



35 years

PINNT

A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

1987 - 2022

Registered Charity: 1157655



Top Tips Guide - Living with an Enteral Tube

Kimberley Pett | Project coordinator

Contents

Introduction	3
Feed preparation	4
Bolus feeding	5
Improving tolerance of feed and fluids	6
Equipment storage and space-saving ideas	7
Nasogastric and nasojejunal tubes	8
Managing tube sites	9
Using tubes for venting and drainage	10
Unblocking a tube	12
Managing medications	13
Out and about (what to take and how to pack)	14
Travel	16
Children with enteral tubes	17
Clothing and accessories	18
Adaptations for disabilities	20
Living well with a tube	21
Glossary of Terms	22
Offers and contact details	24



Introduction

Living with an enteral tube comes with many challenges. When we first get a tube, we are given the basic information by healthcare professionals and sent on our way, but there is so much more to managing a tube than what they can tell us. Along the way most of us pick up our own tips, tricks, and techniques. The little things we do that make it just that bit easier; our own expertise in what works and what doesn't in the real world - the things you can only really know by living with a tube yourself. Wouldn't it be great if you could pick up all that expertise from day one?

We recognise that tube users are the experts on their own conditions, and that the best knowledge on managing an enteral tube only comes from living with one and experiencing problems or challenges yourself. It is this wealth of experience and knowledge that we have drawn on to create this guide. It encompasses tips and tricks that have been collated from PINNT and GiftUK members.

The aim of the guide is to troubleshoot problems around enteral tube use and to provide a source of ideas for living well with a tube. We also hope that this guide will be a useful resource to refer to for discussions with health professionals – helping to ensure that you have the right information to hand to help them to help you.

Thank you to everyone who has contributed their tips and comments.

DISCLAIMER: PINNT has made every reasonable effort to ensure that the content of this guide is accurate but accepts no responsibility for any errors or omissions. The views expressed are those of individual members not those of PINNT and no reference to any product or business is intended as a recommendation or endorsement. This guide is not intended as medical advice. You should always seek advice from your own team of healthcare professionals in relation to your specific needs/treatment.

©PINNT 2022





Feed preparation

Preparing feed can seem overwhelming at first, but it gets much easier with practice. Here are a few ideas to help you:

- Always wash your hands before doing anything to do with your feed or tube. If you don't have access to water then use hand sanitiser. (For advice on hand washing go to www.nhs.uk/live-well/healthy-body/best-way-to-wash-your-hands/).
- Use a dedicated area that is wipeable and easy to clean – some people like to use a tray.
- Take your time – don't rush!
- Lay everything you need out before you start, and make sure you have access to spares in case something is faulty or goes wrong. Some people like to work along the boxes of equipment to make sure they don't forget anything.
- Keep instructions nearby in case of problems.
- For pre-mixed feeds, make sure they are room temperature and shake before use.
- For feeds mixed from powder, some people find using a blender can help mix the formula if you don't want to shake it. (Caution: In some cases this may cause feed to be overly aerated resulting in the pump alarming or stomach discomfort).
- If using Elemental 028 Extra powder it can be stored in the fridge for 24 hours. Make up a few bottles at a time and pop them in the fridge to make night changes easier.
- If you need sterile water, use baby bottles. You can sterilise the bottles in the microwave, and they are a great size to carry out and about.
- Sterilised baby bottles can also be used to make up feed if making from powder – Nutricia now provide caps to attach these to giving sets and provide 250ml and 500ml sterilisable bottles rather than the single use bottles. Sterifeed bottles fit the Nutricia caps.
- Equipment that is not single use can be sterilised using Milton solution or microwave sterilisers.
- Fortisip screw caps are not watertight and will leak if not kept upright. Push the seal back into the bottle to help reduce mess from sticky foil.

???

Q&A

Q: "I can't get the cap off the end of the Nutricia giving sets."

A: Try pulling on the tubing of the giving set rather than the end itself – it comes off more easily!

Q: "I can't undo the connection between my tube and giving set – it's stuck!"

A: Try soaking the connector in warm water to see if this expands it. If this doesn't work, try using two pairs of scissor clamps, one on each side of the connection, to help grip and undo a stuck connection. If you don't have these, Dycem grip is great to help get a firm grip on each side. A scrunched-up glove can also help grip, or pliers are another thing to try.

Q: "My FreeGo pump is really unstable and constantly falling over on its stand."

A: Some people have found that rotating it on the stand, so it is NOT how it is shown in the instructions makes it more stable.

Q: "My feed bottle doesn't have anything to hang it by."

A: Try making a hanger out of tape by making a loop on the bottom of the bottle, and then taping around the bottle to make it secure. You can also use hair ties or elastic bands to make a loop that you can hang it from.



Top Tips

- If you squeeze all the air out of your feed bottle/container before you attach the giving set, you can lie the bottle down flat rather than having to hang it upside down. This makes it much easier to store in a bag and it can be smaller and more discreet.
- If you are connected to your pump overnight and have a nasal tube, put your pump and feed on the same side of the bed as the side the tube comes out your nose, this stops you getting tangled in the tube quite so much.
- Try priming your giving set by putting pressure on the bottle while pinching the plastic part that sits in the pump – this can save time if you are in a hurry.

Bolus Feeding

- Take it slowly.
- Clamp it partway through for a pause so it doesn't all go in at once and cause discomfort.
- If you are doing it using a syringe rather than a bolus set, you can just leave the syringe attached to the tube and push a little at a time over a long period, so it is easier to tolerate rather than trying to push the whole thing through at once.
- Have a distraction e.g., book, music, or tv to take your mind off it.

**Do you have any tips
on bolus feeding?**

Please email

kpett@pinnt.com



Improving tolerance of feed and fluids

Finding the right feed regime can take time, and not everyone is suited to the same feed. It is important to work together with your dietitian to find what is right for you. Sometimes you will need to try several different feeds before you find the one that is right for you. If you feel your regime is not working for you, don't be afraid to ask your dietitian to help you experiment to find something that suits you. Your tolerance may change as you go between good periods and flare ups. It can be affected by many factors such as position, hydration status, activity levels, etc. You may need to adjust your feed rate up or down depending on how you are feeling. This doesn't have to be done in a linear fashion; the best way is to listen to your body and adjust it based on how you are feeling. Don't beat yourself up if you are struggling or if one day your rate is lower than the previous day. Many people find that if they are nervous about increasing the hourly rate, it is easier psychologically to increase it by small increments of 1-5ml at a time, as you can see how small the differences are.

