

As you are not able to eat food in the same way as a lot of people, your body must have a special food, known as medical nutrition or enteral nutrition. Your doctor or dietitian may call this food a “tube feed”.

To keep things simple, on these fact sheets we will call it a tube feed.

A tube feed is a liquid that contains all the things your body needs, just like normal food. There are a lot of people who have to have their food this way.

Hopefully you will find some useful tips in our fact sheets. There are different fact sheets covering different topics, here is a list so you can choose the ones suitable for you and hopefully find the information you need.

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This information is intended for patients who have been prescribed a tube feed by a healthcare professional.

Accurate at time of publication: December 2019.

Nutricia Ltd.

White Horse Business Park, Trowbridge, Wiltshire BA14 0XQ

AMN0494-12/19

FACT SHEET 1: GENERAL INFORMATION — STARTING TUBE FEEDING

WHAT IS TUBE FEEDING?

A feeding tube can be used to deliver liquid food to your body through a flexible tube. It is a way of helping you get the nutrition that your body needs to function in every day life.

Tube feeds contains all the nutrients you need on a daily basis, including carbohydrates, protein, fats, vitamins, minerals, and water.

Here are some examples of what your tube feed might look like:



Your dietitian will make sure you receive the right one for you.

WHY DO I HAVE TO HAVE A TUBE?

There are lots of different reasons why you may need to have a feeding tube. Tube feeding may be used to make sure you get all the nutrition and water you need because of a medical condition, which means you're not able to have your nutrition through your mouth or maybe you are unable to swallow safely.

You may find you need a feeding tube even if you are still able to eat and drink. There are several reasons for this; it might be because you have a medical condition that means you burn energy very quickly, making it difficult to maintain a healthy weight, or a condition that means you just don't feel hungry and therefore don't eat enough to get all the nutrition you need. If this is the case you will have a feeding tube and it will be used to supplement your oral dietary intake.

There are lots of different types of medical nutrition your dietitian can prescribe for you to have through your feeding tube; all of these will provide the energy, protein, fluid, vitamins and minerals your body needs.

Your dietitian will explain the reasons why you need a feeding tube and will create a feeding plan with you. The dietitian will work with you to fit the feeding routine around your lifestyle, giving careful thought to your medical and nutritional requirements.

DOES TUBE FEEDING MEAN I HAVE TO STAY IN HOSPITAL?

No, just because you have your food through a tube doesn't mean you will have to stay in hospital. It may take a while to get used to having your food this way but you will get used to it. Before you go home with your feeding tube, you and those looking after you will be shown how to use and look after the feeding tube. There will be lots of people who will be able to give you information about your feeding routine and there are lots of leaflets available about how to care for the feeding tube.

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You will also be given a list of contact numbers of healthcare professionals, such as your dietitian or your Nutricia Homeward Nurse, who you can get in touch with if you have any problems with the tube when you are at home. You will receive the equipment and tube feed that you will need to use with your feeding tube at home from Nutricia Homeward; this will be arranged by your dietitian.

There are also lots of groups, like PINNT (pinnt.com) — Patients on Intravenous and Nasogastric Nutrition Therapy — who will be there to answer questions and help support you.

IS TUBE FEEDING SAFE?

Providing you follow the instructions from your healthcare professionals about how to care for the tube and how to use your feeding tube, then tube feeding is safe.

The reason you and those looking after you are trained by your healthcare professional about how to use and care for your feeding tube before going home is so you can use it safely.

If you have any problems with your feeding tube that are not answered in your home enteral feeding booklet, then contact a healthcare professional for advice.

Sometimes a small number of people may experience some challenges when they first start to tube feed, but it is very important to remember that most of these challenges can be stopped and corrected very quickly. Speak to your Nutricia Homeward Nurse if you are worried.

WHEN WILL I HAVE MY TUBE FEED?

Your dietitian will talk to you about the best way and the best time for you to have your tube feed.



It could be a longer tube feed during the day or while you sleep overnight, or it might be a shorter tube feed through a syringe. Your dietitian will help you decide what will work best for you. If you want to make any changes at any time you need to talk to your dietitian before you do so.

WHEN CAN I START TUBE FEEDING?

Usually you will have to go into hospital to have a tube put in place and the doctors or nurses will tell you how long you need to stay there.

Once you are used to using the feeding tube, and the doctors and nurses are happy that you can look after your tube feed, you will be able to go home.

HOW WILL TUBE FEEDING HELP ME?

Because you are not able to eat food in the usual way, having your medical food through a tube will help your body get everything it needs.

HOW LONG CAN I HAVE A TUBE FOR?

You can have your food through a tube for as long as you need to. Some people only have food this way for a short time, while others have their food this way for the rest of their lives.

HOW LONG WILL IT TAKE TO GET USED TO?

When you start to have your food by a tube it can seem a bit strange, but you will soon get used to it. If you have any questions make sure you ask your dietitian, doctor or nurse, who will be able to explain things to you.

IF I FEEL BETTER, CAN I STOP TUBE FEEDING?

The doctors and dietitians who look after you will make any changes to the way you have your food to make sure you get the right food for you.

WHAT IF I WANT A DRINK BECAUSE I FEEL THIRSTY? WHAT CAN I HAVE TO DRINK?

Your dietitian will let you know if it's OK for you to drink. If it is, they will be able to tell you what you can have and how much. If you are getting these symptoms but are unable to have fluid by mouth, your dietitian may suggest having some extra fluid through the tube to help stay hydrated.

WHAT IF I GET HUNGRY? WILL I FEEL FULL?

When you have food through a tube you will still feel full up. If you do feel hungry talk to your dietitian, who will make sure you are getting the right amount of food you need. Your dietitian may also suggest altering the timings of your tube feeds to help prevent you from feeling hungry at points in the day.

HOW DO I LOOK AFTER THE TUBE?

