

Children's Services/Paediatric Gastroenterology, Hepatology and Nutrition

Teaching guidelines for parents and carers administering parenteral nutrition (PN) at home

The aim of this booklet is to provide you and your child with information on caring for parenteral nutrition at home. You may feel anxious at the prospect of taking your child home and are unsure whether you will be able to cope. The nursing staff will give you all the time and attention you need until you feel totally comfortable, capable and able to cope at home. The time taken to learn the procedures varies from carer to carer; there is no rush.

At the back of this booklet is a sheet, which both parents, and the nurse training you, will sign once you feel confident. This is not the end of your training but an indication of what you have learnt. The support and guidance will be ongoing once your child is discharged. There is a list of professionals and their contact details at the back of this booklet.

We hope you will find this booklet interesting and helpful. This is your copy to keep, please feel free to write comments and reminders on it for yourself.

Why does a child need Home Parenteral Nutrition (HPN)?

The specific reasons why your child needs to have HPN have been discussed with you. As you are aware, your child's digestive system does not allow him/her to absorb enough nutrition. Therefore to allow your child to grow and develop it is in his/her best interests that he/she is fed with HPN. This will involve feeding him/her through a tube (catheter / Central line / Hickman line) that lies under the skin in his/her chest and leads into a large blood vessel. This will carry fluids and nutrients directly into the blood stream, bypassing the normal digestive system.

General information about managing your HPN

- Usually two people (mostly parents/ guardians) will be taught how to care for your child's central line. A trained person must be available for your child at all times.

- Your child's feed will be prepared as white bags (containing lipid) and clear bags (no lipid); vitamins and trace elements will be included daily.
- You need to learn all aspects of how to care for your child's PN and central line, this includes: 'Put up the PN', 'Flushing off the catheter', changing the dressing and connection (bionector) and managing your child's fluid balance.
- The duration and volume of PN will be specific for your child's needs; the team will discuss this with you.
- Usually the PN will be given overnight using the portable pump in the backpack or fixed to an infusion stand by the bed.
- Your child will have some hours off PN during the day.
- PN should be stored in its outer protective bag in your dedicated PN refrigerator at 2-8 °C. You should hang the PN at room temperature for a minimum of two hours and a maximum of six hours before using. This allows any air bubbles produced during warming to rise to the surface.
- Always cover the PN to protect it from light once it is removed from the refrigerator. Use the coloured plastic bag or put the PN in the pump rucksack.
- It is important that your child does not lose more fluid than he/she is taking in, therefore it will be important that you know how to manage this effectively.
- If there is anything you are unsure of please ask.

Essential knowledge in managing Home Parenteral Nutrition

What is sterile Aseptic Non Touch Technique (ANTT)?

Bacteria are found on our skin even after thorough hand washing. These bacteria may stick to parts of the PN infusion system and enter your child's bloodstream carrying the risk of serious infection. Your bare hands should therefore never come into direct contact with '**key parts**' of the system. These include:

- PN bag infusion port
- Both ends of the giving set
- Syringe tip
- Catheter hub
- Open ends of the Bionector
- Clinell wipes

Bacteria can also enter from the catheter skin exit site, which also needs your expert care.

Follow the procedures as described in the next pages.

Before all procedures, wash and dry your hands, then apply alcohol rub, touch non 'key parts' with confidence, keep your hands away from the 'key parts' and put on sterile gloves where indicated.

Never touch the key parts of the system (even if wearing sterile gloves).

