# Can't go in toilets when others are around?

## Then you may suffer from Shy Bladder Syndrome (Avoidant Paruresis)

UKPT
UK paruresis trust

# Warning and Disclaimer

This brochure is NOT a substitute for medical advice and does not constitute the practice of medicine, psychiatry, clinical psychology, clinical social work or any other mental health profession. If you are having trouble urinating, you should always contact a GP because difficulty with voiding can be a symptom of a serious medical condition.

We are a group of people who have suffered with avoidant paruresis. We have organised ourselves into a self-help organisation to help people cope with this urinary dysfunction that has a psychological or social origin. In this brochure, we are NOT practising medicine, psychiatry, clinical psychology, clinical social work or any other mental health profession.

You should have your doctor evaluate your condition before diagnosing yourself, and seek the appropriate necessary mental health counselling if warranted. The UKPT disclaims all legal liability whatsoever.

## Is Paruresis a Recognised Condition?

It certainly is: it was first researched and defined by Williams and Degenhardt in their paper "Paruresis: a survey of a disorder of micturition" in the Journal of General Psychology, 1954, 51 , 19-29.

As a social anxiety condition it is covered by the NHS website http://www.nhs.uk /conditions > phobias > complex phobias > Social phobia

Even the Home Office Prison Service has procedures to cater for paruresis in prison. The letter from the Home Office detailing these is on our website: see News & Blog > Letters from Agencies

The fact that your GP urologist or clinical psychologist may say they have not heard of the condition is due to the secrecy surrounding it. Point them to the references above.

## What is Shy Bladder Syndrome?

"Whenever I try to use a toilet when there's others about, everything freezes up!"

"No matter how badly I need to go, nothing happens if I'm not at home."

"I can urinate when I'm alone at home - no problem. But if I'm at a match, the pub, someone else's home, or wherever - even if I'm at home and somebody's over visiting, I can't pee. This crazy problem has done nothing but interfere with my life!"

These are a few representative comments of the men and women who experience shy bladder syndrome (SBS), also referred to as bashful bladder, pee-shy, urophobia, psychogenic urinary retention and avoidant paruresis (the official clinical term).

In contrast to physiological conditions like prostatitis (inflammation of the prostate) that block the flow of urine, SBS is a psychological disorder that involves the urinary system. More precisely, SBS is a specific social anxiety, meaning the individual is usually anxious about being scrutinised or criticised by others when "performing in public" - in this case, urinating in the presence of others.

The psychological conflict that generates this particular form of social anxiety is expressed through the physical symptom of being unable to urinate whenever the person desires.
This is due to the body's autonomous nervous system (over which the individual has no control) reacting to a perceived threat by closing the internal urethral sphincter, and relaxing the detrusor (the bladder wall muscle).

The experience of SBS varies from person to person; however, certain general patterns are evident. First, SBS occurs mostly in public toilets, but it can also occur in the homes of friends and relatives, or even at home if visitors are nearby or a family member is "waiting". Typically, though, she or he finds the home bathroom to be the only truly "safe" toilet - the only place where the she is consistently able to void.

Secondly, SBS ranges in intensity from "mild", in which the person can urinate in public facilities under certain circumstances, to "severe", in which the person can only urinate when alone at home. Thus, the degree of SBS hesitancy ranges from a momentary delay in initiating the process to chronic and acute retention. Most people occasionally experience at least some hesitancy in public toilets, but this differs from SBS in the matter of degree and context. A person who every now and then must wait an few seconds before being able to urinate does not have avoidant paruresis. Rather, SBS is often a life-long condition characterised by excessive hesitancy or a total inability to urinate. The problem also causes distress in relationships, and in everyday activities like travel, social engagements, long business meetings, and it interferes in a significant way with the person's ability to carry on with these normal activities.

Thirdly, most sufferers describe a personal "comfort threshold" required for urinating, whether in public facilities or at home. When this comfort threshold is eclipsed by too many "negatives" in a particular situation - such as noise, odours, lack of visual privacy, other people in the toilet talking, people waiting for the person, stress, tiredness - SBS "kicks in" and prevents the person from urinating at that time.

## Typical Characteristics of SBS

What are some of the triggers for SBS? Sufferers most commonly refer to three triggers that influence them. These triggers must be removed, or the person must try another toilet, for urination to occur on a particular occasion.

