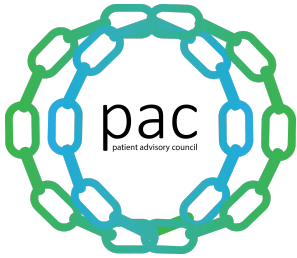


Patient Advisory Council

Nutrition Toolkit

In this resource you will find PAC member stories about using nutritional therapies, including TPN, special diets, nutritional drinks, NG tubes, and tube feeding, as well as reflections about working with nutrition experts as part of IBD treatment and management.





Disclaimer

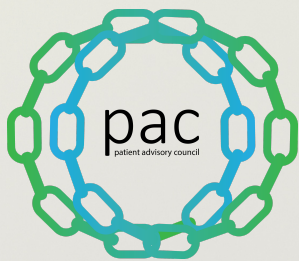
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apply to this document.

About the PAC

The Patient Advisory Council (PAC), is a community of young (14+) patients with Inflammatory Bowel Disease (IBD) who come together to give and receive support, ask questions, share information, and network with each other. For more information, and to join the PAC, please visit: improvecarenow.org/patients

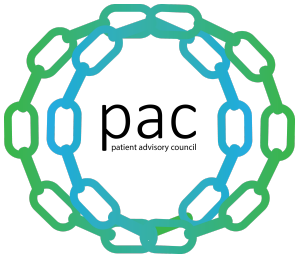




Working with a Nutrition Expert

IBD Nutrition therapy
from the patient and
provider perspective



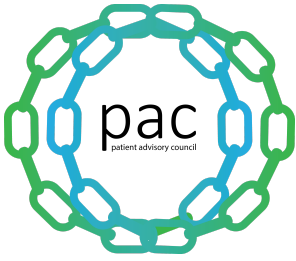


Working with a Nutrition Expert



A **nutritionist** is an expert in the use of food and nutrition to promote health and manage diseases.

A **Registered Dietitian (RD)** is a trained nutrition professional who has met the strict educational and experiential standards set forth by the Commission on Dietetic Registration for the Academy of Nutrition and Dietetics.



Q: What do you enjoy about being an IBD Nutrition expert?

"Working with children and their families to help them modify diet to feel their best and being part of an amazing interdisciplinary team." -**Elizabeth Rogers**, MS, RD, CNSC

"Seeing the positive impact we can make in their **quality of life**." -**Teresa Lee**, MS, RD, LD

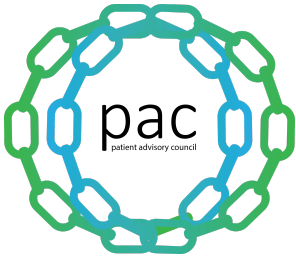
"I enjoy helping children and teens adjust their diets so they can improve their quality of life and disease symptoms." -**Greta Breskin**, MS, RDN, LDN

Q: What is unique about working with IBD patients?

"[IBD] Patients are often already very **in tune with how what they eat affects their body**." -**Greta Breskin**, MS, RDN, LDN

"Educating families on the many important roles of nutrition with IBD. These **patients are truly an inspiration** and often come to a nutrition appointment following a restricted diet or unsure of what foods to avoid or consume. I love helping IBD patients try new foods and help them gain weight. It is rewarding to see our patients at multiple visits and hear them tell me that they feel strong enough to participate in the things they love to do!" -**Natalie Stoner**, RD, CSP, LDN

inspire



Using Nutritional Therapy as a Treatment for IBD

Benefits

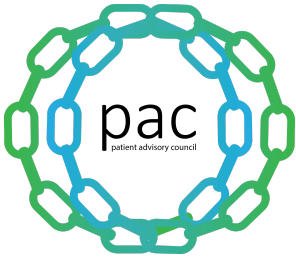
"Nutritional rehabilitation, some families prefer nutritional therapy vs. medication or biologic use, that **supports linear growth**, improves bone health, and decreases symptoms." -**Natalie Stoner**, RD, CSP, LDN

"**Reduced reliance on medications** and **ownership** of disease management." -**Teresa Lee**, MS, RD, LD

Challenges

"Not eating solids (or being able to chew), as well as refusing NG tube feedings, or not being able to drink enough formula." -**Kay Mullin**, RD, LE, CDE

"Compliance and the insurance coverage/cost of formula for EEN." -**Greta Breskin**, MS, RDN, LDN



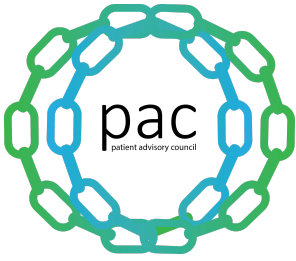
Relationship Between Overall IBD Health and Nutrition

Nutrition plays a large role in the treatment of IBD. A well balanced diet provides essential vitamins/minerals, as well as adequate calories and protein. Good nutrition can decrease IBD symptoms, improve linear growth, provide good bone health, and provide the body with vitamins and minerals.

