



TUBE FEEDING

THINGS I HAVE LEARNT
ALONG THE WAY

**THIS BOOKLET HAS BEEN
WRITTEN BY PEOPLE LIVING
WITH TUBE FEEDING AND/
OR THEIR HEALTHCARE
PROFESSIONAL FOR PEOPLE
LIVING WITH TUBE FEEDING.**

WHAT YOU HAVE IN YOUR HANDS IS A COLLECTION OF THE MOST USEFUL HINTS AND TIPS FOR LIVING WITH TUBE FEEDING, WRITTEN BY THE PEOPLE WHO KNOW BEST — PEOPLE WHO ARE BEING TUBE FED, THEIR FAMILIES OR CARERS, AND THEIR HEALTHCARE PROFESSIONALS.

AN ENTERAL NUTRITION PRODUCT, WHICH MAY BE MOST COMMONLY REFERRED TO BY YOUR DIETITIAN OR HEALTHCARE TEAM AS A 'TUBE FEED', IS A WAY OF GETTING YOUR BODY THE NUTRITION IT NEEDS. A TUBE FEED IS A LIQUID FORM OF NOURISHMENT THAT'S DELIVERED TO YOUR BODY THROUGH A FLEXIBLE TUBE. FOR THE PURPOSE OF THIS BOOKLET WE WILL USE THE TERM 'TUBE FEED'. THE NUTRIENTS WITHIN THE LIQUID ARE SIMILAR TO WHAT YOU WOULD GET FROM NORMAL FOOD, AND ARE ALSO DIGESTED IN THE SAME WAY. TUBE FEEDS CONTAIN ALL OF THE NUTRIENTS YOU NEED ON A DAILY BASIS, INCLUDING CARBOHYDRATES, PROTEINS, FAT, VITAMINS, MINERALS, AND WATER.

IT IS ESTIMATED THERE ARE OVER 30,000 ADULTS WITH A VARIETY OF DIFFERENT CONDITIONS LIVING WITH TUBE FEEDING IN THEIR OWN HOMES, OR CARE HOMES, IN THE UK.

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TUBE FEEDING IS UNIQUE TO EVERYONE, AND WE ALL MANAGE IT IN DIFFERENT WAYS. THE TIPS IN THIS BOOK ARE RELEVANT TO PEOPLE LIVING WITH TUBE FEEDING, THEIR FAMILIES AND CARERS.



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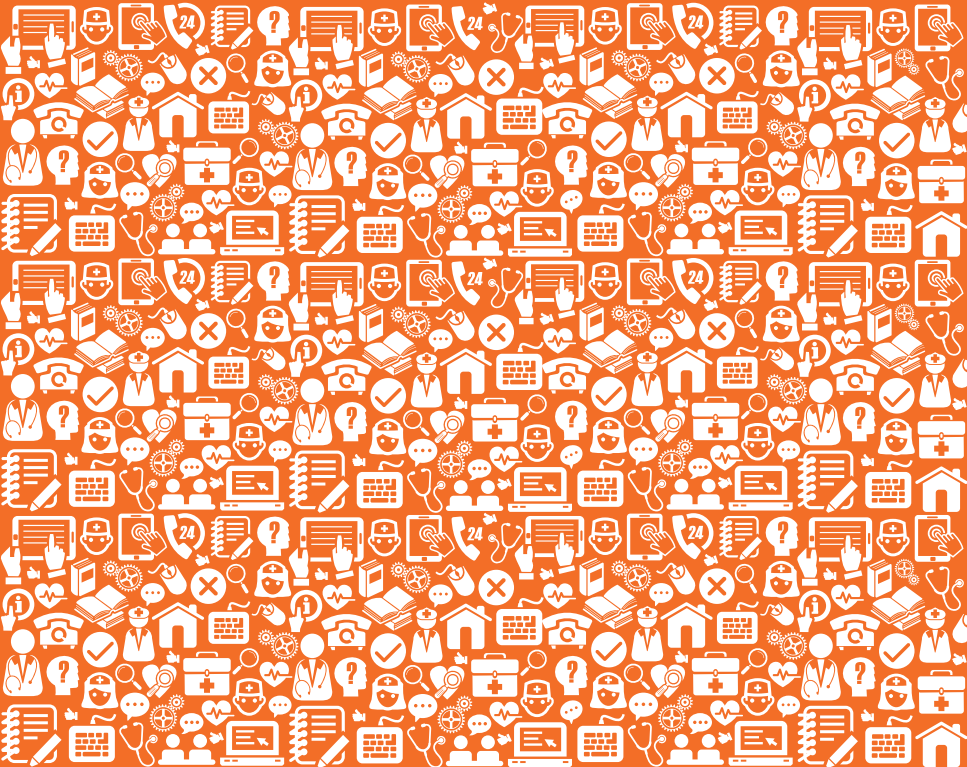


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GENERAL INFORMATION



WHAT IS TUBE FEEDING?

Tube feeding is a way of getting your body the nutrition it needs. A tube feed is a liquid form of nourishment that's delivered to the body through a flexible tube. The nutrients within the tube feed are similar to what you would get from normal food, and are also digested in the same way. Tube feeds contain all the nutrients you need on a daily basis, including carbohydrates, protein, fat, vitamins, minerals, and water.

Q1

WHAT IS THE BEST TUBE FEEDING ROUTINE?

