group is for those who are living with Diabetic Gastroparesis.

GP Support for Teens & Young Adults

(<https://www.facebook.com/groups/GPSupport4TeensAndYoungAdults/>): This Gastroparesis group is for teens and young adults from the ages of 13 to 26.

GP Support Group for Parents & Children

(<https://www.facebook.com/groups/GPSupportGroup4ParentsAndChildren/>): If you are a parent with Gastroparesis or have a child with Gastroparesis, we welcome you! We hope this group will offer the support and information you, as a parent, need to meet the unique challenges that accompany raising children with GP or raising children while living with GP.

GP Support Group for Gainers

(<https://www.facebook.com/groups/GPSupportGroup4Gainers/>): This group is for those living with Gastroparesis who tend to gain or fluctuate in weight. We welcome you to share your insight and encourage you to support others who experience this often misunderstood effect of GP.

Working with Gastroparesis

(<https://www.facebook.com/groups/WorkingWithGP/>): This group is designed for those with GP who remain in (or would like to re-enter) the workforce. Please join us and share your frustrations, struggles, tips for coping, and daily victories!

GP Grief & Memorial Group

(<https://www.facebook.com/groups/GPGriefAndMemorialGroup/>): This group serves as a memorial to all those who have passed in our Gastroparesis community. We post all passings here as soon as we have information and welcome you to share with us. We hope this is a place where we can honestly discuss everything regarding death, fear of death, the grieving process, and any other issues you might wish to delve more deeply into. It is tough to address these issues in the larger groups, but we hope having a smaller, central location to do so will help us all.

Gastroparesis Support Group for Tubies & TPN

(<https://www.facebook.com/groups/GPTubiesandTPN/>): This group is for those living with Gastroparesis whose nutrition is provided via tube feedings or TPN. We welcome you to share your stories, experiences, tips, and concerns in the hope of helping all those in similar circumstances.

Gastroparesis Seniors Group

(<https://www.facebook.com/groups/GPSeniors/>): This group is for those 50 years of age and older who live with Gastroparesis.

Gastroparesis: Beautiful You

(<https://www.facebook.com/groups/GPBeauty/>): This group is for those living with Gastroparesis who still wish to feel beautiful inside and out. We will discuss and offer tips for skin and hair care, dental care, makeup, clothing, self-esteem, self-worth, and all other issues which affect your inner and outer beauty. Note: This is NOT a place to offer or sell products.

Chronic Illness Gamers Unite

(<https://www.facebook.com/groups/GPSupportGamers/>): This is a group that seeks to unite online gamers who have a chronic illness. We are here to have fun and make new friends!

Gastroparesis: A Positive Fight

(<https://www.facebook.com/groups/GPSupportGroupPositiveFight/>): This group is a positive, drama-free, safe place for all those living with or in some way affected by Gastroparesis. Our focus is on finding the bright spots in a sometimes dark world, working toward solutions, and supporting each other in uplifting ways as we navigate this illness.

Gastroparesis: The Men's Room

(<https://www.facebook.com/groups/gpmensroom/>): This group is for men who are living with Gastroparesis.

We also have an advocacy group, **Gastroparesis: Fighting for Change**, available to you at <https://www.facebook.com/groups/GPMarch/>. The description is as follows: “This group seeks to unite those with gastroparesis and other digestive/motility disorders to work for change. It is not a typical GP support group, as we do not discuss personal medical issues; rather, it was established as a place where we can discuss ideas regarding our mission, vision, goals, needs, services, and resources and work toward solutions. If you want to make a difference for our GP community, share your ideas, fight for change in legislation, help raise funds, and/or spread awareness, please join us! We would love to have you!”

Gastroparesis: Fighting for Change also maintains a community page at <https://www.facebook.com/GastroparesisFighting4Change/> and a website at www.curegp.org as well as groups for each state. You can find your particular state group by doing a Facebook search for “Gastroparesis: Fighting for Change in (Name of Your State)” or by visiting our “Resources” web page at <https://curegp.org/resources/>.

In addition to our set of groups (above), there are many other Gastroparesis groups in our community you might enjoy. Please see the links below for additional information.

