# Continence Life Study Review 2017/18

*Increasing adherence in Continence Care by improving clinical practice*

The Continence Life Study Review is a recurring publication developed by Coloplast

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# It's all about providing you with the latest insights and tools. So you can deliver the best possible care to your patients.


Coloplast
Northern General Hospital
Hydrophilic-Coated Catheters
Catheterisation Reduce Ureth
A Prospective, Randomised, P
Crossover Study of Three Diff
J. Stensballe
D. Looms
P.N. Nielsen
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Abstract

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# Introduction

**Leading the way in intimate healthcare**

For 60 years, we have been developing innovative products and services that have made life easier for millions of people with intimate healthcare needs.

We were never alone on this journey; nor did we achieve these results alone. Healthcare professionals like you have shared your experience from the frontline of care. Across different fields of expertise, we've worked together to turn our know-how and your expertise into products and services that deliver better outcomes to benefit the patients.

**Sharing insights**

We're committed to such collaboration and on-going sharing of insights. And our Life Study publications are good examples of this. Focusing on key topics within intimate healthcare, they aim to update you on the latest research and provide tools and inspiration that can support you in your work.

The Continence Life Study Review 2017/18 is the first in the series within continence care. In this issue, we focus on adherence to intermittent self-catheterisation (ISC) treatment – or more specifically, how to overcome the barriers to adherence that exist among a large number of patients living with continence issues.

**The gold standard**

ISC has long been recognised as the gold standard for neurogenic bladder management. As numerous studies show, ISC ensures better bladder health[1] and lowers the risk of urinary complications compared to other treatments, such as indwelling catheters[3]. It also gives patients a greater sense of freedom and control – which we know is key to quality of life[2].

But studies also show that adherence to ISC is a challenge[3]. Despite our best efforts, we see a critical dropout rate amongst ISC users[4,5]. Why is this? And how can we work together to reverse this trend?

**On the road to adherence**

Based on recent research as well as engagement activities with health-care professionals and patients from all over the world, the articles in this review explore the reasons behind these adherence issues. They shed light on patients' fears and concerns – and how such issues impact their ability to accept their situation, engage with the training, and adhere to the routines you're advising them to adopt.

Understanding the factors influencing patient behaviour is a critical first step in being able to change patient behaviour. Only then can we put them on the road to adherence – and ultimately help them live the life they want to lead.

**Medical Marketing, Coloplast A/S**


1 Blok B, Pannek J, Castro-Diaz D, del Popolo G, Groen J, Hamid R, Karsenty G et al. EAU Guidelines on neuro-urology, European Association of Urology, 2016.
2 Vahr S, Cobussen-Boekhorst H, Eikenboom J, Geng V, Holroyd S, Lester M et al. Evidence-based guidelines for best practice in urological health care. Catheterisation; urethral intermittent in adults; dilatation, urethral intermittent in adults. European Association of Urology Nurses (EAUN). 2013.
3 Wyndaele JJ. Complications of intermittent catheterization: their prevention and treatment. Spinal Cord. 2002;40(10):536-41.
4 Cameron AP, Wallner LP, Tate DG, Sarma AV, Rodriguez GM and Clemens JQ. Bladder management after spinal cord injury in the United States 1972 to 2005. J Urol 2010;184(1):213-7.
5 Krebs J, Wöllner J, Pannek J. Bladder management in individuals with chronic neurogenic lower urinary tract dysfunction. Spinal Cord. 2016; 54(8):609-13.

# Helping patients overcome physical barriers to adherence

When it comes to treating bladder issues, intermittent self-catheterisation (ISC) has long been recognised as best practice treatment[1]. Yet barriers to adherence persist.

In this article, we address the misconceptions patients typically have about their anatomy, and show how these misconceptions can present real barriers to acceptance of, and adherence to ISC. You will also find some simple tools that you can use to help patients understand their own anatomy, so they become more receptive to the treatment prescribed.

As professionals dedicated to providing optimal care for people with intimate healthcare needs, there is a shared interest in working closely with patients to identify the best course of treatment for them. One also has to make sure they adhere to that treatment, as long-term adherence gives the best chance of leading healthy, active lives.

1 Blok B, Pannek J, Castro-Diaz D, del Popolo G, Groen J, Hamid R, Karsenty G et al. EAU Guidelines on neuro-urology, European Association of Urology, 2016.



Anna

# Intermittent self-catheterisation (ISC) is the gold standard[2] – yet adherence is still an issue

For decades, ISC has represented the best way to help patients manage bladder issues[3,4,5]. We've seen that it not only ensures better quality of life[4]; it also helps ensure good bladder health[5].

Research supports this and documents that ISC gives patients greater independence[4]; offers less interference with sexual activity[4]. It also provides better symptom management, giving patients a greater degree of freedom to participate in daily and social activities that may otherwise have been difficult[6].

Although healthcare professionals and scientists all agree that ISC is the gold standard[2], the rate of non-adherence amongst patients remains alarmingly high[7].

As the results from a 2010 study in the Journal of Urology reflect, over 50% of patients stop ISC within the first five years after starting the treatment[7]. Another more recent study followed 164 new spinal cord injured patients after discharge[8]. The most common bladder management method at discharge from the inpatient rehabilitation centre was ISC. But at follow up, 42% of the patients who started with ISC changed their bladder emptying method. The rate of patients converting to indwelling was 21.4%[8].

A study from 2010 showed that the majority of individuals who stop ISC seemed to change to indwelling catheterisation[7].