When it comes to deciding on the best tube feeding routine, your dietitian will discuss the options with you. There are three ways that the tube feed can be given:

Continuous feeding — the tube feed (e.g. 1000ml or 1500ml) is given slowly over a number of hours using a pump that controls the flow rate. Continuous feeding can take place during the day or overnight, or a combination of both.

Bolus feeding — tube feeds are given in smaller volume (e.g. 200ml), one at a time, several times throughout the day with the use of a pump, a syringe or gravity.

Combination of both — a combination of these routines can be chosen based on a number of factors; for example, giving you more flexibility.

Always discuss with your dietitian/healthcare team first before changing the feeding routine as they can help choose your optimal feeding method.

Q2

Q3

WHEN CAN I START TUBE FEEDING?

Before tube feeding can begin, the tube has to be placed. The procedure for feeding tube placement usually takes place in hospital and depends on the type of tube that has been recommended by the healthcare team. After the feeding tube has been placed you will be given advice by the healthcare team and they will explain how long you might have to stay in hospital.

The timing of when to start using your feeding tube varies greatly, however you will be kept informed by the healthcare team. You will be discharged home when feeding is established and well tolerated. This usually depends on the condition and confidence with the tube feeding process. It is important to follow the advice that was given by the healthcare team.

Q4

DOES TUBE FEEDING MEAN I HAVE TO STAY IN HOSPITAL?

Tube feeding does not mean you have to stay in hospital. Tube feeding at home is a life-changing experience and will affect many aspects of your life, but it is manageable and will eventually fit into your everyday routine and life. There are many different organisations and groups alongside your healthcare team to help support you in this.

Q5

HOW WILL TUBE FEEDING HELP ME?

The reason you have been recommended to start tube feeding is because you are not receiving the right amount of nutrition, or you are unable to swallow or tolerate food by mouth. Receiving all the nutrients you need through tube feeding may support your daily nutritional needs.

IS TUBE FEEDING SAFE?

Advances in the sciences of food, food technology, nutrition and medicine have established tube feeding as a standard measure for restoring or preserving nutritional health in chronically or critically ill patients. Occasionally, some people will experience challenges when adjusting to tube feeding. While it's important to be aware of potential tube feeding problems, it's important to remember these problems can largely be anticipated and prevented.

Q6

HOW LONG CAN I SURVIVE BEING TUBE FED?

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

Q7

HOW LONG WILL I NEED TO BE TUBE FED?

Some people need tube feeding for short periods of time, while others may need it long term. The healthcare team will discuss the expected length of time you will require a feeding tube. Progress will be reviewed regularly by your dietitian and healthcare team.

Q8

HOW CAN I COPE WITH THE DECISION TO TUBE FEED?

Feeling overwhelmed is perfectly natural when starting anything new. Fully understanding the reason why tube feeding has been recommended for you, and the implications of this, are really important in helping you cope and feel calm during this period.

Q9

Q10

HOW DO I KNOW IF THIS IS THE BEST OPTION FOR ME?

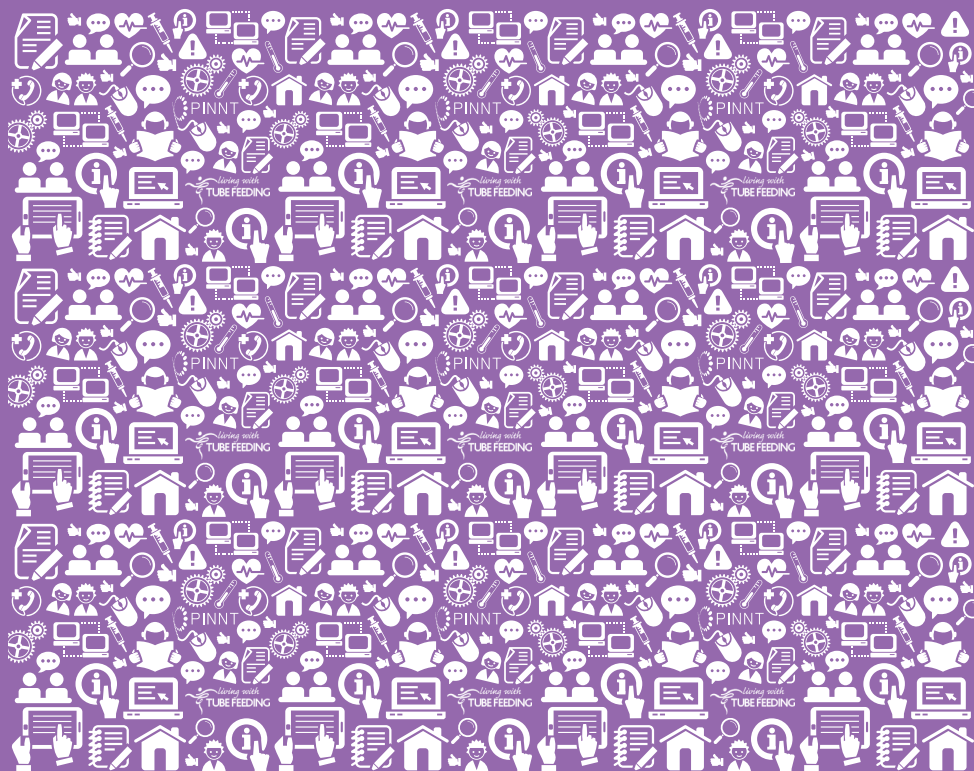
You need to be confident enough to probe and ask “why?” If you don’t understand, don’t be afraid to ask your healthcare team again. You only know your options if you ask. And if you find information isn’t forthcoming, don’t give up, keep on asking and you’ll eventually get your answer.

