

Managing the pain of scoliosis

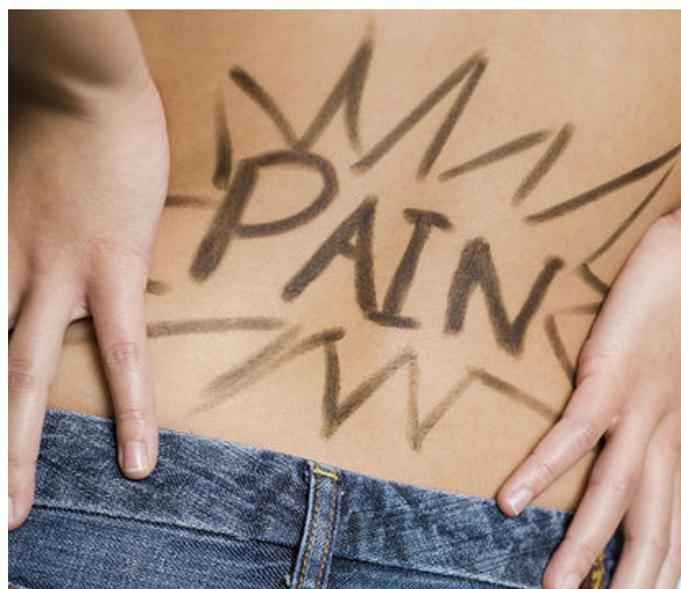
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Back pain is very common in the general population and is even more so in those with scoliosis. For some people pain may be very severe and affect every aspect of daily life but many others do not have pain or it is not a major issue. There are many reasons why pain may occur such as problems with joints under strain that have become worn or inflamed. Pain may be due to posture causing tension and fatigue of muscles and ligaments. It may also be due to pressure on nerves that have been irritated, squashed or stretched as a result of the curvature of the spine. This is not a complete list. Indeed often we may not be able to tell for certain what is causing pain for a person.

There is also a big overlap in the causes of pain between the different types of scoliosis. For example; much of the pain of adult onset scoliosis is due to uneven wear of the discs, which sit between the vertebrae and act as a kind of cushion. The worn discs themselves may cause pain but the strain on the facet joints (the paired joints at the back of the spine) may lead to further pain as may the strain on muscles if posture becomes unbalanced. The curvature may also squash and stretch nerves. All or some of these problems can also be seen in some adult patients who had scoliosis as children, especially if their scoliosis has never been treated.

To make things more difficult; although an enormous amount has been discovered in the last 50 years about the science behind what causes all of us to have pain at different times, what we experience is personal to us. Although we can try to describe how we are feeling to other people, no-one (and that includes doctors) ever truly knows what another person is feeling. This can be

very upsetting as it can be difficult to explain our suffering to family, friends and doctors, which can cause people to feel lonely and misunderstood. It is not uncommon for people to say things like 'the doctor didn't believe me' or the 'the doctor thinks the pain is all inside my head' or even for a doctor to say 'I believe you have pain'. None of this is helpful.



What we each experience does not depend on whether or not someone else believes us, not even if that person is a professional. Also, all our experiences are ultimately inside our heads whatever is going on in the rest of our bodies or the outside world. This may all sound somewhat philosophical but these are important points as pain is what we feel and not what causes it.

For example; if you have a slipped disc, what you experience depends on all sorts of factors. These include not only the irritation and pressure on the nerve but how well our nervous system can block these signals from reaching the brain. There are nerves that come down from our brain to our spinal cord that can reduce the signals going back from the spine to the brain and so can reduce what we ultimately feel as pain. How well these nerves work in reducing pain signals can depend on our genes, environment, medication and even our beliefs. This all happens automatically so we cannot always say for certain what is causing our pain. All that we can do is describe it to others as best we can.

So what can we do to manage our pain? Often this is simply a matter of looking after ourselves by controlling our physical activities or taking over-the-counter pain killers when the pain gets very bad. More severe or long lasting pain may be managed by your doctor (GP) who can help with diagnosis, arranging outpatient physiotherapy and providing stronger pain killers. GPs may be able to refer patients to psychological services such as counselling.



Psychological services can help when pain is long term, and when physical and chemical treatments do not work well. A type of counselling called cognitive behavioural therapy (CBT) can be used to help patients manage pain. CBT is where a psychologist will discuss with a patient the patient's views on the causes of their pain and how this affects the way they manage it. A good example would be a patient with a back spasm who believes that staying in bed is better for them because the pain is much worse when they get up. They are afraid that this means they are doing more damage to their back by moving when the opposite is true.

