

**Multidisciplinary Macroglossia Service for Children with  
Beckwith-Wiedemann Syndrome Clinic**  
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Dear Parents,

We hope you find the following information useful for the upcoming admission for your child's tongue reduction surgery.

If your child is not weaned off a baby bottle, or not yet comfortable with purees, please let the admissions coordinator know on extension 0190, as this influences your child's preparation for and timing of surgery.

If you have any questions, please do not hesitate to contact myself or a member of the team. You will also be able to ask any questions at your pre-op assessment appointment with the clinical nurse specialists.

Yours sincerely,



Claire Yule  
Coordinator for the Macroglossia Service for Children with BWS.  
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### **Getting your child ready for surgery:**

- After surgery your child will not be able to suck from a bottle or breast feed for a few weeks while the tongue is healing. You will therefore need to get your child used to drinking in other ways so that they are not solely dependent on the breast or bottle. Good alternatives are a medicine syringe, an open cup, or a sports water bottle where you can squeeze liquid gently and slowly into your child's mouth.
- Your child should also be comfortable with having smooth pureed foods (with no lumps) as this is the texture that your child will find easiest after surgery.
- It is helpful for your child to be used to drinking water as it is used to keep the mouth clean.
- If your child sucks a dummy, they should be weaned off this prior to the operation.
- You will need to bring your child for a pre-admission appointment to make sure that they are fit for surgery, any tests required are done and any paper work including consent is completed.
- You will be called the day before admission with the time that you need to check-in and which ward to go to. Usually it is Woodpecker ward. You will also be told of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic.
- It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.
- Read the tongue reduction surgery in Beckwith-Wiedemann syndrome leaflet which you may have already - it's available to download from the GOSH web (<http://www.gosh.nhs.uk/medical-information/procedures-and-treatments/tongue-reduction-surgery>). This provides more detailed information about preparation for surgery, the surgery, and caring for your child after the surgery.

**What to bring:**

- Dark coloured, loose clothes for you to wear (enough for a week)
- Clothes for your child, but they do get a gown to wear if you want
- Bibs, muslin cloths and wipes for your child
- Your child's favourite puréed foods
- Your child's drinking cups, some medicine syringes, food, a soft coated feeding spoon and bowl
- Lip balm for dry lips
- A buggy for walking in and around the hospital area
- Your child's favourite books and toys
- Comfort blanket if your child uses one, however it can't go in the mouth for a few days!
- Preferred brands of medications if needed, eg Calpol, Nurofen etc
- Snacks and drinks for yourself – tea and coffee are available on the ward

**What to expect on the day of your child's operation:**

- Check in to ward, usually Woodpecker.
- Both parents are able to go to the anaesthetic room when your child is going to be put to sleep.
- After the operation and once your child is stable, you will be called down to the recovery room. Two adult members of the family are allowed in at any one time. Your child might be upset and drowsy when you arrive and there might be some blood in and around their mouth.
- Once your child has recovered safely you will return to the ward which you will be on for the rest of your stay. This is usually Peter Pan ward.
- Only one parent is able to stay with your child on the ward. If you contact Weston House (0207 405 9200 ext 7977) they will be able to give you a list of nearby available accommodation.
- One of the Plastics Clinical Nurse Specialists will visit your child on the ward after their operation. If not one of them will visit the next day but not over the weekend.

**Other information:**

- If you are travelling a long distance from home it might be possible to arrange to stay in the Patient hotel the night before your admission (speak to the admissions coordinator to organise this – 020 7405 9200 ext 0190).
- The ward has a kitchen for parents to make tea, coffee and other drinks but the ward does not provide food for parents.
- There is also a freezer, so it is possible to store home-made puréed food for your child and heat it up when required.
- Parents have a chair pull out bed if they are in the main ward, parents have a z bed if their child is in a cubicle.
- There is also a bathroom that the parents can use.
- On Peter Pan ward visiting hours are 10am to 8pm but if you are on a different ward you will need to check visiting time with the staff as they may be different.