



PACIFHAN celebrates World Home Artificial Nutrition (HAN) Day

15th October 2020

Our focus for World HAN Day 2020 is homecare. As our members come from different countries, we can share what is available to them. We realise there is variation in how people receive their essential medical nutrition and consumables/ancillaries, as well as what type of feeding pump they have access to.

There is also variation between enteral and parenteral nutrition.

The stories include personal aspects of their own homecare or give a broader picture of what happens within their country.

Henning, adult HPN, Denmark

I was discharged with Home Parenteral Nutrition (HPN) 5 years ago. My HPN program composes of standard products, where to I add vitamins and trace elements. The program is continuously adjusted in connection with quarterly follow-up visits with my chief physician at the hospital. Some HPN patients in Denmark need more individual HPN formulas, and get these compounded by the hospital pharmacy, lasting 2 months in the refrigerator. Most are trained to be able to manage HPN at home.

In collaboration with the hospital's outpatient clinic, it is ensured that my delivery from the pharmacy is adapted to holidays, hospitalizations etc. It is generally a system based on trust. HPN and sterile consumables are delivered every two weeks to my home or holiday address by a distribution company that has an agreement with my hospital. Both service and flexibility are

experienced very positively by the HPN patients. There are some very small regional differences in delivery and logistics in Denmark. The hospital pharmacies take care of most things. I am responsible for ordering the consumables (syringes etc.). Some HPN patients have home nurses to administer HPN and order sterile goods.

There are four Intestinal Failure centres in Denmark treating patients with HPN, with a few administrative variations. I have been offered an outpatient pump, chosen by the hospital. The pump is handed out when discharged and the pump company or the distribution company handles service and possibly replacement.

HPN in Denmark is free of charge and is well organized to patients with intestinal failure.

Chris, PNDU, Australia and New Zealand

In Australia, the provision of Home Parenteral Nutrition (HPN) and all the consumables/ancillaries required to set up and connect HPN, varies between all states and local area health districts (treating hospitals).

#WorldHANDay2020

HPN is funded by the health care system, each treating hospital orders the parenteral nutrition (PN) from one of two pharmaceutical companies, the pharmaceutical companies deliver the parenteral nutrition, giving sets and HPN infusion pumps directly to the HPNers home, PN deliveries twice a week, giving sets once a month, HPN Infusion pumps are recalled annually for servicing.

Consumables/ancillaries vary considerably, some treating hospitals have agreements where the Pharmaceutical company supplies all the consumables/ancillaries direct to the home of the HPNer, the HPNer orders their supplies directly from the pharmaceutical company using a spreadsheet order form. Some treating hospitals supply all the consumables/ancillaries to the HPNer, either to their home or the HPNer must pick them up from the hospital.

Some treating hospitals supply part of the consumables/ancillaries either through the hospital or pharmaceutical company and the balance of the supplies required are purchased by the HPNer themselves.

There isn't any access for HPNers to a homecare nursing service and all our set up connection procedures vary, based on the treating hospitals understanding of what an aseptic non touch technique is.

Monika, adult HPN, Czech Republic

For my treatment I use all-in-one multi chamber nutrition bags to which I need to add various admixtures (amino acids, glucose, vitamins, minerals, etc.) before each infusion.

My supply of HPN nutrition bags and consumables is delivered to my home every five weeks by my hospital. A week before each delivery I get a simple Excel table to fill in where I indicate what I need for the next five weeks and the quantity for each item. I then email the list back to my HPN nurse who checks it and forwards it to the hospital pharmacy for completion and dispatch. The following week I receive the order to my home address.

There are no homecare companies operating in the Czech Republic. Patients get their HPN supplies organised in different ways depending on which hospital they belong to.

Some patients get what they need when they go for a check-up or an examination. By the time their hospital visit is over all the necessary supplies are prepared for them to take home. Others need to go to the hospital pharmacy themselves on separate occasions to collect what they need. Some hospitals provide transport some don't in which case patients need to organise it themselves. The first ambulatory pump for HPN patients became available only five years ago and it is up to the hospital to decide if a patient gets one or not.

HPN in my country is paid for by the Czech national health insurance system.



France

In France, home artificial nutrition is supervised and funded by healthcare service providers highly regulated by law. Patients are free to choose the company in charge of delivering at home all the consumables and the pumps to ensure infusions and nutrition. Around 300 companies exist for home enteral nutrition (HEN), either local or national and almost the half for home parenteral nutrition (HPN). They also ensure delivery of all the products to holiday places and emergency services.

Doctors or prescribing hospitals define the procedure for the treatment and write the prescription for all the required consumables that will be delivered by the care providers once or twice a month. In the case of EN, those companies also provide the nutrition.

The pumps for EN or PN can be chosen by the patient but not all the companies have a full range of pumps. So, the patient can choose the providers according to the pump he wants. All have ambulatory pumps. For standard PN, bags are distributed by the care company or the local public pharmacy. For compounded bespoke PN, cooled bags are delivered under the strict control of the treating hospital each week and distributed directly at home by a dedicated carrier.

Most additional medicines can be either taken in the town pharmacy or directly delivered home. It is also compulsory for the companies in charge of the patients to guarantee a 24-hour emergency service to provide any necessary supplies or respond to technical failure of the pump.



