Home Parenteral Nutrition – Frequently Asked Questions (FAQs)

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Disclaimer: The below questions and answers are intended to provide general information on home parenteral nutrition. However, please refer to a healthcare professional to address any specific questions or concerns you may have.

WHAT IS IT?

What is parenteral nutrition?

Parenteral nutrition - also known as 'intravenous feeding' - is a medical treatment of getting nutrition directly into the blood circulation, by-passing the gastrointestinal tract (digestive system). Parenteral nutrition is delivered via a catheter inserted into a peripheral or central vein. Parenteral nutrition refers to a combination of nutrients: macronutrients (amino acids, glucose and lipid emulsion called proteins, carbohydrates and fat when we use the digestive system), sterile water for injection, with or without electrolytes (salts), vitamins and trace elements.

What is home parenteral nutrition?

Home parenteral nutrition is defined as parenteral nutrition administered outside the hospital, either at home or at nursing home.

Home parenteral nutrition is an integral part of the management of adults and children for all where food and fluids cannot be absorbed normally or if oral/enteral feeding is not possible or sufficient.

Home parenteral nutrition is considered a valid option for improving quality of life in patients whose conditions require long-term parenteral nutrition.

What kinds of nutrients are administered with parenteral nutrition?

Parenteral Nutrition refers to a combination of nutrients: macronutrients (amino acids, glucose and lipids called proteins, carbohydrates and fat when we use the digestive system), sterile water, with or without electrolytes, vitamins and trace elements.

- Amino acids are important component parts of body proteins that serve to sustain important body functions.

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- Glucose is the smallest building block of the carbohydrate family and serves to provide energy and is especially important for the functioning of the brain.

- Fat is, alongside glucose, an important supplier of energy to the body.

- Electrolytes are to be found in the form of salts and play an important role when it comes to regulating water balance in the body.

- Body water, on a quantity basis, is the most important component of the body.
    - Water serves as a means of transport and as a solvent and regulates body temperature.

- Trace elements are inorganic elements that are found in the body in small quantities only.
    - They are the building blocks of other important substances, for example iodine, which is a component of the thyroid hormone.

- Vitamins are vital for certain body functions.

WHO AND WHY?

Why is parenteral nutrition necessary?

The human body needs to be supplied with life essential nutrients and fluids on a daily basis and normally the patient supplied with these things in the food she/he takes in. Parenteral nutrition becomes necessary if food and fluids cannot be absorbed normally or if oral/enteral feeding is not possible or sufficient.

Who receives home parenteral nutrition?

Typically, the patients who need home parenteral nutrition are those presenting intestinal failure or dysfunctions and any life-threatening malnutrition. The cause often lies in the underlying illness itself, in the accompanying nutritional status, and in therapy measures that have already been carried out: intestinal failure, severe mucositis, diarrhoea, vomiting, etc.

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WHAT'S IN IT FOR ME?

What are the potential benefits of home parenteral nutrition?

Home parenteral nutrition may allow patients with chronic or acute diseases to manage their need for additional nutritional intake outside the hospital. For certain patients this may mean:

- **less pressure to eat in sufficient quantities**
- **ability to perform daily activities, including family life**
- **ability to work**
- **ability to travel**
- **increased independence in daily life**
- **better quality of life**

Home parenteral nutrition may also increase **therapy tolerability & success** (in cancer treatment for example) and support **maintenance of nutritional status** and body weight for prolonged periods of time.
Furthermore, home parenteral nutrition may be more **cost-effective** in comparison to hospital parenteral nutrition treatment.

How long can a patient be on home parenteral nutrition?

It can be short- or long- term, or even life-long depending on her/his specific condition. Home parenteral nutrition is life-sustaining for patients with Short Bowel Syndrome, who could otherwise die of malnutrition or dehydration. Experience from a 20-year programme of HPN in a single academic centre shows that average survival was excellent in benign disease patients.

What are the potential complications of home parenteral nutrition?

Complications may be related to central venous access and may include blood stream infections, thrombosis and catheter malfunction/breakage.
Signs of suspected complications should be reported immediately to the healthcare professionals.
See some examples here below:

- Fever > 38.0 C
- Pain or burning in the shoulder, chest, back, arm, or leg
- Racing or irregular heartbeat
- Signs of infection at the catheter site (pain, redness, drainage or burning)
- Noise coming from the catheter
- The catheter falls out, breaks, cracks, leaks, or has other damage
- Chill, coughing, wheezing, or shortness of breath
- Vomiting
- Diarrhoea

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Will a patient on home parenteral nutrition be mobile?