It is important to look after your tube using the following care instructions.

- Always wash your hands before and after using your feeding tube.
- Always flush your feeding tube with water before and after each use.
- It is important for anyone who is touching the tube to always follow hand-washing instructions for clean hands.
- It is important that anyone handling the feed or equipment is not sick, have an upset stomach or diarrhoea.
- Anyone touching the tube should have any cuts covered with a plaster.
- It is important that your tube and equipment does not touch unwashed hands or surfaces.
- Check your feeding tube daily — is the feeding tube clean around your skin? — is the skin a healthy colour?
- Your nutrition nurse will show you how to unblock your feeding tube but if it becomes blocked and you are unable to unblock it using the information your nutrition nurse has given you please contact your nutrition team or your Nutricia Homeward Nurse who will advise you what to do next.
- If your feeding tube is no longer in your tummy, please contact the nutrition team as soon as possible.

WHAT DO I DO IF THE TUBE FEED BOTTLE LEAKS?

If a bottle of feed leaks before you start to tube feed, throw it away by pouring the contents down the sink and putting the container in your recycling bin. In its place use a sealed bottle of feed.

If the bottle of feed begins to leak during tube feeding, pause your feed using the correct buttons on the pump, disconnect the tube feed and throw away the leaking bottle; open a new bottle and connect it to the giving set in the usual way. The pump will have recorded how much feed you have already had and will continue to provide your programmed dose. Let the Nutricia Homeward Customer Service team know as soon as you can to ensure you do not run out of tube feed.

ANY TIPS ON STORING EQUIPMENT AND SUPPLIES?

- You need to keep your bottles of tube feed in a cool, dry place, away from sunlight. Always check the date on the bottle before opening and give the bottle a good shake.
- Make sure you use up the old tube feed before opening a new box. The Nutricia Homeward delivery driver can help by stacking the new boxes at the back.
- Ensure that giving sets are thrown away after 24 hours.
- Every day, during a rest period, unplug and wipe down the pump with sterile wipes.
- If you are using reusable syringes these need to be thoroughly cleaned as per the instructions with warm soapy water, then air dried after each use.
- Reusable syringes should be used and should be thrown away if they are damaged. Reusable syringes should not be used for longer than a week.

Accurate at time of publication: December 2019.

All products mentioned are Foods for Special Medical Purposes for the dietary management of disease related malnutrition and must be used under medical supervision.

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AMN0494A-12/19

FACT SHEET 2: ADVICE, HINTS AND TIPS

WHAT EQUIPMENT DO I NEED TO START TUBE FEEDING?

When you are in hospital you will be shown how to use the equipment you need.

When you are ready to go home all of the things you need will be delivered to your home by Nutricia Homeward.



- A feeding pump to deliver the feed through a flexible tube, called a giving set
- 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
- A feeding pump frame, designed to hold the tube feed and feeding pump
- A spare feeding tube may be provided depending on the type of feeding tube you have
- Syringes* — these may be single use or reusable (your dietitian will tell you which type of syringe is the right one for your needs) — to use with your tube feed, water and medication. Syringes come in different types and sizes (e.g. 10ml or 60ml)
- Additional equipment, e.g. pH paper, container, will be provided by the healthcare team or Nutricia Homeward (the company who deliver your tube feed)

*Syringes used for balloon checks (if you need these) are different to enteral flushing and feeding syringes.

CAN I MAKE THE PUMP GO FASTER?

The pump rate will have been set by your nutrition team at the hospital, this will have been decided because of your medical condition and how active you are.

If you would like to make any changes to your tube feeding plan, or the speed of your feeding pump, you should make sure you talk to your dietitian first. Making changes, like having your tube feed too quickly, may make you feel unwell. You may have tummy ache, or you may feel sick or actually be sick, or you may have diarrhoea. Making sure your dietitian is aware of any changes to your feeding routine means they can make sure it's still safe for you and that you are getting the right nutrition. It also means they can tell the delivery company of any changes in the amount of tube feed and/or equipment you need for any changes.

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CAN I PUT MY OWN FOOD DOWN THE TUBE?

You should only put the sterile tube feeds, water flushes and, for some people, medications, down the feeding tube. These have been safely prescribed for you by your healthcare professional.

You will not need to put your own food down the feeding tube, as the feeding routine created by your healthcare professional has been tailored to meet your nutritional needs. Putting other foods down the feeding tube can cause problems. It may make you feel sick or give you a bad stomach ache. It could also block your feeding tube.

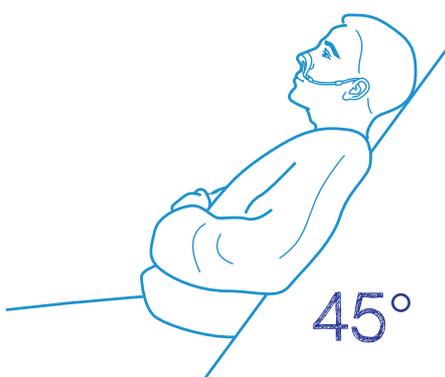
Your dietitian will talk you about this, but your Nutricia Homeward Nurse will also be able to help and answer any questions.

WHAT SHOULD I KNOW BEFORE GOING HOME WITH TUBE FEEDING?

Make sure you ask your doctor, nurse or dietitian any questions you have before going home. Your Nutricia Homeward Nurse will teach you how to use your pump and make sure you know all you need to before you go home. You will get time to practice and ask lots of questions. They will also come and see you when you get home. If you have any questions about your pump and how it works you can phone and speak to someone at Nutricia Homeward.

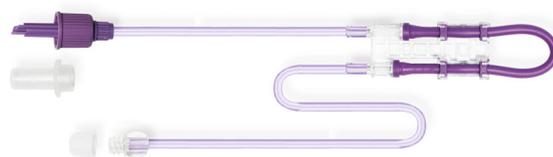
IS IT BETTER TO LIE DOWN OR SIT UP WHEN I HAVE MY TUBE FEED?

