



An introduction to parenteral nutrition at home: information for families

Parenteral nutrition is used when the gut is unable to absorb enough nutrition to enable your child to grow and develop normally. A liquid solution that contains nutrients (vitamins, minerals, carbohydrates, proteins and fats) needed for growth and development is given directly into a vein. This leaflet is an introduction to parenteral nutrition at home and what you can expect when you leave Great Ormond Street Hospital (GOSH). In a planned teaching programme, we will teach you how to give parenteral nutrition to your child and how to look after the equipment involved.

Parenteral nutrition is only suggested when other methods, such as nasogastric or gastrostomy feeding, have been tried and failed to maintain enough nutrition for your child to grow and develop.

Why does my child need parenteral nutrition at home?

Children needing long term parenteral nutrition usually have a problem with their gut. These include short bowel syndrome or other 'malabsorption' problems, motility problems, or gut inflammation where the gut cannot absorb enough nutrients for a child to grow and develop normally.

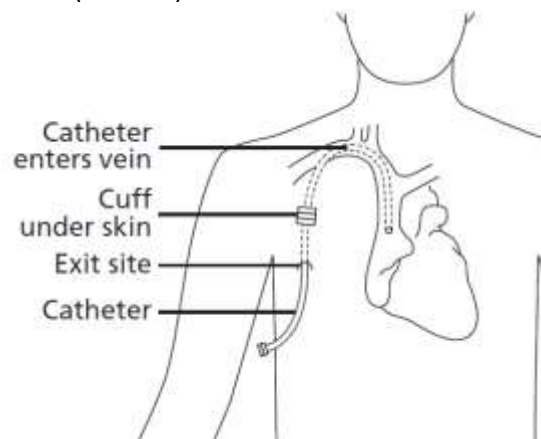
Some children having treatment for cancer also use parenteral nutrition at home if they are not well enough to eat.

At present, your child requires parenteral nutrition to provide adequate nutrition. It is beneficial for your child to be at home with the family than in hospital long term. With that aim in mind, we can teach you to give the nutrition at home in a safe and supported way.

Your child will need to be medically stable with a suitable parenteral nutrition solution before we can consider home parenteral nutrition. Your medical team and the nutrition support team will discuss this with you.

How does parenteral nutrition work?

Parenteral nutrition delivers a solution of nutrients directly into a vein. A central venous catheter is needed for longer term parenteral nutrition. The catheter is tunnelled under the skin and into a vein leading to the heart. The other end comes out through a small incision in your child's chest (exit site).



An intravenous (IV) pump delivers the solution to the central venous catheter. The solution of nutrients is made specifically for your child and contains the vitamins, minerals, carbohydrates and fats that your child needs to grow and develop.

Getting ready to go home

There will be a lot to learn but we will make sure you feel confident before you go home. Although it may feel daunting at first, it will quickly become easier once you develop your own routine.

Remember, there is always someone on the end of a telephone to advise and reassure you. The first few weeks are often the hardest.

Equipment

Before we start the teaching programme, the intestinal care nurse or your children's community nurse will visit your home to check that it is suitable for giving parenteral nutrition. All of the equipment, supplies and parenteral nutrition bags you will need are supplied by a commercial homecare company and delivered to your door every one to two weeks.

Learning to look after your child's central venous catheter

The ward staff will start to teach you about looking after your child's central venous catheter soon after the operation to insert it. As it is a direct route to your child's bloodstream, it needs to be looked after very carefully and kept extremely clean.

Learning to give your child parenteral nutrition

Before you go home, the intestinal care nurse will teach you everything you need to know to give your child parenteral nutrition.

This will include when and how to give your child parenteral nutrition, setting up and using the IV pump. This training programme usually lasts two to three weeks.

As a guide, you will need to learn about the following before you go home:

- Why the central venous catheter is needed
- What equipment you will need to look after the catheter
- The safety pack and how to use it
- How to change the dressings
- Problems to watch out for and how to deal with them
- How to safely administer the parenteral nutrition

Going home

You will be able to go home once you are confident in dealing with both the central venous catheter and giving your child parenteral nutrition. There will be a 'discharge' meeting involving you and members of the nutrition team at GOSH, including your intestinal care nurse, consultant and social worker. Your local team will also be involved. The intestinal care nurse will come home with you when you leave GOSH to help with your child's first connection to parenteral nutrition.

Regular check-ups with the multidisciplinary team at clinic will be arranged for your child to make sure that they are getting all the nutrients needed, developing well and to see how you are getting on generally.

Frequently asked questions

What support can I expect once I get home?

The intestinal care nurse at GOSH is available during office hours to help and support you over the telephone. Your local community health care team will be able to help you too. This may be your local paediatric community nurse or children's homecare nurse, if your area has one, or the dietitian at your local hospital. You will also have a consultant at your local hospital, where some aspects of your child's care will be provided.