General

<https://www.facebook.com/groups/GastroparesisSupportGroup/>

<https://www.facebook.com/groups/GPSupportGroupPositiveFight/>

<https://www.facebook.com/groups/Gastropeoplehelping/>

<https://www.facebook.com/groups/GPACT/>

<https://www.facebook.com/groups/rkh78gastrodaybyday/>

<https://www.facebook.com/groups/the paralyzed stomach group/>

<https://www.facebook.com/groups/GastroparesisSupportVentingCorner/>

Advocacy

<https://www.facebook.com/groups/GPMarch> (Gastroparesis: Fighting for Change)

<https://www.facebook.com/GastroparesisFighting4Change/> (GFFC Community Page)

www.curegp.org (Gastroparesis: Fighting for Change website)

<https://curegp.org/resources/> (GFFC State Advocacy Group List)

<https://www.facebook.com/helpnicole/> (Nicole's Hope)

<https://www.facebook.com/GastroparesisGraphics/> (Gastroparesis Graphics)

<https://www.facebook.com/groups/545456308959231/> (Weston's World)

<https://www.facebook.com/groups/246652919607945/> (TAG – Texas)

<https://curegp.org/legislation/> (Legislative Updates)

Posting Fundraisers/Solicitation/Personal Appeals

<https://www.facebook.com/groups/GPSupportGroupCommunityInfoPage>

<https://www.facebook.com/groups/690069241017050/>

Prayer Groups

<https://www.facebook.com/groups/GastroparesisSupport4Christians/>

<https://www.facebook.com/groups/DTPrayers/>

<https://www.facebook.com/groups/354738731338929/>

Teens, Children, & Young Adults

<https://www.facebook.com/groups/GPSupport4TeensAndYoungAdults> (Teens & Young Adults to Age 26)

<https://www.facebook.com/groups/GutsyTeenLounge/> (Teens)

GP & Related Conditions

<https://www.facebook.com/groups/GPSupportGroup4DiabeticGastroparesis/> (Diabetes)

<https://www.facebook.com/groups/gpanddiabetes/> (Diabetes)

<https://www.facebook.com/groups/76026339528/> (Achalasia)

<https://www.facebook.com/groups/1502494416657717/> (IVs, Ports, & PICCS)

<https://www.facebook.com/groups/painipedia/> (Chronic Pain)

<https://www.facebook.com/groups/337279919988846/> (EDS, POTS, & GP)

<https://www.facebook.com/groups/598876153485778/> (EDS, POTS, Chiari, MCAD)

<https://www.facebook.com/groups/1520089144930779/> (POTS)

<https://www.facebook.com/groups/hypoparalodge/> (Hypoparathyroidism)

<https://www.facebook.com/groups/GPTubiesandTPN/> (Tubies/TPN)

<https://www.facebook.com/groups/532377730222400/> (Pregnancy)

Diet and Nutrition

<https://www.facebook.com/groups/GPSupportGroupRecipes/>

<https://www.facebook.com/groups/320843258119944/>

<https://www.facebook.com/VitamixCommunity/>

<https://www.facebook.com/groups/304065876600934/> (Vegan Approach to GP)

<https://www.facebook.com/groups/108988359208122/>

Disability

<https://www.facebook.com/groups/657618414335098/>

<https://www.facebook.com/groups/2000725450173418/>

Pen Pals, Gift/Card Exchanges

<https://www.facebook.com/groups/GastroparesisHome4Holidays/>

<https://www.facebook.com/groups/1383291288664709/>

<https://www.facebook.com/groups/2436340119920530/>

Parents, Spouses, Caregivers, and/or Other Loved Ones

<https://www.facebook.com/groups/GPSupport4LovedOnes/> (Loved Ones)

<https://www.facebook.com/groups/GPSupportGroup4ParentsAndChildren/> (Parents & Children)

<https://www.facebook.com/groups/KidBits/> (Parents & Children)

Medical Supplies

<https://www.facebook.com/groups/MedicalSupplyExchange>

<https://www.facebook.com/groups/GPACTSupplyDepot/>

<https://www.facebook.com/groups/specialneedsexchange>

<https://www.facebook.com/groups/401702433344733/>

<https://www.facebook.com/groups/109222116081061/>

Other Interests

<https://www.facebook.com/groups/GPGriefAndMemorialGroup/> (Grief/Memorial for GP)

<https://www.facebook.com/groups/EDSGPinmemoriam/> (Grief/Memorial)

<https://www.facebook.com/groups/197419897280748/> (Grief/Memorial for IBD & Crohn's)

<https://www.facebook.com/groups/GPHospAndPallCare/> (Hospice & Palliative Care)

<https://www.facebook.com/groups/GPSupportGroupBooksAndHobbies/> (Hobbies & Books)

