

After your child's Jejunostomy Discharge Information

Children's Services

This leaflet provides information and advice following the insertion of your child's jejunostomy tube. It is important that you are aware of what problems you may experience following discharge and when you should seek advice. You will be shown what to do and told how to get the equipment you need.

How to care for the jejunostomy tube:

- To prevent infection, always wash your hands well, before and after touching the tube or after giving feeds and medicines.
- Your child's tube will be secured onto their tummy with a stitch which is covered with a dressing. This dressing needs to be changed whenever it becomes wet, dirty or loses its stickiness. Your ward nurse will show you how to do this.
- Clean the skin around the jejunostomy tube whenever the dressing is changed using sterile water. Your ward nurse will show you how to do this.
- If the site is inflamed, oozing blood or pus see your GP or children's community nurse.
- For two weeks do not let water get in the jejunostomy site. Use the shower or have shallow baths.

Checking tube position:

- When your child's jejunostomy tube is inserted in hospital an x ray will be taken to check that the end of the tube is in your child's bowel.
- At this time, the measurement on the tube by your child's skin will be written down and this is how you will check that the tube has not moved at home.
- Before using the tube, check that the dressing is still secure and not loose.
- If the tape is loose or not secure check the measurement by your child's skin on the tube is the same as when the tube was first put in. Your ward nurse will show you how to do this

If the measurement has changed or if your child begins to get symptoms they had before with feeding into their stomach, i.e pain or vomiting, the jejunostomy tube may have moved from your child's bowel. If this happens contact your children's community nurse for advice on numbers provided.



- **If there is a leak of fluid around the jejunostomy tube**
- **If there is pain on feeding**
- **If there is fresh bleeding**

Stop the feed immediately and contact the hospital

Contact details overleaf

Flushing and Feeding via the jejunostomy:

- The jejunostomy tube should only be used for prescribed feed, water or medication.
- Before using the jejunostomy tube check the tube position (as advised above)
- Make sure the prescribed amount of water (at least 10mls of water) is flushed through tube using a stop/start action after feed and medications. If your child is on a continuous feed the jejunostomy should be flushed every four hours as described above.
- Medicines given should always be in liquid form (as prescribed).
- You should use water that has been boiled and cooled to room temperature. This water should be stored in a clean jug in the fridge for no longer than 24 hours.
- Unopened bottles of feed may be stored in a cool dark place, away from direct sunlight. Once opened, bottles should be stored in the fridge.
- Any opened feed that has not been used within 24 hours should be thrown away.
- A feeding set cannot be used for longer than 24 hours.
- If the tube blocks, cool boiled water (cold or warm) can be used to try and unblock the tube. Use a push/pull action with a 60mls syringe to try and unblock the tube.
- A smaller gauge syringe can be used to try and unblock a tube – reasonable caution needs to be taken when applying pressure with a smaller gauge syringe to prevent any tube damage.
- If unable to unblock the jejunostomy tube contact your children's community nurse for advice on numbers provided.

NB It is recommended that 60mls syringes are used when flushing the tube. Cool boiled water is necessary when flushing the jejunostomy tube.

Jejunostomy tube falls out

If this happens, the hole in your child's tummy will start to close within 1-2 hours

- If the jejunostomy tube has been in place for less than 12 weeks, do not place anything into the hole and contact the hospital for advice as soon as possible.
- If the jejunostomy tube has been in for longer than 12 weeks the jejunostomy tube can be re-inserted into the hole up to the length that it was inserted to.
- If you are unable to replace the jejunostomy tube or have not been shown how to replace the jejunostomy tube get help as soon as possible, because within 1-2 hours the hole will begin to close up.
- Only if you have been taught to do so, replace it with a new jejunostomy tube.

How to get supplies

Feeds/Delivery sets/Pump and other equipment

- When your child leaves hospital you will be given the equipment you need to feed and your nurse will explain how you get equipment in the community. This will be from a home delivery company.
- If required, a feeding pump will be supplied by the hospital. You will be taught how to use the pump by your nurse on the ward.
- You will need to remind your GP to send the prescription for the special milk to the company, so that the feed can be delivered each month.
- If you choose to continue to collect feeds from a local chemist, then the other equipment can still be delivered by the company.

Waste Disposal at Home

- Ask your children's community nurse how you get rid of used equipment and any feed that is left.

What to do if you have any questions?

- If you have any questions these can be answered by the nurse on the ward. After you go home, these can be answered by your children's community nurse. It is sometimes a good idea to write them down.

Checklist for healthcare professionals and parents for minimising risk of jejunostomy feeding:

- The child should sleep in the same room as the parents/carers OR a suitable alarm or monitor should be fitted in child's room.
- The child needs to be positioned at a minimum of a 30 degree angle, preferably using a wedge or sleep system as recommended by an Occupational Therapist or Physiotherapist.
- Feeding regimes should be reviewed regularly as the child grows and develops, especially at the stage where movement during the night is likely to change.
- The feeding pump should be positioned at the top end of the cot or bed with the giving set threaded through the bars of the cot not dangling over the top.

Contact Details

Monday to Friday between the hours of 9am to 5pm

Please contact your child's community nurse or telephone the ward that you were discharged from.

Contact number community nurse:

Contact number ward:

Outside the hours stated above:

Please telephone the ward that you were discharged from.

Contact number:

The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS. You can contact them on freephone 0800 032 02 02 or e-mail northoftynepals@nhct.nhs.uk

Useful websites

If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful

Patient Name (Print)

has had a jejunostomy tube inserted

Jejunostomy tube Manufacturer:

Jejunostomy tube gauge:

Jejunostomy tube length:

Date of Insertion:

See dietitian's plan for feeding regime

The patient has been reviewed by Consultant or Registrar and is fit for discharge and this has been documented in the case notes. **Yes/no**

If no, the patient must not be discharged.

Discharge Nurse (signature).....

Discharge Nurse (print).....

Parent/carer (signature).....

Parent/carer (print).....

Date.....

Information produced by Nurse Specialist (CYP Gastroenterology and Nutrition)
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