If you do lie down, make sure you have at least two pillows, so you are propped up. It's important to make sure you lie at a 45° angle, just as the picture shows. You need to stay like this for at least 60 minutes when you have finished your tube feed. It isn't safe to lie flat when you are tube feeding.



CAN I TAKE A BREAK DURING TUBE FEEDING?

The giving set — the tube that connects the pump to your tube feed — needs to be thrown away after 24 hours. If you undo the tubes and connect them up again several times you could make your feeding tube dirty. Speak to your dietitian if you want to change how you have your tube feeds.



WHAT FLAVOUR IS THE FEED?

A lot of the tube feeds are not flavoured. If you do find you are getting heartburn with your tube feeds, which means you are getting a taste in your mouth, talk to your dietitian — they may be able to alter your tube feeding routine to stop this from happening.

If you have an oral nutritional supplement (ONS) used for bolus feeding, these come in lots of different flavours. Some patients do taste the ONS — ask your dietitian for more information on the different flavours available.



WHAT TEMPERATURE SHOULD THE FEED BE? CAN I WARM IT UP?

Tube feeds should be taken at room temperature, not heated up or chilled.

If the medical nutrition is too cold, it might make you sick or may give you diarrhoea.

If it has been warmed, it might destroy some of the nutrients in the medical nutrition and there may be more of a chance of getting an infection.

IS IT NORMAL THAT THE COLOUR OF MY TUBE HAS CHANGED WITH TIME?

If you are worried the tube looks a funny colour, make sure you speak to your Nutricia Homeward Nurse. It might be because the tube is getting old!



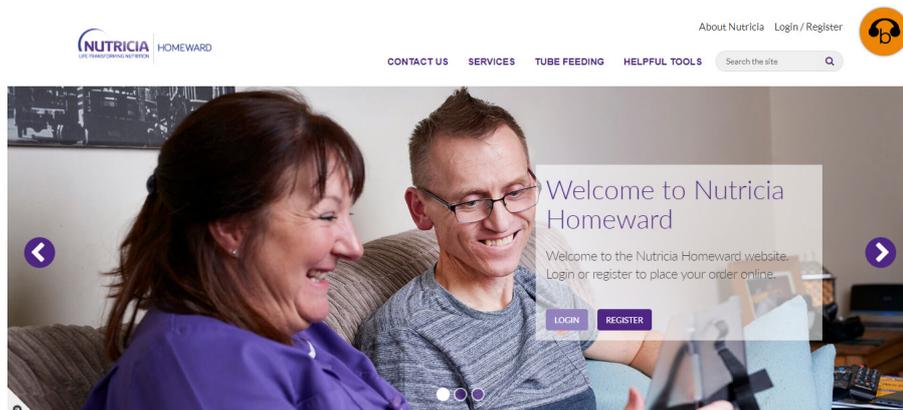
WHERE CAN I MEET OTHER PEOPLE WHO HAVE A FEEDING TUBE?

It may be nice to speak to other people like you, who have their food through a tube. PINNT (pinnt.com) is a charity for people just like you and they have a website with lots of great information. They often have events and get together where you can make new friends.

HOW WILL I GET ALL THE FEED AND EQUIPMENT I NEED?

Nutricia Homeward will deliver your tube feed, your giving sets and your pump to your home.

Every month someone from Nutricia Homeward will phone to see how many bottles of tube feed you need, or if you want to you can do your stock check online. There is a handy work book to help you learn how to do this. Go to nutriahomeward.co.uk — don't worry if you forget, someone from Nutricia Homeward will call you if you haven't filled in the form on time.



You can download a delivery date calendar to help remember when to order and know when everything will be delivered.

DO I STILL NEED TO GO TO THE DENTIST?

Not many people like going to the dentist but you do still need to look after your mouth and teeth. Make sure your dentist knows you have food through a tube. They may be able to give you some great hints and tips.



I NO LONGER REQUIRE THE FEEDING PUMP, WHAT SHOULD I DO?

If you don't need your pump any longer, someone else may need it. Please phone Nutricia Homeward on 0800 093 3672 and ask them to collect your pump. One of the delivery drivers will be happy to arrange to come and collect it.

Accurate at time of publication: January 2020.

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AMN0494B-01/20



FACT SHEET 3: QUESTIONS THAT ARE OFTEN ASKED

HOW DO I TAKE MY MEDICINE?

If you are able to eat and drink then you may be able to take all of your medication orally. It is important that you feel confident to do this following the training you have been given. If you are unable to take some or all of your medication orally, then you can have them through your feeding tube. If possible your doctor or pharmacist will give you liquid medicines, as these are absorbed better and less likely to block the tube. If some of the medications you are taking do not come as a liquid your pharmacist will tell you how to prepare them to put them down the tube.

Before and after putting medication down the tube you will need to flush it with water, your healthcare professional will show you how to do this and how much water you need to use.

Your Nutricia Homeward Nurse will be able to help you when you are home if you forget any of the information.

Please make sure you ask lots of questions and let people know if you do not feel able to do this yourself.

CAN I TAKE EXTRA VITAMIN AND MINERAL SUPPLEMENTS?

Always speak to your dietitian before you take any supplements, they will tell you if there is anything you need to take. Many of the tube feeds that you are prescribed by your dietitian will be 'nutritionally complete', which means they provide all the vitamins and minerals you need.

CAN I EAT NORMAL FOODS WHILST BEING TUBE FED?

Your dietitian will talk to you about any foods you are able to eat. They will tell you the types of food and how much you are able to have.

HOW CAN I MAKE TAKING MEDICINE EASIER?

If you have to take any medicines, ask for the sugar-free liquid version.

WHAT ARE THE MOST IMPORTANT THINGS FOR ME TO REMEMBER?

