

National Phobics Society (NPS)
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www.phobics-society.org.uk

1975 Golden Rail Award
1989 National Whitbread Community Care Award
2002 BT/THA Helpline Worker of the Year Award
The Queen's Award for Voluntary Service 2006



unsung heroes

The Queen's Award for
Voluntary Service 2006



Community
Legal Service



Toilet Phobia:

breaking the silence

National Phobics Society
The anxiety disorders charity



Toilet Phobia

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what is toilet phobia?

Toilet Phobia is rarely just one condition. It is a term used to describe a number of overlapping conditions (see diagram below):



These conditions have one thing in common - everyone affected has difficulties around using the toilet. These difficulties vary but with the right support, the problems can usually be alleviated, reduced or managed.

The fears around the toilet include:

- not being able to urinate/defecate
- fear of being too far from a toilet
- fear of using public toilets
- fear that others may be watching or scrutinising/listening

Due to the nature of this problem, people are often reluctant to admit to the condition or to seek help. Those who do seek help can usually overcome or improve their ability to cope with the problem, even after many years of difficulty. Seeking help is the first step to finding real improvements.

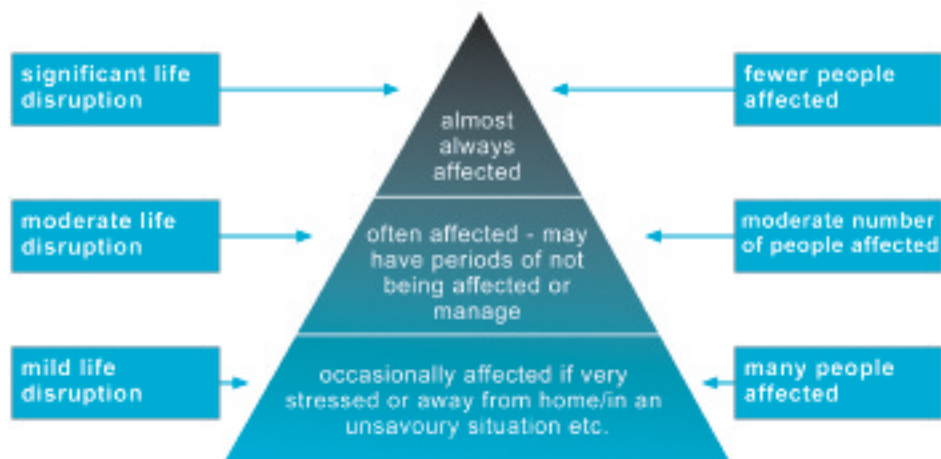
who can be affected?

Almost anyone - Toilet Phobia is not as rare as you may think.

Exact statistics are not known as more population based research is required. However, the British Psychological Society (BPS), the representative body for psychologists and psychology in the UK report that:

Nearly four million people in the UK are unable to urinate in public toilets because of a social phobia commonly called 'shy pee', which can affect relationships, dent confidence and even lead to suicidal feelings

Some people are affected significantly, others moderately and a large number of people are affected mildly as shown in this pyramid:



what causes toilet phobia?

Toilet Phobia and overlapping/inter-related conditions are often caused by:

- Anxiety
- Fear
- Specific experience/trauma
- Learnt behaviour from someone close

does everyone have the same experience of toilet phobia?

Everyone is different, but many of the people with Toilet Phobia share common characteristics:

- Fear of not being able to urinate/defecate
- Fear about the cleanliness of public toilets (this is a form of OCD)
- Fear that others may be watching/able to see you whilst using the toilet
- Fear that others may hear you whilst using the toilet.

No one is exactly the same, so it is important to establish what form of Toilet Phobia affects you, so that you can get the right kind of help.

forms of toilet phobia

Fear of urinating in public places

This fear which is often accompanied by difficulties in urinating is sometimes called 'avoidant paruresis', 'psychogenic urinary retention', or 'shy bladder syndrome'. It is recognised as a form of social anxiety which can develop at any age and can affect men, women and children. This type of Toilet Phobia is more prevalent amongst men probably because of the design of public toilets and the openness of urinals.

Sufferers often think/feel that someone may see or hear them urinating in public or that their motives for being at a urinal may be questioned if they can't urinate. In the main there is not usually a problem at home.