**All these statistics beg the same question –**
**If we all agree that ISC is the best standard of care, why are the dropout rates among patients so high?**

### Adherence to ISC

More than

**50%**

of patients stop ISC within the first five years after starting the treatment[7]

**42%**

of the patients who used ISC changed their bladder emptying method[8]

The rate of patients converting to indwelling was[8]

**21.4%**

2 Pannek J, Blok B, Castro-Diaz D, del Popolo G, Kramer G, Radziszewski P et al. EAU Guidelines on neurogenic lower urinary tract dysfunction. European Association of Urology. 2013.
3 Blok B, Pannek J, Castro-Diaz D, del Popolo G, Groen J, Hamid R, Karsenty G et al. EAU Guidelines on neuro-urology, European Association of Urology, 2016.
4 Vahr S, Cobussen-Boekhorst H, Eikenboom J, Geng V, Holroyd S, Lester M et al. Evidence-based guidelines for best practice in urological health care. Catheterisation; urethral intermittent in adults; dilatation, urethral intermittent in adults. European Association of Urology Nurses (EAUN). 2013.
5 Weld, K.J. and R.R. Dmochowski, Effect of bladder management on urological complications in spinal cord injured patients. J Urol, 2000. 163(3): p. 768-72.
6 Pilloni SKJ, Mair D, Madersbacher H, Kessler TM. Intermittent catheterisation in older people: a valuable alternative to an indwelling catheter? Age Ageing. 2005;34:57–60
7 Cameron AP, Wallner LP, Tate DG, Sarma AV, Rodriguez GM and Clemens JQ. Bladder management after spinal cord injury in the United States 1972 to 2005. J Urol 2010;184(1):213-7.
8 Afsar SI, YemiscibOU, Cosar SNS and Cetin N. Compliance with clean intermittent catheterization in spinal cord injury patients: a long-term follow-up study. Spinal Cord. 2013; 51: 645-9.
9 Krebs J, Wöllner J, Pannek J. Bladder management in individuals with chronic neurogenic lower urinary tract dysfunction. Spinal Cord 2016;54(8):609-13.



### Faulty perceptions can lead to lack of adherence

Patients may have a hard time accepting the idea of self-catheterising. In fact, this might even be one of the most challenging aspects of your conversation with them.

Our research indicates that there is often a fundamental disconnect in the way a patient perceives ISC and what it actually involves[10]. This is often due to the patient's lack of understanding of his or her own anatomy. In many cases, lack of understanding has led to false perceptions, which, in turn, makes the patient unable to understand or engage with what you are telling them.

Most people go through life without giving their urinary system much thought. For this reason, it may be difficult for patients to articulate their own perceptions of how these organs function. Yet these perceptions, no matter how inaccurate, form the basis of the patient's reality, and can present a potential barrier to adherence if they prevent the patient from accepting ISC as a viable treatment option.

> *...you sometimes get the ones saying, "I'm not going to do that to myself," and they want the easy route, which is an indwelling catheter, or a suprapubic catheter. They just say, "Oh, no. I can't do that". Some of them don't even understand their anatomy, where things are and how they work.*
> **Female nurse, UK[11]**

### Helping patients understand their urinary system

For example, if patients are unaware of how flexible the urethra is, this might lead to them worry about hurting or damaging the urethra when inserting the catheter. If they see their urethra as a tube – an organ with a finite width incapable of expanding – they will assume that inserting a catheter into the urethra will be painful. By helping them to understand that the urethra is indeed flexible, you can address this fear, ease it, and improve the likelihood of acceptance and ultimately adherence.

The lack of knowledge regarding the anatomy is not just limited to the urethra; it typically applies to the entire urinary system. For example, many people don't know that their bladder is a muscle and not something static, like a gas tank. For this reason, they don't understand that the bladder, like other muscles, needs to be exercised. This lack of knowledge also means that they don't see how emptying the bladder on a regular basis with a catheter mimics the natural function of the bladder[11].

To address such misconceptions, it can be helpful to show how the bladder functions, using practical illustrations rather than clinical definitions. This can help patients replace their 'gas tank' perception with the 'muscle' reality.

**Figure 1A**
**Bladder during storage**

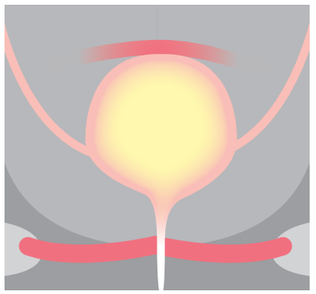
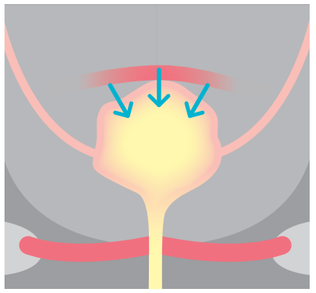


**Figure 1B**
**Bladder during emptying phase**



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11 Coloplast_Market_Study_IC adherence insights_2017_Data-on-file (VV-0206731)

### Helping men deal with physical barriers to ISC

As mentioned above, studies indicate that non-adherence is high, also among men. Many men view continence issues as a potential attack on their virility and masculinity[12]. Our study among ISC users revealed that almost 50% of men have barriers to inserting the catheter[13]. As one nurse explains:

> *It is invariably a shocking moment for male patients to see the length of tubing they have to insert. Many have trouble believing such a long tube is actually safe and necessary*[14].

A urologist explained the typical male reaction she encountered:

> *Many men tense up – they anticipate a very high level of pain, which makes it very challenging to insert the catheter.*
> **Female urologist, US**[13]

One patient expressed it this way:

> *I don't know if it's purely being a male, but it was a very, very scary subject. The whole idea of having to do an invasive procedure on myself, especially on... quite a personal area... It was quite daunting at first.*
> **Male ISC user, UK**[15]

As some of you may have experienced when working with male patients performing ISC, using diagrams to help them understand the flexibility and length of the male urethra can address these misconceptions and help them to overcome the physical barriers to performing ISC (Figure 2).