The battery for the pump should last for a whole day, you just need to remember to charge it.

Make sure your feeding tube is secure.

WHAT IF I FEEL FED UP ABOUT HAVING A TUBE?

The reason you now have a feeding tube is to help you have the best quality of life by giving you all the nutrition you need. It's quite normal to feel fed up, you will have had to make some changes since you have had a feeding tube. Make sure you speak to someone and let them know how you feel so they can help. You may prefer to speak with a friend or family member, or a healthcare professional.

You can also talk to your Nutricia Homeward Nurse about your tube and how you are feeling, as well as your dietitian and nutrition team. It is very important people know how you feel so they can make sure you get the help and support from the right professionals to deal with any worries or concerns.

Remember, there are many, many people who have feeding tubes — you are not on your own.



CAN I STILL BRUSH MY TEETH?

Yes, you can. It's really important to brush your teeth and keep them healthy as well as keeping your breath fresh.



I AM A BIT SCARED/WORRIED ABOUT GOING HOME.

Make sure you ask lots of questions so you know what will happen when you get home.

Have all the important telephone numbers for your dietitian, Nutricia Homeward Nurse, and Nutricia Homeward in one place so if you have any questions you know who to phone.

Before you leave hospital make sure you know how much stock you will be getting (tube feed, giving sets, syringes); ask someone to explain what you will need to do to order more when you need it. If you can, see if it's possible to organise the delivery while you are still in hospital - it will make it easier. Try to make sure you understand as much as you can before you go home by asking questions and taking notes of everything that is being said because people tend to forget so much of it.



FACT SHEET 4: DEALING WITH WORRIES AND CONCERNS

WHAT SIGNS SHOULD I LOOK OUT FOR THAT MIGHT MEAN THERE'S A PROBLEM?

Having a tube placed is an operation where they make a small incision into your stomach and place a short tube. After the operation it is normal to have some pain around the tube, known as the stoma site, for a few days, and for it to feel sore for around a week while it is healing.

Sometimes people who are new to tube feeding can experience a few issues when they first start, if you feel sick, have a painful stomach, or feel very hot and sweaty two hours after the tube was put in, speak to your doctor as soon as possible and follow their advice.

If you notice redness, blood or swelling around the site of your tube, tell your doctor and follow the advice they give you. Your dietitian will create a tube feeding routine for you to try to prevent these symptoms from occurring, but if you are experiencing any side effects contact your dietitian so they can help you alter your routine.

WHAT SIDE EFFECTS MIGHT I HAVE AT FIRST? WHEN WILL I START TO FEEL BETTER?

At first, you might experience some funny sensations in your stomach, or even some stomach cramps. These should go away after a short time, but if they don't and the symptoms get worse as you have your tube feed, stop the tube feed and contact your doctor straight away.

Side effects will vary in everyone, you might find you don't have any side effects at all. If you do feel anything different, uncomfortable or painful, please ensure you inform your doctor as soon as possible.

WHAT IF I GET SICK, WHAT SHOULD I DO?

If you feel sick wait for 1-2 hours before you have your tube feed. If you don't feel better, if you still feel sick, are sick, or have diarrhoea, speak to your doctor.

If the medicines you are taking make you feel poorly speak to your doctor to see if there are other medicines you can take instead.

WHAT IF THE TUBE COMES LOOSE OR FALLS OUT?

If your feeding tube becomes loose, see if you can use some tape to tape it down as close to the entry site as possible and then contact your nutrition team immediately.

If your feeding tube comes out during feeding then it is important to stop feeding immediately and inform your nutrition team.

If your feeding tube falls out and the balloon has deflated, please inform your nutrition team immediately and follow their guidance. You may need to attend hospital as soon as possible (depending on how long you have had the feeding tube in place), or they may advise you to place another device (already provided to you) into the hole to keep it **open** and then you to call your Nutricia Homeward Nurse to see if they can visit you at home to replace your tube. In some cases such a device is not provided and so prompt action is required to ensure another tube can be placed as soon as possible.

If your feeding tube falls out and the balloon is still inflated, please attend your local hospital and inform your nutrition team you are on your way and the reason for this.

HOW CAN I PREVENT THE TUBE FROM GETTING BLOCKED?

Flushing your tube before and after any tube feed or medication helps to prevent the tube from getting blocked. If you are doing this but your tube becomes blocked try flushing the tube with 30-50ml of warm or carbonated water — just as your nutrition team or Nutricia Homeward Nurse will have shown you — only use carbonated water and not other fizzy drinks.

If this does not unblock the tube, then try the ‘pull and push’ technique. Using a 60ml syringe, gently draw back on the feeding tube, then pause and push a small amount of water back into the feeding tube; you can repeat this process a few times to see if it can help to dislodge the blockage.

Flushing your feeding tube helps the tube to remain clean and free from anything that might cause a blockage.

WHAT IS OVER-GRANULATION AND WHAT DO I DO ABOUT IT?

Over-granulation is when there is too much skin tissue that comes to the surface of the wound. It happens when the skin around the tube starts to heal; the skin can look pink coloured, bumpy and shiny. If too much of this forms it can prevent the healing process, and lead to a wound that does not heal.

Following the feeding tube after-care advice provided by your healthcare professionals, such as:

- Cleaning the site daily
- Keeping the stoma site dry
- Preventing excessive friction by keeping the fixation plate close to your skin
- Prevent over-granulation tissue from developing by inspecting it daily to look for signs of redness, swelling and pain.

Inform your nutrition team as soon as you notice anything different or the site becomes painful. If it does develop your nutrition nurse can discuss with you how to treat the area and reduce the granulation.

WHAT IF THE PUMP BREAKS DOWN?

Always make sure your pump is charged or plugged in. If you can't make it work call Nutricia Homeward on 0800 093 3672 and they will arrange to get a new one to you.

