

# Tongue reduction surgery in Beckwith-Wiedemann syndrome

A close-up photograph of a baby with light brown hair and blue eyes, sticking out its tongue. The baby is wearing a blue and white horizontally striped long-sleeved shirt and is holding onto a light-colored wooden railing. The background is a plain, light grey wall.

Information for families

Great Ormond Street Hospital  
for Children NHS Foundation Trust

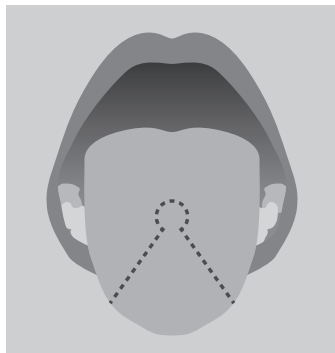
**This leaflet explains tongue reduction surgery, what to expect when your child comes to Great Ormond Street Hospital (GOSH) for the operation and provides practical advice on preparing your child for the surgery and recovering afterwards.**

## **What is tongue reduction surgery and why does my child need it?**

Some children have a large tongue (macroglossia). It can cause difficulties with feeding, breathing, drooling, speech, the position of the teeth and jaw and may affect your child's facial appearance. Tongue reduction surgery will help overcome the difficulties caused by having a large tongue by making it smaller. The decision as to whether your child will benefit from surgery is made by a team of specialists, which includes a surgeon, a specialist speech and language therapist and an orthodontist if your child has teeth present. The speech and language therapist will assess the effect of the large tongue on your child's feeding skills, speech and mouth movements and an orthodontist will assess your child's teeth and jaws.

## **Is there anything that I should do before the operation?**

Your child will not be able to suck from a bottle or breast feed immediately after the operation while the tongue is healing so it will be helpful to get them used to an open cup and not dependent on a bottle. It would also be an idea to get them to try taking liquids from a medicine syringe and a soft silicone-tipped spoon, as they might find these easier ways to drink after the operation initially. Your child should also be comfortable with having smooth puréed foods (such as smooth yoghurt without bits) as this will be the texture offered in the days after surgery. It will also be helpful for your child to be used to drinking water as water is used to keep the mouth clean. If your child sucks a dummy or pacifier, it is recommended that they are weaned off this prior to the operation.

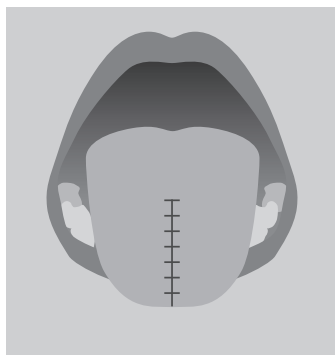


## Diagram of a tongue reduction procedure

The aim of the surgery is to reduce the length and width of the tongue so it sits comfortably within the mouth.

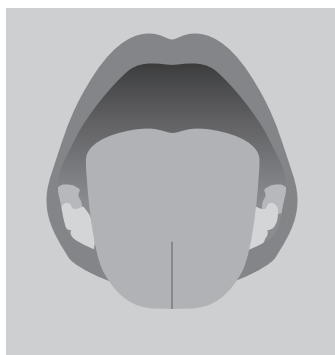


The nerves of the tongue are left intact.  
The ability to taste food is not affected.



Three layers of stitches are placed in the muscle and mucosa of the tongue.

The stitches are dissolvable and usually fall out 1 to 3 weeks after surgery.



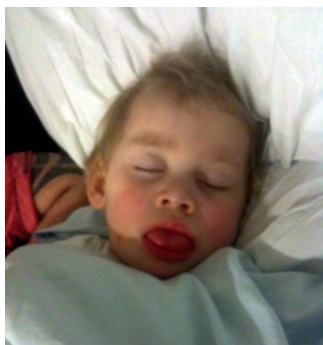
It will take several weeks for the swelling of the tongue to disappear after surgery.

Once the tongue has healed, there is minimal scarring or no scarring on the surface of the tongue.