Q11

I'M FEELING BETTER, CAN I STOP TUBE FEEDING?

The objective of tube feeding is to provide the right amount of energy, protein and nutrients your body needs that may support your recovery. Tube feeding should be continued until you can receive all the nutrients you require by mouth. Therefore, always discuss with your healthcare team before stopping tube feeding or altering anything in your dosage or routine.

PRACTICAL ADVICE



WHAT EQUIPMENT DO I NEED TO START TUBE FEEDING?

All the equipment you need to start tube feeding at home will be given to you by your healthcare team, who will also explain how to use it. You will receive training in hospital (and/or at home) by the healthcare team (and/or the home enteral tube feeding provider) and, if possible, should be given plenty of time to practice before being discharged home.

The equipment for home may include the following:

- A feeding pump to deliver the feed through the giving set at a controlled rate recommended by the dietitian
- 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
- A giving set — a flexible tube that helps to deliver the 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 administer feed, water and medication. Syringes come in different types and different sizes (e.g. 10ml or 60ml)
- Additional equipment, e.g. pH paper, container, will be provided by the healthcare team or the home enteral tube feeding provider.

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

CAN I INCREASE THE RATE OF THE PUMP TO GET IT OVER WITH QUICKER?

Q2

When tube feeding starts becoming more familiar, you might begin to look for ways to optimise your tube feeding routine. Based on your mobility, your social or working life or your daily activities, you might want to have more flexibility to structure your day in the way you'd like that suits your lifestyle.

Just be sure to talk to your dietitian or a member of your healthcare team first before changing the feeding rate as delivering the feed too fast may cause complications, such as bloating, cramps, nausea and vomiting — and remember, they can help you find the optimal tube feeding routine that best fits into your life.

CAN I PUT MY OWN FOOD DOWN THE TUBE?

Q3

It is not recommended to put anything else other than the prescribed feed, water and medications through the tube. This can lead to tube blockages, tube replacement, and can potentially cause infections due to contamination.

WHAT SHOULD I KNOW BEFORE GOING HOME WITH TUBE FEEDING?

Q4

Before you go home, it's important to know why tube feeding is the best option for you. You will also need to receive training and know the basics of how to administer tube feeding, how you can order or receive the tube feed and accessories, and what kind of support you can expect at home. Make sure you receive all the information from your healthcare team before leaving hospital. If you do not feel confident or are unsure of what to do, ask the right questions to feel more confident.

Q5

WHAT'S THE BEST POSITION DURING TUBE FEEDING?

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

Q6

CAN I TAKE A BREAK DURING FEEDING?

It is important to remember that giving sets used for tube feeding should be discarded after 24 hours. If giving sets are connected, disconnected and reconnected multiple times a day, the risk of any contamination is increased. Please consult your dietitian with regard to taking breaks during feeding.

Q7

WHAT FLAVOUR IS THE FEED?

Most tube feeds are not flavoured however there are some small volume tube feeds that are flavoured. Oral nutritional supplements, available in small bottles, are used for bolus feeding and come in a variety of flavours like vanilla, strawberry and chocolate.

Q8

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

Tube feeds should always be administered at room temperature (20-25°C). Cold feeds can lead to gastrointestinal intolerance problems such as upset stomach, nausea, vomiting, or diarrhoea. If you warm up the tube feed (such as with hot water or in a microwave), there's a risk of 'cooking' the formula, which will reduce its nutritional value. Warming up the tube feed can also increase the risk of infections.

WHAT IF I WANT A DRINK BECAUSE I FEEL THIRSTY? WHAT TYPES OF DRINK ARE ACCEPTABLE?

Q9

Your dietitian will recommend the correct fluid volume and advise you on altering the prescribed fluid volume in hot weather/ during exercise/illness.

Whether or not you can drink and what kind of drink is suitable depends on your personal condition. If you have difficulty swallowing, drinking could pose a risk of choking and with that, infections. Discuss with your healthcare team what is appropriate in your medical condition.

WILL I GET HUNGRY? WILL I FEEL FULL AND SATISFIED?

Q10

Tube feeding can give the sensation of fullness, the same way you would by eating food. However, when the feed is administered continuously in small amounts over the course of a day, you may feel less sensation of fullness. If your intake is less than the recommended amount, or if you take more time in between the feeds, you can feel hungry. If you feel hungry for a longer period of time, discuss with your dietitian who will review your feeding regimen and make changes if necessary.

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

Q11

With good care of your tube, the colour should not change. However if the tube has been in place for a long period of time some discolouration may occur due to the feed and medications. If you are concerned about the tube and its colour, please contact your healthcare team.

Q12

HOW DO I LOOK AFTER THE TUBE?

Proper care of your feeding tube will go a long way in preventing problems. For preventative maintenance for your tube, follow these steps:

1. Clean the skin around the stoma site* with saline solution or as instructed 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 thoroughly.
3. Percutaneous Endoscopic Gastrostomy (PEG) only: You should follow the guidelines given to you with regards to advancing and rotating your tube. This is important to keep the stoma site healthy and prevent buried bumper (the tube becoming embedded in the stomach wall).
4. Balloon retained gastrostomy only: You should follow the guidelines given to you by your healthcare team with regards to checking and replacing the water in the balloon.

If you are concerned about the stoma site or tube, please contact your healthcare team.

Q13

ARE THERE SUPPORT GROUPS FOR HOME TUBE FEEDERS, LIKE ME?