Public toilet facilities anywhere can be a problem at school/college on trains or ships, at work, in pubs or restaurants, on holidays, even friends' homes. Problems usually disappear at home but visitors in the house can cause problems for some. The difficulty largely disappears if sufferers are certain there is no-one else around and they are confident of their surroundings. Sufferers can rarely urinate on demand so giving urine samples for testing is usually not possible. Those affected may change their drink/food habits to try to control when they need to urinate.

Fear of defecating in public places

This fear is known as 'psychogenic faecal retention', 'shy bowel syndrome', 'bashful bowel syndrome' and 'parcopresis'. It is recognised as a form of social phobia. It can affect men, women and children. Sufferers of this problem experience increased anxiety when others are nearby. This increased anxiety causes an increase in muscular tension which in turn, decreases the likelihood of passing a bowel movement. Like avoidant paruresis, those affected often develop 'safe' places such as their homes, and are only able to pass a motion in these places. They therefore feel the need to be close to their 'safe' toilet, which is usually at home. Sufferers may change their diet to try to control bowel movements.

Fear of being unable to use a toilet in public places

This fear is common in women (but not exclusively), especially those who have a history of anxiety and/or panic attacks. Sufferers fear having a panic attack whilst outdoors and being unable to reach a toilet during an episode of panic/peak anxiety. The sufferer can gradually withdraw from society, preferring to stay indoors, or may keep to places where he/she knows there is an accessible public toilet. Alternatively, the sufferer may become obsessed with finding out the locations of public toilets and develop a form of obsessional anxiety. Sufferers may adapt their diet and movements/lifestyle to prevent the risk of needing to have to use a public toilet. This can occur regardless of whether the use of the toilet is to pass a motion or to urinate. The problem is entirely associated with the location and immediate accessibility of toilets.

Fear of using public toilets/contamination issues

This fear is usually associated with worries and concerns about cleanliness and the subsequent possibility of catching germs from toilet seats etc. It is classified as a form of Obsessive Compulsive Disorder (OCD). Whilst public toilets are rarely very clean, most people can use them if need be. Sufferers of this form of Toilet Phobia however go out of their way to avoid using public toilets even if this means ultimately soiling/wetting themselves. This is in contrast to other sufferers who view soiling/wetting themselves a shameful act. Sufferers will often go to great lengths to avoid touching things around toilets, for example, they will only turn off the taps or pull the door open with a paper towel or tissue. This problem can affect men, women and children and again people often change their diet to try to control their use of toilets. Most sufferers feel more in control at home because they are sure of their home's cleanliness.

real life experiences

Toilet Phobia is quite common, but those who suffer from it often feel isolated. Below are some real life experiences from Toilet Phobia sufferers which you may identify with.

murray - rarely goes out and has turned down work

Murray has suffered from shy bladder syndrome and agoraphobia for 50 years. His problem has affected his life dramatically. He refers to his problem as 'life-inhibiting'. His mother used to suffer in a similar way. If anyone was near when she was about to use the toilet she would just flush it and go away.

Murray rarely goes out because of shy bladder syndrome. If he does go out, he finds it extremely stressful. He has to make sure that he knows where the toilets are and that he is away from people. He would rather not go out than deal with the stress. He gets invitations from people but turns them down. He does not want to reveal his problem as he feels this would make him appear weak. He considers himself very sociable but now avoids being with people. He has only recently told his sons about his problem. He wouldn't visit them and they thought he was being unsociable.

Murray can't do anything and this frustrates him as he has always

led a very full life. He has to turn down work as he can't travel. His work always gave him great satisfaction but he feels this has been taken away from him.

If Murray has a hospital appointment he will stop drinking hours before it. He says he knows he is ruining his kidneys but this does not stop his avoidant behaviour although it does add to his anxiety.

Professor Karina Lovell says:

Murray has had Toilet Phobia for a number of years. Many, but not all phobias start in childhood and go unabated for years without effective treatment. The shame that people feel with Toilet Phobia is acute which is demonstrated by Murray who has only recently been able to tell his sons. His phobia has affected many aspects of his life including avoiding going out if at all possible. The safety behaviours that Murray uses when he goes out show the extent to which phobias affect people's lives. Murray, although aware of the dangers, restricts his fluid intake before going out to try to ensure he does not have the urge to urinate when away from home.

What can be done?

