

## Luton and Dunstable's ebd journey

*It's nine in the morning. You haven't been eating or sleeping properly and you don't feel well.*

*You've made a stressful journey to the hospital to see the consultant. You follow the outpatient signs and turn the corner into a packed clinic. People look ill. Most are sitting in long rows, some facing blank walls and several others are standing.*

*After a long wait you see your consultant, he confirms that you have cancer. There seem to be a lot of staff around you – you're not sure who they all are or why they're there.*

*You're told you'll need surgery, followed by radiotherapy. But first you'll need an overnight stay in hospital to have a feeding tube inserted in your stomach. You'll need to learn how to use the tube and clean it. You're overwhelmed and emotional - you can't take it all in. You've a thousand questions racing through your mind. The nurse specialist wants to take you to a quieter place to offer support and explain a bit more; the nutritionist wants to talk to you about the feeding tube; the speech therapist comes in to introduce herself and explain her role.*

*It's a blur - all you can think about is getting back home to process what's happened.*

It's not hard to imagine the sense of panic a scenario like this could cause – not just for patients, but for the staff who carry out consultations and care for patients in stressful, crowded clinics. Yet, for some patients and carers at Luton and Dunstable Hospital NHS Foundation Trust's head and neck cancer service, this was often the reality.

Like so many other services, the head and neck team were aware that things could be better – especially in the over-crowded outpatient clinic but in other areas too. There had been other improvement initiatives before; some very successful and some tending to fizzle out as resource pressures impeded progress.

Then they decided to try something very different and became one of the first trusts to formally pilot the ebd approach (experience based design) in the NHS.

*"The power of patients in service improvement is phenomenal and amazingly almost completely untapped in this country,"* says chief executive Stephen Ramsden. *"That's why we've been so keen to be involved in new thinking about how to genuinely empower patients – not just in terms of service redesign, but in terms of their own care and treatment as well."*

Their pioneering work with ebd proved to be a remarkable turning point. Using the principles of ebd, patients and carers were invited to tell and share their stories - many on camera – and to reflect on the deep and detailed events that shaped their own personal experiences of their care.

### **'People are still talking about the film':**

In fact, the 30-minute film where patients tell their own stories about their care has become one of the most powerful and lasting legacies to come out of the Luton and Dunstable ebd pilot.

The film itself was four months in the making – not because it was a hugely complex or expensive process, but because, in the spirit of the ebd approach, patients were deliberately given time and space to first share and reflect on their own experiences, and then decide collectively which they most wanted staff to see in the final cut.

*“When our consultant invited me and the rest of the head and neck cancer services team to be involved in experience based design, I have to confess I didn’t see it as anything different from the usual patient involvement things we’d done in the past,”* admits head and neck nurse specialist, Carole Glover. *“But the real crunch point came for me when we got together with all the patients for the first time and I saw the film they had made. Here we were seeing people we recognised and had cared for, telling real stories with real emotion on their faces. People are still talking about the film, months down the line.”*

#### **Identifying the touchpoints – good and bad:**

So what sort of experiences did patients share? One patient describes his surprise and reassurance when after turning up for his surgery at 7.30 in the morning, he was met at reception by his surgeon who greeted him with a friendly ‘good morning’ and offered to carry his bags. One of the defining things about the ebd approach is that it aims to capture the positive touchpoints too, so these can be retained and shared across the service.

Overall, however, the film (as well as the diaries and photo journals other patients kept) do deal with difficult moments and are a moving and uncompromising record of the whole care pathway through the eyes of patients and carers.

Feeling unsafe when weekend ward staff were unsure about how to reconnect a feeding tube; being shocked and confused when ‘radiotherapy planning’ turned out to involve an examination and mask fitting, not a discussion of appointment dates – were just some of the defining moments patients wanted to share.

*“These weren’t just anonymous comments from some survey or discovery interview. They were people who staff recognised and remembered caring for, and that’s a very powerful driver,”* says nurse and project facilitator Elaine Hide.

#### **New territory:**

Experience based design digs deep for emotions, using these to identify the defining moments (or touchpoints) along the care pathway. But it then goes a crucial step further by involving patients and carers in the improvement process itself, so they become genuine ‘co-designers’, rolling up their sleeves and getting on with the real work of redesign.

