

LIVING WITH

# Tube Feeding

HINTS & TIPS  
TO HELP YOU



INSIGHTS & EXPERIENCE FROM PATIENTS, THEIR FAMILIES, CARERS  
AND HEALTHCARE PROFESSIONALS

AN ENTERAL NUTRITION PRODUCT IS OFTEN CALLED A 'TUBE FEED' BY YOUR DIETITIAN OR HEALTHCARE TEAM. IT IS A WAY OF GIVING YOUR BODY THE FOOD IT NEEDS.

A tube feed is a liquid form of food, delivered to your body through a flexible tube.

In this publication, we will use the term tube feed.

TUBE FEEDING  
IS DIFFERENT  
FOR EVERYONE

*in this book*

WHAT IS A FEEDING TUBE? QUESTIONS AND ANSWERS

PRACTICAL ADVICE

GOING HOME AND SUPPORT AVAILABLE

HOME & AWAY: CHECKLISTS

MANAGING ANY PROBLEMS

LIVING WITH A TUBE - HOLIDAYS, SPORT, RELATIONSHIPS

WHO TO CONTACT

The Nutricia Homeward service supports over 30,000 adults and children with many different medical conditions all living with tube feeding in the UK.

Some live in their own homes, others in care or residential homes.

# general information



## What is tube feeding?

Tube feeding is another way of your body getting the food it needs. It's used when it is not possible to get all the food you need by eating. A tube feed is a liquid form of food, delivered through a flexible tube to the body. Tube feeds are often made to contain everything your body needs each day, including carbohydrates, protein, fat, vitamins, minerals, and water. There are many different reasons for how long, how much and why people need to be tube fed, and tube feeding can be different for everyone.

## What is the best way to tube feed?

Your dietitian will help you decide the best way for you to tube feed. There are three ways you can do this:

- **Continuous feeding:** the tube feed (e.g., 1000ml or 1500ml) is given slowly. This can be over a number of hours using a pump to control the speed. Continuous feeding can happen during the day or overnight, or sometimes both.
- **Bolus feeding:** tube feeds are given in smaller amounts (e.g., 200ml), one at a time with breaks in-between. This is done a number of times a day using a pump, a syringe or gravity.
- **Mixture of both:** you can use both ways to fit in with your way of life.
- Always talk to your dietitian or your healthcare team before changing your feeding plan. They can help you choose the best way for you to tube feed.



### **When can I start tube feeding?**

Before tube feeding can begin, the tube has to be put in place. The procedure for feeding tube placement usually takes place in hospital. It depends on the type of tube suggested by the healthcare team. After the feeding tube has been put in place, the healthcare team will let you know if, and how long you will stay in hospital.

When to start using your feeding tube varies for everyone, but you will be told by the healthcare team. You will be allowed to go home when tube feeding is well tolerated. This usually depends on how quickly you get used to your tube. It is important to follow the advice given by the healthcare team.

### **Does tube feeding mean I have to stay in hospital?**

Being tube fed does not mean you have to stay in hospital. Tube feeding at home can be lifechanging. Things will be a bit different, but you will get used to it. Over time, it will fit into your life and your routine. There are many different groups as well as your healthcare team to help support you with this change.

### **How will tube feeding help me?**

If it has been suggested that you need to start tube feeding, it is because you are not receiving the right amount of nutrition. Or it may be that you are unable to swallow or eat food orally. Getting all the nutrients you need through tube feeding may support your daily nutritional needs and well-being.

### **Is tube feeding safe?**

There have been a lot of advances in the science of food, nutrition, and medicine which provide evidence for tube feeding safety. This now allows tube feeding to be used to help



restore or manage nutritional health. Tube feeding is used for people who need both short term, and long term support. Some people may take longer to get used to tube feeding than others, but it's important to remember that you will be supported by your healthcare team to manage any problems you might face.

### **How long can I live being tube fed?**

Tube feeding can be used as the only source of nutrition for as long as it's needed. It gives a balanced, healthy diet and contains all the nutrients you need, day after day.

### **How can I make the decision to be tube fed?**

Feeling worried or scared is perfectly normal when starting anything new. Make sure you understand the reason why tube feeding has been suggested for you. Make sure you know what it means for you. This is really important in helping you cope and feel calm.