## What happens before the operation?

You will receive information on coming into hospital with your admission letter. You will need to bring your child for a pre-admission appointment. The purpose of the appointment is to make sure your child is fit for surgery, any tests required are done and paper work completed. This is so you can come to the hospital on the day of the operation. The medical staff will explain the operation in more detail and discuss any worries you may have. Your consent for the operation will be taken at the pre-admission appointment if this has not already been obtained.

Where possible, we advise you to keep your child away from people who have colds, flu or other infections in the weeks running up to the operation. This will reduce the chance of the operation being postponed if your child is unwell.



Ava had tongue reduction surgery at GOSH when she was two years old.

## What does the operation involve?

The surgeon will carry out the operation while your child is under a general anaesthetic. The operation will usually last for under an hour, but you should expect your child to be away from the ward for about two hours, as time is needed before the operation to prepare them for the anaesthetic, and afterwards until awake.

The surgeon reduces the size of the tongue using a keyhole procedure (see diagram). The wound is closed with dissolvable stitches and these take between one and four weeks to gradually disappear.



## Are there any risks?

Swelling of the tongue can occur in the first few days after the surgery. This can occasionally make breathing difficult. The ward staff will monitor your child's airway after the operation.

Infection and bleeding can occur.

Antibiotics may be given at the end of the operation to prevent infection occurring. Increased saliva in the mouth after the operation can give the impression that there is more blood than there actually is.

There is also a small chance that some of the stitches may come un-done. If this happens, a doctor will decide if another short operation is needed to re-stitch the tongue. If this happens it should not cause any long-term problems.

## How will my child eat and drink after the operation?

If your child drinks from a bottle with a teat or is breast fed, this will not be possible for at least a couple of weeks after the operation because they will not be able to suck while the tongue is healing as it will be swollen. A feeding tube called a nasogastric tube (NG tube) is passed through the nose to the stomach in theatre. Your child may be given liquid and pain relief via the NG tube for the first few days after surgery. It is a good idea to keep the tube in place until your child is eating sufficient quantities by mouth before removing the tube.

When your child is ready, they may find it easier to drink from a medicine syringe, medicine cup or sports water bottle or sometimes liquid from a soft silicone-tipped spoon may be best.

Runny purées from a spoon are the easiest food to eat after the operation. Please bring a variety of favourite foods such as fruit/vegetable purées, yogurt, jelly, custard and so on. You will also need a soft spoon with a deep enough bowl to hold a runny purée. Salty and acidic food should be avoided as these can cause discomfort. The temperature of food should also be cool to lukewarm in the first three to five days while the tongue is healing.

It will also help if you bring the spoon, bowl and cup that your child usually eats from, as familiar things will be comforting after the operation. Feeding will take much longer for a couple of weeks following the operation. It may be best to give your child smaller meals more frequently. Try to keep mealtimes calm and relaxed and do not force your child to eat. If you are at all worried about feeding your child after the operation, please ask us to help.

It is advisable to have a smooth purée for the first week and a smooth diet for the second and third week. See pages 10 & 11 for a list of food suggestions following the operation.

It will also help if you put your child's baby bottle temporarily out of sight until your child's tongue has healed enough for your child to be able to drink from the bottle without it hurting.

When their tongue has healed sufficiently to be given the bottle again, it will help if the bottle is a soft silicone squeezable one such as a MAM® or Vital Baby® Nurture bottle with your child's normal teat. At first, gently squeeze very small amounts of liquid, pausing between each squeeze to give your child time to swallow. If your child coughs or shows any sign of discomfort during bottle feeding, stop and return to other methods of giving your child liquid.

## What medications will my child receive?

Your child's tongue will be sore after the operation, but the ward staff will monitor your child's pain on a regular basis and give the appropriate medication. Pain relief medicines will be given at regular intervals for approximately one week. The recommended pain relief is usually a combination of ibuprofen and paracetamol taken at different times. If stronger pain relief, such as morphine, is required, ward staff will arrange this.