Raising awareness of Toilet Phobia will help health care professionals to be more

sympathetic towards people suffering from this condition. Murray may well find Cognitive Behaviour Therapy (CBT) helpful as it would help him to manage his anxiety and enable him to work out a programme, allowing him to take small steps towards achieving his overall goal (i.e. being able to urinate in a public toilet). CBT would explicitly help Murray to challenge and change the unhelpful thoughts and behaviours that he experiences, thereby gradually overcoming his difficulties.

emma - affected since childhood

Emma has had issues around toilets for as long as she can remember. She was bullied at school and there was a particularly unpleasant incident in a toilet after which she developed Toilet Phobia.

Emma's problem is around soiling herself, even though she has never done so. She has developed avoidance techniques around eating and does not go out. She avoids a lot of foods in case it causes her to have problems with her bowels and says she would completely avoid eating, however she needs to eat because the medication that she is on makes her sick if she has an empty stomach. She takes Imodium

every day, increasing the dose if she is particularly anxious and takes it whilst her mother is at work just in case there is an emergency and she is called out to her. Another safety technique Emma uses is the clothes she wears. She prefers winter as she can wear clothes which hide everything and also wears only dark-coloured clothing. Emma has lost contact with most people but always avoided telling people about her problem in case she was considered 'weird'. She is happier to let people know she suffers from anxiety and panic rather than admit to her Toilet Phobia.

Professor Karina Lovell says:

Emma has a severe Toilet Phobia which manifested itself in childhood following a traumatic incident. Her phobia has now extended to all areas of her life, impacting on everything that she does to the extent that she is unable to go out. She also engages in a range of safety behaviours such as taking Imodium and restricting her diet. Emma's case history clearly brings out the element of shame that people feel when they have any phobia (but particularly Toilet Phobia).

What can be done?

Raising awareness of this problem will help other people to

realise that people should not feel ashamed and that these phobias are common. Emma would also benefit from psychological help and CBT is likely to be helpful. Although there are many interventions used in CBT, I would suggest exposure therapy where Emma would be asked to write down all her feared situations and put them from 'highest fear' to 'lowest fear'. Following this we would ask Emma to decide which fear she would be most prepared to tackle from the list and then encourage her (at her own pace) to gradually and repeatedly face the fear until her anxiety reduced and she was no longer fearful. We would continue to work with the hierarchy of fears until the fears that impacted on her life had decreased.

caroline - couldn't even visit her sons

Caroline is 34 and has suffered from emetophobia (vomit phobia) since she was 8 years old. Her Toilet Phobia is more recent. She was brought up by her grandparents and remembers her grandmother always talking about being constipated.

Caroline feels she has developed agoraphobia because of her other two phobias. She will go out but with great difficulty. She always

fears picking up a bug which will make her sick or affect her bowels. Her first marriage ended because of her difficulties and her toilet-related problems became extreme after her second marriage. Caroline finds it distressing using the toilet when her husband is around. She dreads holidays and gets upset with her husband for using the toilet even though they have separate toilets. She has even phoned him at work because she has been so distressed by the thought that he had used the toilet there. They do not have people to the house. There was a brief visit from family at Christmas but this was very difficult and has not been repeated. She manages a trip to her in-laws about once a month.

There are also aspects of Obsessive Compulsive Disorder in Caroline's story and she finds a change in routine very disturbing. If her husband is on holiday or she sees or hears her neighbours, she gets very agitated. She also gets upset if she hears her neighbours using the toilet.

Caroline only eats food that will not make her sick or affect her bowels - mostly carbohydrates.

Professor Karina Lovell says:

Caroline has a severe phobia. Her main fear appears to be centred around 'picking up a bug' which could either result in her

becoming ill or being sick (which she is fearful of), or it affecting her bowels (which she also fears). Caroline's response to this has been to avoid more and more things and this is making her life very difficult. From the case study, it would seem that Caroline's phobia has extended out (we use the word generalisation) because of the stressful life events that she has experienced.

What can be done?

Caroline would benefit from a full psychological assessment to gain a better understanding of her difficulties. It is difficult to ascertain from the case study whether Caroline has OCD, agoraphobia, specific phobia, social phobia or a combination of these problems. As with the other case studies, the best evidence we have for helping these types of difficulties is CBT. In Caroline's case I would want to know more about her difficulties and how they fit together before I recommended a specific treatment plan. However all such plans would be based on working in a collaboratively way - doing things together.

pete - worries about the cleanliness of toilets

Pete suffers from Obsessive Compulsive Disorder and constantly worries about dirt, germs and contamination issues. He thinks he has felt this way since he was six years of age.