This behaviour may make their back weaker so they take much longer to recover, which can have a bad effect on their work and family life. The psychologist works with the patient to challenge these understandable but incorrect beliefs to help them take back control of their life. This type of therapy can be helpful for some patients with scoliosis. However, because scoliosis is a life-long condition and people often have their own ways of coping with pain CBT does not always work as well.

If the GP is not able to help then she or he may refer patients to the pain clinic. Pain clinics have teams of staff who specialise in different areas. They all differ slightly from hospital to hospital depending on the needs of their patient groups. The point of these large teams is that spinal problems are complex and often the specialist knowledge of a wide range of people is needed. For example; a patient may benefit from physiotherapist advice on posture. The psychologist may help them to deal with the difficulty of coping with ongoing disability and pain or treat conditions such as depression. The surgeons may be needed at times when surgery could stop things becoming worse or could help with pain. There is an overlap in the skills of these groups of staff. The areas that pain medicine specialists like myself, work in, include spinal injections and medication.

Spinal injections are when steroids are injected into the nerves and joints to help ease pain. Doctors can't agree on how well they work and whether they should be used. Injections do seem to be helpful for some patients. However, for people with long term conditions such as scoliosis the effect of injections nearly always wear off. Also if

a patient keeps having injections they often seem to have less effect over time. It is rare for things to go wrong, but nerve damage from injections is possible. Therefore, injections are used sparingly and only when we have good reason to think they will help. They are often useful in the short to medium term but often not in the long term.

Special cases of injection treatments are when needles containing wires are used to burn off the tiny nerves to the facet joints at the back of the spine. This is known as radiofrequency denervation and can give much longer pain relief than ordinary injections, sometimes for several years. However, it usually lasts for about 6 to 9 months and is difficult to use on a curved spine. Therefore, it is a treatment that may only be useful for a small group of patients. Another treatment that we are now using for people with pain from damaged spinal nerves, is spinal cord stimulation. This is where electrical wires are placed along the back of the spinal cord and attached to a small stimulator box that can be buried under the skin and controlled with a hand held remote control.

Nearly all patients who are sent to the pain clinic are on some form of medication to relieve pain. These include opioids (morphine, oxycodone, codeine, fentanyl patches, buprenorphine patches), non-steroidal anti-inflammatories (ibuprofen, naproxen, diclofenac, celecoxib etc), nerve pain agents (gabapentin and pregabalin are the most common of these), hybrid medications such as tramadol and tapentadol. Tricyclic antidepressants such as amitriptyline can also be used as pain relief because they have a direct effect on pain as well as affecting mood. Paracetamol can help. Diazepam is sometimes used alongside other medications for very severe pain, but it is very addictive so usually much more trouble than it is worth and would not be prescribed at all in most pain clinics.

Even with such a wide range of pain medication, it is no simple matter to control chronic pain. Chronic pain behaves very differently to acute pain because it alters our nervous systems so that the pain will not easily be switched off by pain killers alone. The body also adjusts to the presence of pain killers. This means that pain killers (especially opioids) can become less effective over time, sometimes very quickly. Patients can become physically dependent on a drug, which means their body becomes used to the drug and so if they stop taking it they suffer

symptoms as the body readjusts, which can take from days to weeks. Much rarer but by no means uncommon is addiction. It is not something that we can control directly although we can fight it with the right help. Opioids also often produce severe constipation, part of a condition known as opioid bowel syndrome. They can also impair our ability to think straight. Because of all these issues, pain clinics will keep doses of opioid medications low and monitor their effectiveness. If there are side effects or lack of benefit they will be stopped.

The non-steroidal anti-inflammatories have also been through rises and falls in popularity. There were concerns over effects on the stomach and bowel and later concerns over the effect on the circulation. Again like opioids, they have a place for use in some patients at carefully monitored doses. Even paracetamol must be used with caution and daily doses are now often limited to 6 tablets a day where possible.

All this may sound somewhat gloomy and I do apologise if it appears that way. We do continue to prescribe all these medications but we are careful how we do so. Unfortunately we cannot completely entirely get rid of pain for many people but by working and cooperating as a team with our patients we can give them the tools to help manage their pain and make it less of a limiting factor in their daily lives.

Additional support and advice

Contact the Helpline team

020 8964 1166 or info@sauk.org.uk

Go online

Check out the Information Standard accredited medical information and personal accounts on our website, at www.sauk.org.uk/scoliosis-information.

Connect with others

Contact the SAUK office for information about SAUK members, volunteers, and Regional Representatives who may have particular experience of this area.