

Managing your Inflammatory Bowel Disease (IBD) with tube feeds

(Enteral nutrition)



This is Nicholas. During this part of his treatment for IBD, he gets all his daily nutrition with tube feeds.

Your health care team will help YOU learn how to manage your IBD with tube feeds. This booklet answers some common questions.

If you have any questions or need more information, please ask any team member. We are here to help!

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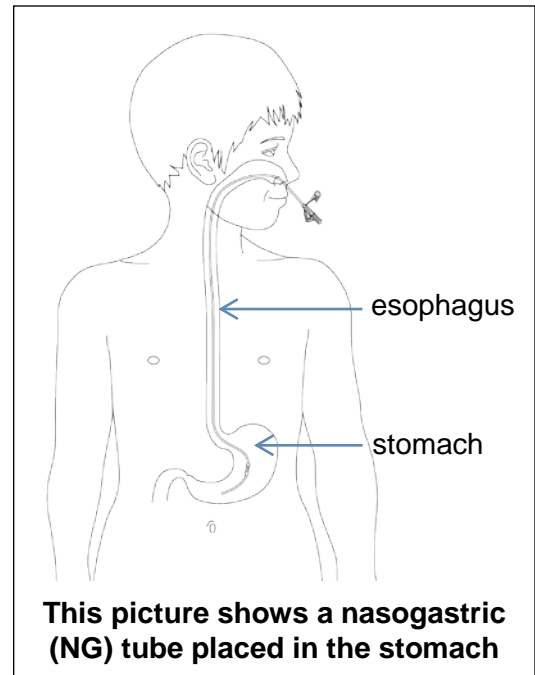
Starting tube feeds

What is tube feeding?

Tube feeding is a type of treatment that involves taking all your daily nutrition in a liquid formula.

The formula is put into your stomach through a nasogastric (NG) tube. This is a soft, flexible tube that goes from your nose into your stomach.

Since the formula gives you all your nutrition, you will not eat regular meals while receiving tube feeds.



How are tube feeds started?

This is done in the hospital. You will need to stay for a few days to place the tube and start the feeds. During this time, we will teach you about the feeds and prepare you to continue them at home.

What does it feel like to have the tube put in? Does it hurt?

Most kids say that inserting the tube is uncomfortable, but not painful. This feeling starts to go away soon, as your body becomes used to having the tube there. A child life specialist can help prepare you for the tube insertion and support you as it is put in.

Can I eat anything else while I'm on tube feeds?

The formula provides all the nutrition you need, so you should not eat other food. However, you can continue to drink clear fluids. A list of what you may eat and drink is on page 7.

How do we use tube feeding in the treatment of IBD?

Tube feeding has proven to be a very effective therapy for IBD. It can heal the damage to your intestines, reduce swelling, and make your symptoms improve just as well as medications.

What are the benefits?

- ✓ With tube feeding, nutrition is used to manage your disease and help heal the lining of your intestines. It also will help you gain weight and height.
- ✓ Tube feeding has very few side effects compared to most of the medications that are used to treat IBD.

Are there any side effects?

Side effects are very uncommon with tube feeding.

Some people may develop problems like:

- nausea, or bloating, and stool may remain slightly loose
- skin irritation around the tube or where the tape is placed
- clogging of the tube

Contact the clinic if you have any of these problems. We can offer tips to help improve your symptoms.

Continuing tube feeds at home

Who can I call if I have questions?

IBD nurse: _____

Clinic dietitian: _____

Who manages the feeds at home?

We will arrange for a nurse and dietitian from the Hamilton Niagara Haldimand Brant Local Health Integrated Network, HNHB LHIN (formerly CCAC) to come to your home. They will:

- ✓ give you the feeding pump, tubing and any other equipment you need
- ✓ teach you how to give feeds
- ✓ work together with your health care team to monitor your progress and offer support

How long will the tube stay in?

Treatment will continue for 8 weeks or longer if needed.
A tube change will be discussed at the next clinic visit.

What happens if the tube falls out?

If the tube falls out, call the clinic. It is okay to miss one night's feed.

