

UKPT Confidentiality Statement

Our Commitment

The UK Paruresis Trust started in 2002 as a group of people experiencing, or having experienced, avoidant paruresis. We organised ourselves into a self-help charity to help people cope with urinary dysfunction that has a psychological or social origin. We now aim to provide information and relief for adults experiencing the social anxiety Avoidant Paruresis (aka Shy Bladder Syndrome), particularly by:

- the provision of internet based information and support
- the promotion and provision of local support groups
- the provision of desensitisation workshops
- the promotion of the concept of individual privacy in the design of public toilets
- the promotion of research into all aspects of the condition, particularly its cause and treatment
- the raising of public awareness, including that of the medical profession.

We want to provide an efficient and high quality service. We aim to be open and accessible, and to provide information quickly and politely. Confidentiality is fundamental to our work and we want everyone using our services to feel confident that any personal information they share with us will be treated in confidence and with respect.

As a general principle the organisation keeps minimum information about all users of its services. This may be just email contact details if the individual attended a workshop, and a record of any feedback received post-workshop.

Your electronic personal details will be stored sensitively on a private password protected computer and in accordance with the Data Protection Act 1998. We will not sell or share your personal details with anyone, nor will we use them without your permission, unless directed to do so by a court of law.

Some people remain in occasional contact with UKPT over a number of years. For that reason, we will keep your contact details on file unless you ask us to destroy them.

The Data Protection Act 1998

The Data Protection Act 1998 is concerned with personal privacy and regulates how information about living individuals may be collected, used, retained and disclosed. It applies to all personal data, whether it is in manual or electronic format. The UK Paruresis Trust is registered as a data controller with the Information Commissioner's Office.

Under the Act, individuals have the right to be informed whether personal data held about them is processed, a description of the data held, the purposes for which it is processed and to whom the data may be disclosed. They are also entitled to a copy of all the data held, and information as to its source. Anyone wishing to see the information held about them by UKPT should contact the Chair.

Workshop confidentiality

Respecting confidentiality is an essential part of working with people who experience paruresis, and this is particularly true of workshops. Group workshops offer a safe place for those who experience paruresis to disclose issues which cause them difficulties and/or distress, and it can be particularly liberating for people who have never spoken about their urination problems before.

Confidentiality will be discussed and agreed at an early stage in each workshop so that participants have a clear understanding of the issue, and can make an informed decision how much personal information they wish to share with workshop leaders and with other participants.

Any digital photographs taken at the end of a workshop will only be used as a record-keeping reminder for workshop facilitators as a reference tool for any future contact with the individual. No photographs or names of attendees will be displayed publicly or on social media.

Any filming undertaken for purposes such as training video media will protect the identity of any participants unless otherwise specified. No-one's identity will be revealed without their express permission, and there will be no pressure for anyone to disclose their identity.

Online discussion board confidentiality

It is each individual's decision how much personal information they choose to disclose on the online discussion boards. The level of anonymity they wish to attribute to any discussion board postings is also their own decision. The moderators of the board will not compromise that information.

Email confidentiality

Some people email the organisation with a personal query which they are not willing to put on the discussion boards. Any subsequent email exchange will be confidential. On rare occasions, however, information about an individual's situation may need to be shared in a purposeful and considered way, eg with a health professional or trustees in order to be able to provide the individual with a more meaningful response. Should this be considered to be in the individual's best interests, the minimum effective information will be shared with the professional on a need to know basis. This will be done privately and anonymously so that the individual will not be identified.

The UK Paruresis Trust will ensure that trustees and volunteers are kept up to date with current legislation and guidance around issues of confidentiality.

All trustees and volunteers are expected to observe the principles of this statement.

The trustees will keep the issue of confidentiality under review, and will ensure that any volunteers are adequately briefed and supported to handle the issues that confidentiality poses.

Our contact details:

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Chairperson: Andrew Smith