### **How do I know if this is the best choice for me?**

You need to ask "why?" If you don't understand, don't be afraid to ask your healthcare team again. If you don't get the information you need, ask again and don't give up. Keep asking until you feel happy with the information you have been given.

### **I am feeling better, can I stop tube feeding?**

The reason for tube feeding is to give you the right amount of energy, protein, and nutrients your body needs. This is to help you get better. You need to tube feed until you can get all the nutrients you need by mouth only. Always talk with your healthcare team before stopping tube feeding, changing the amount or your routine.





# practical advice



## What equipment do I need to start tube feeding?

- You may need a feeding pump to deliver the tube feed through the giving set. Not everyone who is tube fed will have a pump. This will be decided by your dietitian and discussed with you.
- A feeding pump frame, to hold the tube feed and feeding pump.
- A spare feeding tube may be given. This depends on the type of tube you have.
- A giving set — a flexible tube that helps to deliver the tube feed. It is attached to the tube feed at one end and the feeding tube at the other end, with the pump in the middle.
- Syringes to give tube feed, water, and medication. Syringes come in different types and different sizes (e.g., 10ml or 60ml)
- Extra equipment, such as pH paper or a container. These will be given by the healthcare team or by Nutricia Homeward.
- Syringes used for balloon checks (if needed). These are different to enteral flushing and feeding syringes.



## Can I increase the rate of the pump to tube feed more quickly?

When you get more used to tube feeding, you might look for ways to change your tube feeding routine. It will depend on your lifestyle. You might want to alter your tube feeding to fit in with your daily activities.

Talk to your dietitian or your healthcare team before making any changes. Things like delivering the feed too fast may cause complications, like bloating, cramps, nausea, and vomiting. Remember, they can help you find the best tube feeding routine for you.



## Can I put my own food down the tube?

It is not a good idea to put anything other than the prescribed tube feed, water and medications through the tube. It can lead to your tube getting blocked, or a tube needing to be replaced, and may cause infections due to contamination. Speak to your managing dietitian if this is something you are considering.

## What should I know before going home with my feeding tube?

Before you go home, it's important to know why tube feeding is the best choice for you. Make sure you get all the information you need from your healthcare team before you leave the hospital. Nutricia Homeward are the company who will help look after you when you get home. They will train you to give yourself your tube feed and explain the support you will receive. Nutricia Homeward will tell you all about ordering your tube feed and accessories. If you are not sure, keep asking questions, until you have the information you need.



## What's the best position during tube feeding?

The best position for you when tube feeding is sitting up straight. If this isn't possible, prop yourself up on at least two pillows to lie at an angle of 45° or more. You should stay in this position during tube feeding and for up to 30-60 minutes after tube feeding. It's not safe to tube feed while lying flat.

## Can I take a break during tube feeding?

It is important to remember giving sets used for tube feeding should be thrown away after 24 hours. If giving sets are connected, undone and reconnected many times a day, the risk of contamination is increased. Please ask your dietitian about taking breaks during feeding.

## What flavour is the tube feed?

Most tube feeds do not have a flavour, but some small volume tube feeds do have a flavour. Oral nutritional supplements, in small bottles, are used for bolus feeding. They come in different flavours like vanilla, strawberry, and chocolate.

## What temperature should the tube feed be? Can it be warmed up?

Tube feeds should always be given at room temperature (20-25°C). Cold tube feeds can lead to problems such as an upset stomach, nausea, vomiting, or diarrhoea. If you warm up the tube feed (with hot water or in a microwave), you risk 'cooking' the formula. This may change the nutritional value. Warming up the tube feed can also increase the risk of infections.

## What if I feel thirsty?

### What types of drinks can I have?

Your dietitian will suggest the right amount of fluid. They will tell you about changing the prescribed amount of fluid in hot weather, if you exercise, or if you are ill.

If you can drink, your dietitian will tell you which sort of drinks are suitable for you. If you have problems swallowing, drinking could mean a risk of choking and possible infections. Talk with your healthcare team (including Speech and Language Therapist if you have one) about what is right for you.