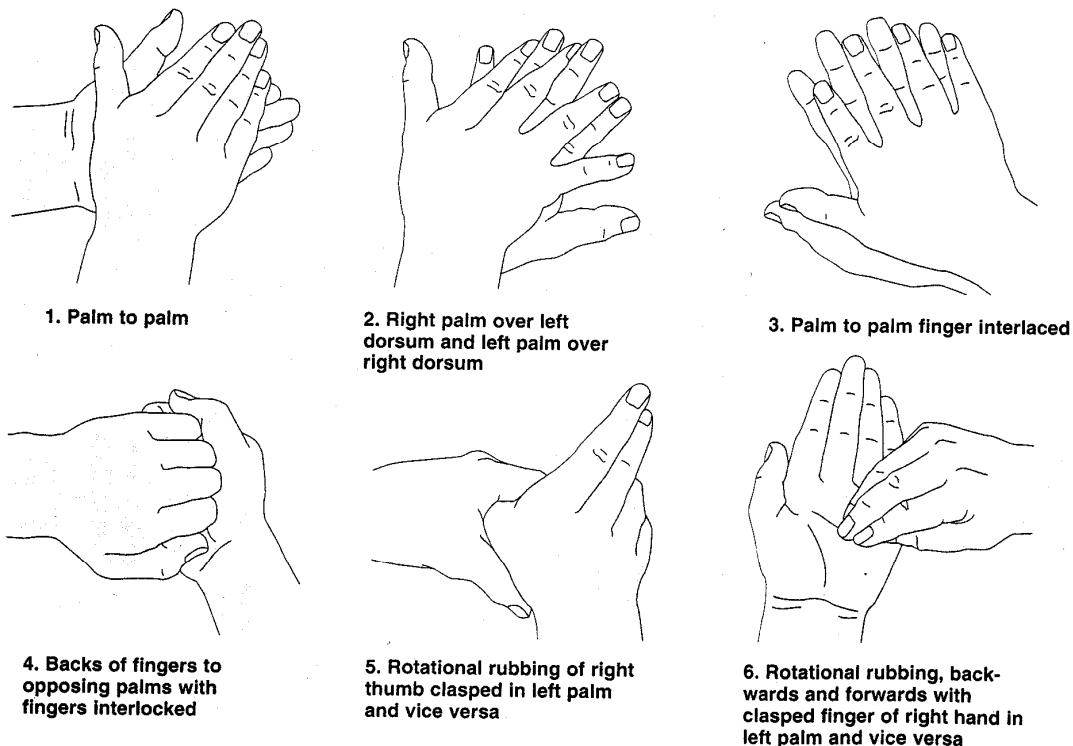
Why do I wash my hands?

To stop the line getting infected from the outside, you must wash your hands very carefully before you touch it. Washing your hands properly as demonstrated below will help to reduce the risk of infection.

How do I wash my hands?

The diagrams below show the different movements you should make while washing your hands. Do each movement five times. It is very important that you wash your hands the way the diagram shows – make sure you wash your hands in the correct way. It is also important to ensure you dry your hands, please use disposable towels. This way you will be doing all you can to reduce infections getting into the line.

Fig. 1. Handwashing technique (Aycliffe et al 1978, Lawrence 1985)



Setting up the PN

You may hang the PN bag on the stand to allow warming to room temperature for a minimum of two and maximum of six hours before use. Cover with a light-occlusive bag to avoid exposure to daylight which can start to break down the vitamins in the mixture.

Environment

Ensure the room is tidy; put away toys and anything on the floor that may cause an accident. It is important to get your child into a routine; therefore it is advisable you attach your child's PN on their cot/ bed. When your child is still too young to understand the need for them to be still and not touch their catheter or PN, or cause accidental removal of the line, two people will be required for the attaching and removal of your child's catheter and PN.

Equipment list

- Metal trolley, already cleaned with hot soapy water and dried (use paper towel).
- Tall infusion stand with fully charged pump attached (if two bag system dual pump).
- Sterile pack.
- One/two sterile giving set (depending on system used).
- One pair sterile gloves.
- Alcohol gel.
- PN bag(s).
- Cover for PN.
- Clinell Wipes x 8.
- 10ml pre-filled syringe of 0.9% Sodium Chloride.
- Syringe x 1.

Method

- Place the dressing trolley in your child's room as near as possible to the infusion stand.
- Wash and dry your hands as you have been shown.
- Apply alcohol rub and allow to dry.
- Wipe the trolley top with Clinell wipe and allow to dry for at least 30 seconds.
- Wash hands again.
- Apply alcohol gel.

Prepare trolley top

- Open sterile pack onto your cleaned trolley top. Open it out touching only the corners of the towel with your hands.
- Open one sterile giving set, 10ml pre-filled syringe of 0.9% sodium chloride onto the towel on the sterile pack.
- Open gloves away from the sterile towel, at the other end of the trolley. Do not put them on yet.