### Helping women address the physical barriers to ISC

For women, it's more than just understanding how the urinary system function, it's also a matter of locating the urethral orifice.[13]

**53%** of women find it difficult to locate the urethra[13]

One of the nurses interviewed in our study shares her experience with this problem:

> *Women tend to accept the idea (of ISC) better (than men), but actually the physicalities are a problem for them. To actually help them work out their anatomy, we often have to get positions and mirrors involved with women.*
> **Female nurse, UK**[16]

Here, the task is not just to explain the way the urinary system works, but also to use visual aids and diagrams to help female patients understand how to actually locate the opening of the urethra (Figure 2B).

### Tips for tackling physical barriers

By helping patients understand how their anatomy actually works – connecting or reconnecting the dots in the right way – you can address their physical fears and hopefully ease what we know to be one of the fundamental obstacles to effective training and ultimately ISC adherence (Figure 2A and 2B).

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13 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
14 Coloplast_Market_Study_GfK IC Research_2015_Data-on-file (VV-0206730)
15 Neil Malcolm
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**Figure 2A**
**Male anatomy**

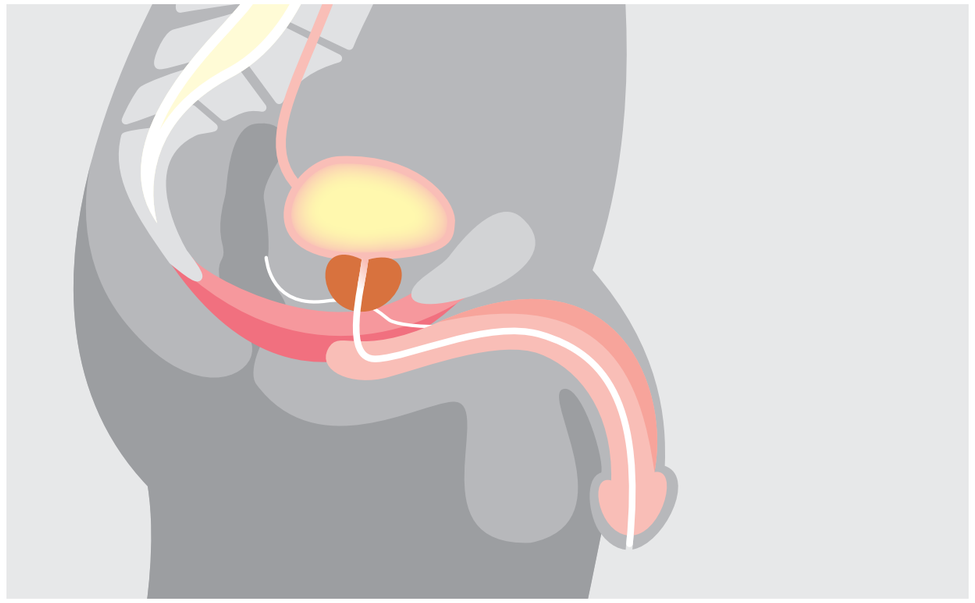
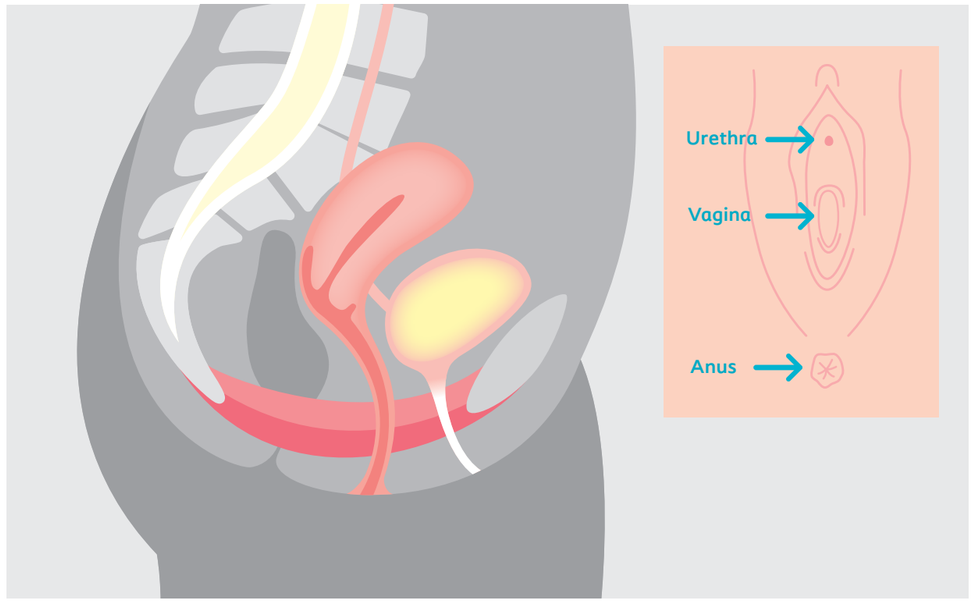


**Figure 2B**
**Female anatomy**



*By helping patients understand their anatomy, you can address their physical fears and hopefully ease one of the fundamental obstacles to effective training and ultimately ISC adherence.*

Olga and Vladimir

Neil

Overcoming challenges

# 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".*
**Neil**

### 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[1,2].

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[3].

**Patient benefits with ISC[4]**

**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[4]**

**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

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 Coloplast_Market_Study_ReD Associates Study_2007_Data-on-file (VV-0206734)
4 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)