Natalie Stoner, RD, CSP, LDN

I believe that nutrition is the vital piece of the puzzle to achieving and maintaining remission in IBD. I think the mistake that is often made is to think that it is the entire puzzle or that it is too small of a piece.

Elizabeth Rogers, MS, RD, CNSC

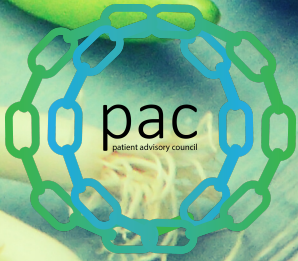


Key Takeaways When Considering Nutrition Therapy to Treat and Manage IBD

Just like medication and lifestyle, nutrition is an important part in maintaining your IBD health.

Remember:

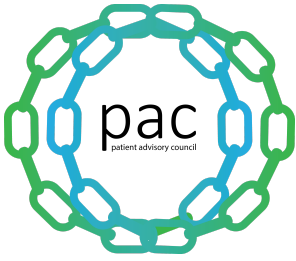
- It really depends on your condition, current medications, and lifestyle to determine the best nutritional therapies for you.
- Talking with a **nutrition expert** can be helpful to learn more about how nutrition can play a role in your IBD health, as well as get recommendations that may help you.
- Weighing the **pros and cons** can be useful when making decisions about diet changes to treat your IBD.



Dietary Interventions

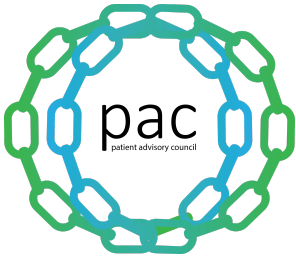
Overview and patient experiences

Dietary Interventions can include Special or Therapeutic diets. These interventions help control the intake of certain foods or nutrients thought to be impactful to IBD.



Special and Therapeutic Diets: Overview

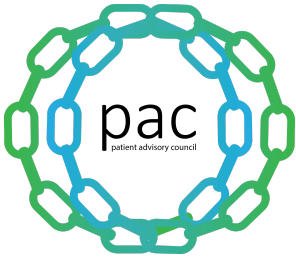
- **AIP:** Autoimmune Protocol (AIP) diet focuses on an **initial elimination phase of food groups** including grains, legumes, dairy, eggs, coffee, alcohol, nuts and seeds, refined/processed sugars, oils, and food additives. It also emphasizes consumption and preparation of fresh, nutrient dense foods, bone broth, and fermented foods. The elimination phase is followed by a **maintenance phase until measurable improvement in symptoms** and overall well-being is achieved. **Staged reintroduction** of food groups is then initiated gradually, as patients identify unique foods or food groups that may contribute to symptoms while liberalizing their diet (Konijeti et al., 2017).
- **SCD:** Specific carbohydrate diet (SCD) is a nutritionally balanced diet **low in carbohydrates and processed foods**. The diet focuses on natural, nutrient-rich foods including vegetables, fruits, meats and nuts. People on the diet can still have breads and pastries but ingredients are shifted from grain flours to nut flours such as almond flour and coconut flour.
- **IBD-AID:** The anti-inflammatory diet (AID) is a nutritional regimen for IBD that restricts the intake of certain carbohydrates, includes the ingestion of pre- and probiotic foods, and modifies dietary fatty acids to demonstrate the potential of an adjunct dietary therapy for the treatment of IBD (Olendzki et al., 2014).



Special and Therapeutic Diets: Overview

- **EEN:** Exclusive enteral nutrition (EEN) involves treating patients solely with a **liquid diet** orally or through a tube feeding, using a specialized formula to treat IBD.
- **Dairy Free:** A dairy-free diet is one that omits milk and all related products. Products that contain casein and whey proteins are also excluded.
- **Gluten Free:** A gluten-free diet excludes the protein gluten. Gluten is found in grains such as wheat, barley, rye, and a cross between wheat and rye called triticale.





