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Hidradenitis Suppurativa

Introduction

This leaflet is for people whose daily lives are affected by Hidradenitis Suppurativa (HS). The aim is to provide you with a basic understanding of HS and introduce you to some of the more common symptoms and treatments.

What is Hidradenitis Suppurativa (HS)?

Hidradenitis Suppurativa (HS) is a chronic, inflammatory, recurrent skin disease of the hair follicle that usually occurs after puberty, and although rare, cases of HS in children do exist. It often starts as painful boil-like abscesses. These boils can cause scarring in the armpits, genitals, groin, breasts, perianal region and buttocks.

It is estimated that between 1 and 4 people per every 100 will have HS. It is possible that many more have the condition, but have not told their doctor about their symptoms. It is recognised HS effects patients' quality of life more than other skin conditions.

What causes HS?

We do not know for sure what causes HS but some doctors and researchers believe it is probably linked to inflamed sweat glands and blocked hair follicles. There is research being carried out to see whether HS is an autoimmune condition (where the immune system mistakenly attacks and destroys healthy body tissue). HS runs in some families, which means there is sometimes a genetic link. HS is **not** contagious.

What are the effects of HS?

Physical effects:
HS is associated with a number of uncomfortable and unpleasant symptoms which vary from person to person and from flare-up to flare-up. Symptoms include:

- Visible lumps and abscesses which may leave scars
- Pain and discomfort from the abscesses
- Discharge (pus) from the lumps which can be smelly
- Infection - but remember that not all abscesses with discharge are infected, this can lead to feeling generally unwell and disturb your sleep causing tiredness
- Unwanted side effects of the medications used to treat HS – steroids may cause weight gain and fluid retention, for example, while antibiotics may result in yeast infections
- Acne and/or unwanted excess hair (hirsutism) together with the symptoms of HS
- Pain or discomfort due to treatments such as surgery, cryotherapy or laser therapy
- Difficulty sitting or moving about due to painful lumps
- Other symptoms, including fever, fatigue and sleep disturbance
- Steroid medication can lead to unwanted side effect which include, weight gain.

How is HS diagnosed?

There are no tests used to diagnose HS. The diagnosis is usually made by your dermatologist after discussing your symptoms.

What are the treatment options?

There is no one treatment that works for everyone who has HS. Sometimes, a patient will need to try a few different treatments to find one that helps. Most treatments are to reduce flare ups and manage symptoms. Some treatments may continue over several months or years, and may include a combination of different medications and therapies. Treatment options include creams, antibiotics and surgery.

Further information

Hidradenitis suppurativa UK and Ireland support group (Facebook)
Website:
https://m.facebook.com/groups/1640719816154803/

This is resource of information and advice about HS, and includes an online support group

Hidradenitis suppurativa foundation
Website: https://www.hs-foundation.org

Changing Faces
Website: www.changingfaces.org.uk

This is a charity for everyone with a scar, mark or condition on their face or body that makes them look different.

You may find the following resources available from Changing Faces useful:

‘Living with Confidence’, by Changing Faces, is a booklet for people who live with a visible difference.

‘Intimacy, Love and Relationships’ (Parts 1 and 2), by Changing Faces, is a booklet for people who live with a visible difference that affects their intimate relationships.

Contact information

If you have any concerns or questions, please contact the number below.

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Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.

Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you asked to make a choice about your healthcare.



1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation.

***Ask 3 Questions** is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial.

Patient Education and Counselling, 2011;84: 379-85

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NHS https://aqua.nhs.uk/resources/shared-decision-making-case-studies/

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