Pain relief should be given 30 to 60 minutes before a feed to make eating and drinking more comfortable. If your child has a preferred brand of ibuprofen or paracetamol, please bring this with you. Your child will need to continue pain relief at home until their routine returns to normal.

## What else can I expect after the operation?

- Drooling will be increased for at least a week after the operation. It is a good idea to bring lots of bibs, muslin cloths, wipes and tissues to hospital.
- The tongue will be swollen and not be very mobile after the operation until it has healed.
- Your child's lips can become very dry so bring some lip balm.
- Your child's mouth will need to be cleaned regularly after the operation, but this is usually just done with water to dislodge any leftover milk or food particles. Water in a medicine syringe is often a good way to do this.
- It can be difficult to brush your child's teeth initially. If possible, use a mouthwash for the first week so that sutures are not rubbed by the brush. On the ward you can also use a mouthcare pack.
- It is normal for your child's mouth to smell for one to two weeks after surgery as this is due to the healing process.
- Once your child is eating and drinking normally and the tongue is recovering well, you and your child will be able to go home. Most children stay in hospital for approximately five days. Some children stay in hospital longer than this.
- If your child has morphine, this can sometime cause the face to be itchy. The hospital staff can give you medicine for this.
- Your child may have constipation and wind after the operation. Ask the ward staff for help if this happens.
- The tongue will be slightly thicker after surgery. This is expected following this type of surgical procedure, even after the swelling has reduced.



## When you get home

Your child may feel uncomfortable for a while after returning home but this will gradually improve. They may need continued pain relief before eating. Keep your child away from anything hard that could end up in their mouth, such as pens, keys or even hard, plastic play figures. This can be painful and could damage the healing of the operation site.

Your child will need a one week post-operative check. You can come back to GOSH for this or if you live a long way from the hospital, your family doctor (GP) may check the wound to ensure it is healing well. You can also email photos to [bws@gosh.nhs.uk](mailto:bws@gosh.nhs.uk) to be reviewed by the team.

Your child will need to come back to hospital approximately 12 weeks after the operation to check the outcome of the surgery. This appointment is to see the team who will check the tongue. Following this at approximately six months after the operation, you will be seen by the speech and language therapist who will review your child's feeding, speech and mouth movements. We will send you details in the post. After these post-op appointments your child will then be reviewed at ages four and a half years, six years, nine years, 12 years and 16 years.

### You should call the hospital if:

- Your child is in a lot of pain and pain relief does not seem to help
- Your child has a temperature of 38°C and paracetamol does not bring it down
- You are concerned about the amount your child is eating and drinking
- You notice discharge or bleeding around the wound
- The wound site starts to open or there is an unpleasant odour

### Checklist of things to bring to hospital:

- Dark coloured loose clothes for you to wear
- Bibs, muslin cloths, wipes for your child
- Favourite pureed 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
- Favourite books and toys
- Preferred brands of medication if needed
- Snacks and drinks for you – tea and coffee are available on the ward



### Appointments – for parents to complete

Please note the details of your appointments here as a reminder

One week wound review

3 month clinic review

6 month clinic review

1 year post-op review

Any other appointments

## Top 10 tips for restarting feeding after tongue reduction surgery

1. Bring a silicone-tipped spoon with you to hospital
2. Wait until your child is alert and interested in having some food!
3. Pain relief should be given up to an hour before each feed or drink. Ensure you follow the prescription guidelines.
4. Thin purées only, which have no 'bits' and are not sticky in the mouth. Avoid spicy and salty food.
5. Stick with foods and tastes that you know your child likes.
6. Tiny mouthfuls at a time! Start with swipes of purée on your child's lips and sides of tongue.
7. Give plenty of time to swallow. Parents can eat their meal at the same time to help normalise eating. Breakfast is a good one to try.
8. Eating and drinking will take much longer – this is to be expected!
9. Leave the baby bottle at home! By the time of surgery, your child will be used to having sips from a cup (a spouted cup with no valve or an open cup such as a Doidy® cup). You may also use a sports bottle or even a medicine syringe if your child is not content with a cup.
10. Read the BWS information sheet on feeding given by the Speech and Language Therapist or CNS for more details. Also refer to earlier section in this leaflet.

