

HOMEWARD

Jan Scho

> **PAEDIATRIC** HOME TUBE Feeding Guide

## Introduction

Welcome to the Nutricia Homeward Paediatric Home Tube Feeding Guide. Nutricia Homeward is a service provided by Nutricia to facilitate your child's transition from hospital to home tube feeding.

This guide should be used together with the pump instruction booklet to answer questions you may have about tube feeding. You will also find further contact resources on the back of this booklet.



This guide is intended for patients or their carers who have been referred to the Nutricia Homeward Service by a Healthcare Professional.



## Home Tube Feeding Guide

### Topics covered in this guide

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## What's inside this guide?

Your healthcare professional has recommended tube feeding for your child. As with anything new, it's natural to feel concerned or overwhelmed when you're first faced with the prospect of tube feeding. Asking questions, such as *"What happens next?"* and *"Can I manage this?"* is normal at this stage.

Adjusting your child to life with a feeding tube may take some time, and it's likely that more practical questions will arise as you get into a routine. Over time, with the right information and support, you will adapt and live confidently with tube feeding in your life.

Do not feel nervous about discussing any concerns and questions you have with the healthcare professionals involved in your child's care.

Many people want to learn more at this stage, and have expressed the need for more general tube feeding information and practical tips, so they feel more confident when handling a feeding tube.

The aim of this guide is to provide some information and easy-to follow guidance on the day-to-day aspects of tube feeding. With practice and support, all of these things will become second nature to you and your family.

"The best way to learn is slowly. After time, you'll be surprised at how much more you know than in those first few days. It's like riding a bike – someone else can't tell you how to ride a bike, you just need to go and learn it. And remember, it's okay if it's not perfect!"

John (Caring for his son)



## What is Enteral Nutrition and why is my child on it?

Enteral nutrition (enteral nutrition support) is a term that describes taking nutrients into your body via your gastrointestinal tract. Tube feeding is a type of enteral nutrition support. In tube feeding, you use a tube that is placed in either your stomach or small intestine (parts of your gastrointestinal tract) to give your body nutrition. Your healthcare professional has recommended tube feeding for your child so that you can give their body the nutrition it needs when you are unable or less able to take enough nutrition orally. The types of feeding tubes are described on page 8.

#### How will tube feeding help my child?

Your healthcare professional has recommended tube feeding for your child because they cannot take enough food orally. If they are unable to get enough nutrition from their diet, they are at risk of losing weight or developing nutritional deficiencies. Tube feeding will provide them with the nutrients needed to maintain weight and in some cases, support recovery, help respond to treatment and maintain independence. The nutrition they take in through their feeding tube comes from a tube feed.

#### What is a tube feed?

Tube feeds are a liquid form of nourishment that contain the nutrients your child need to maintain health. The nutrients in a tube feed are similar to what you would get from normal food and are digested in the same way. These include different carbohydrates, fat, protein, vitamins, minerals and water. Some tube feeds also have fibre. Your child may also take oral nutritional supplements via your feeding tube.

#### Are there different types of tube feeds?

There are lots of different types of tube feeds to suit children with different nutritional needs. Their needs depend on factors such as age, weight, medical condition and whether they can still eat or drink. Your healthcare professional will advise which tube feed is most suitable for your child.

#### Can my child eat normal foods while being tube fed?

Your healthcare professional will let you know if it is safe for your child to eat while tube feeding. Tube feeding may have been recommended for your child because taking food orally is not safe anymore or it may be too difficult to get enough nutrition in this way. In this case, tube feeding will become your child's main or only source of nutrition and you will follow a tube feeding plan that provides enough nutrition to meet your child's individual needs. A dietitian or other healthcare professional will determine your child's nutritional needs and advise on the most suitable tube feed(s) for them.

Tube feeding may have been recommended for your child as a means to 'top-up' their diet. If your child is able to eat, you'll be given information about the types of food and amounts that are safe. If they're being tube fed because of a swallowing difficulty, 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 them.