Please note that there are a number of ways to re-insert it:

- The HNHB LHIN nurse can re-insert the tube.
 - If it falls out during the day, it can be re-inserted in the clinic.
 - If it falls out during the night, it can be re-inserted the next day or it can be re-inserted in the emergency department.
 - You can reinsert it yourself if you have been taught how.
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Does the tube stay in all the time?

Most kids find it easier to keep the tube in all the time. However, some children and teens prefer to remove it during the day and re-insert the tube themselves at night. Talk with your clinic nurses and doctor about this. You can learn how to insert the tube if you are interested.

When do my feeds need to run?

At first your feeds will run 24 hours a day, but the number of hours will be decreased quickly. Soon your feeds will only run overnight. This means you will receive all the nutrition you need for an entire day in about 12 hours.

Can I go to school with the tube in?

Yes, you can attend school and take part in all your usual activities with the tube in place. We encourage your parents to talk to your teachers to explain the treatment and what is expected of the school. If you need any help talking about the tube with your school, talk with your clinic nurses for support.

Can I shower with the tube in?

Yes, it is safe to take showers and baths with the tube in place. However, you should not go swimming or put your head underwater while the tube is in.

Can I drink my feeds?

You will receive your feeds through your NG tube. Since the formula has partly digested proteins, sugars and fats, it may not be very tasty (and you need a lot to provide your daily nutrition). You can try to drink it if you'd like, but please let your clinic nurse and dietitian know.

What do I do if I'm hungry?

Tube feeds provide all the nutrition you need each day. Most kids will feel full. However, if you are still hungry, call the clinic and ask to speak with the dietitian. The dietitian can help you increase the volume of your feeds so that you won't feel hungry.

How do I know if I'm getting better?

You should start to feel better within a few days of starting tube feeds. This means your energy will increase and your IBD symptoms (such as pain, fever and diarrhea) will lessen. Please call the clinic if any symptoms return.

When will I see my clinic team again?

During your treatment, you will visit the clinic often. You will see your doctor, dietitian and other team members to plan your ongoing treatment and tube changes.

Clinic visits are usually scheduled at these times:

- After 2 weeks of treatment: a visit with the clinic team
- After 4 weeks of treatment: a visit for a tube change, you will see the clinic nurse, child life specialist and dietitian
- After 8 weeks of treatment: a visit with the clinic team

This schedule is only a general guide. The timing of your clinic visits may vary, depending on your needs.

You can call the clinic at any time if you have questions or need an appointment sooner.

Completing tube feeds

When can I start eating normal food again?

After about 8 weeks of tube feeds, you will slowly reintroduce food back into your diet. Your dietitian will tell you how to do this.

As you begin eating foods, you will start to decrease the volume of the tube feeds. This process takes about 1 to 2 weeks and then, the tube feeds will stop completely.

After your last scheduled feed, we will tell you when your tube can be taken out. The tube may be taken out by:

- You or your parents, at home
 - Your family doctor
 - Your clinic nurse
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Will I need other treatment for my IBD after my tube feeds?

Tube feeds are a proven way to get your disease under control (which we call 'induction'). Unfortunately, tube feeds are not as effective at keeping your disease under control and preventing you from having flares (which we call 'maintenance').

When you see your doctor in the clinic, he or she will discuss the next steps of your treatment for your IBD.

Foods you may have while on tube feeds:

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| <ul style="list-style-type: none"> ✓ Water, including carbonated water (sparkling) ✓ Clear juices such as apple or cranberry. No juice with pulp or fruit pieces. ✓ Gatorade (any flavour) ✓ Kool-Aid (any flavours) ✓ Clear pop such as Sprite, 7-Up, Ginger ale ✓ Ice tea ✓ Iced fruit drink | <ul style="list-style-type: none"> ✓ Herbal and natural black or green tea ✓ Strained soup broth (any flavour) ✓ Popsicles (except chocolate) ✓ Freezies (any flavour) ✓ Jello (any flavour) ✓ Hard candies such as Lifesavers and Jolly Ranchers (up to 6 a day) ✓ Gum |
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Our team would like to thank Nicholas for allowing us to have his picture in our booklet!