Common Special Diets Used by PAC Members

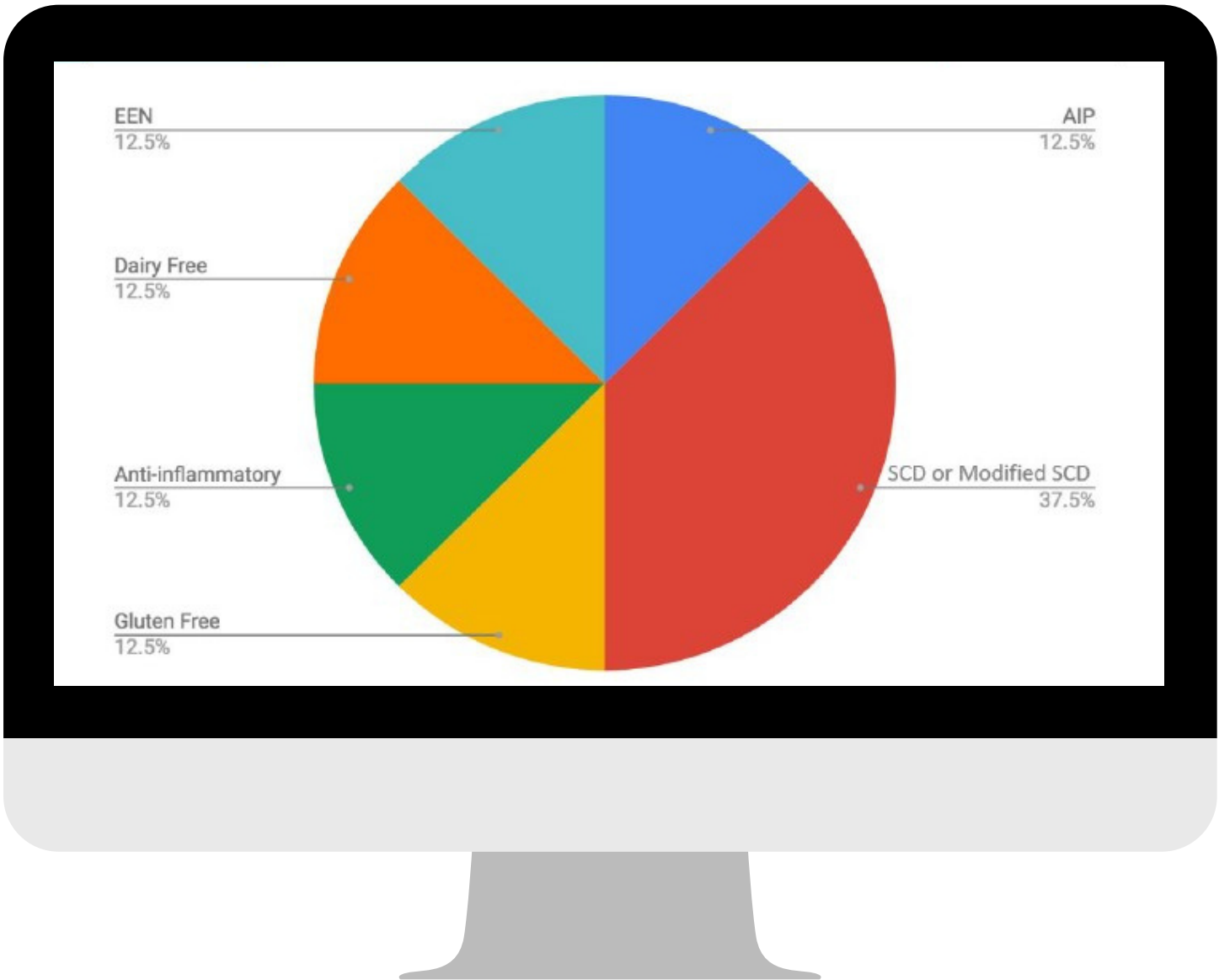
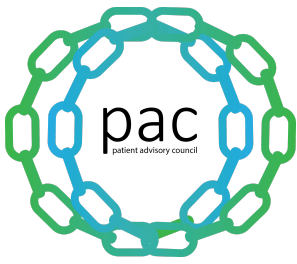


Figure 1. Percentages of patients using specific diets. Represents the percentages of PAC members surveyed that have used these diets at any point in their IBD journey.



Pros of Dietary Interventions

"I liked that it **challenged me to learn more about nutrition** and how food is so vital to healing." -**Maha**

"I liked that I didn't have to deal with additional medication side effects. In the past, every time I started a new medication or upped the dosage I had lots of frustrating experiences. Being on strict diets did **help my symptoms** in cases and stopped my IBD flares from getting worse." -**Rosa**

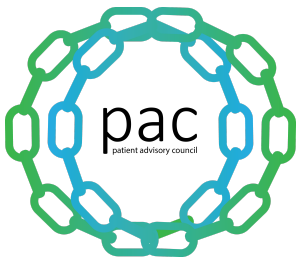
"I felt much better throughout the day after eating I wouldn't feel sick or be in the bathroom... less bloating." -**Natalie**

"I loved the fact that I was able to use diet as my primary treatment. I have never had to use a steroid because of nutritional treatment." -**Maddie**

Challenges with Dietary Interventions

"Dietary interventions **take time and commitment** to be successful. The SCD requires dedication. Staying on a diet carefully, as well as setting aside time for food preparation are important." -**Maddie**