- Continuous feed through a pump can be easier to tolerate than boluses.
- Start off your feed rate lower and increase slowly, listening to your body.
- Many people find using warm water for flushes and to make up powder-based feeds helps to reduce intestinal spasms, compared to using cold water.
- However, others find warm water increases nausea and make them feel fuller. Some have reported sipping cold water helps contract muscles – experiment with what works for you.
- Don't lie flat when sleeping – use pillows to prop yourself up, or you can get adjustable reclining backrests to use in bed (an occupational therapist may be able to provide this).
- Try sucking mints if allowed.
- Hot or cold packs on the abdomen or head can help relieve some symptoms of discomfort.

Some questions you could ask your dietitian:

- Are there any other feeds I could try?
- Is it possible to have regular breaks throughout feeding? (Some people find pausing the feed for half an hour or so allows their bowels to settle and any nausea to subside.)
- Can you get the same volume of feed over a different rate/time that would suit you better? Some people feel better running feed slower over longer, whereas others prefer faster over a shorter period so their bowel can have a longer break. You should be able to experiment with different regimens to find what works best for you providing you get the correct total volume of feed.
- Can you run feed and water at the same time using two pumps rather than one after the other? Some people have found this helps increase tolerance and reduces pain.

Equipment storage

The number of boxes you come home with when you first start tube feeding can feel quite overwhelming, so here are some ideas that might help keep things tidy:

- It helps to have a specific storage area – there will be lots of it so be organised!
- It can be helpful to keep your main supply stored away but have a smaller supply easily accessible in the place where you set up your feed, whether this is the bedroom, bathroom or kitchen and replenish this supply regularly.
- Make sure you use a rotation system to prevent older supplies going out of date.
- Keep supplies stored away and use nice boxes or storage units to keep your house from looking too clinical.
- Label boxes and baskets with specific stickers to keep them organised and easy to find what you need quickly.



Send in your storage snaps!

Do you have an inventive storage setup? Do you have pictures of your setup that could inspire others?

Send in your storage snaps to kpett@pinnt.com

Space Saving Tips:

- Wind your patterned NG/NJ tapes round credit card-sized pieces of card and store them in a credit card wallet/bus pass wallet with plastic sleeves so you can see them all.
- If you are on a feed you mix from powder, ask your team if you can switch to reusable Sterifeed bottles which can be sterilised instead of single use bottles. This saves a huge amount of storage space as well as being better for the environment – Nutricia provide these bottles and caps to use them with giving sets.
- Some supplies can be condensed. For example, individually wrapped dressings have an instruction leaflet in each box, so you can save space by keeping only one leaflet and condensing into fewer boxes.

