Appendix 5A: EEN Handout - Guide for Patients

Guide to Nutritional Therapy for Patients with Inflammatory Bowel Disease (IBD)

Why has nutritional therapy been suggested?

Nutritional therapy is a change of diet which may help get your bowel disease under control. It can also help to improve your growth. Many children and teenagers have used this therapy around the world with great success. The change in diet works to undo the changes in the lining of the bowel. This helps to improve symptoms, such as abdominal pain and diarrhoea. Often the therapy is used without other medicines being needed. Sometime it may be used in combination with other medicines.

What does nutritional therapy involve?

Nutritional therapy involves drinking a special milk type drink instead of eating food. These drinks are often called formula.

The name of your formula is _____________________. This formula provides all of the energy, vitamins and minerals that your body needs. It replaces what you would usually get from food. It looks like milk and tastes slightly sweet like a milkshake.

How much will I need to drink?

You are required to drink _______________ mls of formula per day to meet your body's requirements and to help you reach a healthy weight. Depending on weight gain this volume may need to increase. If this volume does not satisfy your appetite, you can drink more.

Should I drink this amount on the first day?

No! Your body should get used to the volume of fluid slowly. Your dietitian will work with you to decide how much to drink on the first few days. By the third or fourth day you should be drinking the full amount.

How long will I be doing this for? Your Doctor will tell you exactly how long, but usually the best results are seen after 6-8 weeks on the diet.

When should I drink? Your dietitian will discuss a daily drinking routine with you and your family. How much and how often you drink is very individual. It is best to split the volume up into 6 – 10 drinks per day to satisfy your appetite. Some people
like to take small sips every hour or every 2 hours. School and other activities in your life must be considered when designing a plan.

For example, if you needed to drink 1800mls per day: You could have 300mls, 6 times per day: at breakfast, morning tea, lunch, afternoon tea, dinner and supper OR you may choose to drink 180mls, 10 times per day.

What if I can't drink it all? If you find the amount is too much for you to drink or that this diet is becoming too hard for you, we can help you. We can put a tube in your nose that goes into your stomach. This is called a naso-gastric tube. Some of your formula can be given during the night through this tube. This means that you only need to drink what is comfortable during the day. With lots of support from family and the IBD team, we will help you through the difficult early stages.

What will I do at meal times? Family meal times can be hard when everybody else is eating except for you. We suggest to families that that they are very supportive around this time. They can do things like not discussing food and eating in another room. Some families don’t cook their child’s favourite meal until they are able to eat again. This way the family is also missing out on something and can understand what their child is going through. Some people are very happy to sit at the table and drink while their family eats. It does get easier after the first few weeks.

Can I still go to school? Yes you can. Provided you have the energy, you should be able to continue with your normal daily activities. School, sport, hobbies, helping around the house and activities with friends should happen during this time. Parents should talk to your school year adviser or classroom teacher about your nutritional therapy. It needs to be treated with the same importance as taking medicine. The formula should be kept cold. Take it in a cooler bag to school, or arrange for it to be stored in a fridge (usually the staff room of a favourite teacher). Some people take sips during class, others manage well at meal breaks only. You may like to tell your friends about your nutritional therapy so they will understand why you can’t eat for 6-8 weeks.

What else will I be able to eat or drink? Several studies have shown that this treatment works the best when given by itself, without ordinary food. Even having a small amount of ordinary food along with the formula may mean that it does not work as well. Because of these studies, we do not allow you to eat any food whilst following this treatment. You can drink water, but be aware that if you fill up on too much water, there won’t be a lot of room for your formula!
Some children and teenagers find they miss out on chewing. It’s OK to have some sugar free gum when really needed. Be careful not to go ‘overboard’ with the sugar free gum though. The artificial sweeteners can cause diarrhoea.

**Can I add anything to my drink?** For the same reason as explained above, it is ideal that you drink the formula only. Adding ice keeps your drink chilled which often tastes better than having it at room temperature. You may prefer to drink through a straw or from a sports drink bottle. Bottles make travelling and school easier.

**Will there be any side effects?** We expect these feeds will settle down your bowel symptoms. We would also expect your energy levels and weight will improve. You may find that while you are having this diet that your bowel movements are softer than usual. This is mainly because you are having a completely liquid diet. Some children and teenagers report feeling full in the beginning, but this improves as your body gets used to having the formula. We don’t expect that you will have any other side effects related to the therapy.