## What is Enteral Nutrition and why is my child on it?

#### What will my child's feed look like?

Tube feeds come in different packs and sizes. You may be recommended for your child to take one or more tube feeds per day. These come in a bottle and the usual volume is 500ml per bottle. If they are bolus feeding (explained further on page 11), or need to use a combination of products to meet their unique needs, they may take oral nutritional supplements via their feeding tube. These come in smaller volumes such as 125mls, 200mls or even smaller doses. Your healthcare professional will recommend a tube feeding plan that meets their unique nutritional needs. They will consider your child's medical diagnosis and feeding routine when making this decision. Therefore, your child's tube feeding plan (what feed(s) your child is taking and how much they take in a day) may change over time in response to their needs.

Alternatively, you may be recommended a powdered feed which can be made up to a liquid before your child takes it. Powdered feeds will come in a tin.



## Types of feeding tubes

When in hospital, your healthcare professional will recommend the type of feeding tube that best suits your child's unique circumstances. The main types of feeding tubes are described below. Each feeding tube differs slightly in terms of placement, however their overall aim is the same — to provide your child with the nutrients needed to maintain weight, and in some cases, support their recovery, help them respond to treatment and maintain their independence.

#### You will have one of the following feeding tubes: (tick as appropriate)

#### 1. Nasogastric

Often referred to as an **NG** tube. This is a feeding tube which is inserted through the nose and passes down into the stomach.

#### 2. Percutaneous Endoscopic Gastrostomy

Often referred to as a **PEG**. This is a feeding tube which is inserted directly into the stomach through an incision in the skin.

#### 3. Jejunostomy

Often referred to as **JEJ**. This is a feeding tube which is inserted directly into the small intestine through an incision in the skin. Or a JEJ extension can be placed through a PEG, inserted through the stomach and extended into the small intestine. This is called a **PEG-J**.

A jejunostomy can also be inserted through the stomach, held inside the stomach via a water-filled balloon and extended into the small intestine. This is called a **Balloon Retained Gastric Jejunal Tube**.

#### 4. Balloon Gastrostomy Tube

A balloon gastrostomy tube (**BGT**) is a feeding tube which is inserted directly into the stomach and held inside the stomach via a water-filled balloon.

#### 5. Balloon Gastrostomy Tube – Low Profile Device

Often referred to as a **button**, this is a low profile feeding tube which is inserted into the stomach and held inside the stomach via a water filled balloon.

#### 6. Naso-Jejunal

Often referred to as an **NJ** tube. This is a feeding tube that is inserted through the nose into the small intestine.

#### 7. Radiologically Inserted Gastrostomy

Often referred to as a **RIG** tube. This is a feeding tube which is inserted into the stomach. X Rays will be used to place this feeding tube. Instructions on the type of RIG tube inserted will be provided to you by the hospital.

Your healthcare professional will provide further advice regarding your child's feeding tube.

## What you need and where to get them

Once the feeding tube has been placed, your dietitian or doctor will advise you when it is safe to start tube feeding. You will probably have many questions about what you need to get started. You will receive training on how to tube feed in hospital and/or at home. Listed below are some of the things you will need to start tube feeding and where you can get them.

| Ite          | ms you will need:   | Provided by:                  |
|--------------|---|-------------------------------|
| ~            | Pump - A feeding pump delivers the feed through the giving set at a controlled rate recommended by the dietitian.   | Nutricia Homeward             |
| $\checkmark$ | Pump frame/stand - A feeding pump frame is designed to hold the tube feed and feeding pump.   | Nutricia Homeward             |
| $\checkmark$ | Feed - As outlined on pages 6 & 7.  | Pharmacist                    |
| $\checkmark$ | Feeding plan (regimen).   | Dietitian                     |
| ~            | Giving sets & accessories - A giving set is a flexible tube which<br>helps to deliver the feed. It attaches the tube feed container<br>to the feeding pump. | Nutricia Homeward             |
| ~            | Syringes - Syringes can be used to administer feed, water or<br>medication. Syringes come in different types and different sizes<br>(e.g. 10 or 60 ml).*    | Nutricia Homeward             |
| ~            | Other - e.g. pH indicator strips to check position of the tube (mandatory for nasogastric tubes).   | Ask your dietitian for advice |