*“Working with patients like this was new territory for us so we were glad to have a separate facilitator from the ebd project,”* said Jacqui Arnold-Jellis, nutrition nurse specialist with the PEG (tube feeding) team. *“We were pretty nervous about the whole thing,”* she admits. *“But we needn’t have worried. That first face-to-face meeting between us and a small group of PEG patients soon developed into a fascinating session as people began to tell their stories and we all worked together to map the experiences and emotions being described on the day.”*

One patient described feeling rushed from having been informed of her diagnosis to an appointment with the PEG nurse – with no time to take in what had happened. Discussions

also revealed that some patients were opting to have their feeding tube removed without the aid of sedation, and there was a feeling that the information available was confusing and wasn't always offered at the most appropriate time.

### **Turning emotion into action:**

Some of the changes agreed between patients and staff were immediate, including giving patients a choice of appointments to see the PEG nurse where possible and giving fuller advice to patients about their pain relief options - sedation or an anaesthetic spray. Other changes would take more time and teamwork - including a much-needed overhaul of the patient information literature on PEG.

Feeling more confident now, the PEG staff arranged and ran a second co-design meeting with the patients themselves – this time to review the literature in detail. They knew they could expect some insights and valuable ideas from the group – but what they were less prepared for is the growing sense of camaraderie and the willingness of their patient co-designers to take on the workload themselves.

*“At one point – all the patients were talking about the fact a PEG leaves you with a second belly button and how this isn't explained in any of the patient leaflets,”* remembers one member of the PEG team. “Suddenly, everyone had their jumpers hoisted up comparing PEG scars. That was just another poignant moment when you didn't know whether to laugh or cry because there was such a powerful sense of patient and staff togetherness.”

By the end of the session, one patient offered to edit down a wordy leaflet into a more manageable single side of A4. A week later it was done. Another patient, with a background in information analysis, worked on rationalising the weightier booklet on PEG procedure.

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### **Hard and soft improvements:**

According to consultant otolaryngologist John Pickles, it's the concrete service improvements that are the real testament to the ebd approach.

*“The ebd technique is about capturing emotions, but that doesn't make it a soft or fluffy process. It's these emotions – the way patients feel at certain points of their care – that lead us to the hard improvements, many of which we can do quickly and at little or no cost.”*

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Chief Executive Stephen Ramsden adds: *“We can now point to more than 40 real improvements in our head and neck cancer services as a direct result of the ebd work. That’s very exciting.”*

**The patient perspective:**

Patients taking part in the ebd pilot were offered a choice of which co-design teams to join. Cancer patient Sheelagh Wren chose to be part of the ‘psychological support and information’ team because one of the things that had really struck her was how poorly written a lot of the patient leaflets and literature were. *“As a team we reviewed information from right across the service. We then selected a new set of leaflets and information sheets that staff could give patients at diagnosis. We made them into a pack, tested it with patients, and now it’s in use.”*

*“The thing that’s amazed me about this whole experience is how much can actually be achieved with little or no money – simply because we’re working as equals alongside staff, sharing ideas and finding commonsense solutions.”*

**Keeping the momentum going:**

Undoubtedly ebd has meant extra work for staff - with many of the improvement actions unavoidably falling to them. But it’s interesting that in an already pressured environment, staff have embraced the workload with purpose and enthusiasm. One explanation might be that the ebd process pays as much attention to the experiences and perspectives of staff as it does to those of patients.

According to some staff in the pilot, it’s the strong new relationship between the team and their patients that continues to motivate them.

*“The whole ebd process has given patients the confidence to call us on the phone or catch staff in clinic and ask how we’re progressing with the different improvement actions,”* adds Carole. *“In many ways it’s the patients’ energy that’s driving us; we’re the ones keeping up.”*

**These are just some of the 40-plus improvements that have come out of Luton and Dunstable's first ebd pilot:**

**Quality and efficiency**

- Outpatient appointments rescheduled and spaced out - patients seen quicker and staff have more time to spend with them.
- Long-term follow-up appointments shifted to a separate general clinic - more time for staff to focus patients with more immediate needs.

**Patient safety**

- Review of training needs on post-surgical ward and new tracheostomy learning pack.
- Role of health care assistant being extended to include stoma care - more staff with right skills to respond to tracheostomy patients on a routine and emergency basis.

**A better experience for patients and staff**

- New location for post-surgical ward, to include more rationalised storage for equipment and new day area for patients - alternative place for patients and carers to sit and easier access to equipment for staff.
- New mirror with light purchased for ward - easier for patients to clean and look after stoma and feeding tubes.
- Dedicated quiet time on ward after lunch - better environment for sleep and rest.
- Patients and staff reorganised outpatient clinic - pleasant, less stressful environment.
- New patient info packs and better information for those with feeding tubes (both done by patients) - patients have the information and reassurance they need, when they need it.