## Will I get hungry?

Tube feeding can give you the same full feeling in your stomach as eating food. When the tube feed is given in lots of small amounts during the day, you may feel less full. If you have less than the suggested amount, you may feel hungry. If you have bigger gaps between the tube feeds, you may feel hungry. If you feel hungry for a longer period of time, talk to your dietitian. They will look at your tube feeding routine and make changes if needed.



## Is it normal that the colour of my tube has changed with time?

Taking care of your tube will help stop the colour changing. If you have had the tube for a long time some changes in colour may happen. This is because of staining from the tube feed and medications. If you are worried about the tube and its colour, please speak to your healthcare team.



## How do I look after the tube?

Looking after your feeding tube properly will help stop problems from happening. Follow these steps to help care for your tube:

1. Clean the skin around the **STOMA SITE\*** with saline solution or as shown by your healthcare team. Begin at the centre of the stoma site and work outwards.
2. When you have finished washing the stoma site, gently dry the area completely.

### \*STOMA SITE:

AN OPENING (HOLE) FROM THE OUTSIDE OF THE BODY THROUGH THE SKIN WHERE THE FEEDING TUBE ENTERS INTO THE STOMACH OR THE SMALL INTESTINE (JEJUNUM).

## Percutaneous Endoscopic Gastrostomy (PEG) only

You should follow the guidelines given to you for advancing and rotating your tube. This is important to keep the stoma site healthy and prevent a buried bumper (the tube becoming embedded in the stomach wall).

## Balloon retained gastrostomy only:

You should follow the guidelines given to you by your healthcare team to check and replace the water in the balloon. **If you are worried about the stoma site or tube, please get in touch with your healthcare team.**

## What do I do if the feed pack or bottle leaks?

The materials used to make the tube packs and bottles are strong. It is very unusual for them to leak. If they do, the best thing to do is to stop feeding, check the tube and all other equipment. If there is a leak, it is safer to throw away the feed pack and the giving set. Start again with a fresh tube pack and giving set.



## Are there any hints and tips for storing supplies?

It is important to store your tube feed in a way that keeps it at its very best. You should store tube feeds in a cool, dry place (5-25°C), away from direct sunlight and hot radiators.

Once you open the tube feed, you should handle it in a sterile way. This is straight forward and you will be shown how to do this.

Always check the best before date and shake the tube feed before opening. Make sure you use the oldest tube feed first. This can help to stop the risk of the tube feed going out of date.

## How will I get all the tube feeds and equipment I need?

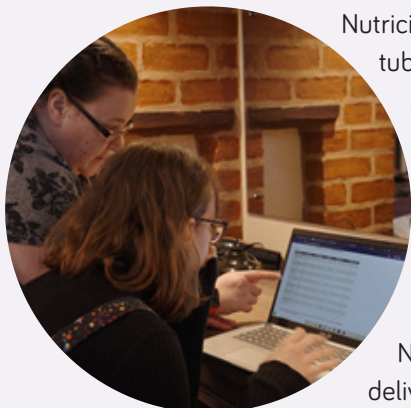
Nutricia Homeward, your tube feeding company, will deliver the tube feed and equipment to your home.

The easiest way to order your monthly tube feeds is online. Each month Nutricia Homeward will let you know when you can place your order. Count your tube feed and equipment and fill in the details about what you need the following month. You can also place your order by phone.

Nutricia Homeward will text you the day before your delivery to let you know when it's on its way. Place your online orders through [nutriahomeward.co.uk](https://nutriahomeward.co.uk)

## I no longer need the feeding pump - what should I do?

It is important to return the pump to Nutricia Homeward when you have finished using it. You can arrange to return the pump by calling them on **0800 093 3672**. They will arrange to collect all the equipment at no cost to you.



# going home & support available



## **How can I make taking medications easier?**

You may have to take lots of different medications every day. Your healthcare team may suggest you take your medication through the feeding tube. You will need a syringe, your prescribed medications, and water; your healthcare team will advise what type of water you should use (e.g., sterile, tap or cooled boiled water). Your feeding tube is for liquids only. If possible, ask your pharmacist for your medication to be dispensed in a liquid or dissolvable form. Ask for sugar-free (non-syrupy) liquid medicines, so they don't stick to the tube. Only crush tablets if you have to and there is no other way. It may increase the risk of your feeding tube getting blocked. Not all medications can be crushed so it's important to check with a pharmacist. They will tell you which medications are suitable for crushing. Make sure you have a grinder at home if you are told to crush tablets. Do not crush any medications without talking to a healthcare professional first.