#### Where do you get the feeding pump and feeding pump frame?

- The feeding pump and its frame are supplied **on loan** by Nutricia Homeward on your discharge from hospital.
- The pump requires servicing every two years.
- To check the service date on the Flocare Infinity Pump please see the side of the pump (see image below).
- When your pump is due for a service please contact Nutricia Homeward on our Freephone number located on the rear of this booklet. We will send you a replacement pump and arrange to pick up your existing pump.
- Please refer to the Flocare Infinity Pump instruction book and guide for information on maintaining your Flocare Infinity Pump. This guide is also a troubleshooter in the event that a malfunction or alarm is activated.
- You can call our Freephone number for further help and advice. Please see numbers on the rear of this booklet.
- As the Flocare Infinity Pump is provided on loan from Nutricia Homeward, please return the pump when it is no longer required. Please call the relevant number on the rear of this booklet and we will arrange collection.

\*Please note: You may have different types of syringes. Some may not be suitable for flushing and feeding.



## What you need and where to get them

#### Where do you get your child's feed?

- Your dietitian will recommend the type of feed that best meets your child's needs.
- An initial supply of feed will be provided by Nutricia Homeward when your child is discharged from hospital.
- You will be given a prescription to take to your local pharmacy.
- It is important to remember to renew your child's prescription and to ask your pharmacy to reorder their feed at least a week before your supply runs out.

#### Where do you get giving sets and accessories?

- An initial supply of giving sets (and accessories if required) will be provided by Nutricia Homeward when your child is discharged from hospital.
- Giving sets and accessories will be delivered direct to your door each week.
- Nutricia Homeward will call you the day before your delivery to book a time in for delivery within a 2 hour time slot.

#### Where do you get syringes?

• Syringes will be provided by Nutricia Homeward along with your child's weekly supply of giving sets.

"Tube feeding has saved my life. Think of it as allowing you to retain as much of your independence as possible. Accommodating a tube can be daunting and the fact that you can't eat anymore can be tough – but at the end of the day, I'm grateful for the fact that it keeps me alive. Keeping your humour alive and realising you'll have your good and your bad days is important."

#### Lisa (Living with tube feeding)



## Your child's feeding routine

When it comes to deciding on the best tube feeding routine your child's dietitian will discuss the options with you based on their needs. Depending on your child's nutritional requirements, medical needs and lifestyle, there are three ways that tube feeding can be given:

#### **Continuous feeding**

Feed is given slowly over a number of hours using a pump that controls the flow rate of the feed. Continuous feeding can take place during the day, overnight or a combination of both.

#### **Bolus feeding**

Feed is given in smaller volumes (e.g. 200ml) several times throughout the day, with the use of a pump, gravity, or a syringe.

#### **Combination of both**

A combination of these methods can be chosen based on a number of factors to give you more flexibility.

If your child is bolus feeding, you and your healthcare professional can work together to determine the times that suit them best to take their boluses of feed. They may like to take their boluses at mealtimes or you may choose to take them at different times so that feeding fits in with their lifestyle and other medical treatments. If they are taking some diet orally, you may choose for them to eat during the day and feed at night. Alternatively, you may choose to feed them through their feeding tube after meals if they cannot eat enough food by mouth.

### Details of your child's feeding plan (regimen) can be recorded on the following page so you have all the information you need in one place. Please check with your dietitian that these details are correct.



| Your child's feeding plan |
|---------------------------|
| (Regimen)                 |

The name(s) of my child's feed is

The bottle size is

The amount of feed they take in 1 day is

The amount of sterile or cooled boiled water I take in 1 day is

The flow rate I set on the pump is

The amount of water I use to flush is

#### Continuous feeding:

**Feeding instructions** 

#### **Bolus feeding:**

**Feeding instructions** 

mls of

mls/hour

To be given at the following times every day

## Other key information for feeding

#### My pump is a Flocare Infinity:

Serial no.

