

How to talk about uncertainty with families of infants & young children with unilateral hearing loss

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Introduction



- A diagnosis of unilateral hearing loss (UHL) in infants and young children leads to significant **uncertainties** for parents: **"What does UHL mean? What is the right thing to do? Do interventions help?"**¹
- Good communication about uncertainty supports informed decision making, builds trust, reduces misunderstanding and can improve patient outcomes^{2,3}
- Aim:** To present an overview of learning from our previous research ^{1, 4, 5, 6} & relevant literature to guide clinicians when discussing uncertainty relating to UHL with parents

Talking about uncertainty

What influences uncertainty?

Parental trust in professionals (↓UC)



Child is **asymptomatic** & responds to sound (↑UC)



Mismatch between parental observations of their child & professional information and advice giving (↑UC)



Parents' **ability to seek additional information** (↓UC)



How much **value** parents put on **scientific & medical information** vs their own or others' **experiences** (↑ ↓ UC)

Ambiguity in the research evidence on prognosis (↑UC)^{7,8}



UHL is **invisible**, so parents don't understand what it means for their child, now or in the future (↑UC)



Child is **pre-verbal**, so parents can't assess any impact on speech (↑UC)

Parents awareness that there is **geographical variation** in service provision & options (↑UC)



Lack of research and **ambiguity** in evidence on effectiveness of interventions (↑UC)

- No trials** on effectiveness of interventions in babies & pre-school children with sensorineural UHL⁵

- Ambiguity** in results of trials on effectiveness in older children^{5,9,10}



- Observational evidence does **not show a benefit** of hearing aids for young children with UHL¹¹

Parents **continue to monitor** their child's behaviour & speech development with/out a hearing aid and compare whether this **matches** (↓ UC) or **doesn't match** the information given in clinic (↑ UC)



Worsening of hearing (due to progressive loss or glue ear) (↓ UC)



Testing



Sharing the news



Prognosis



Discussing interventions



The future



Recommendations

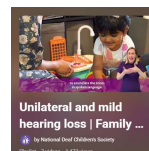
Prepare parents that they may be faced with uncertain outcomes after testing:

"Several things are unpredictable right now – this means I may not have all the answers for you"

Recognise that for some parents, discussing uncertainty is **positive** and can **drive information seeking and action**. For others, it may be perceived **negatively** and as a **threat**

Provide access to **peer support** and **health experience resources** to hear other parents' stories

Use a hearing loss **simulator**



Acknowledge the **type of uncertainty**: **Natural unpredictability of children's development & Limits in current knowledge**

"There's still a lot we are learning about unilateral hearing loss, so we can't be certain about the long-term outlook"

Present **potential scenarios** (best case, most challenging, most likely) to facilitate sense of **hope**

Acknowledge the **type of uncertainty**: **Limits in current knowledge**

Practice **shared decision making**

Explain there are **trade-offs** to make

Present **pros and cons** of the options
Explore parents' **attitudes to hearing aids**

- Fear of stigma or discrimination
- Good support for those with additional needs & visual reminder

Be **honest** about disbenefits



	Pros	Cons
Positive communication	✓	✗
Hearing aid – soft band	✓	✗
Hearing aid – air conduction	✓	✗
Remote microphone	✓	✗

Explain that plans can **change**, so **"Let's make a plan for now"**

Check parents' **emotional responses**

"Many people find it difficult to hear there is so much uncertainty. How do you feel about hearing all of this?"

Discuss the **future** & give resources on potential changes/actions eg UCL **podcasts**



References