Firstly, familiarity with other people present in the toilet can trigger SBS leading to greater inhibition with friends or relatives. However, some people find familiarity a help, and strangers a threat. So, peeing can depend on the degree of familiarity with the other person, and on the perceived acceptance by the other person.

Secondly, proximity plays a role in the problem. Proximity is both physical, involving the relative closeness others in or near the toilet, and psychological, involving the need for privacy. The most frequent complaint about physical stimuli in public facilities is the absence of suitable partitions and doors on cubicles, and the absence of suitable screens between urinals. Many remark that they cannot urinate (or sometimes defecate) in a cubicle if the door is missing. They feel embarrassed about their "personal space" being invaded visually.

Discomfort with lack of partitioning is central to the issue of perceived lack of privacy in public toilets. Of course, the perception and need for privacy differs considerably across people. One individual is comfortable only at home with the bathroom door locked; conversely one man is comfortable using a urinal in a crowded toilet, and another woman is comfortable sharing a bathroom with friends. Those with SBS tend toward the former.

Thirdly, temporary psychological states - especially anxiety, anger, and fear - can interfere with urination. Individuals who are overly sensitive about the sounds and smells they make while urinating are usually fearful of being criticised for such, which in turn triggers their nervous system. Also, excessive emotional states may explain why attempts to urinate under "favourable" conditions are often unsuccessful if the individual is overly excited or feels pressured to hurry.

## Typical Behavioural Patterns

For some individuals, SBS appears to start "out of nowhere", but "for most" an unpleasant experience or group of experiences appear to precipitate the onset of the problem. In the case of the latter, after some negative event - such as being bullied in a school toilet, or chastised by parents for taking too long - the individual begins to catastrophise: that is, she worries about being able to urinate "next time". In this way "performance anxiety" - the key feature of social anxieties - develops and becomes associated with urinating in the presence of others. The individual enters the situation with aroused sympathetic nervous system activity, which creates a level of anxiety that is incompatible with urinating. As each forcible attempt to control the process fails, increased performance anxiety due to mounting levels of sympathetic nervous system activity decreases the individual's chances of voiding at that time. In many cases, this performance anxiety eventually generalises to all or most public situations, so that the only "safe" toilet the person can reliably use is at home.

Generally, sufferers try to adjust to the problem by urinating as much as possible when at home and before leaving their home toilet, restricting the intake of fluids, and refusing extended social invitations. When away from home, they will try to locate vacant toilets. Most commonly, though, they cope by avoiding public toilets at all costs.

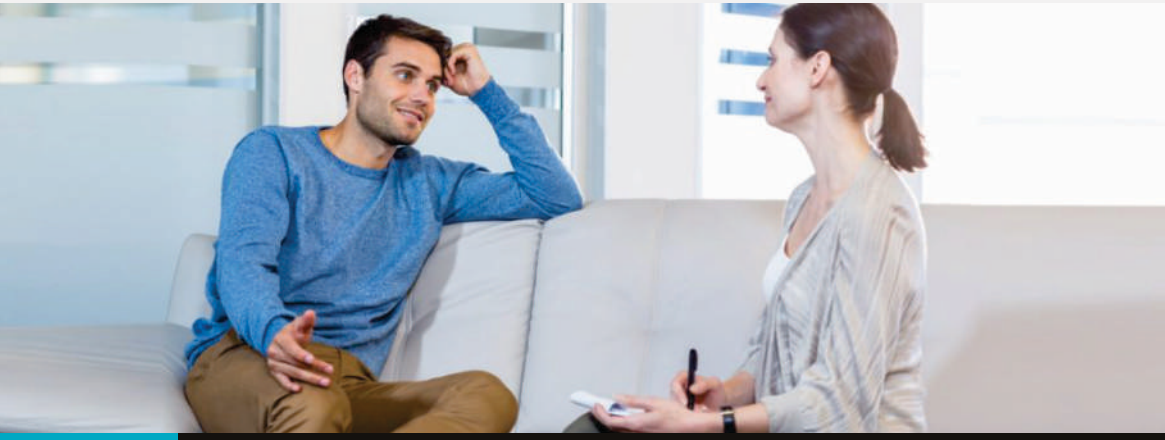
## How Can I Cure Paruresis?

