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Persistent Idiopathic Facial Pain

This leaflet is from the British society of oral medicine (www.bsom.org.uk) and has been written to help you understand more about persistent idiopathic facial pain (also called atypical facial pain, chronic facial pain or persistent orofacial pain). It tells you what persistent idiopathic facial pain is, what causes it, what can be done about it, and where you can find more information.



What is persistent idiopathic facial pain?

Persistent idiopathic facial pain is a chronic (long term) pain condition in which continuous deep pain is felt on the face or in the mouth. Idiopathic means that the cause of the condition is not fully known. The pain lasts a long time and is difficult to treat. The pain is not usually eased by common pain killers e.g. *paracetamol*. When the face, mouth or jaws are examined no disease or abnormality is found. Persistent idiopathic facial pain is an uncommon condition; Men and women are equally affected.

What causes persistent idiopathic facial pain?

The cause of persistent idiopathic facial pain is unknown. In some people, the pain starts after they have had surgery, dental treatment or an injury to the face or mouth. Instead of the pain stopping, it continues even when everything has healed. Recent research has suggested that the pain conducting nerves of the face or mouth may become overly sensitive in this condition.

Is persistent idiopathic facial pain hereditary?

Persistent idiopathic facial pain is not thought to be a hereditary condition.

What are the symptoms of persistent idiopathic facial pain?

The pain in persistent idiopathic facial pain can be a dull ache, crushing sensation, burning sensation or throbbing in the face or mouth. The pain may not always stay in one area but may radiate to other parts of the face. The pain is usually continuous but may vary in severity. It does not usually ease on taking common pain killers. The pain is usually unilateral (on one side of the face only). Sometimes patients with this condition have other symptoms which include neck pain, back pain, irritable bowel and itchy skin.

What does persistent idiopathic facial pain look like?

There are no outward physical signs of this condition. People with persistent idiopathic facial pain can have a normal, healthy face and mouth. The lack of outward signs of this condition can make it hard for others to understand this condition.

How is persistent idiopathic facial pain diagnosed?

There is no diagnostic test for idiopathic facial pain, so the diagnosis relies largely on your description of your symptoms and by examination of the face, neck, jaw, mouth, teeth and gums to rule out any disease or abnormality. Radiographs (X-rays) or scans of the teeth, jaw, neck or brain may be required but are not necessary in all cases. Blood tests may also be required in some cases to exclude other causes of facial pain.

Can persistent idiopathic facial pain be cured?

Persistent idiopathic facial pain cannot be cured. The aims of treatment are to reduce the severity of pain and to help you manage your symptoms. There are no known long-term or serious health problems associated with persistent idiopathic facial pain but due to the burden of persistent pain you may be affected by irritability, anxiety, low mood and depression. This should be openly discussed and your pain specialists or doctor will ask about mood and other mental health conditions during consultations.

How can persistent idiopathic facial pain be treated?

- Treatment of persistent idiopathic can be challenging and is best undertaken initially in a specialist unit. A multi-disciplinary (many different specialists) approach may have the most success.
- Treatment may involve medication such as low dose antidepressants e.g. *nortriptyline* or selective serotonin reuptake inhibitors e.g. *sertraline*. These medications aim to reduce the severity of the pain by reducing the sensitivity of the nerves controlling the pain.
- Other treatments include cognitive behaviour therapy and pain management programmes which are designed to help you cope with your long term symptoms.
- Alternative or complementary therapies may also be considered as part of a comprehensive pain management plan.
- Further information on treatment options is available through the British Pain Society (links below).

What can I do?

- Learn about chronic pain and its management. This will assist in your management of your own pain symptoms. Discuss all concerns about the diagnosis and management of your persistent idiopathic facial with the pain team. This will ensure that you are involved in pain management decision making and you will receive the most appropriate care.

- If you find that you are feeling sad or unable to cope with your condition, you should seek professional help. It is common for people with painful conditions to develop a low mood, and there is treatment available to help.
- Keep active and try not to let the presence of pain impact on your daily activities. Make sure you set aside time to do pleasurable activities and reward yourself if you have coped well with the day. These types of measures have been shown to be more effective than any medication

If you are given medication please take it regularly and be patient as it may take several weeks to improve symptoms.

- Continue to visit your dentist regularly and maintain good oral hygiene to prevent any tooth decay or gum disease which may make pain symptoms worse.

Where can I get more information about persistent idiopathic facial pain?

There are a number of sources of information on facial pain conditions. It is important that when searching on the internet information is gathered from reputable and, accurate, medical and dental websites. Listed below are a few links to such websites and recommendations on available publications.

Information on Persistent Idiopathic Facial Pain

International Association for the Study of Pain - http://www.iasp-pain.org/AM/Template.cfm?Section=Fact_Sheets4&Template=/CM/ContentDisplay.cfm&ContentID=14459

The Facial Pain Association - <http://www.fpa-support.org/2011/01/headache-and-chronic-facial-pain>

Persistent Idiopathic Facial Pain- Stanley J Krolczyk, DO, RPh; Chief Editor: Robert A Egan, MD - <http://emedicine.medscape.com/article/1142187-overview>

International Headache Society Headache Classification Subcommittee of the International Headache Society. The International Classification of Headache 6

Disorders: 2nd edition. Cephalalgia. 2004;24 Suppl 1:9-160. http://ihs-classification.org/en/02_klassifikation/04_teil3/13.18.04_facialpain.html

Information on Pain Management

British Pain Society http://www.britishpainsociety.org/book_understanding_pain.pdf

Pain Management Programme http://www.britishpainsociety.org/book_pmp_patients.pdf

Pain Medications http://www.britishpainsociety.org/patient_publications.htm

Explain pain - David S. Butler and G. Lorimer Moseley (2003) Noigroup Publications, ISBN-10: 097509100X and ISBN-13: 978-0975091005 <http://www.noigroup.com/en/Product/EPB>

Overcoming Chronic Pain. Frances Cole, Helen Macdonald, Catherine Carus & Hazel Howden-Leach (2010) London: Robinson ISBN 978-1-84119-970-2 http://www.britishpainsociety.org/patient_suggest_reading.htm

Manage your pain. L Beeston, A Molloy, M Nicholas & L Tonkin (2011) London: Souvenir Press ISBN 9780285640481 http://www.britishpainsociety.org/patient_suggest_reading.htm

Managing Pain Before It Manages You (3rd Ed.) Margaret Caudill (2008) New York: Guilford Press. ISBN: 978-1-59385-982-4 http://www.britishpainsociety.org/patient_suggest_reading.htm

"Living with Chronic Pain". A CD or cassette tape produced by Consultant Clinical Psychologist Neil Berry. www.paincd.org.uk

Pain Toolkit - Pete Moore http://www.britishpainsociety.org/patient_suggest_reading.htm 7