Next service date

| My giving set is:   | Order code: |
|---|-------------|
| Flocare Infinity pack giving set                                | 95347       |
| Flocare Infinity mobile giving set                              | 101586      |
| Flocare Infinity pack giving set (without med port)             | 95349       |
| Flocare Infinity mobile giving set (without med port)           | 86484       |
| Flocare Infinity bottle/universal giving set                    | 101587      |
| Flocare Infinity bottle/universal giving set (without med port) | 90086       |
| Other   |             |

| My container is:                     | Order code: |
|--------------------------------------|-------------|
| Flocare container (35746) 500ml      | 40441       |
| Flocare container (35724) 1 litre    | 40455       |
| Flocare reservoir (570139) 1.3 litre | 70139       |

| Accessories:               | Order code: |
|----------------------------|-------------|
| Flocare two pack connector | 69915       |
| Flocare bolus adaptor      | 89740       |
| Flocare bottle adaptor     | 59943       |
| Other                      |             |

#### Syringes:



When setting up the feed, it is important that everything is kept as clean as possible in order to prevent contamination of the feed. Wipe down the area where the feed will be set up with a clean cloth and wash your hands. For specific instructions on pump set up please refer to your pump instruction booklet for a step by step guide.

| Make sure you have the following items: |   |
|---|---|
| ✓ Feed                                  | ✓ Plan (regimen)  |
| ✓ Pump                                  | ✓ Giving set  |
| ✓ Pump frame                            | <ul> <li>✓ For flushing – Sterile or cooled boiled water and<br/>a single use syringe unless otherwise advised by<br/>your healthcare professional</li> </ul> |



## How to store and handle your child's feed

Nutricia feeding systems have been designed to reduce the risk of feed contamination and have proven to be extremely safe. If feed becomes contaminated, you can develop complications such as vomiting and diarrhoea. Therefore it is very important that you store your child's feed correctly. Contamination can be introduced at any time during the setting up process. To reduce the risk of contaminating the feed, you should adhere to the following advice regarding storage and handling.

#### Storage:

- Feed and equipment needs to be kept clean and could be damaged if kept at the wrong temperature.
- Store unopened feed and equipment between 5°C-25°C in a cool, dry place away from direct sunlight it is NOT necessary to refrigerate unopened feed.
- Avoid placing feed and equipment next to radiators or other sources of heat.
- Once open, store closed bottle in a refrigerator (less than 5°C) for a maximum of 24 hours. Discard any unused contents after 24 hours.

#### Handling:

- Wash your hands before starting to set up feed.
- To lower the risk of contamination, set up equipment using a clean work area. Avoid touching any internal part of the feed container, giving set or feeding tube with your hands. Avoid unnecessary handling of equipment.
- Sterile feeds can be hung for up to 24 hours from opening, provided they are handled using a clean technique and have been kept as a closed system i.e. remain connected to the giving set.

- If you are using a collapsible bottle and have removed the cap (open system), then the feed has a hanging time of maximum 8 hours.

- Powdered feeds made up with liquid, have a limited hanging time of no more than four hours to prevent microbiological contamination.

- It is advisable to consult with your healthcare professional to discuss your individual needs in terms of hang times; taking into account the type of feed you are using and your method of administration.

- Feed containers must not be topped up with feed once feeding has started; the total volume must be decanted at the start of the new feed.
- Dispose of any unused feed after the above time periods.
- Change giving sets every 24 hours, or more frequently if advised by your healthcare professional.
- Before disposing of enteral feeding waste products you will need to check with your healthcare professional, local hospital or authority that it is acceptable to dispose of them in your normal household rubbish.
- Check with your healthcare professional which type of water is recommended for flushing. You can use sterile or cooled boiled water and a single use syringe unless otherwise advised by the healthcare professional.
- Check that the bottle is undamaged and unopened and observe the expiry date prior to use.
- Always gently shake the bottle before use. If the feed appears to have curdled, use a different bottle and contact Nutricia Homeward.