## Can I take extra vitamins and supplements?

Your healthcare team will let you know if you need to take extra vitamins and minerals. They will be able to tell which ones you can take.

## Can I eat normal foods when being tube fed?

Your healthcare team will let you know if you are able to eat when you have your feeding tube. If you can eat, you'll be given information about the types of food and amounts that are safe. If you're being tube fed due to swallowing problems, you might be visited by a Speech and Language therapist. This may be when you are in hospital or at home. They will be able to tell you which foods are safe for you.

## How can I be ready?

As you get used to tube feeding, you will learn ways to make life easier:

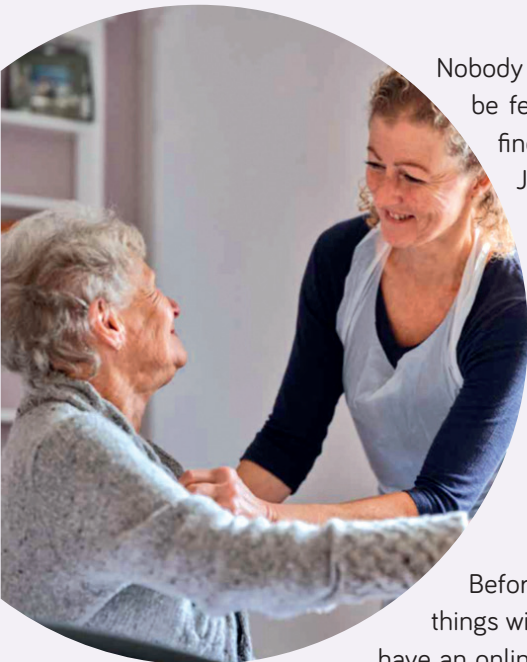
1. Charge the pump! The battery should last for a full day.
2. Make sure you always have a spare set of everything - always think "what if?"
3. Allow yourself to be creative about how you hang the feed. Rucksacks work on the back of wheelchairs or use hangers in hotel rooms.
4. Make sure your feeding tube is always secure to prevent it from being pulled out by accident.

## How can I stay positive?

Nobody can tell you how to cope, or how you should be feeling. At times, it might be hard and you may find different things frustrating from time to time. Just remember that this is normal, and you are not alone. Think of tube feeding as helping you to stay free and independent as much as possible. It is understandable to have good and bad days. Keep your sense of humour, and don't let tube feeding take over your life or define who you are. Always speak to your family/caregivers, friends and healthcare team if you need support.

## How can I cope with going home?

Before you leave hospital, make sure you know how things will work when you get home. Nutricia Homeward have an online guide, called 'Preparing to go home'. Reading



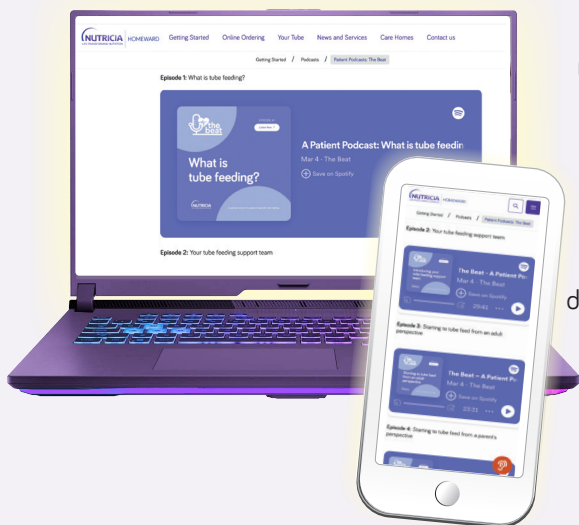
this will help you and your family understand the service provided. It will help you to feel more prepared for what's to come. It will give you information about the Nutricia Homeward Nursing Service and deliveries. You can look at this information as many times as you want to before you leave the hospital and when you get home.

