Carolyn Wheatley
HPN patient - Chair PINNT

Improving the patient experience for those receiving home artificial nutrition

Twitter/Facebook: @PINNTcharity

TPN/HPN (Total/Home Parenteral Nutrition) Home Enteral tube feeding (PEG, Button etc)
Support and Advocacy
Artificial feeding routes

- Intravenous
- PPN
- TPN
- Nasogastric tube
- Gastrostomy tube
- Jejunostomy tube
- Nasoduodenal tube
- Nasojejunal tube
Types of feeding systems

- Patient are discharged and overwhelmed with information, hope and expectation

- Parenteral and enteral patients use ambulatory pumps

- Often told ‘it’s an overnight feed’

- ‘You can return home and get back to normal’

- What is normal?

- 12-14 hour feed + additional IV fluids

- Different lifestyles…
Many PINNT members were reporting issues in respect of ambulatory rucksacks in terms of security screening in public places!

Rucksacks with tubing, pumps, batteries noises/alarms

- People need/want to infuse in public
- We wanted to support patients, the public and security services
- Support people to live as they so wish
- Integrate into the community, not be excluded from it.
A dedicated tag for ambulatory feeding rucksacks to verify genuine medical equipment

A free resource for PINNT members

To provide security for PINNT members, the general public and security services

It was agreed that it would be launched during our Home Artificial Awareness Week in 2017
Phase 1: PN ambulatory pumps

- Invited the three suppliers/distributors to support the project: BD (formerly CME Medical Ltd, Inspiration Healthcare and Fresenius Kabi)

- All agreed to work as equal partners for the good of patients

- A bespoke medical tag and info card was designed
• A PINNT member was enjoying a trip to the cinema while connected to his feeding pump…

• His pump alarmed, he opened the rucksack to rectify the issue: a pump, alarms, flashing lights and tubing…

• The little boy behind expressed concern to his mum…

• The PINNT member and PINNT then worked with Dorset Firearms to produce an education video for HAN week 2018.
Medical tag & card

On a variety of PN rucksacks

Out and about...

#verify

PINNT medical tag – home enteral and parenteral feeding

For ambulatory life-saving medical rucksacks
- All EN ambulatory pumps were added to the system in May 2018
- One year after we launched it we have achieved our goals
- Tags have been sent all over the UK, Europe, South Africa and Australia
- We are already looking to upgrade the tag and information in 2019
- Working with police colleges to education officers about rucksacks for essential medical equipment and feeding.

"The medical tag has gone onto my sons’ rucksack. He’s deaf, as is his carer so it’s a great help. The letter and card have been put inside too. It’s hard for them to explain with the communication barrier so this is perfect, thanks."