Prepare the PN

- Remove all covers from PN. Check your child's name and PN expiry date.
- Check fluid for particles, cloudiness or 'creaming' (the fat layer floating to the top). **(If this occurs please do not use the bag. Leave it out of the fridge and inform home delivery company that this bag could not be used and has been wasted)**. Use a new bag.
- Using a Clinell wipe, hold the infusion port of the bag.
- Wipe the lower half of bag with new Clinell wipe. Allow to dry for at least 30 seconds.
- Snap the cap off the PN infusion port using the Clinell wipe. Allow to dry for 30 seconds.

Sterile Gloves

- Apply alcohol rub to hands and allow to dry. **Put on sterile gloves.**
- Remember you are now wearing sterile gloves. If at any time you contaminate them, take them off and put on a second pair.
- If you are doing the procedure on your own you will need to change your gloves after preparing the catheter.

Insert the giving set into the PN

- Close the clamp on the giving set. Remove the spike cover. Avoid handling the spike surface.
- Hold the insertion port with Clinell wipe. Insert the spike fully into the bag entry port using a screwing action.
- Run the PN fluid through the giving set as you have been shown. Push the round priming button and hold the filter with the arrow pointing to the ceiling. Run fluid through the set until it reaches the end. Close the clamp at the tip of the giving set. Ensure there is no air in the giving set.
- Place the set on the sterile towel on the trolley.
- Repeat process for second bag (if appropriate).

Prepare the catheter

- Your helper should remove your child's top to expose the catheter. Make sure the catheter clamp is closed.
- Check the site for signs of infection.
- Clean the Bionector with Clinell wipe and allow to dry for at least 30 seconds before accessing.
- Place the sterile towel beneath the catheter.
- After cleaning with Clinell wipe, you can drop the catheter onto the towel (if child lays still enough not to contaminate it).
- Aspirate 1-2 ml fluid from the catheter and discard the syringe.
- Flush the catheter with 10 mls of 0.9% sodium chloride from the pre-filled syringe using "pulsing action".
- Get help from helper to hold the top of the towel to child's chest.
- Remove the cover from the tip of the giving set and shake any drops of PN off the tip.
- Connect the PN giving set onto the Bionector without touching the ends of the giving set or the Bionector.

This is the end the sterile part; you may now remove your gloves.

- Put PN into pump(s).
- Set up as instructed specifically for your child.
- Once running, transfer the PN bag and pump into backpack. If you prefer to leave the PN bag hanging on the tall drip-stand, protect from daylight with a light occlusive cover.
- Dispose of all waste; it is not hazardous and may be placed with your domestic rubbish (unless your council has specified that they wish you to use yellow bags).

Flushing off PN

Immediately after the PN infusion is complete, the catheter must be flushed with 10ml 0.9% sodium chloride; any delay may cause blood to enter the catheter, risking blockage.

Equipment list

- Metal trolley, already cleaned with hot soapy water and dried (using paper towel roll).
- Clinell wipes.
- Sterile pack.
- One pair sterile gloves.
- One pre-filled syringe with 10ml 0.9% sodium chloride.
- Taurolin (if prescribed).
- Alcohol rub.

Remember to add a Bionector **if** it is to be changed. It will be changed on a weekly basis. If the Bionector accidentally is removed/ falls off or is cracked it needs to be changed immediately.

Method to flush catheter

Immediately after the PN infusion is complete, the catheter must be flushed with 10ml 0.9% Sodium Chloride; any delay may cause blood to enter the catheter risking blockage. (Finally flush with Taurolin as directed and clamp with positive pressure again in order to avoid blood flowing back into the system, increasing the risk of blockage).

Equipment list

- Trolley, already cleaned with hot soapy water and dried (using paper towel roll).
- Clinell wipe.
- Two sterile towels.
- One pair sterile gloves
- One pre-filled syringe with 10ml 0.9% sodium chloride.
- One pre-filled syringe with 1.5mls of Taurolin.
- Alcohol rub.
- Add a Bionector **if** it is to be changed.
- Add a Chloraprep 3ml applicator if the catheter exit site is to be cleaned.

