

### Mitzi- Mai's story October 2022

**Name of service:** Children's Speech and Language Therapy

**Main purpose of service:** Locala' Speech and Language Therapists (SLTs) work with children aged 0-18 years who have communication and/or feeding and swallowing difficulties.

**About the person:** Mitzi- Mai is 5 years old and was diagnosed with an 'unsafe swallow' when she was a toddler. The swallowing problems were due to a laryngeal cleft, an abnormal opening between the voice box and the windpipe. Food and drink can enter the lungs – known as aspiration – which causes coughing and choking. Mitzi- Mai's Mum Hannah talked with Locala's Engagement Team about the support they have had from Speech and Language Therapist Alyson Knights and Locala's Community Children's Nursing service. Mid Yorkshire Hospital's Children's Dietitians have also supported Mitzi.



**Being diagnosed:** Hannah explains, **“Most children with a Laryngeal Cleft would be diagnosed when they were a baby, but with Mitzi, she was an anomaly! We didn't find out until she was older. She was an unwell child with breathing problems and kept getting chest infections. She was even tested for Cystic Fibrosis.”** Hannah continues, **“She doesn't fit the book. She didn't cough. It was silent aspiration. No one suspected.”** A video fluoroscopy (an X-ray of someone swallowing) found the route of the problem.

**What happened next:** **“Mitzi had to have all drinks thickened. It wasn't a liquid anymore, it was more like a puree or a mousse.”** Mitzi became clinically dehydrated on several occasions because she wouldn't drink thickened fluids. Mitzi needed an Naso- Gastric tube fitted, so she could take liquids directly into her stomach through a tube up her nose. **“The NG tube kept coming out and we had to go to hospital each time to have it put back in. It could be 3 or 4 times a day!”** The Children's Community Nursing team taught Hannah how to safely put Mitzi's NG tube back in. **“This was massively helpful. It wasn't so traumatic for Mitzi, as we didn't have to keep going to hospital and it saved us so much time and money too! Also, it saved the NHS money, as it stopped wasting NG tubes. Sometimes in hospital it would take 3 or 4 attempts and each time needed a new tube.”** Mitzi had a PEG fitted. A PEG (Percutaneous Endoscopic Gastrostomy) is a feeding tube that goes through the abdominal wall into the stomach. She also had surgery to close the laryngeal cleft and also to have tonsils and adenoids removed.

**Drinking:** Alyson started trials of un-thickened drinks in 2021, with Mitzi first trying tiny amounts of sterile water, then gradually moving onto larger volumes and a variety of drinks and foods. Mitzi can now take these without aspirating. Hannah explains that a decision will be made later this Autumn whether Mitzi's PEG can be removed. It all depends on whether she is able to drink enough fluids on a daily basis. Hannah is very positive about Alyson, who gave advice and helped to increase Hannah's confidence **“Alyson never rushes you. She explains things amazingly.”**

**Support and care:** Hannah appreciates the level of care that Alyson has given. **“She hasn't rushed any steps. She 100% makes sure that Mitzi is safe and goes at a rate that Mitzi can tolerate. Mitzi can be stubborn! All along it's been about her safety and care.”** Hannah feels that everyone helping with Mitzi, **“sing from the same hymn sheet. Everyone is so friendly and personable. The level of care that Mitzi gets is phenomenal. I'm extremely grateful. We've never had a bad experience. Alyson and the nurses have helped Mitzi integrate into school by training school about drinks and signs of aspiration. They've helped in so many ways.”**

*Hannah spoke with Jo from Locala's Engagement Team and gives full consent to share Mitzi Mai's story.*