*Old system for enteral nutrition
(before bags & industrial nutrition)*



enteral nutrition



parenteral nutrition

Svea, paediatric HPN, Sweden

We get the drip and the locks for the Port-a-Cath delivered to the door every Friday, directly from the pharmacy. The other materials needed to connect the drip are provided by the hospital. We make about 4 orders per year directly from the hospital's supplier, and it is delivered directly to our home. Now this is with a little modification, some things can be ordered via the pharmacy, and then I can key in these products via the pharmacy's website.

It is the patient or their relatives that keeps track of prescriptions and stocks of materials etc. at home. The pumps we have are provided by the hospital. When a pump needs to be serviced, the hospital provides us with a loan pump.

In Sweden, this is free for all children, and when you become an adult, it costs a maximum of SEK 2,200 per year.



There are variations across the country, which are divided into regions. They make their own procurements, so it is not always possible to choose which pump you want or even other material, but the price is the same all over the country that has a high-cost protection.

The drip is prescribed by a responsible doctor, and blood samples are taken 4 times a year. In our region, we have mobile nurses who come to our home and take 2 of these 4 samples.

As everywhere in the world, you always go a little further with a smile and a nice welcome, something you become a bit of an expert on when you are the mother of an adorable drip-child.

Svea has her drop 7 days a week, she is 10 years old

Carolyn, adult HPN, UK

I receive home parenteral nutrition (HPN) and it is delivered to my home by a homecare provider. They are engaged via a national framework to supply and deliver all my fluids and related medical ancillaries. I am self-caring; I do my own procedures and dressing changes. My compounded parenteral nutrition (PN) has twenty-one days stability. Strict storage and temperature control, between 2° and 8° C is necessary to maintain stability. In the early days I had to make additions to a PN bag, thankfully it now comes complete with all my nutritional requirements.

My PN is delivered every two weeks and my medical ancillaries are topped up every four weeks. A monthly stock check is done when they ring me. An ambulatory feeding pump is also supplied to me as part of my supplies. If I travel within the UK, my PN can be delivered to a different address or a departure point such as a ferry port, train station or airport if I travel further.

The provision of my HPN is supplied via the National Health Service (NHS). There is a national framework in place which has 7 homecare providers on which cover England. While it would be easy to say it is free, it is actually paid for via the NHS and by the taxpayer.

I have been with the same home provider for thirty-six years; it has changed over that time both in terms of ownership of the company and how they provide the service to me. Most of the changes have been positive. I am thankful that all my needs are met, and I have the NHS which oversees the governance and provision of HPN.



Compounded PN in a dedicated fridge

Marek, adult HPN, Poland

Due to complications of Crohns disease, I have been a home parenteral nutrition (HPN) patient since 2008. I have experience with two nutrition centres, which take care of my nutritional status and provision of services related to nutrition care at home environment.

At the very beginning, I was asked to prepare my parenteral nutrition (PN) bags by myself at home from the components delivered monthly by the hospital. Nowadays, PN formulas are prepared in a hospital

pharmacy and delivered once a week to my home. In addition, we have a delivery of ancillaries (i.e. syringes, dressings, sets, disinfectants) once a month.

The system is fully organized and funded by the National Health Fund under the regulations given by the Ministry of Health. However, the weak point is the access to the ambulatory pumps.

In general, only pediatric patients are provided with infusion pumps. The adult population of patients have to bear with this problem by themselves. They are only supported by the patients' organization. Fortunately, the majority of the adult centres try to do their best also in this aspect and there are predictions that the situation will change soon.

Generally, Home Artificial Nutrition is a well-established system of nutrition services provision and it was introduced in Poland in the early 2000s. Patients have got an access to both home enteral nutrition (HEN) and home parenteral nutrition. Nevertheless, the coverage of the services vary from region to region.

Italy

Home artificial nutrition in Italy concerns about 12 thousand patients (195.6 cases per million inhabitants). Among these about 800 patients (of which 150 are pediatric) are affected by IICB (benign chronic intestinal insufficiency) who need it for long periods, often for life.

Although it is a service provided and guaranteed free of charge by the SSN (National Health Service), access to this therapy is not homogenous in all Italian regions, just as it is not provided according to a certified, guaranteed and homogeneous protocol throughout the country.

Each Region, each territory, each Local Health Authority provides this life-saving therapeutic service according to its own and different criteria. This situation depends on the lack of a defined and uniform regulation on the entire national territory: only in 4 Italian regions there is a regulation with a consequent simplified and guaranteed protocol for the NPD, in all the others the path is very difficult. This leads to serious risks in our patients, who face significant problems, ranging from the difference in quality of the bags and materials provided, to the clinical and nursing care often not sufficient and inadequate. Methods and materials used by non-experts can cause damage to the patient, causing serious complications (sepsis, hydroelectrolytic and metabolic alterations, complications related to catheter access and others), frequent hospitalizations, stunting of growth in pediatric patients and increase in health care expenditure related to them. These critical issues would be solved if the IICB was recognized as a rare disease by our NHS.

In Italy patients do not have the possibility to choose the company in charge of home delivery of all consumables and pumps to ensure infusions and nutrition. Depending on the region of residence and the corresponding health district you can find the reference provider.

Disclaimer: Where products or services are mentioned or shown, PACIFHAN is not endorsing nor recommending them. Alternatives for each are available.

We suggest people read the following guideline published by ESPEN; Pironi L et al., ESPEN guideline on home parenteral nutrition, Clinical Nutrition: https://www.espen.org/files/ESPEN-Guidelines/ESPEN_guideline_on_home_parenteral_nutrition.pdf



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