Prepare trolley top

- Wash hands.
- Apply alcohol gel.
- Clean trolley.
- Wash hands.
- Apply alcohol gel.
- Onto your cleaned trolley top, tip one sterile towel. Open out touching only the corners with your hands.
- Open onto it, the second sterile towel, pre-filled 0.9% sodium chloride syringe and pre-filled Taurolin syringe.
- Add the opened Bionector, and Chloraprep applicator and dressing **if needed**.
- Open gloves away from dressing area. Do not put them on yet.
- **Expel all air from syringes.**

Prepare catheter

- Your helper should remove your child's top to expose the catheter. Make sure his/her catheter clamp is closed.
- Turn pump off. Turn giving set clamp off.
- Apply alcohol rub to your hands and put on sterile gloves.

Remember you are now wearing sterile gloves. If at any time you contaminate them, take them off and put on a second pair.

- Using Clinell wipe disconnect the giving set from the Bionector.
- While holding the catheter hub and bionector, using another Clinell wipe, clean the bionector end. After drying place on the sterile towel.

Give the flush into your catheter as described below

- Push the 0.9% sodium chloride syringe tip into the Bionector, turn to lock into place.
- Open the catheter clamp; inject 10 ml 0.9% Sodium Chloride into the catheter over about eight seconds using a pulsing action. Clamp the catheter while flushing the last 1ml of solution in order to maintain 'positive pressure'. Remove the syringe and discard.

If you are changing the Bionector, do this now.

- Unscrew the old Bionector, remove it and discard. Holding the new Bionector by its rigid cover, push it onto the catheter hub and lock in place. Remove the cover and discard. Continue with the flush, see below.

Method to change the dressing over the Hickman exit site

- Wearing the used gloves, loosen and remove the old dressing. Remove gloves.
- Wash hands.
- Alcohol gel hands.
- Put on a new pair of sterile gloves.
- Pinch the wings on the applicator to break the ampoule and release the antiseptic. Do not touch the sponge.
- Wet the sponge by repeatedly pressing and releasing the sponge against the treatment area until the liquid is visible on the skin.
- Use repeated back-and-forth strokes of the applicator for approximately 30 seconds. Completely wet the treatment area with antiseptic. Allow the area to air dry for approximately 30 seconds. Do not blot or wipe away.
- Apply the new dressing, coiling the catheter against the skin, directing the hub towards the shoulder.
- Secure the catheter hub well away from any source of infection such as nappies, gastrostomy tube, mouth or little fingers. Preferably the line hub will remain under the clothing.
- Dispose of used equipment.

Possible complications associated with PN

Accidental removal of line

- This is extremely rare.
- Stay calm.
- Lie your child flat.
- Place the heel of your hand – where you are taught for your child's individual line.
- Call an ambulance.

Infection

Infection is a serious risk when using a central venous line. That is why it is so important to follow the procedures you have been taught. Even with meticulous catheter care infections do happen, so try not to blame yourself if your child develops a line infection.

What happens if my child develops a temperature?

Young children commonly develop a temperature with minor illnesses. We would suggest that you contact the hospital for advice if your child has a temperature of 38° C for more than two hours or seems unwell. You will probably be asked to bring him/her to the Emergency Department to be checked over by one of the doctors and for a blood test to be taken to look for the possibility of a serious infection. (Please see your emergency contact numbers at the back of this booklet).

How can the line get infected?

There are two ways that the line can get infected – from the outside or from the inside. Infections from the outside get into the line when it is being used to give drugs or to connect or disconnect the infusion set. Skin bacteria from around where the line enters the chest can also cause a line infection from the outside. By being very careful in looking after the line, we can prevent most infections from the outside. Infections from the inside happen when bacteria (bugs) get into the blood stream from somewhere else (for example bacteria living inside the bowel), settle on the line and infect it. These infections can be very difficult to prevent.

The Paediatric Gastroenterology/nutrition team will advise on appropriate treatment if an infection occurs. This is likely to involve a hospital stay of seven to ten days for intravenous antibiotics and/or removal / replacement of the line.

