

What you **need to know** about

HS HIDRADENITIS SUPPURATIVA



HS
Hidradenitis
Suppurativa

The Irish Skin Foundation is a national charity with a mission to improve quality of life for people with skin conditions, promote skin health and the prevention of skin disease through support, advocacy and by raising awareness.

We hope you find this booklet about hidradenitis suppurativa helpful and informative. If you would like more information, visit our website www.irishskin.ie or call our Helpline on (01) 486-6280.



**Welcome to your
guide to living with
hidradenitis suppurativa**

What you need to know about:

HS HIDRADENITIS
SUPPURATIVA



What is Hidradenitis Suppurativa?..... 4

What causes HS?..... 5

How common is HS?..... 6

HS symptoms..... 7

Diagnosis..... 8

HS can affect you emotionally and socially,
as well as physically..... 8

How HS is evaluated?..... 10

Measuring the impact of your condition..... 11

Associated conditions..... 11

How do doctors treat HS?..... 12

Primary care..... 12

Secondary care..... 13

Pain management..... 14

Localised anti-inflammatory therapy..... 15

Surgery..... 15

Self care tips: The following general measures can
also be very helpful in the management of HS..... 16

Suggestions for talking with your doctor..... 20

Know that you are not alone..... 21

Support..... 21

Where can I get more information about HS?..... 21

What is Hidradenitis Suppurativa?

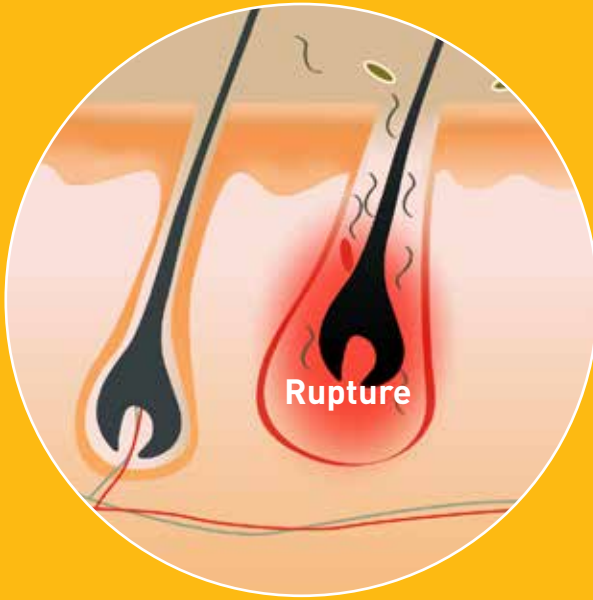
Before we begin, let us start by explaining a few words that will help you to understand the information in this booklet.

- A **pustule** is a small, raised area on the skin, with a yellow or white centre containing pus.
- A **nodule** is a firm raised area or swelling under the skin, greater than 5 mm in diameter, which can be painful.
- A **boil** is a red, tender, lump that develops on the skin at the site of an infected hair follicle. Sometimes the symptoms of HS can be mistaken for an infection or boils.
- A skin **abscess** is a painful, collection of pus which develops under the skin.
- A **sinus tract** (also known as a tunnelling wound) is a narrow channel beneath the skin that can connect abscesses to each other and/or allow the escape of fluid on to the surface of the skin.
- **Apocrine glands** are a type of sweat gland found in certain areas of the body such as the armpits and groins which have an abundance of hair follicles.

Hidradenitis suppurativa (HS), also known as acne inversa, is a chronic or long-term inflammatory skin disease of the hair follicle, characterised by recurrent, painful nodules, 'boil-like' lumps or abscesses that can occur in the armpits, groin, perianal area, buttocks or under the breasts.

HS usually occurs where skin touches skin.

The condition involves the abnormal blockage of hair follicles in areas where certain sweat glands (apocrine glands) are located, leading to recurrent inflammation, nodules and abscesses.



Blocked hair follicle

Secretions cannot escape from blocked hair follicles, which may then swell and burst, or form abscesses.

What causes HS?