## **Administration of Medications**

For administration of medications via the feeding tube please follow the instructions provided by your healthcare professional. It is important not to use the feeding tube for the administration of medications which have not been prescribed as suitable for enteral use. If you require further information on your child taking medications, contact your pharmacist or healthcare professional for advice.

Please remind your pharmacist or GP if your child is prescribed medication that it will be administered via your child's feeding tube.





## Things to look out for

#### Positioning

Positioning your child correctly and maintaining the correct position during and after tube feeding, will allow the feed to settle in your child's stomach and help to prevent complications. If they are feeding whilst lying down, it is important to position them at an angle of at least 30° during feeding and for at least one hour afterwards. This advice should be followed unless otherwise specified by your healthcare professional.

#### Leakage or Discomfort

If your child experiences any leakage around the feeding site or any pain or discomfort whilst using the feeding tube, you should stop using the feeding tube immediately. This advice should also be followed if you notice that their feeding tube has changed position or fallen out\*. You should then contact your GP or healthcare professional immediately for advice. If you cannot reach your GP or healthcare professional, you should seek emergency assistance.

#### **Breathing Problems**

In the unlikely event that your child starts to feel short of breath, stop feeding immediately and seek urgent medical advice, or call for an ambulance.

#### Temperature

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. Prior to tube feeding, check if you child's feed is at room temperature and if not, allow time for the feed to come to room temperature before feeding. However, do not heat the tube feed (i.e. with hot water or in a microwave) as there's a risk of 'cooking' the formula, which will reduce its nutritional value. Warming the tube feed can also increase the risk of infection.

#### Other Considerations

If your child experiences significant weight gain or loss, diarrhoea, constipation, wind or back pain, you should contact your GP or healthcare professional for advice.

\*Before feeding, you should always ensure that your child's feeding tube is in the correct position as advised by your healthcare professional.



## Your Nutricia Homeward Support Team

Nutricia's Homeward service, together with your child's dietitian and their district nurse, will help to make the transition from hospital to home as easy as possible for you and your child.



#### 24 Hour Freephone Support

Our experts are available to answer any questions regarding your pump or giving set.

- ✓ Available 24 hours a day, 7 days a week
- ✓ Manned by customer care and qualified nurses

0800 231 5487 (8am - 8pm)



Out of hours line 0800 093 3672 (8pm - 8am) Northern Trust patients (all hours) Freephone 0800 169 5173



#### Nutricia Homeward Delivery Service

- ✓ Giving sets and feeding equipment are delivered directly to your home
- ✓ All delivery drivers carry ID, are DBS checked and have received specialist training to understand enteral feeding
- $\checkmark$  If required, drivers will carry heavy boxes into the home and rotate stock
- $\checkmark$  We call you the day before your delivery to book a time in within a 2 hour time slot



#### **Emergency Pump Delivery**

You can always get a replacement pump **24 hours a day, 365 days a year**. Just call our **24 hour freephone support line (please see relevant numbers above)**.

✓ If at any time you need a replacement pump we will arrange for a new one to be delivered directly to your home



#### **Holiday Support Service**

We support your holiday by **organising to send your feed, pump and accessories to your holiday destination**\* so you can relax the moment you arrive.

#### Quick tips when using our holiday service

- 1. Be sure to contact us at least 4 weeks in advance of your holiday.
- 2. Ensure you have your feed ordered from the pharmacy in time for when we collect it.
- 3. Have contact details ready for the person who will receive your feed at your holiday destination.



#### **Online Support**

Interactive training tools & support available online.

•••

WWW.NUTRICIAFLOCARE.COM

WWW.TUBEFEEDING.CO.UK

\*exceptions apply



## Holiday support service

If you are planning a trip overseas, our Nutricia Homeward Coordinators can advise you on how to transport your child's feed and devices. You can contact Nutricia Homeward by Freephone on the numbers below.

#### Before you go - essential advice

#### ✓ Pack a plug adaptor

If you are travelling outside Ireland and the UK you will need a plug adaptor for your child's pump so that you can charge it. A standard travel plug adaptor should suffice but please contact our Nutricia Homeward team if you have any queries on this.