"Being on an extremely restricted diet was really difficult for me since a lot of **social activities revolve around food**. It was also challenging to not eat any ready-made or packaged food. I found it difficult to get enough calories/ maintain a healthy weight while on some of the diets, and **cost was prohibitive** in many cases." -**Rosa**



Impact of Dietary Interventions on IBD

"Dietary intervention has worked wonderfully for my body! The times my health has been the best since my diagnosis has been while managing by IBD using diet." -**Maddie**

"My daily symptoms have improved to less cramping, pain, and bloating." -**Natalie**

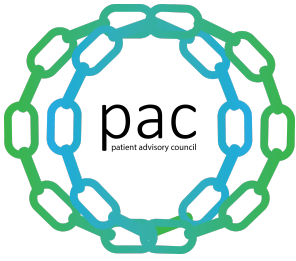
"It seems to be working! Combined with my Remicade treatments, I think it's helping me heal from the damage that was done to my intestines." -**Maha**

Advice for Starting a Dietary Intervention

"Learn the best brand for vegan cheese/ milk! Also learn how many things actually have dairy in it! **Reading labels!**" -**Natalie**

"It makes a huge difference to have **others supporting your diet plans**, whether they are able to help you plan, cook, buy food, or just offer encouragement. Don't go anywhere without snacks!" -**Rosa**

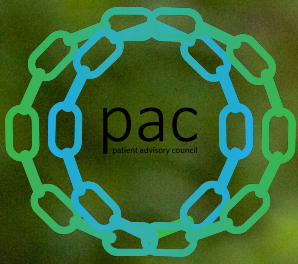
"Find creative ways to engage what you are allowed to eat! I find that making my food exciting allows following a strict diet to be fun. Getting into the kitchen to learn more about your food can make it more enjoyable to consume it. Relationship with our nourishment can be so important and life giving!" -**Maddie**



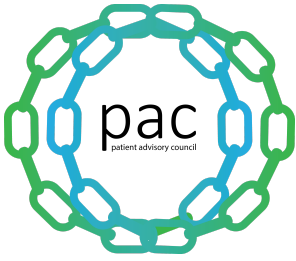
Key Takeaways for Dietary Interventions

- Special or Therapeutic diets may be useful for some patients in maintaining their IBD
- Doing research and learning more about the different things that may trigger your IBD can be very useful.
- Don't give up, even it takes a while to find the foods or special diets that work for you. You are moving towards health!
- Engage friends and family in your journey with nutrition so you don't feel alone.





Nutritional Drinks



Supplemental Nutrition Drinks

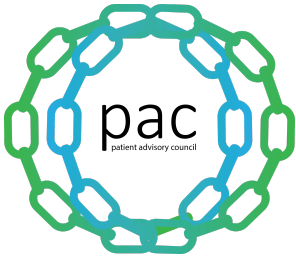
Supplemental nutrition drinks can provide a healthy balance of protein, carbohydrate, and fat. There are countless varieties of supplements that fall into two general categories:

Shakes such as Pediasure or Boost Kids Essentials, are intended for oral consumption and are formulated to help meet general nutrition goals.

Formulas are designed for more specific disease states. They CAN be consumed orally, but are not designed to taste good. They are frequently used in feeding tubes, requiring doctor supervision.



Figure 2. Percentages of patients using nutrition drinks. Represents the percentages of PAC members surveyed that have used these nutrition drinks at any point in their IBD journey.



Common Reasons for Use of Nutritional Drinks

- ❖ Underweight
- ❖ Medications are no longer working
- ❖ Needing extra calories
- ❖ Avoid steroids
- ❖ Manage a flare
- ❖ Malabsorption problems



Pros of Nutritional Drinks

"It saved me from further treatments and pain so I owe a lot to Pediasure." - **Maha**

"My body tolerated Exclusive Enteral Nutrition (EEN) well following my diagnosis and I was able to achieve **remission** without the use of a steroid." - **Maddie**

"[Nutritional drinks] didn't involve much preparation to do and also didn't look weird. It was generally pretty **easy** to do." - **Becky**

Challenges with Nutritional Drinks

"It was hard to find dairy free ones (nutrition drinks)." - **Natalie**

"I was very picky as a child and **did not like the flavors** of any of them. I also had to force myself to drink them since I was often not hungry for them." - **Becky**

"Formula can be boring at times, and it can feel lonely to have to consume it while others enjoy solid food. **Treatment compliance** can be hard to maintain." - **Maddie**



Impact of Nutritional Drinks on IBD

"Helped me maintain weight and keep hydrated." -**Natalie**

"It helped using [nutritional drinks] exclusively so I could give my **bowel rest**." -**Maha**