Although your friends and family will support you, you may want to speak to other people that are also tube fed. PINNT is a support group for people receiving home enteral nutrition. The charity has a website with useful resources and members benefit from regular meet-ups allowing for a chance to make friends.

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

WHAT DO I DO IF THE TUBE FEED PACK/BOTTLE LEAKS?

Q14

The materials used to make the tube feed packs/bottle are sturdy, however in rare case there is the possibility they can leak. In general the safest and easiest thing to do is to stop feeding and check the feed and all other equipment. It is safer to discard the feed pack and the giving set and start again with a fresh pack and giving set.

ANY TIPS ON STORING EQUIPMENT AND SUPPLIES?

Q15

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. Once you open the tube feed it is advised you handle it in a sterile way. Always check the best before date and shake the tube feed before opening. Rotating the tube feed and using the oldest first can help to reduce the risk of the tube feed going out of date. The tube feeding provider delivery driver may be able to do this for you.

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

Q16

The tube feeding provider will deliver the tube feed and equipment to your home. They will contact you each month to check the supplies you need and then arrange a delivery for the coming month. Count the feed and equipment supplies each month and let them know how many of each item you have. They will calculate how much feed and equipment you require for the next month so that you do not end up over stocked.

There are two main ways they may manage this process; by phone or using an online ordering system (if applicable). Some tube feeding providers can also arrange your next delivery by email, text or through a translation service if needed.

Q17

DO I STILL NEED TO GO TO THE DENTIST?

It is very important that you still visit your dentist and that they know you cannot manage to eat or drink. We all need to care for our mouths and teeth, and your dentist may be able to offer some good advice and care if you have limited or no oral fluids.

Q18

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

It is important to return the pump to your tube feeding provider when you have finished using it. You can arrange to return the pump by contacting them on the phone. They will arrange to collect all the equipment and pay for any charges related to the return of equipment.

Q1

HOW CAN I TAKE MEDICATIONS?

If you are taking several medications a day your healthcare team may advise you to take the medication through the feeding tube. You will need a syringe, your prescribed medications, and water (sterile, tap or cooled boiled water). Since your feeding tube has been designed to take liquids only, where possible you should request your medication in liquid or soluble form from your pharmacist. Crushing tablets is a last resort as it greatly increases the risk of tube blockage — not all medications can be crushed and you should be given advice from your pharmacist on which medications are suitable before crushing any medications.

Do not try this without first discussing with your managing healthcare professional.

Q2

CAN I TAKE EXTRA VITAMIN AND MINERAL SUPPLEMENTS?

Whether or not you can take extra supplements and what supplements are acceptable depends on your personal condition. Discuss with your healthcare team what is suitable for your individual situation.

Q3

CAN I EAT NORMAL FOODS WHILE BEING TUBE FED?

Your healthcare team will let you know if you are able to eat while tube feeding. If you are able to 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 difficulties, you might be visited by a speech and language therapist in hospital and/ or at home who will advise you on what types of food are safest for you.

HOW CAN I MAKE TAKING MEDICATIONS EASIER?

Q4

Ask for liquid solutions rather than tablets because tablets take ages to crush up. Not all medications can be crushed and you should be given advice about which medications are suitable to be crushed by your dietitian or pharmacist. You also have to be careful with crushing a tablet so it doesn't block the tube. With liquid solutions, ask for sugar-free (non-syrupy) medications because they can stick to the tube. Have a mortar and pestle at home if you are advised to crush tablets.

HOW CAN I BE BEST PREPARED FOR WHATEVER COMES MY WAY?

Q5

With time, you will learn some practical tips about heading out into the world with tube feeding:

1. Charge the pump! The battery should last for a full day.
2. Make sure you always have a spare set of everything. Keep some lubrication with you – always think “what if?”
3. Allow yourself to be creative about how you hang the feed. Improvise! 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 being pulled out by accident.

HOW CAN I STAY POSITIVE?

Q6

Nobody can tell you ‘this is what you do to cope well’. It might not be an amazing time, and things are likely going to be frustrating on an almost daily basis. Think of it as allowing you to retain as much of your independence as possible. Keeping your humour alive and realising you'll have your good and your bad days is important. You just need to make this the new norm. The trick is to not let it take over your life.

Q7

CAN I STILL BRUSH MY TEETH?

Good oral healthcare remains important to help keep breath fresh, teeth healthy and prevent infections and tooth decay. You can apply cream or lip balm to your lips to prevent dry or chapped lips. If you have dentures, they should be cleaned with a brush and stored in a denture pot filled with fresh water overnight. Your mouth will still need to be cleaned and you should use mouth gel to keep your mouth moist (if needed).

Q8

HOW CAN I COPE WITH GOING HOME?

Before you leave hospital, make sure you know what amount of stock you'll be getting and how the stock will work – what's the procedure? Try to get those things organised even before you go home. Organise the delivery while you are still in hospital and try to figure out the procedure ahead of time. Ask questions and make sure you take notes of everything that is being said because you tend to forget so much of it.