You can find a troubleshooting guide on the Nutricia Homeward website to help if you have any problems with the pump — it can be found at nutriciahomeward.co.uk.



FACT SHEET 5: CHECK LISTS

THINGS TO DO EVERY DAY

Your Nutricia Homeward Nurse will show you the things you need to do every day.

THINGS TO CHECK BEFORE YOU HAVE YOUR MEDICAL NUTRITION

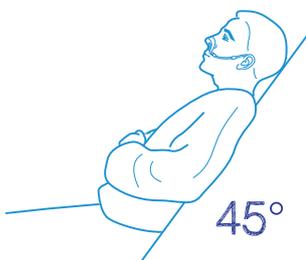
Check the tube feed label, make sure it has your name on it and is still in date.

Hygiene:

Make sure the tube is in the right position.

Flush the tube with water before and after your feed or medication.

Make sure you are sitting at a 45° angle.



THINGS TO CHECK FOR FEEDING AWAY FROM HOME

Use this check list to help you plan so you have everything you need, whatever you're doing:

- Tube feed
- Medication, if applicable
- Water for flushing
- Syringes
- Feed container
- Feeding pump (if needed) and pump charger
- Spare giving sets, syringes, and sterile water
- Spare feeding tube (if applicable)
- Towels, wipes, tape
- A way to hang the tube feed (usually in a carry system)
- Plastic containers/bags to store feeding supplies
- Phone number for your healthcare provider
- Your tube feeding care plan.

You can plan holidays in the UK and abroad, and Nutricia Homeward can help you with your tube feed and equipment. It is important to speak to Nutricia Homeward two weeks before you go on a UK holiday and six weeks before you take a trip abroad.

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Accurate at time of publication: December 2019.

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AMN0494E-12/19



FACT SHEET 6: PERSONAL LIFE

CAN I HAVE A NORMAL RELATIONSHIP?

When you have a feeding tube you can still have a relationship with someone.

AM I GOING TO BE ABLE TO HAVE CHILDREN?

There are many different reasons why people need to have feeding tubes. Your nutritional needs will change during pregnancy so it is important to discuss your plans with your doctor and healthcare professionals; doing so will help to ensure you get the support you need whilst tube feeding during pregnancy.

Please make sure you discuss with your healthcare professionals and ask all the questions you have so you are fully informed and have the necessary information to plan for your future.

HOW CAN I EXPLAIN TUBE FEEDING TO MY FRIENDS?

Your feeding tube may be hidden under your clothing, however, your giving set may be visible. It is totally up to you what you tell your friends — you have control over what you want them to know.

If you need to have your tube feeds when you are at school or work, or with your friends, it is completely up to you to give them as much information as you want to.

If you don't feel ready to discuss details about your feeding tube you could direct them to the PINNT website (pinnt.com) to answer their queries.

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AMN0494F-12/19



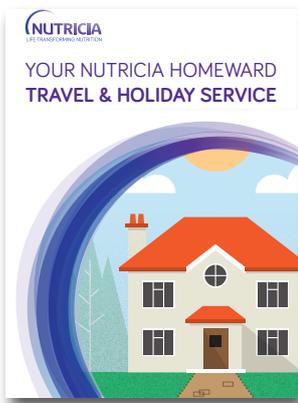
FACT SHEET 7: GOING ON HOLIDAY

CAN I GO ON HOLIDAY?

Yes, you can still go on holiday when you are tube feeding. Discuss your holiday plans with your nutrition team so they can give you advice about managing your tube feeding when you are away.

If you have been registered with the Nutricia Homeward service for three months, we may be able to arrange for your tube feed delivery to be made to your home address with a special travel trunk for you to take with you or deliver to your destination.

There is a booklet designed to tell you everything you need to know about the holiday and travel support services available from Nutricia Homeward, it can be downloaded from nutricia.homeward.co.uk.



WILL I STILL BE ABLE TO GO SWIMMING AND PLAY SPORTS?

You can play sport with a feeding tube although rough contact sports are not advised as they can cause the feeding tube to become dislodged.

You can also swim with a feeding tube using a waterproof dressing to protect the site once the site has healed.

WHO DO I CONTACT?

When you have talked about your holiday plans with your nutrition team and your doctor, you can contact Nutricia Homeward on 0800 093 3672 to talk about the holiday service.

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AMN0494G-12/19



FACT SHEET 8: SCHOOL

WILL I BE ABLE TO GO TO SCHOOL?

As long as you have discussed this with your doctor and nutrition team, and you feel well enough, you can go to school with a feeding tube. There will be support for both you and your school from your healthcare professionals to help you return to school.

Useful things for your school to have a copy of:

- Feeding routine
- Information about how to care for the feeding tube
- Spare ancillaries, e.g. giving sets, syringes
- A copy of the guidelines about hand washing procedures
- Guidelines and information about what to do if the tube comes out.

Your Nutricia Homeward Nurse will even visit you in school if you would like, to ensure you do not miss vital classes.

WHAT WILL I TELL MY FRIENDS?

You can tell your friends exactly what you would like them to know when you feel ready to discuss it with them. Your feeding tube may be hidden under your clothing, however, your giving set may be visible. It's your choice, tell them about your feeding tube and the tube feeds only if you want to.

If you need to have your feeds when you are in school or with your friends, it is completely up to you to tell them how much you want them to know.

WHAT HAPPENS WHEN I NEED TO TUBE FEED AT SCHOOL?

Your Nutricia Homeward Nurse can come and see you at school and train your teachers to support you with your tube feeds at school.

Nutricia also provide a 'rucksack' (Go-bag) that will carry your tube feed. You can wear this on your back as a normal rucksack, which means you can still be moving around when you are having your tube feed.

WHAT HAPPENS ABOUT PLAYING SPORT?

You can play sport with a feeding tube, although rough contact sports are not advised as they can cause the feeding tube to become dislodged.