"It helped me **gain some weight** and height and I felt less tired." -**Becky**

"The first time I used Exclusive Enteral Nutrition (EEN), it worked well as a treatment for my IBD. I achieved **remission** without the use of a steroid and maintained remission using dietary therapy as my primary treatment for several years." -**Maddie**



Advice for Using Nutritional Drinks

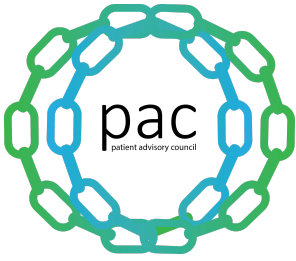
"I really recommend it. It's an easy-to-do therapy and doesn't make people stare since it's a normal activity." -**Becky**

"Highly recommended, because they allow you to go on with your daily routines. Just make sure you use some trial and error to find the flavors you like!" -**Missy**

"**Find the flavors you like the best** and make sure to +keep the drinks cold!" -**Natalie**

"Add a bit of **honey** (a little goes a long way). It will drown out that artificial taste!" -**Maha**

"You are so brave for doing this! Remember that it's just temporary and you will get through it. I found making my formula exciting helped a lot! Try freezing it into **popsicles** or heating it up to drink warm." -**Maddie**

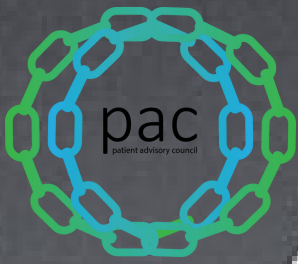


Key Takeaways for Nutritional Drinks

Nutrition drinks may be useful for some patients in maintaining their IBD

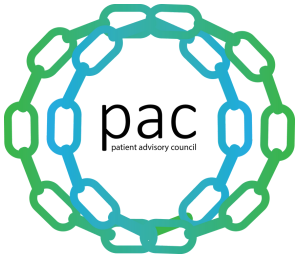
- ❖ Doing research and learning more about the different things that may trigger your IBD can be very useful.
- ❖ Experimenting can be fun, because you may find things that you never knew that you liked!
- ❖ Don't give up, even it takes a while to find the nutritional drinks that work for you. You are moving towards health!
- ❖ Engage friends and family in your journey with nutrition so you don't feel alone.





Enteral Nutrition

Tube Feeding



Tube Feeding

Tube feeding is a way of getting your body the nutrition it needs through a liquid formula via a flexible tube. The nutrients within the tube feeding formula are similar to what you would get from normal food, and are digested in the same way.

A nasogastric (NG) tube is a special tube that carries food and medicine to the stomach through the nose. It can be used for all or supplemental feedings to help meet a person's nutritional needs.

Tube Feeding Duration Experience of PAC Members

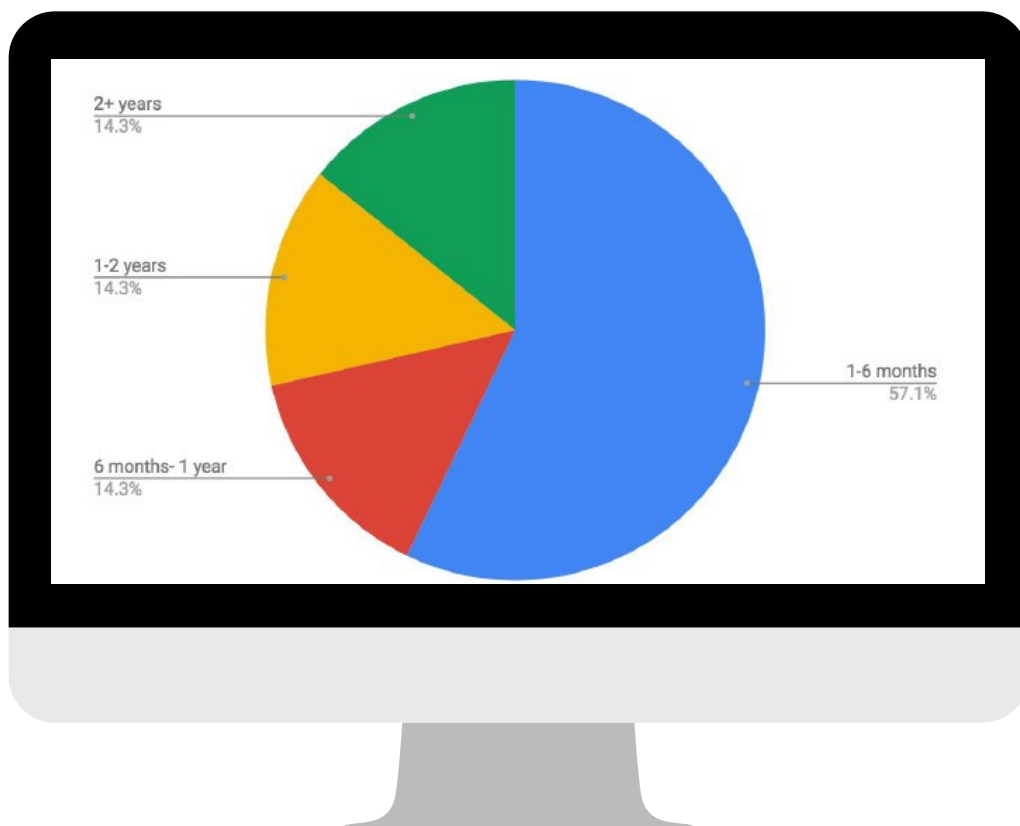
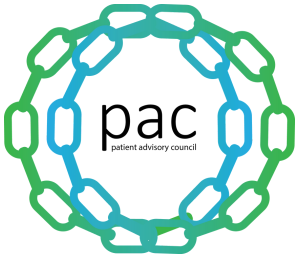