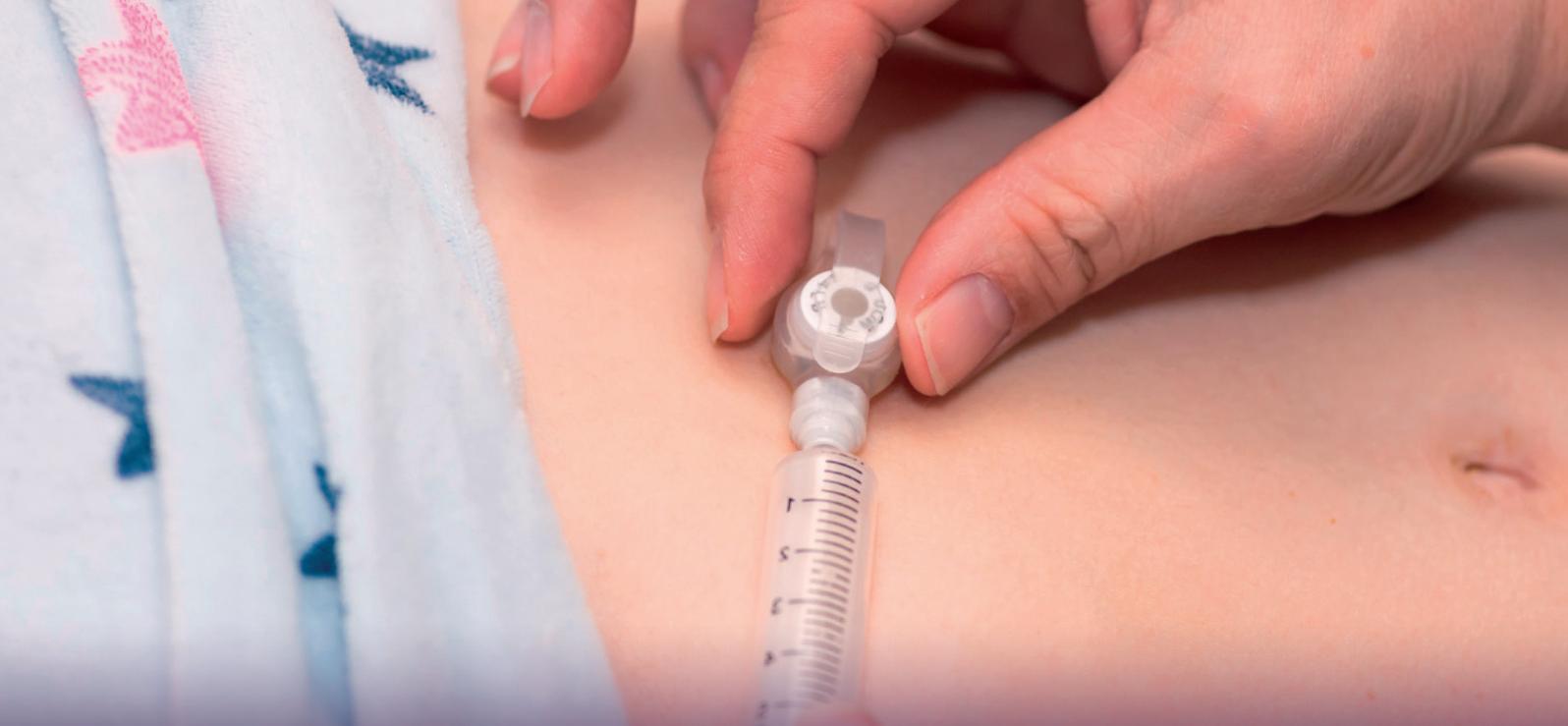
Nasogastric and nasojejunal tubes

- Use alternate nostrils when the tube is changed if you can.
- Consider a bridle as an alternative to tape.
- Moisturise your skin regularly and let it dry before applying tape.
- Most people find it more comfortable to tape the tube to the cheek rather than downwards – start about 0.5cm from the nose, this gives enough movement to be comfortable but not so much it rubs.
- Try to use a slightly different area of skin each time you apply the tape.
- Use a barrier cream on your face before applying tape to the face if it is getting sore, for example Cavilon cream.
- Use a clothes peg (pegged to whatever you are wearing) to help take the weight of your tube.
- If you have long hair, you can also tie your tube into your ponytail to keep out of the way when not in use – this is particularly good when exercising.

Finding the right tape can be a matter of trial and error – it is a good idea to get several different tapes and test them out over a week or so and see what is most comfortable for you. There are a variety of tapes available. The following suggestions are based on individual experiences only and are not medical advice:

- 3M tape – Micropore. This is a paper-like tape used by many hospitals. Some patients said they like this as they can put a little makeup over it to conceal it a bit, however many people report reacting to this tape.
- Mefix – good sticking power and doesn't leave marks.
- Duoderm – this is recommended for sensitive skin. It is also often used as a protective layer underneath the tube.
- Rock tapes – Not really used to secure the tube but can be used over the top of other tapes to brighten up and make them more secure and personalised.
- Hypafix – hypoallergenic and breathable so good for sensitive skin and comes in a transparent version if you want to be discreet. There are also many printed patterned versions if you want to make your tube more fun!
- A popular combination is to use Duoderm underneath the tube to protect the skin with Hypafix over the top to secure it and add a pattern.
- Tapes can come in all sorts of colours and patterns to suit your personality. Two popular shops for patterned tapes are Tubie Cheeks and Tubie Doodles (see page 24 for details and offers).





Managing tube sites

There are several issues that can occur around tube sites. The most important thing is to clean well around your tube site using soap and water, and for most people this will be enough. However, some people find additional products beneficial.

Please remember, everything in this guide is based on the experiences of individuals and is not medical guidance. If you think you have granulation tissue or a tube site infection you should consult with a member of your healthcare team.



- Cotton buds can be useful to clean well around the tube.
- Make sure to dry your tube site well after cleaning.
- Inspect the site daily - using a mirror to see the underside can help to spot early signs of redness or discharge.
- Remember to rotate the tube daily if you have a PEG – make it part of your routine with something else to help you remember, like when you brush your teeth.
- If getting pain around the tube, try draining the balloon and replacing the water earlier than you might otherwise (for balloon retained tubes) – sometimes it helps. Also, sometimes you get increased leakage around the tube if the balloon is not quite full enough.
- There will be exudate from time to time. Don't worry unless it smells offensive or exudes a lot and/or bleeds.
- Barrier creams can help protect the skin from any leakage around the site, especially from acid around a PEG.
 - Some examples you may wish to discuss with your healthcare professional are: Sudocrem, Sorbaderm, Medihoney barrier cream, Orahesive powder, Cavilon barrier film spray, Cavilon barrier film foam applicators, Mediderm barrier cream.
 - Flaminal hydro gel is also great for soreness around the tube site.
 - Some patients have reported that if these don't appear to be effective, they may work better in combination, e.g., Sudocrem with Sorbaderm, and Medihoney with Orahesive powder.

Granulation tissue:

- Taping dangling tubes can help prevent movement of the tube at the site and help prevent granulation tissue from forming (see Nasogastric and Nasojejunal tubes on page 8 for types of tape).
- An alternative to tape is Grip-Lok or Clinifix securement devices which can be used to hold tubes in place (medium is the right size for most tubes). These may be available on prescription.
- Tubie clips allow you to clip tubing to your clothing to prevent tugging on the tube site and G-tube belts are also available.
- If you have granulation tissue, some options others have found useful that you may wish to discuss with your healthcare professional are:
 - Hydrocortisone cream (Boots Dermacare 1% w/w cream) – this only needs to be spread very thinly.
 - Maxitrol eye ointment – this needs prescribing by a GP and often isn't recommended initially, as it is meant for eyes but is very effective for granulation tissue.



“Barrier creams can help protect the skin from any leakage around the site, especially from acid around a PEG.”

Dressings:

- Tube sites generally don't need dressing, and covering them can promote bacterial growth, so only use one if your healthcare professional advises.
- If you have lots of exudate, use gauze or makeup pads to soak this up and prevent from ruining clothes – cut a slit halfway and tuck around the tube, holding in place using tape or the bumper from the tube.
- A popular alternative to this is reusable tubie pads – these can be towelling or bamboo-backed so are softer and more absorbent. They also come in a huge variety of colours and patterns so are also great for feeling a bit 'less medical'.
- Some of the most popular tubie pads with members are from LoulaBellie by Ellie and Tubie Doodles (see page 24 for details and offers).

Using tubes for venting and drainage

Draining into a bag:

- Ideally try not to drain all the time - if you must, be sure to consult your team or put the electrolytes you lose back by using Dioralyte, Nuun, or ORS mixed with sterile water for your flushes and when running fluids.
- Dangler style tubes drain better than button style tubes.
- Always carry spare drainage bags – they leak and burst frequently!
 - Use a food clip at the bottom of the drainage bag to reduce the risk of the emptying nozzle detaching if you have the brand where this frequently happens.
- Catheter bags drain better and are sturdier than the Enfit drainage bags or bile bags - you can get an adaptor to convert the catheter connection to an Enfit connection to attach to your tube. Catheter bags then come with a choice of tube length depending on what suits you and how you like to wear it, bag size and tap style.

