



## Botulinum toxin type A injections into the urethral sphincter for idiopathic chronic non-obstructive urinary retention

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For people with idiopathic chronic non-obstructive urinary retention caused by external urethral sphincter dysfunction (also known as Fowler's syndrome in younger women and people with female anatomy, primary disorder of urethral sphincter relaxation or high-tone non-relaxing urethral sphincter), this procedure can only be done with special arrangements. This means you'll have regular appointments after the procedure to check how well it's working or whether it's caused problems. This is because there is uncertainty about how well this procedure works in this group, and how safe it is in the long term.

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For people with idiopathic chronic non-obstructive urinary retention from all other causes, this procedure can only be done as part of a research study. This is because there's not enough evidence to be sure how well it works or how safe it is in this group. Your healthcare professional should talk to you about the research.

Difficulty passing urine or being unable to completely empty the bladder (urinary retention) can happen if the muscle controlling release of urine from the bladder (urethral sphincter) does not relax or the muscle lining the bladder does not contract. In some people, it can happen without any known cause (idiopathic) and with no physical obstruction to the urine flow (non-obstructive). In this procedure, botulinum toxin type A is injected into the urethral sphincter. The aim is to relax it and allow urine to be passed more easily, without needing to use a catheter to empty the bladder. The effects are temporary, and the procedure may need to be repeated every few months.

Using botulinum toxin type A in this procedure is an off-label use of the medicine. For more information, on off-label use see NICE's information on prescribing medicines.

You can <u>search the NHS website for information about consultants and hospitals</u> that offer this procedure.

## Is this procedure right for me?

You should be included in making decisions about your care.

Your healthcare professionals should explain the risks and benefits of this procedure and how it is done. They should discuss your options and listen carefully to your views and concerns. They should offer you more information about the procedure. Your family or carers can be involved if you want or need them to be.

You will be asked to decide whether you agree (consent) to have the procedure. Find out more about giving consent to treatment on the NHS website.

## Some questions to think about

- How many appointments will I need?
- What are the possible benefits? How likely am I to get them?
- What are the risks or side effects? How likely are they?
- Will I have to stay in hospital?
- What happens if it does not work or something goes wrong?
- What happens if I do not want the procedure?
- Are other treatments available?

## Information and support

- NICE's information on interventional procedures guidance explains what an interventional procedure is and how we assess it.
- <u>NICE's information on interventional procedures recommendations</u> explains what special arrangements are and only in research means.

Bladder Health UK, 0121 702 0820, can give you advice and support.

You can also get support from your local <u>Healthwatch</u>.

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