

People living with indwelling urinary catheters were asked about their experiences with the aim of learning what can be done to improve care

# Living with an indwelling urinary catheter

## In this article...

- › Problems often associated with indwelling urinary catheters
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- › Recommendations for professionals

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**Abstract** Prinjha S, Chapple A (2013) Living with an indwelling urinary catheter. *Nursing Times*; 109: 44, 12-14.

Despite 450,000 people in the UK using long-term catheters, there is very little information available about the experience. This study aimed to gain an understanding of patients' perspectives of living with an indwelling urinary catheter.

An estimated 450,000 people in the UK use long-term urinary catheters. Urinary retention or incontinence is devastating for any individual, coupling indignity with a deep sense of helplessness. Contenance care and catheters are extremely personal topics that many find difficult to discuss and there is limited medical literature or information about patients' perspectives of living with an indwelling urinary catheter.

Some health professionals have called incontinence the "Cinderella subject" – the condition no-one wants to discuss (Millard and Moore, 1996). Journalist Melanie Reid, who was fitted with a permanent catheter after a spinal injury, called it "healthcare's hidden scandal of neglect" as the design of indwelling catheters has not changed since 1937 despite catheters accounting for more healthcare-associated infections than any other medical device (Reid, 2011). As many as half of users of long-term catheters experience recurrent infections with blockages and leakages (Stickler and Feneley, 2010).

In the UK, permanent catheters are used by 3% of people living in the community and 13% of care home residents (Royal College of Physicians, 2005). These figures are

likely to rise as the population ages but people of any age or background may need a permanent catheter; multiple sclerosis, enlarged prostate, spinal cord injury and stroke are common underlying reasons.

The aim of our study was to improve understanding of living with an indwelling urinary catheter from the patients' perspective. The research was led by the Health Experiences Research Group at the University of Oxford.

## Methodology and analysis

Having obtained ethics committee approval, people living in the UK with an indwelling catheter were invited to take part in a study of personal experiences. Potential participants were recruited through urologists, specialist nurses, expert advisory panel members, support organisations and "snowball sampling" via personal contacts. We aimed for a diverse sample, including people from different social and ethnic backgrounds and age groups, and with different reasons for needing a catheter. Almost all participants lived in the community and all had used an indwelling catheter for at least three months. Participants were aged 22-96 years.

After signing a consent form, participants were asked to talk about their experiences for as long as they wished. People talked about a range of issues, including their physical and emotional experiences. After this narrative part of the interview, an interview guide was used to explore other relevant issues that had not been discussed.

Thirty-six semi-structured audio or video recorded interviews were conducted with adult patients during 2011-12. Four interviews were conducted with informal carers. The interviews lasted 1-2 hours and

## 5 key points

**1** Catheters account for more healthcare-associated infections than any other device

**2** There is limited literature on the patient perspective of having an indwelling catheter

**3** People who use catheters often experience problems, such as urinary tract infections, catheter blockages, leaking and bladder spasms

**4** Having a catheter can have a negative impact on a person's sex life

**5** Patients may have preferences over the type of catheter they use and the options should be discussed with them in detail



Having a catheter can hugely affect sexual relationships but this is often not discussed

were transcribed for analysis. The transcripts were analysed by the social science researchers responsible for data collection.

A qualitative interpretive approach was taken, combining thematic analysis with constant comparison. The data were entered into a specialist software package (NUD\*IST®, QSR N6), which was used to help organise and analyse emergent (unexpected) and anticipated themes, using the constant comparison method. More information about our research methods can be found at [tinyurl.com/health-talk-online](http://tinyurl.com/health-talk-online).

### Findings

The research shows that living with an indwelling urinary catheter can have advantages and disadvantages, but the people we interviewed said more information from health professionals would help. Information can help patients to accept and manage their own catheter. The research also highlights the need for skilled nursing care and new catheter design.