Pete lived in Jamaica until he was eleven and thinks his earliest experience of contamination issues was connected with a cousin who used to pull out his milk teeth for him. He remembers becoming very anxious about dirt and germs one time she did this after combing a woman's hair.

Toilets are a particular problem for Pete. He always makes sure he uses the toilet at home before he goes out in order to minimise any need he might have to use a toilet away from home. He will never sit on the seat of a toilet or allow his children to. After he has used the toilet he will only touch taps and door handles if he uses paper towels. If there are no towels available he will use his elbows or even his feet.

If Pete has to use a public toilet whilst out this will result in him being unable to eat afterwards. He won't use a public toilet at all if he feels it is too dirty.

In food shops and take-aways he often finds himself thinking about what the assistants may have been doing before serving the

food, and in particular he worries about their standards of hygiene.

Professor Karina Lovell says:

It is clear from Pete's story that he has Obsessive Compulsive Disorder (OCD) and experiences thoughts (e.g. I will become contaminated from dirt and germs from toilets) and exhibits ritualistic behaviour (e.g. avoids using public toilets, not sitting on any toilets or allowing his children to, avoids touching bathroom taps and doors with his hands).

What can be done?

There is clear evidence in the NICE (National Institute for Health and Clinical Excellence) guidelines that the most effective treatment for OCD is CBT. The treatment that may help Pete would be exposure therapy and response prevention - i.e. gradually and in collaboration with Pete, exposing him to his fear of toilets and asking him to refrain from ritualising until his anxiety reduces. Pete's treatment would also (indirectly or directly) involve his family, particularly his children so that they too are 'allowed' to sit on a toilet.



anxiety and fear: understanding the effects

By Professor Karina Lovell

As described earlier, Toilet Phobia can occur in many different forms. It is clear from the experiences of sufferers that Toilet Phobia affects people in a range of ways. The common factor experienced by all Toilet Phobia sufferers is however, anxiety. To understand how to overcome Toilet Phobia we therefore first need to understand what anxiety is.

Anxiety (or any other emotion for that matter) can be seen to consist of three separate but inter-related parts:

- Things we feel physically
- Things we do or stop doing (behaviours)
- Things we think (cognitions)

Things we feel physically:

When anxious or panicky we experience a number of physical symptoms including a racing heart, butterflies in the stomach, sweating, shaking (either visibly or feeling as though we are shaking) and jelly legs.

Things we do:

This usually includes avoiding, or escaping from situations in which we feel panicky. For example people with Toilet Phobia will often avoid using public toilets. The

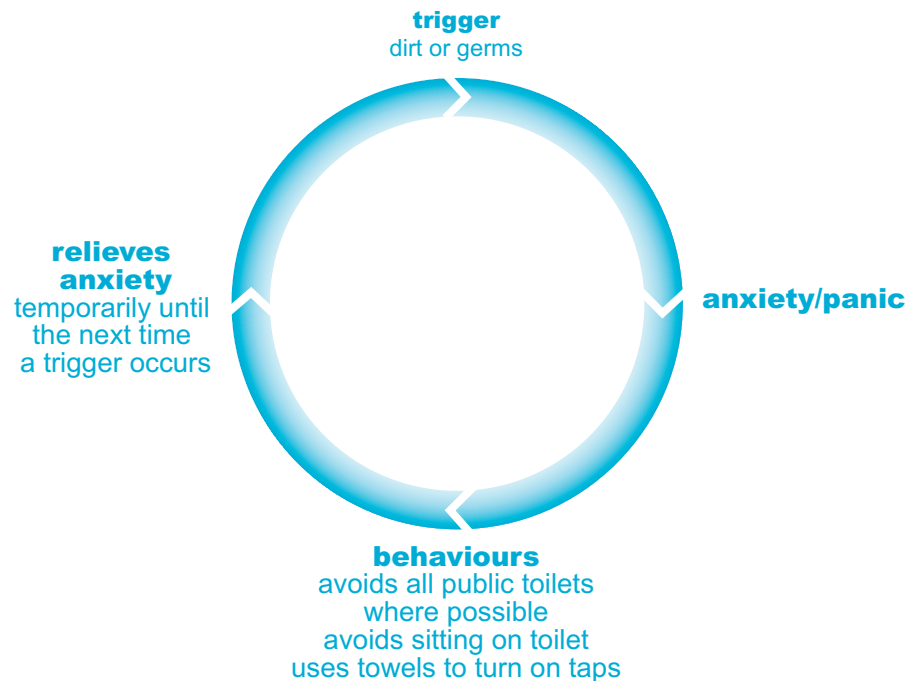
individual experiences of Toilet Phobia outline many of the behaviours that people exhibit when feeling anxious. For example, Murray avoids invites from his friends, Caroline avoids using the toilet if her husband is at home, Emma avoids eating certain foods and Pete avoids public toilets. Murray, Caroline and Emma all avoid going out as much as possible.