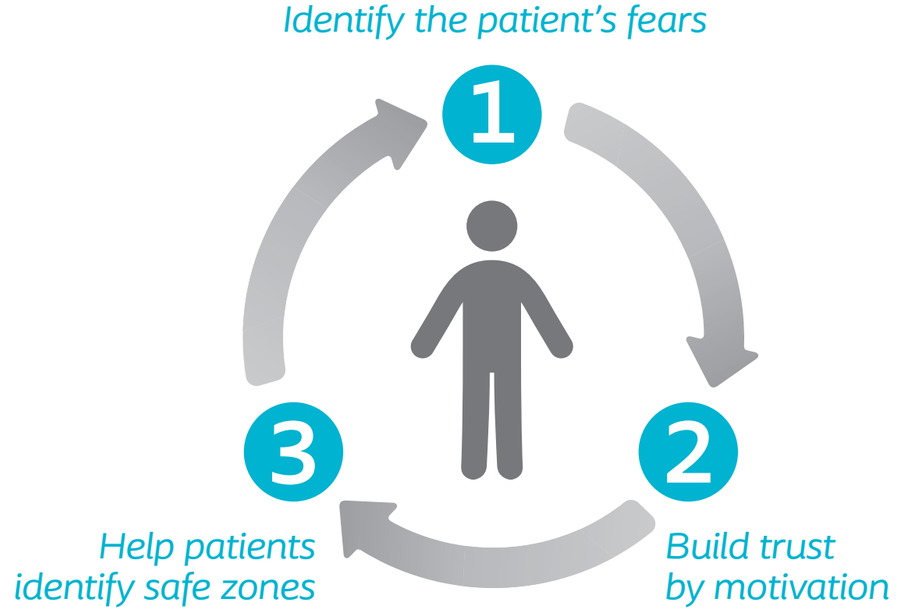
## Moving the patient from fear to trust in treatment

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[6]**

**Figure 1[5]**
**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.**




5 Coloplast_Market_Study_ReD Associates Study_2007_Data-on-file (VV-0206734)
6 Coloplast_Market_Study_IC adherence insights_2017_Data-on-file (VV-0206731)

# 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[7]. 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[7]**

**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[7]**

**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[7]**

**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[8]. 41% cite getting a UTI as a daily concern[8]. 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[9]**

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8 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
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**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 to 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."

> *"If 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[10]**

10 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)

# 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 long-term perspective is typically not strong enough to motivate the patient to adhere to the treatment but needs to be combined with **short-term rewards.**[11] 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**[11]

*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**[11]

11 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)



**Figure 2**
**This figure illustrates both the short-term benefits of ISC, and long-term risks of non-adherence.**[11]


**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'[12]. 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[12]**

**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[12]**

**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[13].

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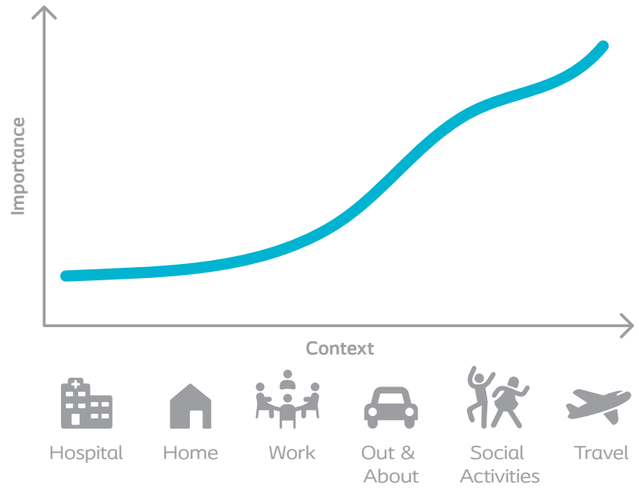
13 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)



**Figure 3[14]**
**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[15]**

**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.

14 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
15 Coloplast_Market_Study_IC adherence insights_2017_Data-on-file (VV-0206731)

*Getting the patient's acceptance and involvement increase the likelihood that they will adhere to the treatment in the long term.*

Liselotte and her friend

# Effective intermittent self-catheterisation training

In addition to addressing patients' physical and psychological barriers to intermittent self-catheterisation (ISC), effective training also plays an important role in achieving long-term adherence to ISC. In this article, we will look at how you can get the most out of a training session and give patients the confidence they need to perform ISC and adhere to treatment.

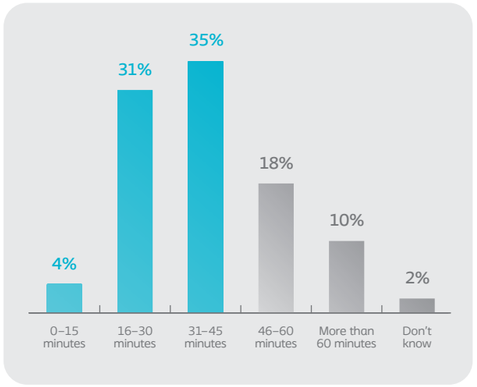
### Effective training – not an easy task

As you know, effective training is critical to help patients adhere to ISC. With the right training, patients are more likely to have the confidence they need to perform ISC correctly – and the understanding of why they need to stick to routines. But there are a number of circumstances that make effective training quite a challenge.

## *Lack of time*

If you sometimes feel that you don't have enough time to adequately train patients in ISC, you're not alone. In a survey we conducted, 70% of respondents stated that they had 45 minutes or less to teach patients ISC. Many stated that the amount of time they had available was inadequate to train their patients properly[1]. And patients feel the same way. Studies show that the length of the visit is a factor that is likely to increase patient satisfaction[2,3].

**Figure 1**
**Time spent on training**
**70% of the nurses surveyed spend 45 minutes or less on teaching patients ISC[1].**




## *Complex topics*

Our research shows that patients need a high level of knowledge in order to perform ISC correctly[1].

In addition to learning how to use a catheter, patients have to acquire an understanding of the anatomical properties of their urinary system. When that's been established, you also have to discuss with them how to establish good bladder management routines. That's a lot for you to cover – and a lot for the patient to take in.

*"You teach them so quickly so they don't always grasp it..."*
**Nurse, UK[1]**

1 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
2 Morrell DC, Evans ME, Morris RW and Roland MO. The "five minute" consultation: effect of time constraint on clinical content and patient satisfaction, BMJ. 1986;(292); 870
3 Robbins JA, Bertakis KD, Helms LJ, Azari R, Callahan EJ and Creten DA. The Influence of physician practice behaviors on patient satisfaction, Fam Med. 1993;(25); 17-20.

