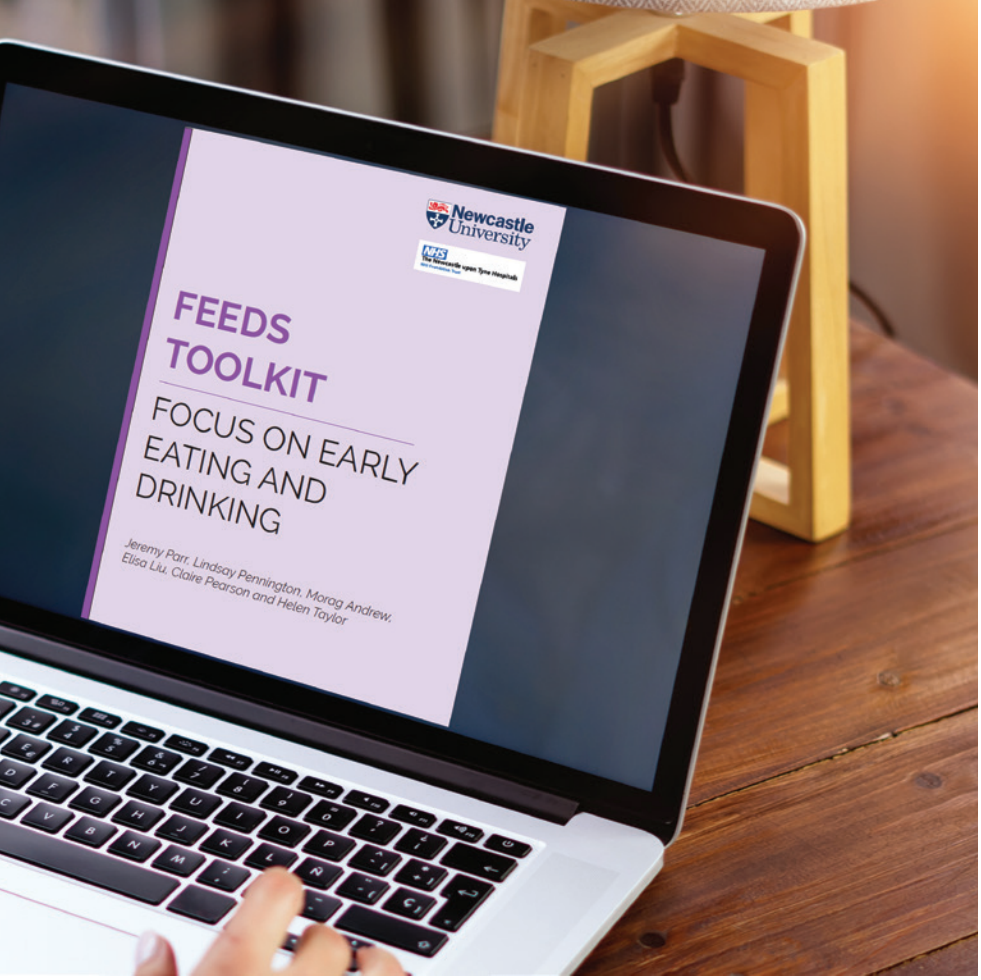
**ELISA LIU**
Speech and
Language Therapist

**LINDSAY PENNINGTON**
Speech and
Language Therapist

**MORAG ANDREW**
Consultant
Paediatrician

**JEREMY PARR**
Consultant
Paediatrician

# Introducing the new evidence-based resource for shared decision-making with parents of children with eating, drinking and swallowing needs



FEEDS TOOLKIT

FOCUS ON EARLY EATING AND DRINKING

Jeremy Parr, Lindsay Pennington, Morag Andrew, Elisa Liu, Claire Pearson and Helen Taylor

> Parents stressed the importance of having a Toolkit of interventions that a healthcare professional could introduce them to – the FEEDS Toolkit.

Children with eating, drinking and swallowing (EDS) difficulties as part of a neurodisability or neurodevelopmental condition often face significant challenges with nutrition, growth, and mealtime participation. Inadequate nutrition can affect growth, hydration, energy levels, and overall health and development. There may be specific concerns about swallow safety, sensory-based feeding challenges, or gastrointestinal and respiratory health. Parents report stress related to EDS, and anxiety about what the future may hold, whilst navigating potentially complex care pathways, limitations in services offered, and waiting lists that may delay the support needed.

These difficulties can affect many aspects of family life. Difficulties engaging in mealtimes at home and elsewhere can impact quality of life for children and their families. For example, mealtime challenges can result in families being unable to eat outside of the home or affect wider family willingness to help care for a child around mealtimes, leading to reduced social networks or support for a child and their family.

Families report a lack of reliable information about EDS difficulties and interventions, and would value access to reliable resources. Shared decision making is an important part of personalised care and intrinsic to our professional standards.[1] Accessible resources are required to facilitate this.