- The exact cause remains unclear.
- It is an inflammatory disorder, which is thought to be linked with certain defects in the skin's immune system.
- Problems with the structure of the hair follicle may also play a role.
- HS may run in families. Approximately one third of patients have a family history of the condition.
- Women are three times more likely to be affected than men.
- HS usually starts after puberty, and may get worse before menstrual periods. It is less active after the age of 50–55 in females, and is usually in complete remission following the menopause. It is thought that sex hormones may play a role. However, as yet, there is no direct evidence of such a link.
- Cigarette smoking and obesity appear to be risk factors for developing HS.
- HS is not an infection, so it cannot be passed on to other people and is not caused by, or connected to poor hygiene.



How common is HS?

European studies have suggested that HS may affect between 1–4% of the population, while a recent Irish study (October 2016*) indicated a prevalence of 1.4% amongst the patient population in those clinics.

*Women
are three
times more
likely to be
affected
than men.*

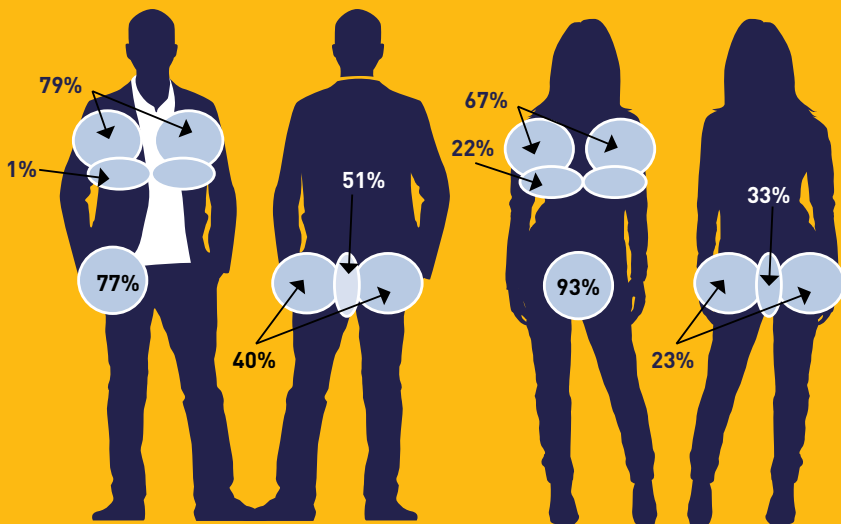
- Many people living with HS do not always feel comfortable talking about their symptoms.
- Some may see a doctor that is not familiar with HS and as a result, HS is thought to be under-recognised.
- HS is sometimes misdiagnosed, often mistaken for an infection or boils.
- The repeated nature of symptoms is a clue to the diagnosis. Delay in diagnosis is not uncommon.

* Delany E, Gormley G, Leonard M, Murphy M, Tobin AM, Markham T, Kirby B. SHIP A cross sectional epidemiological Study of Hidradenitis suppurativa in an Irish Population. Presented at the EADV Annual Meeting October 2016.

HS symptoms

The symptoms of HS and the location of lesions can vary from person to person. Common locations include the armpits, groin, buttocks, perianal area, inner thighs or under the breasts.

THE DIAGRAM BELOW SHOWS THE AREAS THAT ARE MOST FREQUENTLY AFFECTED IN MEN AND WOMEN.



Adapted from Revuz J. *J Eur Acad Dermatol Venereol.* 2009;23(9):985-998

- Mild cases of HS may consist of blackheads, a few small bumps or nodules.
- People with more severe forms can suffer from painful nodules that develop into abscesses, and join up to form sinus tracts, which can release fluid/pus that may have an unpleasant odour. The inflammatory process can result in scarring.
- Lesions caused by HS can be very uncomfortable and painful, often interfering with the quality of life of those living with the condition.

While not all cases of HS get worse over time, HS can continue to recur and sometimes become more severe if not properly managed. As a result, establishing a diagnosis and early intervention (treatment) is important.

Diagnosis

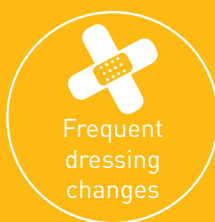
Your GP is the first doctor you will see about symptoms. HS is usually diagnosed by the history, appearance and distribution of recurrent nodules and abscesses. HS is often under-recognised and repeated symptoms may require referral to a hospital based consultant dermatologist for confirmation of diagnosis and treatment.

