

Botulinum toxin surgery

This information leaflet explains about botulinum toxin for the bladder, including the benefits, risks and any alternatives, and what you can expect when you come to hospital. If you have any further questions or concerns, please speak to a doctor or nurse caring for your child.

What is botulinum toxin for the bladder?

This is an operation where botulinum toxin medicine is injected into the lining of the bladder. In children the treatment is given under general anaesthetic. A special telescope (cystoscope) is passed through the urethra (water pipe) and used to inject the treatment into the bladder. There are no wounds.

Why does my child need botulinum treatment for the bladder?

Botulinum toxin is a treatment that weakens the muscle it is put into.

The main benefit of this treatment for the bladder is to reduce the pressures in the bladder when it is storing urine. This is done for one of two reasons:

- To control leaking (urinary incontinence)
- To reduce pressures in the bladder that may cause damage to the kidneys

The effects of botulinum toxin will wear off 6 to 9 months after the operation. This means that the treatment will need to be repeated if it is successful.

What are the risks?

Although the operation is usually done without any problems, sometimes things do not go to plan.

There is a small risk of urinary infection. Antibiotics are given during and after the operation to reduce this risk.

Bleeding can occur, which may cause the urine to become pink or red. Drinking more fluid will allow this to be washed away. It is very rare for anyone to need more treatment such as a return to hospital, another operation or a blood transfusion (except for repeated treatment if the operation is successful).

If a child has botulinum toxin it may become difficult for them to empty their bladder. They may require a tube to drain the urine away (urinary catheter). This can either be left in place or the catheter passed and removed regularly (intermittent catheterisation).

Sometimes the botulinum toxin does not work to reduce the pressures in the bladder, your doctor will discuss this with you.

Very rarely the botulinum toxin can spread and cause weakness of other muscles in the body. If this occurs you should contact Beach Ward.

Are there any alternatives?

The most common way of dealing with high pressures in the bladder is with medicines (e.g. oxybutynin).

Sometimes treatments that stimulate nerves (neuromodulation) can help. In children this can be done with stimulators put on the skin, for example TENS machines. This may not help where the kidneys are being damaged by high pressures in the bladder.

If other treatments have not worked then more complicated operations might be considered. Examples include urine diversion (e.g. vesicotomy) and bladder enlargement (cystoplasty). These operations have important drawbacks. Your doctor will discuss with you whether these are appropriate choices for your child.

How can we prepare for botulinum toxin?

There is no specific preparation for botulinum toxin, however all children that need to have an operation involving a general anaesthetic will be asked to attend a pre-assessment clinic.

At the pre-assessment, we will make sure your child is fit for their general anaesthetic. You will also be given information about what will happen on the day of your child's operation. You and your child will get the chance to ask any questions you may have.

Please make sure you bring a list of any medication that your child may be taking, including any over-the-counter or alternative medicines.

On the day of surgery you will need to come to the ward on time so that you can meet the surgeon and anaesthetist.

Consent – asking for your consent

We want to involve you in decisions about your child's care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

What happens during botulinum toxin surgery?

Your child needs to have a general anaesthetic before they can have their operation. We'll take your child to the anaesthetic room next to the operating theatre. You can go with your child to the anaesthetic room and wait with them until they have fallen asleep. A nurse will come with you and then take you back to the ward once your child is sleeping.

The operation is performed without any cuts or wounds. A telescope is passed into the bladder and the botulinum toxin injected into the lining of the bladder.

The whole procedure, including the anaesthetic and operation, will take approximately one hour.

Once your child begins to wake up, you can come and sit with them in the recovery room while the anaesthetic wears off.

When your child is fully awake and comfortable, they will be able to go back to the ward.

Will there be any pain?

There may be some stinging when your child passes urine the first time which should settle quickly and reduce with each subsequent time your child passes urine. This can be assisted with basic pain relief medicine as advised on discharge by your pharmacist.

What happens after botulinum toxin surgery?

Your child will have regular nursing checks on the ward. It will be important to know that they can empty their bladder. Your child should be able to go home the same day.

What do I need to do after I go home?

Your child should drink well and empty their bladder regularly. They should be able to return to normal activities by the following day.

Your child's urine may have some blood in it causing it to be pink or red.

You should seek medical attention for your child if they have signs of urine infection. Signs of urine infection include needing to pass urine more frequently, increasing pain, cloudy or smelly urine and a high temperature.

You will need to seek medical attention for your child if they're not able to empty their bladder.

Will there be a follow-up appointment?

There will be a follow-up appointment with a doctor to check on your child's progress after the operation. It will be important that you fill in a bladder diary for your child and bring this to clinic.

Contact us

If you have any questions or concerns following your child's surgery, please contact Beach Ward, **t:** 020 7188 8844 (For a reply within two working days email the medical team, **e:** evelinaurologydoctors@gstt.nhs.uk)

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership



Leaflet number: 4555/VER1

Date published: March 2018

Review date: March 2021

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A list of sources is available on request