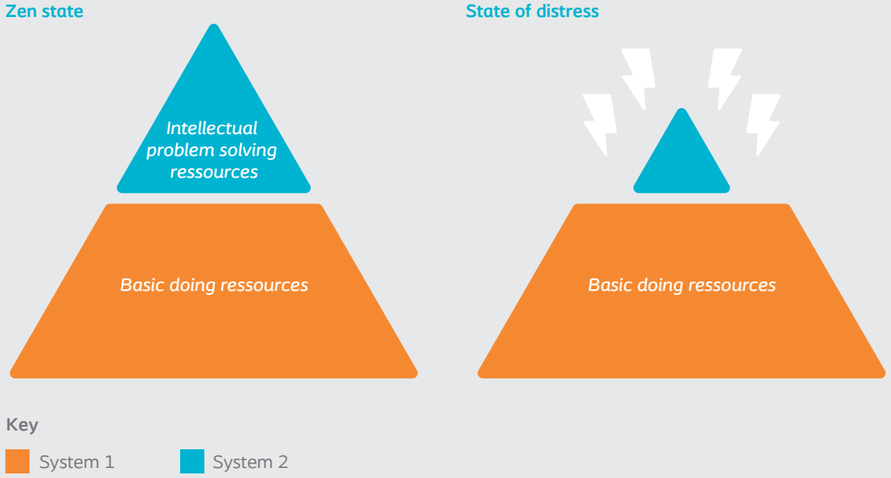
## *The patient's state of mind*

A third critical factor working against optimal training is the patient's state of mind at the time the training is delivered.

We all know how external stress factors can adversely impact our ability to take in new information and acquire new skills. And we would be hard-pressed to find a more stressful external factor than a life-altering injury or illness.

Figure 2 is a very basic illustration of how our brain works[4]. The area in orange, called System 1, is the part of our brain we use for daily activities and intuition. This would include tasks we perform everyday as a matter of routine, such as shopping, cycling or driving a car. System 2, the area in blue, is the part of our brain we use for intellectually demanding exercises, like advanced problem solving, playing chess or filling out tax forms. Acquiring new skills requires both areas of the brain[4]. But there is an issue.

**Figure 2[5]**
**How the brain works in an ideal situation and underpressure**




*It was something that I didn't want to do, when they told me it was something I had to do. I wanted it to change, I wanted to be able to pee again normally. I didn't want to be reliant on tubes. I didn't want to have to put tubes into myself, it was very, very scary... unnerving....*
**Male user, UK[6]**

### Stress makes learning difficult

When we are in the 'zen' state – our ideal state of mind – the System 1 and 2 areas of our brain are perfectly in balance. However, our System 2 is somewhat fragile. A bit of stress, even just from multi-tasking, will diminish its capacity. System 2 will become significantly compromised when patients are coping with an injury, getting to grips with a new condition or experiencing pain. When the patient's intellectual resources, System 2, are compromised, so is the ability to take in and process new information[4,5].

Having to train patients in ISC when they are in a state of distress and, for this reason, less receptive to information, presents a barrier to an effective training session[7].


Kevan

4 Kahneman D, Thinking, Fast and Slow, Farrar, Straus and Giroux, 2011
5 Coloplast_Symposium_ISCoS_2016
6 Neil Malcolm
7 For tips on how to help patients be more receptive to training by addressing their state of mind, see CLS Review 2017/18, Chapter 2 "Getting patients on the road to acceptance"

# Topics to cover during training

**As you probably know, an effective ISC training should cover the following key topics[8]:**
**– Anatomy**
**– Insertion and withdrawal techniques**
**– Establishing good ISC habits**

## *Anatomy*

The introduction to the anatomy paves the way to your demonstration of actual insertion and withdrawal techniques. As you know, patients vary in their understanding of the urinary system. Most patients don't know how this system works, and many have misconceptions about the bladder and urethra. They typically think of the bladder in terms of a tank that's either empty or full, rather than a muscle – or think their urethra is an inflexible tube. These misconceptions can make it difficult for patients to understand the purpose and value of the training you provide.

When you introduce anatomy in your training, you can use alternative anatomical drawings that address the most common misconceptions patients may have about their anatomy and give them a clearer understanding of how their bladder and urethra actually work.

## *Insertion and withdrawal techniques*

One of the most important aspects of the training session is teaching the patient the proper bladder emptying techniques.

*Pain generally occurs if the patient is scared during insertion, so the body is tense.*
**Female nurse, Germany[8].**

**36%**

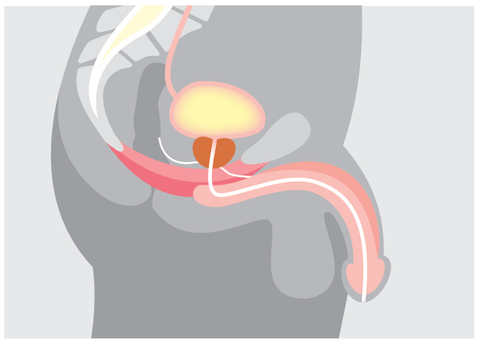
of those surveyed in our study mentioned having difficulty overcoming the fear of insertion[8].

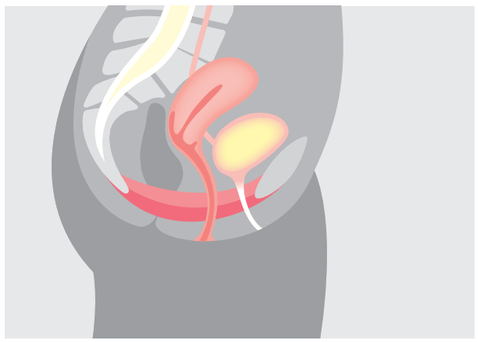
This fear can cause patients to tense up during training, which can make it challenging to teach the insertion technique. If the first experience with ISC is a painful one, it can have a negative impact on long-term adherence.