#### ✓ Documentation

Carry your child's documentation with you such as the GP letter or a copy of the completed airline medical form should airline personnel require it.

#### ✓ Additional fluids

Your holiday destination may have a warmer climate than at home. In order to prevent dehydration, flush the tube with extra water. Request advice from your health care professional on additional volume of water required.

#### ✓ Bottled water

If the tap water is not safe for drinking, we suggest using bottled water for hand washing before commencing any procedures. Use bottled water for washing your child's teeth also.

#### ✓ Storage of feed

All unopened feed should be stored in a cool dry place (5°C-25°C) and away from direct sunlight. In either very cold or hot climates, make sure the feed is not stored at extreme temperatures.

#### ✓ Oral food intake

If your child can take normal diet in addition to your enteral feed, always make sure that it has been correctly cooked and there is minimal risk of food contamination.

#### ✓ Telephone numbers

Always take the telephone numbers of your dietitian/hospital (plus personal hospital number), Nutricia Homeward and any others you think you might need in an emergency.

#### Nutricia Homeward Freephone:

Northern Ireland: 0800 231 5487 (8am - 8pm) Out of hours line: 0800 093 3672 (8pm - 8am) Northern Trust patients (all hours) Freephone: 0800 169 5173

#### International Phone Number:

+ 44 800 231 5487 (8am - 8pm) Out of hours line: +44 800 093 3672 (8pm - 8am) Northern Trust patients (all hours): +353 1 429 1828. Please note that this international number is not a Freephone number



Complete details of your child's dietitian, district nurse, local pharmacy and community dietitian below.

Nutricia's Homeward service, together with your child's dietitian and their district nurse, will help to make the transition from hospital to home as easy as possible for you and your child.

| Dietitian is:                                   |        |
|---|--------|
| and their phone number is:                      | bleep: |
|   |        |
| District nurse is:                              |        |
| and their phone number is:                      |        |
|   |        |
| Local pharmacy is:                              |        |
| and the phone number is:                        |        |
|   |        |
| Community dietitian (if applicable) is:         |        |
| and their phone number is:                      |        |
|   |        |
|   |        |
|   |        |
| "I'm very happy to know that support is there." |        |

Nutricia Homeward patient



## How to use the Flocare Two Pack Connector (If Applicable)

The Flocare two pack connector will allow you to connect two packs or bottles of feed or a pack/bottle of feed and sterile water to your child's giving set. The Flocare two pack connector has two purple ends and one white end.

#### Step 1

Check the feeding tube position and flush as per your dietitian's instructions.

#### Step 2

Make sure that the two white clamps on each arm of the two pack connector are open. Remove both dustcaps.



#### Step 3

Stand bottle on flat surface before connecting. After you have removed the purple caps from the two bottles of feed, attach the purple end of the connector to both bottles. Remember to screw on tightly.

#### Step 4

Attach your child's Flocare Infinity giving set to the two pack connector by screwing the purple cap on the top of the giving set onto the white end of the connector. Hang both bottles on the frame supplied.

#### Step 5

Proceed as normal to programme your child's pump and fill the set as per the instructions in the pump instruction booklet.



#### Step 6

The feeding rate, volume given and the feeding time will remain unchanged.



## How to use the Flocare Bolus Adapter (If Applicable)

#### You will need

- Flocare Bolus Adaptor
- Tube feed, as prescribed
- Water for flushing
- A 60ml syringe

Check all expiry dates and wash hands thoroughly. Open the packaging and lay contents on a clean dry surface.



#### Step 1



Remove the dust cap from the bolus adaptor.

#### Step 2



Remove the cap from the prescribed tube feed.

#### Step 5

# Step 3

Insert bolus adaptor into bottle and screw firmly to ensure there is a tight seal.

Step 4



Remove cap from the bolus adaptor. Flush the feeding tube with prescribed amount of water.

Step 7

Attach the filled syringe onto the end of the feeding tube or extension set. Push the plunger gently to administer feed and repeat until prescribed amount has been administered.