**What else do I need to know?** Please speak with your Gastroenterologist or dietitian if you have further questions. You can write the answers below.

**Answers to questions:**

**My drinking plan:**

(your Dietitian will help you with this)
Guide to Nutritional Therapy for Patients with Inflammatory Bowel Disease (IBD)

Guide for Parents

Why has nutritional therapy been suggested?

Nutritional therapy is a change of diet which may help get your child’s bowel disease under control. It can also help to improve your child’s growth. Many children and teenagers have used this therapy around the world with great success. The change in diet works to undo the changes in the lining of the bowel. This helps to improve symptoms, such as abdominal pain and diarrhoea. Often the therapy is used without other medicines being needed. Sometime it may be used in combination with other medicines.

What does nutritional therapy involve?

Nutritional therapy involves drinking a special milk type drink instead of eating food. These drinks are often called formula.

The name of your child’s formula is ____________________. This formula provides all of the energy, vitamins and minerals that your child’s body needs. It replaces what he/she would usually get from food. It looks like milk and tastes slightly sweet like a milkshake.

How much will your child need to drink?

Your child will be required to drink _____________ mls of formula per day to meet their body’s requirements and to help reach a healthy weight. This volume may need to increase depending on weight gain. If this volume does not satisfy your child’s appetite, he/she can drink more.

Should my child drink this amount on the first day?

No! Your child’s should get used to the volume of fluid slowly. Your dietitian will work out how much for your child to drink on the first few days. By the third or fourth day they should be drinking the full amount.

How long will my child be doing this for? Your Doctor will tell you exactly how long, but usually the best results are seen after 6-8 weeks on the diet.
When should my child drink? Your dietitian will discuss a daily drinking routine with your child. How much and how often they drink is very individual. Often it is best to split the volume up into 6 – 10 drinks per day to satisfy your child’s appetite. Some children like to take small sips every hour or every 2 hours. School and other activities in your child’s life must be considered when designing a plan.

*For example, if your child needed to drink 1800mls per day:* they could have 300mls, 6 times per day: at breakfast, morning tea, lunch, afternoon tea, dinner and supper OR they may choose to drink 180mls, 10 times per day.

What if my child can’t drink it all? If your child finds the amount is too much to drink or that this diet is becoming too hard for them, we can help you. We can put a tube in your child’s nose that goes into their stomach. This is called a naso-gastric tube. Some of your child’s formula can be given during the night through this tube. This means that they only need to drink what is comfortable during the day. With lots of support from family and the IBD team, we will help you and your child through the difficult early stages.

What will my child do at meal times? Family meal times can be hard when everybody else is eating except for the person having this liquid diet. We suggest to families that that they are very supportive around this time. They can do things like not discussing food and eating in another room. Some families don’t cook their child’s favourite meal until they are able to eat again. This way the family is also missing out on something and can understand what their child is going through. Some children are very happy to sit at the table and drink while their family eats. It does get easier after the first few weeks.

Can my child still go to school? Yes, they can. Provided they have the energy, your child should be able to continue with normal daily activities. School, sport, hobbies, helping around the house and activities with friends should happen during this time. You should talk to your child’s school year adviser or classroom teacher about their nutritional therapy. It needs to be treated with the same importance as taking medicine. The formula should be kept cold. Your child can take it to school in a cooler bag, or arrange for it to be stored in a fridge (usually the staff room of a favourite teacher). Some children take sips during class, others manage well at meal breaks only. Your child may like to tell their friends about their nutritional therapy so they will understand why your child can’t eat for this time.
What else will my child be able to eat or drink? Several studies have shown that this treatment works the best when given by itself, without ordinary food. Even having a small amount of ordinary food along with the formula may mean that it does not work as well. Because of these studies, we do not allow your child to eat any food whilst following this treatment. They can drink water, but be aware that if they fill up on too much water, there won’t be a lot of room for the formula!

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Will there be any side effects? We expect these feeds will settle down your child’s bowel symptoms (such as pain). We would also expect your child’s energy levels and weight will improve. You may find that while your child is having this diet that their bowel movements are softer than usual. This is mainly because they are having a completely liquid diet. Some children and teenagers report feeling full in the beginning, but this improves as their body gets used to having the formula. We don’t expect that your child will have any other side effects related to the therapy.

What else do I need to know? Please speak with your Gastroenterologist or dietitian if you have further questions. You can write the answers below.

Answers to questions:

My child’s drinking plan:

(your Dietitian will help you with this)