Paediatric Society New Zealand

NZCYCN
New Zealand Child & Youth Clinical Network

FAQs for Tube Feeding Families

Tube feeding definition

What is tube feeding?
Tube feeding involves using a tube to give a liquid feed through the nose (nasal tube) or stomach (gastrostomy tube). Tube feeding helps your child to meet their nutritional needs when they are not able to eat or drink enough by mouth. Liquid feed types include expressed breast milk, infant formula or a specialised liquid feed (also called enteral feed or enteral formula).

Nasal tubes

What is a nasal tube?
There are 2 types of nasal tubes: nasogastric (NG) tubes and nasojejunal (NJ) tubes.

Nasogastric or NG tubes
A soft polyurethane tube is put into your child's nose and runs down your child's food canal (oesophagus) to their stomach. This type of tube is called a nasogastric or NG tube.

Nasojejunal or NJ tubes
In some cases, the tube may go beyond the stomach and end in a part of the intestine called the jejunum. This type of nasal tube is called a nasojejunal or NJ tube. Your child may need an NJ tube if they cannot tolerate feeding into the stomach.

Will my child need an operation to have a nasal tube put in?
Your child will not need an operation - nasal tubes are usually put in by a nurse. Nasal tube feeding is a temporary way of feeding.
A few things to keep in mind about nasal tubes:

- before putting anything down the tube you need to ensure the tube is in the correct position using pH indicator tape, or other methods taught to you by your medical team
- you will need to tape the nasal tube to your child's cheek - this may irritate them. Your nurse can help you find taping that will reduce irritation to your child’s skin.
- your child may pull the tube out, but you can be taught how to replace the tube at home by your medical professional. The tube will also need to be changed regularly
- you may see increased reflux, gagging, or refusal to eat by mouth when the tube is in place
- the nasal tube may be replaced by a gastrostomy tube if it is appropriate and your child needs longer term tube feeding

General tube or stoma care

What are the different ways you can tape to secure an NG tube?
Taping from the edge of the nostril to the tragus (the little triangle shaped part of the ear) is the most secure. Different taping may be used depending on your child’s age, skin condition, medical condition and how often it is requiring changing. Alternate tape placement can be done in NGT care. Different taping methods can be demonstrated by your nurse

Are there different types of tape I can try?
Use the tapes and consumables provided through your nurse unless there is a problem. These are products that have been tried and tested and may have more specific uses such as providing a protective skin layer onto which tape can then be applied e.g. extra thin Duoderm and Hypafix tape. Preparation of the skin with a barrier wipe e.g. Cavillon may be used prior to tape placement.
It is good to spend time with your nurse to find the most comfortable and easy to use tape for your child.

Should I wrap my baby up when securing the tape to avoid their hand grabbing it?
Gently wrapping your child to prevent grabbing hands is a sensible solution if it adheres to acceptable restraint practices and helps minimise a prolonged reinsertion procedure. Promote a calm environment and approach and it is best to work with your nurse/health professional to tailor method to the individual child.

What is the best way to remove the tape gently?

Depending on the type of tape used, usually ‘Remove wipes’ will be effective. ‘Remove wipes’ should be applied over the length of the tape to be changed and also at the base of the tape and skin as it is being lifted. Ask your Nurse to demonstrate this if you are unsure.

Should I change where I place the tape each time?
This is not necessary unless there is a problem with skin integrity. Consider using a protective layer before applying tape to minimise trauma to the area if you are concerned.

What can we wipe on the skin to remove sticky patches left by tape?
The best method is using ‘remove wipes’ as acetone (though effective) can be harsh and drying on sensitive skin

What if my child gets a reaction from the tape, what else can I use?
There will be a variety of other tapes (or transparent films) which can be used as alternatives. It is best to discuss with your Nurse or health care provider and/or continue to experiment with the products available.

Will I need a special cream to treat skin reactions to the tape?
You can use a barrier cream/wipe unless the skin is infected. See your doctor for appropriate treatment otherwise.

Can I get the homecare nurse to teach me to put the NG tube back down myself?
Yes, your community nurse or hospital nurse can teach you how to replace a NG tube if you would like to learn to do this at home. Learning to reinsert the NG tube will help to reduce the number of times you have to return to hospital to have it reinserted. Including other members of the family in the education process of NG tube reinsertion will also maximise your chances of Out of Hours help when you need it.