Things we think:

When anxious or panicky we often have a lot of unhelpful thoughts. For example Pete's thoughts are focused on becoming contaminated, and Emma's thoughts are focused on her losing control of her bowels.

All these 3 aspects of anxiety are separate but inter-related. For example, Pete fears that he will be contaminated from dirt and germs associated with toilets. Each time this is triggered, he becomes anxious - experiencing physical feelings and unhelpful thoughts which leads to him avoiding certain situations. Avoidance leads Pete to feel less anxious but this relief in anxiety is only temporary until the next time it is triggered. This process is called the vicious circle of anxiety.

the vicious circle of anxiety



The vicious circle

To make this clear I will use another case study to explain the vicious circle of anxiety. Murray has shy bladder syndrome. His fearful situation is using the toilet particularly when other people are around. In this situation or even when thinking about it, Murray becomes anxious and panicky. To relieve this anxiety, Murray avoids going out whenever possible and avoids travel. Murray also uses a number of safety behaviours such

as limiting the amount he will drink before going to specific places - hence avoiding the need to use the toilet. Such avoidance results in a reduction in anxiety. However this reduction is only temporary and reoccurs the next time a similar situation arises.

what types of help are available?

More research is needed on this condition. By improving understanding, we would hope to see improvements in the management of this condition. Currently it is generally accepted that CBT (Cognitive Behaviour Therapy) is the most effective form of management for Toilet Phobia and its associated conditions. However as everyone is different, people may find other methods work for them and so we have included information on other available treatments.

Generally recommended treatment:

- Cognitive Behaviour Therapy (CBT)

Other treatments which may be of use:

- Graded Exposure
- Clinical Hypnotherapy
- Diet
- Relaxation
- Exercise
- Medication

What is Cognitive Behaviour Therapy (CBT)?

CBT is based on the vicious circle of anxiety, as described earlier. It helps people overcome their anxiety by working with people's thoughts and behaviours.

Cognitive restructuring is a way of changing our unhelpful and anxious thoughts by looking at them and challenging them. When we are anxious or panicky we have many unhelpful thoughts such as "I am going to soil myself", "I might pick up a bug and become ill", "I won't be able to urinate in a public toilet". These unhelpful thoughts often stop us doing things that we want to. The more unhelpful thoughts that we have, the stronger they become and then we have even more unhelpful thoughts. It is yet another vicious circle.

The features of unhelpful thoughts are:

- They are automatic - we don't think them on purpose, they just appear in our heads
- They seem believable and real at the time they appear
- They are the kind of thoughts that would upset anybody

There are 3 main stages to cognitive restructuring. These are:

- Identifying exactly what the content of your unhelpful thoughts are
- Doing something to help you examine the thought more objectively. Sometimes this includes collecting 'evidence' as to how accurate the thought really is

- Finally, reconsidering the thought in light of the evidence you have collected. You can then test the thought by doing a brief experiment (like exposure) to see whether it is true or not.

For example, using Emma's story, one of her thoughts is probably centred on the belief that she would lose control of her bowels if she did not take the Imodium when her mother was at work.

In cognitive behaviour therapy we would look at this thought in detail, for example, by asking Emma to rate how much she believed it and what emotions the thought evoked. Emma would then be encouraged to challenge the thought. The simplest way of doing this would be to ask Emma to identify the evidence for and against the thought. Having generated a list of evidence we would ask her to rate the thought again; usually the intensity of the thought reduces following this exercise. We would then try to devise an experiment to test whether the thought was a fact. For example, we might suggest that she does not take the Imodium when her mother is at work and see if her prediction that she would lose control of her bowels is true. We would then challenge other thoughts in a similar manner.

