



Support makes the difference



PNDU

Parenteral Nutrition Down Under

HPN Quiz

HPN = Home Parenteral Nutrition

HPNer = someone living on Home Parenteral Nutrition

1. **What can cause those on HPN to wake up during the night (sometimes multiple times) leading to lack of productive sleep?** (choose as many as apply)
 - a) Cramps
 - b) Needing to go to the toilet
 - c) Air in the line alarms
2. **What is often the biggest fear for HPNers/their carers when needing to stay in hospital?**
 - a) Needles
 - b) Bad smells in the gastro ward
 - c) Noisy roommates (or roommates' visitors)
 - d) That nurses won't care for their central line with the appropriate meticulous care needed for a lifeline required for the rest of an HPNer's life
 - e) Having to share the bathroom/toilet
3. **For what reason must an HPNer head straight to the Emergency Department, no matter what time of day/night or where they are?**
 - a) Temperature, rigors with no obvious cause
 - b) Frizzy hair
 - c) A yearning for hospital medical smells
 - d) Sore feet for no obvious reason
4. **What is the only specific peer support group available for those living with HPN in Australia and New Zealand?**
 - a) AuSPEN (Australasian Society of Parenteral & Enteral Nutrition)
 - b) Rare Voices Australia and New Zealand Organisation for Rare Disorders
 - c) PNDU (Parenteral Nutrition Down Under)
 - d) Starlight Children's Foundation
5. **What are the 3 life-threatening risks of HPN?**
 - a) Social isolation
 - b) Liver damage
 - c) Poor body image
 - d) Loss of central venous access
 - e) Central line sepsis
 - f) Shrinking height
 - g) Warts on toes
6. **What frustrates many HPNers?** (choose as many as apply)
 - a) Friends and family telling them they look well when they actually feel sick or in pain
 - b) Doctors not believing their Intestinal Failure symptoms because they don't fit what they think should be normal
 - c) Their football team losing
 - d) The weather
 - e) Friends who tell them that they wouldn't need HPN if they improved their diet by eating this super food or that special juice.
7. **Can HPNers go out at night?**
 - a) Only if their hospital team gives them permission
 - b) Yes, and made a whole lot easier if they have a backpack pump and the energy
 - c) No, because their PN will turn into pumpkin soup at midnight

8. **Why is it difficult for the average person on the street to understand HPN and Intestinal Failure?** (choose as many as apply)
- a) It is rare
 - b) It's not cancer therefore it's irrelevant
 - c) Many people don't understand how the digestive system works
 - d) Many HPNers look well
 - e) Their auntie's neighbour's son's accountant's cousin has never read about it in a magazine
 - f) It is a hidden condition with mostly no visible indications
 - g) Bowels are still a taboo subject for many people
 - h) No-one in the Royal Family or the Kardashian family have it
9. **Is it correct that no-one (adults and children) on HPN can eat?**
- a) Yes, otherwise they jeopardise the effectiveness of the PN
 - b) Yes, because Intestinal Failure means the intestines are completely stuffed and cannot absorb anything
 - c) Yes, because they risk contracting cancer if they do
 - d) No, adult HPNers can eat, but children on HPN cannot
 - e) No, some adults and children on HPN can eat (usually a restricted diet), which is helpful for keeping the intestines and liver healthy
10. **What is a risky pastime for an HPNer?**
- a) Collecting stamps because the glue on the back of stamps can cause central line sepsis
 - b) Swimming because, depending on the water quality, there is a risk of central line sepsis
 - c) Bike riding because if an HPNer was to infuse during the day, the giving set may get caught in the bike wheels
 - d) Reading because paper harbours microscopic bacteria which can cause central line sepsis
11. **If an HPNer wants to go on a trip,** (choose as many as apply)
- a) They can take advantage of cheap last minute holiday deals
 - b) They need to notify their hospital team /PN service provider at least 4 weeks prior to a domestic holiday (for easy destinations; 2 months for involved domestic travel; and 5-6 months for overseas travel) to organise PN deliveries
 - c) They can buy cheap plane tickets which only allow 1 carry on bag (and no checked-in luggage) and squeeze everything into it
 - d) They either need to purchase or get carrier permission (needing letter from doctor) for extra bags to allow for all the peripheral supplies and equipment needed for HPN
12. **For most HPNers, what time of day do they feel most tired?**
- a) In the morning at the end of a PN infusion because the body has had to work hard all night processing it
 - b) At lunchtime because it's often half-way between infusions
 - c) Late afternoon/evening because they have gone the whole day without effective nutrition/hydration and are exhausted

Answers

- 1. All of the above
- 2. d)
- 3. a) - possible line infection requiring blood cultures to be taken peripherally and from the central line
- 4. c) www.pndu.org
- 5. b), d) and e)
- 6. a), b) and e)
- 7. b) - a backpack pump significantly improves the quality of life of HPNers
- 8. All of the above, although we hope no-one seriously thinks along the lines of b), e) or h)
- 9. e)
- 10. b)
- 11. b) and d)
- 12. c) - which is the same time many HPNers need motivation and concentration to connect up again

For more information about HPN, living with HPN, and PNDU, visit www.pndu.org