

Top Tips for Managing the Psychological Well-being of Adults Requiring Home Parenteral Support (HPS)

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This document aims to give practical advice to healthcare professionals to support the psychological well-being of adults requiring HPS.

HPS is a common treatment for patients with intestinal failure (IF) or intestinal insufficiency. The impact of these lifesaving treatments on psychological well-being is well documented, particularly in terms of the impact on quality of life. Winkler *et al.* (2010) reported that many adults dependant on nutritional support at home maintain a good quality of life and take ownership of their nutrition in a proactive and highly successful way. However, dependence on nutritional support has also been shown to negatively impact psychological well-being, particularly in terms of individual relationships, autonomy and independence, body image, and self-esteem (Heaney *et al.* 2018). Clinical levels of depression and anxiety are also common, with poor social support networks and loss of employment known to exacerbate risk of heightened psychological distress (Ennis *et al.* 2018).

Providing key information to healthcare professionals so that they can both recognise the psychological well-being of patients requiring HPS, and have sufficient knowledge about where to direct people to gain appropriate psychological support is thus vital.

Key points

1. Individuals requiring HPS can be more susceptible to social isolation.
2. Promoting psychologically informed self-care is vital for ensuring individual psychological well-being.
3. Coping with the daily demands of nutritional support at home and long-term physical illness can lead people to overlook other important aspects of life that are not related to nutrition.
4. Individuals requiring HPS should be reassured that changing emotions during their journey of living with HPS are to be expected. Healthcare professionals should therefore encourage individuals to speak openly about their psychological wellbeing and know where to signpost people to for further advice and support when needed.
5. Healthcare professionals should be equipped with knowledge about how to refer for immediate/crisis psychological support in a mental health crisis situation.

Explanations

1. **Encourage creative ways to connect.** Healthcare professionals are advised to encourage individuals to develop creative ways to connect that help minimise social isolation and bolster social support. For example, Skype, text messaging and video calls, as well as face to face contact. Social media can help people to gain reassurance, but for some this can feel unhelpful and anxiety provoking. It is thus important to remember that each individual is unique, and any decision to engage with social media is a personal preference. Encouraging participation in shared online activities, such as virtual book clubs, film clubs or quiz nights, may help individuals to increase pleasure and achievement and their overall mood. Patient support or advocacy groups can also be helpful for some patients, to connect with other patients and help to answer practical questions. While this type of support does not appeal to many patients it is best practice that patients are made aware of these groups.

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Finally, where employment can be maintained or modified, this should be encouraged, given that for some people the introduction of HPS will enable them, not necessarily restrict connectivity with life outside the home environment

2. **Encourage self-care regimens.** Taking time to enjoy activities around a nutritional support regime is vital for individual psychological well-being. Thus, it is important that healthcare professionals encourage individuals to engage with enjoyable activities, individual hobbies, employment and interests on daily basis. Encouraging activities that help occupy time and give purpose and pleasure to a day are highly recommended. Autonomy and the maintaining of independence should be promoted, along with an understanding of the underlying medical condition and treatments.

Healthcare professionals should recognise that, for some individuals, having daily routines around nutrition can be helpful and bolster psychological well-being. Some common examples that may benefit from discussion with individuals where appropriate include:

- Having regular times for waking, going to bed and getting dressed each day.
- Having a regular time to take a daily walk or do physical activity.
- Including some relaxation time into a daily routine to help maintain mood and manage any anxieties and worry.
- Regular use of NHS recommended smartphone apps that promote relaxation and well-being.
- Recognising that while routines are encouraged and are useful for some people, the impact of HPS and long-term illness may potentially prevent routine due to managing the unexpected or 'new normal' of life on HPS – i.e. disturbed sleeping patterns, frequency of visiting the bathroom or needing to manage feeds and feeding equipment.

3. **Nurture what is important for every individual.** Healthcare professionals should encourage individuals to keep in touch with aspects of life, or life 'values' that are most important to them outside of nutritional regimens (e.g. being a good parent, friend, being spiritual, being creative, being intimate, going to work). This can facilitate thinking and reflection

about the extent to which individuals are living life according to what is most important to individuals outside of and beyond their HPS regimen, and help to develop goals, hopes and plans that will maximise overall psychological well-being.

4. **Encourage formal help seeking when needed.** It is vital that professionals refer people to their GP in a timely manner to request referral to local psychological services. Common reasons for referral to psychological services may include (this is not an exhaustive list):

- Feelings of anxiety, depression, hopelessness, and anger.
- Traumatic stress responses, specifically in relation to health care experiences.
- Adjustment to losses or changes relating to the body, functioning and/or identity.
- Self-management/coping with discomfort and/or fatigue related to gastrointestinal or nutritional difficulties.
- Difficulties coping with or adhering to treatment or medical advice.

Healthcare professionals should always take time to listen to the individual and try to make sense of a person's psychological distress (within the realms of their professional knowledge, skills and qualifications). It is vital to ensure an individual is in agreement about the making of any referral to local psychological services, and this should be clearly documented in written format within an individual's healthcare record.

5. **Refer for immediate/crisis psychological support in a mental health crisis situation.** A mental health emergency should be taken as seriously as a physical one. Where someone's life is at risk – for example, they do not feel able to keep themselves or someone else safe, it is vital that healthcare professionals call 999 or present the individual to their local Accident and Emergency department.

Healthcare professionals should be aware of the NHS website (www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/dealing-with-a-mental-health-crisis-or-emergency/). This portal provides comprehensive information and direction about how to support individuals to get immediate help in a crisis situation across the United Kingdom.

Suggested reading:

- Ennis L, Ablett J, Taylor M and Lal S. The active problem solving of patients dependent on home parenteral nutrition: A qualitative analysis. *Clin Nutr.* 2018; 26(1): 77-83
- Harris R. (2009) ACT made simple: A quick-start guide to ACT basics and beyond, Oakland CA, New Harbinger.
- Heaney A, McKenna S, Wilburn J, et al. The impact of Home Parenteral Nutrition on the lives of adults with Type 3 Intestinal Failure. *Clin Nutr.* 2018; 26(1): 35-40
- Manson B (2019) Living with artificial nutrition: Information booklet. Accessed on PINNT website 24th September 2020: <https://pinnt.com>
- Winkler M, Hagan, E, Wettle T, et al. An exploration of quality of life and the experience of living with home parenteral nutrition. *J Parenter Enteral Nutr.* 2010; 34: 195-407
- Wong C, Lucas B and Wood D. Patients' experiences with home parenteral nutrition: A grounded theory study. *Clin Nutr.* 2018; 24 (2): 100-108
- PINNT: Support and advocacy Association for people on home parenteral or enteral nutrition and oral supplements – <https://pinnt.com/Home.aspx>