What is the best way to unblock a tube?
A push-pull technique of flushing with 10-20mls of warm water is the most effective method of unblocking a tube. This can be done more than once before contacting your health provider or nurse for further advice. Sparkling water, and mixing baking soda with water can also be used, but neither are as effective as warm water. We do **not** recommend using carbonated beverages such as Coca-Cola down the tube.

What are good ways to secure a loose tube to clothing?
Draping the tube over the ear and taping it to the nape of the neck is one method. Another is to thread it down the back of a onesie or top ensuring that it does not tug or pull out.

Are some clothes more suitable than others for NG tube fed children?
Useful clothing can be tops that have a button/snap at the back of the neck, or a label that is a loop so that you can thread the NG tube through it a few times to keep it secure and stop it from getting in the way or being unintentionally pulled (or intentionally when it comes to little people). Loose trousers with an elasticated waist will make it more comfortable around gastrostomy site.

How long will my child have an NG tube before we change to a gastrostomy or MicKey button (stomach tube)?
A NG tube is designed to feed your child for 6 weeks before it is changed. It is possible after 6 weeks that you will change to a gastrostomy tube that may be either a PEG, MicKey button or another tube of tube that enters through the stomach. This will depend if tube feeding is long term or if feeding via a gastrostomy tube is appropriate

What can and can’t my child do wearing a NG tube?
There will always be safety considerations for a child with a NG tube and care should be tailored to the individual. This should not prevent them from engaging in normal child play and activity but discuss this with your Nurse for further advice.

Gastrostomy tube

What is a gastrostomy tube?
A gastrostomy tube goes directly into your child's stomach from the skin of your child's tummy. The tube may be put in during an operation, or by a procedure called endoscopy. Endoscopy is a way of looking inside the body using a flexible tube with a small camera on the end of it. The endoscope is put in through your child's mouth and down the food canal (oesophagus), which leads to the stomach. There will be a recovery period for a few days after the gastrostomy tube goes in.

Types of gastrostomy tubes
Your child's health professional will discuss the best type of tube with you. Types of gastrostomy tubes include retention disk PEG, PEG-J, balloon gastrostomy or MicKey button.
A few things to keep in mind about gastrostomy tubes:

- gastrostomy tubes are a safer and more comfortable long-term option

- you may be able to replace some tubes at home (for example, balloon gastrostomy or MicKey button) following training with your community or hospital nurse
- tubes generally need to be replaced every 6 months for balloon inflated gastrostomy and MicKey tubes and between 2-5 years for retention disk PEG and PEG-J tubes - tubes may need to be replaced sooner if there is any deterioration of the tube or it is not working properly
- during the healing process, red, bubbly tissue (granulation tissue) may form around the skin where the tube goes in - this is not dangerous and can be treated by your doctor or with ointment
- gastrostomy tubes may become blocked if food or some medications are put down the tube - ask your health professional before putting unprescribed foods or medications down the tube
- if your gastrostomy tube becomes blocked then you can try to unblock it with extra water flushes and/or contact your healthcare professional
- The single most effective way of maintaining patency is to always flush before during and after medication or liquid feed administration.
- Also, it is important to follow medication preparation as instructed as some medications are viscous (thick), require effective crushing or can interact with food or other medications and cause blocking of the tube.
- Important to attach the medication/bolus extension set to the gastrostomy as shown before using a push-pull technique of warm water to flush the tube. It is important not to attach a syringe directly to the top of the Low-profile Mickey button as this will break the valve mechanism

Are some clothes more suitable than others for gastrostomy tube fed children?

Loose fitting trousers or skirts with elastic will be more comfortable for your child with a gastrostomy. For overnight gastrostomy feeding you may want to run the giving set down one trouser leg and over to the pump to avoid your child getting tangled up in the tubing.

How can I tell if the stoma has an infection?

Education around stoma health should be provided by your community nurse. However, things to look for with infection include rash or skin excoriation, redness, stomal tenderness and a foul-smelling discharge. Other considerations may be the child’s overall appearance, irritability, vomiting or gastro-intestinal disturbance and fever.

What is granulation?

Granulation is the process of new connective tissue and tiny blood vessels that form on the surface of a wound during the healing process. This process of healing takes place once the stoma is formed to accommodate a gastrostomy tube.