Accessing CBT:

You may have to wait some time for CBT if you want to access it through the NHS as waiting lists are often long. Your GP however may be able to refer you to your local primary care mental health service which usually offers brief therapeutic interventions which are underpinned by CBT.

You can also access CBT through the NPS. We have a team of volunteer trained therapists who offer their time to NPS members at special reduced rates. We are also able to offer CBT over the phone.

CBT can also be accessed privately. For more information on this and to find out about accredited CBT practitioners contact:

The British Association for Cognitive and Behavioural Psychotherapies (BABCP)
The Globe Centre
PO Box 9
Accrington
BB5 0XB

Tel: 01254 875277
www.babcp.org.uk



What is Graded Exposure?

Graded Exposure means gradually facing your fear until anxiety falls. From the vicious circle of anxiety we know that avoidance, escape and undertaking other safety behaviours reduce anxiety but only on a short term basis. We know that confronting anxiety will lead to it decreasing on its own (usually within 40 - 60 minutes). However, exposure is not about confronting your biggest fear in one go, it is about starting with your smallest fears; facing them systematically and gradually- hence the term 'Graded Exposure'.

If you want to use Graded Exposure it is helpful to list all the situations you avoid from the least difficult to the most difficult. The most important thing about Graded Exposure is that it should be practiced regularly (every day if possible). It is also helpful to have support from friends/family members.

In Emma's experience, her lowest fear might be to resist taking Imodium when her mother is at work and her largest fear might be going out and eating a meal. If Emma resisted taking the Imodium whilst her mother was at work and tolerated the subsequent anxiety, it would reduce gradually. If she

did this every day for a week or so, it would be likely that her anxiety would have reduced to the extent that she would feel confident that she was not going to have a problem with her bowels and could then move onto the next fear.



What is Clinical Hypnotherapy?

Some people find this form of therapy helpful as it focuses on bringing about deep levels of relaxation and therefore helps reduce levels of stress and anxiety. Clinical Hypnotherapy is not the same as Stage Hypnosis and should be practised by an experienced Clinical Hypnotherapist.

Accessing Clinical Hypnotherapy:

If you are a member of NPS you can access our in-house therapy service for Hypnotherapy and the other related therapies, such as the Fast Phobia Technique, Neuro-Linguistic Programming (NLP), Eye Movement Desensitisation and Reprocessing (EMDR), Thought Field Therapy (TFT), Emotional Freedom Techniques (EFT) and a range of other holistic therapies such as aromatherapy, reflexology etc.

Some people find Reiki, Yoga and other complementary therapies useful.

For further information please call the helpline on 0870 122 2325 or visit our website:
www.phobics-society.org.uk

You can also access Hypnotherapy privately through the British Society of Clinical Hypnosis (BSCH)
Tel. 01262 403603
www.bsch.org.uk

Diet

Some people find that their diet is a particular problem due to the connection between eating and needing the toilet. Many sufferers adapt their eating habits to accommodate their fear of needing to use a toilet. Some people may avoid eating at all if they can whilst others will only eat certain types of food they know will not affect them. Some sufferers will reduce their fluid intake or completely avoid fluids at certain times.

It is important to try to eat a sensible, balanced diet and it is recommended that sugar fixes and caffeine are avoided. Drinking water is beneficial but again this is poses a problem for sufferers of Toilet Phobia. However, good nutrition and fluid intake underpin good health. If you are physically

unhealthy this can lead to weakness and tiredness which in the long run can make anxiety worse.

How can relaxation help?

Relaxation training is a technique that aims to reduce physical tension in the body. It also helps to lower the heart rate, blood pressure and slow down the rate of breathing. People may experience a feeling of well-being and tranquillity. Relaxation Training for many is a very valuable and life-long skill to acquire. There are many teach-yourself videos, DVDs and tapes available to buy where you can learn relaxation techniques.

The NPS shop has a varied selection of such products - visit our website at:
www.phobics-society.org.uk

How can exercise help?

We all know that exercise keeps us not only physically healthy, but mentally healthy as well. Any exercise will release the body's natural endorphins creating a feel good 'buzz' and raises self-esteem. Exercise also helps to lower stress levels and therefore aids the management of anxiety.