The **FEEDS Toolkit** was developed to address this gap. Co-produced by parents and a multidisciplinary team (MDT) of speech and language therapists (SLTs), paediatricians, a dietitian and a clinical psychologist, the FEEDS Toolkit brings together evidence-based interventions for early feeding difficulties in a format designed to support collaborative, personalised care.

This article explores the clinical context for the FEEDS Toolkit, the evidence behind it, and how it can support MDT working. It also draws on parent and professional experiences from a small quality improvement (QI) evaluation within a Trust, that provides initial evidence of its feasibility, acceptability and utility in routine practice. More than 200 healthcare professionals from over 40 NHS Trusts have now been trained in FEEDS Toolkit use. At the end of the article there is information for those interested in being trained to use the FEEDS Toolkit with subsequent free access to the materials.

## Evidence for resources to support shared decision-making

The *Focus on Early Eating, Drinking and Swallowing* (FEEDS) Review looked at what EDS interventions are available and can be delivered at home by parents of young children with neurodevelopmental conditions.[2] Through an evidence review, surveys and workshops with parents and professionals, the study identified **evidence-based interventions** addressing both physical and non-physical (e.g. sensory and behavioural) issues for children with EDS difficulties.

Parents and professionals agreed that they needed a Toolkit to bring together all the information to support shared decision-making. This led to a core multidisciplinary team of SLTs, paediatricians, a dietitian and a clinical psychologist, alongside local parents and professionals, co-producing the Toolkit. Participating parents had varied experiences and backgrounds. The professionals included a range of allied health professionals and education staff supporting pupils with EDS difficulties in school. Feedback from parents and professionals informed all aspects of the Toolkit, including the content, organisation, and visuals. Further work has described how intervention use varies by neurodevelopmental diagnosis and professional role, and how this informed the Toolkit's development.[3]

## What is the FEEDS Toolkit?

The FEEDS Toolkit is designed to support shared decision-making by helping families understand the rationale behind interventions and how to implement them safely and effectively at home. The Toolkit is an A4, full-colour booklet designed for ease of use. It includes:

- **Intervention summaries:** evidence-based approaches drawn from the FEEDS Review, for example, 'Enhancing Diet', 'Scheduling of Meals' and 'Graded Exposure to New Food'.
- **Background context:** key considerations about paediatric EDS and early feeding.
- **Visual aids:** diagrams, icons, and illustrations.
- **Reproducible action plan templates:** for completion by parents and professionals working together.

## Introducing the Toolkit to a family

During the co-production process, parents stressed the importance of a professional introducing the Toolkit to families, ensuring shared decision-making personalised to each child. Parents can be directed to the interventions most relevant to their child, or most useful sections of information in the Toolkit. Using the Toolkit, parents and healthcare professionals can jointly agree and prioritise which interventions to use at any given time and create a personalised action plan.

Parents and professionals have highlighted that timing is important; for example, some families may feel unable to engage with the Toolkit effectively at certain times in their child's health journey. However, it can help structure conversations, clarify options, and support parents to feel more confident and informed.

> Parents described the Toolkit as helpful, reassuring and easy to use.

## Supporting broader conversations

Parents agreed that the Toolkit should be kept by families to aid discussions and share information with other healthcare professionals and caregivers. For example, parents have told us the Toolkit has helped them explain their child's needs to other family members and nursery/school settings, supporting more consistent implementation of strategies across home and education environments. It can also support professionals working with a holistic approach, for example by providing an overview of different interventions from different disciplines. It may also help with multi-disciplinary working and accountability between different professionals when there are clear aims and interventions written down for a child, especially if these are accessible to everyone supporting a particular child.

In the words of a dietitian who took part in our quality improvement (QI) evaluation (see below) "*The action plan including dietitian advice and SLT advice was a nice way of referring back to current goals and interventions. As a dietitian, you often get asked for advice from SLT, so the action plan helped*".

## Toolkit user experiences from our NHS quality improvement (QI) evaluation

The aim was to explore whether parents and professionals used the Toolkit, found it easy to understand, and felt it supported shared decision-making around EDS interventions.

We used a **mixed-methods** approach of **pre- and post-Toolkit questionnaires** for parents and professionals, and **semi-structured interviews**.

Participants included **three SLTs** trained in the FEEDS Toolkit, who used the Toolkit with **six parents** from six families. We also interviewed some of the professionals who had worked as part of each child's MDT: a dietitian and a play specialist. The children all had mixed physical and non-physical EDS difficulties, neurodisability conditions, and received support from multiple healthcare and education professionals.

## What we found

Questionnaire responses indicated that the Toolkit helped to increase parents' understanding of interventions that may be appropriate for their child, and their satisfaction with their level of involvement in selecting interventions. SLTs reported that parents' understanding of EDS interventions, participation in decision-making, and satisfaction with and implementation of strategies increased following Toolkit use.