## Notes

## Food suggestions after operation

Here are just some food suggestions, which you may wish to give your child in the weeks after surgery to vary their diet as this will be limited to softer foods. Your child may already eat many of these foods, so these are simply ideas to broaden their choice. The food you offer will obviously depend of which foods and flavours your child already enjoys. Remember to encourage your child to have sips of water to help clean the mouth after all meals or milky drinks.

### Cereals

- Porridge or Ready-Brek® made with milk
- Weetabix®, cornflakes, Rice Krispies® well soaked in milk

### Meat and poultry

- Skinless sausages cut into small pieces
- Tender finely-chopped or minced meat in stews, hotpots or casseroles
- Finely chopped chicken in white sauce or gravy
- Shepherd's pie or cottage pie

### Fish

- Flaked fish in white, cheese or parsley sauce
- Fisherman's pie, fish cakes, fish and potato nests
- Tuna mayonnaise

## Eggs and cheese

- Scrambled or poached eggs
- Egg mayonnaise
- Soft cauliflower cheese
- Cottage cheese, grated cheese, Dairylea® triangles

## Pulses

- Mashed baked beans with grated cheese
- Mushy peas
- Lentil dhal

## Pasta and rice dishes

- Bolognese sauce over soft chopped pasta
- Finely chopped macaroni cheese or ravioli
- Small pasta shapes or noodles with different sauces, such as mushroom, carbonara, cheese or creamy tomato
- Tinned spaghetti
- Noodles
- Well-cooked rice with sauce
- Potatoes and vegetables
- Soups
- Avoid raw vegetables or whole pieces of vegetables in the first few weeks
- Soft-cooked and mashed butternut squash, swede and courgettes or parsnip, turnip and carrots - try adding extra cheese, butter or margarine.
- Ratatouille
- Mash the inside of a jacket potato with butter and add a suitable filling,

such as tuna or egg mayonnaise

- Instant or frozen mashed potato
- Dips such as hummus

## Fruits

- Stewed fruits, such as apples, pears or peaches
- Tinned fruits are also suitable if they are soft
- Fresh fruit, such as banana, peach or soft plums
- Fruit smoothies

## Desserts and snacks

- Milk puddings, such as rice pudding, semolina or tapioca
  - Yoghurt, fromage frais
  - Ice cream or sorbet
  - Jelly, trifle or blancmange
  - Mousses and whips
  - Crème caramel
  - Home-made, powdered or ready-made custard
  - Fruit fools and purees
  - Cake or sponge pudding with custard or cream
  - Chopped pieces of pancake
  - Biscuits dunked in warm drinks to soften them
  - Soft cake
- ## Drinks
- Milkshakes
  - Smoothies
  - Warm milky drinks
  - Fruit juices



**If you have any questions,  
please telephone the Plastics  
Clinical Nurse Specialists on 020  
7405 920 ext 5057 or 6945.**

**You can contact the CNS at any  
time during your stay for  
advice, help and reassurance.**

**Out of hours and at weekends,  
please contact the on-call plastic  
surgery registrar via the main  
hospital switchboard on  
020 7405 9200.**

### **Helpful tips and comments from other parents**

- The first few days are the hardest but it does get easier/ better.
- You might feel that you're never going to get through but you will.
- Prepare for the worst as it is not going to be a nice experience.
- Try to relax and get off the ward when you are able to.
- Do not feel pressured to feed - let your child take their own time.

© GOSH NHS Foundation Trust October 2016

Ref: 2016F0653

Compiled by the Plastic Surgery Clinical Nurse Specialists and the Beckwith Wiedemann Macroglossia Team in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Foundation Trust  
Great Ormond Street  
London WC1N 3JH

[www.gosh.nhs.uk](http://www.gosh.nhs.uk)