

### **Parents' feedback about their experience of tongue reduction surgery**

The families are contacted 6 weeks after their child had had tongue reduction surgery for their feedback about the preparation for surgery; the surgery; their stay in hospital and their child's post operative recovery. Below are some of their recent comments and tips.

"We have had great support with brilliant communication from start to finish. The BWS service coordinator was very good at keeping us informed about all the steps/appointments along the way."

'We found the initial speech and language assessment very informative, thorough and helpful. In particular, the information about after care including feeding post-op was very helpful'

"The speech and language therapist showed us videos of children before and after surgery. This was very reassuring as we could see for ourselves how well the children can do with surgery and this made me less anxious. "

"Definitely prepared for surgery – everything was explained in detail at the appointments by the speech and language therapist, the doctors and the Clinical Nurse Specialist (CNS)."

"Leaflets were the most useful so we could refer back to them and they included all of the information we needed"

At the pre-op appointment with the CNS, we were given medicine syringes to take home to help with drinking water after surgery. We made a game of it for our daughter so that she got used to using them before coming in which worked well.

"We found this book really helpful for preparing our 3 year old daughter for surgery"

- Katie goes to hospital (this is not related to tongue reduction surgery, but introduces children to what happens in hospital).

There were other BWS children having tongue reduction surgery on the ward at the same time, which was helpful as we got to chat with other families going through the same thing.

The day after the operation was tough but it did get better each day.

When we needed to ask questions, we felt we could. Everyone was very nurturing.

"When we went home after the surgery, it was reassuring that we could call or email the team photos if we had any concerns."

"Can't praise the service enough. Happy from start to finish. Everyone at GOSH seems to do so much more".

We are pleased that our son had the surgery and thrilled with the results, we do not have any regrets about having done this.

Some parents have written about their experience in more detail – [click here for their stories](#)