

## Patient information factsheet

# Going home on parenteral support (adults)

This factsheet contains useful information about going home from hospital on parenteral support (fluid or nutrition given through a central venous line). If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

### What is parenteral support?

Parenteral support is a mixture of fluid, electrolytes (salts) and/or liquid nutrition that is given directly into your bloodstream. It is given through a central venous line (a tube placed in a large vein). It is given to people who cannot absorb enough food or fluid through eating, drinking or tube feeding to maintain good health. If parenteral support infusions are needed for a long period of time, they can be given at home.

### How is home parenteral support organised?

Once you are ready to go home, the nutrition support and intestinal failure team will arrange for a homecare company to provide parenteral support for you at home.

The nutrition support and intestinal failure team is made up of doctors (consultant gastroenterologists and surgeons), specialist nurses, dietitians and pharmacists who have experience in managing people who need parenteral support.

The team will work with you to plan your discharge on home parenteral support and will follow you up as an outpatient to monitor your condition. You will be visited by different members of the team during your time in hospital and will be reviewed in the outpatient clinic.

You will be allocated a homecare company and a member of the team will talk you through the registration forms and answer any questions you may have. Your prescription will then be sent to the homecare company. You will have a pre-discharge visit from a member of the homecare company nursing team. You will be talked through their service and they may also visit your home to make sure there is space for the equipment you need.

Your equipment will be delivered to coincide with your discharge from hospital. Please note that the whole process to set up home parenteral support usually takes between two and four weeks.

### Equipment

To safely store and administer your parenteral support, the homecare company will need to deliver some equipment to your home. Depending on the type of parenteral support you need, this may include a fridge to store the fluid or nutrition bags. You will also be provided with a pump, backpack, and drip stand to make sure the infusions are administered safely. You will also be given all other necessary items for your home parenteral support by the homecare company.

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The homecare company will deliver these items on a regular basis (usually every two to four weeks) and they will help you to order items if needed.

## Nursing support

If appropriate, you will be trained to disconnect and/or connect your parenteral infusions. This will support your independence once you are at home.

You will have discussions about training to give your own infusions and caring for your line as part of your discharge planning in hospital. You will need to have a tunnelled central venous line inserted (sometimes referred to as a Hickman line). This line sits in your chest rather than your arm and allows you to carry out the procedure safely.

If you are unable to be trained to give your own infusions, it may be possible to arrange nursing support for you. If this is the case, a specially trained nurse will visit you at home twice a day to connect your infusion in the evening and then disconnect it in the morning. You will be given a two-hour window for each visit by the homecare company who provide the nursing support.

Sometimes a member of your household can be trained in the administration of your home parenteral support. This needs careful consideration as it means that they would need to be available every day to connect and disconnect you at the correct times. If a member of your household can no longer administer your infusion, nursing support may need to be organised. This could take several weeks to organise and can only be put back into place if there is availability.

## Risks of home parenteral support

Parenteral support is an important treatment but it carries a number of risks, as outlined below. While most of these problems are rare, it is important that you are aware of them. Before going home on parenteral support, you will be given further information about how to recognise and reduce these risks.

### Infection

If you have an infusion through your central venous line, there is a risk that this line can become infected. This can lead to infection in the blood which can be very serious. It is vital that your line is kept clean and dry and only accessed using the correct technique in order to reduce the risk of infection.

### Blood clots

Having a central venous line placed increases your risk of blood clots. If you experience any of the following symptoms, you will need emergency medical attention:

- swelling in your arms, neck or head
- severe shortness of breath
- sharp chest pain when breathing.

### Blocked line

If your line becomes damaged or blocked, it may not work properly. This means you will not be able to have your home parenteral support.

You should make sure your line is secured well and not pulled, cut or accidentally caught in clothing. Your line must be flushed before and after every infusion and you will be taught the technique for this. Any damage or blockage can increase the risk of other complications, including infection.

## **Effects on other areas of your body**

Being on long-term parenteral support can affect the way some parts of your body function, for example, your liver and your bones. You will have regular blood tests to monitor this and further investigations will be discussed and arranged if needed.

## **Lifestyle activities on home parenteral support**

You can still enjoy everyday activities while receiving home parenteral support. You can continue to work, drive, spend time with your family and take part in sports and other hobbies.

It is important these activities are done safely and that your line is secured at all times to prevent it becoming damaged, dislodged or infected.

## **Swimming and water sports**

We do not recommend any activity where your central venous line is submerged in water. This is because water contains microorganisms that can cause infection. Submerging the line in water, even for a short period of time, increases the risk of infection.

## **Can I go on holiday?**

You can go on holiday with home parenteral support, but this will take at least six to eight weeks to organise.

If you are receiving home nursing support, you can only go away in the United Kingdom. However, this is dependent on whether the homecare company have nurses available in the area you wish to visit.

If you have been trained to look after your own line, you can travel with your home parenteral support. Your infusion bags may be delivered to your location in the United Kingdom or to your point of departure (port or airport). However, it is your responsibility to make sure the fluid or nutrition bags and all additional items are appropriately transported and stored correctly when you reach your destination. For more information about this, please speak to a member of the nutrition support and intestinal failure team.

## **Monitoring**

You will be reviewed regularly in the outpatient clinic by the nutrition support and intestinal failure team. You will need to have some blood tests, either at the hospital or at your GP surgery, to help the team monitor you and make sure your prescription is still appropriate. This is important, as any change to your home prescription usually takes two weeks to arrange.

You will be asked to measure your weight and to let the team know if your legs or arms become swollen. You will be provided with a homecare folder with further information and the contact details for the team.

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## Contact us

If you have any questions or concerns about home parenteral support, please speak to a member of the nutrition support and intestinal failure team.

If you are in hospital, please ask your nurse to contact a member of the team.

Once you are home, please direct your queries to: [ifteamadmin@uhs.nhs.uk](mailto:ifteamadmin@uhs.nhs.uk)

You can also call the intestinal failure coordinator on telephone: **07909 008365** (Monday to Friday, 8am to 4pm).

## Useful links

### **PINNT (Patients on intravenous and nasogastric nutrition treatment)**

PINNT provide support, education and practical information for patients living with artificial nutrition at home.

Website: [www.pinnt.com](http://www.pinnt.com)

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