<https://www.facebook.com/groups/500155120327428/> (Crafts)

<https://www.facebook.com/groups/GPSupportGroup4Gainers/> (GPer's Who Gain Weight)

<https://www.facebook.com/groups/WorkingWithGP/> (GP & Employment Issues)

<https://www.facebook.com/groups/GPSupportGroupCommunityInfoPage/> (Blogs & Links)

<https://www.facebook.com/groups/GpAtheistsAgnostics/> (Atheists and Agnostics)

<https://www.facebook.com/groups/GPBeauty/> (Beauty and Body Image)

<https://www.facebook.com/groups/GPSeniors/> (Seniors – 50+)

<https://www.facebook.com/groups/598012270739313/> (Humor)

<https://www.facebook.com/groups/267669440442461/> (Humor)

Groups Outside the US

<https://www.facebook.com/groups/1651708898415716/> (UK)

<https://www.facebook.com/groups/GPACTUK/> (UK)

<https://www.facebook.com/groups/678429378932145/> (UK)

<https://www.facebook.com/groups/TheInsideStoryAU/> (Australia)

<https://www.facebook.com/groups/gastroparesisdownunder/> (Australia & New Zealand)

<https://www.facebook.com/groups/gastroparesiscanada/> (Canada)

<https://www.facebook.com/groups/GPACTCanada/> (Canada)

AUSTRALIAN RESOURCES

Melissa Adams VanHouten

Public Health Association Australia

Description from web site: “The Public Health Association of Australia Incorporated (PHAA) is recognised as the principal non-government organisation for public health in Australia and works to promote the health and well-being of all Australians. The Association seeks better population health outcomes based on prevention, the social determinants of health and equity principles.”

Link: <https://www.phaa.net.au/>

The Gut Foundation

Description from web site: “The Gut Foundation specialises in medical research to understand the causes of gut problems, better methods of prevention and treatment, and continually educating the public on the latest findings.”

Link: <http://www.gutfoundation.com.au/>

Western Sydney University GI Motility Disorders Unit

Description from web site: “The research mission statement of the Gut Motility Network is to ‘advance the field of understanding and treatment of gastrointestinal motility disorders through basic and clinical scientific research beginning with the people of Greater Western Sydney’... This website is part of our engagement strategy to connect to patients and their families as well as disseminate to the broader community relevant information about gastrointestinal motility and functional disorders.”

Link: <https://www.westernsydney.edu.au/gimotility/home>

The Public Health Advocacy Institute of Western Australia

Description from web site: “PHAIWA was established in April 2008. PHAIWA is an independent public health voice based within Curtin University, with a range of funding partners. The institute aims to raise the public profile and understanding of public health, develop local networks and create a statewide umbrella organisation capable of influencing public health policy and political agendas. PHAIWA focuses on a number of areas of public health advocacy activity. These range from providing general advocacy processes for public health, conducting advocacy related research and project, building capacity within the public health workforce for more effective advocacy lobbying and communicating through our partners and the media.”

Link: <http://www.phaiwa.org.au/>

Support Groups

<https://www.facebook.com/groups/gastroparesisdownunder/> (Australia & New Zealand)

<https://www.facebook.com/groups/TheInsideStoryAU/> (Australia)



CANADIAN RESOURCES

Melissa Adams VanHouten

GI Society: Canadian Society of Intestinal Research

Description from web site: The GI Society is “committed to improving the lives of people with GI and liver conditions, supporting research, advocating for appropriate patient access to health care, and promoting gastrointestinal and liver health.”

Link: <http://www.badgut.org/>

Canadian Health Coalition

Description from web site: “The Canadian Health Coalition is a public advocacy organization dedicated to the preservation and improvement of Medicare. Our membership is comprised of national organizations representing nurses, health care workers, seniors, churches, anti-poverty groups, women and trade unions, as well as affiliated coalitions in 9 provinces and one territory.”

Link: <http://healthcoalition.ca/main/about-us/>

Health Charities Coalition of Canada

Description from web site: “HCCC, a member based organization, is dedicated to advocating for sound public policy on health issues and promoting the highest quality health research. HCCC strives for excellence in health policy and seeks to ensure that the federal government and policy makers look to the Coalition and its members for timely advice and leadership on major health issues of concern to Canadians; and that they recognize the competence, commitment and contributions of health charities in improving the health and well-being of Canadians.”