**53%**

of the women we surveyed indicated that finding the urethra was difficult in the training situation[8].

**Figure 3**
**Male and female anatomy models**



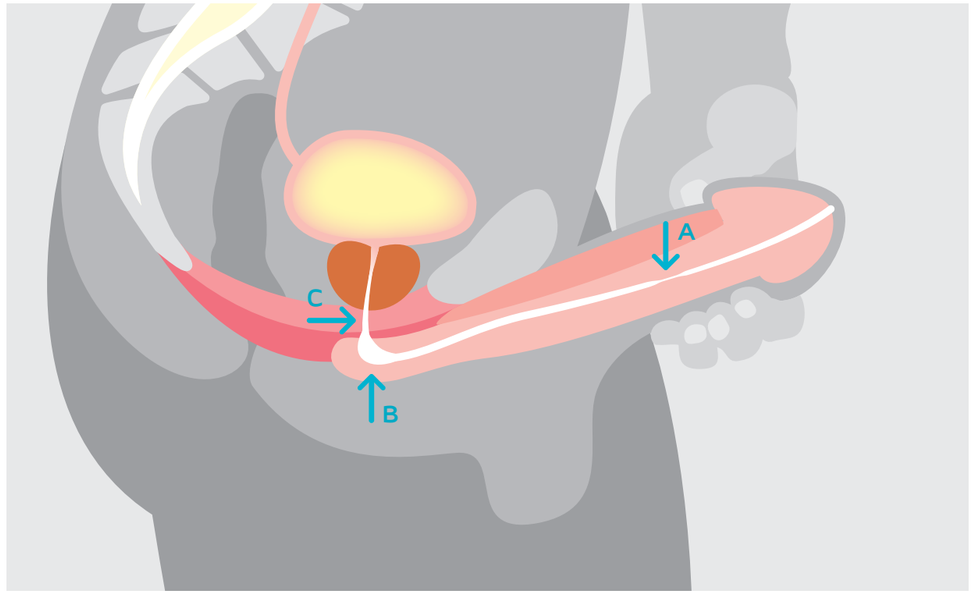


8 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
For tips on how to help patients be more receptive to training by addressing their state of mind, see CLS Review 2017/18, Chapter 2 "Getting patients on the road to acceptance"



*Many men tense up – they anticipate a very high level of pain, which makes it very challenging to insert the catheter.*
**Female urologist, UK[9]**

**Figure 4**
**Key waypoints for male catheterisation**




**A – Strictures**
Make them aware of areas where strictures might occur.

**B – Urethra curves**
Help them guide the catheter along the urethra by lifting the penis and straightening the urethra.

**C – Sphincter muscle**
Take a deep breath of air to relax. When doing this the likelihood of tensing the sphincter is less, which can make the insertion easier. A tense sphincter is a closed sphincter. Help them guide the catheter through the sphincter muscle and into the bladder.

**Tips for tackling physical barriers**
When you use diagrams of the anatomy to teach the insertion technique, make the patient aware of the key waypoints – points along the insertion path that will signal to the patient that they are on the right track.

9 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)

### Teaching bladder emptying technique

*"You don't really know if the bladder is empty – there's nothing that tells you."*
**Male user, UK[10]**

Only **30%** of IC patients surveyed know when their bladder is empty[10]

### Tips for tackling physical barriers

- Help patients see the connection between frequent and complete bladder emptying and good bladder health – i.e. the connection between residual urine and UTIs.
- Make patients aware of how much urine his/her bladder can hold.
- Give patients specific indicators that can help them ensure they are emptying the bladder correctly. Bladder volume, times of catheterisation and fluid intake can be managed with a bladder diary.[11]

*"We have to carefully teach the patient the right removal technique to avoid residual urine… but patients do not empty completely because they cut off the right emptying technique, moving the catheter back and forth before withdrawal."*
**Urologist, France[10]**

## *Establishing good ISC habits*

As you know, for patients to adhere to ISC, it must become a part of their daily routine. In other words, it's all about good habits.

Some patients performing ISC find it difficult to be adherent to treatment. Some will find it difficult to integrate this regime into their daily lives. They will need to try and establish a habit that is more fitted to their routines. Keeping this in mind when training them will reduce their need to adapt on the fly, and avoid patients developing bad ISC habits.

If a new habit is not established, the mental focus needed to manage the bladder will consume unnecessary amounts of energy, and in some cases the patient will experience a feeling of being controlled by the bladder[11]. For this reason, the key to adherent behaviour lies in establishing the right trigger for the patient in question – which in turn will lead to establishing of a new habit and an ISC routine that is almost instinctive, if not automatic.

*"There are some patients who can feel whether they are full and there are some patients who have no feeling. So you have to establish immediately whether they are going to void by the clock or are they going to be relying on the physical feedback."*
**Urology nurse, UK[10]**

"Patients should empty **4 to 6** times a day"
Female urologist, France[10]

10 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
11 Blok B, Pannek J, Castro-Diaz D, del Popolo G, Groen J, Hamid R, Karsenty G et al. EAU Guidelines on neuro-urology, European Association of Urology, 2016.



Carlos and his nurse

### The reward plays a crucial role

As with the triggers, the reward needed will vary from patient to patient. The important thing is for the reward to be clear to the patient – something very tangible that can drive adherent behaviour.

Examples of short-term rewards could be avoiding incontinence. Reduce risk of wetting accidents between catheterisations, e.g. so the patient can play a round of golf or go to the cinema, or being able to have an active sex life.[12]

### Effective ISC training: challenging, but possible

As you undoubtedly experience in your daily work, conducting an effective ISC training session can be challenging. The time you have available is limited, patients are not in the ideal frame of mind to learn, and their lack of knowledge and understanding regarding their urinary system might mean you are starting at ground zero.

Yet by being aware of patient challenges and preconceptions, using models and visual aids to help them learn, and assisting them in finding triggers and rewards that can establish a good ISC routine, you can help your patient accept ISC – and develop good habits that will lead to long-term ISC adherence.

