



PAIN

Pain, in particular the kind of ever-present **intractable** (*difficult, stubborn, hard to control*) **chronic** (*persisting for a long time, possibly severe*) pain may, for some people, be of low intensity but continually be there; for others it can be intense and come and go perhaps several times a day.

Up until fairly recently, MS was considered to be a painless disease. However, now it seems that over half of people with MS will experience pain at some stage. There are two widely recognised forms of pain in MS:

- Neuropathic pain – nerve pain.
- Musculoskeletal pain – nociceptive pain.

Some people say that they and their medical advisors often face a real problem in reliably assessing the source and strength of these kinds of pain. Many people are wary of the continuous use of ordinary pain killers which often have little effect anyway. Therefore a number of people just simply 'put up' with this highly demoralising symptom. Not to say that everyone experiences this type of pain but for those who do it is grossly invasive, wielding enormous influence over their lifestyle and that of their families. There is no doubt that effective treatment can sometimes be difficult to find and it is not unknown for people to hide the true nature of their pain. They put up with it for the sake of their children, partners and family carers and those with a job often manage to keep it from their colleagues at work.

It is also quite important to remember that not *all* pain experienced by people with MS is due to the MS. It could possibly be due to things such as infections or an accident. Therefore other possible causes of the pain should be thoroughly looked into.

No two people will experience pain in the same way. It is best described by the person experiencing it.

In a recent survey, on average, people with MS experience pain at a level of 4-6 out of 10.

How is pain described?

By patients, who find it difficult to describe...Burning or gnawing, like immersion in ice cold water, too painful to touch the skin, disturbs sleep, stabbing, exhausting, throbbing, mind numbing, crushing. Often people find it hard to characterise.

"It sometimes feels like someone is pouring burning oil down my skin. The burning feeling is worse in my hands and arms."

"A burning, aching sensation that does not last for too long."

"Generally I experience just a dull ache. On other days sharp pains, blinding, searing flashes."

By professionals – A raised sensitivity, unlike any 'expected' pain response, interferes with activities of living, stubborn and hard to control. It is often *mistakenly* thought to be embellished or over-dramatised. There can be partial irritation or interruption of the central sensory pathways to and from the brain.

Descriptions of clinical experience suggest that pain may occur more frequently in older people, those with a long history of MS or with levels of disability.

There are a number of MS symptoms that may be classed as 'pain':

- Pins and needles
- Burning sensations
- Tingling
- Numbness
- Tightness, such as the 'MS Hug'
- Stabbing pains
- Sensitive skin

Some people may not *describe* these suggestions as painful, whereas others will. It is very subjective.

Pain is quite often divided into two categories - **Acute** and **Chronic**.

Acute pain is generally described as very intense, sharp or a shooting pain. This can be intermittent and come on very quickly. Equally this can disappear very quickly too. Some types of acute pain can then become chronic.

Chronic pain is traditionally defined as a pain that can last for more than a month. It is sometimes described as a continual pain. The difference to acute pain is that it can onset very slowly. It can fluctuate in severity and sometimes never fully go away.

Pain Management

Management of pain is not necessarily easily solved or successful. Some cases will just never completely go away. After some time the body adapts to learn to tolerate to a certain level. After a while the pain may not seem as bad as originally felt. Treatment will depend on the type of pain and what is causing it. It may be that a drug treatment is the only answer; it may be that physiotherapy will relieve the pain without the need for any drugs' at all.

There are a number of factors that can make the pain feel a lot worse. This can be anything from the heat, to extreme fatigue or anxiety.

Neuropathic pain can be treated by a number of drug treatments. Sometimes these can be used in a combination if one isn't enough to relieve the symptom.

The list of drugs includes:

- Carbamazepine (Tegretol)
- Gabapentin (Neurontin)
- Amitriptyline (Tryptafen)
- Pregabalin (Lyrica)

Amitriptyline was originally used as an anti-depressant. However, trials of this drug showed that

a very useful side effect is how it can provide pain relief.

All of these drugs can be prescribed by a GP, although your Neurologist may wish to get involved.

Treating Acute Neuropathic pain

A condition such as *Trigeminal Neuralgia* can be common amongst people with MS. This is a very intense, severe stabbing pain, which may also feel like a burning sensation or electric shock that travels down the face. It normally only affects one side of the face at a time. The pain travels the pathway of the trigeminal nerve. The pain can be absolutely excruciating and set off by simply eating, drinking or talking. The onset is sudden and will reduce/disappear over time. Unfortunately this pain can become *chronic*.

It can be difficult to treat but all the drugs mentioned above can be tried to help to reduce the severity somewhat. In long term cases surgery is an option to cut off the nerves connection to the brain. This is usually a last option if all drug treatments fail to relieve it at all.

Optic Neuritis is another form of acute neuropathic pain. It can feel like a sharp stabbing like pain behind the eyes. It is very often a common first symptom of MS. This is caused by the optic nerve becoming inflamed. In some cases a course of steroid treatment is prescribed if this symptom does not improve over a length of time. Usually methyl prednisolone is used, which helps to resolve the inflammation, resulting in the pain subsiding.

Another form of acute pain is from *spasms*. This is when a muscle seizes into an extended, outreached position resulting in pain. These are mostly felt in the legs and are usually related to spasticity - muscle stiffness. The main cause of a spasm is the disruption of messages from the brain to the nerves at the bottom of the spinal cord that are used to control the legs. Spasms are sudden and at times can be incredibly painful.