Q1

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

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

- Redness around the stoma site: If you see redness which persists or is painful, inform a member of your healthcare team.
- Oozing from the stoma site: If you notice oozing from your gastrostomy or jejunostomy site after it's been dry, tell your doctor, who may need to send a swab to a hospital laboratory and test for infection. You may be advised to apply an antibiotic cream, however do not apply an antibiotic to the site unless advised to do so by your healthcare team. Continue cleaning and drying the site thoroughly. You may be advised to use a dressing to protect the skin and absorb the ooze.
- Overgrowth of skin around stoma: The skin may overgrow around the stoma site and require treatment. This is known as granulation tissue and is a result of the body trying to repair the surgical incision. If this occurs, contact your doctor or a member of your healthcare team.
- Leakage of stomach contents from around the gastrostomy stoma site: Leakage of gastric contents around the stoma site can cause burning and pain to the surrounding skin. You should contact your dietitian or a member of your healthcare team when this occurs.

If the problems are persistent or you are concerned about any issues with your tube or feed, always contact your dietitian or a member of your healthcare team.

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

It can take time to figure out the tube feeding routine that works best for you. While making these finer adjustments to your routine, you might experience some side effects. However, there are many ways to manage these symptoms.

- **Upset stomach:** If you are nauseous (feeling sick), delay the tube feeding for 1-2 hours and start feeding again if you are feeling better. You can also try a smaller volume of feed or set the pump to a lower rate if recommended by your healthcare team.
- **Diarrhoea:** First make sure that the pump is delivering feed at the correct rate. The rate should have been given to you as part of your tube feeding plan. Ensure the feeding equipment is clean and your giving set is changed every 24 hours. Always deliver the feed at room temperature. Make sure to cover and refrigerate any opened feed that's not actually being used through the pump. When ready to use the feed again, remove it from the fridge and allow it 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:* Ensure you're taking any extra fluids that are recommended by your dietitian or healthcare team, and don't miss any water flushes. If possible, and recommended by your healthcare team, try to exercise and move around. If this doesn't resolve the problem it's important to let your dietitian and healthcare team know.

Whether or not you will experience side effects, and how long it will take to resolve, will vary from person to person. If the side effects are persistent or you have any doubts about what to do, always contact your dietitian or a member of your healthcare team.

Q3

WHAT IF I GET SICK — WHAT SHOULD I DO?

If you feel nauseous (sick), wait 1-2 hours before feeding and then resume feeding if you are feeling better. If you continue to feel sick, start vomiting and/or diarrhoea persists, stop feeding and contact your doctor for further advice.

Some medications, such as antibiotics, can cause diarrhoea. Ask your doctor about any possible side effects from medications you are taking.

Q4

WHAT IF THE TUBE COMES LOOSE OR FALLS OUT?

Your tube might become loose or dislodged with coughing, sudden movements or accidental or excessive pulling of the tube. If this happens, stop feeding straight away. If you have a nasogastric (NG) tube and you've been shown how to replace it, please do so. Otherwise, you'll have to go to hospital and have your NG or nasojejunal (NJ) tube replaced by a healthcare professional. A handy tip: contact the hospital beforehand to avoid waiting in the Accident and Emergency Department.

If you have a gastrostomy (PEG or radiologically inserted gastrostomy (RIG) button) or jejunostomy and it is accidentally removed, please put a dressing over the site and go as quickly as possible to the hospital Accident & Emergency Department or get in touch with your emergency contact, as the stoma will begin to close up.

HOW CAN I PREVENT THE TUBE FROM GETTING BLOCKED?

Q5

A feeding tube can get blocked because of:

- Medication that wasn't crushed finely
- Inadequate flushing before and after feeding and administering medication
- A closed tube clamp.

If you have a blocked NG tube you should not attempt to unblock it yourself. Instead, seek assistance from a member of your healthcare team.

If you experience a blocked tube, don't panic — this is a common problem that can easily be resolved and prevented with precautions. Make sure to flush the tube before and after each feed or medication, you should use either sterile, tap, or cooled boiled water. Your dietitian will advise you on what type of water to use and how much you need for adequate flushing. However, if your gastrostomy or jejunostomy tube becomes blocked you can use the advice below.

- Using a gentle pull and push technique, flush the tube with a syringe using lukewarm water or soda water, the type and volume as recommended by your healthcare team. Do not use acidic solutions like fruit juices or cola as this could curdle the feed and block the tube further.
- Still blocked? Gently squeeze the tube between your fingers along the length of the tube and repeat flushing. It can take up to 30 minutes to unblock the tube. If this does not work, get in touch with your tube feeding provider nurse (if applicable) or a member of your healthcare team.

