



# Why do Adults with Learning Disabilities need Speech and Language Therapy (SaLT) for dysphagia?

## The Problem:

Adrian has a learning disability and had a seizure and pneumonia 18 months ago. He had to be moved from a normal diet to puree texture food during his hospital stay, and had a PEG fitted. He was no longer able to walk.

Adrian was upset. He used to walk to the shops to buy a fresh warm pie, which he always used to do before getting ill. He did not want it if it had to be modified.

## The Solution:

Community SaLT sat down with Adrian and we came up with a plan. We used simple pictures to explain why the pie was too risky now but that it might be ok in future if Adrian worked with SaLT and Physio and if he would accept some hand signs to remind him how to eat safely. Adrian agreed!

Adrian started to get stronger and he was able to start walking again with help from physiotherapy. He no longer needed his PEG for food and drink.

SaLT and Adrian's carers worked together to gradually increase the difficulty of food textures to support his chewing skills as he could not follow instructions for more complicated recommendations. We started small, with snacks that only needed a very little chewing. We slowly built up to full meals and then started with more challenging food textures as Adrian's chew became stronger and stronger.

It took some time, but... Adrian has been able to walk to the shop and buy his pie! Adrian understands quite a lot about chewing and swallowing by now and he has decided that it is ok to add gravy and cut it up to make it a little easier to chew. It isn't quite how his pie used to be but he no longer minds. It tastes the same and he knows he can eat it easily.

## The Problem:

Jim has a learning disability and a brain tumour. He has been getting progressively weaker over the last six months. He gets tired when eating and he coughs increasingly.

## The Solution:

First we set up a communication system with cards to reduce the effort as his voice became weaker and quieter.

We helped Jim's sister to make his meals softer so he can manage with less effort. However, he loves jelly babies, so we worked out how he can still have them and other party-snacks at Christmas, safely.

His hospice changed his medication to liquid to make it easier, but this then made him cough. SaLTs found out the capsules could be opened and sprinkled, which was easier to manage. Drinks are made a little thicker which helps him cough less (this is not the case for everybody). He doesn't mind.

His sister understands the importance of keeping his mouth clean to reduce the risk of chest infection. SaLTs liaised with physiotherapy and community learning disability nursing colleagues to reach practical solutions that work for the family.

- In 2004, the National Patient Safety Agency (NPSA) identified dysphagia as one of the five key areas of risk for people with learning disabilities.
- Swallowing problems can result in people breathing in food or drink, which can then lead to aspiration pneumonia. The confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) identified aspiration pneumonia as a significant cause of death.
- Dysphagia has been linked to avoidable hospital admissions such as dehydration and constipation, as well as aspiration pneumonia. In addition to the significant health risks posed by dysphagia, there is also a huge impact on quality of life for individuals. (Public Health England 2016).
- People with a diagnosis of learning disability are well known to be at higher risk of choking than other people, Thacker (2007).
- Eating and drinking are fundamental aspects of people's lives. Dysphagia may prevent people from being able to enjoy the taste and textures of food they like, as well as the social aspect of shared meals. Modified meals and eating and drinking apparatus can make people feel different and excluded at mealtimes. In some cases, dysphagia can contribute to malnutrition. (Public Health England 2016)
- Expected outcomes from Specialist SaLT input in relation to dysphagia include: improved life expectancy, improved physical health, and improved emotional wellbeing. (Baker V et al 2006)

All these people and situations are real. We have made some changes to some of the detail and names to make sure people's lives remain private.

## The Problem:

Gareth has recently had two choking episodes in his bedroom, which is located far from the office and communal areas of his supported living home. He is independent enough to travel into town by himself and buy food and drink. Gareth is keen to carry on as usual and not have his life controlled by other people. Staff care deeply about Gareth and worry about him choking; so much so that they are too restrictive in the food they cook with him and the relationship is in trouble.

## The Solution:

Firstly, SaLT needed to know how much Gareth understood about eating risky foods in risky places. Would this be an 'unwise decision', or would this mean a shift in how Gareth lives his life? Gareth showed on several occasions he knew what choking on food might do to him. SaLT talked to his staff team to find out what sort of foods he wanted to eat in his room, what he liked to buy when in town and foods he was choosing at home. Gareth was making sensible choices most of the time but wanted to have food in his room still. He could choose to eat risky foods like Werther's Original, but needed to understand the consequences of his choice.

Easy-read posters to remind Gareth of sensible foods were made for his bedroom food cupboard, and a 'wallet reminder' made for him in town. The staff team organised a call alarm for him in his room in case he had difficulty, which worried them less. Gareth chose a reward when he had a week of choosing sensible foods. His support has been maintained and he eats less risky food in his room but takes more chances in public places, whilst maintaining his sense of control and independence.

## The Problem:

Jamie is a 34 year old woman with cerebral palsy and learning disabilities, referred due to an increase in coughing at mealtimes and chest infections. With her fifth course of antibiotics due to finish Jamie's breathing presented as laboured and rapid, with persistent coughing when eating and between mealtimes and she was beginning to lose weight.

Staff at Jamie's care home reported that approximately half her oral dose of medication was being lost from her mouth, due to tongue movements and difficulties with coughing

## The Solution:

On talking with Jamie's mother, it transpired that she needed regular movement and time out of her wheelchair, both key factors in maintaining good chest health. SaLT liaised with her care team to remind them of the importance of free movement for Jamie, even when she was ill.

Staff were advised to liaise with Jamie's GP to increase the dosage of antibiotics due to her oral loss. A chest x-ray was booked to confirm whether her issues related to possible aspiration or ill health.

Within one week of higher dosage antibiotics coughing at mealtimes had reduced and Jamie's health appeared to be improving, particularly in relation to her respiratory presentation. A follow up chest x-ray at two weeks confirmed no indication of long term aspiration.

Six weeks on and Jamie has gained weight, her chest is still clear, and she has had no further incidents of ill health. The most appropriate seating for her at mealtimes has been identified and incidents of coughing significantly reduced.