- Experiment with what type of bag works for you. For example, the T-type valve has the advantage that it is harder to catch by mistake and cause a spill, but the disadvantage is that it blocks more easily compared to a flip type valve.
- Try taping connections or turning up the end valve inside a bag cover to help reduce “accidents”.
- Extension tubing is also available for drainage bags if required.
- Try using tubie clips or clothes pegs to clip drainage bags to clothing to hold the weight of the bag, especially when full.
- Another alternative is to carry it in a small cross body bag. Waterproof bag liners are a good idea if you have your drainage bag inside a bag and don’t want to ruin the contents if the drainage bag bursts.
- Covers are great for disguising the contents of the drainage bags and making the whole thing more pleasant and less medical and allowing a bit of personalisation.
- Some popular drainage bag makers are LoulaBellie by Ellie and The Confidence (see page 24).

General drainage tips:

- Make sure you have wipes to hand!
- If you feel things are not flowing well, some things you could try to get things moving better are:
 - Use gravity – try and hold/pull your tube down and if using a bag make sure it is below where you are draining to.
 - A syringe can be helpful – sometimes using a pumping motion back and forth can help get flow going and then you can leave the tube open and allow it to drain freely.
 - Alternatively, you can use a syringe to aspirate directly from the tube.
 - Try lying on your side or changing position.
 - Try “milking” the tube.



Top Tips

- Choose your foods carefully and learn what causes issues for you – for example, sweetcorn may prevent you from venting for a number of days, meat fibres may cause problems for about a day, whereas yoghurts, jelly, ice cream etc may drain easily. Decide what is worth the trouble and symptoms - sometimes you may decide it’s worth enjoying things anyway! It’s ok to indulge in that Christmas Dinner!
- Don’t assume that only liquids will drain – some hard foods are good too. For examples some biscuits drain well because they crumble and form a ‘paste’ that drains easily. It is a good idea to experiment with foods you like and see what does and doesn’t work.
- Sometimes how well a food drains can be changed by how you eat it. For example, if you nibble a food so it breaks down into small crumbs and wash it down with a drink then it may drain well, whereas when you eat it ‘normally’ it may form more of a ‘lump’ that doesn’t mix well with the liquid and won’t drain. Nibbling will drive the family mad, but it will surprise you some of the foods that you can drain eating this way!

Unblocking a tube

A blocked tube is the thing we all worry about, but there several techniques that can be tried:

• **Don't panic!**

- Do not try to force water through.
- Start with the easiest solutions first.
- If there's a clamp on your tube, move it, sometimes it's as simple as that.
- Massage the tube to break up any lumps – it can help to place it in warm water.
- Use the 'push-pull' technique with a syringe to try to release the blockage – try different sizes of syringe. Smaller syringes such as 5ml or 10ml syringes are often more effective for unblocking tubes but take care as they can rupture or kink tubes if not done carefully.
- Use warm water.
- Sodium bicarbonate can be more effective than water as it is slightly fizzy. This is also more effective warm. Either use to flush the tube and with the push-pull technique, or another method is to leave a syringe full of sodium bicarbonate attached to the tube for an hour or so for the bubbles to sit there and work on the blockage, and then try to use the syringe as above.
- Try pushing air.
- Try running warmed sterile water or bicarb via the pump on the lowest rate it will go at and gradually increasing, so it will eventually either clear by increasing the rate or loosening the blockage enough so it will shift (this only works if the pump will run without occlusion alarms).
- If you have pancreatic or digestive enzymes as part of your treatment, these are great for clearing a blockage – let 20ml sit in the tube for half an hour then flush it to clear.
- These methods are best used in combination – e.g., use the push-pull technique with a syringe of warm water or sodium bicarbonate, and massage the tube while flushing in case it loosens any blockage.
- The main thing is persistence – it can take a long time, but most blocked tubes will clear in the end so keep at it even if it doesn't feel like it's working!
- Sometimes just waiting a few hours, moving around, and coming back another time makes the difference (sometimes it is how it is sitting against your bowel wall).
- Get moving. Try doing the hula hoop!





Managing medications

- Pharmacists can be helpful regarding what formulations of medications are available – many come in liquid or dispersible versions.
- If administering medication in a different way to the recommended method on the instructions, you are advised to check with a pharmacist.
- Don't assume that liquids are always best! Liquids often require large volumes which some people find hard to tolerate whereas the tablet form may dissolve in a much smaller volume. Tablets are much smaller to store and transport and can be put into pill organisers which is helpful if you have lots of medications. Some liquids such as antibiotics are also very thick and easily block tubes. Some liquid medications also contain sugars which can affect blood glucose levels.
- There is a handbook available which gives very useful information on most medications as to what can and can't be put down and tube and what formulations are most suitable: The BPNG Handbook of Drug Administration via Enteral Feeding Tubes, 3rd Edition, written by Rebecca White and Vicky Bradnam.
- Prepare your medications in advance to allow plenty of time to dissolve thoroughly.
- Pill Mill pill crushers are good if you are struggling to crush tablets – they are easy on the joints and crush to a fine powder.
- You can get cheaper pill crushers on Amazon or in most pharmacies.
- Another alternative if you struggle with a pill crusher is to use a pestle and mortar – some people find this easier on the wrists.
- Many medications will dissolve without crushing – put the tablet directly in the barrel of the syringe and draw up a few ml of water, shake well to dissolve it and then you can administer it directly from the syringe.
- In theory, the above method does not work with film coated tablets but many still do dissolve this way - so it is worth trial and error to see which of your medications will dissolve as it saves a lot of crushing. Some need more time/shaking than others.
- However, do not dissolve or crush slow-release medications. These cannot be given via tube.
- If you are struggling to dissolve your medications, try using slightly warm water.