Do I need to do anything about granulation?

Sometimes the process of granulating can be more prominent in some individuals. This can cause discomfort or pain, an ill-fitting gastrostomy device or infection. It is important to seek further medical advice or treatment.

What can I do to prevent the button rubbing on the skin?

Good skin care and stomal management. Ensuring that the device is the correct fit and sitting comfortably on the surface of the skin. Discuss concerns with your Nurse or Surgeon before placing gauze beneath the GTT to prevent problems with friction. Consider the use of a barrier skin wipe/cream to promote skin integrity

Why is the button leaking?

This is often due a faulty or ill-fitting gastrostomy device which may need replacing. Please discuss with your health provider/Nurse for further help.

What can I do to prevent the button leaking back onto the skin?

This is often due a faulty or ill-fitting gastrostomy device which may need replacing. Please discuss with your health provider/Nurse for further help. Also consider the child’s position for feeding or the presence of gas in the abdomen.

Are there products available to hold tubes and prevent a child tugging at it?

There are products available to stabilise both nasogastric and gastrostomy tubes with new products becoming available regularly. Discuss this with your Nurse or health professional for recommendations.

Formula and feeding

What is a feeding plan?

Your child’s Dietitian and feeding team will provide an enteral feeding plan for your child. This will include times and type of feed. The type of feeding plan will depend on your child's medical condition and how much feed they can tolerate. Specialised liquid feeds are only available on prescription from your dietitian, family doctor, or paediatrician. Feeding can be given in either of the following ways:

- bolus feeds - larger amounts of liquid feed given at set times over the day, being similar to mealtimes
- small amounts given continuously by a feeding pump

It is a good idea to keep a copy of your child's feeding plan at home, school and take it to the hospital if your child has an appointment or needs admission.

Do we have a choice of feed / formula?

The enteral feed / formula that your child is receiving has been decided by your Dietitian. If you are unsure why your child is on a particular feed / formula or you want to change it, then contact your Dietitian to discuss this. There are a large variety of commercially prepared formulas available to suit your child's age, and/or medical condition.

Can we use real food through the tube i.e. blenderised diet?

We do not recommend that you use blenderised food down the tube as this can:

- increase risk of blocking the tube
- increase the risk of bacterial contamination
- give less nutrients through the tube if you water down the food

However, there are some families who have given food down the tube with the help of their Dietitian. If you would like to discuss using blenderised foods down the tube, then contact your local Dietitian.

Should I put something in my child's mouth while they feed to make the food/mouth connection? What could I use?

This will depend if your child is safe to have food given in their mouth. Your Speech and Language Therapist (SLT) can give you guidance as to whether your child can have food orally or not. If your child is 'Nil by Mouth' your Speech and Language Therapist (SLT) can give you some advice on appropriate ways to manage oral health.

Who will be involved with my child's care?

There will be a range of professionals supporting you and your child with tube feeding. These professionals may also help your child begin to change to feeding by mouth (oral feeding). Your child needs this range of professionals (called a multidisciplinary team) because of the different factors that contribute to feeding. The professionals can include:

- family doctors (GPs)
- paediatricians
- children's community nurses
- dietitians
- speech and language therapists
- psychologists
- occupational therapists

Where do I get more feed supplies for my child?

After discharge from hospital your child should be sent home with some enteral feed / formula and supplies to carry on feeding at home. Depending on the area you live in New Zealand you might have feed and supplies delivered to your house, or you may need to pick-up supplies through your community pharmacy and/or your local Dietitian or Community Nurse. Ask your Dietitian or Nurse if you are unsure how to get future supplies.

How will tube feeding affect my child and our family?

Tube feeding takes some adjustment, but many families report relief at seeing that their child is getting the nutrition, liquid (hydration) or medications that they need. With the help of your health professionals, you will be able to learn to use the feeding tube safely at home. If safe, your child will still be able to eat by mouth (orally) while they have a feeding tube.

Your child will still be able to take part in most activities and go to day care or school. People who care for your child will also be able to learn to use the feeding tube.

It can be helpful to have some prepared responses to questions people in the community may ask about the tube (what it is for, why it is there, etc).