The aim is for your child to have 'shared care' between GOSH, your local hospital and community team. This means that some parts of your child's care can be provided locally to save you a trip to GOSH. We will give you all the necessary contact numbers before you go home.

There is also an internet website called 'Patients Know Best', which many parents use to communicate by e-mail with GOSH, your local hospital, community nurses, and anyone else involved in your child's care.

Can my child have a shower or bath?

Your child can have a bath, but ideally, should avoid soaking the exit site. Occasional splashes of water should not cause any problems, as it should be covered all the time with a waterproof dressing.

How do I look after my child's mouth?

Even though your child may not feed normally, you still need to look after their mouth, with twice daily brushing and regular visits to the dentist.

Will my child be able to go to school?

If your child is old enough, we will teach him or her how to look after the catheter and deal with it in an emergency. However, you may feel anxious and nervous about leaving your child there without someone knowing all about the catheter. If the teaching staff want more information, ask them to phone one of the numbers in this booklet. The community nursing team can visit the nursery or school to explain more about parenteral nutrition and the central venous catheter.

Can my child swim?

Your child will be able to swim in the sea or in swimming pools depending upon their underlying condition, but should avoid lakes.

The catheter should be covered with a waterproof dressing at all times and an extra dressing on top.

What about sports and PE?

Your child should be able to take part in PE lessons if they want, but we would advise avoiding contact sports like rugby and any other activities where the catheter could get pulled or dislodged.

Can we go on holiday?

There should not be any problems with going on holiday while your child is having parenteral nutrition. The home care company can deliver all the supplies you need for your holiday to any address in the UK. If you are planning to travel abroad, some insurance companies might not be willing to offer you insurance, so you will need to find one that specifically offer insurance to people with illnesses or disabilities.

The home care company should be able to deliver your supplies to the airport if you contact them in advance. Keep your safety pack in your hand luggage so that, if your suitcases go missing, you will still be able to look after the catheter.

It is often a good idea to carry a letter from the nutrition team explaining your child's medical condition to avoid any problems with customs or security en route and if any problems develop while you are away.

If you are having a beach holiday, you should also avoid getting sand near the exit site or catheter, as it could irritate your child's skin, cause an infection or damage the catheter.

How will we cope with parenteral nutrition?

It affects every family in a different way, but the following are problems that commonly crop up. If you would like to talk through any of the following, please contact your child's community paediatric nurse who will be very happy to help.

Keeping things normal

Try to treat your child as normally as you can. Children who are overprotected or treated differently can become demanding. Your child is only 'different' in the way they feed. Your child will be happier if rules stay the same and life carries on much the same as before. Remember to sleep and look after yourself.

Behaviour problems

When you leave hospital, you may find your child is more demanding than usual. This is a common reaction to being in hospital, so you should expect it. Your child may become clingier or revert to earlier behaviour, such as bed wetting, until they are used to being at home with you again. If you are worried about your child's behaviour, please talk to your GP or community paediatrician. They may be able to offer you help and advice about settling back into a normal routine once your child returns home. We will offer you psychology support while your child is staying with us before you go home – if you have not seen a psychologist, please tell us.

Feeling tied down

Your child, you and the rest of your family may feel that everything has to revolve around feeding. Keeping to your normal routine as far as possible by maintaining the usual mealtimes and bedtimes, for example may help.

Further information and support

If you have any questions, please contact your community team or the Clinical Nurse Specialists for Intestinal Care on 020 7813 8304 or 020 7405 9200 bleep 0921 or 1027.

PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy) offers help, advice and support to people on parenteral nutrition or with a gut problem. Call them on 01202 481 625 (9.30am - 4.30pm, answerphone at other times) or visit their website at www.pinnt.com

Body image

Your child may feel self-conscious about their catheter. Talking to other people can help – you could try contacting the support organisations listed at the end of this leaflet for support and advice.

Sibling rivalry

If you have other children, they may feel upset at the attention their brother or sister is receiving. Having 'special time' with your other children may help. If relatives and friends seem to focus on the child on parenteral nutrition and pay less attention to your other children, you could ask them to treat all your children equally.

Will my child ever be able to feed normally again?

This depends on the reason your child needed parenteral nutrition. Your team will discuss with you if and when they would like your child to try feeding by mouth or tube again. They might suggest reducing the number of parenteral nutrition feeds each week to see whether your child can manage with less.

At first, your child may seem to have 'forgotten' how to eat and drink by mouth. If this is the case, the feeding nurse specialist at GOSH can offer advice and support.

When your child is feeding well and absorbing the nutrients, the doctor will stop the parenteral nutrition. If your child does well, they will remove the central venous catheter.