Parenteral nutrition must be infused at the rate advised by the healthcare professionals. If a patient on home parenteral nutrition is up and mobile, she/he has the possibility to take the bag of parenteral nutrition with her/him in a pouch or backpack.

In such a case, the dosage of the parenteral nutrition is taken care of by a mobile pump that can also be packed into the pouch or backpack.

Will a patient on home parenteral nutrition be able to shower or take a bath?

In general, bathing and showering are allowed during infusion-free periods.

Waterproof dressings are available for all catheter types when it comes to covering the catheter exit site. Puncture site should be healed soon after line insertion.

These may enable patient to take a shower without the catheter exit site getting wet. Usually the part of the infusion hub that extrudes from the dressing is best wrapped in a gauze swab and fixed separately with a large piece of transparent bandage.

Can a patient on home parenteral nutrition travel?

It is possible to travel with home parenteral nutrition. However, the patient shall discuss her/his travelling on home parenteral nutrition with the healthcare professionals. For instance:

- Establish a plan that would allow to pack the right number of bags, according to the patient's specific needs during the travel time and consider non-refrigerated parenteral nutrition solution for travel when possible;
- Check if home parenteral nutrition supply can be shipped to the destination in advance of the trip and if a refrigerator is available to stock the supplies;
- Consider modes of transport and what each may entail;
- Check if support is available via patient groups/organisations;
- Also prepare a list of medications that may be needed and an emergency kit.

It is also recommended to ask healthcare professional/physician to help finding a doctor and/or a hospital nearby, in case of emergency; as well as to get a letter explaining the patient nutritional needs and home parenteral nutrition supply.

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Can a patient on home parenteral nutrition work or study?

Home parenteral nutrition should not restrict the patient's ability to live a normal life outside home, but this will very much depend upon the patient's general underlying condition and whether (s)he is not exposed to bacteria.
It is recommended to discuss this with her/his healthcare professional/physician.

Are there any patient associations or self-help groups?

The number of non-profit organizations who gather patients with chronic intestinal failure is growing. Nevertheless, due to large disparities in access to home parenteral nutrition systems around the world, presence of dedicated patient organizations varies. The largest presence of such groups can be found in Western and Central Europe countries, North America and Australia-New Zealand.

There is currently a patient groups' effort to create an international platform for sharing patients experience in the field of home nutritional therapy, which should become formal entity in the near the future.

There are also a number of self-help groups for patients who are fed intravenously on social media or any other digital channels. **However, it is of paramount importance to check and consult any advice related to treatment, gathered on internet, with healthcare professionals.**

Here below a list of patient associations of potential interest that federate national patient organisations:

- European Patients Forum (EPF)
- European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA)
- European Cancer Patient Coalition (ECPC)
- International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN)

HOW DOES IT WORK?

How is home parenteral nutrition carried out?

Patients receiving home parenteral nutrition are usually discharged from the hospital and provided with all relevant information to carry out home parenteral nutrition. A monitoring plan in the hospital could be provided for follow-up of patient's condition.

Patients may be entirely responsible for administering their own home parenteral nutrition or they might have access to home care assistance. This depends on local practices, reimbursement policies and systems, and availability of local home care services.

Home parenteral nutrition should be managed by a multi-disciplinary team, the so-called 'nutrition support team'. Nutrition support teams are commonly composed of physicians, dietitians, pharmacists, nurses, psychologists and social workers.

The patient and/or the carer shall ideally receive a training program, including on catheter care, pump use, as well as preventing, recognizing and managing potential complications.

How safe is home parenteral nutrition?

International safety standards, approved by authorities, are used for compounding parenteral nutrition bags and for devices used to infuse home parenteral nutrition.

A number of elements contribute to ensure safe administration of home parenteral nutrition, such as continuously improved catheter/venous access care procedures; high production standards; and strict rules regarding formulating home parenteral nutrition bags.

For instance, a safe connection between each of the components is established by using a Luer-Lock, a standardised system across small-scale fluid fittings in order to make leak-free connections between two parts. Procedures will be in place for the connection and disconnection of PN; these are designed to minimise the risk of infection.

Where is parenteral nutrition prepared?

Preparation of a parenteral nutrition can be carried out in a pharmacy (compounded patient individual bag) or even directly at home (using industrially manufactured multi-chamber bags) provided that hygienic measures are adhered to.

What is parenteral nutrition composed of?

The healthcare professional creates a prescription especially suited for the specific patient's daily energy, protein/amino acid and fluid, electrolyte, vitamin and trace element needs.

