

Supporting Home Enteral Feed Patients in Rotherham



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“The management of care for people with long term conditions should be proactive, holistic, preventative and patient centred”¹. There are an increasing number of patients that are now discharged to their own home or community care on home enteral tube feeding (HETF). In Rotherham, there has been a 52% increase in HETF from 2010-2017.² Optimising quality of life in HETF patients has been found to be challenging.³ It is important that these patients receive continuous support. Supporting patients and carers of HETF patients is a key part of the Dietitian’s and Homecare Nurse role. It is recommended that all patients who receive enteral nutrition should be kept fully informed and have access to appropriate sources of information and support, in formats, languages and ways that are suited to an individual’s requirements.⁴ As a result of this, we wanted to find a way to best support HETF patients in the Rotherham community.

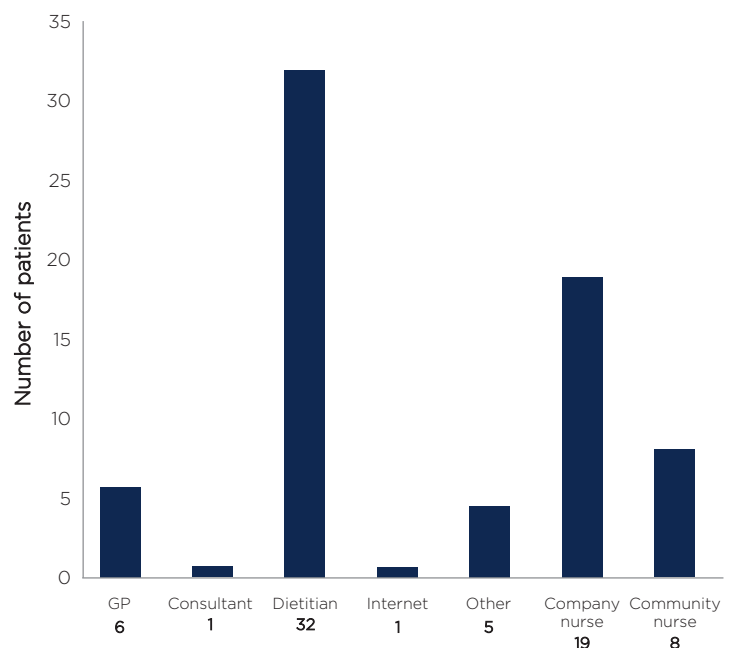
Background to the project

Adult HETF patients, who were registered with the Fresenius Kabi Homecare service in Rotherham, completed a questionnaire so we could obtain information on how HETF patients and carers could be best supported in the community. The questionnaire was produced in August 2015 and consisted of 12 questions; it was delivered to all patients and carers. The questions focused on the following areas: patient demographics, how long they had received enteral tube feeding for and what the best platform of support would be.

Findings from the questionnaire

Sixty-three per cent of patients or carers completed the initial questionnaire of which 50% lived in care homes and 50% of patients lived in their home. Findings highlighted that the highest proportion of patients and carers would prefer to talk to their Dietitian or Fresenius Kabi Homecare Nurse for support and advice – see **Figure 1**.

Figure 1: If you had a question relating to home enteral feeding where would you go?



Patients and carers reported that they would prefer a different platform of support rather than a face-to-face support group; 73% of patients and carers reported that they would not want to meet or talk to any other patient's relatives or carers as a form of support. The questionnaire also highlighted that only 50% of Rotherham HETF patients and carers used the internet daily.

It was asked: "What type of support patients currently require, that they do not already have?"

The following suggestions were made:

- Newsletters/information booklets
- Help with maintenance of percutaneous endoscopic gastrostomy's (PEG)
- Contact information for all healthcare professionals
- Support from other patients which receive HETF
- Local support/out of hours service
- Easier access to giving sets and syringes
- Flow chart to follow problems if they arise.

The Homecare newsletter project

Findings from this questionnaire highlighted the need for a regular support tool to be provided to HETF patients and carers. As patients preferred not to seek advice face-to-face, and not everyone used social media as a support tool, a newsletter was deemed to be the most appropriate for patients and carers in Rotherham. We identified that the majority of patients and carers would seek support and advice from the Rotherham HETF Dietitian and Fresenius Kabi Homecare Nurse. This encouraged a working partnership to produce the 'EN Today' newsletter, with the

Figure 2: The 'EN Today' Editorial Team



From left to right: Sharran Wainwright (Scientific Affairs Dietitian Fresenius Kabi), Natalie Whittle (Account Manager Fresenius Kabi), Anna Hardman (Specialist Dietitian, Rotherham), Claire Jackson (Homecare Clinical Nurse Advisor Fresenius Kabi).

Rotherham HETF Dietitian collaborating with the Fresenius Kabi Scientific Affairs Dietitian, Clinical Nurse Advisor and Account Manager - see **Figure 2**.

From the comments relating to the type of support required, we were able to determine the contents of the newsletter. This included: an introduction to your healthcare professional, an education page, projects in the trust, patient stories, important contact information and frequently asked questions - see **Figure 3**.

Feedback since the launch of the 'EN Today'

Since the launch, we have produced and circulated three editions of 'EN Today' and are currently working on our fourth edition. We have also collated feedback via a questionnaire on how the newsletter has been received by HETF patients and carers. Twenty-one questionnaires were collected; the results have shown to date that 90% of patients found the newsletter useful. The 10% that did not find the newsletter useful commented that they were already very experienced and established in HETF - see **Figure 4**.