- A pill organiser can really help keep on top of medication times.
- If you have lots of medications have a plan for doing them – for example, the tablet ones you dissolve first, then the thinner liquids, then finish with the thick liquids that need mixing with water. This helps make sure nothing gets forgotten and helps with tolerance.
- Many people like to prepare all meds at the beginning of the day and store them, for example in a makeup bag. Syringe caps are really useful for doing this as you can store the medication in the syringe and label them. This reduces the time you spend doing your meds throughout the day and saves carrying lots of bottles with you.
- Ask for a two-way Y connector for your tube if you are administering meds while connected to feed so that you have a second port for administering meds. These are easier to use than the med ports on the giving sets.
- If you can't tolerate the volume of your medicines down your tube, the Nutricia bottle lids fit the Cow & Gate 90ml bottles or Sterifeed bottles perfectly so you can mix meds in there and run them through your tube at a rate you can tolerate. Remember that sometimes you need to take the meds within a certain time frame.



Out and about (what to take and how to pack)

It can be a good idea to have a pre-packed bag with all the spares and equipment you might need when out and about packed and ready to go so that you can just grab it quickly rather than having to get everything you need every time you go out.

This can be kept inside your normal bag. Different people vary in how comprehensive their kit is – you probably won't need to include every item listed below as it will depend on your individual needs. Some people take spares of everything whereas others choose to carry very little. Use a makeup bag, wash bag, pencil case, lunch box, medical bag or anything that is the right size that reflects you and your personality. If you need something medical/official there are pouches available with a red cross or medical symbols on.

First aid kit example

- Sterile water – Cow & Gate sell small pre-filled bottles. You can fill your own bottle/flask with cooled boiled water - Sterifeed 130ml are great for this as they can be sterilised, and the top is wide enough for a syringe. They also have 250ml for longer days out. Urine sample bottles are the perfect size for a couple of flushes if you need to save space.
- Syringes and syringe caps – empty syringes and syringes pre-filled with water as flushes are useful. Medications can also be pre-measured into syringes to save carrying the bottles.
- Feed/formula – especially if you are in the car, it is good to put some in the boot in case of unexpected delays.
- Plastic cup/pot.
- Wet wipes or reusable wipes.
- Tissues or paper towel.
- Giving set and extension sets – spare in case of problems.
- Tubie pads/tubie clips.
- Dressings – in case these need replacing when out.
- Tape – particularly important for NG/NJ tubes in you need to replace the tape on your face if it gets caught.
- Scissors – can be used to cut dressings or tape.
- Nappy bag or other waste bag – useful to dispose of dressings or other waste. Can pop in your bag until you can find a bin to dispose of.
- Spare feeding tube (balloon tubes) – even if you cannot replace the tube yourself while out and about, if your tube comes out you can go to the nearest hospital and will have a tube with you that they can use. This is helpful as the tract can close very quickly.
- Enplug Enteral plugs that you can put in if your tube comes out to keep the tract open until your tube can be replaced.
- Spare connectors or adaptors e.g., catheter connectors for drainage bags.
- pH strips.
- Hand sanitiser.
- Spare drainage bags if you have PEG drainage – this is essential as they often burst!



- Spare clothes in case of leaks.
- Vomit bags – you can get bags that contain a gel designed to turn the vomit into a more solid form so that you can dispose of it in a bin. This is also useful to empty PEG drainage bags into when they are full so you can throw them away if you are somewhere that you can't empty them.
- Radar key – this allows access to disabled toilets in many places so you can have space and access to a sink to sort out your tube.
- Scissor clamps/Dycem grip – in case your tube gets stuck this is helpful to undo connections.
- Piece of plastic tablecloth or similar – useful to use as a clear surface.

It is helpful to carry a summary of your medical history – medications (repeat prescriptions), allergies, medical conditions etc – in case of any problems.

- Be organised – in the early days use a list to make sure you remember everything.
- Take spares of everything.
- Find yourself a comfy backpack you like the style of. If you don't like the backpack provided by your feed company, you can buy more stylish ones or modify your own.
 - Hydration rucksacks are popular as they are designed to carry fluids and so have pockets and holes for tubing, e.g., Vibedration and Camelbak.
 - Baby changing bags make great feed rucksacks as they have loads of pockets and sections and are waterproof.
 - You can also buy specially adapted rucksacks (TubieeGo and Tubie Life – see page 24).
- It is possible to get feeding systems into a handbag if the air is removed from containers.
- Some people prefer other options – bum bags can be good particularly for wheelchair users, some people like to store their supplies in pockets of their clothing for example cargo shorts.
- And of course, don't forget PINNT's medical tag for your backpack! (see contact details on page 24 for how to order).



Travel

- Ask your homecare company about a delivery to a UK destination. If travelling abroad ensure you know what they are able to offer in terms of a delivery.
- You are allowed extra baggage for medical supplies when flying, which you can use for your feed supplies. This must be arranged prior to travelling. See 'PINNT Travel and Holiday Guidelines' for full information.
- Take enough feed and supplies for at least 2-3 days longer than you are going.
- Distribute feeds over several bags. Duplicate tubes in different bags.
- Some people like to set up daily pouches to ensure nothing is forgotten.

- Have multiple changes of pre-cut dressings in your cabin bag when flying, as you can't take scissors.
- Have with you a summary of your medical condition and all the phone numbers of your doctors/ dieticians/ support team just in case something happens, and you need to visit a hospital different to your usual one. A doctor's letter is also useful if travelling abroad, particularly to explain any flushes or liquids you may need on the plane.
- Book assistance – this is available both at airports and for train travel and is free. It is particularly useful for wheelchair users as they will help you around the airport/station.
- Contact your hotel in advance and let them know about your feed in advance so they can accommodate your needs, for example giving you a kettle in your room, or giving you a ground floor room.
- Ensure you have the right insurance. Do not go with standard package holiday insurance offers.



Top Tips

- Preparation is key – plan well in advance.
- Refer to the PINNT travel guides.
- Remember to add the PINNT medical tag to your bag.
- Be creative with how you hang your feed containers, e.g., carrying a piece of ribbon can help with this. You can hang off drawers, door handles etc.

Children with enteral tubes



- Make it colourful – use patterned tapes, and tubie pads with designs on that they can choose themselves.
- Use tubie clips to clip tubing to clothing to prevent getting tangled and caught during play or sleep.
- Having toys and teddies that also have a tube 'like them' can help them feel more normal and help to explain things. This is also good for people with learning difficulties or autism.
- Choose clothing that helps keep tubes tucked away to stop young children playing with them if this is a problem. For example, dungarees can be good to keep tubes out of the way.

