

# Getting *patients* on the road to acceptance

In addition to physical barriers to intermittent self-catheterisation (ISC), patients might also have psychological barriers that need to be addressed. In this article, we examine what our research has revealed about these barriers – and how you can help patients overcome them.

*“ The initial feelings were that I wanted to pee again, that I wasn't bothered about the inability to move my legs. It was more... I wanted to be able to pee, I wanted to be able to pee normally, I didn't want to have to use tubes, I didn't want to have to rely on tubes for the rest of my life”.*  
Neal

## The barriers to acceptance are many and varies

Many of you may recognise the patient reactions in the quote above. Accepting ISC can be difficult for patients, and some patients even mention that loss of walking ability was easier to accept than loss of control of their bladder and bowel function<sup>1,2</sup>.

Although the barriers patients have to ISC are as different as the patients themselves, certain concerns recur, as the statistics from our study show.

Based on our qualitative study, we believe that we can work more proactively with the patients' mind-set<sup>3</sup>.

### Patient benefits with ISC<sup>4</sup>



**69%**  
makes my life easier



**55%**  
is not my main medical concern



**58%**  
gives me the confidence to engage in social activities and events

### Patient concerns with ISC<sup>4</sup>



**33%**  
is difficult to accept



**31%**  
is something I never talk about with anyone



**29%**  
limits my sex life



**29%**  
limits how much I go out

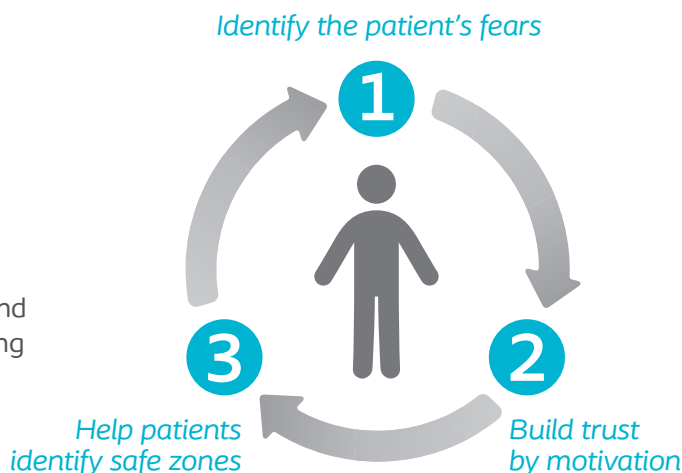
### Moving the patient from fear to trust in treatment

In the following, we present a series of steps that can help you identify fears and concerns, build trust through motivation, and establish 'safe zones' outside the hospital setting. By following these steps, you can help give your patients the reassurance and peace of mind they need to trust and engage with ISC as the right mode of treatment for them.

*"None of us are robots, everyone's different. We all have different personality traits. Some people are very much make do or mend, or get on with things or go 'Okay, that's fine. You've told me bad news, I'll get on with it. I'll deal with it.' Other people absolutely can't confront it, can't face it, can't move on to the next stage."*  
Female nurse, UK<sup>6</sup>

**Figure 1<sup>5</sup>**  
**Three-steps for achieving adherence to ISC**

This three-step model can help you address the psychological barriers a patient typically has to ISC and move the patient from fear of the treatment to trusting it as a means to living a healthy, productive life.



# 1 Identify the patients fears

No two patients are alike. Yet by understanding the general types of fears that ISC patients have, you can adapt your questioning to reveal the individual patient's concerns.

Our research indicates that fears primarily fall into four categories<sup>7</sup>. While not all of these fears will be relevant in the initial training session, they might occur at a later stage, impacting long-term adherence:

#### Fear of insertion

Many patients feel that inserting objects into the urethra is "unnatural". Often, they lack basic anatomical knowledge, and for this reason they assume it must be a very painful procedure.

*"It took me three years to convince one man to catheterise – he just couldn't make himself insert the catheter into his penis."*

Female nurse, DK<sup>7</sup>

#### Existential fear

For some patients, the catheter can be a reminder that they are ill and that their lives have fundamentally changed. Patients who fear social isolation, or who have a hard time coming to terms with their illness, may be reluctant to accept ISC.

*"Having a condition like this is like being transformed back to the early stages of childhood. Being able to walk, feed yourself, put on your clothes... being continent... all the things you would want your 2-year-old to be able to do."*  
Male user<sup>7</sup>

#### Fear of accidents

The embarrassment associated with wetting yourself can be difficult for patients to handle. This fear might lead them to reject ISC altogether.

*"Like any other woman, I hate wetting myself... it's just so nasty and embarrassing. If I know there is a high risk I will just stay home."*  
Female user<sup>7</sup>

## Fear of urinary tract infections (UTI)

More than half of the ISC users surveyed in our study indicated that they were concerned about inserting bacteria into the urethra<sup>8</sup>. 41% cite getting a UTI as a daily concern<sup>8</sup>. Such fears can pose a barrier to the patient accepting ISC.

