LIVING WITH HIDRADENITIS SUPPURATIVA

Hidradenitis suppurativa (HS) may impact everyday life both physically and emotionally. This impact will vary from person to person depending on a number of factors, including severity and location of HS, but also as each person and their HS is different. Therefore a diagnosis of HS may lead to people feeling a range of emotions. However, there are various coping mechanisms, some of which are included in this resource, that some people find useful to help manage the condition.

COPING WITH HS PHYSICALLY

Developing your HS management plan: Creating, and keeping to, a self-care routine is important to relieve the discomfort of HS. It’s important the self-care routine works for you; a number of tips are provided below:

- If you have an abscess filled with fluid, applying a warm cloth to it for a few minutes may help to drain it.
- Wear loose, comfortable clothing.
- Take your medications as prescribed.
- Be aware of any lotions or creams that may make your HS worse, and discuss these with your GP or dermatologist at your next appointment.
- Daily gentle cleansing of the affected areas of skin may help to reduce any smell and risk of an infection.

Drawing-up your own self-management plan in conjunction with your healthcare professional may enable you to feel more in control of your condition.

Nutrition and exercise: Eating a balanced diet and taking regular exercise may help to reduce any stress you may be feeling. Exercise shouldn’t feel like a chore, and it can be anything that motivates you or gets you moving! Think of an activity you enjoy either by yourself or with friends/family and try to incorporate it into your routine a few times a week. Whether it’s enjoying walks with your family or Zumba dancing with friends, whatever helps to keep you active will not only improve your fitness but will also help your emotional health. If you are experiencing a flare-up you may need to limit your level of activity for a short period until you are feeling better.

Sleep, rest and relaxation: HS can disrupt a good night’s sleep. Reducing the amount of caffeine and alcohol in your diet may help to improve the quality of your sleep. Trying a few changes to your night time routine can also have a positive effect, such as having a relaxing bath, reading a book or listening to relaxing music. It’s important to try to make time for yourself in the evenings, so that you can fully relax and unwind.

Stopping smoking: While smoking is not a cause of HS, studies suggest it may make symptoms worse. You may wish to talk to your healthcare professional or pharmacist about the support available to help you stop smoking, or reduce the amount you smoke in the first instance. There are also a range of apps you can explore to support you on this journey.

This resource aims to provide practical information about living with HS. The information provided in this resource is not intended to replace the advice given to you by your healthcare professional.
TREATMENT AND MANAGEMENT OPTIONS

There is currently no cure for HS. However, there are a number of treatment options available to help you manage your condition. It’s important to discuss treatment options with your healthcare professional as treatment will be tailored for each individual, as every person and their HS is different. Some of the following treatment options may be offered by a GP and some by a dermatologist in consultation with the individual.

- **Topical (meaning applied to the skin) antiseptic wash:** This allows you to gently cleanse the affected areas of skin. It may help to reduce any smell and risk of an infection. It is normally prescribed alongside other treatment.

- **Antibiotics:** These are taken orally for at least 3 months and aim to prevent inflammation and reduce the number of lumps that develop. Antibiotic cream which can be applied directly to affected areas of skin can also sometimes help with easing symptoms. If lumps become infected with bacteria, this is known as secondary infection, and will normally be treated with a short course of antibiotic tablets (however, secondary infection is not very common in HS).

- **Retinoids:** These are vitamin A based medicines normally used to treat acne. However, they may help some people with HS. They can only be prescribed by dermatologists after consultation with the patient.

- **Hormone therapy:** For women whose HS flares before each period, the combined contraceptive pill may help to ease symptoms.

- **Immunosuppressive treatments:** If your HS is moderate to severe, your dermatologist might prescribe immunosuppressive treatments, which aim to reduce the body’s inflammatory response to HS. These include corticosteroids (which are normally taken as tablets or by injection) and specialist treatments (which are taken by injection).

- **Surgery:** This option may be considered by your dermatologist in combination with other treatments, in areas where there is persistent inflammation.

All medicines can cause side effects and it is therefore important to read the patient information leaflet provided with your medicine and discuss these with your healthcare professional.
COPING WITH HS EMOTIONALLY

- **Build a network of support**: HS can be an isolating condition, so it’s important to build a network of support to help you cope emotionally. Tell your friends and family about the condition, so that they can understand the extent to which HS affects your life and offer you support when you need it. It’s also important to remember that you are not alone! There are over 600,000 people living with HS in the UK. There are support groups, such as the HS Trust, where you can become part of an active community and talk about your experiences with others who understand what you are going through.

- **Do the things you enjoy**: As hard as it may sometimes be, try not to let your condition impact or stop you from doing the things you enjoy in life. Meet with friends who make you laugh - try not to let your condition stop you from going out and socialising. You may not always be able to do as much, but keeping in touch with friends and family may help to remove any sense of isolation.

- **Set yourself a challenge or goal**: Why not set yourself a personal challenge? This may help balance your mindset and alleviate any negative feelings you may be experiencing. Write your goal down, including the steps you will need to take to achieve the goal and share it with a trusted friend or family member. Try not to set yourself an unrealistic or difficult challenge – this will only set you up for a fall! When you achieve your goal, give yourself a reward – something you would enjoy, like a trip to the cinema or dinner out. If you experience a setback and do not manage to achieve your goal, don’t give yourself a hard time. Think about what got in the way so you can be prepared if you encounter this obstacle next time.

- **Get support in employment**: HS may affect your ability to work. This will depend on the type of work you do and the severity of your HS. It may mean you have to take a number of days off work to attend healthcare appointments for your HS. However, there is support available to help you manage your HS and your work. If you need support you may want to contact The Hidradenitis Suppurativa Trust listed in the useful resources section at the end of this document.

- **Talk to your healthcare professional**: Discussing how you feel with your healthcare professional is important, they will be able to recommend a range of online resources to help you cope with HS as well as any local support groups that may be available in your area.

There are over 600,000 people living with HS in the UK.

If you think you are suffering with HS, it is important that you go and see your GP as soon as possible. They may be able to diagnose you or will refer you to a specialist, such as a dermatologist. If you do have HS, receiving treatment when the condition is in its early stages, may prevent it from getting worse.
FIRST SIGNS AND SYMPTOMS OF HS

What is hidradenitis suppurativa?

SEEING A GP

Seeing a GP about hidradenitis suppurativa

SEEING A SPECIALIST

Seeing a dermatologist about hidradenitis suppurativa

LIVING WITH HS

Living with hidradenitis suppurativa

Taking care of sore spots and wounds

Dealing with pain associated with hidradenitis suppurativa

USEFUL RESOURCES

You may also find the following resources useful:

- **The Hidradenitis Suppurativa Trust (the HS Trust)**: A UK registered charity dedicated to raising awareness of HS and supporting those living with the condition
- **NHS Choices**: The official website of the NHS providing comprehensive health information on many conditions
- **British Association of Dermatologists (BAD)**: Although primarily an organisation for healthcare professionals, the BAD has a section on their website for the public. This section provides patients with access to information, resources and tools around a number of skin conditions

References: