

Home parenteral nutrition— the stakeholders' perspective into how to best equip patients for a better quality of life

The European Society for Clinical Nutrition and Metabolism (ESPEN) held its 41st congress in Krakow, Poland from 31 August-3 September 2019. On the second day, BD hosted a lunchtime symposium that was moderated by Ms Manuela Rancati, EMEA Product Marketing Manager Infusion Solutions, BD Medication Management Solutions.



Bitter-sweet taste of life – the patient’s perspective on parenteral nutrition at home

Mr Marek Lichota

President of the Apetyt na życie (Appetite for Life) Association, Krakow, Poland



“Sometimes bitter experiences make us stronger, so that we can appreciate the sweet things in life.”

Marek Lichota

“If you can’t change your situation, the only thing you can change is how you choose to deal with it.”

Marek Lichota

“With determination and organisation, you can really reach almost any destination.”

Marek Lichota

Mr Lichota was diagnosed with Crohn’s disease in 2002. According to his medical record, he developed sepsis, an intestinal fistula, gastrointestinal haemorrhaging and abscesses. In 2008, he underwent several segmental bowel resections, leading to short bowel syndrome (*i.e.*, his small intestine was shortened from 6–8 m to 80 cm and his large intestine from 2 m to 1 m). In addition to what was noted in his medical record, Mr Lichota also suffered from severe weight loss, a burning pain, unhealed wounds, weakness, insomnia and loss of inde-

pendence. He felt psychological pain, hopelessness, a lack of confidence, anger and a fear of death.

After a six-month hospital stay, he was discharged and fed with home parenteral nutrition (HPN) for 18 hours a day, seven days a week. He experienced a lack of mobility due to being attached to an intravenous (IV) pole. He could not participate in family life and endured emotional disorders. All of this had a negative impact on his quality of life. However, the possibility of going back home, was a big step towards stabilising his condition. HPN gave him energy and time to heal, so that his double lumen stoma could be removed. Once his bowels were reconnected, he was able to reduce HPN to 14 hours a day, four days a week and eat food again (*60% of his nutritional requirements*).

Once he felt stronger and discovered portable pumps, his quality of life greatly improved and he regained confidence. He became a father, went back to work and started travelling again. Thanks to the freedom that a portable pump offers, Mr Lichota has travelled around the world in spite of the logistics that this requires. He thinks that for some healthcare professionals, travel is insignificant to people receiving HPN, but he feels that it is important for quality of life in patients with life-long therapies.

Besides the ability to travel, portable pumps may also offer increased safety by letting patients control the infusion rate, improving treatment adherence and lengthening catheter life-times. Mobility allows people on HPN to participate in social and professional activities. The Appetite for Life Association was founded in 2002 and it supports, educates and empowers patients with digestive disorders, especially those receiving enteral and parenteral nutrition.

The role of mobile pumps in home parenteral nutrition

Prof CMKP, Dr hab n med Jacek Sobocki

Head of General Surgery and Clinical Nutrition, Centre of Postgraduate Medical Education, Warsaw, Poland



“Patient choice is very important to us.”

Jacek Sobocki

“Quality of life [is] significantly improved with portable pumps.”

Jacek Sobocki

Prof Sobocki began his talk by mentioning reasons against using portable pumps: increased costs, additional patient training, more work for the nutritional team, extra equipment at home, more responsibility and more time needed to service and maintain them. However, patients report higher levels of happiness and ease of use with portable pumps than stationary pumps¹.

Prof Sobocki's team shows the patient 3–4 portable pumps based on minimum standards (*set by the nutritional team*) and medical requirements (*set by a medical doctor*), then the patient makes the final choice. ESPEN recommends providing patients on HPN with portable pumps that have standard safety features². Patients expect portable pumps to be durable, resistant, easy to install, intuitive (*less options are better*) and with long battery life. The nutritional team prefers porta-

ble pumps with more options. Each one offers specific features for specific situations.

His team then trains the patient on how to use the pump and prevent it from overheating. Finally, they supply home equipment (*i.e., PN bag, IV lines, portable pump and a central venous catheter*), provide technical support and come to the patient's home once a year to service the equipment. Patients' feedback is used to write, evaluate and improve training manuals.

Prof Sobocki explained why portable pumps are helpful. They offer patients the freedom to leave home, improve their social lives and help them get back to work. Portable pumps also make it possible to participate in physical activities. They provide a stable infusion regardless of patients' activities and physical positions (*e.g., sitting, standing*). For two groups of patients, portable pumps are indispensable: patients requiring prolonged infusion (*i.e., 18–24 hours*) and those with unclear metabolic instability. Portable pumps improve the quality of life of most patients on home therapy.

References

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2. Pironi L, Arends J, Bozzetti F, et al. ESPEN guidelines on chronic intestinal failure in adults. *Clin Nutr.* 2016;35(2):247–307. doi: 10.1016/j.clnu.2016.01.020.

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