*“ My experience is that no matter how much I wash or disinfect I can't keep the infections at bay. Unfortunately, it is just a part of my life. Every time I talk to the doctors they say, 'Remember to keep a high level of hygiene, wash your hands thoroughly before.'”*

*Male user, Denmark<sup>9</sup>*

### Try this

Ask open-ended questions to identify which fears a specific patient has. This type of questioning will help patients speak more freely about their concerns. Once you have identified their current fears, you can use the same type of questions to 'uncover tomorrow', finding out where they would like to be and what they would like to do. The final step is then to 'bridge the gap' between their current fears and tomorrow's dreams – which will enable the patient to see how ISC can help them live the life they want to lead.

Figure 2

Open-ended questions can help you identify the patient's current fears and tomorrow's dreams

## Identify today's fears

- How do you feel about your condition?
- How does it impact your life?
- How do you feel ISC will impact your life?
- How do you feel about having to perform ISC?



## Uncover tomorrow's dreams

- What would you like to be able to do?
- What activities do you enjoy?
- If you didn't have to deal with bladder issues, what would your life look like?

### Bridging the gap

Did you know that if you do 'x', it can make it possible for you to do 'y'?

**Scenario** – A patient has told you that he is having difficulty accepting his condition. He feels isolated. Before ISC, he had an active social life and enjoyed playing golf. Now he's afraid to go out for fear he might have an accident. He would love to be able to just play a round of golf again with his friends.

Now that you have identified his current fears (isolation, having an accident) and uncovered tomorrow's dreams (resuming his active lifestyle and playing golf), you can bridge the gap for the patient.

**For example** – “Did you know that you can use a catheter that is able to fit in your pocket, or you can carry it in your golf bag, so no one has to see it? This will enable you to play golf with your friends, without having to worry about having an accident.”

*“ I'm planning to go out, I might do one before I go, also when I have done one within the three hours, so I know I am clear for another 3 to 4 hours when I'm out.”*  
*Male user, UK<sup>10</sup>*

# 2

## Building trust through motivation

In order to get into good routines and stick to them, the patient must see the value of adherent ISC behaviour. It's the old 'what's in it for me' proposition.

As healthcare professionals, you're probably used to thinking in long-term health scenarios. So, to encourage adherence, we typically use argumentation such as: 'If you stick to the ISC routine and empty your bladder six times a day, you'll maintain good bladder health, and avoid UTIs and kidney problems.'

But these long-term scenarios often provide insufficient motivation for patients. Infections and kidney problems may not be something they are experiencing right now, and the importance of good bladder health might be somewhat abstract to them. So this longterm perspective is typically not strong enough to motivate

the patient to adhere to the treatment but needs to be combined with short-term rewards.<sup>11</sup> To motivate your patient to stick to good ISC routines, one could try to focus more on the short-term rewards of such behaviour.

*"We see the potential problems if they don't do it that await them in the future. But they don't see that. They see this as a mundane monotonous daily chore that they're going to do."*

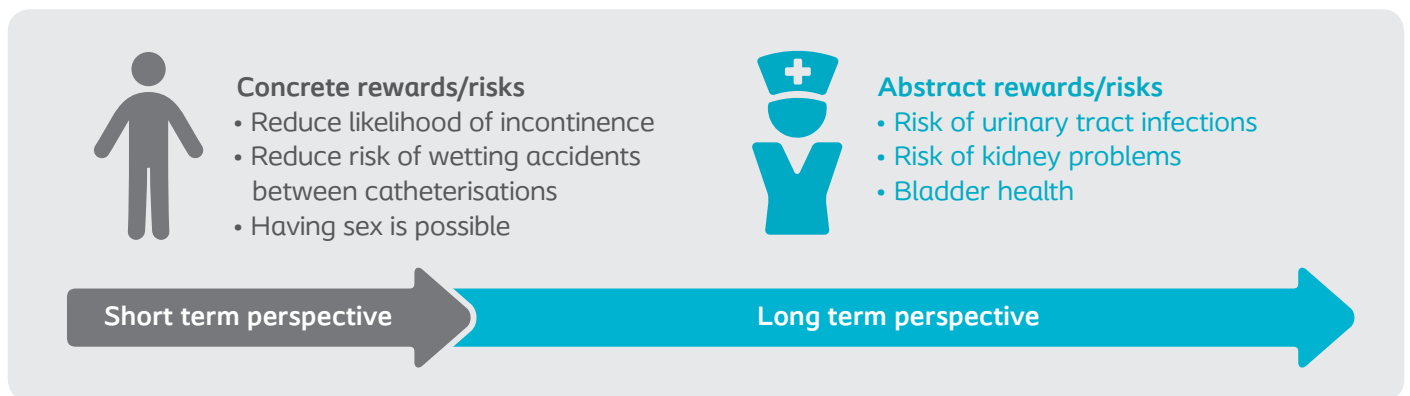
*Doctor, UK<sup>11</sup>*

*"Many patients fail to see the reward of catheterisation. The reward is not having a problem, whereas the positive reward is difficult to see."*

*Female Urologist, UK<sup>11</sup>*

Figure 2

This figure illustrates both the short-term benefits of ISC, and long-term risks of non-adherence.<sup>11</sup>



### Try this

Motivate with short-term rewards. Tie the rewards back to the fears or desires you uncovered in step 1 – and show the patient how adherence can enable them to do what they like.

