

Pain Management for Adults Living with Sickle Cell Disorder

Information for Patients, Family and Carers



Information for patients



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Why Do I Have Pain?

Pain can be a major problem for people living with sickle cell disorder (SCD), and it is very important that you get the right treatment and support for your pain.

There are different types and causes of pain which need different types of treatment.

Acute Pain

You might have short-term pain (this is also called 'acute pain') caused by a vaso-occlusive crisis (VOC) – this is the same as a 'sickle cell crisis' or 'painful crisis'. This pain usually lasts for a few days and then gets better.

If you feel that your pain feels different and might not be caused by a VOC, then please let your specialist team know as you might need different help and treatment.

Remember that you can still experience different types of pain in addition to pain caused by VOC, but the following information will help most forms of pain regardless of its cause. The important thing to do is to seek help if you cannot manage at home, or if your pain is different from your expected pains.

How Should Acute Pain Be Treated At Home?

You probably already have ways of managing your pain at home, which work best for you. Here are a few suggestions. Even if you need to go to hospital, these things are still important to carry on with as much as possible:

- It is always a good idea to make sure you stay warm and that you are drinking plenty of fluids. Remember that drinks with caffeine or alcohol in can actually be dehydrating, so avoid alcohol or a lot of tea or coffee
- Staying calm with relaxation and breathing exercises. Being stressed and anxious (the “fight or flight” response) will act to compress your blood vessels further, so taking control of your breathing can help induce the relaxation action which opens blood vessels and helps your blood flow to the areas that need it.
- Distracting yourself from the pain such as watching a movie, TV show or listening to music can also be helpful and can help reduce pain.
- If you have access to acupuncture or someone can give you a massage, these can help relieve your pain.
- Try to stay mobile and keep moving around as much as you can manage, this helps you to recover more quickly and keeps the blood moving. Even gentle movement such as Tai Chi, Yoga or Pilates, can improve pain and maintain blood flow.

Medications you can use at home

You might take over the counter paracetamol, or a non-steroidal anti-inflammatory medication (NSAID) such as ibuprofen can be helpful. However, always read the label to make sure that it is safe to take a medication for you, for example, if you have had a problem with stomach ulcer, or if you have asthma, kidney problems or are pregnant, speak to your doctor before taking ibuprofen or other NSAID medications.

If this is not working, then some people find weaker opioid medications such as codeine or tramadol for a short period of time can be helpful. If you are needing to take any opioid medication for more than 5 days, please speak to your specialist team to find out if alternative treatment might be more helpful for you.

We know that stress, whether this is physical or psychological, could increase the chance of sickle cell crisis. Our psychology team may be able to support you better understand lifestyle triggers and manage stress that contribute to painful crisis.

When Should I Go To Hospital?

If your pain is severe, or if your home medication and the approaches above are not controlling your pain, please call your specialist team and come into hospital for review. It is also important to come to hospital if you have any of the following problems:

- High temperature (fever) such as over 38°C
- Pain in your chest, difficulty breathing or coughing
- Unable to drink or take medications because you are vomiting
- Weakness or not being able to feel sensation in any area of the body
- Headache which is more than just mild or normal for you

It is a good idea to bring a copy of your personal care plan when you come to hospital, if you have one. You might choose to carry a photograph or electronic copy of this on your phone or other device, for example, or carry a paper copy with you.

Medications Used In Hospital

Your Individualised Care Plan should be available to be seen by the hospital team, and they should give you the treatment outlined in it which you have agreed with your specialist team when you first arrive to hospital. This might include an injection, or oral dose of a strong opioid medication such as oxycodone or morphine. You might also be given pregabalin, which is another medication which helps with severe pain, as well as paracetamol and ibuprofen (or similar) if you usually have this. Sometimes other treatments are also used and these will be discussed with you.

Strong Opioid Medications

Opioid medicines are not usually able to take your pain away completely. The aim is to improve your pain and make it manageable, so that you can recover and get back to normal as quickly as possible.

You might receive injectable opioid treatment as a PCA (patient-controlled analgesia), or you might just have one-off injections when you need them. If you are given a PCA, we will give you separate information about this. It is usually best to move to taking this medication orally after 1-2 days, because each dose will last longer, and because using injectable opioids for longer than this puts you at risk of harm. Once your pain is controlled, try to reduce the oral opioid medicines as well. Most people find they do not need opioid medicines longer than 5-7 days at the most for a VOC, as pain is usually improving by then. Speak to your specialist if you feel that you need these medications longer than 5 days.

Opioid medications in the long-term can cause significant harm to a person. Even short-term use can lead to addiction and dependence. If you are struggling to come off these medications, speak to your specialist or GP about a gradually tapering dose to minimise any risk to you and should make it easier to come off and control your pain.

Chronic pain

It is very common for people with SCD to develop longer-term pain, which is called 'chronic pain'. Pain is called chronic if it lasts for 3 months or longer.

Chronic pain can be just as bad as acute pain, but the causes are different, and the treatments that work for chronic pain are often different as well.

What Causes Chronic Pain?

Chronic pain can be caused by quite a few different things. It can be the result of damage to the body that hasn't healed, such as when it is caused by avascular necrosis in a joint (this is where the bone is damaged because of poor blood supply). This is 'nociceptive pain' due to ongoing damage and processes that have not yet healed.

It can also be caused by damage to the nerves that detect pain, or the way your brain receives and processes those signals. Nerve damage pain might be called 'neuropathic pain'.