**Do you have any tips
on helping children with
enteral tubes?
Please email
kpett@pinnt.com**



Clothing and accessories

Accessories:

- As well as being functional, tube pads, tube clips and tapes are a great opportunity for personalisation and making things feel less medical. You can accessorise to match your outfit, go with something that matches your personality or your favourite cartoon characters or just match your mood that day!
- You can also get transparent tapes if that is your preference and prefer it not to be visible – both ways are perfectly ok!
- Tube clips are really useful to gather up excess giving set length and clip it to clothing (e.g., waistband or pocket) or your bag to avoid tripping while walking around or getting caught in wheels of wheelchairs or pushchairs. If you find it makes your pump alarm, make a bigger loop with the tubing.
- Drainage bag covers are another popular item to personalise or express your personality. These are useful accessories, because as well as hiding the contents of the bag, they can also take the weight of the bag, either by clipping to clothing, or with a strap to hang over the shoulder. They also catch any drips from the tap if you want to put it in another bag to carry around.
- Pump stickers can be used either just as decorative items to put your name or a design on your feed pump, or if you have two pumps for feed and fluids, they can be really useful to distinguish between the two. If you don't want to buy them, you can make your own with paper and Sellotape.
- Etsy has a number of shops that sell these products.
- Although PINNT cannot recommend any providers, some shops recommended by individuals include (see details/offers on page 24):
 - LoulaBellie by Ellie (tube pads, tube clips and drainage bags).
 - The Confidence (Drainage bag covers).
 - TubieDoodles (tape, tube pads, other medical accessories).
 - TubieLife (tape, pump stickers).

Clothes:

There was a lot of variation in the tips and advice received around clothing, with some very contradictory tips that were the exact opposite of each other. The main takeaway message was everyone is different – there is no one solution that fits everyone. So be creative, experiment, and find what is most comfortable you personally.

- Patches can be sewn into clothes to let your tube through so you can still wear what you like. You can buy these in all sorts of shapes to suit your style.
- You can also sew a small 'buttonhole' into clothes. If you add two overlapping elastic straps inside, it closes it off but still allows the tube through. This works well for dresses, playsuits, etc.
- If they have pockets, sew holes in the pockets for the tube to come out of so the holes can't be seen, especially when you aren't connected to the tube.

- Dresses with buttons down the front are great for discreet access, and comfortable to wear as no pressure on the tube site. Pinafore dresses are also good for tube access.
- Most people prefer to wear separate top and bottoms (whether skirt or trousers).
- The only consensus on trousers is not tight around the tube area:
 - A lot of people prefer high waisted (but baggy), so the waist band is above the tube area and plenty of room for tubes below it. This is particularly popular for new tubes.
 - A lot of people prefer low-waisted trousers, particularly low-rise leggings or leggings with the top folded down (can adjust how far to fold depending how your stomach feels).
 - A minority said they like tight around the tube e.g., high waisted leggings to secure the tube in place and stop it moving around (but definitely not with a new tube that is still healing).
- Maternity jeans can be great as you can get them fitted around the legs and hips but with a stretchy section for the waist to allow for tubes and for bloating, and also handy to tuck drainage bags into.
- Belt loops are useful to tuck the end of the tube into when not in use.
- If you get a lot of bleeding or discharge from your tube site, you may prefer darker coloured tops or those that aren't too tight, or it can show through or mark them even with tubie pads.
- Zip up hoodies are easier than pull over ones because you can take them on and off without having to disconnect the tube (if you have an NG/NJ).
- Clothing can be easier with a button tube than standard tubes – if you feel self-conscious about this, it could be worth discussing with your team if a button would be appropriate for you.

?? Q&A

Q: "When I'm outside in winter, running my feed makes me feel freezing cold. How can I keep warm?"

A: If your feed is mixed from powder, you could mix it using warm water, or warm it up slightly. To keep it warm you could then insulate the bottle within your feed rucksack. Camelbak make insulated neoprene tube covers for skiing (others are probably available or you could make your own) to keep the feed warm on its way from the bottle into you. To keep you warm, try tucking small hot water bottles into the waist band of your trousers, and wear thermal leggings and t-shirts under your clothes. You can also buy heated clothing, such as socks and gilets and jumpers that have heating elements in, powered by USB packs or rechargeable batteries which are great when your own body heat just isn't enough!

"If you want to wear a crop top or bikini, go for it, don't worry about other people."

"Just embrace it."

"Your tube is part of you and is helping you to live so don't be ashamed of it."

Adaptations for disabilities

Disabilities are extremely varied. Be it affecting dexterity, mobility or something else, all of it can affect setting up and managing our feed. Speak to your nutrition team if you are having difficulties as they may be able to make changes to help. For example, for one patient who was having problems with the screw cap on their tube due to dexterity issues, their nutrition team were able to change the end of the tube, which has caps that flip open instead and were much easier. This is just one example, but many problems will have solutions if you raise them with your team rather than struggling alone. Some general suggestions:

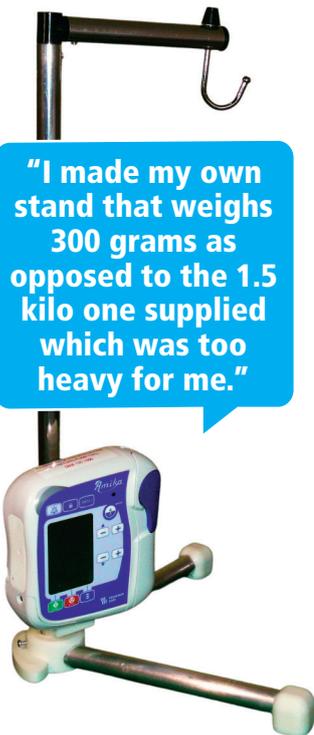
- Jar openers can be useful to open medication bottles.
- Dycem grip helps with small connectors when tight if struggling to grip, as do scissor clamps.
- If you use a wheelchair, try hooking your backpack on the handles to carry your feed around (be careful the tubing is clear of the wheels).
- Another alternative is to attach a drip stand to your wheelchair – you can buy specific IV stands made for this purpose.

