

Living with an enteral tube

We receive numerous requests to support research projects, our priority is always to determine how the project and expected outcomes will support our members. When Sue Green contacted us and outlined her ideas, we knew this was a no brainer! Talking to people on tube feeding then using the feedback to aid the development of standards, raise awareness and be used as an education resource, was a brilliant suggestion! Please continue to read the feature written by Sue. We were also delighted to assist with the making of a video.

People with enteral tubes and their carers' views of living with a tube and managing associated problems: A qualitative interview study.

Why did you carry out the research? I was involved in setting up a home enteral nutrition team with dietetic and speech and language therapy colleagues about seven years ago. This made me realise that there are big differences in the type and amount of support available for people with enteral tubes and their carers depending on where they lived. I wanted to understand what people with enteral tubes and their carers want from services in the community to support them to manage their therapy at home and use this to inform the planning of services.

What did you learn during the research that you didn't expect to? Undertaking the research gave me the opportunity to really listen to people when they talked about their experiences of having an enteral tube. When I started the research project I wanted to find out about the services and support people wanted with their tubes. However, as the research allowed people to tell me what they wanted, I learnt much more about what it is like to live with a tube. Previous research I had read described having an enteral tube as a burden, so I was surprised at how many people talked about the positive aspects of having a tube. I also did not expect so many people to talk about how they found the tube uncomfortable at times.

What difference do you see the results of the research making? I want the research to make a difference by making healthcare practitioners, commissioners and policy makers much more aware of the experiences of people with enteral tubes and their need to have good services that support them to manage at home. I have talked about the research at conferences and meetings, published two academic papers and made a film so far! Having the Chair of PINNT and the BAPEN President involved in the making of the film should really help to share the findings of the research.

Do you think it will affect future care and education for HCP/decision makers? It is already affecting the education of healthcare professionals as they are reading about the research. I have been talking about the findings to healthcare professionals in practice and to student nurses during their university programme.

If you could list up to three things, what would you like to see as positive outcomes from the research:

1. The research supports the need to develop a national standard for support for people living at home with enteral tubes and I would really love to see this happen.
2. Recognition that home enteral nutrition services should be designed in partnership with people with enteral tubes and their carers.
3. Increased healthcare professionals' knowledge and understanding of enteral tube management.

Sue S M Green RN, PhD

**Nursing and Clinical Sciences, Faculty of Health and Social Sciences
Bournemouth University Green**

Sue Green was funded by National Institute for Health Research (NIHR)/Health Education England (HEE) and Clinical Academic Training (CAT) Clinical Lectureship for this research project. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, HEE or the Department of Health and Social Care.

A short video can be seen on:

<https://bit.ly/2Kl8Nel>

You can read the full paper on this link:

<https://onlinelibrary.wiley.com/doi/full/10.1111/jocn.14972>

