

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 treatment¹. 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.

Intermittent self-catheterisation (ISC) is the gold standard² – 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 life⁴; it also helps ensure good bladder health⁵.

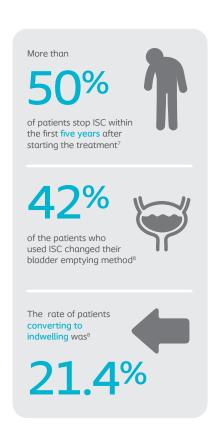
Research supports this and documents that ISC gives patients greater independence⁴; offers less interference with sexual activity⁴. It also provides better symptom management, giving patients a greater degree of freedom to participate in daily and social activities that may otherwise have been difficult⁶.

Although healthcare professionals and scientists all agree that ISC is the gold standard², the rate of non-adherence amongst patients remains alarmingly high⁷.

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 treatment⁷. Another more recent study followed 164 new spinal cord injured patients after discharge⁸. 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 catheterisation⁷.

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?



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 involves¹⁰. 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, UK¹¹

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 bladder¹¹.

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

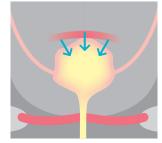


Figure 1B Bladder during emptying phase

Helping men deal with physical barriers to ISC

As mentioned above, studies indicate that nonadherence is high, also among men. Many men view continence issues as a potential attack on their virility and masculinity¹². Our study among ISC users revealed that almost 50% of men have barriers to inserting the catheter¹³. 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 necessary¹⁴.

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, US¹³

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, UK¹⁵

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 orifice¹³.

of women find it difficult to locate the urethra¹³

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, UK¹⁶

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).

Figure 2A Male anatomy

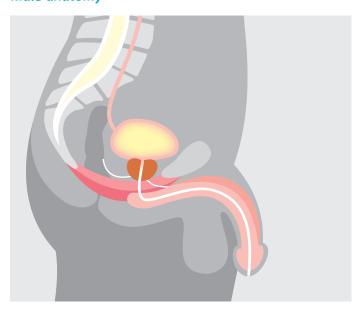
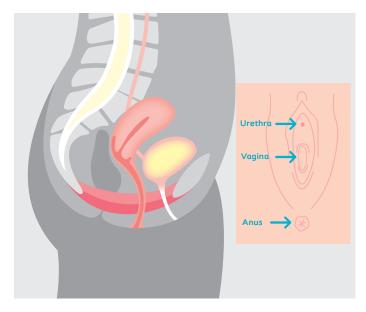


Figure 2B Female anatomy



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