Key findings included:

- » Participants talked about the advantages of having an indwelling catheter, acknowledging it solved the problems of urinary retention and incontinence, and gave them the freedom to leave the house for social activities or work. However, they also noted the problems they had to deal with, including urinary tract infections (UTIs), catheter blockages, leaking and bladder spasms.
- » Some participants had negative or ambivalent feelings about having a catheter – they found it embarrassing or a nuisance or it negatively affected their self-image. The positioning of the suprapubic catheter was important to some women who were unsure where it would go. Lack of confidence and poor self-image can deter catheter users from having intimate relationships.
- » Most participants wanted more information after having a catheter fitted. They wanted to know how it was inserted and worked, how to secure it to the drainage bag, how to position the bag most comfortably, and the different catheters, bags and valves available. They also wanted to know more about managing the catheter on a daily basis, including information on hygiene and self-care, how much they should drink, and how to prevent problems such as UTIs, blockages and leaking.
- » People stressed that sex may still matter to catheter users and that having a catheter can really affect it. They said health professionals had not discussed sex with them or given them any

information. Men and women often noted soreness or pain during sex, and women sometimes found blood in their urine or had infections after having sex. They wanted more information from health professionals but had not been encouraged to raise the subject during consultations. Many people felt sex should be discussed more openly and not ignored by health professionals.

- » Catheter changes were a straightforward, quick procedure for most people and were carried out by a district nurse at the patient's home. For some, though, changes were painful, sometimes because of bladder spasms. People felt some district nurses were better at changing catheters than others and preferred seeing the same few nurses than a different nurse every time. Some thought district nurses and GPs lacked experience in changing suprapubic catheters and needed more training.
- » Since the introduction of the Foley catheter in 1937, its design has not really changed. People wanted a new design that would reduce complications, promote independence and be more discreet. Users who lacked dexterity hoped a new design would allow them to empty the drainage bag themselves, and a few wanted a device they could change themselves. Some felt strongly about "having a bag of urine strapped to the leg" and wanted a more discreet catheter or one that stored urine inside the body. Others stressed the importance of a catheter that helped cut the risk of UTIs, blockages and leaking, and did not cause trauma around the catheter site, soreness or overgrowth of granulation.

### Recommendations for practice

The decision to use either a urethral or suprapubic catheter should be discussed with the patient where possible. When joint decisions are made about the most effective catheterisation route, factors such as self-image, a sense of control, comfort and a desire for an intimate relationship may affect the patient's decision as much as other factors such as infection rates. To help people adjust to living with a catheter, health professionals must be sensitive to patients' individual needs and priorities.

The siting of suprapubic catheters should be discussed before surgery. If the patient decides to have a suprapubic catheter, health professionals should explain that it will probably be sited just above the pubic bone; patients should also be shown images if they would like to see them.

Patients know little or nothing about

### ONLINE RESOURCE

Our findings were used to create a free web resource featuring interviews with 36 people about their experiences of living with a long-term indwelling catheter, and four carers. Around 250 video, audio or written interview excerpts can be seen. The website can be used by patients, health professionals, policy makers, tutors and researchers.

● [tinyurl.com/Living-with-Catheter](http://tinyurl.com/Living-with-Catheter)

catheters until they need one and it can be hard remembering the information they are given when they are first fitted. Health professionals should be prepared to give patients information on: technical aspects of the catheter; preventing catheter-related physical problems; promoting self-care and self-management; sex and self-image; and social life with a catheter in place.

Having a catheter can be hard for people wanting a good sexual relationship. Patients wanted more information about sex when living with an indwelling catheter. Lack of time in clinics may mean health professionals do not discuss psychosexual concerns but, if possible and appropriate, these issues should be raised gently. Health professionals must be wary of making assumptions about who is and is not sexually active.

Good hygiene during catheter changes was important to patients but so was continuity of care, an integrated service and time to do the job properly. Training and experience were seen as important in being able to change the device efficiently. Nurses should keep up-to-date with research and attend training but, above all, listen to their patients as they know which techniques/products work best for them. **NT**

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