You will need to talk to your doctor and nutrition team to make sure they are happy for you to play sports. You can either stop your tube feed while you are playing and start again when you have finished what you are doing, or plan your tube feeds around the sport you wish to play, as long as you have discussed this with your doctor and nutrition team.

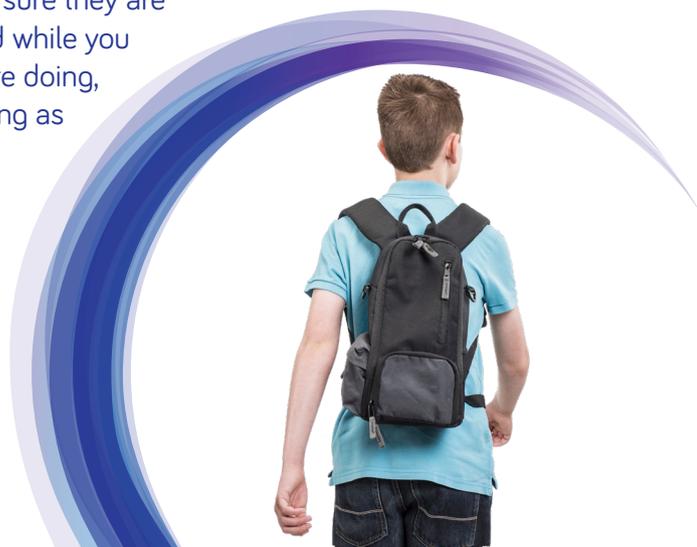
You can also swim with a feeding tube, using a waterproof dressing to protect the site once it has healed.

This information is intended for patients who have been prescribed a tube feed by a healthcare professional.

Accurate at time of publication: December 2019.

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AMN0494H-12/19



FACT SHEET 9: COLLEGE

WILL I BE ABLE TO GO TO COLLEGE?

Yes, you will be able to go to college. You will need to let the college know about your medical condition and feeding tube so they can provide any additional support you may need to manage your feeding tube.

HOW CAN I EXPLAIN TUBE FEEDING TO MY FRIENDS?

Tell your friends when you feel ready to discuss your feeding tube and tell them only what you want them to know.

If you do not feel ready to discuss details about your feeding tube you could direct them to the PINNT website (pinnt.com) to answer their queries.

WHAT HAPPENS WHEN I NEED TO TUBE FEED AT COLLEGE?

Making sure your college is aware that you have a feeding tube means they will be able to do what they can to support you. Discuss with the college about needing an appropriate environment where you can tube feed when you are on site if you need to.

WHAT HAPPENS IF I NEED/WANT TO PLAY SPORT?

You can play sport with a feeding tube. You will just need to have a discussion with your doctor and nutrition team to make sure they are happy for you to do so.

You can also swim with a feeding tube, using a waterproof dressing to protect the site once it has healed.

Rough contact sports are not recommended as they can cause the feeding tube to become dislodged.

Discuss your tube feeding routine with your doctor and nutrition team so they can help plan and advise around your sporting activities.

WILL I BE ABLE TO GO AWAY TO COLLEGE?

Yes, you will need to let your current healthcare professionals know that you are planning to move away to college so they can transfer your medical information over to the healthcare professionals in your new location.

WHAT DO I NEED TO KNOW WHEN I LIVE ON MY OWN?

You will need to be able to care for the feeding tube yourself so should have a good knowledge of:

- Hand-washing practices
- How to clean the feeding tube
- How to push and rotate the feeding tube daily
- How to administer your tube feed, flushes and medication correctly and safely
- Have a copy of your feeding schedule
- Understanding what to do in case the feeding tube comes out
- Be able to arrange your monthly deliveries of tube feed and ancillaries
- Have the contact numbers for the healthcare professionals who can help if you are having any problems with your tube feeding.

You need to make sure you know who to contact if you feel unwell or you experience any pain and/or discomfort around your stoma site or when tube feeding.

Your local nutrition team and current Nutricia Homeward Nurse will provide you with this information for your new home. You also need to know where to go if your feeding tube falls out or comes loose — this is usually the Accident and Emergency Department.

DO I NEED TO REGISTER WITH A NEW DIETITIAN?

This depends on how far away you are moving. If you are moving to another region or county, your current dietitian will make a referral to the closest dietetic team to your new address to inform them of your medical history and nutrition needs and requirements.

HOW DO I KNOW MY RECORDS WILL BE TRANSFERRED?

Your current dietitian will ensure you receive a copy of the referral letter to your new team. The new team will then contact you to make an initial appointment and go through your notes with you during this session.

All documentation is now electronic so your new team will have access to all of your notes as soon as your referring dietitian provides them with a link to these encrypted documents.

WHAT ABOUT THE HOLIDAYS?

If you will be regularly returning to your original address during the college holidays, then your local dietitian and your college dietitian may decide to share your care and keep each other updated on your progress. This may not be necessary in all cases and needs to be discussed with your healthcare professionals so you can decide and organise what's right for you and your care.

WHAT ABOUT DELIVERIES?

You can let Nutricia Homeward know that you will be at a different address for over the holiday period so they can make sure the deliveries are made to the correct location.

WHO DO I CONTACT IF I HAVE ANY PROBLEMS?

Your healthcare professionals will provide you with details of who to contact. You may have two different sets of contact details if you are receiving shared care. Make sure you have all of these details listed so you know who you need to contact.

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AMN0494I-12/19



FACT SHEET 10: UNIVERSITY

WHAT ABOUT GOING TO UNIVERSITY?

Yes, you will be able to go to university. You will need to let the university know about your medical condition and feeding tube, so that they can provide any additional support you need to manage your tube.

Your Nutricia Homeward Nurse team will inform the same team local to your university. Your tube feeds can be sent to your new address during the time you are away.