There are numerous exercise books, DVDs etc. which can help you put together an exercise plan which can then become part of your daily life.

How can medication help?

Like most anxiety disorders, medication (usually antidepressants), may be of help. You should discuss this possibility with your GP. NPS has a Psychiatric Pharmacy Helpline which offers information and advice on any form of psychiatric medication to its members.

Can I talk to others who will understand?

Gaining support from other people is often extremely useful in beginning to manage an anxiety condition. Talking to other people who have had similar experiences can be the first step to acknowledging and seeking help for a problem. Talking takes away the need to explain or justify your anxiety and most importantly for Toilet Phobia sufferers, it reduces the embarrassment experienced. Many people benefit greatly from support groups, as well as from internet support and information websites.



NPS operates a chat room and an online bulletin board for its members, where you can meet other anxiety sufferers and share knowledge, experiences and coping mechanisms. You can become an NPS member by visiting our website or by calling us on 0870 122 2325. There is a small fee per annum to join.

real life experiences

"If we go in a pub/ restaurant I always need to know where the loos are and I hate it if there is a queue in the ladies as this adds to my anxiety. Toilet Phobia affects our plans for holidays or days out to places I'm not familiar with."

"I can afford to do lots of things; I am qualified to do lots of things; but I am unable to do anything."

"I have had to inform my doctor because he was trying to get me to eat breakfast, which makes me need to go to the loo and inhibits my travelling to work."

"My sons live far away but I could not visit them and they thought I was being unsociable"

"I will stop drinking hours before an appointment. I know I am ruining my kidneys but it doesn't matter"

"After using the toilet I will only touch the taps or doors if I have a paper towel. If I don't have a paper towel I will use my elbows or feet"

"Toilet Phobia affects my life greatly. I am always planning when it's going to be 'safe' to go to the toilet and make sure no-one knows where I'm going. Holidays are a particular problem as I find it impossible to 'go' when someone else is in the room."

"It's like being in a prison - but an invisible one"

"I cannot go abroad as I am not sure what the toilet situation might be in any town I visit. My wife would love to go to Paris but I cannot bear the thought of it"

"I have not told anyone, even my husband"

"I would rather be considered unsociable than to tell people the truth"

"My problem is life-inhibiting and I live a deviant life"

"I have curtailed any promotion chances I have at work as it may involve travelling to meet clients"

success stories

We are all different and experience anxiety uniquely. Similarly people have a variety of experiences of treatment:

"I have been seeing a CBT practitioner and have found that I am more able to challenge my behaviours and face my fears around Toilet Phobia"

"I have made contact with another sufferer through NPS. This has helped enormously as the support we give each other is invaluable. Talking to someone who understands has been a big step forward."

"The thing that really helped me was Clinical Hypnotherapy"

"I did an Anxiety Management course which I found really helpful and it helped me to realise the social aspect of my problem"

"I had telephone counselling therapy with NPS which helped me to learn methods of dealing with general anxiety and Toilet Phobia"

"I tried Reiki and learned to do it for myself. I find this quite helpful"

"I have been receiving help now for the last 3 months from a psychologist. He is fantastic and already I know he has helped me so much. I have gone from not being able to go out of the gate where I live, to now being able to walk around the block all on my own. Some days are better than others but now I have the support from the right people, I believe that I can beat this. I know I am at the beginning of a long journey to recovery but I now believe that there is light at the end of the tunnel"

"I correspond with a pen-pal I found through the internet, which has been really helpful and comforting. Although he doesn't suffer from Toilet Phobia he is very understanding as he suffers from panic attacks"

"I eventually got NHS Cognitive Behaviour Therapy after a considerable wait. This was useful in giving me coping techniques"

"At the moment I am trying to help myself by slowly exposing myself to my fear. So, for example, building up the amount of time I can last on the train and stopping myself constantly going to the toilet before I travel"

your next step

If you recognise, or are affected by any of the symptoms or difficulties in this booklet please don't delay seeking help.

Toilet Phobia is not a sign of weakness. Whatever the cause of your difficulty, you do not need to be alone with Toilet Phobia; help is available.

Call the NPS helpline - in total confidence on **0870 122 2325**

NPS' Commitment

We are committed to providing information and support for anxiety sufferers. Furthermore we are committed to alleviating the distress caused by anxiety and to help develop greater understanding of anxiety disorders and their treatment. We support many people with toilet-related anxiety problems and know that due to the particularly distressing and embarrassing nature of this problem, people are often reluctant to seek help. We hope that this guide will go some way to explaining Toilet Phobia, how it manifests itself and what can be done in terms of self-help and treatment.