*Do not be embarrassed.
Speak openly and honestly to your doctor about your symptoms to help ensure an accurate diagnosis.*

HS can affect you emotionally and socially, as well as physically

Each person living with HS will have different experience, depending on whether their condition is mild, moderate or severe.

For people who have more severe forms of HS, the location of the lesions and nature of the symptoms, can cause embarrassment, challenges in carrying out day-to-day activities, and affect personal and work life. Problems may include:



As a consequence, HS can greatly impact on quality of life and has been associated with depression and anxiety.



How HS is evaluated?


Doctors usually grade the signs and symptoms of HS according to how severe they are, on a scale, which ranges from 1–3, called the **Hurley staging system**:

| Hurley stage 1 (Mild cases): | Hurley stage 2 (Moderate cases): | Hurley stage 3 (Severe cases): |
|---|--|--|
| Single or multiple abscesses | Recurrent abscesses, sinus tract formation | Widespread HS in particular areas, with multiple interconnected sinus tracts and abscesses |
| <ul style="list-style-type: none">• Painful bumps, pustules and abscesses in the armpits, groin, under the breasts, the perianal area, buttocks or inner thigh.• These bumps generally start as firm, pea-sized nodules. | <ul style="list-style-type: none">• Recurring spots, pustules and abscesses in multiple areas with scarring and skin tunnelling.• Scarring can occur as a result of long-term or repeat occurrences in a single location. | <ul style="list-style-type: none">• Widespread spots, pustules and abscesses with multiple interconnected sinus tracts.• Abscesses can be painful and develop into deep sinus tracts under the skin. Areas of skin involved may split and leak fluid/pus, which can have an unpleasant odour. |
|  |  |  |

Image **A** courtesy of Jurr Boer, M.D. Image **B** and **C** from The New England Journal of Medicine. Jemec GBE. Clinical Practice: Hidradenitis Suppurativa. 366(2): 158-164 ©2012 Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society.

Measuring the impact of your condition

Doctors sometimes ask patients to fill out a questionnaire called the Dermatology Life Quality Index (DLQI). It measures, in 10 questions, the impact HS has, on the affected person's life, physically, emotionally, socially, and sexually in the past week, as well as how troublesome the treatment has been. Patients may be asked to complete the DLQI questionnaire during a visit to help their doctor measure how well their treatment is working.



You should try to be as honest as you can when answering the questions.

Associated conditions

Although HS affects the skin, it is an inflammatory disorder, which means the condition is brought on by irregularities in the body's own immune system.

There are a number of other conditions that have been associated with HS, including inflammatory bowel disease and arthritis.

It is common for some conditions to occur alongside HS. Doctors often use the words 'associated' or 'secondary', or even 'concomitant' to describe the occurrence of these conditions that may co-exist with HS. This does not mean that one condition causes the other or that you will necessarily develop any of these other conditions; it only means that doctors have noticed a link that has yet to be explained.

How do doctors treat HS?

Although there is currently no cure for HS, treatments are available and may include a combination of medication and surgery. HS can continue to recur and sometimes become more severe if not properly managed, so early intervention (treatment) is important.

HS can be a challenging condition to treat, as no single medication is effective for all patients with HS. As a result, a number of medications may be prescribed before an effective treatment is found. The choice of treatment is tailored to the individual and will depend on the person's medical history, as well as the severity and extent of the disease.

Primary care (your local GP)

If your HS is mild, your care may be managed by the GP. The following treatments may be prescribed:

► **Topical treatment - applied directly to the skin**

Topical antibiotics - topical clindamycin may be prescribed for milder disease.

► **Systemic treatment - medications that work throughout the body to control HS**

Oral antibiotics (taken by mouth) - Tetracyclines may be prescribed for a period of at least 3 months to suppress the inflammation associated with HS.

Secondary care

(hospital dermatology clinics)

If your disease is moderate or severe, you will be referred to a dermatologist.

- ▶ **Consultant dermatologists typically prescribe the following medications, as patients require monitoring during treatment**

Recommendations may include:

Oral antibiotics (taken by mouth) - a combination of antibiotics: clindamycin + rifampicin may be prescribed initially for a period of 10–12 weeks. They work by suppressing the inflammation associated with HS rather than destroying the bacteria.

