



Services for Children and Young People who have Eating, Drinking and Swallowing needs







The following slides provide an overview to clinical staff, local authorities, parent & carer groups, third sector and voluntary organisations, schools, nurseries and parent & carers about the current support, signposting, services and treatment available for children and young people who have eating, drinking and swallowing needs across Shropshire, Telford and Wrekin.

The information has been grouped together using the iThrive model, to help provide clear detail depending on the level of support or treatment the child or young person may need to access.





PREVENTION AND PROMOTION:

Skilling up staff, parents, carers, children and young people



Inspiring Social Change for all children and young people:

Swallowing Awareness Day

An annual day dedicated to raising awareness of swallowing difficulties.

www.rcslt.org



Swallowing Awareness Month

Dysphagia, or eating, drinking and swallowing difficulties, can affect a person's quality of life and can lead to other health complications



GETTING ADVICE:

Universal: Signposting, self-management, one off contact or ongoing support

Getting Advice

Aim for Parents/Carers:

- Increased understanding of child's eating and drinking skills level
- Know how to seek further help when required
- Provide reassurance
- Reduce anxiety

Aim for Child:

- Develop eating drinking and swallowing skills inline with their developmental level
- Improve enjoyment of eating and drinking
- Reduce anxiety





GETTING ADVICE:

Universal: Signposting, self-management, one off contact or ongoing support



Getting Advice

- Health Visitors and school nurses can give advice on developmental feeding issues linked to weaning and fussy eating patterns. Please contact Central Point of Access 0333 358 3654 Shropshire or 0333 358 3328 Telford.
- The Speech and Language Therapist (SaLT) eating drinking and swallowing service provides joint working opportunities, training and advice to other professionals Physiotherapy, Occupational Therapy, Speech and Language Therapists, School staff, Health Visitors, Respite staff and Carers, so that they can provide initial support to families at first contact.
- htpps://www.shropscommunityhealth.nhs.uk/chslt-eating-drinking-swallowing-needs general advice is available from the local Speech and Language Therapy service website regarding eating, drinking and swallowing issues.



Website Links – Support with eating, drinking and swallowing difficulties

www.allergyuk.org - support, information and resources regarding allergies

<u>www.arfidawarenessuk.org</u> – for advice regarding significant self-restricted feeding patterns including extreme presentation of ARFID (Avoidant and Restricted Food Intake Disorder). Parent and professional support available.

www.ataxia.org.uk - support related to Friedriech's Ataxia a neuromuscular condition

www.bliss.org.uk/parents/about-your-baby/feeding – support related to being born premature

<u>https://www.breastfeedingnetwork.org.uk/shropshire</u> - The Breastfeeding Network (BfN) is an independent source of support and information for breastfeeding women and others.

www.breastfeedingnetwork.org.uk - BFN Expressing Leaflet 2019.pdf

www.cerebralpalsy.org/information/dysphagia - support related to cerebral palsy

www.clapa.com/treatment/feeding - support related to cleft lip and/or palate

www.firststepsnutrition.org - Recipe ideas and portion sizes

<u>www.iddsi.org</u> – 'International Dysphagia Diet Standardisation Initiative' website for full facts and information regarding modified food textures and liquid thickness

www.infantandtoddlerforum.org - for advice regarding weaning and fussy eating patterns

www.jillrabin.com – adapted baby led weaning approach for children with complex needs

<u>www.livingwithreflux.org</u> – support for gastro-oesophageal reflux disorder







Website Links – Support with eating, drinking and swallowing difficulties



www.Makaton.org – signs to support mealtimes

www.musculardystrophyuk.org/conditions/Duchenne-muscular-dystrophy-dmd - support related to Duchenne muscular dystrophy

www.rcslt.org - Royal College of Speech and language Therapists website

https://redcross.org.uk/first-aid/learn-first-aid-for-babies-and-children/choking-child - along with other first aid websites information on how to manage choking in infants and children

www.nhs.uk/start4life/weaning - information regarding weaning preterm babies

www.tongue-tie.org.uk - support related to tongue tie

www.tracheostomy.org.uk/healthcare-staff/swallowing-communication-child - support related to tracheostomy

www.unicef.org.uk/babyfriendly/baby-friendly-resources/breastfeeding-resources/ - support breast feeding

www.unicef.org.uk - Bottle feeding resources





GETTING HELP:

Targeted Support: Goal focused, evidencebased and outcome focused interventions



Getting Help

Aim for Parent/Carers:

- Increased understanding of how to directly support their child/young person's eating and drinking skills
- Know how to seek further help when required
- Provide reassurance
- Improve parental/carer problem solving skills related to their child/young person's eating drinking and swallowing difficulty
- Reduce anxiety

Aim for Child:

- Develop eating drinking and swallowing skills inline with their developmental level
- Where appropriate increase understanding of their eating drinking and swallowing difficulties
- Establish/maintain a safe swallow by reducing the risk of aspiration (liquid or food going into the lungs)
- Improve enjoyment of eating and drinking and reduce anxiety
- Improve/maintain independent eating and drinking skills



GETTING HELP:

Targeted Support: Goal focused, evidencebased and outcome focused interventions



Getting Help

Telephone consultation to provide advice. This is followed up with advice in an email provided as a single contact.

Initial appointment for eating drinking swallowing assessment may include:

- Asking about the past history, experiences and medical background
- Observing their eating drinking and swallowing skills
- Listening to the swallow using a stethoscope placed on the neck
- Advice
- Referral on to other services (Consultant, Dietetics, Occupational Therapy, Physiotherapy, etc)
- Discharge after single contact OR may require review appointment(s)

Self-restricted feeding patterns workshops for parents and carer – This is a single two hour workshop delivered online providing information and strategies to families and professionals to support children and young people with sensory-behavioural feeding issues



GETTING HELP:

Targeted Support: Goal focused, evidencebased and outcome focused interventions



Getting Help

Advice may cover some of the following areas:

- Moving onto more challenging textures
- Pacing and packing
- Modified diet IDDSI [International Dysphagia Diet Standardisation Initiative]
- Develop oral motor skills e.g. chewing, lip closure
- Sensory messy play, expanding sets, reduce pressure while providing opportunities
- Reflux management in collaboration with the medical team
- Nutrition in collaboration with the dietitian
- Seating and positioning in collaboration with the Physiotherapy or Occupational Therapy services
- Information regarding utensils in collaboration with the Occupational Therapy services
- Independent feeding skills in collaboration with the Occupational Therapy services



GETTING MORE HELP:Specialist Support/Extensive treatment



Getting More Help

Children and young people with medically complex eating drinking and swallowing difficulties may require:

- Multiple appointments
- Frequent reviews
- Support with graded progression to develop oral motor skills
- Multidisciplinary liaison/discussion/appointments Consultants, Community Children's Nurses, Dietitians, Health Visitors, Occupational Therapists, Social Workers, Specialist Nursery Nurses, Speech and Language Therapists, etc
- Written guidance for how to support the individual establish/maintain a safe swallow by reducing
- the risk of aspiration (liquid or food going into the lungs)
- Training for carers related to reducing risk of aspiration and modifying food textures and liquid thickness
- Referral to other professionals



GETTING RISK SUPPORT:

Acute: Risk management and crisis support



Getting Risk Support

In collaboration with the multidisciplinary team around the child/young person, management of:

Enteral feeding – nasogastric tube, nasojejunal tube, gastrostomy

Eating and drinking with acknowledged risks

Referral for videofluoroscopy swallow study (moving x-ray of the swallow)

Referral for psychological support related to eating drinking and swallowing difficulties

Advocate referral to specialist multidisciplinary traded services for Avoidant Restricted Food Intake Disorder (ARFID)



Glossary:



Gastrostomy – a method of giving nutrition without having to eat or drink orally. A tube is inserted directly into the stomach through the skin. Training is required to feed a child/young person with this method. Also known as a PEG

Nasogastric tube – a method of giving nutrition without having to eat or drink orally. A tube is inserted down one nostril into the stomach. Training is required to feed a child/young person with this method.

Nasojejunal tube — a method of giving nutrition without having to eat or drink orally. A tube is inserted down one nostril through the stomach into the small intestine. Training is required to feed a child/young person with this method.

VFSS – videofluoroscopy swallow study – a moving x-ray which allows the medical team to identify the safety of the child/young person's swallow and plan management of safe oral food and/or drink intake





