BAPEN

PNGSIG
Patient Network Group

Experiences and views of support services for people living at home with an enteral tube

Executive Summary

This national UK study explores the experiences and needs of individuals living at home with an enteral feeding tube (HEN) and their carers. With an estimated 40,000 people in the UK relying on tube feeding, the study aimed to identify what services are most valued and needed to support this population effectively.

Study Overview

Design	Cross-sectional survey with both quantitative and qualitative components.
Partipcipants	242 respondents (193 tube users, 49 carers).
Methods	Online and paper-based survey disseminated via the PINNT support network.
Ethics	Approved by Bournemouth University Ethics Committee.

Key Findings

Training and preparation

- Only 52% felt adequately prepared to manage the tube at home.
- Training was inconsistent, with significant variation in who provided it (hospital nurses, dietitians, nutrition nurses, etc.).
- Many relied on online resources (e.g., YouTube, support groups) for additional learning.
- Participants emphasized the need for better emotional preparation and practical guidance before discharge.

Managing at home

- 68% managed the tube independently; others relied on family or professional carers.
- 44% experienced tube dislodgement post-discharge, often requiring emergency care.
- Participants reported inconsistent advice between hospital and community care teams.
- Many expressed frustration with supply logistics and lack of emergency support.

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Impact on daily life

- 60% reported a significant impact on daily activities.
- Emotional and psychological challenges were common, including anxiety, fatigue, and social isolation.
- Carers often felt overlooked and unsupported.

Support services

- Most received support from homecare companies.
- Participants desired more frequent reviews, better-coordinated care, and 24/7 support access.
- Written information and contact lists were inconsistently provided.

Qualitative themes

- **Variation in training:** Some received excellent support; others had none.
- **Being prepared:** Need for comprehensive, paced training and emotional support.
- **Living with a tube:** Participants wanted guidance on integrating the tube into daily life.
- **Effort and burden:** Managing the tube was described as time-consuming and emotionally taxing.
- **Carer experience:** Carers felt under-supported and excluded from care planning.

Recommendations

1. **Individualised Care Plans:** Tailored to patient needs with early post-discharge contact.
2. **Standardised Training:** For both patients and healthcare providers, with accessible written and digital resources.
3. **Coordinated Multidisciplinary Care:** Seamless hospital-to-home transitions and regular reviews.
4. **Accessible Support Services:** Including out-of-hours help and emergency tube replacement protocols.
5. **Adherence to National Guidelines:** Including NICE and BAPEN standards.
6. **Person-Centred Approach:** Emphasising quality of life, mental health support, and feedback mechanisms.

Conclusion

This study highlights significant variability in the support provided to people with enteral tubes at home. It underscores the need for consistent, person-centred services that address both the clinical and emotional aspects of living with a feeding tube. The findings provide a foundation for improving HEN services across the UK.

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