[www.nutriciahomeward.co.uk](http://www.nutriciahomeward.co.uk)

## Want to hear from others who are tube feeding at Home?

It can help you to feel less alone when you hear about the tube feeding experience of others. On the Nutricia Homeward website you will be able to read stories, watch videos and listen to a series of podcasts from patients and carers who were once new to tube feeding. They offer their thoughts and advice to help you:

[nutriciahomeward.co.uk/getting-started/podcasts/patient-podcasts-the-beat](http://nutriciahomeward.co.uk/getting-started/podcasts/patient-podcasts-the-beat)



Click on the **Reachdeck** symbol to navigate the website in a way that suits you. It is simple and easy to use, with functions such as:

- **Text to speech**
- **Reading aloud**
- **Magnifying text**
- **Translation**

You can personalise the settings so it defaults to the setting you need each time you visit the site.



## Are there support groups for people who tube feed at home, like me?

Your friends and family will support you, but you may want to speak to other people who tube feed. PINNT is a charity, who have a support group for people receiving home enteral nutrition. They have a website with useful information. More information can be found at [www.pinnt.com](http://www.pinnt.com)

Members of PINNT have regular meetups giving them a chance to meet and make friends with others who are also using a tube for feeding.



# home & away: checklists

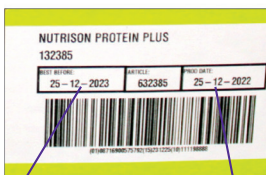
## Things to check every day.

Every day, clean around the site of the feeding tube, as your healthcare professional has shown you.

- Look after the skin around the tube so it doesn't become sore. Your healthcare team will show you how to do this.
- Your dietitian will let you know how much water you need every day. Make sure you stay hydrated by using enough water for flushes through the tube, or by mouth if safe for you to do so.
- Keep your teeth and gums healthy. Clean your teeth twice a day even if you are not eating or drinking.
- At the start, it may seem that there is a lot to remember. You will soon get used to what everything means and what you have to do.

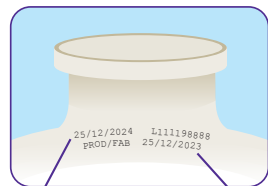
## Things to check at tube feeding time

Check the label of the tube feed to make sure it is the right tube feed for you. Check the date. There may be two dates: the best before and the production date. It is the best-before date you need to check.



BEST BEFORE

PRODUCTION DATE



BEST BEFORE

PRODUCTION DATE

## Things to check when tube feeding away from home

If you are travelling abroad make sure to contact Nutricia Homeward at least 6 weeks before for advice and information.

### Away from home checklist

- Tube feed
- Medications, if you need them
- Water for flushing
- Purple syringes
- Tube feed container/bottles
- Feeding pump (if needed) and pump charger
- Spare giving sets, syringes
- Spare feeding tube (if applicable)
- Spare extension sets for feeding tube (if applicable)
- Spare PEG end (if applicable)
- pH indicator strips (if applicable)
- Syringes for balloon water checks (if applicable)
- Any stoma site creams or dressings that have been prescribed (if applicable)
- Towels, wipes, tape
- A way to hang the tube feeding pack, usually in backpack
- Plastic containers
- Phone numbers for Nutricia Homeward
- Your tube feeding care plan
- Emergency contact numbers

Use this list to help you plan your travel away from home, and make sure you have everything you need. Ensure you have enough (including a few spares) to last your entire trip.



# managing any problems

## Is there a problem? What signs should I look for?

It is a good idea to get into the habit of checking for these signs of problems every day:

- Redness around the stoma site. If you see redness which continues or is painful, tell a member of your healthcare team and they will advise on the next steps, i.e., nurse review, GP review etc.
- If you notice leakage from your stoma site after it's been dry, tell your GP .
- Overgrowth of skin around the stoma: The skin may overgrow around the stoma site and need treatment. This is known as granulation tissue and happens because the body is trying to repair where you had your operation. If this happens, contact your doctor or a member of your healthcare team.
- Leakage from the gastrostomy stoma site. If the gastric contents leak from the stoma site it can cause burning and pain to the skin. If this happens you should contact your doctor, dietitian or a member of your healthcare team.
- If problems continue or if you are worried about any problems with your tube, always contact your dietitian or a member of your healthcare team for further advice.