You may find it emotionally overwhelming if your child is on long-term tube feeding. It will be helpful to seek support from your feeding team, other professionals, or parents. You can ask your health professionals if there are support groups in your area. There are also links at the bottom of this page to New Zealand and international support networks.

How long will my child need to be tube fed?

The duration of tube feeding varies from child to child. Your child will need to tube feed until they are able to eat or drink enough by mouth (orally) to meet their nutritional needs. Some children will have medical conditions that mean they may always need some degree of tube feeding.

To be ready for feeding by mouth (oral feeding), your child will need to show that they can swallow safely and are otherwise medically stable.

How does my child move from tube feeding to eating by mouth?

It is helpful to plan for feeding by mouth (orally) with your health professionals as early as possible. You may start to include 'mealtime' experiences into your child's tube feeding routine, such as:

- giving tube feeds in a food context (for example, for a younger child cuddled up with you, for older children at a small table with finger food or in a highchair with the family at dinner time)
- encouraging tube feeding to be done by other people and at other places (for example, by grandparents in their kitchen), just like children who are fed by mouth and who eat with different people and in different places
- involving your child in mealtime preparation and other food experiences (such as birthday parties, visits to cafes and restaurants)
- encouraging your child to explore food through their other senses such as touch, smell, vision
- considering changing from a nasal tube to a gastrostomy tube early to minimise discomfort to the mouth and face caused by nasal tubes

Approaches for tube weaning/changing to feeding by mouth

Seek guidance regularly from your health professionals about when your child may be ready to change from tube feeding to feeding by mouth (oral feeding).

If your child is ready, your health professionals may recommend a plan for weaning your child from tube feeding. This plan will depend on your child's medical condition, nutritional status (for example, their height and weight on growth charts), oral motor skills (for example, chewing), anxiety and behaviour, as well as the services available in your area. At the minimum, your Paediatrician/Doctor, Dietitian, and Speech and Language Therapist will be involved.

While there are many different treatment approaches, your child's plan may involve some of these common elements:

- medical monitoring and oversight by your Doctor or Paediatrician
- nutritional monitoring and oversight: your child's Dietitian will regularly assess your child's growth, how much feed they are having, and help you with choosing nutritional foods to introduce
- hunger manipulation: your child's tube feeds may be decreased by your Dietitian, or scheduled differently so that your child is more likely to feel hunger at mealtimes when they will be fed by mouth (oral mealtimes)
- oral motor and sensory techniques: your Speech and Language Therapist can help with improving skills such as drinking from a cup and using a spoon, and introducing new tastes or textures to your child
- behavioural techniques: your Psychologist or other medical professional may help you learn strategies to increase structure and routine in meals, introduce new tastes or textures, decrease mealtime problem behaviours, and reward desired behaviours

How do I increase calorie intake orally?

When a tube fed child starts oral feeding they may only have very small amounts. Offering a variety of different flavours is good to get them started on their journey to eating. Ask your Dietitian to help with ideas to increase your child’s energy intake. Adding high calorie foods such as cream, butter/margarine, full fat milk, olive oil etc can help increase the calorie intake without increasing the volume. Offering protein foods, such as meat, fish, chicken, lentils, beans and egg regularly over the day helps your child to grow. Offering small and little meals and snacks over the day may be useful for a child who eats smaller amounts.

How will I know my child is ready to start weaning?

The medical team involved in the care of your child can help you progress your child to oral feeding if this is appropriate. There are many steps that need to take place to see if your child is ready for tube weaning. For more information, please read the resource “Transitioning from Tube to Oral Feeding” on the Starship website.

What help is there for weaning?

Weaning from tube feeding to oral feeding will depend on whether your child is ready for this. Weaning off a tube is usually done in an outpatient setting with the help of your Paediatrician, Dietitian, Nurse, Speech and Language Therapist, and other team members. Very occasionally your child may have an admission to hospital to start tube weaning.

Is there a risk to long term tube feeding?

Long term tube feeding can reduce normal oral stimulation of the young child which may affect development and future ability to tolerate tastes and textures. The Speech and Language Therapist will provide ideas on how to maintain oral stimulation to support this development even while tube feeding continues.

Tube feeding always carries a risk of a misplaced tube and so correct placement and checking is a necessary regular part of care. If you are concerned and if there is any doubt about the position of the tube do not hesitate to get it checked before continuing to use.