Figure 3. Percentages of patients using NG tubes. Represents the percentages of PAC members surveyed that have used NG tubes at any point in their IBD journey.



Common Reasons for Tube Feeding

- ❖ Underweight
- ❖ Avoid Steroids
- ❖ Flare management
- ❖ Lack of Appetite
- ❖ Malnutrition
- ❖ Infections
- ❖ Bowel rest
- ❖ Achieve remission

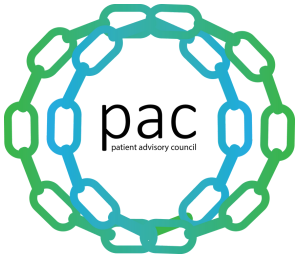


Experiences with NG Tube Feeding

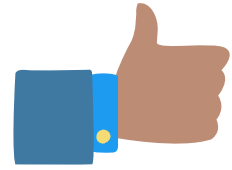
"I went to [the hospital] where the doctors showed me how to put down the NG tube on a big teddy bear. Then they put one down for me so I could get used to the feel on the car ride home. It did hurt a little, but I find it doesn't hurt if you do it yourself, since you can feel how to guide it." -**Becky**

"It wasn't the most pleasant to get it put in. Takes a little while to get used to how it feels when you swallow or sniff and how it feels laying against your face." -**Natalie**

"The first time I used an NG tube was when I was hospitalized for NG tube training. I was both excited and nervous about the idea of tube feeds. I didn't know what to expect, but the idea of feeling better was really motivating. I was determined to place my own tube, and was not anticipating how uncomfortable it would be in the beginning. The first night was definitely hard, as I was not used to the tube. However, within several days, I was placing my NG tube easily, and I no longer noticed it when I pumped formula through the night." -**Maddie**



Pros of NG Tube Feeding



"It was the only thing that allowed me to attain a normal height and weight."

-**Becky**

"It helped me get through the fecal impaction without surgery." -**Natalie**

"It wasn't intrusive on my life, since I could infuse overnight. I wasn't worried that my friends would see it or that I would be embarrassed." -

Missy

"Using Exclusive Enteral Nutrition (EEN) with NG tube feeds, I was able to induce remission following my diagnosis, without the use of a steroid." -**Maddie**

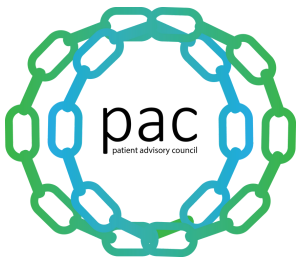
Challenges with NG Tube Feeding

It is time consuming to prepare and do and it made sleepovers more complicated. I've also had an increased amount of nosebleeds." -**Becky**

"Placing a tube every night did become tiring at times and it was not always super comfortable to sleep with it in. Using Exclusive Enteral Nutrition (EEN) can be **lonely** at times as well; while other people can enjoy solid food, being limited to only formula can be sad." -**Maddie**

"Learning how to put the tube in was psychologically hard for me, since I was so afraid that it was going to hurt. I eventually got over that but I often worried that I wouldn't be able to put my tube in, so it took a lot of time." -

Missy



Impact of NG Tube Feeding on IBD

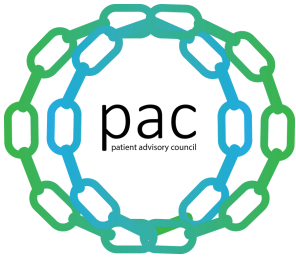
"It definitely saved me from further invasive treatments and procedures and from lots of future problems and pain." - **Maha**

"I used Exclusive Enteral Nutrition (EEN) by NG tube feeds as my induction phase treatment and achieved remission without the use of a steroid." - **Maddie**

"It didn't put me in remission, but is allowed me to become a normal weight for the first time in my life." - **Becky**

