

Home parenteral nutrition – the stakeholders' perspective

The European Society for Clinical Nutrition and Metabolism (ESPEN) held its 40th annual congress at the Feria de Madrid on 1–4 September 2018. On the second day, BD hosted a lunchtime symposium. Samuel Garcia, BD's MMS Infusion Systems associate clinical director for Europe, introduced the speakers: Carolyn Wheatley and Krista Murray.

THE PATIENT'S PERSPECTIVE

Carolyn Wheatley is an executive committee member of Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT). She shared her perspective as a person fed via home artificial nutrition (HAN).

A really long road

Mrs. Wheatley became ill at a very young age with unexplained weight loss. Doctors could not figure out what medical condition she had. It was difficult for her to be heard by the healthcare professionals of the time. She suffered greatly, both physically and psychologically. It was not possible for her to go to school. She was in and out of hospitals. When she was not hospitalised, she had to stay home.

A diagnosis, at last

After several years of suffering, she was diagnosed as having visceral myopathy with chronic intestinal pseudo-obstruction at age 20 (in 1984). This is an extremely rare condition and hers was the first diagnosed case in the

United Kingdom. A central line was put in her. The sedation of the time was used (diazepam and pethidine) and PN was started soon after. It saved her life, but it also changed her life and required a lot of adjustment. She went home and was very grateful. However, it was standard equipment that was not adapted to the home setting. She still felt like a prisoner, but for different reasons. She was confined to the second floor of her house attached to her infusion pump on an intravenous pole. Her quality of life was poor.

A portable pump and freedom, at last

While attending a nutrition conference in the United States, Mrs. Wheatley discovered portable pumps. She wanted one for herself and fought to obtain one. It completely changed her life. She became the master of her own therapy. She gained freedom of movement. The biggest thing it gave her was empowerment.

Empowering others

Mrs. Wheatley is one of the founding members of PINNT. This association provides support and advocacy for people who are fed via HAN and their loved ones. Through education, they showcase what life is like on HAN. As an information resource, they work with different stakeholders to ensure patients have access to the best equipment possible. They also offer a user assessment to help improve products. They act as an intermediary between patients and decision makers.

Pushing the boundaries further

Each individual who is fed via HAN is unique and each one has the right to work toward their own goals (*i.e., education, relationships, travel and work*). It is up to those around them, especially healthcare workers, to support them in their quest to achieve these goals. Individual needs and lifestyles should always be considered when choosing equipment. Patients want to push boundaries further, including taking trips abroad. It is important that everyone be treated with dignity. No matter what role you play in the patient's journey, you have an opportunity to restore their confidence and ultimately, contribute to their freedom.

A CLINICAL UPDATE OF PATHWAYS AND PRIORITIES

Krista Murray was a nutrition clinical nurse specialist at University College London Hospitals (UCLH) for three years. Nutrition nurses play a wide and varied role in home parenteral nutrition (HPN). They coordinate the patient's discharge from hospital and educate them on this important lifestyle change.

The prevalence of home parenteral nutrition in the United Kingdom

Ms. Murray said that about 2,500



On the left, Samuel Garcia from BD and the nurse Krista Murray.
At the lectern, Carolyn Wheatley from PINNT.

patients in the United Kingdom are fed via HPN. Out of these, 30% have been on it for over five years. The number of HPN patients has been rising each year by around 20%. Out of these new patients, 25% have intestinal failure because of advanced cancer.¹

Discharge planning

Nutrition nurses are heavily involved in discharge planning for new patients. It starts at admission or as soon as it is known that HPN will be required. They book the appropriate long-term central venous catheter. And they liaise with the homecare provider, the primary care team and the patient to coordinate the time frame for discharge. They try to save time, by streamlining the process as much as possible.

Patients who are already on HPN often come to hospital because of intestinal failure-related issues such as line infections, dehydration and nutritional imbalance. These hospitalisations may last for long periods of time. It is important to liaise with medical teams if they are at another hospital. Services are on hold when patients are hospitalised, so they need to have advanced notice to re-plan homecare nursing and

product delivery.

Educating the patient

Nutrition nurses tell new patients what HPN involves and why they need it. HPN duration varies from patient to patient. They then explain lifestyle restrictions (*e.g., bathing and swimming*). Holidays are very important to patients, but they require careful planning and logistics. Some patients are very motivated and want to get trained in self-care from the very beginning. Others need nursing support throughout the HPN period.

Follow-up care

Patients are told how they can contact healthcare professionals and when they should call the emergency department. Nutrition nurses work closely with homecare nurses. They see patients regularly in outpatient clinics (*i.e., once every three months on average*).

Types of venous access

The lines used most often by UCLH for HPN patients are Hickman lines, followed by peripherally inserted central catheters (PICCs). There are important risks associated with using central lines. Patients and homecare nurses need to know what to look out for.

Conclusion

HPN is led by the clinical nurse specialist, but it is a team effort. Patients need a lot of support during the transition to this new way of feeding and regular follow-up afterwards. Good line care in hospital and at home is very important. Communication between healthcare professionals at different facilities is vital.

Question from the floor: If you had a request for a medical device company like BD, how could we support patients in a better way today and in the future, say five years from now?

Mrs. Wheatley: First of all, I think we need to keep the ambulatory pumps on the market. I think, in the future, you need to be looking at technology, while focusing on freedom and quality of life for patients. It's very important to keep looking at battery life, the weight and the size of products. These are sick people, so starting with good and making it better is the way forward. We need to continue to look at all aspects of pumps. So, we're looking at the battery, the chargers, the rucksacks and what we need to add on to that to give the patient a better experience.

Question from the floor: You mentioned before that HPN seems to be an increasing trend especially with the high level of intestinal failure in cancer patients. How do you see healthcare responding to these needs? Do you have some limitations from a clinical perspective?

Ms. Murray: The trend is only going one way and that is up. Lots of patients are on and off HPN. We are doing lots of new registrations for people who might go home for a few weeks and months at a time. Unfortunately, with a growing cohort of patients, you do not get the funding for the growing infrastructure. So, for our team, we have still got the same number of people on the team as we did years ago when we had far less patients. So, we are all learning to do more in less time and we are under great pressures from the hospital, from more senior members of the hospital, to have our patients discharged quickly. And unfortunately, it does not work like that for PN. It can be a really slow process. We have limitations and things that we cannot hurry, and we have to just make sure we are still looking after our patients safely.

Question from the floor: How much time do you have to organise the patient's discharge?

Ms. Murray: It is very difficult to give a set time frame from when patients are identified as needing HPN until they go home. It is an open-ended number of days because it depends on how long it takes to get them on a stable prescription. We then need at least five working days for the HPN bags to be made and delivered to the patient's home. All of our patients go home with full nursing, and then nursing care is quite flexible from there. The U.K. National Health Service framework suggests that patients have 28 hours for training but this can be extended if needed. We have so many who do it in much less than that and some who need much more. ■



The nurse Krista Murray

1. Smith T, Naghibi M. BANs Report 2016: Artificial nutrition support in the UK 2005-2015. Adult home parenteral nutrition & home intravenous fluids. Accessed on 4 September 2018: www.bapen.org.uk/images/pdfs/reports/bans-report-2016.pdf.