

Experiences and views of support services for people living at home with an enteral tube: It's time to listen and take action





What is Enteral Feeding?

When illness or injury affects a person's ability to eat or swallow, getting proper nutrition can become difficult, or even impossible. Conditions such as neurological disorders or cancer and its treatments may interfere with appetite or the mechanics of eating. In these situations, enteral feeding offers a vital alternative.

Enteral feeding delivers nutrients directly to the stomach or intestines through a tube placed via the nose, mouth, or abdomen. While this method can be life-saving, it can also be life-changing and challenging for many individuals.



Our Report

This report explores the experiences of people across the UK transitioning to home enteral nutrition (HEN) and highlights opportunities to improve care, enhance outcomes, and support a better quality of life. While many people will be introduced to enteral feeding in a hospital setting, the majority of patients will continue to receive their nutrition enterally at home after discharge. Ensuring a smooth and well-supported transition is essential.

What did we find?



52% of participants felt adequately prepared to manage their enteral tube and feeding at home.

45% of participants reported feeling only partly prepared or not prepared at all following hospital discharge.



What do people with enteral tubes and their carers want from services to support them to manage at home?



More consistent training and support before discharge.

Some individuals described receiving little to no guidance before returning home. One respondent explained: "I had the tube place[d] and was sent home without a single ounce of help or compassion."

Effective online resources and peer support networks

to bridge gaps during the transition from hospital to being at home managing their enteral nutrition.





Access to written materials and links to clinical teams

to allow for those leaving hospital to revisit their training on an ongoing basis should they need assistance.

Standardised easy-to-understand written resources

that can continue to be referred back to. Many respondents felt overwhelmed by the volume of information presented before discharge.





Communication channels with multidisciplinary teams to help manage challenges that arise after transitioning home.

Our Recommendations

Based on insights gathered through this survey, we recommend the following to support HEN patients in the transition from hospital to home:



Assessment and Planning

It is essential that those relying on tube feeding receive an individualised care plan and contact with a healthcare professional within 24 hours of hospital discharge.



Training and Education

People with the tube and their carers should receive training prior to leaving and once in the home setting, including in a written and recorded format.



Co-ordination of Care

Multidisciplinary teams are essential in the development of care plans and the monitoring of those reliant on enteral feeding. These teams are similarly key in ensuring patients leave hospital with the necessary supplies and support services to continue enteral feeding at home.



Monitoring and Support

Once home, it is essential that patients monitor their feeding and have access to out-of-hours support and delivery services should the need arise for additional assistance when they are in the home setting.



Guidelines and Standards

The administration and monitoring of enteral nutrition should always adhere to NICE guidance. This is particularly true for infection prevention protocols following discharge from hospital.



Person-centred Care

The person relying on tube feeding must be central to the care plan. The feeding regimen must fit within their daily routine and allow for feedback mechanisms wherein the patient has the ability to codesign their care plan with healthcare professionals.