"It helped tremendously because it released my impaction before I perforated or needed surgery." - **Natalie**





Advice for Patients Starting NG Tube Feedings

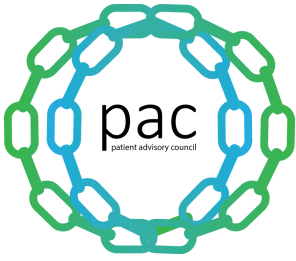
"Drink something and have someone hold down your hands during insertion. Maybe suggest how you want it taped to face." -**Natalie**

"Trust me, it's not as hard as it looks. The best thing you can do for yourself is to know what's happening. **Watch your parents set up the tube** or do it yourself if possible. I find that it's much more comfortable to place the tube yourself since you can best feel how to guide it down. Also, I recommend doing the feeding when and **where you feel comfortable**. Don't keep the tube in during the day if you don't want to. And don't feel embarrassed if you decide to keep it in during the day." -**Becky**

"Start out by breathing. I was very negative about the whole experience and it really impacted my mental health. Once I found a new perspective, I actually loved using NG Tubes because they made me feel so good. I also loved showing my friends how it worked, because it made me feel more confident." -**Missy**

"Try giving your IV pole or NG tube a **funny name**. Sometimes **decorating** your pole helps too! Also, make sure to find a tube that fits best with your body and tapes that are soft enough for your face." -**Maddie**

"1. Stay strong, you are a fighter and you'll get through this.
2. Make sure you have a good support system in place because you'll need them!
3. Don't be afraid to share your story, people might be interested and more kind than you think (I know they were to me, and there were definitely people who were interested in hearing my story, which I didn't expect at all!)
4. Also, don't be afraid to dress up with your tube, because it will help you feel more confident and like yourself! All in all, you will come out of this a stronger and more resilient person!" -**Maha**



Key Takeaways About Tube Feedings

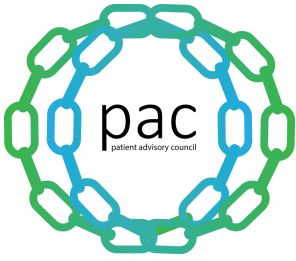
NG tube feedings may be a useful therapy for some IBD patients in maintaining their IBD

- ❖ Learning about the process and how it works may help you feel more at ease before you start using NG tubes.
- ❖ Focusing on the things NG tube feedings allow you to do or the things you are allowed to eat can be really helpful when you miss the stuff you cannot eat.
- ❖ Find support from family and friends when it is hard to manage and talk about ways you can feel better about tube feedings.



Total Parenteral Nutrition (TPN)

TPN is a way for one to receive their nutritional needs by infusing a specialized form of food through a vein (intravenously). The use of TPN allows the bowel to rest when it is severely compromised, while supplying adequate caloric intake and essential nutrients. TPN provides liquid nutrients, including carbohydrates, proteins, fats, vitamins, minerals, and electrolytes.



Pros of TPN

"It was a perfect balance of nutrients and prevented me from needing to lose part of my colon." - **Becky**

"It allowed me the freedom to leave the hospital and be a kid! Without it, I would've been stuck in the hospital for weeks. I am very thankful for TPN." - **Missy**

Challenges with TPN

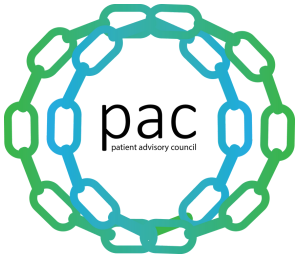
"It [TPN] takes a while to do since it involves preparing the tube and the multiple-hour infusion. I still felt hungry since I wasn't eating by mouth." - **Becky**

"My biggest challenge with TPN was the **body image** issues that came with having to wear the tube and complete an infusion as a child. I never felt like I could go out with my friends because I couldn't eat, which made it very awkward and hard." - **Missy**

Advice for Patients Starting TPN

"It [TPN] seems really hard at first. You can't eat and it's pretty complicated. But you will have help getting through it, from nurses, family, and friends." - **Becky**

"TPN allowed me to rest my gut and get some pain relief. Since I wasn't able to tolerate real food, energy was a big issue. It [TPN] gave me the energy I needed. Focusing on other things that made me happy was really helpful while I wasn't able to eat and when I was off TPN, I was able to continue doing those things!" - **Missy**