Fifty-three per cent of patients were happy with the current content, 33% were not sure what they would like to see in the next edition and 14% gave other suggestions. These suggestions included: information on bolus feeding, more pictures and troubleshooting relating to feeding tubes.

When patients and carers were asked what they liked about the newsletter, 38% made comments relating to the newsletter being helpful and supportive for patients and carers.

Figure 3: Screenshots of 'EN Today' Newsletter Design

Page 1 - Introduction and meet your healthcare professional



Page 2 & 3 - Education page, projects in the trust and patient story



Page 4 - Important information, useful contact number, frequently asked questions and puzzles

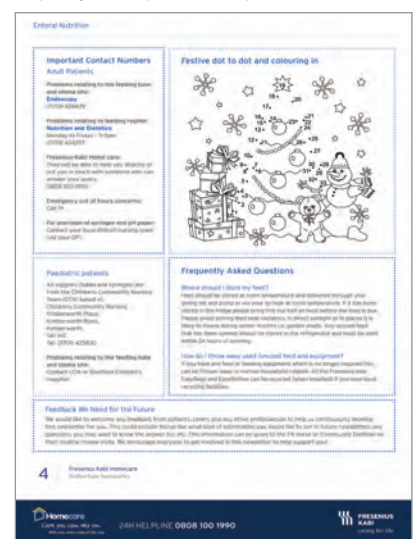
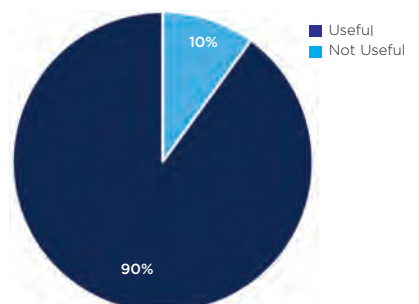


Figure 4: What do you think of the newsletter content?



Below is a selection of patient and carers comments relating to 'EN Today'.

We wanted the patient story feature to be an essential part of 'EN Today' – see Betty's Story in **Figure 5**.

Betty also provided feedback on what it meant to her writing her story and contributing to 'EN Today'.

"Writing in the newsletter was really important for me; it has allowed me to share my experiences with everyone and help to share what I have been through and make them feel that they are not alone. I wanted to share with new and established enteral feeds that life does not change when you have a PEG and you can go on holiday and do what you want. I thought my story could help and support other people. I definitely enjoy reading the newsletter and would like it every month if we could! I like to see other healthcare professionals and I think that the education page is very useful for new home enteral feed patients who have PEGs. I think it's a

really good tool to support patients, what the healthcare professionals do and help to answer some commonly asked questions. It's great!"

Moving forward

As a large proportion of our patients were interested in being updated via the Internet we now encourage them to join the Fresenius Kabi Facebook group. This Facebook group is a safe and positive environment for patients, relatives and carers to share experiences and to provide support and learn from each other. The contents topic includes: meeting and 'Day in the Life' of the Fresenius Kabi team, living on enteral nutrition and socialising and patient stories.

The editorial team is currently in the process of creating edition four of 'EN Today' and we will continue to collate feedback from patient and carers in order to improve the newsletter and holistic support we offer HETF in Rotherham.



Figure 5: Betty's Story

Betty is a widowed mum of four and thoroughly enjoys going on holidays, cruises and the odd game of bingo and this is her story about how she felt when she was first diagnosed with mouth cancer and using her PEG for the first time.

I was diagnosed with Mouth Cancer in 2005, which came as quite a shock to me despite being a smoker all of my life and being aware of the risks involved, but this had never entered my mind.

I was transferred to Rotherham General Hospital and told I needed an operation the following week. I was meant to be going on a family holiday at the time to Turkey and I really didn't want to let my grandson down. The doctor reassured me and took my hand and said "Betty you have to have this surgery." Reluctantly I agreed. Prior to having the tumour in my mouth removed the doctor informed me that I would have to have a PEG placed into my stomach, so I could be fed by tube whilst my mouth recovered from the surgery. As a person who always loved my food it wasn't an idea I relished, but I told myself that it was going to save my life. I cried on the first night home from hospital and found it very daunting putting up my own overnight feed. Surprisingly I slept well and have never looked back.

When I had my first holiday to America with the enteral feeding pump I got there and it did not work, I was told the electric was not strong enough. I rang the Homecare 24 hour advice line who talked me through bolus feeding, which put me at ease and allowed me to still have my feed. The new pump was then delivered to my hotel reception the next morning. This was fantastic; I could not fault the service I received and it meant I could continue enjoying my holiday.

The Endoscopy department at Rotherham General Hospital has also been a massive support throughout my whole journey and I can ring them anytime. The Dietitian at Rotherham and Kerry the Fresenius Kabi Homecare Nurse has regular contact and will always visit out of schedule if I request.



References: **1.** Coulter A, Dixon A, Roberts S (2013). Delivering better services for people with long term conditions. Accessed online: www.kingsfund.org.uk (July 2017). **2.** Rotherham Homecare Home Enteral Tube Feeding data (July 2017). **3.** Brotherton AM, Judd PA (2007). Quality of life in adult enteral tube feeding patients, *Journal of Human Nutrition and Dietetics*; 20(6): 511-631. **4.** National Collaborating Centre for Acute Care (UK). Nutrition Support for Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition. London: National Collaborating Centre for Acute Care (UK) 2006 Feb. (NICE Clinical Guidelines, No.32.) Accessed online: <https://www.ncbi.nlm.nih.gov/books/NBK49269/> (July 2017).

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