WHAT DO I NEED TO KNOW WHEN I LIVE ON MY OWN?

You will need to be able to care for the feeding tube yourself so will need a good knowledge of:

- Hand-washing practices
- How to clean the feeding tube site
- How to push and rotate the feeding tube daily
- How to administer your tube feed, flushes and medication correctly and safely
- Have a copy of your feeding regimen
- Understanding what to do in case the feeding tube comes out
- Be able to arrange your monthly deliveries of tube feed and ancillaries
- Have the contact numbers for the healthcare professionals who can help if you are having any problems with your tube feeding.

You need to ensure you know who to contact in the event you feel unwell or you experience pain and discomfort around your stoma site or when tube feeding. Your local nutrition team and current Nutricia Homeward Nurse will provide you with this information for your new home.

You also need to know where to go in the event your feeding tube falls out or comes loose — this is usually the local Accident and Emergency department.

DO I NEED TO REGISTER WITH A NEW DIETITIAN?

This depends on how far away you are moving. In the event you are moving to another region or county, your current dietitian will make a referral to the closest dietetic team to your new address and inform them of your medical history and nutritional needs and requirements.

HOW DO I KNOW MY RECORDS WILL BE TRANSFERRED?

Your current dietitian will ensure you receive a copy of the referral letter to your new team. The new team will then contact you to make an initial appointment and go through your notes with you during this session. All documentation is now electronic and will be accessible by your new team as soon as your referring dietitian provides them with access to these encrypted documents.

WHAT ABOUT THE HOLIDAYS AND MY DELIVERIES?

You will need to inform Nutricia Homeward about all of your holidays and when you will be returning home. Deliveries and nursing input can then be coordinated around these times.

WHO DO I CONTACT IF I HAVE ANY PROBLEMS?

Your healthcare professionals will provide you with details of who to contact. You may have two different sets of contact details if you are receiving shared care. Make sure you have all of these details listed so you know who you need to contact.

If you experience any issues or problems with deliveries, or for change of address dates, you can contact the Nutricia Homeward Customer Service team on 0800 093 3672.



FACT SHEET 11: WORK

CAN I GO TO WORK?

Yes, you can work; you may find it useful to let your employers know about your medical condition and feeding tube, so they can provide any additional support you need to manage your tube.

Your Nutricia Homeward Nurse can visit you at work if you would like them to. They can help you to assess your working environment and support you with your tube feeding while you are at work.

WHAT WILL MY EMPLOYERS/COLLEAGUES NEED TO KNOW?

Your employers will need to know how they can best support you to manage your feeding tube when in your work environment. Your feeding tube will be hidden under your clothing, although the giving set may be visible. It's your choice to give your colleagues as much information as you feel comfortable with.

WHAT ABOUT LUNCHTIMES AT WORK?

Tell your work colleagues when you feel ready to discuss your feeding tube and tell them only what you feel you want them to know. If you do not feel ready to discuss details about your feeding tube, you could direct them to the PINNT website (pinnt.com) to answer their queries.

If you are unable to have your nutrition via your mouth, what you do on your lunch breaks is entirely up to you. You may decide that you would still like to sit and chat with your work colleagues and use this as a socialising time, or you may decide you would rather spend the time going for a walk or run.

WHAT ABOUT HAVING A TUBE FEED AT WORK?

Ensuring that your employer is aware of the fact you have a feeding tube means they can do what they can to support you to provide an appropriate private environment for you to be able to administer your tube feed whilst on site if needed.

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AMN0494K-12/19



FACT SHEET 12: NASOGASTRIC TUBE

WHAT IS A NASOGASTRIC FEEDING TUBE?

A nasogastric (NG) feeding tube is a type of temporary feeding tube that is usually kept in place for weeks or months rather than years, and is used to give you your nutrition, water, and medications. It is a thin plastic tube, which is placed through your nose, it then goes down your throat and then into your stomach.

Once the NG feeding tube is in the right position a very small wire that is inside the tube will be taken out; the wire helps put the tube into the stomach. There is a clamp/clip at the end of the NG feeding tube, which will be shut when it is not in use.

The end of the feeding tube is usually taped to your cheek when it is not in use, to stop it from getting in your way, and to try to stop it being pulled out by accident.

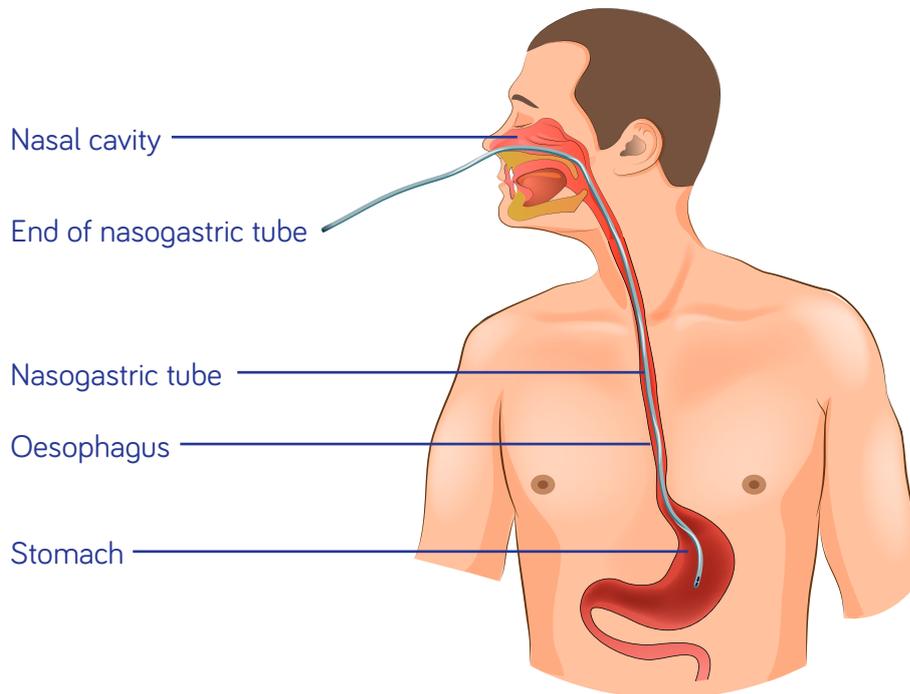


Your nutrition will be given in a specially prepared liquid feed, which can contain all the nutrients you need in a day. The liquid feed can be given by attaching a syringe to the end of your tube or by using an electronic feeding pump. Your dietitian will discuss these options with you and your Nutricia Homeward Nurse will show you how to use the tube.