## **What side effects might I have at the start? When will I start to feel better?**

It can take time to work out the tube feeding plan that is best for you. While you are getting used to things you may notice some side effects. There are many ways to manage these.

### **Upset stomach**

- If you are feeling sick, stop tube feeding for 1-2 hours and start tube feeding again if you are feeling better.
- You can also try a smaller amount of tube feed or set the pump to a lower speed if suggested by your healthcare team.

### **Diarrhoea**

- First make sure that the pump is delivering feed at the right speed. The speed should have been given to you as part of your tube feeding plan.
- Make sure the tube feeding equipment is clean and your giving set is changed every 24 hours. Always deliver the tube feed at room temperature.
- Make sure to cover and put any opened feed that's not actually being used through the pump in the fridge. When ready to use the tube feed again, take it out of the fridge.
- Allow the tube feed to stand at room temperature for 30 minutes before using.
- After a pack of feed has been open for 24 hours, you should throw it away.

## **Constipation**

- Make sure you're taking any extra fluids that have been suggested by your dietitian or healthcare team.
- Make sure not to miss any water flushes.
- If possible, and suggested by your healthcare team, try to exercise, and move around.
- If this doesn't help, it's important to let your dietitian and healthcare team know.

## **Side Effects**

Side effects will be different for everyone. It will also be different in how long they last, and how long they take to get better. If your side effects continue, or you have any worries about what to do, always get in touch with your dietitian or your healthcare team.

### **If I get sick, what should I do?**

If you feel sick, wait 1-2 hours before tube feeding and start tube feeding again if you are feeling better. If you continue to feel sick, start vomiting and/or diarrhoea carries on, stop tube feeding. Contact your doctor who will give you advice about what to do. Some medications, such as antibiotics, can cause diarrhoea. Ask your doctor about any side effects from medications you are taking.

### **What if the tube becomes loose or falls out?**

Your tube might loosen with coughing, sudden movements, or if there is accidentally too much pulling of the tube. If this happens, stop tube feeding right away.

If you have a nasogastric (NG) tube and you've been properly trained on how to replace it, please do so. If not, you will need to go to the hospital. A healthcare professional will place a new NG tube.

If you have a nasojejunal (NJ) tube, you must not attempt to replace this yourself. You will need to go to the hospital where a healthcare professional will replace it for you.

If your gastrostomy (PEG or radiologically inserted gastrostomy (RIG) button) or jejunostomy is accidentally removed, put a dressing over the site. Go as quickly as possible to the hospital Accident & Emergency Department or get in touch with your emergency contact. It's important to do this as fast as possible as the stoma will begin to close.

A handy tip is to contact the hospital before you go. This can help cut down on waiting time in the Accident and Emergency Department.

### **How can I stop the tube from getting blocked?**

A feeding tube can get blocked because:

- Medication hasn't been crushed enough or dissolved properly
- Not enough water has been used for flushing before and after tube feeding and taking medication
- A closed tube clamp





**If you have a blocked NG tube, you should not try to unblock it yourself. Instead, you must ask for help from a member of your healthcare team.**

Make sure to flush the tube with water before and after each tube feed or medication, as this will stop the tube from blocking. Your dietitian and healthcare team will tell you what type of water to use and how much you need to flush properly.

However, if your gastrostomy or jejunostomy tube becomes blocked, you can use the advice below.'

- Use lukewarm water or soda water, your healthcare team will tell you how much and which type. Attach a 60ml enteral syringe to your feeding tube and using a gentle

pull-and-push method with the syringe plunger, the tube will become unblocked. Do not use liquids like fruit juices or cola, these could make the tube feed curdle and block the tube more.

- Still blocked? Gently squeeze the tube between your fingers along the length of the tube and repeat flushing. You can also wrap your tube inside a lukewarm flannel as the heat may help to break down any blockages. It can take up to 30 minutes to unblock the tube, so be patient and don't panic. If this does not work, get in touch with your Homeward Nurse or your healthcare team who will support you further.

### **What is over-granulation and what do I do about it?**

Over-granulation is the overgrowth of skin around the stoma site of the feeding tube. This may happen because your body is trying to repair the area where you had your operation. Over-granulation is common and can be treated. If you notice it developing around the stoma site please let your healthcare team know.



