

Supporting people who use catheters to live their life to the fullest: *Our Calls to Action*

Campaign Objective

Most people don't like to talk about wee or toilet stuff – it's still a taboo and embarrassing subject for many people. But it shouldn't be – every one of your constituents has to wee somehow. Despite bladder problems being some of the easiest medical issues to solve, too many people live with these problems in silence. We aim to get people talking about the challenges and barriers faced by people who use catheters. In our Calls to Action, we have outlined clear solutions which will improve the quality of life for patients who use urinary catheters. These solutions will also free up precious workforce time and save the NHS money.

Why is it so important to get catheter care right?

Sadly, across the country there is significant variation in catheter care and support provided to patients, their families, and carers. This leads to significant personal challenges for catheter users, as well as real challenges for the NHS in terms of potentially avoidable spend. Catheter associated urinary tract infections (CAUTI) are estimated to cost the NHS up to £99 million per annum, or £1,968 per episode.² Getting catheter care right will not only improve patient outcomes and experience, but it will also reduce financial and resource burdens placed on an already overstretched NHS.

Background

Good bladder health is important for overall wellbeing. There are over 90,000 people in the UK who use indwelling catheters.¹ This does not include patients who use intermittent catheters and whilst published data is more limited it is estimated this is also in excess of a further 90,000 patients based on industry data. For people who need to use a catheter as a result of urinary incontinence, it is vital that there is equitable access to specialist care, advice, and support regardless of where they live in the UK. We want to drive positive change so that everyone using and living with a catheter is able to live their lives to the fullest, whatever that means for them in their individual circumstances. No one should be suffering in silence or feel unable to ask for help. Optimal catheter care means that a person is given the right catheter for their specific individual needs and that they are provided with the information and specialist support needed to use them safely. Using the most clinically appropriate catheter for self-catheterisation is crucial for reducing the risk of urinary tract infections (UTIs), which can occur when the bladder is not fully emptied and lead to considerable discomfort and even hospitalisation, in some instances. Patients need to be equipped with the right knowledge and skills if they are to safely undertake intermittent self-catheterisation and benefit from the quality of life improvements this should bring.



90,000

The amount of people living in the UK who use indwelling catheters in order to empty their bladder. This does not include patients who use intermittent catheters and whilst published data is more limited it is estimated this is also in excess of a further 90,000 patients based on industry data.



£99 million

The estimated cost of Catheter associated urinary tract infections (CAUTI) to the NHS each year.

People using urinary catheters may do so as a result of a range of conditions, such as **Multiple Sclerosis or Spinal Cord Injury**.

We believe that in order to achieve the best outcomes for all...



Healthcare professionals need to...

- › Provide optimal bladder care for people with urinary incontinence, in line with national guidelines.
- › Ensure that people requiring catheters are provided with the information and support needed to fully understand their options and that decisions on treatment and products are made in a collaborative way with patients, to suit their individual needs.
- › Provide specific support for people living with catheters to ensure patients are empowered to take control of their health and understand how to use individual treatments and products.
- › Facilitate open conversations with patients to understand their lifestyles, what is important to them and the emotional impact of their condition.



Healthcare providers need to...

- › Commission high-quality continence services that deliver the necessary joined up care and support for patients with bladder issues, including those with urinary incontinence arising from another condition, such as MS.
- › Ensure that nurses and other HCPs who support people requiring catheters have the knowledge to provide patients with optimal care.
- › Ensure people using and living with a catheter are given direct access to additional specialist support i.e., mental health support, where required.
- › Provide NHS-funded, continence care-specific education and training for new nurses.



Communities and employers need to...

- › Be educated on the impact that living with and using a urinary catheter can have on a person.
- › Recognise that as an intimate healthcare issue, people may not disclose that they are living with or using catheters, and so ensure that disabled toilet facilities are clean, spacious, and accessible. This includes providing appropriate hand washing facilities and shelves in cubicles.



Policymakers need to...

- › Commit to reviewing continence care pathways and care for every person living with / using a catheter in the community in order to tackle geographical variation.
- › Recognise the need for patient choice and a one size fits all approach does not work in intimate healthcare, which is deeply personal in nature.
- › Ensure that NHS England guidance is implemented across catheter care pathways, so that all patients receive optimal treatment and care.



Catheter users need to...

- › Feel empowered to have informed conversations with their healthcare professional about their condition, the impact on their lives and their aspirations for what 'living well' looks like to them.
- › Be able to access specialist advice and support in a timely manner to support self-care of their condition and prevention of complications, such as UTIs.
- › Receive the care and treatment that is most appropriate to their personal needs and reflects their preferences, as outlined within the NHS Constitution.³



Manufacturers and suppliers need to...

- › Ensure that healthcare professionals and people using a catheter are provided with the relevant information so that they can understand the range of products that are available.
- › Operate within the NHS roadmap milestones to deliver clinically safe products whilst aligning with the net zero goals.
- › Engage and collaborate with patients during the design of products and clinical trials

1. Gage H, Avery M, Flannery C, Williams P, Fader M. Community prevalence of long-term urinary catheters use in England. *Neurourol Urodyn*. 2017 Feb;36(2):293-296. Available: <https://pubmed.ncbi.nlm.nih.gov/26878267/> [date accessed: June 2023]

2. <https://www.england.nhs.uk/wp-content/uploads/2018/07/excellence-in-continence-care.pdf> (p8)

3. <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>