Parents and professionals together reported that:

- information in the Toolkit was **useful** and **easy to understand**
- they all used the Toolkit to varying degrees, with some using it regularly
- most would like to **continue using** the Toolkit in the future.

Parents described the Toolkit as helpful, reassuring and easy to use. One parent commented:

*"Just the little things we've been able to put in place have really made a big difference."*

Another parent valued being able to revisit the information:

*"I could check how we were implementing interventions, read more about what might help, and then ask the SLT."*

Professionals found the Toolkit to be a valuable resource to support structured personalised care. They appreciated having *"all the information in one place"* and felt it helped formalise feeding plans and make strategies more "*concrete*" for families. One clinician noted, *"I really like the content,"* while another said it was *"very useful"*.

Professionals thought that timing was key; introducing the Toolkit too early, especially before a discussion about a neurological or neurodevelopmental condition, could overwhelm families. Overall, clinicians valued the Toolkit but emphasised the need for tailored use and professional guidance.

## What this means

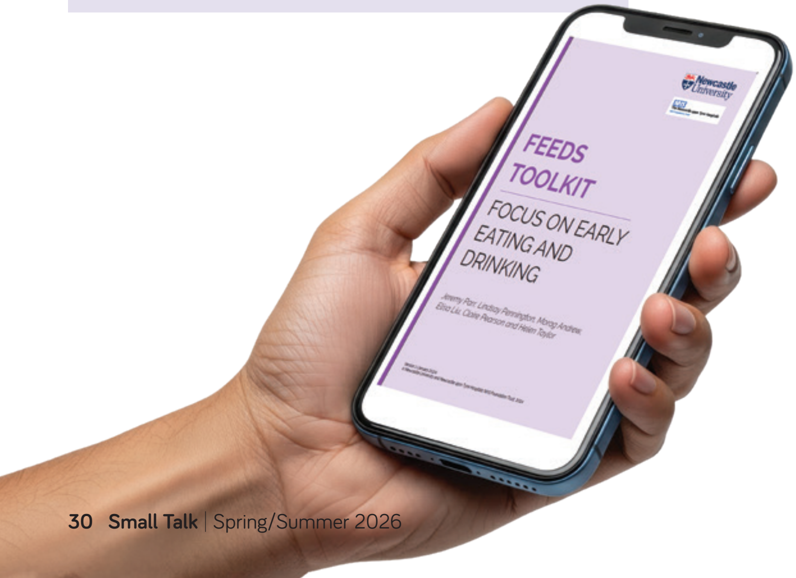
Overall, parents and health professionals found the Toolkit easy to understand and helpful in joint decision-making around interventions for eating and drinking. The FEEDS Toolkit is unique and low cost, and this NHS evaluation shows it is **feasible** to use in NHS services, **acceptable** to parents and professionals, and considered **useful**. Most participants thought they would continue to use the Toolkit in the future.

## Tips for using the Toolkit with parents:

- **Take a little time to introduce the Toolkit**, explaining what it is, why it might be useful and how you and they can use it together.
- **Direct parents to the relevant section(s)** for them at that time. Make it clear they do not have to read it cover to cover.
- **Highlight or write down page numbers** with parent carers in the Toolkit itself: there are blank note pages and action plans you can use. Action plans can be added to a child's health record.
- **Keep a printed Toolkit with you** to share with a parent during appointments.

After introducing the Toolkit to one parent, they emailed the SLT afterwards with a list of ideas to discuss and the following feedback:

*"I just want to say that this booklet is amazing....it's really got me looking and thinking about everything. This is going to be great for parents!... I can't wait to see what progress we can all make together. It's got me really excited again!"*



## Training and access

The FEEDS Toolkit is available through a low-cost two-hour online training course. This is open to all professionals involved in shared decision-making around EDS. Individuals from a range of disciplines and from more than 50 UK and international organisations have already been trained, including more than 40 NHS Trusts. We are producing additional supporting content over time: an infographic for professionals is already available.

We are also seeking collaboration opportunities, including translation partnerships to broaden accessibility, and collaborations for clinical evaluation studies, so please contact us to find out more.

**Elisa Liu and Lindsay Pennington, SLTs**

**Morag Andrew and Jeremy Parr, Consultant Paediatricians**

Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University

FEEDS@newcastle.ac.uk

## Find out more

Learn more about the FEEDS Toolkit training:
**go.ncl.ac.uk/FEEDStraining**

## References

**1.** *NHS England [Online]. 2025. www.england.nhs.uk/personalisedcare/shared-decision-making/why-is-shared-decision-making-important [Accessed Feb 2026].*

**2.** *Parr, et al. Health Technol Assess. 2021;25(22).1-208.*

**3.** *Shaw, et al. BMJ Paediatr Open. 2024;8(1):e002394.*