*"It needs to be a simple process. It needs to be something that can be so easily integrated into what they do that it becomes an automatic thing, like brushing your teeth every morning."*
**Female nurse, UK[13]**

12 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)
For more information about short-term rewards, see Chapter 2 in this series, "Getting patients on the road to acceptance".
13 Coloplast_Market_Study_IC adherence insights_2017_Data-on-file (VV-0206731)

*By being aware of patient challenges, and assisting them in establishing a good ISC routine, you can help them accept and develop good ISC habits.*

Peter and his coach

Interview

# Sharing best practices

Sharon Holroyd, a nurse with 20 years of experience in urology and working with patients with bladder issues, shares her experiences helping patients adhere to intermittent self-catheterisation (ISC).

**What is the typical patient reaction to intermittent self-catheterisation, ISC?**

Most of them are horrified by the idea. Quite a few of them think it's something that they will never be able to do. I think some are disgusted by the idea of it. And depending on when they come to you, some are still coping with the idea that their bladder doesn't work as it should. So they have a lot of anger and grief, and feelings of 'Why me? Why do I have to do this?'

**How do you help them overcome these initial barriers to ISC?**

It's about being honest with them. At times, we have to revisit why they needed to end up with this treatment in the first place. We reinforce the benefits to them and try to reiterate that ISC gives them control. That it's something that, once they're confident with it, can be adapted to suit their needs and personal lives, so they've got some flexibility with it.

**In your experience, what are the barriers to adherence to ISC?**

It depends on the age group. With teenagers, it's very much they don't want to be different. With adults, it's very individual. It depends on what their lifestyle is, and if they can fit it into their normal work pattern or hobbies. A lot of them feel that their life has to change significantly and that they can no longer do the things they want to do. So it's about getting over that barrier and saying to them, 'Yes, you can'.

*"First and foremost, I show them a choice of products and make it clear that it's their choice. I compare it to buying a pair of new shoes; it's important that you pick the ones that are comfortable for you."*
**Sharon**

**How do you get them to trust ISC as the best treatment option for them?**
We let them tell us what they think the issues are. Whilst it might not seem like a big deal to a health professional, it is a big deal to them. So, a lot of it is about letting them discuss it, helping them identify where they think the issues are and then working with them to find solutions. For example, if it is something like, 'I can't do this at work because I don't have access to a private toilet', then we look at ways we can change the schedule of when they need to use the catheter so that they can do it at home. It's just giving them solutions to where and how it can work for them. But, at the same time, making them a part of that decision so that they feel they've made the choice rather than being told what to do.

In some cases, it's also about putting them in touch with another person who's confident in doing ISC to have a chat with them. It just depends on the individual. You get a feel for what people are comfortable with and what avenues are available to them.

**Once you've gotten them to accept ISC, how do you go about the mechanics of training them in performing ISC?**
First and foremost, I show them a choice of products and make it clear that it's their choice. While, in theory, any hollow tube could be used, they need to find the product that's easy for them to open and use. I compare it to buying a pair of new shoes; it's important that you pick the ones that are comfortable for you. I get them to play with a couple of different types of products, getting them to touch and feel them without using them, just so they can see what the sensation is like.

Sometimes I use an anatomical model. That is very patient-specific. A lot of patients don't realise what the urethra is, where it is and how it works, so the model can be quite useful. And because the anatomical model sometimes can cause a bit of humour, it sort of breaks the ice and gets them to relax a bit more.

Then it's about assessing where they're going to do ISC; how they're going to do it; what part of their lives it's going to impact on – so we can adapt the technique they're going to use.

**How do you ensure they develop good habits?**
We always say that it is like learning to drive: I'm going to teach you the best, safest possible way to do it, but we all pick up tips and shortcuts along the way. I don't know what they're going to do when they get back home, so it's just reiterating the safety side of it – that it needs to be a clean technique, and that there is a risk of infection that they need to be aware of, without making it seem that it's the end of the world.