Link: <http://www.healthcharities.ca/>

Canadian Digestive Health Foundation

Description from web site: The mission of the CDHF is to “reduce suffering and improve quality of life by providing trusted, accessible, and accurate information about digestive health and disease,” and it aims to “empower all Canadians to manage their digestive health with confidence and optimism.” Their site further states: “Because we are directly connected to Canada’s leading digestive health experts, physicians, scientists and other health care professionals, you can trust us to provide you with practical, science-based information that is up to date and unbiased.”

Link: <http://www.cdhf.ca/>

Public Health Agency of Canada

Description from Web Site: “The Public Health Agency of Canada empowers Canadians to improve their health. In partnership with others, its activities focus on preventing disease and injuries, promoting good physical and mental health, and providing information to support informed decision making. It values scientific excellence and provides national leadership in response to public health threats.”

Link: <http://www.phac-aspc.gc.ca/index-eng.php>

Support Groups

<https://www.facebook.com/groups/GPACTCanada/>

<https://www.facebook.com/groups/gastroparesiscanada/>



UNITED KINGDOM RESOURCES

Melissa Adams VanHouten

National Health Service (NHS)

Description from Web Site: The NHS is the UK's collective health service system. Their website states: "We believe it's important that people engage with their health, care and wellbeing so they can stay healthy and help manage any long-term health conditions. We provide thousands of clinically validated articles, videos and tools... When people need help, our clinically safe, accessible and effective digital content aims to prompt them to take the right action at the right time."

Links: <https://www.nhs.uk/> and <https://www.nhs.uk/conditions/gastroparesis/>

Gastroparesis and Intestinal Failure Trust (GIFT)

Description from Web Site: GIFT is "a UK Charity group, focusing on patient support and fundraising for research... We aim to provide reliable information and resources to all our members. We write from the heart and tell our own personal stories. We want the world to know what it's really like to live with Gastroparesis, to help others know they are not alone. In hope of changing some of the common misconceptions in health care today."

Link: <https://www.giftuksupport.org/>

National Institute for Health and Care Excellence (NICE)

Description from Web Site: NICE "provides national guidance and advice to improve health and social care... NICE's role is to improve outcomes for people using the NHS and other public health and social care services. We do this by producing evidence-based guidance and advice for health, public health and social care practitioners, developing quality standards and performance metrics for those providing and commissioning health, public health and social care services, (and) providing a range of information services for commissioners, practitioners and managers across health and social care.

Links: <https://www.nice.org.uk/> and <https://www.nice.org.uk/search?q=gastroparesis>

Support Groups

<https://www.facebook.com/groups/1651708898415716/>

<https://www.facebook.com/groups/GPACTUK/>

<https://www.facebook.com/groups/678429378932145/>

SOURCES FOR HELP IN SUICIDE PREVENTION

- US/Canada Suicide Prevention Hotline: 1-800-273-TALK (8255) or 988
- US Crisis Text Line: Text 741741 or 988
- UK/Ireland (List of hotlines): <http://www.suicide.org/hotlines/international/united-kingdom-suicide-hotlines.html>
- Australia: <https://www.lifeline.org.au/> and Kids Helpline Australia: <https://kidshelpline.com.au/>
- You can view a list of suicide prevention hotlines in other countries at <http://www.suicide.org/international-suicide-hotlines.html> and <http://www.befrienders.org/> and <https://www.facebook.com/help/103883219702654/?ref=cr>
- Additional information provided by Facebook can be found at <https://www.facebook.com/help/594991777257121/#resources> and https://www.facebook.com/emotional_health
- You can directly report a suicide threat on Facebook at <https://www.facebook.com/help/contact/305410456169423>.



Overcoming

People seem to think there is some magic point at which you "overcome" an illness. But it does not work like that. Every day is an "overcoming," and some days probably look like losses to the outside world, which knows nothing of the never-ceasing struggle surrounding chronic illness.

Days are better or worse but never perfect, never even normal. Your past life is gone and the fight to accept that is constant, never-ending, moment by moment. You manage to cope better some moments than others, and there are setbacks and steps forward along the way, but the path is never smooth or stumbling block-free.

Perhaps the best you can do is start anew each day and strive to make the best life possible, a new life, lived in each instant, focused on the small, beautiful moments, a forward-and-back dance. Cherish the good, cling tight to the joy, and embrace the still, small voice which encourages you to push on, despite the hardships, in the hope that you will indeed unceasingly "overcome."

Melissa Adams Van Heuten