

PAIN AND TOURETTE SYNDROME

PAIN CAN BE PART OF DAILY LIFE FOR SOME PEOPLE LIVING WITH TOURETTE SYNDROME (TS), BUT THERE ARE THINGS YOU CAN DO TO MANAGE PAIN AND ITS IMPACT ON YOUR WELLBEING

Biting the inside of your mouth, swinging your arm out wildly or jerking your head repeatedly are all examples of tics people with Tourette Syndrome (TS) can have. Tics like these can be painful to your body.

It can be frustrating to know what is causing a pain, but not to be able to stop it. If pain continues for a long time, it can feel overwhelming, but there are things that can be done to help.

HOW COMMON IS PAIN IN PEOPLE WITH TS?

Most people with TS feel some physical discomfort due to their tics and many people will experience pain due to their TS. Common areas for people with TS to feel pain are the neck, back, throat, shoulder, eyes and joints, but often pain occurs in more than one place at a time. Unfortunately, pain caused by TS can have a negative effect on mood, sleep and general enjoyment of life.

WHY IS TS ASSOCIATED WITH PAIN?

TS symptoms can cause pain in a variety of ways:

- **The physical effort of tics can cause muscle and joint pain (or nose and throat pain in the case of vocal tics)**
- **Repetitive tics can cause repetitive strain injury**
- **Physical injuries can occur, e.g. jerking your arms or head**
- **For some people, the premonitory urge (the feeling you get before a tic) and the act of trying to suppress a tic can be painful**
- **People with TS are more prone to headaches and migraines, which are also painful conditions**

DID YOU KNOW

...that people with TS may be more sensitive to pain than those without tics? The exact reason for this is not known, but one theory is that their bodies can't filter out harmless sensations as well as other people's bodies can. Another theory is that the body's nerve sensors for detecting sensations do not always communicate properly.

PREVENTING PAIN



Some pain can be avoided or lessened by using tactics that either change the tic or prevent the tic from hurting. People from the Tourettes Action community shared strategies they use to help lessen the impact of pain caused by tics and here are some of their suggestions:

- tic softly and slowly if you can
- try to find alternative tics that are less painful (e.g. substitute closing your eyes tightly for painful eyerolling tics)
- if your tics only hurt while you are walking, try to stop walking to release tics, then carry on
- sometimes hitting tics can be replaced with muscle clenches, in the area you would have hit or try to hit a less sensitive area (e.g. leg instead of groin)
- for finger-flicking tics, try using plasters to protect your skin
- support your neck during coughing fits
- try using a soft, padded collar when neck tics are bad
- chew on a plastic ring instead of your mouth try using a gum shield for gnashing teeth tic



TREATING PAIN

Living with pain can be difficult – it might make you feel frustrated, hopeless or even angry at times. However, there are options available to treat pain. You don't need to suffer in silence.

In addition to medication, there are a number of different services available to people living with persistent pain, some of which are described below. If your GP is not sure what to do about your painful tics, it might be helpful if you have an idea of what you feel might work for you, so that you can ask for a referral to that service.

PAIN SPECIALISTS

Many hospitals have specialist pain clinics, where people with pain can go for an assessment, treatment and advice on managing their pain. On attending a pain clinic, you may be seen by a medical doctor with a particular interest in pain or they may have a team of specialists, including physiotherapists, psychologists and occupational therapists.

PHYSIOTHERAPISTS

Physiotherapists may be able to recommend exercises or give you advice on posture to help alleviate pain. The website of the Chartered Society of Physiotherapy offers information on the different routes to accessing physiotherapy:

www.csp.org.uk/public-patient

OCCUPATIONAL THERAPISTS

Occupational therapists aim to enhance people's ability to participate in the activities of everyday life. This can be achieved by making changes to the environment (e.g. using aids or adaptations to your home or workplace) or by adapting the activity to make it easier for that person to participate. The British Association of Occupational Therapists provides further information on occupational therapy: www.rcot.co.uk

PSYCHOLOGIST

Psychologists work with people who experience pain to develop understanding and strategies which may help them to understand unhelpful patterns and perceptions such as thoughts and response. The psychologist may help build adaptive techniques with more effective thinking and behavioural responses which emphasise coping and improved day to day life based on the person's own goals. The British Psychological Society has more information on psychological therapies: www.bps.org.uk



→ TREATING PAIN AT HOME

Before you decide to try any therapy, always discuss it with your doctor to make sure it's right for you. Here are some strategies for treating pain at home that you might like to try:

- use hot water bottles, deep heat gel, heat lamps or cold packs on sore muscles
- suck ice for mouth ulcers caused by mouth tics or use ulcer gel
- stretching and exercises can help painful muscles or joints
- TENS machine (Transcutaneous Electrical Nerve Stimulators), a device which eases pain in some people by delivering small electrical pulses to the painful area via sticky pads placed on the skin

COPING WITH PAIN

If treatment is not available or you choose to manage the pain on your own, there are things that you can do to lessen the impact that pain can have on your life. Learning to relax your muscles, learning to pace yourself and finding an exercise that you enjoy can help. Find what works for you but make sure that you get medical advice to ensure that any exercise you choose won't make the pain worse.

Here are some activities you could try:

- practice relaxation skills, such as breathing techniques and meditation
- exercising in a way that you find fun and energising
- have a warm bath or shower
- find a distraction, such as a favourite TV programme or playing/listening to music
- massage, either from a family member or a professional or by yourself
- try asking someone to hold or support your head to get temporary relief from neck or head tics

OTHER INFORMATION

PAIN MANAGEMENT PROGRAMMES

Pain management programmes may be available in your area. These aim to improve quality of life for people in pain, rather than treat the pain itself.

To access these, you can ask your GP to refer you to your local pain clinic for a free self-management course on managing pain. More information about NHS pain services can be found at www.nhs.uk/live-well/pain/how-to-get-nhs-help-for-your-pain

You might also consider trying meditation. Apps such as Headspace – www.headspace.com/meditation/pain – and Calm – www.calm.com – have guided meditations designed to help with pain.

ORGANISATIONS OFFERING ADVICE ON PAIN

Pain Concern

A national charity providing information and support for pain sufferers and those who care for them. Their services include free leaflets and a helpline.

www.painconcern.org.uk

Action on Pain

A charity providing advice for people affected by chronic pain. They also have a helpline.

action-on-pain.co.uk

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