Having a stoma (gastrostomy and jejunostomy) is also a risk factor for catheter related infections. The catheter hub should be kept well away from any stoma. Very careful general and hand hygiene will help prevent bacteria being transferred from the stoma or tubes to the catheter. This should be secured so it cannot come in contact with the tubes or the nappy area.

There is a risk of build-up of blood clot or lipid deposits in / at the tip of the catheter. This could cause partial or total blockage and also predisposes to infection. If a blockage cannot be cleared, the line may have to be removed.

How do I know if the line is infected?

Line infections will usually make your child unwell, mostly with a high temperature. Your child may look or feel flushed, be hot or rosy-cheeked. Sometimes they may look pale, feel cold and have the shakes or shivers. You know your child best, so if you are concerned please contact us or use the open access / emergency contacts out of hours.

How do I know if the line site is infected?

The skin where the line goes into the chest should look a normal colour. If it looks red, or you see some pus or dampness in that area, then it may be infected.

What do I do if I think there is an infection?

If your child develops a high temperature and/or seems unwell or if you think the skin around the line may be infected contact the hospital / member of the paediatric gastroenterology / nutrition team as per contact details at the back of this booklet.

Broken line

What do I do if catheter leaks or breaks?

On very rare occasions it is possible for the catheter to break or leak. This can be dangerous as air and bacteria could enter the bloodstream, therefore you need to take your child to hospital.

- Clamp the line above the break / leak as shown.
- Call 999.

What do I do if there is swelling or fluid leakage around the catheter?

If the catheter site leaks, the area around it will swell up and/or can become painful. If this happens, the pump may or may not alarm ('line occlusion'). If you see leakage or swelling around the exit site:

- Clamp the line.
- Switch off the infusion.
- Go to the hospital using the open access form.

Blocked catheter

What do I do if the catheter blocks?

You will know that this has happened as the alarm on the pump will sound ('line occlusion'). Contact the hospital for advice. This is very rare, however, it will need treatment. Contact the hospital for advice if you notice that your child's chest/ neck/ face becomes painful or looks swollen.

Air embolus

It is very important to prevent air from entering the line and being pushed into the vein. A large 'air embolus' can cause serious breathing and heart problems. To prevent an air embolus, you must always check the line for air bubbles before you start the pump or when you are flushing your child's line.

What do I do if an air embolus happens?

- Call 999.
- Make sure that a responsible adult supervises your child.

Going home

Will my child be able to eat while she/he receives PN?

As your child grows bigger and stronger the gastroenterology team will continue to look for ways to help your child tolerate some food by mouth. We will discuss with you what types of food to try and we will monitor symptoms such as abdominal bloating, pain or diarrhoea. It will be beneficial if s/he can tolerate even small amounts of food as this helps to keep the bowel working. Eating food is a very important social event and we would recommend that you sit down together as a family at meal times.

What about bathing?

We advise you to keep a protective dressing over the exit site at all times to keep it in place. When your child has a bath, shower or swim, it is essential not to get the skin exit site or the Bionector wet; this will risk infection. Cover your normal dressing and the whole catheter with two overlapping Bioclusive plastic dressings which should be removed immediately after bathing. A gauze square placed under the Bioclusive will stop the occlusive dressing being pulled off. If at any time the occlusive dressing becomes loose, damp or wet, change it as soon as possible.

You may feel concerned at the prospect of using PN at home without hospital support. However, you will have been allowed home because we have confidence in your safe management of this treatment. We will arrange for the nurse that trains you to visit you for an hour on the first few evenings and mornings (for disconnections) at home to help ensure a smooth transition to homecare.

The children's Community Nurses can also visit and offer you support as needed.

The paediatric nutrition/ gastroenterology team will be available via telephone and will review your child at short notice. An out of hours plan will be given to the on call registrar and senior nurses. Direct access arrangements for your child will be in place.

The home care company also offers a nurse-on-call service for times when you may only need telephone advice and feel you don't need to contact the hospital. Helping you regain your independence as a family is part of this program, so do not be afraid to call for advice at any time.