Some talented and creative PINNT members have created their own solutions:

"I printed some parts on my 3D printer. There is a coffin shaped piece to snap off the feeding bag seal, a butterfly one to steady the top, while a pear shaped one slides onto the giving set tube to enable more pressure to be applied to the connection."



"I made my own stand that weighs 300 grams as opposed to the 1.5 kilo one supplied which was too heavy for me."



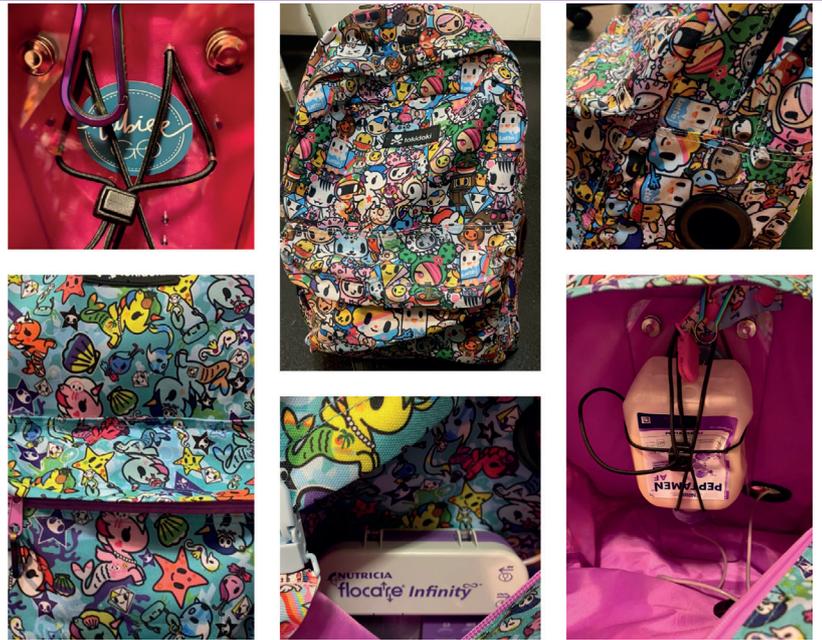
"I have an adapted trolley (created by my dad) that makes moving around my home during daytime feeding so much easier."



**Do you have any tips on helping adaptations for disabilities?
Please email kpett@pinnt.com**

Living well with a tube

- Try not to be self-conscious about your tube.
- Use a backpack for your feed – it's much less limiting than an IV pole.
- If you're going to have to carry the same backpack all the time, make sure it reflects your personality! You can get lots of great adapted backpacks which look good but are also adapted for feed pumps (see page 24):
 - TubieeGo: adult and child backpacks. They also offer a service to adapt bags bought elsewhere for use with feeding pumps.
 - TubieLife: adult and backpacks and other items.
- An alternative is to use any backpack the Nutricia Go frame fits in or adapt it yourself by putting a carabiner clip inside to hang the feed bottle from it.
- If you are using the backpack provided by your feed company, you can personalise it yourself. Some suggestions from members on how they have done this include painting with fabric paints, decorating with badges and pins, sewing on patches and badges.
- Some people just use a handbag and squeeze all the air out of the feed bottles and find this works okay without hanging the bottle.
- Use the time you are asleep to plug the feeding pump in to charge so you will not be restricted during the day.
- Cable protectors (the ones that look like springs) are good to stop the tube bending and causing occlusions if you put them at the top of the giving set where it comes out of the bottle.
- If you have an NG/NJ and find it gets in the way when exercising, tie it up into your ponytail (if you have one!).



Living with a tube can be difficult, especially when you are new to it, but here are a few things that may make it easier:

- As one respondent said "Just keep carrying on" – practice makes perfect, and it will get easier over time.
- Remember that your tube is keeping you alive and allowing you to be here to spend time with friends and family.
- Try to see it as food rather than something medical.
- It can be hard to deal with responses from people around you, especially in public. Some people react to this by going out of their way to avoid drawing attention, others have said they will go about doing their tube feeds in public e.g., in the golf club and actively engage anyone who is watching and take the chance to educate them. It's very personal – you have no responsibility to share your medical condition or educate anyone, but if you feel you would like to, more knowledge is always a good thing!



- It can feel very isolating – don't struggle alone, try to talk to other patients in a similar situation. PINNT has a member-only Facebook group, for example, where you can always post if you are having difficulties. Other patients can always understand in a way that family and friends may not, for example, how hard social events are when you can't eat.
- It can be hard to know how to talk about it with those around you – advice from members is "Laughter is the best medicine". Except with close family (where you are going to have more serious conversations), talk about not eating in a light-hearted way, make a joke of it to put them at their ease. While we should not have to do this, many people feel bad for us and this makes them uncomfortable so keeping it light-hearted helps!
- Join your hospital's patient panel, and any user experience initiatives you can find - it feels good to feed your experiences back and improve services for other patients.



Top Tips

- Remember that your tube will enable you to live a full and active life.
- "I used to draw with Sharpies all over each new feed bottle - disposable artwork! Battery powered LED light sets are a fun and lightweight addition at Christmas."
- Make sure you have one of PINNT's Restaurant Cards if you are going out to feel more confident ordering smaller portions or just having a drink (see contact details on page 24 for how to order).

Glossary of Terms

Balloon retained tube – This refers to the way that the tube is held in place: a small water filled balloon sits inside the bowel/stomach wall to prevent the tube from slipping out through the stoma. A bumper on the skin side holds it in place. The water can be removed from the balloon using a syringe making it easy to insert and remove the tube, which needs changing every so often. In some trusts, patients are taught to do this themselves for gastrostomy tubes (into the stomach) or jejunostomy tubes (into the small bowel). This is not possible for PEG-J tubes due to the jejunal extension. Balloon retained tubes come as both button style and dangler style tubes.

