

Patient testimonies on IP1877 Electrical stimulation of the pharynx for neurogenic dysphagia

On 30/05/2023, Helen Crosbie (NICE public involvement programme) spoke to two people who had been treated at two separate centres with electrical stimulation of the pharynx for neurogenic dysphagia, below is a summary of their testimony.

Patient S:

S was Nil by Mouth since January 2023, following admission to critical care with a serious spinal injury. She required a tracheostomy and also had recurrent aspiration pneumonias. She required non-oral feeding via an NG tube, and did not demonstrate any significant rehab potential following usual treatments provided by Speech and Language Therapy (SLT). She presented with significant low mood as a result of her poor swallow.

S's SLT suggested that S uses pharyngeal electrical stimulation (PES). The stimulation was provided for 6 days in total, for 10 minutes each day. S reported that, initially, the sensation of the stimulation was 'strange, but [she] carried on as it seemed worth it'.

S reported that all she wanted was a 'glass of ice cold water'. Following the treatment, she was reassessed by the SLT and deemed safe to commence all oral intake, including crisps and normal, thin fluids. Her feeding tube was removed and she could finally have the water she longed for!

As a result of being able to eat and drink, S has increased motivation to participate in her rehabilitation. She now has control over some aspects of her life again, by being able to choose what meals she has. This small piece of independence has been life-altering for her. Her occupational therapy now provides functional goals in cutting up food with cutlery; all

of which is something which she says she wouldn't have done if she wasn't able to swallow, eat and drink. S says that the treatment is a 'miracle' and 'this should be available in every hospital'. S says if she hadn't tried electrical stimulation she would definitely still be Nil by Mouth. To other people in a similar situation she would say: "it does work, take every opportunity to get better".

Patient J:

J (36 years old) presented with severe pharyngeal dysphagia (inability to swallow) after surgery to remove a tumour pressing on his medulla (brainstem tumour secondary to Von Hippel Lindau disease; a rare genetic disorder). He remained an inpatient for two months purely due to his inability to swallow. He said he felt lost and frustrated during this time as his overall recovery and ability to be discharged from hospital was delayed due to not being able to eat or drink. His therapists had no other intervention to offer him prior to the pharyngeal electrical stimulation, and so he simply had to 'wait' to see if his swallow would recover, with no timeframe to work towards.

He said he 'would have tried anything at that point' so went with the speech and language therapist suggestion to try pharyngeal electrical stimulation (PES), which he was hugely grateful for, as he found the lack of active therapy particularly frustrating. Although this was the first time his therapist had used it and, obviously, J's first experience, he felt that the procedure "100% helped speed up" his recovery, as he returned to full oral intake after just 1 week of starting the treatment.

J said the stimulation felt "strange but not massively uncomfortable", and he reported that he felt tired after each of the treatments. J had 10-minute sessions, once a day for 3 consecutive days. He felt like this was the only option to aid his recovery.

J said it was "torture not being able to eat or drink". J also commented that he believes eating and mealtimes set structure to the day so not having that was "absolutely everything" and contributed to his determination to recover. Now back at work, J said how thankful he was to the clinicians who cared for him.

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He reported that you 'completely take for granted' being able to swallow, and that 'everything tastes incredible now', even commenting on how he devoured a portion of chips with his dad; something he didn't know if he would ever be able to do again.

J said he would '100% recommend this treatment' to someone in a similar position. J said "I really wanted to do everything I could within my control to make myself as well as I could" and was hugely grateful for the opportunity to use this treatment.