We would like to express our thanks and appreciation to all those who helped in the compilation of this booklet, particularly those who gave their personal experiences. The contributions of everybody involved have been invaluable.

Acknowledgements:

The Lewis Family Charitable Trust is pleased to support the National Phobics Society in its national project highlighting the incidence, effects and treatment of this important condition 'Toilet Phobia'. In doing so, they hope to support those affected, their families and professionals.

This information has been compiled by Pauline Gregson, Clare Mayo and Nicky Lidbetter of the National Phobics Society with editorial support from Professor Karina Lovell of The University of Manchester.

glossary

Agoraphobia	Agoraphobia is a complex phobia usually manifesting itself as a collection of inter-linked phobias. For example, many agoraphobics fear being left alone (monophobia), dislike being in any situation where they feel trapped (exhibiting claustrophobia type tendencies) and fear travelling away from their 'safe' place - usually the home. Some agoraphobics find they can travel more easily if they have a trusted friend or family member accompanying them, however this can quickly lead to dependency. The severity of agoraphobia varies between sufferers from those who are housebound, even room-bound, to those who can travel specific distances within a defined boundary.	Graded Exposure	A treatment method based on the idea that a therapeutic effect is achieved when sufferers confront their fears in a systematic manner, discontinuing the escape response.
		NHS	National Health Service
		NICE	National Institute for Health and Clinical Excellence
		NPS	National Phobics Society
		OCD	Obsessive Compulsive Disorder. An anxiety disorder based on obsessions, compulsions and rituals.
		Panic Disorder	An anxiety disorder characterised by repeated and apparently unprovoked panic attacks. A panic attack is a period of intense fear or psychological distress, typically of abrupt onset. Symptoms may include trembling, shortness of breath, heart palpitations, sweating, nausea, dizziness and hyperventilation.
CBT	Cognitive Behaviour Therapy is a treatment option for anxiety. The focus is on specific psychological and practical skills (e.g. in reflecting on and exploring the meaning attributed to events and situations and re-evaluation of those meanings) aimed at enabling the client to tackle their problems by harnessing their own resources.	Parcopresis	Parcopresis can be described as the inability to defecate when other people are perceived or likely to be around (e.g. in the same public toilet, the same house, or the same building). This inability limits the sufferer to being able to defecate only in a limited number of 'safe' places thus restricting their lifestyle.
Clinical Hypnotherapy	A treatment that attempts to address the client's subconscious mind. Hypnotherapists often (but not exclusively) require the client to be in a relaxed state, enlisting the power of the client's own imagination and may utilise a wide range of techniques from story telling, metaphor or symbolism to the use of direct suggestions for beneficial change. (General Hypnotherapy Register).	Paruresis	Paruresis is also known as pee shyness, shy kidney, bashful bladder or shy bladder syndrome. It is a type of social anxiety disorder, that can affect both men and women, in which the sufferer is unable to urinate in the (real or imaginary) presence of others, such as in a public restroom.
Cognitions	Mental processes such as memory, attention, perception, action, problem solving and mental imagery and emotion. Also includes one's awareness of strategies and thoughts.	Social Phobia/Social Anxiety	Social anxiety is an experience of fear, apprehension or worry regarding social situations and being evaluated by others. People vary in how often they experience anxiety in this way or in which kinds of situations. Anxiety about public speaking, performance, or interviews is common. Social anxiety disorder or social phobia, is an anxiety disorder involving overwhelming anxiety and excessive self-consciousness in everyday social situations. People experiencing social anxiety often have a persistent, intense, and chronic fear of being watched and judged by others.
Defecate	The act or process by which humans eliminate solid or semisolid waste material from the body.	Toilet Phobia	A term used to describe a range of anxiety related conditions associated with the use of the toilet
Emetophobia	An excessive or irrational fear of vomiting or of being around others who are vomiting. Sufferers are known as Emetophobics and are known to go to great lengths to avoid people who may be sick or where a threat of infection is perceived	Urinate	The passing of urine
Generalisation	A premise about a sample is applied to a conclusion about the population e.g. I had a bad experience in one toilet - I will have a bad experience in all toilets.		