### **What if the pump breaks and won't work?**

It is important to make sure the pump is charged or plugged into the wall socket. If it is definitely broken, get in touch with Nutricia Homeward, who will deliver a new replacement pump as soon as possible. It may be possible for you to bolus or gravity feed until your new pump arrives.



# living with a tube



## **Can I continue to work?**

There are many people who tube feed and who still carry on working. Ask your healthcare team how you make your tube feeding fit in with your work.

## **What can I tell my work colleagues?**

Most people find it quite easy to be open with the people they work with. If you explain and talk about why you need to tube feed and how it works, they are more understanding. You may prefer to have some time to yourself at work to tube feed. The more relaxed you are about it, the more they will be.

## **Will I be able to go to school?**

Yes, tube feeding will not stop you from going to school. Your healthcare team will talk to you about this. The teachers at school will be there to look after you. They may need to be shown how to help with your tube feed and equipment. Training can be arranged, talk to your dietitian or Homeward Nurse.



## Can I have baths and showers?

For about 2-3 weeks after you've had the gastrostomy or jejunostomy put in place, you should only take showers. If you don't have a shower, a shallow bath is also fine. This is to give the stoma site a chance to heal. After that, taking a normal bath, and going swimming, is possible. You must make sure your tube is well protected, the wound has healed and is healthy. You can protect the tube with a waterproof wound dressing but, remember to remove this as soon as you have finished, and clean/dry your stoma thoroughly. You should try to avoid poor quality water when swimming. If you're unsure, speak to your doctor or healthcare team about what's safe and possible for you.

## Do I still need to go to the dentist?

It is very important that you still visit your dentist. The dentist will know you cannot manage to eat or drink. Your dentist may be able to offer some good advice and care if you have little or no oral fluids.

## Can I still brush my teeth?

Taking good care of your mouth and teeth is important. This is to help keep your breath fresh, your teeth and gums healthy and, stop infections or problems from happening. You can put cream or lip balm on your lips to stop dry or chapped lips. If you have false teeth, they should be cleaned with a brush. Overnight, store your teeth in a denture pot filled with fresh water. Your mouth will still need to be cleaned. If you need it, you should use mouth gel to keep your mouth moist.



## How can I explain tube feeding to my family and friends?

It's up to you to tell family and friends what and how much you want them to know. You only need to explain what feels right for you. With children it is better to talk to them, so they feel included and don't spend time wondering or worrying. Talk honestly and openly, and make sure you use words they will understand.

## **How will my family and friends react?**

People will react in different ways. Not all of them will understand what tube feeding is but then some people may surprise you. Although it's a very big change for you, you're the one living with tube feeding. Try to take it easy with your family and friends while they get used to the idea. It may take them a while to get used to your new normal.

## **Can I have a normal relationship?**

Tube feeding should not stop you from being in a relationship with someone. You can be intimate with your partner. Getting used to having your tube and how it looks may take time. It is important for you to feel comfortable with this.

## **Am I going to be able to have children?**

Tube feeding is possible during pregnancy. If you tube feed and would like to have children, it's important to talk to your doctor. Starting a family may need some planning. It will be very important to make sure you receive all the right nutrients for the baby to help it grow and develop. Your healthcare team will help you with the best feeding route before you become pregnant.

## **Will I be able to have a social life?**

Once you are home and have got used to your new routine, it is important to continue with social activities. You will find tube feeding may take some time, and it might feel a bit limiting. With planning and small changes, you can fit tube feeding around your social life. If you have to stay at home, there may be other ways of keeping in touch with your friends and family. Get people to visit you at home, make phone calls, or use social media. You could also use this time to find new hobbies and interests. Make sure you have plenty of time to rest, especially if you find you are getting tired.

## **How active can I be?**

Activities or light exercise are healthy if your medical concern allows it. Make sure to protect the tube and skin around it as much as possible. Try to avoid big sudden movements that could dislodge your tube. There are different tools to make it easier to go outside or move around. Ask your doctor or a member of your healthcare team about what might help you.

