

Causes of Pain

- Neurofibromas on the surface of the skin rarely cause pain. They can, however, be uncomfortable or itchy or become painful if infected (often as a result of broken skin).
- Neurofibromas that occur slightly underneath the skin are rarer in NF1 but can be associated with discomfort, especially when bumped or caught on something. They can be removed if their position is favourable.
- Neurofibromas (or Schwannomas in NF2) that develop on deeper nerves can cause significant discomfort with feelings of pain, pins and needles, numbness and, occasionally, weakness. If discomfort or pain is felt, then an experienced doctor can advise on whether they can be removed or if the symptoms should be managed with medication instead. Sometimes it is necessary to use scans (often an MRI scan) to locate the problem.

The pain that people with neurofibromatosis can experience will vary from person to person.

Treatment

Surgery is sometimes required to deal with internal lumps. As with any surgery there are some associated risks and this should be discussed fully with your doctor before any treatment is agreed. In some cases, surgery will make the problem worse and is therefore not always recommended. If surgery is not advisable and the regular use of standard painkillers (such as paracetamol or ibuprofen) does not control your pain, other specific pain medication might be used to target nerve pain. This type of medication will need to be prescribed by your doctor.

An example of a specialist drug used is Amitriptyline. This drug is started at a very low dose and built up over a period of time. It can take 2-3 weeks before it becomes fully effective and any changes in dosage should not occur at less than 2 weekly intervals. This is a well-tolerated medicine, but all medication has side effects and with this drug you may experience a dry mouth and some grogginess. The tablet is taken at night to avoid daytime drowsiness. If larger doses are required the side effects may be more of a problem and your doctor will discuss this with you.

Other more specialised drugs include Gabapentin that can be built up quite quickly. Sometimes a combination of Amitriptyline and Gabapentin will be used.

Always follow the doctor's advice and prescription carefully. If in doubt – seek advice.

Alternative Ways of Managing Pain

Some people prefer not to take tablets and there are other things you can do to

try and manage your pain. Remember though that you should always have your pain assessed by a doctor and **never ignore persistent pain.**

Pain is partly psychological!

Many people who have pain feel angry when this is said or suggested. **You** know that your pain is real — **you** can feel it! However, pain is affected by our psychological and emotional state.

We all use techniques for dealing with pain already. You may notice that pain often seems much worse at night time or when you are sitting quietly and this is often because there are few distractions. When we are busy we can sometimes forget our discomfort and so when people are in pain they often try to keep themselves busy. We often try to think of other more pleasant things if we are in discomfort. These are examples of psychological techniques in pain reduction.

Controlling Pain

Many people cannot tolerate pain inflicted by others — think of waiting for that injection at school! Most of us can tolerate a lot more discomfort if we are inflicting it upon ourselves!

This unusual phenomenon is about being in control of your pain, rather than the pain being in control of you. Pain that occurs inside the body is experienced as if someone else is causing it and it is by understanding it more that we can try to gain some control over it.

If we do not like something we move away from it and pain is no different. Often our response is to try and ignore it and when this occurs we withdraw into ourselves. With a little practice you can start to investigate your pain by reaching out to it — exploring it, instead of running away from it.

You might be surprised what you learn about it. People often find that their pain is more controllable than they thought. This type of pain management requires a lot of strength — it may not work on its own and it takes a lot of practice and support to get right.

Here is where seeking the advice of a pain clinic can be crucial. Pain clinics can offer excellent advice about managing your whole condition, but their priority is managing your pain. They use lots of different ways to do this, including introducing specialist medication if they feel it is going to help.

- Aromatherapy
- Relaxation
- Visualisation techniques
- Physiotherapy (especially for scoliosis)
- Acupuncture
- Massage
- Reflexology
- TENS machine

Pain can cause anxiety and depression. But anxiety and depression also make pain worse. Don't avoid finding out what is causing your pain — your imagination and fear are often much worse than actually finding out and learning about what causes it.

Other Help

Depending on the cause of your pain the following may also be helpful:

Many alternative therapies are not available on the NHS so it is best to try and look around to see what may be on offer. Do not be afraid of trying new things, but always discuss your plans with your doctor and check the qualifications of the therapist.

Further Help

The Pain Society

Tel : 020 7631 8870

www.painsociety.org

Recommended reading:

Pain: The Science of Suffering. Wall PD (1999) Weidenfeld.

ISBN: 0297842552

Coping Successfully with Pain. Neville Shone (1992) London: Sheldon Press.

ISBN 0-859-69750-9

Produced
with financial
support from



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For more information and a full list of publications please contact:

**The Neuro Foundation,
HMA House, 78 Durham Road,
London SW20 0TL**

T: 020 8439 1234

W: www.nfauk.org

E: info@nfauk.org

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Updated 07/09