Q6

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

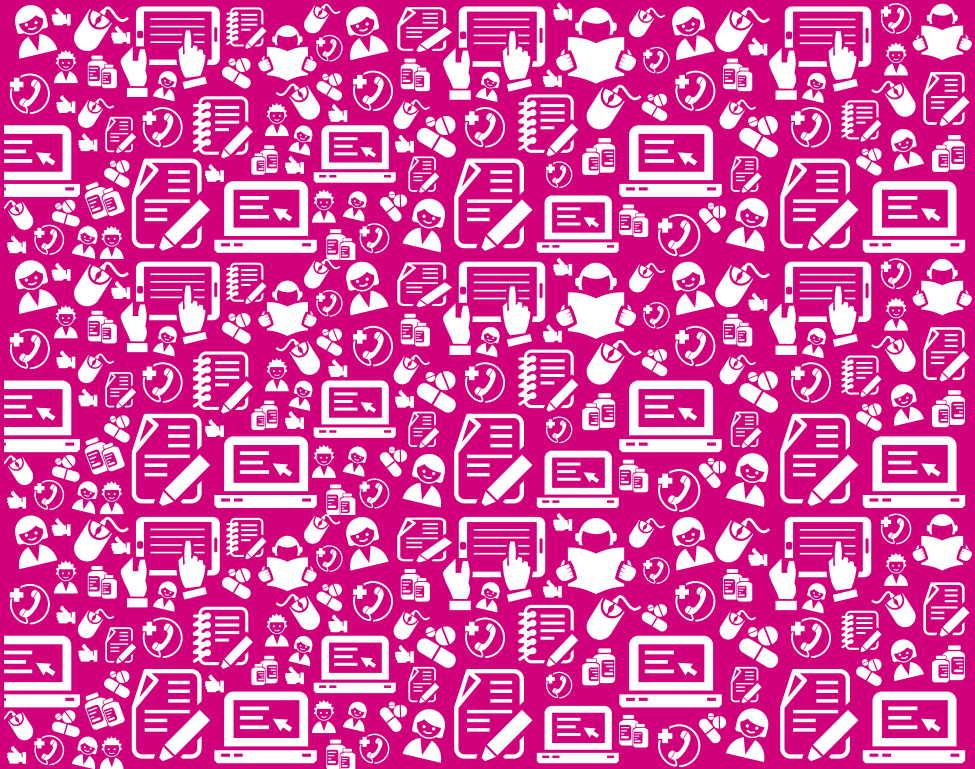
Over-granulation is the overgrowth of skin around the stoma site of the feeding tube. This might happen because your body is trying to repair the surgical incision. Over-granulation is common and treatable so if you notice it developing around the stoma site please inform your healthcare team.

Q7

WHAT IF THE PUMP BREAKS DOWN?

This is a common concern to which the first step is to ensure that the pump is adequately charged or plugged in to the wall socket. If it is definitely broken, the first port of call should be your tube feeding provider. They will get a replacement pump sent to you as soon as is possible, but occasionally holidays and geography can make things difficult. Depending on your particular circumstances it may be possible for you to use the bolus or gravity method until your new pump arrives, but they will try to make sure that it is with you as quickly as possible.

CHECKLISTS



Q1

THINGS TO CHECK EVERY DAY

- Clean around the site of the feeding tube every day, as advised by your healthcare professional.
- Look after the skin around the tube to avoid irritation — your healthcare team will advise you about what this entails.
- Make sure you stay hydrated with adequate water flushes through the tube, or by mouth if safe — your dietitian will advise you on how much water you need per day.
- Keep your teeth and gums healthy by cleaning your teeth twice a day even if you are not eating or drinking.
- At the beginning, it may seem that there is a lot to remember but, with time, all of these things will become second nature to you.

Q2

THINGS TO CHECK AT FEEDING TIME

- Check the label of the tube feed to make sure it is the correct tube feed for you, and that it is in date.
- Follow the hygiene rules as outlined on the label of the tube feed.
- Check that the feeding tube is in the right position before feeding (your healthcare team will show you how to do this).
- Flush the tube through with water before and after adding the feed (or medication) to avoid blockages, or follow the instructions provided by your dietitian or healthcare team
- It is important that you are in an upright position whilst feeding and for one hour after feeding. If this is not possible prop yourself up on at least two pillows at an angle of 45° or greater.

THINGS TO CHECK FOR FEEDING AWAY FROM HOME

You can plan holidays at home or abroad with family and friends with the support of your tube feeding provider, who can help with the necessary arrangements and deliver the feed and equipment to your holiday destination (if applicable).

Your healthcare team will provide the relevant documents to allow you to obtain travel insurance, supply fitness to fly certificates (if applicable), and give practical advice on managing tube feeding away from home.

Use this checklist to help you plan your travel away from home, to ensure you have everything you need.

- 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 feeding pack (usually in a carry system)
- Plastic containers/bags to store feeding supplies
- Phone numbers for the healthcare provider
- Your tube feeding care plan
- Contact your tube feeding provider at least six weeks in advance of a holiday abroad for information on their holiday service.

PERSONAL LIFE



CAN I HAVE A NORMAL RELATIONSHIP?

Tube feeding should not prevent you from being involved in a relationship with someone. You can be intimate with your partner however adjusting to your new body image may take time and it is important to progress at a pace you feel comfortable with.

Q1

AM I GOING TO BE ABLE TO HAVE CHILDREN?

Tube feeding is possible during pregnancy. If you are a woman on tube feeding and would like to have children it is important to discuss this with your doctor. Starting a family may require some planning and consultation to make sure you receive all the necessary nutrients needed for the baby to develop normally. Your healthcare team will also advise you on the most appropriate feeding route before you become pregnant.

Q2

HOW CAN I EXPLAIN TUBE FEEDING TO MY FAMILY?

Explain what feels natural to you and your family – the worse thing to do is not tell them anything and have your children left wondering. Straight talking, honesty and using simple language that the children will understand will make it easier.

Q3

SOCIAL LIFE



HOW WILL MY FRIENDS AND FAMILY REACT?

Q1

Not all of them will understand, and then some people will surprise you. Try to take it easy with your family and friends – although it's a massive adjustment for you, you're the one living with tube feeding. People think it's a last resort so are scared by it, and it may take them a while to get used to your new normal.

WILL I BE ABLE TO HAVE A SOCIAL LIFE?

Q2

Once you are at home and settled in your routine, it is important to continue with social activities. You will find that feeding may take some time and feel a bit restrictive, however with planning and small adjustments you can fit tube feeding around your social life.