## **Will I be able to play sports?**

Taking part in sports will depend on your medical concern and your mobility. Your doctor will give you advice about the sports you are able to take part in and which ones should be avoided. Physical contact sports are not really the best choice, there is risk of the feeding tube getting dislodged and coming out. Speak to your dietitian who will give you more advice. They may adjust your tube feeding plan, and you may need extra water when you are training.





## **Will I be able to go back to school?**

You may need to have tube feeds and/or medications through your feeding tube when you are at school. Some of the teachers or carers will be able to supervise.

PINNT have a section for children called half PINNT. Why not get in touch and chat about how others cope at school too?

## **Planning your holiday**

To plan your holidays at home or overseas with family and friends contact Nutricia Homeward. They will be able to give you travel advice for your trip. Nutricia Homeward will be to help with your tube feed and equipment. Your healthcare team will help with the things you need for travel insurance and fitness to fly certificates if needed. They will also be able to give you advice about tube feeding away from home.

Use this list to help you plan your travel away from home, and make sure you have everything you need. Ensure you have enough (including a few spares) to last your entire trip:

- Tube feed
- Medications, if you need them
- Water for flushing
- Purple syringes
- Tube feed container/bottles
- Feeding pump (if needed) and pump charger
- Spare giving sets, syringes
- Spare feeding tube (if applicable)
- Spare extension sets for feeding tube (if applicable)
- Spare PEG end (if applicable)
- pH indicator strips (if applicable)
- Syringes for balloon water checks (if applicable)
- Any stoma site creams or dressings that have been prescribed (if applicable)
- Towels, wipes, tape
- A way to hang the tube feeding pack, usually in backpack
- Plastic containers
- Phone numbers for Nutricia Homeward
- Your tube feeding care plan
- Emergency contact numbers



You will need to make sure you have the right equipment and enough tube feeds with you. Nutricia Homeward will help with ordering the tube feed. They will be able to suggest the best way to get all that you need to your destination. It is a good idea to plan your travel as far ahead as you can. Give your healthcare team and Nutricia Homeward lots of time so they can help you to make your arrangements.

### **Can I still drive?**

If your doctor thinks you are well enough to drive, then there should not be a problem. You may have to tell the DVLA of your current medical status. They may ask for a letter from the doctor, letting them know you are fit enough to drive. Generally, many people who are tube fed are still able to drive.

# information, advice & support

## **Nutricia Homeward**

The Nutricia Homeward service looks after over 30,000 enterally fed patients, giving the support needed to tube feed at home. This includes online ordering, deliveries, and support from our Nutricia Homeward Nursing service.

**Support is available 24 hours by calling 0800 093 3672**

**[www.nutriciahomeward.co.uk](http://www.nutriciahomeward.co.uk)**

## **Nutricia**

A specialist medical nutrition company providing medical nutrition for those who need it: **[nutricia.co.uk](http://nutricia.co.uk)**



# who to contact

[www.nutriciahomeward.co.uk](http://www.nutriciahomeward.co.uk)

Call 0800 093 3672 24 hours a day, 7 days a week

Office Hours: Monday - Friday 8.00am - 8.00pm, Sat 9.00 - 1.00pm

(Outside of office hours advice and support is available on pumps, equipment and feeding tube problems, but not individual deliveries)

CONTACT	TELEPHONE	EMAIL
HOMEWARD NURSE		
NUTRICIA HOMEWARD		
DIETITIAN		
COMMUNITY NURSE		
GENERAL PRACTITIONER		

**OUT OF OFFICE HOURS: PLEASE CALL 0800 0933672**

## Further information, advice and support

### Nutricia

A specialist medical nutrition company providing medical nutrition for those who need it.  
[nutricia.co.uk](http://nutricia.co.uk)

### PINNT

A support group for people receiving artificial nutrition [pinnt.com](http://pinnt.com)

### HALFPINNT

A support group for young people receiving artificial nutrition.  
[pinnt.com/support/half-pinnt.aspx](http://pinnt.com/support/half-pinnt.aspx)



Nutricia Homeward is provided by Nutricia Limited.

Nutricia is a company registered in England & Wales under company number 275552, whose registered office is at Newmarket Avenue, White Horse Business Park, Trowbridge, Wiltshire BA14 0XQ.

This information is intended for those registered with the Nutricia Homeward Service

SCC4413 4/11/24