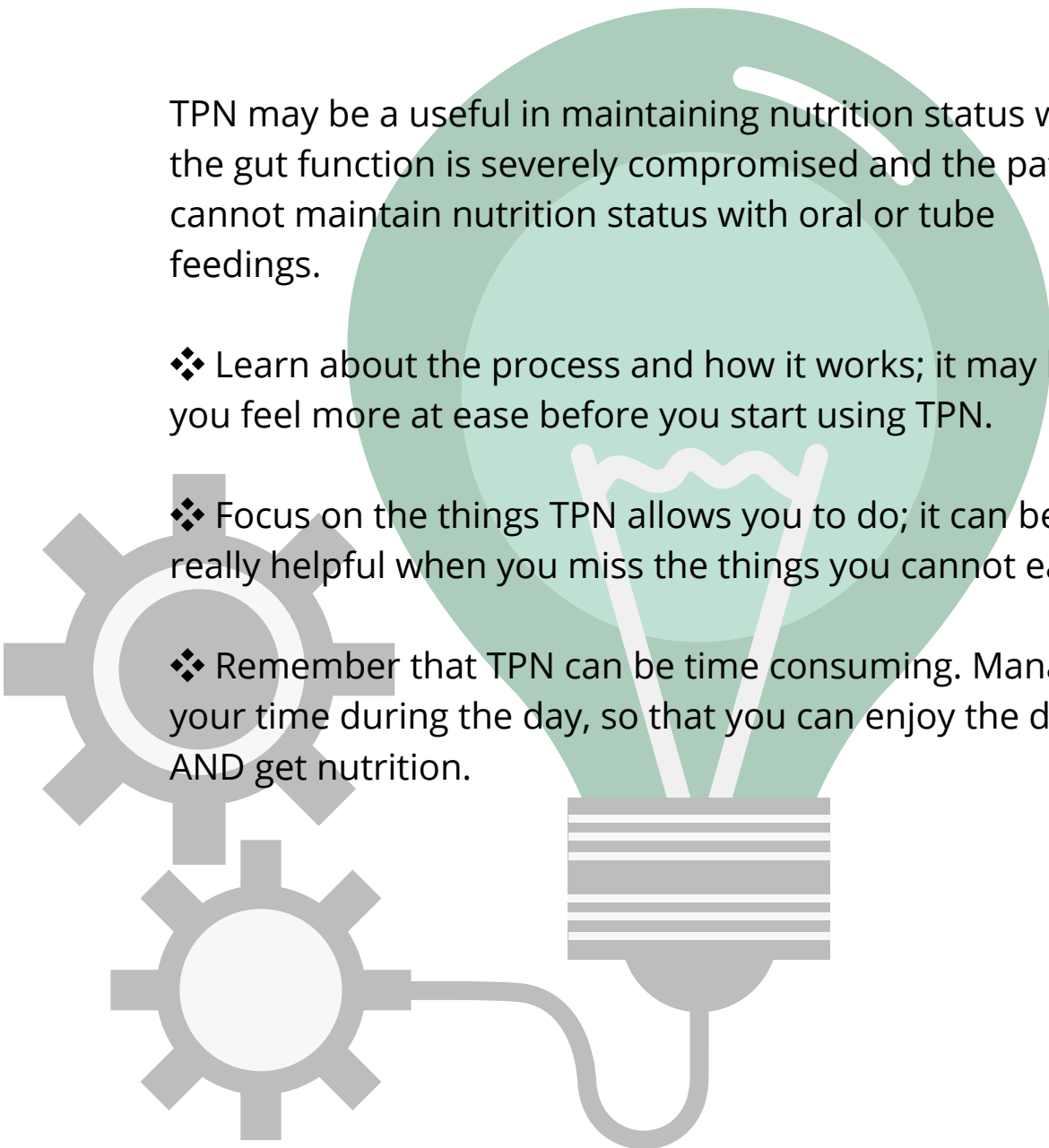
Key Takeaways About TPN

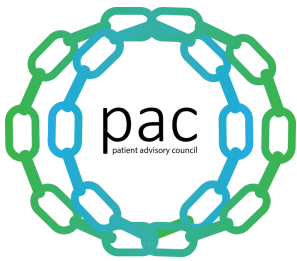
TPN may be a useful in maintaining nutrition status when the gut function is severely compromised and the patient cannot maintain nutrition status with oral or tube feedings.

❖ Learn about the process and how it works; it may help you feel more at ease before you start using TPN.

❖ Focus on the things TPN allows you to do; it can be really helpful when you miss the things you cannot eat.

❖ Remember that TPN can be time consuming. Manage your time during the day, so that you can enjoy the day AND get nutrition.

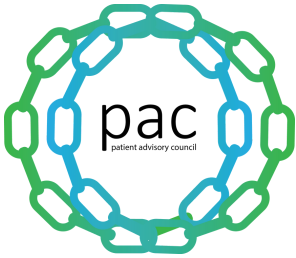




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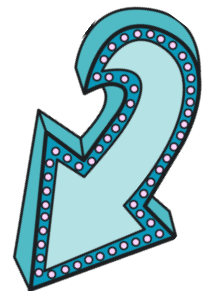
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