There is also another type of spasm called a *Tonic Spasm*, which is a spasm of the arm or leg in an unusual position. They usually last for less than 90 seconds. These can occur a number of times throughout the day.

Baclofen and Gabapentin are two of the more common drugs prescribed for relief of spasms. If these are unsuccessful then other drugs, such as Tizanidine, Diazepam or Dantrolene may be prescribed instead.

Treating Chronic Neuropathic Pain.

Spasticity is stiffness of the muscles that most often occurs in the legs and can cause constant pain. There are a number of drug treatments used to relieve this ongoing pain. These include:

- Baclofen
- Gabapentin
- Tizanidine
- Diazepam
- Clonazepam

A GP can prescribe all these but they may well refer you to a Pain Clinic or your Neurologist. Some anti-spasticity drugs can cause the muscles in the legs to weaken, reducing mobility, so it is important to get the correct dosage and find the balance between getting the right amount of pain relief whilst maintaining muscle function. Exercise is also important in treating spasticity. Physiotherapy may be used in conjunction with a drug treatment to help achieve pain relief and

improve muscular function. You can easily be referred to a Physiotherapist by a GP or Neurologist. Also, if there is an MS Therapy Centre nearby you can contact them directly to book an appointment.

Paraesthesia/Dysaesthesia is the technical terms for altering sensations. This type of pain is described in many different ways. From burning, pins and needles, tightness, prickling, itching, numbness. Some people also describe it as a feeling of ants crawling over the skin.

Mostly this is experienced in the extremities but is possible to experience it all over the body. As previously mentioned, the symptoms can vary from person to person.

Banding, or otherwise known as the *MS Hug* – is described as a feeling of tightness, being constricted, or squeezed around the chest. This is where the intercostal muscles (thin sheets of muscle between each rib in the chest cavity) go into spasm. This can be incredibly uncomfortable and painful. Usually this is treated with one of the standard drug therapies such as carbamazepine, gabapentin or amitriptyline. If these are unsuccessful a referral to a Pain Clinic may be needed.

Musculoskeletal pain

Standard therapies

This type of pain is very different to that of neuropathic pain and is quite often successfully treated by either physiotherapy or exercise. Changes to a person's posture and inputting exercises that can help to strengthen certain muscle groups can help to relieve some amounts of pain.

According to the NICE Clinical Guidelines every person with MS that experiences musculoskeletal pain should be assessed by a Specialist Therapist. Therefore the cause should be identified and then how it is to be best managed. Specialists like Physiotherapists and Occupational Therapists may be best for a combined assessment. They can see if any new equipment is required to help improve the muscle function and relieve pain. Something simple like a different type of walking stick can help to improve balance problems which may be impacting on the body and causing postural problems for example.

General painkillers can help with musculoskeletal pain, such as paracetamol or anti-inflammatory drugs such as ibuprofen. Complementary and Alternative Therapies are often beneficial (see our Alternative and Other Therapies leaflet for more information).

How to treat acute musculoskeletal pain?

Pain caused by general muscle problems such as cramp/spasms occur when the muscle shortens, resulting in a rather uncomfortable cramping. This can be caused by a muscle strain, muscle fatigue, lack of potassium or sodium in the body and things like regular stretching exercises can help. It will also help if you make sure your water intake is balanced with the right amount of potassium and sodium. Bananas are a good source of potassium; eating one a day can reduce the risk of a potassium deficiency therefore maybe helping to reduce cramps/spasms.

How to treat chronic musculoskeletal pain?

If immobility is a problem this can result in very painful hips, pelvis, lower back etc. Misalignment of the hips/pelvis can be caused by a lack of mobility. Painkillers may be required and regular exercise can help.

Physiotherapy is best for this to help keep the body moving and helps to realign the body. If the limbs are stiff due to lack of mobility, pain in muscles, tendons and ligaments can occur.

Treatments such as physiotherapy, massage, heat therapy or even ultrasound may help.

Further treatments available

Pain Clinics

If all other treatments offered fail to help reduce the pain, a referral to a specialist Pain Clinic is available by your GP or Neurologist. If the pain is not completely eradicated by various treatments tried, then the goal will be to help reduce it to a level that is bearable and manageable for the person. However, not all hospitals have a Pain Clinic. To find out where your nearest Pain Clinic is, details can be obtained from The British Pain Society. Their details are at the end of this leaflet.

Complementary & Alternative Therapies

A number of people prefer to try this route of treatment rather than the conventional medicine route. Some conventional drugs have side effects that may not be tolerated, therefore some turn to something less harsh. It is mainly anecdotal evidence that is used to report the benefits found from having such therapies, there isn't much science based evidence. Please see our 'Alternative and Other Therapies' leaflet for more details on specific treatments.

It is possible that some treatments may be available through your GP but mostly privately. It is most important that a reputable qualified practitioner is used.

More information...

The British Pain Society

The largest multidisciplinary professional organisation in the field of pain within the UK.

The British Pain Society
Third Floor
Churchill House
35 Red Lion Square
London WC1R 4SG
Tel: 020 7269 7840
Fax: 020 7831 0859
Email: info@britishpainsociety.org

Pain Concern

An organisation that offers support and information for pain sufferers. A listening ear helpline giving the chance to talk to others in the same situation.

Pain Concern
PO Box 13256,
Haddington,
EH41 4YD,
United Kingdom
Telephone (UK): 01620 822572
Telephone (International): +44 (0)1620 822572

Fax: +44 (0)1620 829138
E-mail: info@painconcern.org.uk