| Please use the space below to write down any questions you may have and bring this with you to your next appointment. |
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Mindelsohn Way, Edgbaston

Birmingham, B15 2GW Telephone: 0121 371 2000 Wolfram Syndrome and Dysphagia

PI19/2123/01 Author: Georgette Smith Date: October 2019 Review date: October 2021 **UHB** is a no smoking Trust

Building healthier lives

What is dysphagia?

Dysphagia means difficulty in swallowing, which can occur in people with Wolfram Syndrome.

It is important to recognise the symptoms of dysphagia as they can vary, and you may not experience all of them.

Symptoms to look out for when swallowing include:

- Coughing
- Wheezing
- Throat clearing
- Gagging
- Choking
- Regurgitation of food/fluid
- Wet/'gurgly' or strained voice
- Laboured breathing after swallowing
- Eye watering or colour change in the face
- Throat irritation

Why is this a problem?

Difficulty in swallowing can be very distressing. In certain cases it can lead to weight loss, dehydration and cause a chest infection or pneumonia.

What should you do if you have difficulty swallowing?

Firstly, contact your GP as soon as possible. They will refer you to a Speech and Language Therapist for assessment and advice for your dysphagia. The Speech and Language Therapist will assess your swallow with a variety of fluid and diet options and provide you with recommendations.

Whilst waiting to be seen by a Speech and Language Therapist, you may want to consider the below strategies:

- Taking small, steadily paced, sips of fluid or mouthfuls of diet.
- Trying not to talk straight after (or during) eating or drinking.
- Reduce distractions when eating and drinking.
- If you are having difficulty taking tablets, you may want to try taking them with a spoonful of yoghurt or custard to help them go down more easily.
- Make a diary of your difficulties and look for patterns of swallowing

- difficulty, i.e. does it happen on hot/cold drinks? Are particularly dry/crumbly/hard foods difficult?
- Does it happen first thing in the morning or when you are more tired?
- If you notice that particular food, drinks or situations regularly lead to difficulties with swallowing, please try to avoid these if it is practical to do so.

Please note: If you are unable to eat or drink anything at all or are having significant breathing difficulties please go to A&E or call 999