Seek a medical evaluation before attempting to treat a shy bladder problem. Rule out a physical medical condition before diagnosing paruresis. However, a general rule of thumb is that if you can go in what you consider to be a safe place without a problem, but have difficulties in other social situations, then you probably suffer from paruresis.

The most commonly used treatment for shy bladder is cognitive behaviour therapy.

## Cognitive Behaviour Therapy

This involves turning round the person's illogical view of reality (reframing). The client has to work on the logic that no-one is interested in them in a WC situation, and probably does not notice they are there. The client is taught what behaviour patterns are normal in a WC (e.g. that male non-sufferers often prefer to use a cubicle than to stand next to stranger at a urinal.), They are encouraged to see use of a WC in their own time as a right for which they owe no-one an explanation or apology. In this they are encouraged not to rush the situation, but that it is acceptable to take one's time. Techniques to improve self-esteem can be used where necessary, along with ways of developing a "can do" positive attitude. They are taught how to relax, both physically and mentally.



# Graduated Desensitisation

This involves the individual urinating in a "safe" situation under his or her control, and gradually attempting to urinate in more and more difficult locations, as defined by the individual. This treatment is usually called graduated exposure therapy. Each session of exposure therapy involves several attempts at briefly urinating.

The individual prepares an initial ladder of a maximum of ten steps, each step being a small increase in difficulty from the individual's perspective. These step must be very small and typically could be:

**1.** In a hotel en-suite bathroom, door locked:

**a.** Other person in the corridor.
**b.** Other person in the bedroom at far side of room.
**c.** Other person in the bedroom half way across room.
**d.** And so on..

Gradually, the various factors: e.g. proximity, sitting/standing, door locked/unlocked/ slightly ajar/fully open, being heard, hearing others, line of sight, level of urgency, stranger /friend/acquaintance, are each worked on under the individual's control.

Typically, after the first session, the individual gains a better understanding of what bothers them, and so reorganises the ladder of steps.

However, in order to use desensitisation therapy in this way, a substantial amount of urine is needed. Usually drinking about one litre of water one hour prior to the practice session is best. Some people may require more water or more time to pass before they feel a strong need to urinate. Most people with shy bladder are more successful if their need to urinate is high but comfortable. But some have more trouble when they are very urgent, so experimentation may be necessary. lt is helpful to use a scale to record how strongly one feels the need to go. A 1- 10 scale works well, with 1 indicating feeling empty, and 10 indicating extreme urgency. The optimal urgency is around 7 or 8. lt must never become uncomfortable.

For most people, initial practice sessions should take place in an isolated private toilet. lt is very helpful to have a partner to work with at this point. Because having only one partner can create a pressure - he is waiting for me, she is unoccupied and so is thinking about me - it can be more effective to have two partners, who can then chat to each other. This partner

can be a trained behavioural therapist, a "buddy," a close friend or family member. Use is made of the ladder of steps described above. Once you and your partner are in place, you should attempt to urinate. If you are successful, allow urine to flow for approximately three seconds and stop. After successfully completing the urination trial, meet up with your partner and take a short break of up to three minutes, after which you should try again.

If you have trouble initiating urine, wait at the toilet for two minutes before giving up and taking a break. If you feel that you are just about to urinate after two minutes, wait up to two minutes more at the toilet before giving up. Usually waiting beyond four minutes is not helpful. If the trial is unsuccessful, take a short three minute break before trying again. Also, have your partner move back to where you were last successful, and then once successful again, move incrementally toward the point where you last failed. Consider how to introduce half-steps if necessary. If you do not have a partner, practice urinating in toilets that are empty at first then move on to situations where one person is present.

Once you have succeeded in the safe home or hotel room situation, move on to relatively undemanding public toilets such as motorway services at quiet times.

Some general guidelines are important to review here. It is best to practice often, preferably several times per week. Longer sessions are generally more helpful than shorter sessions. About one hour is best, with the goal of getting 15-20 practice trials in each of these one-hour sessions, You may also need to continually top up during your session to have enough pressure and urine for your session. If you have trouble initiating one day and then have success the next, do not be overly concerned, since many people experience inconsistency in their progress.

If you do have trouble with a given step in the exposure process, try and find the halfway point between your previous success and the step that is giving you difficulty. One of the most frequent mistakes people make in doing the graduated exposure work is to move too quickly up their ladder of steps. In fact, just a few inches can make the difference, since our boundaries around unsafe and safe situations are so clearly delineated in our subconscious!

