

Whilst pain is not conventionally directly linked with ataxia, it is still a real problem for many people. If not managed effectively, chronic pain may become as debilitating as ataxic symptoms.

## WHAT CAUSES PAIN?

Because nerves are responsible for “carrying” pain signals, it is often assumed that any pain associated with a neurological condition is neurological in origin. This is not always the case; in ataxia pain is largely a secondary effect and generally musculo-skeletal in origin. Co-ordination problems lead to muscles becoming weak through lack of use, which can lead to a person adopting unusual ways of walking or standing. This puts unnatural pressure and strain on joints that in turn lead to pain. Long periods of time in a wheelchair also lead to muscle weakness, stiffness in joints and pains down the legs.

## TYPES OF PAIN EXPERIENCED

People who experience pain with their ataxia usually describe a **constant, chronic pain** that is with them night and day. One Friend of Ataxia UK describes it like having “a nagging toothache, constantly throbbing all the time with occasional flare-ups, which are *horrendous*”. Two body regions seem particularly affected. Firstly, many people suffer pain at the base of the spine, in the hips, legs, knees and feet. These pains are usually described as **cramping** or **gripping** muscular-type pains. Secondly, people may experience pain across the base of the neck, along the shoulders and down one or both arms; many people have the classic symptoms of **frozen shoulder** (onset of pain with no obvious causal factor, often worse at night, followed by a progressive limitation in the range of movement at the joint).

Another Friend, diagnosed with cerebellar ataxia 12 years ago, described to us pain at the base of her spine, spreading through her left hip and along her neck, and at the base of her skull like a “**tight stretched band**”. Generally, people agree that their problems have been caused by adopting an unusual posture or walk, with one side often worse than the other, and that the pains have gradually worsened.

## CONVENTIONAL TREATMENTS

Many people with ataxia are prescribed ‘simple’ painkillers such as **paracetamol** or **diclofenac**. Less commonly people may receive painkillers containing a mix of **paracetamol with codeine** (co-codamol, Tylex®). To control muscle cramps, patients may be prescribed the muscle relaxants **baclofen** or **tizanidine**. Other options for reducing pain caused by muscle spasms include anticonvulsants such as **gabapentin** or **clonazepam**, or the antidepressant **amitriptyline** which also has pain relieving qualities. Both these type of drugs also have sedative effects and may be given at night to help sleep.

People who have chronic pain may worry about taking medication long-term and there are some alternative approaches to pain control available.

## CLOSING THE GATE TO PAIN

One alternative is **Transcutaneous Electrical Nerve Stimulation** or **TENS**, which has been used for many years as a drug-free type of pain control. TENS machines are small, portable units, which via small pads placed against the skin apply a low-level electrical current to the body, felt by the user as a gentle tingling sensation. This current blocks the pain signals from nerves, by closing ‘the gate to pain’ before the signals reach the brain. The technique has been compared to ‘electronically rubbing yourself better’. Low-level currents are also thought to help stimulate the body to make its own pain-relieving substances called endorphins.

Because there are many types of pain and every individual is different, TENS machines may work in slightly different ways for different people. Some people find that the device can relieve pain only whilst it is being used, whilst others will get hours of relief from a single session. Although they have been highly successful, TENS machines do not work for everybody and are expensive so you should ask to borrow one from your GP or pain clinic to see how successful it is for you before buying one. *It is essential* to get proper instruction before using a TENS machine to be sure that you are using it correctly.

## THE HOLISTIC APPROACH

Increasingly, healthcare professionals are recognising that managing pain is not always as simple as identifying an underlying cause and giving painkillers, but that there are many factors influencing the pain experienced by an individual. **Multidisciplinary pain clinics** bring together a team of specialist doctors and nurses and other practitioners who can advise on ways to cope with pain. There will also be therapists on hand who can help address the **emotional** and **psychological factors** that have an important influence on pain. Anxiety and fear can heighten pain so seeing a specialist who understands and can explain the cause of pain often helps reduce the intensity of the pain.

**Physiotherapists** can be involved in managing pain, and can teach exercise regimes which may strengthen core muscles and improve posture in addition to easing pain. **Occupational therapists** may also be helpful to assess positioning or personal aids which may be contributing to pain and suggest improvements.

If you are suffering from chronic pain you may ask your doctor or neurologist about a referral to a **pain clinic** or local **pain management team**.

## WHAT WORKS FOR YOU

Many people with ataxia have told us that adopting a **positive attitude** helps them to cope. By looking for ways in which they can help themselves and experimenting with different approaches, people have come across techniques that work for them. One lady who was diagnosed with Friedreich's ataxia in the 1950s has found that **deep-breathing exercises** and **yoga** have helped her reduce stress and control her pain. Other Friends have told us about different methods they have tried; including **shiatsu therapy** which has helped control one lady's chronic pain in her lower spine and shoulder, and **self-hypnosis** which can be learned to help individuals self-manage their pain.

Similarly, we have heard how self-discipline and a **positive approach** have helped one Friend to cope with pain. He wears bright and cheerful clothes and tries to get out as much as possible and talk to people. He also suggests **massage** and relaxing **footbaths** can help. Many people have agreed that soaking in a **warm bath** helps to soothe cramps and aching muscles and can be a great way to relax at night and encourage sleep.

**The information in this leaflet was checked by Dr Simon Hammans (Consultant Neurologist, St Richard's Hospital, Chichester and Wessex Neurological Centre, Southampton).**

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