



Pain Management

Fighting for people affected by
Hidradenitis Suppurativa



What is the purpose of this leaflet?

This leaflet is for people whose daily lives are affected by Hidradenitis Suppurativa (HS). It has been produced in order to provide you with advice on dealing with the physical pain that you may endure as a patient. The information in this leaflet is not intended to replace the advice of your doctor.

How can HS-related pain affect me?

Living with the pain experienced by many with HS is not easy, and can prevent patients taking part in everyday activities such as:

- Working
- Driving
- Shopping
- Housework
- Socialising
- Relationships
- Leisure activities
- Simple activities such as sitting comfortably, standing, lifting, general movement, etc.

Pain may lead to inactivity, tiredness/fatigue, weight gain/loss, dependency on painkillers, mood swings, and sometimes depression.

Of course pain will affect everyone differently, depending on the pain threshold of the individual (the lower the threshold, the less pain they can endure; the higher the threshold, the more pain they can endure).

Can the pain be managed?

There are a few ways in which the pain can be managed, and although the pain may not go away completely, it may be possible to ease it to a tolerable level, enabling you to continue with daily activities.

Interventional approach

The interventional approach to pain management is usually by pharmacological intervention. There are many types of medication that can be used to manage pain in HS. However, in selecting the appropriate approach, your clinician needs to consider the effectiveness, adverse side-effects, dosing frequency, patient preference, and cost in selecting medication for pain management.

The most common types are:

- Paracetamol based analgesics (pain relief medication).
- Non-opioid analgesics, including non-steroidal anti-inflammatory drugs (NSAID), such as Ibuprofen, Naproxen, Diclofenac.
- Opioid analgesics, which include Codeine, morphine based drugs such as Oramorph, and patches such as Fentanyl.
- Adjuvant analgesics. These are drugs that were developed for uses other than pain, but have been found to enhance analgesic effects. Such as antidepressants and steroids.

Patients should speak to their clinician about any concerns about possible side-effects of taking pain medication, and always be careful to take the recommended dosages.

Non-interventional approach

Non-interventional pain management involves helping you to cope with the pain through self-management. This can involve attending a pain clinic, and a pain management programme (PMP).

There are around 300 pain clinics in the UK. Most are in hospitals and have teams of staff from different medical areas, including occupational therapists, psychologists, doctors, nurses and physiotherapists. They all work together to help people with pain.

NHS PMPs are a series of sessions, attended by groups of patients, aimed at teaching them to learn ways of dealing with the disabling effects and distress caused by being in pain. Instead of treating your pain, you learn to cope with it and, research shows, can improve quality of life, sleep and mobility afterwards.

Some hospital pain clinics offer PMPs, and some are held within GP surgeries. You will require a referral to attend a pain clinic or PMP, so speak to your consultant or GP if you feel this would benefit you.

Cognitive Behavioural Therapy

Cognitive behavioural therapy (CBT) can change the way your mind influences your body. When you shift your thinking away from the pain and change your focus to more positive aspects of your life, you change the way your body responds to the anticipated pain and stress.

The goal of CBT is to change the way you think about the pain so that your body and mind respond better when you have episodes of pain. For CBT to be most effective, work together with your counsellor toward common goals.

Self-Management

There are things that you can do at home in order to help you cope with the pain, allowing you to continue with your daily life. Below are some handy tips to help you self-manage the pain associated with HS.

Acceptance

This is the first step to recovery in any illness, it's not about giving up, but recognising the need to take control of the pain, and mentally prepares you for the alterations that you will need to make as part of self-management. If you simply try to ignore the pain, you will do nothing about it, and it will not go away.

Support

The best way to self-manage, is to find help and support from others. Speak to your clinician, friends and family about the pain, and what you need in order to successfully self-manage. Support groups and pain management plans can be discussed with your clinician.

Pace yourself

Learning to pace yourself when carrying out your daily activities is very important. If you start to feel the pain increasing, slow down or take a break. If you need to do more than usual, just take it one step at a time.

Set goals

Goal setting is rather like pacing - you can use it to gradually build up the activities that you do. It's all about giving you some control back, rather than letting the pain take over. A goal is something that you would like to achieve.

Plan and Prioritise

This is also a very important part of self-management, and it is worth remembering the saying; “to fail to plan, you plan to fail.” Make a list of all the jobs to need to do throughout the week, then prioritise them, but remember to be flexible and allow plenty of time for breaks.

Patience

Being patient with yourself. If things are not going well, just take a break, accept that you need to rest, and carry on later. Build-up of frustration will only make you feel worse, it may take a while to notice an improvement in the pain, it may be a long road, but it will be worth it in the end.

Relaxation

Relaxing the body and the mind can help you to cope with the pain better. This could involve listening to music, reading a book, or even meditation.

Sleep

A good nights’ sleep can greatly improve your ability to cope with pain. Go to bed at the same time each evening, and get up at a regular time in the morning and avoid taking naps in the day. If sleep problems persist, see your GP.

Breathing

When the pain is intense it’s very easy to start taking shallow, rapid breaths which can make you feel dizzy, anxious or panicked. Instead, breathe slowly and deeply. This will help you to feel more in control of the situation and will keep you relaxed and prevent any muscle tension or anxiety from worsening your pain.

Useful Links

The Hidradenitis Suppurativa Trust

Unit 6

Fort Horsted

Chatham

ME4 6HZ

www.hstrust.org

www.facebook.com/TheHidradenitisSuppurativaTrust

www.facebook.com/groups/hstrust

www.twitter.com/Hidradenitis

British Pain Society

An alliance of professionals advancing the understanding and management of pain for the benefit of patients

www.britishpainsociety.org

NHS Pain Management Programmes (PMP's)

Your clinician may be able to refer you to a PMP in your local area. For more information visit the British Pain Society website. www.britishpainsociety.org

Action on Pain

Action on Pain is run entirely by volunteers who either have chronic pain or are affected by it in one way or another.

Painline: 0845 6031593, weekdays 10am to 4pm

<http://www.action-on-pain.co.uk/>

Pain Concern

Their helpline is staffed by trained volunteers who provide information, support or just a listening ear to people wanting to talk about their own pain or that of a family member or friend.

0300 123 0789, weekdays 10am to 4pm

www.painconcern.org.uk



Raising the profile of Hidradenitis Suppurativa in terms of its impact on physical, psychological and social wellbeing.

The Hidradenitis Suppurativa Trust is a publicly funded charity, providing reliable information and support to both patients and professionals.

www.hstrust.org