Sometimes these nerves can also be over-sensitised or transmit the wrong signals. They might produce signals telling your brain that pain is very severe, when actually it is being caused by something quite minor or even something which would not usually cause pain at all. This can happen as a result of severe or repeated acute VOC pain, especially if it is not controlled well when you first have that pain. When you have been in pain for a long time, your body is able to "learn" more pain, and changes happen in your nervous systems, so that even if all the damage is healed and there is no longer any pain being transmitted to nerves, you still feel significant pain. This is called 'nociplastic pain' and can get worse over time without appropriate treatment, as your body continues to "learn more and more pain".

There are also other types of pain related to your previous pain experiences, your previous traumas, and spiritual and emotional pains, and these will all feed into your pain experience in the present moment.

Sometimes opioid medication (such as morphine or oxycodone) can cause changes in your body's pain detection systems and can make your pain feel worse. Also, if you have been taking opioid medication for a longer period of time, when you reduce the dose, that can cause an increased feeling of pain because the body has become used to this medication. Opioids, at higher doses, can switch from being pain-relieving to pain-producing, and so some people feel a lot better for reducing or stopping their opioid medication.

For some people, more than one of these causes of chronic pain can happen at the same time. We don't fully understand all these causes of chronic pain, but we do know that people with chronic pain benefit from different treatment approaches, and we want to make sure you are getting the right help and advice.

How Should Chronic Pain Be Treated?

Sometimes the cause of the pain can be treated directly – such as surgery for a joint affected by avascular necrosis. However, for most people this is not the case. Often, for very many people with chronic pain, it is impossible to completely remove the pain, even with these recommended treatments. Instead, the aim is to work with you to improve your pain and how you live with it, to help you live a happier and fuller life even though you might still be living with some chronic pain. Pain is just a set of electrical impulses that your brain detects and gives you the experience of “pain” which is different for everyone and why not everything works for everyone. However, just like your brain and body are able to “learn pain”, and upregulate it over time, the opposite is also true, and you can “learn” over time to reduce how your brain and body interprets those electrical impulses and how to reduce your pain experience.

Non-Medical Treatments

The following approaches can be very helpful. Some may work very well for you, and others may not be quite as effective for you – but it is worth trying them to see if they are right for you:

- Relaxation, mindfulness and meditation: regular deep relaxation can really help with your pain, especially when used daily. Our psychology team can help you to learn and use these techniques. Alternatively, there are relaxation and mindfulness apps you can download and use for free on your smartphone or other devices.
- Staying active: Regular gentle or moderate exercise will help you to stay well and improves chronic pain. If it has become difficult to move a particular joint, or to stay mobile overall, getting physiotherapy advice on exercises that can help you strengthen your muscles and become more active will be important. Take a look at these videos produced by specialist physiotherapists specifically for people living with sickle cell which will guide you through some exercises:
 - www.ney-hcc.co.uk/resources



- Yoga, pilates or tai chi can be particularly helpful types of exercise because they help with relaxation as well as keeping your body strong and mobile. These can be done in bed or a chair, as well as standing, and can be found for free on websites such as Youtube. There are also many classes around your local area that may help you even more, and can be quite sociable.
- Helping your emotional wellbeing: living with a long-term condition like sickle cell disorder can be hard, and chronic pain can

impact your emotional and psychological wellbeing. If you are feeling stressed, anxious or depressed this will also make your pain worse, so it is very important to get support with your mental health. Our psychology team can provide tailored support and therapies to help with improving your pain and to help you live well even with pain.

- It is also important to make sure that you are getting the financial support that you may be entitled to – our Benefits Advisor can help with this.
- Massage and acupuncture can be very helpful, although unfortunately these are not routinely available on the NHS outside of hospital. If you have someone who can give you a massage at home this could help, or some people are able to pay for private treatment and choose to do so.

Medication Options

- Sometimes medication such as paracetamol or ibuprofen can be helpful long-term. Speak to your doctor if you are finding ibuprofen (or NSAID medication) helpful long-term so that they can monitor for any harmful effects such as kidney damage.
- Opioid medication is not usually helpful for chronic pain and causes harmful effects if used for more than a short time. If you are on long-term opioids, your medical team can discuss with you the benefits of trying to gradually reduce this medication, and how to do this safely, as whilst opioids are useful in acute sickle cell crises, they are generally not useful in the long-term for chronic pain as they stop working and will cause more harm (see Opioids Aware below). Minimising opioids also means that you keep them in reserve and they will work better when you really need them in future, for example in a painful crisis.
- Other, more specialist medications or treatments might be used to help with chronic pain, and can work much better for you than opioid medications

Specialist Pain Team

If your chronic pain is very difficult to manage, or is not improving with these treatments, you may be referred to a specialist chronic pain team.

They have access to other treatments and can work with you to plan best how to manage your pain longer-term.

*If you have any further questions about managing your pain,
or if you would like referral for any of the services listed here,
please speak to your nurse or doctor.*

Useful Further Information

Whilst there are few websites dedicated to chronic pain specifically for Sickle Cell patients, there are many that are useful to help you manage your pain and to understand your body.

Useful Websites Include:

Sickle Cell Society

www.sicklecellsociety.org

Faculty of Pain Medicine, Opioids Aware Page

www.fpm.ac.uk/opioids-aware

Tame the Beast

www.tamethebeast.org

Live Well with Pain

livewellwithpain.co.uk

Flippin' Pain

www.flippinpain.co.uk

NHS Fife Pain Management Jigsaw

www.nhsfife.org/services/all-services/pain-management-service/pain-management-jigsaw



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