You will inevitably experience occasions of not being able to pee. Do not see these as failures: treat them instead as misfires; they are the result of experimentation, so use them as opportunities to learn about what inhibits you.

You should expect the self-treatment to require 8-12 sessions before you are able to urinate freely. Of course, this is an average; you could require fewer or more. It is important to know that this treatment has been helpful to many people, but there is no guarantee that it will help you. In our experience, about 95 percent of sufferers using these techniques are helped to a significant degree. On very rare occasions, people with shy bladder find themselves unable to initiate urine during their practice session and then are unable to urinate when they return home. If this happens to you, seek medical attention from your GP or A&E immediately; if untreated, this could constitute a medical emergency. Finally, if your self-treatment fails, consult a trained cognitive behavioural therapist. You may also wish to consult your GP again to be sure nothing is physically wrong.

If the step you are about to attempt seems too hard or too anxiety provoking, remove the peeing aspect, but go in and do everything as if going for a pee. That way you can experience how the situation affects you. You may then find you need to alter the situation (e.g. introduce some background noise); or you may find that you just need to repeat this "faking" several times until you grow accustomed to this new situation: at this point you can re-introduce the peeing aspect.

NB This document is by necessity brief; there are other important things to learn, which are covered on our website, or on request from us direct.

# CIC - Clean Intermittent Self-Catheterisation

A significant minority of paruresis cases are severe (i.e. they cannot pee away from home and can experience difficulty even there). Their day-to-day life is very stressful, so much so that it interferes with effective therapy. Such cases find either temporary or permanent relief from symptoms by learning clean intermittent self-catheterisation. This is the use of a thin flexible lubricated and sterile tube you slide up the urethra into the bladder; this results in the urine flowing down the tube into the toilet pan so emptying the bladder. Once empty, you just slide the tube out and throw it away. While this sounds difficult and painful, it really isn't when properly taught. Asking your GP to teach you how to do it is the best approach. For those whose symptoms are severe, or who travel a lot, this may be a good interim step while also seeking other treatment.

Just knowing that the catheter is available as a foolproof last resort can eliminate enough of the anxiety to allow the individual to do without it. A catheter is small and slips easily into a back pocket or a handbag.

Catheters are disposable, single-use and self-lubricated. In our experience, cases of infection in men are rare however infections among women are more common.

Ref: Intermittent self-catheterisation for managing urinary problems: Wendy Naish, BSc (Hons), MA, RN, Clinical Nurse Specialist - Urology, Epsom and St Helier NHS Trust, Epsom. Professional Nurse magazine Vol 18, No 10, 01 June 2003.

# What You Can Do About Paruresis

If you suffer from paruresis or know of someone who does, there are actions that can be taken:

**1.** Work on developing a positive can-do attitude. Whatever anyone else thinks, this is your life and you can change it. This is hard at first, but as you go through the steps below it becomes easier.

**2.** Visit our website at www.ukpt.org.uk and get the latest information about this anxiety disorder. There is also a moderated forum accessible through the website, where you can ask questions anonymously.

**3.** If you already haven't done so, tell your partner or best friend about this condition. A simple script is available on our website, or on demand from us direct. A typical response is: "Oh, I know someone who suffers from that" It can even be: "You know, I have that problem a little bit too!" This allows you to stop pretending in front of them. They can then assist in masking your condition, which can prove very helpful.

**4.** Then extend this to telling some of your family and social group (obviously those you trust) on a "need to know basis". This will again relieve the pressure on you and enable you to feel more relaxed.

**5.** Find someone to help you practice the graduated desensitisation technique outlined elsewhere in this pamphlet.

**6.** Attend one of the UKPT's weekend workshops to begin recovering from paruresis. Check the website or write to us for a schedule of upcoming workshops.

**7.** More than anything else, ongoing practice on a weekly or even daily basis, will allow you to overcome or recover from your paruresis in a timely manner. Persistent, consistent practice is essential for improvement.

# The UK Paruresis Trust

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**The UK Paruresis Trust**
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The UKPT has links with the USA based International Paruresis Association (IPA) and the Association Francaise pour l'Information sur Parurésie (AFIP).



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