

Pain and Tourette Syndrome



Chewing the inside of your mouth, swinging your arm out wildly or even punching yourself in the chest are all examples of tics people with Tourette Syndrome (TS) can have. Tics like these can be painful to your body.

It can be very frustrating to know what is causing a pain, but not to be able to do anything about it because the tics are involuntary. If pain continues for a long time, it can feel overwhelming.

Tourettes Action talked to people in the TS community about strategies they use to help lessen the impact of pain caused by tics

Preventing pain

Some pain can be avoided or lessened by using tactics that either change the tic, or prevent the tic from hurting. Here are some suggested strategies for preventing pain:

- chew on a plastic ring instead of your mouth;
- find alternative tics that are less painful (eg. substitute closing your eyes tightly for painful eye-rolling 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 (eg. leg instead of groin);
- for finger-flicking tics, try using plasters to protect your skin;
- support your neck during coughing fits;
- tic softly and slowly if you can;
- use a soft, padded collar when neck tics are bad;
- use a gum shield for gnashing teeth tic.

Treating pain

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.

Many hospitals have specialist pain clinics, where people in 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 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

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 (eg. 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.cot.co.uk

Here are some suggested strategies for treating pain at home:

- 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). These deliver small electrical pulses to the body via electrodes placed on the skin. This is thought to help ease pain and is sometimes used for pain relief in early stages of labour.

Before you decide to try any therapy, discuss it with your doctor to make sure it won't do you any harm. It's also a good idea to talk to the therapist and get an understanding of what they hope to achieve, how long it should take and how much it might cost.

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, learning to pace yourself and finding an exercise that you enjoy can help.
- Some people may find that they have to take a step back and look at what changes they could make to their life to lessen the disruption that pain can cause.
- 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.

Suggested activities

- find a distraction, such as a favourite TV programme or playing/listening to music;
- massage, whether by yourself, from a family member or from a professional;
- to get temporary relief from neck or head tics, try asking someone to hold or support your head;
- have a bath or hot shower;
- exercise; and,
- practice relaxation skills, such as breathing techniques and meditation.

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, or contact the Expert Patient Programme to find out if their Persistent Pain Programme has a course running in your area. www.expertpatients.co.uk

Other information

- A BBC report on mindful meditation to manage chronic pain can be downloaded at www.bbc.co.uk/news/health-16406814
- A study carried out by Manchester University discusses the use of meditation to reduce the emotional impact of pain: www.manchester.ac.uk/aboutus/news/archive/list/item/?id=5801&year=2010&month=06

The following organisations offer advice on pain:

- **British Pain Society** - A society promoting education, training, research and development in all fields of pain. www.britishpainsociety.org
- **Expert Patients Programme** - The EPP is a self-management course giving people the confidence, skills and knowledge to manage their condition better. www.expertpatients.co.uk
- **Pain Concern** - A national charity providing information and support for pain sufferers and those who care for and about them. Their services include free leaflets and helpline. www.painconcern.org.uk
- **The Pain Relief Foundation** - A charity which funds research into the causes and treatment of human chronic pain and is concerned with education of health professionals about pain management. www.painrelieffoundation.org.uk
- **Patient Advice and Liaison Services** - PALS, provides information about the NHS, helps resolve concerns or problems when you are using the NHS and provides information about the NHS complaints procedure and how to get independent help if you decide you may want to make a complaint. Each area has its own local PAL Service, which you can find by visiting the NHS website. www.nhs.uk/Service-Search
- **NHS Direct** - Information from the National Health Service on conditions, treatments, local services and healthy living: www.nhs.uk