

## PACIFHAN celebrates World Home Artificial Nutrition (HAN) Day 15 October 2021

## 'Time to talk about pumps'

**Introduction:** Our theme this year is '*Time to talk about pumps*.' Why are pumps such an important subject?

People who are dependent on home artificial nutrition (HAN) may have illnesses and a treatment, but they also live in a home just like most people do, not in a hospital or clinical setting. Where pumps are provided there are situations where this is hospital style equipment transferred to be used in the home environment. Is this safe, suitable and appropriate for those with 'life on HAN?'

**Known ways to infuse:** Gravity feeding is a recognised way for people to receive their artificial nutrition. Some countries have introduced pumps, these are usually hospital equipment, large, heavy, limited battery life with few or no safety alarms. The next step saw the introduction of ambulatory feeding systems which allowed the feed, pump and battery to be contained in a rucksack then carried or wheeled during infusions with good safety features.

While we are unable to determine the usage of different feeding systems in the home across countries, we know that where ambulatory feeding systems are used, they offer options not possible with gravity and hospital style feeding pumps and systems in relation to how and when people feed.

Why are ambulatory feeding systems not generally available: There may be many reasons for this, the initial and ongoing costs, funding or reimbursement, lack of awareness or availability. Should any of these be acceptable to prohibit people from having access to medical devices that could greatly enhance the safety and quality of their life?

Who decides what equipment is available and supplied: We know that given different official structures and systems in many countries the decision as to what is provided or offered varies considerably. Are these decisions based on cost, lack of willingness to embrace change and new technology or reluctance to change because what is in place works? Is there any consideration to cost effectiveness incorporating safety and quality of life for those people using the equipment, which also includes their family members?

What difference would an ambulatory feeding system make to someone on HAN: we know that everyone on HAN will have a unique lifestyle, the common denominator is HAN. Instead of the need to sit in one place to allow gravity feeding to happen properly or having to move around a heavy medical pole and feeding pump, usually restricted by needing a power supply to function – an ambulatory feeding system could give great freedom.

Freedom starts within the home. Moving freely from one level to another while connected to HAN, having access to outside spaces as feeding takes place over a period of hours without the need to be plugged into power supplies.

Historic feeding systems work and deliver the artificial nutrition (AN) but greatly limit lifestyles and choices. In contrast, ambulatory feeding systems can allow people access to school, education, employment, hobbies and interests, family events and inclusion in the normal world.

The equipment will enhance the freedom for leaving home. This can start in your own locality, close to home, which then leads to travelling further afield, even vacations overseas or in other countries.

We believe everyone on HAN should have access to an ambulatory feeding system.

## What our member countries say...

"In our country the major type of PN administration is via gravity sets and IV pole. We would like to see higher level of reimbursement, which will include the costs of ambulatory pumps and sets and allow patients to improve their quality of life."

"We would like a choice of HPN pumps, not just one type, with a preference to more modern types."

"In our country pump is legally necessary at home for PN, its administration is forbidden without a pump."

"In our country, when requested, all patients receive the pump. In many cases the pumps are also portable and therefore allow the family to move freely even during the hours in which artificial nutrition is being delivered, with undoubted improvement in the quality of life of patients and families."

"Ambulatory pump in a bag gives freedom and makes it possible to go out while having PN. Patients can rely on nightly infusions, they can sleep safely, home care nurses can plan morning visit, patients can easily move around in wheelchairs, while having infusion. It gives better security, improves quality of life, enables travel, work etc. It gives back control of life to the patient."

"Although ambulatory some pumps can be heavy and cumbersome for some people to carry. Choice of suitable equipment is important! It gives freedom to feed not only within the home environment but allows going outside, social interaction, work, entertainment, travel, etc. Possible initial cost is more than justified in terms of compliance, mental health and acceptance of a long-term treatment."

"A pump is needed to give the right amount of nutrition at a certain time and to warn of occlusion."

## Call to action!

- All those with clinical responsibility for people on HAN should determine what their patients use and if an ambulatory feeding system is available to their patients.
- Where ambulatory feeding systems are not provided those with clinical responsibility for people on HAN should find out why and collaborate with the relevant bodies to access it, determine what the obstacles are for their provision and strive to make it available to those on HAN.

- Patient Associations should provide the lived experiences of those on HAN which could support both the clinical and financial decisions about why ambulatory feeding systems should be used.
- Both patients' and clinicians' representatives should collaborate with manufacturers of ambulatory feeding systems to review and overcome obstacles which prevent the provision of a portable feeding system to those on HAN.

The European Society for Parenteral and Enteral Nutrition (ESPEN) recently published the 'ESPEN guideline on home parenteral nutrition' which has at least three points that support messages for World HAN Day 2021 for HPN:

- ✓ <u>Recommendation 16</u>: HPN should be administered using an infusion pump for safety and efficacy reasons.
- ✓ <u>Recommendation 17</u>: In exceptional circumstances a flow regulator can be temporarily used for HPN; administration sets with only a roller clamp should not be used. Commentary states "The introduction of infusion pumps has been one of the major technologic advances for the safe administration of PN [94]. An infusion pump is a medical device that delivers fluids, such as nutrients and medications, into a patient's body in controlled amounts [95]. The use of electronic (ambulatory) infusion pump with compatible delivery sets is considered as good practice [6, 96,97].
- ✓ <u>Recommendation 18</u>: A portable pump can improve the patient's quality of life when compared to stationary pumps.

For a full version of the guideline, published in Complete Nutrition, 39, 2020 1645–1666, follow this link: https://bit.ly/3t1jQOw

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