Bedding and spills

How do you prevent leaks & spills on the bed sheets?

- Ensure all the connections of the giving set and tubing are fitting well before feeding.
- Slightly raising the cot/bed end may be useful to prevent reflux or vomiting.
- A 'safety sleep' system may help prevent your child rolling in bed and causing tube to be pulled out or tangled.
- A mattress protector (e.g. brolly sheet) is useful to avoid damaging your child's mattress in the event of a feed spill.

Bottles, backpacks and going out

What is a good way to attach and carry feeding gear for wheelchairs, buggies/pushchairs or when walking?

Most feeding pumps come with a pump stand and have a pump backpack that can be used. Some backpacks are suitable for using on the back of a wheelchair or buggy. For mobile children there are some companies that provide small backpacks. If the backpack is too big for your child you can alter a small backpack that they already have by using Velcro and/or insulated bags to find the best fit.

Here is an example of a feeding bag being made for a wheelchair.

Should I take the pump out every time?

If your child is on continuous pump feeding, then they will need their pump with them at all times. If your child is on a bolus regime, then you will be able to leave feeding equipment at home if you are going out for short trips and/or feeding time will not occur when you are out.

What information should I give the preschool or school?

Your child's preschool and school should be aware that your child has a tube for feeding. They will need to know what to do if the tube comes out. If feeding is to be done at preschool or school then a teacher/teacher assistant will need training from your Community Nurse on how to give the feed safely. If you are using a pump for feeding at preschool or school, then your child's teacher/teacher assistant will need to be trained on how to use the pump from the company representative.

General

Who do I call for help with tube feeding "Out of Hours"?

- For pump problems, call the number that is provided on the back of your feeding pump.
- For feeding concerns, contact your local "Out of Hours" Nurse or local hospital. Or wait until the morning to contact your Dietitian
- If you have run out of feed, then contact your urgent pharmacy or local hospital.
- For tube problems, such as the tube coming out, then contact your local hospital.
- For medical concerns or problems with the gastrostomy site, contact your urgent doctors, local emergency department at the hospital.

What support is available to help our child and family to cope?

Starting on tube feeding can be daunting for families. Your medical team can advise you of support services such as counselling that can be accessed.

Are there any support groups?

Parent to Parent https://parent2parent.org.nz/
Facebook support groups such as 'Tube Feeding NZ'
Please remember that Social Media (Facebook groups) and other sites are not necessarily moderated by health professionals and advice given is often from parents or members of the public. Before making changes to your child's feeding regime etc, you should consult with your medical team.

What other websites could I visit for more information?

KidsHealth Website - https://www.kidshealth.org.nz/tube-feeding
Living with Tube Feeding https://tubefeeding.com.au/
Tube Feeding Awareness (US website) - http://www.feedingtubeawareness.org/
For information regarding Nutricia feeding pumps: https://www.nutriciaflocare.com
For information regarding Abbott feeding pumps: https://www.abbottnutrition.co.nz

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Storing Tips from parents

Plastic box - drains, dries and stores whilst keeping away from other dishes.

These ones are for MicKey.

Stick to the wall cable holders great for hanging the tube. Can get from your local hardware store.

Some Messages and Tips from parents

“Always check you have closed the port before starting the feed **-** always check, never assume or you will feed the bed, highchair, car etc.”

“Always have a spare **-** when you go out take extra clothes, feeding tubes, extra formula.”

“Small backpack for a small child. We label ours with **"*do not remove -feeding pump attached*".** People always try and take the backpack off them inside.”

“My son is only 2.5 years. Letting him be involved in learning to care for his tube has been a huge help and has also helped him to become more familiar with it. He loves flushing it with water and he has even nick named it, tubie!”

“We also make sure we do lots of kisses, blow raspberries and have tickles on the side of the face that has the tube. We find that it helps keeps the area normal, as that is what we do on the other side of the face too! “

“We photographed each stage of feeding to take as guide for school, with notes on preparation and cleaning. We then laminated the 2 pages and added a string loop for hanging up.”

“The empty tins have been a hit with local preschools for art projects and maintenance at school too.”

“If you aren't sure, ask. And if you still aren't sure, keep asking.”

“Get out of the house and be kind to yourself. Tube feeding is one of the toughest things you'll ever do. But you've got this.”