If you have to stay inside more often there may be other ways of keeping in touch with your friends and family, such as visits at home, phone calls, and social media. You could also use this time to find new hobbies and interests but make sure you have plenty of time to rest, especially if you find you are getting tired. Most people will understand this.

WILL I STILL BE ABLE TO PLAY SPORTS?

Q3

Participating in sports will depend on your medical condition and mobility. Your doctor will provide advice on what sports you are able to take part in and which should be avoided. Physical contact sports are not recommended as there is risk of the gastrostomy or jejunostomy tube getting dislodged. You may require extra water when you are training so speak to your dietitian who will provide more guidance and adjust your tube feeding plan.

LIFE AND LIVING



CAN I HAVE BATHS, SHOWERS OR SWIM?

Q1

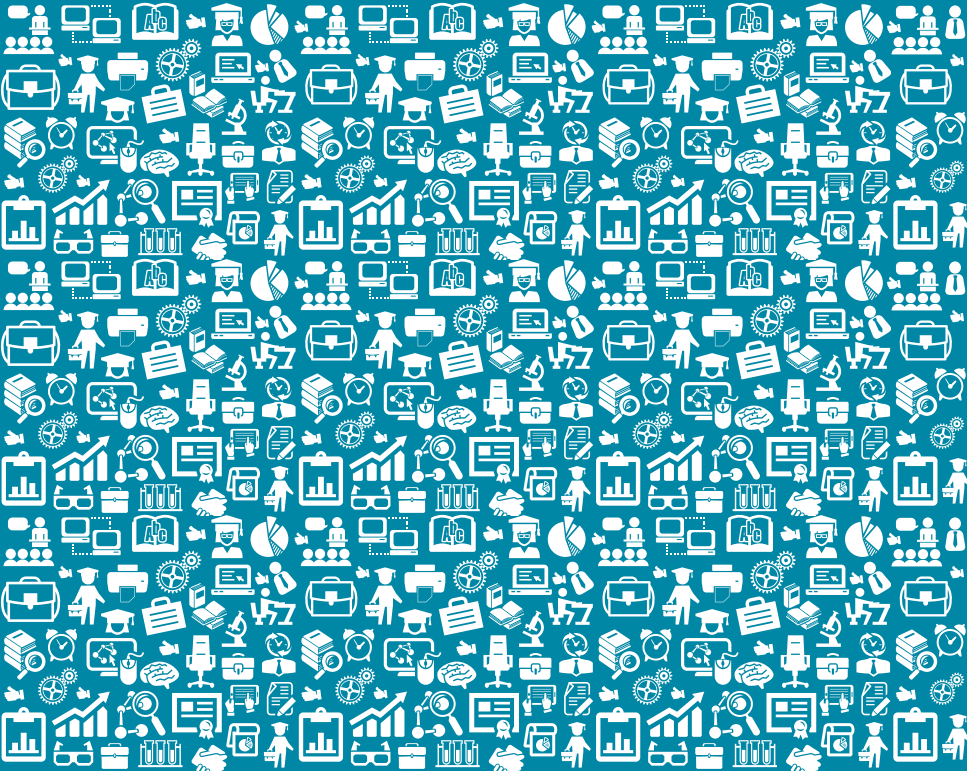
For about 2-3 weeks after you've had the gastrostomy or jejunostomy placed you should only take showers to give the stoma site a chance to heal. Thereafter, taking a bath, or even swimming, is possible as long as your tube is well protected and the wound area has healed and is healthy. You can protect the tube with a waterproof wound dressing. You should, however, avoid sources of poor quality water when swimming. If you're unsure, speak to your doctor or healthcare team about what's safe and possible for you.

HOW PHYSICALLY ACTIVE CAN I BE?

Q2

Doing physical activity or light exercise is healthy if your condition allows it. Make sure to protect the tube and skin around it as much as possible, and avoid big sudden movements that could dislodge your tube. There are different tools available 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.

WORK AND STUDY



CAN I CONTINUE TO WORK?

Q1

There are many people who still have a working life while tube feeding. Discuss with your healthcare team how you can best adapt your feeding routine to the working situation.

Q2

WHAT CAN I TELL MY WORK COLLEAGUES?

Q3

Most people find it easier to be open with their work colleagues about why they need tube feeding and how it works. If you explain and discuss this with your colleagues, you may find they are more understanding when you might have to withdraw yourself to tube feed from time to time. The more relaxed you are about it, the more they will be.

WILL I BE ABLE TO GO TO SCHOOL?