Attach the 60ml syringe to the bolus adaptor.

Step 8

Flush the feeding tube with the prescribed amount of water.



Using the plunger of the syringe, gently withdraw the prescribed amount of feed.

#### Step 9



Reseal tube feed bottle by closing the bolus adaptor & store as directed.



## **Frequently Asked Questions**

#### The feeding pump is not working. What do you do?

Read through the troubleshooting section in your child's pump instruction booklet. **If you have followed this and the pump is still not working call the Nutricia Homeward Freephone Helpline. Please see numbers on rear of this booklet**. Please phone as early in the day as possible, so we can assist you or send a replacement pump if necessary.

#### What do you do with giving sets and containers after they have been used?

Giving sets, reservoirs, containers, bolus adaptors, two pack connectors and used packs/bottles of feed can be disposed of with your household waste. Feed packs/bottles with a recycling logo can be recycled.

#### If your child needs to take a break during feeding what do you do?

If giving sets are connected, disconnected and reconnected multiple times a day, the risk on any contamination is increased. If your dietitian and medical team have advised that your child can take a break during feeding, you should disconnect the tube from the giving set and replace the end cap on the giving set. You then flush your child's feeding tube as instructed by your healthcare professional. If you are taking a short break for personal care or repositioning, your child should not lie flat during this time. This is because it is advised to stay in an upright feeding position for one hour after feeding - see page 17 for more information. After this time, it is fine to lie flat until you commence feeding again. You can keep the feed at room temperature while your child is having a break however the feed and the giving set must be discarded or used within 24 hours, or earlier depending on what feed your child is using and their unique circumstances. Always follow the advice of your dietitian and tube feed manufacturer regarding storage and hang times of your feed.

#### Your child is finished using their pump. What do you do?

It is important to return your child's pump to Nutricia Homeward when you have finished using it. **Returning** your pump can be arranged by contacting the Nutricia Homeward Freephone Helpline. Please see numbers on rear of this booklet. Nutricia Homeward will arrange collection of your child's pump and any charges related to the return of their pump will be paid for by Nutricia Homeward.

#### Do I still need to look after my child's mouth when they are tube feeding?

Your child has recently started feeding via a tube, which means that their mouth won't be used as often for eating and drinking. However, it is still important to care of their mouth to prevent infections.



#### **Frequently Asked Questions**

#### Can my child have baths, showers or swim?

For about 2-3 weeks after they've had the PEG or jejunostomy placed your child 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 their tube is well protected and you have checked the wound area with your healthcare professional, as healing times can vary due to medical conditions. You can protect the tube with a waterproof wound dressing. Your child should, however, avoid sources of poor quality water when swimming. **If you're unsure, speak to your doctor or dietitian about what's safe and possible for your child**.

#### Will my child need the tube forever?

Some children need tube feeding for short periods of time, while others may need them long term. Your doctor/dietitian will discuss the expected length of time your child will require a feeding tube. Their progress will be reviewed regularly by your doctor and/or dietitian.

#### What do I do if the tube feed bottle/packaging leaks?

The materials used to make the tube feed bottles/packaging are sturdy; however, in rare cases 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 tube feed and giving set and start again with a fresh tube feed and giving set.

#### If my child is feeling better, can they stop tube feeding?

The objective of tube feeding is to provide the right amount of energy, protein and nutrients your child's body needs which may support their recovery. Tube feeding should be continued until your child can receive all the nutrients required by mouth. Therefore always discuss with your healthcare professional before your child stops tube feeding, or alter anything in your dosage or routine.

#### Can I put normal food down my child's tube?

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 or the need for tube replacement and can potentially cause infections due to contamination.

## Notes

## Notes

| <br> |
|------|
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## Notes



#### **Nutricia Homeward** We support you every step of the way

Nutricia Homeward Freephone: 0800 231 5487 (8am - 8pm) Out of hours line 0800 093 3672 (8pm - 8am) Northern Trust patients (all hours) Freephone: 0800 169 5173



For further information please visit: www.nutriciaflocare.com or www.tubefeeding.co.uk

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