If you are concerned or need advice you should ring the numbers below for the hospital team, but on discharge you will be given a complete list of contact numbers that you can use for advice as you need them.

Telephone numbers

- **Paediatric Nutrition Team, Monday-Friday 09:00-15:00**
Telephone: 01223 274826
- **Paediatric Gastro Team, Monday-Friday 08:00-17:00**
Telephone: 01223 274757
- **Paediatric Gastro Dietitian, Monday-Friday**
Telephone: 01223 216655
- **If Gastro team and Dietitian are unavailable, contact Ward C3:**
Telephone: 01223 217450 or 01223 245 151 Ext: 3450, 3714

If C3 nurses are unable to help, ask them to contact a senior member of the paediatric gastroenterology team to deal with your problem.

- **Addenbrooke's Hospital**
Hills Road, Cambridge. CB2 2QQ.
Telephone: 01223 245151

Home delivery company co-ordinator and on-call-nurse

For enquiries about your deliveries, pump problems and out of hours problems.
Calea Ltd: 0870 749 2020

Support Group for people on tube feeding

Patients on Intravenous and Nasogastric Nutrition Therapy (**PINNT**)

website: www.pinnt.co.uk **email :** pinnt@dial.pipex.com

Patients on Intravenous and Nasogastric Nutrition Therapy - half PINNT for children is a self help group organised by people needing nutritional support. Family members may apply for associate membership. Members receive a three monthly newsletter written by people on tube feeding or on parenteral nutrition and it features adults and children. It makes an excellent read and is full of ideas, experiences, help and amusement.

Our local PINNT group holds an informal meeting at Addenbrooke's twice a year for you to get to know others in your situation for mutual support.

Education programme: confirmation of training.

The appendix (page 15) should be used as a reminder to you and your trainer. It can be used to allow you to reflect on your learning and allows open discussion on areas of your training that you may like to revise.

Appendix 1**Accessing the line is always a sterile aseptic non touch technique**

This procedure is best undertaken in a quiet, controlled environment, with as little distraction as possible.

Name Carer 1:

Name carer 2:

1. Gather all necessary equipment. (See equipment list).

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

2. Wash and dry hands thoroughly, REMOVE ALL RINGS AND WATCHES.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

3. Clean designated area with soap and water, dry and clean with alcohol wipes.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

4. Check details are correct on HPN bag, including expiry date.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

5. Open up sterile field onto cleaned designated area. Open and drop all sterile equipment onto sterile field without contamination.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

6. Clean lower third of bag with alcowipe; remove the cap off the PN infusion port using the alcowipe

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

7. Alco gel hands. Put on sterile gloves.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

8. Prime the administration tubing, eliminating air and preventing contamination.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

9. Using a circular action, clean bung with Alcowipe and allow to dry

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

10. Flush the catheter with ten mls of sodium chloride 0.9%, having withdrawn on the syringe and achieved a "flash back" of blood.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

11. Connect primed TPN lines to your child.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

12. Insert tubing into pumps.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

13. Ensure the hours to be infused and amount are programmed into the pump. Unclamp catheter. Start Infusion.

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

14. Aware of how to and from whom to get help after discharge

Signature: (carer1)

Date:

Signature: (carer2)

Date:

Name: (nurse)

Signature:

Date:

If the PN administration set is disconnected from your child's central line at any time, the TPN and giving set should be discarded.

A PN infusion should never be restarted once disconnected.

Going home?

Carers

Please sign to indicate that you have worked through this programme thoroughly, have had as much opportunity to practice as you would like. You feel you have the knowledge, skills and are confident to administer PN to your child at home.

Please ensure that all your questions or concerns have been thoroughly discussed before committing to going home.

Name..... **Carer 1**

Signature.....

Date.....

Name **Carer 2**

Signature

Date

Nurse/Practitioner

Please sign to indicate that the carers above have been taught how to administer HPN safely to this child and are able to demonstrate knowledge and skills in all parts of the teaching programme.

Practitioner's Name.....

Practitioner's signature

Date.....

Copies

Carers x 2

Medical notes x 1

Community nurses Notes x 1

GP x1



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

patient.information@addenbrookes.nhs.uk



Document history

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