Bolus Feeding – A type of enteral feeding which involves giving small volumes of feed at regular intervals throughout the day. This can be done with a syringe, bolus sets with a plunger, or gravity set. This may be the sole way of feeding, or used in combination with the other types such as continuous feeding.

Button tube – A button tube refers to tubes which do not have any length of tubing on the skin side of the abdomen. They sit flush against the skin. When they are in use, an extension set is attached to them, which allows for connection of the giving set. These can be used as gastrostomy, jejunostomy or PEG-J tubes. These can be popular as when not in use they are discreet underneath clothing and there is no tubing to get caught, especially if exercising.

BPNG – British Pharmaceutical Nutrition Group. Specialist interest group for pharmacists, pharmacy technicians or scientists with an interest in parenteral or pharmaceutical nutrition.

Dangler style tube – This is a type of tube where there is a length of tubing external to the body. For those that run feed continuously or most hours of the day, these can be easier as there are few benefits to a button when always connected and it is easier than using an extension set (fewer parts to come apart by mistake/leak). They are also preferable for venting/drainage as they work better – the extension sets on button tubes have a small opening and do not drain as effectively.

Enteral – This refers to anything passing through the intestine, therefore enteral tubes include all types, both those through the nose and surgical tubes. Enteral feeding is used to distinguish artificial nutrition through the intestines from parenteral nutrition which is through the veins.

Gastrostomy/PEG/RIG – A gastrostomy tube is a feeding tube into the stomach through the abdominal wall. They can be used for feeding, fluids and medication. In some cases, they are instead used as venting/drainage tubes to help empty the stomach and help reduce vomiting. When used for this purpose, they tend to be placed low down in the stomach, whereas for feeding they may be placed higher up.

PEG stands for Percutaneous Endoscopic Gastrostomy and refers to the way it is inserted via endoscopy (percutaneous means through the skin). An alternative method of insertion is under radiological guidance and these are called a Radiologically Inserted Gastrostomy (RIG). However, in practice once they are inserted they function exactly the same and it is almost always abbreviated to PEG regardless of the method of insertion.

Granulation tissue – This is a sore red tissue that can develop around your stoma, particularly if your tube has been moving around a lot and rubbing. It is a very vascularised tissue and so can be bleed easily and be very painful. It can usually be visible around the tube but can occasionally develop inside the tract. However, it is usually treatable.

Jejunostomy – This is a tube through the abdomen into the jejunal part of the small bowel, not far past the stomach. These allow feed, fluids or medication put down the tube to bypass the stomach.

Nasogastric tube (NG) – A nasogastric tube passes up through one nostril and back down the oesophagus into the stomach. They can be placed bedside or in clinic, and some patients can be taught to insert their own. Like PEG tubes, they can be used for feeding and medication, but are also used for venting and drainage.

Nasojejunal tube (NJ) – A nasojejunal tube also passes through the nostril, down the oesophagus and into the stomach but it then extends further in the jejunum of the small bowel. Unlike an NG, the NJ cannot be placed bedside and usually requires an endoscopy or interventional radiology to place. They are used for feeding, fluids and medication.

PEG-J – A PEG-J is a double tube, where you have a gastrostomy tube with an extension tube into the jejunum. This is usually used to allow feeding/medication into the jejunum, whilst allowing drainage from the stomach, although they can be used for other purposes.

Nutricia – This is one of the companies which supplies enteral feed and associated supplies (e.g., giving sets, syringes etc) for home enteral nutrition to patients around the UK. There are other companies such as Abbott and Fresenius Kabi. Who you are supplied by at home depends on where you live and who the contract is with.

Venting/Drainage – This refers to using a tube from the stomach (either gastrostomy or NG) to remove some of the stomach contents to reduce nausea and vomiting. This can be done by opening the tube and letting it drain out freely into a container periodically, aspirating using a syringe, or collecting into a drainage bag. It is not recommended to drain a tube continuously if using a drainage bag, but instead to clamp/unclamp as needed.

Offers and contact details

PINNT cannot recommend or endorse any products or businesses. All businesses listed below have been recommended by individuals as part as of the process of collecting tips to put together this guide. The descriptions below are the businesses' own wording.



TubieeGo believes strongly in inclusive fashion. We sell stylish and high-quality feeding tube backpacks and bags for adults and children. Our specially adapted bags and backpacks are compatible with all feeding tube systems. We also run a bag adaptation service, so you can send a backpack of your choice to us for adaptation.

10% off for PINNT members at www.tubieego.com between 15th May to 14th July 2022 – discount code needed.



Tubie Doodles is the first custom medical tube tape supplier in the U.K. est. 2017 through the experience of having a tube fed daughter to make the essential medical support brighter and fun. We have since expanded to other items related to helping people with medical tubes to make the process how they want it to look.

15% off PINNT members' first orders at www.tubiedoodles.co.uk – discount code needed.



At Tubie Life we aim to make the world a little more accessible for those with feeding tubes! We offer a range of backpacks, tubie tape, G-Tube pads, and pump stickers to help you accessorise your feeding tube and make it a little more 'you'. As a fellow tubie, I have used these products to increase my confidence and I hope they do the same for you.

10% off PINNT members' first orders at www.tubielife.co.uk until 31st October 2022 – discount code needed.



The Confidence: My custom-made catheter bag covers provide great protection for drainage bags from dust (which can be a source of infection) alongside giving people more confidence to wear shorts or skirts. – Testimonial from a previous customer: "They are quite simply life changing". Very often I receive emails about how confidence is improved since people started covering their drainage bags. I use different platforms for my work:

www.etsy.com/uk/shop/TheConfidence
www.etsy.com/uk/shop/CraftbyTiana
www.facebook.com/groups/1585989068363429
(The Confidence - strictly private to protect members)

15% discount on all products if ordered through The Confidence Facebook group – no discount code needed.

Contact details:

For all PINNT resources mentioned in this guide please use the following details to request them:

Email: comms@pinnt.com

Tel: **020 3004 6193**

Please supply your full name and address along with your PINNT membership number. If you are not currently a PINNT member you can join via the following link: www.pinnt.com/Membership.aspx

To obtain discount codes, please contact kpett@pinnt.com with your name, membership number, and which code(s) you would like.