To make parenteral nutrition therapy at home as easy and safe as possible it is possible to use:

- The so-called **compounded patient individual bags** that are contained in one bag, and that contain all nutritional components (amino acids, carbohydrates, lipids, electrolytes, trace elements and vitamins) individualized according patient's needs. Using only one infusion line, the patient will receive everything that his/her body needs on a daily basis in terms of nutrition.
- **Industrially manufactured multi-chamber bags.** The multi-chamber bags contain standardized amounts of amino acids glucose and lipids all in individual chambers which have to be mixed shortly before administration. Multi-chamber bags are available with/without electrolytes.

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- After that trace elements and vitamins can be injected into the nutritional solution. Using only one infusion line, the patient will receive everything that his/her body needs on a daily basis in terms of nutrition.

How does parenteral nutrition get administered?

The nutrition bag is connected to the venous access via an administration set. The rate at which the parenteral nutrition is infused must be adjusted to suit the patient's individual needs.
The infusion can be administered via a pump or gravity. The pump will allow more control over the length and timing of the infusion.
Rigorous aseptic rules and procedures must be followed before handling the central venous access. Failure to respect these rules can lead to serious complications (including bloodstream infections).

What type of venous access would the doctor place?

Parenteral Nutrition at home should be administered directly into a larger blood vessel. There are several types of access lines into these larger types of blood vessel (central veins).

Central venous lines:

- Non-implanted central-venous catheter
  - With non-implanted central-venous catheters such as Jugular, subclavian and PICC line catheters (Peripheral Inserted Central Venous Catheters), a thin plastic catheter is inserted and forwarded though a blood vessel via a puncture through to a vein in the arm or neck until it reaches a position close to the heart area. These non-implanted catheters also have a limited time of usage.

- Implanted central-venous catheter
  - Implanted central-venous catheters are implanted via a small operative procedure under local anaesthesia. The catheter – such as the Hickman or Broviacs types or port catheter - is tunnelled under the skin. They can exit elsewhere on the torso, not necessarily just between nipple and sternum. This is recommendable for patients who receive nutrition therapy for a long period of time or at home, as non-implanted central-venous catheters have a limited time of usage

How is a port system implanted?

The implantation of a port system is carried out in the hospital under local anaesthesia.
The system can be used right after implantation.

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Can a patient with a port system undergo medical imaging?

Yes, it is possible to undergo medical imaging procedures such as x-raying, CTs (computed tomography) and MRIs (magnetic resonance imaging) with a port system. However, it is important to notify the radiologist in advance about the port implant.

We recommend the patient to verify with the healthcare professionals regarding specific imaging (example mammography).

What is the port passport and how important is it?

The port passport is of utmost importance. It contains information such as the personal details of the wearer, the name of the doctor that introduced the implant, port specifications (manufacturer, model, size and batch number), position of the port chamber, position of the catheter, and instructions in case of emergency.

Patients who have a port should please carry their port passport with them at all times. This can be vital in case of an emergency.

Who does the connections and disconnections of home parenteral nutrition?

Depending on the specific case, the connections and disconnections of HPN may be done by:

- Self-caring patient;
- A carer/nursing support;
- For children there should be at least one adult/parent.

How often do dressings need to be changed with a central venous access catheter?

As a general rule, the healthcare professionals will decide on how often the dressing needs to be renewed. The decision will mainly depend on the state of the catheter exit site, that is to say, on the state of the puncture site.

The type of dressing will depend on outer conditions (temperature, humidity), location of the catheter exit site, state of the catheter, or even on physical characteristics like hairy chest.

At what times should parenteral nutrition be administered?

Our body cells work around the clock, therefore parenteral nutrition can be administered both during the day and the night.

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Infusion takes on average 12 to 14 hours.
If a patient does not need to go through a full 24-hour cycle of nutrition infusion, it would be possible for him/her to perform daily activities without carrying the parenteral nutrition in a pouch or backpack.

The duration of the infusion depends largely on patient's nutritional needs: the parenteral nutrition infusion time needs to be adapted accordingly.

How should parenteral nutrition bags be stored?

Industrially manufactured multi-chamber bags: they can be stored in a cardboard box at room temperature in an unmixed state for up to two years.

Compounded patient individual parenteral nutrition bags: those bags must be stored in a refrigerator and used within validity date placed on the bag label. These bags need to be stored at a temperature between 2°C and 8°C. It is recommended that bags are brought at room temperature before infusion.

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