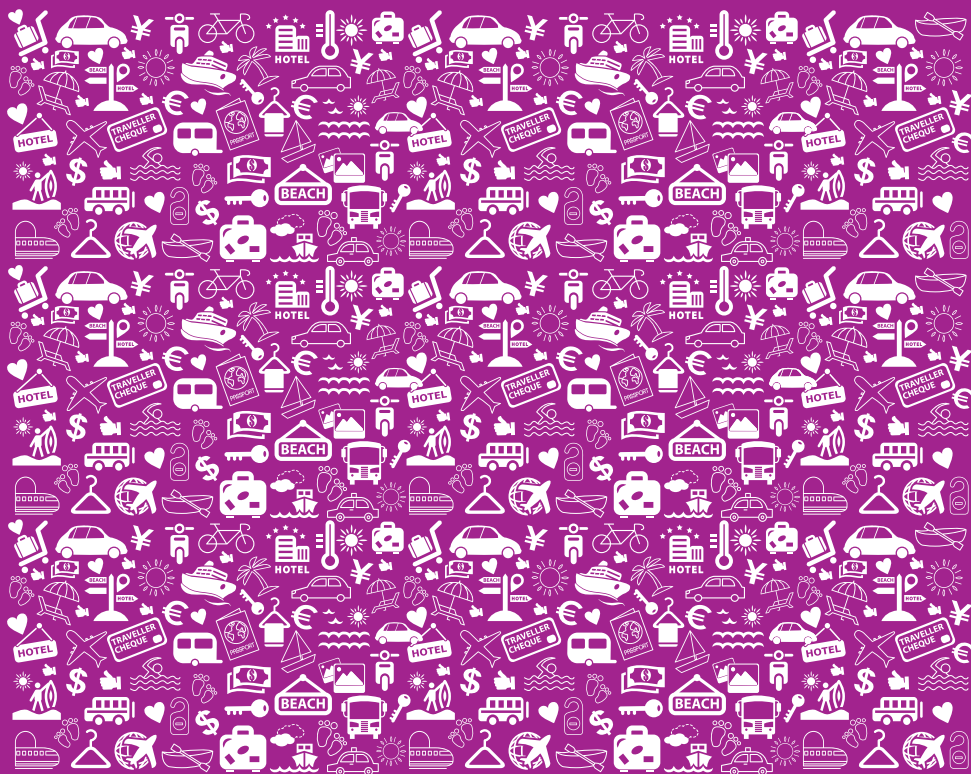
Q4

Yes, your feeding will not stop you going to school. Your healthcare team will talk to you about this. The staff will be there to look after you during school hours and will possibly need to be shown how to manage your feed and equipment if you cannot do this yourself. Training can be arranged, and this can be discussed with your dietitian or nurse and the tube feeding provider.

If you will be receiving feeds and/or medications through your feeding tube during the school day, the school nurse or carer (if applicable) may supervise.

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

DRIVE AND TRAVEL



CAN I STILL GO ON HOLIDAY?

Q1

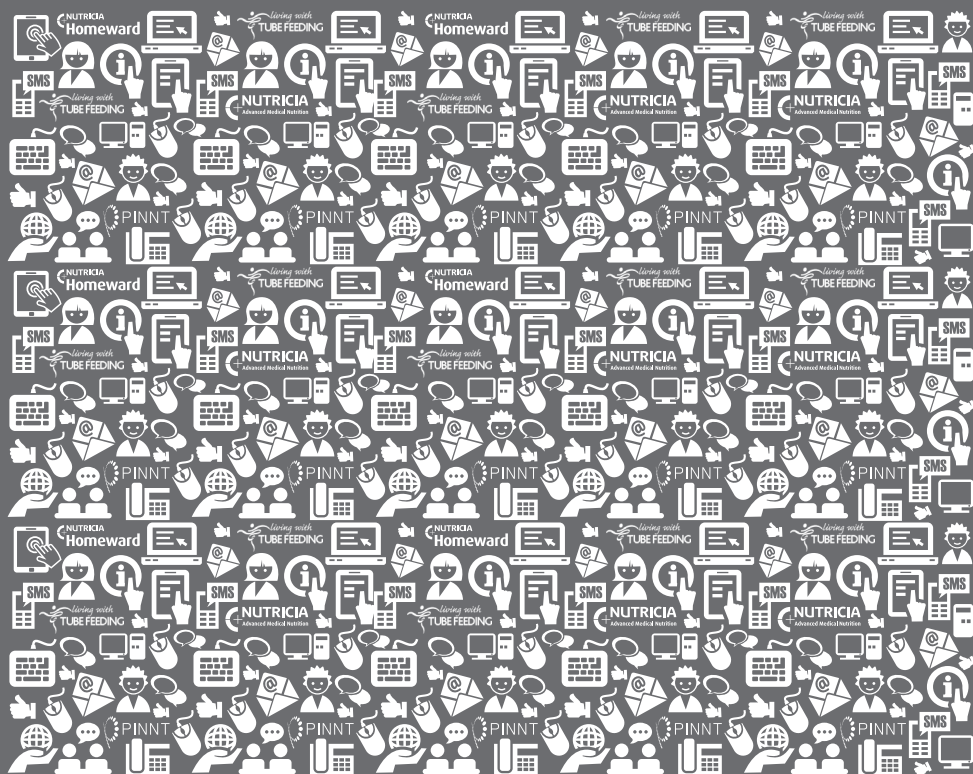
Whether you're being tube fed, travelling (at home or abroad) is possible. There are some unique challenges and considerations to take, but your healthcare team and tube feeding provider can give you the guidance you need. Your healthcare team will provide the relevant documents to allow you to obtain travel insurance, supply fitness to fly certificates (if applicable) and give practical advice on managing tube feeding away from home. You'll also have to make sure that you have the necessary feed and supplies with you, or to find out if your tube feeding provider can deliver the feed and the equipment to your destination. It is advisable to plan in advance to avoid disappointment and give your healthcare team and tube feeding provider plenty of notice to make arrangements.

CAN I STILL DRIVE?

Q2

If your doctor believes that you are well enough to drive then there should be no problem with it. You may have to inform the DVLA of your current medical status and they may request written confirmation from your doctor to declare that you are fit to drive, but in general many individuals who are tube fed are still able to drive.

INFORMATION, ADVICE AND SUPPORT



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

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.

NUTRICIAHOMEWARD.CO.UK



NUTRICIA

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

NUTRICIA.CO.UK



TUBEFEEDING.CO.UK

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





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