### For example

When you speak with patients who are primarily concerned about resuming an active sex life, you can help them to see that the advantage of ISC is that they don't have a permanent catheter with a urine bag attached to their body. This gives them more freedom when having sex and helps them avoid the potential embarrassment of their partner seeing the urine bag.

# 3

## Help patients identify safe zones

To get patients to trust and adhere to ISC treatment, you not only have to demonstrate the benefits of the treatment itself. You also have to help them transition from the security of a clinical training environment to the outside world where things are less structured or 'safe'.

As you know, some patients might worry about the transition back to their homes. They might be concerned that what they've learnt in a clinical setting won't work when they get home; let alone when they go out.

One way to address this concern is to help the patient establish 'safe zones'<sup>12</sup>. Whether inside or outside the home, a safe zone is a place that is:

### Clean

Knowing where to find or how to create a clean environment, is key to ensure adherence to ISC.

*"I don't like to catheterise in other people's toilets... I mean I can handle my own germs, as long as I'm not exposed to other people's."*

**Female user<sup>12</sup>**

### Private

Having privacy when they catheterise helps patients maintain their dignity and sense of control.

*"I once had to cath in a public toilet with no lock on... it was an absolutely horrible experience."*

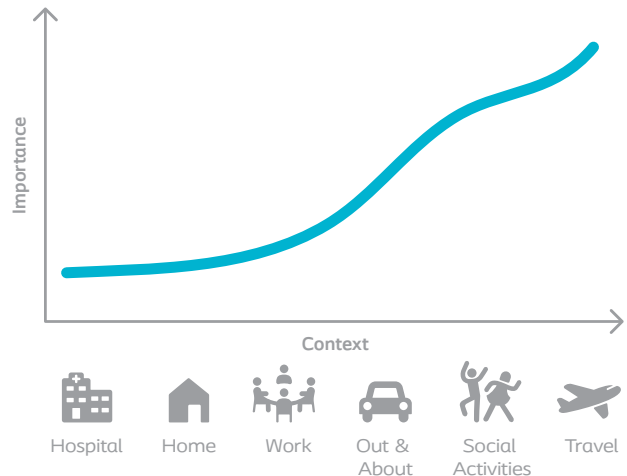
**Male user<sup>12</sup>**

### Accessibly

Patients need to have a space that is within reach when they need to catheterise. It must also fit their need for transfer and posture, and offer soap and water.

31% of ISC users surveyed in our study cited that they have different ISC routines outside of home. Among these, 37% mention that toilets outside their home are built in such a way that it makes following their normal ISC routines too difficult. Furthermore, 26% stated that they lack the space necessary to complete their ISC routine<sup>13</sup>.

Figure 3<sup>14</sup>  
Need for safe zones



Patients' needs regarding the three safe-zone criteria (clean, private and accessible) vary from person to person depending on mobility, hand dexterity and life style.

For patients to feel that ISC is a treatment that can fit easily into their daily lives, they typically need to expand their definition of safe zones. They need to understand how the methods that work in a controlled environment – for example, the clinic or their own home – can also work in the outside world.

For example, if the patient is concerned about finding the right place to perform ISC when away from home, helping the patient use GPS or phone applications to locate public and disabled toilets can give peace of mind and a greater sense of control.

*"We're there... to say 'Look, here's what is one option for you. Yes, there are some adaptations or some adjustments you may need to make, but none of them are insurmountable. But you have to make that decision. It's your choice because no one can actually force you into doing this.'"*

**Female nurse, UK<sup>15</sup>**

### Making it the patient's choice

A central element to all of the steps outlined above is to ensure that the conversation is an open dialogue. The patient needs to feel that they are participating in the process of selecting what's the right treatment for them. Getting the patient's acceptance and involvement increases the likelihood that they will adhere to the treatment in the long term.

References:

- 1 Anderson KD. Targeting recovery; priorities of the spinal cord-injured population. J Neurotrauma. 2004; 21(10):1371-83.
- 2 Coloplast\_Market\_Study\_GfK IC Research\_2015\_Data-on-file (VV-0206730)
- 3,5,7,12 Coloplast\_Market\_Study\_ReD Associates Study\_2007\_Data-on-file (VV-0206734)
- 4,8,10,11,13,14 Coloplast\_Market\_Study\_IC Research\_2015\_Data-on-file (VV-0206732)
- 6,15 Coloplast\_Market\_Study\_IC adherence insights\_2017\_Data-on-file (VV-0206731)
- 9 Coloplast\_Market\_Study\_SC Standard insights\_2017\_Data-on-file (VVV-0206735)