

TOURETTE SYNDROME AND SOCIAL TABOOS - LIVING WITH COPROPHENOMENA

COPROPHENOMENA. THE INVOLUNTARY EXPRESSION OF SOCIALLY UNACCEPTABLE WORDS OR GESTURES, IS OFTEN A WORRYING PROSPECT FOR PEOPLE LIVING WITH TOURETTE SYNDROME. HOWEVER, IT IS POSSIBLE TO A LEAD A HAPPY AND SUCCESSFUL LIFE EVEN WITH THIS SYMPTOM.

WHAT IS COPROPHENOMENA?

Coprophenomena (kop-ruh-FEH-nomun-nuh) is the involuntary expression of socially unacceptable words or gestures which affects around 10-30% of people with Tourette syndrome (TS).

Public awareness and social media content showing coprophenomena in an exaggerated and stereotyped way has led to false beliefs and increased stigma around TS, making it very distressing if you are living with TS and trying to manage your condition. There is help available to manage symptoms of coprophenomena and minimise its impact on your everyday life.

uncontrollable need to use by choice and doesn't represent Coprophenomena can be experienced in different ways:



Uncontrollable spoken or shouted out words and phrases with sexual meanings (called obscenities) and/or swear words with religious meaning (called profanities) that are not always clear.



MENTAL COPROLALIA (KOP-RUH-LAY-LEE-UH)

Obsessively thinking of obscenities and profanities.



Uncontrollable performance of obscene gestures. This type of coprophenomena is around 3 times less common than verbal coprolalia.



(KOP-RUH-GRAF-EE-UH) A compulsion to write down, type or

text obscenities and profanities or draw inappropriate images.

Your experience of coprophenomena is likely to change over time. It may be that a gesture or word disappears for several months and then re-appears again, but coprophenomena is not always a permanent symptom.



WHO DOES COPROPHENOMENA AFFECT?

Children and adults can experience coprophenomena, but as with other symptoms of TS, it usually begins in childhood.

Some people are more likely to experience coprophenomena than others. The condition is more common if you are male and have:



WHY DOES COPROPHENOMENA HAPPEN?

It's not fully understood why coprophenomena happens in some people with TS, but it's thought to be a communication problem in the brain. The brain is complex and made up of multiple areas, each of which has its own role. With coprophenomena, it's thought that the part of the brain which filters unwanted movements gets temporarily interrupted.

DID YOU KNOW?

Feeling stressed or anxious can make coprophenomena happen more often.



Treatments for coprophenomena are very similar to treatments for other forms of tics. In some cases, a doctor may be able to prescribe medications aimed at reducing tics. You may also find behavioural therapy helpful, which includes:

Habit Reversal Therapy

Training to improve awareness of tics and when they are about to happen and learning to use a different behaviour or action instead of the tic.

Comprehensive Behavioural Intervention for Tics

An expanded version of Habit Reversal Therapy that also includes learning to relax and managing the situations that make tics worse.

Exposure and Response Prevention

Gradually facing situations that are likely to bring on tics while resisting the urge to tic, ultimately building better urge control over time.

Tourettes *

ARE THERE ANY DAY-TO-DAY THINGS I CAN DO TO HELP ME?



If you have copropraxia (tics that involve gestures), you may find that wearing long sleeves or items of clothing that cover specific areas where the gestures occur may help you feel a sense of control and reduce self-consciousness.



Talking to people about TS so that they understand that the condition is not something you are in control of can provide you with a sense of empowerment. By openly talking about TS to your employer/teacher, less familiar friends and family members can be helpful not only for you, but for them too.



You may find having one of our Tourettes Action identity cards helps you to explain what TS is and feel more confident in public places.



You are not alone. Reaching out to others with coprophenomena and understanding how they manage their tics can help you feel supported and part of a wider community. Come along to a Tourettes Action support group to meet people or sign up to our **online groups.**

WHERE CAN I GET MORE INFORMATION ABOUT TREATMENT?



Support for coprophenomena often involves a range of specialist healthcare professionals such as neurologists, psychologists, psychiatrists, psychotherapists and specialist nurses. Tourettes Action have a list of registered therapists who work in both the NHS and privately. Reach out to our Helpdesk or email help@tourettes-action.org.uk if you would like a copy of the list.

DID YOU KNOW?

At Tourettes Action we produce lots of factsheets about TS. You can find more detailed information about treatment for TS in our other factsheets:

- Medical options for Tourette syndrome
- Therapy Options for Tourette syndrome



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