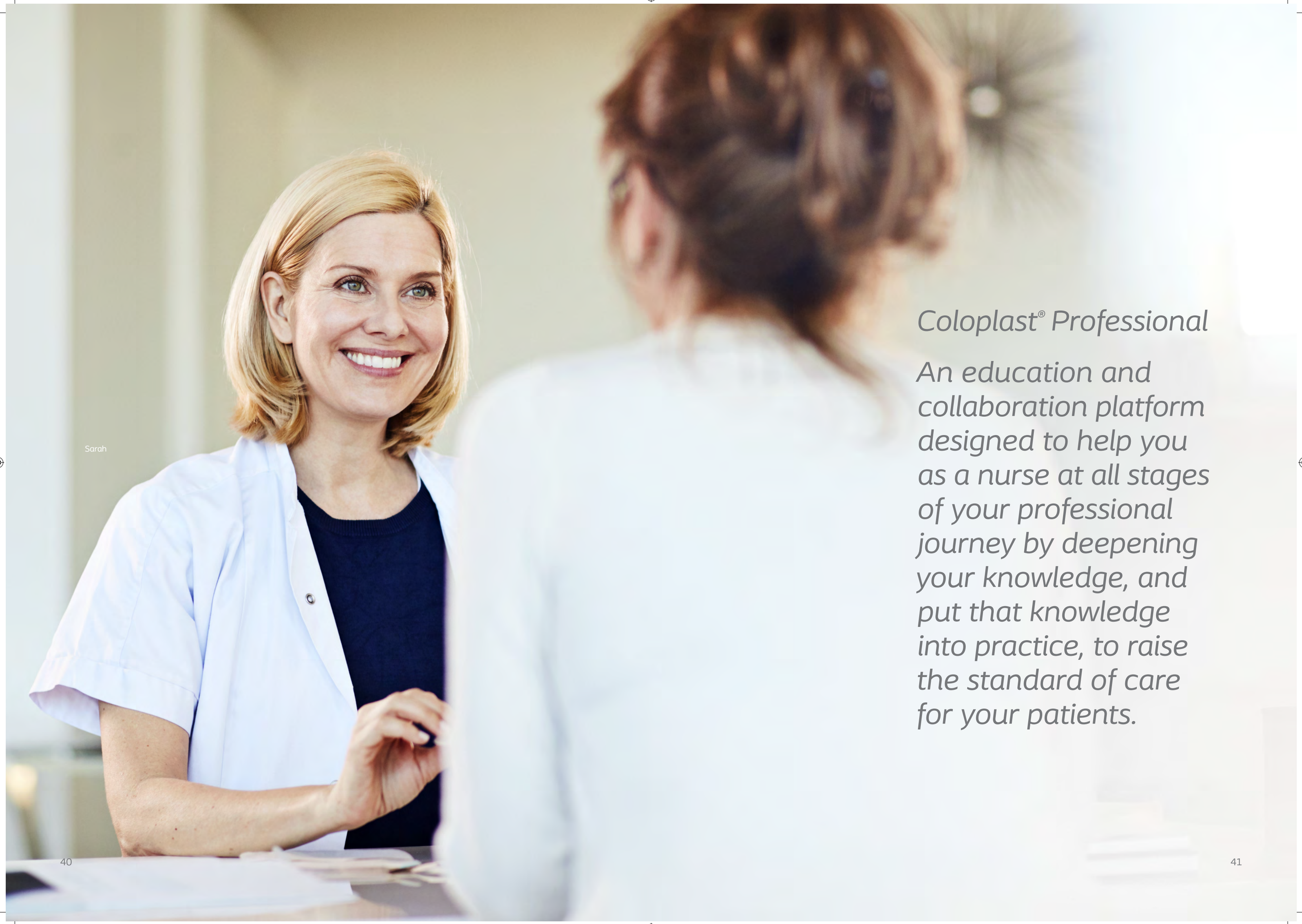
It's about finding something that resonates with them, something that helps them realise, 'okay if I don't do this, there are consequences'. And that comes from knowing the patient.

**You've mentioned the idea of control and choice quite a bit. Would you say those are key factors in getting patients to adhere to ISC?**

Yes, I would. Not that many years ago, a doctor or nurse would stand at the end of the bed and tell you what you need to do, and you would do it. We question things a lot more now, and generally we don't like being told what to do. So by saying, 'There is a choice to make. Here are the good sides of it; and here are the not so good sides, let's see where you fit in to that,' that seems to work better with the majority of people. We can't force anyone into it. The important thing is giving them an element of choice. Whether it's simply a question of choosing the product or the colour of the packaging, or whether it's the frequency of how often they do this, as long as they have the capacity to understand the consequences of their actions, it's their choice to make.

**Given your years of experience, what do you think is most important to keep in mind when working with ISC patients?**
I always try to remember that it's not me who's having to try to do this. ISC feels different for every single person. It is highly individual – and it's all about listening to what that person is trying to say to you, and finding out where their problems lie rather than saying, 'It's just a tube'. It's so easy when working in healthcare to get a bit desensitised to things. But keeping that sensitivity so patients understand that you understand the challenges they have, is so important.

*"I always try to remember that it's not me who's having to try to do this. ISC feels different for every single person. It is highly individual – and it's all about listening to what that person is trying to say to you, and finding out where their problems lie"*
**Sharon**

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## Did you know...[1]

### *In the Clinic*

**88%**

of nurses have **a range of 2 or more catheter types** to choose from when teaching patients intermittent self catheterisation (ISC)

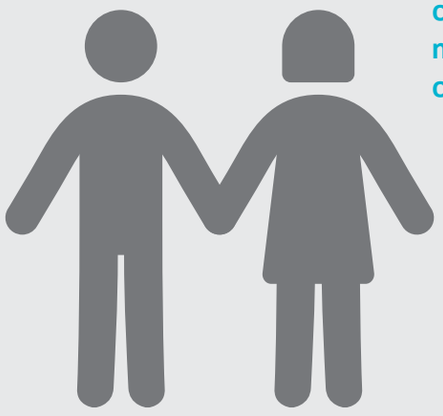
### *At home*

**3** out of **10** users **use 2 or more catheter types**

### *When out and about*

**48%***

state that they **use a different catheter type** when out and about because they **find it easier**



**Those using more than one catheter type are more likely to catheterise outside of home**

* 3 out of 10 users use 2 or more catheter types. Among these 48% state that they use a different catheter type when out and about because it is easier

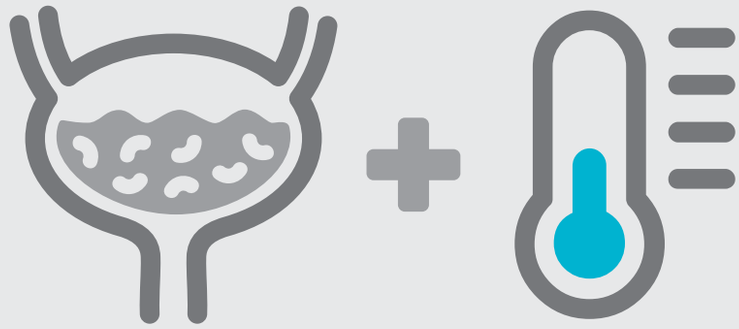
1 Coloplast_Market_Study_IC Research_2015_Data-on-file (VV-0206732)

## *Concerns*

ISC users have

# 2.7

**urinary tract infections (UTI)** on average **per year**



# 45%

of ISC users find that getting UTIs is the **greatest concern in their life**

# 55%

of nurses find the greatest challenge to ISC users to be UTIs

Getting a UTI is a concern for both new and more experienced users of ISC


# 41%

of users say that getting a **UTI is a daily/almost daily concern**

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