It is important to flush the NG feeding tube with water before and after feed and medications have gone down it, to stop it from getting blocked.

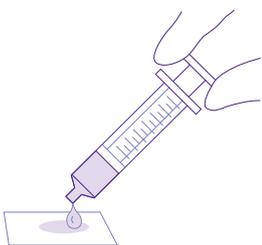
HOW DO I CHECK THE POSITION OF MY TUBE (pH and measurement)



It is **very important** to always check the position of the NG feeding tube before using it. This is because the tube can move out of place. If this happens, the end that should be in your stomach could be in your lung. If the tube feed goes into your lungs it can cause you to cough violently, which can be very dangerous. Your healthcare professional will teach you how to check the position of the NG feeding tube before you leave hospital.

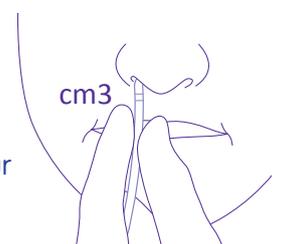
To check that the NG feeding tube is in the right position you must check the pH before each use:

- Always wash your hands thoroughly before doing anything with your tube. Check the handwashing guidelines to make sure you are washing them properly
- Use a 60ml syringe to draw a small amount of stomach fluids from the NG feeding tube — this is called an ‘aspirate’
- Place this fluid onto an unused strip of pH paper, it should hopefully show an acidic pH of less than 5, which means the tube is in the correct position in the stomach.



Every day you should also check and write down how long the NG feeding tube is:

- The tube is labelled in cm
- Check how long the NG feeding tube is by looking at the number by your nose, this will tell you the place of the tube, the number should stay the same each time you check it
- If this number changes, it may mean the NG feeding tube has moved position. Contact your nutrition nurse for advice if this happens.



WHAT DO I DO IF I AM UNABLE TO GET ASPIRATE OR THE PH NUMBER IS TOO HIGH?

There can be different reasons why the pH sometimes reads high, but this does not always mean the tube is in the wrong place. There are some things you can try if the pH is reading too high, or you are unable to get an aspirate:

- Firstly, check how long the tube is, following the steps above. If this has changed a lot it may mean the tube has moved and is no longer in the stomach, you should contact a healthcare professional, e.g. nutrition nurse, if this is the case
- You can try lying on your left side for 10-20 minutes then try again to get stomach fluid (aspirate)
- If you have tried a few times and it hasn't worked, stop and leave it for 30 minutes, then try again. This may help
- If it's OK for you to have a drink, try drinking a little then try to get stomach fluid (aspirate) again afterwards.

If none of this works you will need to contact a healthcare professional, e.g. nutrition nurse, for advice. It might be the NG feeding tube has moved out of place and it may need to be put in again.

WHAT DO I DO IF MY TUBE MOVES OUT OF PLACE?

It depends on where you live — some patients will need to go to hospital to have a new NG feeding tube placed. There will be a plan in place for you and your dietitian or Nutricia Homeward Nurse will be able to tell you what you would need to do.

If you can eat and drink, and the NG feeding tube is just to help you get a top up of nutrition, it won't be an emergency and you will be able to go to hospital the following day if the tube came out at night. If the NG feeding tube is the only way for you to get your nutrition, water and medication, then this is more of an emergency and you may need to go to hospital straight away.

CAN I SWIM?

You can swim with an NG feeding tube in place, make sure the end of the tube is closed and the clip/clamp is shut — this will stop water getting in. Make sure the tape that is keeping the tube in place on your face is waterproof before going swimming.

It is very important to know that NG feeding tubes can move out of place so you will need to be careful and may need to limit some of your activities while you have the tube.

CAN I DO SPORTS?

Having an NG feeding tube should not stop you from playing sports, but as the tube can easily move out place, rough and contact sports would not be recommended. Also, it would not be recommended to have a tube feed running when playing sport.

FACT SHEET 13: USEFUL WEBSITES AND SUPPORT GROUPS

PINNT

A support group for people receiving artificial nutrition.

pinnt.com

HALFPINNT

A support group for young people receiving artificial nutrition.

pinnt.com/Support/Half-PINNT.aspx

TUBEFEEDING.CO.UK

A support website dedicated to people who are tube fed, their families and carers.

NUTRICIA HOMEWARD

Nutricia Homeward is an additional service for Nutricia patients, carers or parents — available 24 hours a day — allowing people who are registered with Nutricia Homeward to place their next months order at a time that suits them.

nutriahomeward.co.uk

NUTRICIA HOMEWARD APP

A safe, secure and simple way of getting the support you need from your Nutricia Homeward Nurse.

What is the Nutricia Homeward App?

- A simple way of connecting with your Nutricia Homeward Nurse
- If you have a smart phone or tablet, search Nutricia Homeward in Google Play or the App Store and download to app
- Your Nutricia Homeward Nurse will advise you of your ID number and password
- Visit nutriahomeward.co.uk for more information on the Nutricia Homeward services and to register for online ordering

NUTRICIA

A medical nutrition company that specialises in the delivery of advanced medical nutrition for the very young, old, and the sick.

nutricia.co.uk

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AMN0494N-12/19