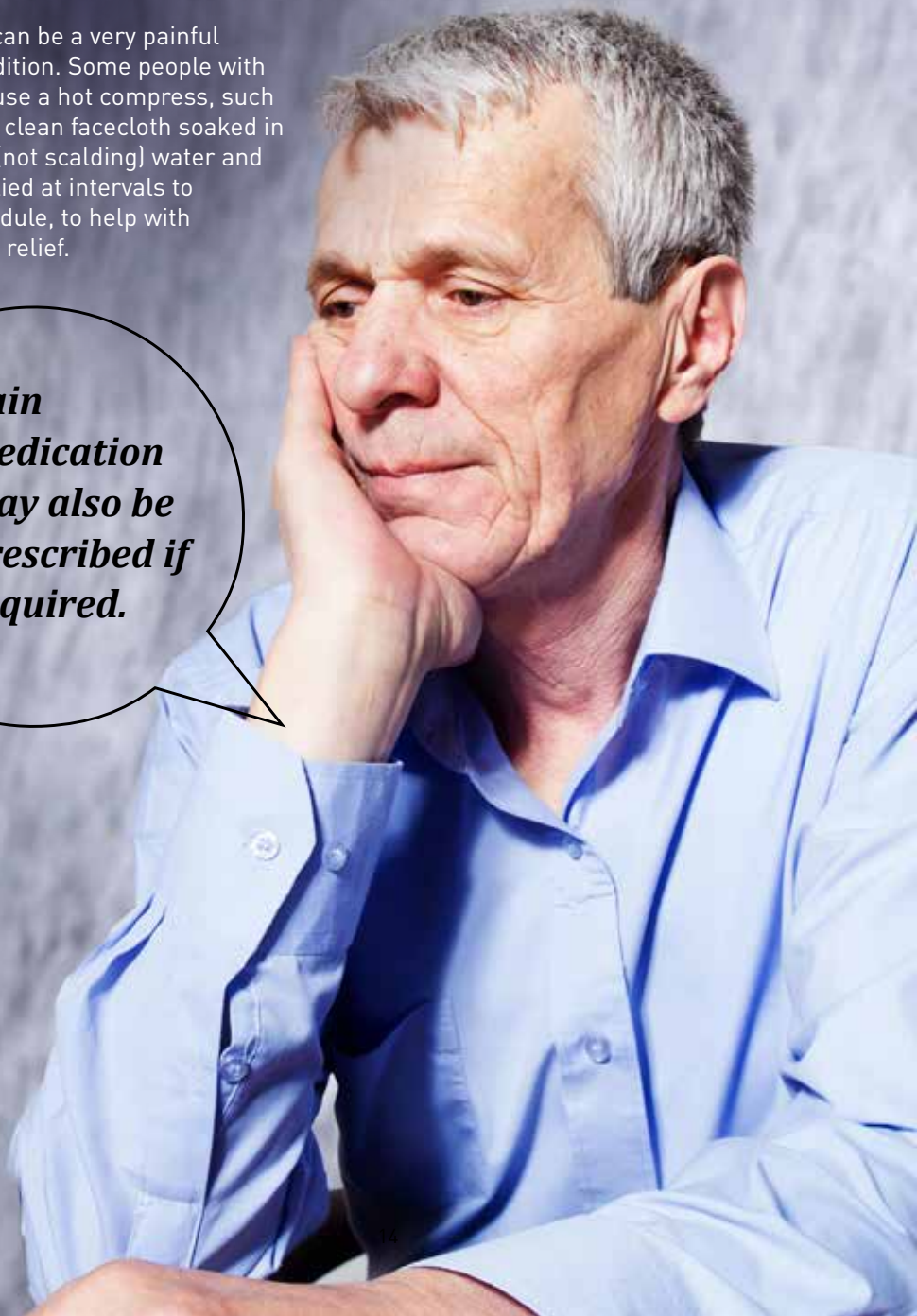
- ▶ **Biologic treatment – medications designed to target and inhibit specific parts of the immune system that drive inflammation**

In circumstances where other treatments are not suitable, have not provided symptom relief, or if the patient is experiencing side effects, the dermatologist may prescribe a biologic.

Pain management

HS can be a very painful condition. Some people with HS use a hot compress, such as a clean facecloth soaked in hot (not scalding) water and applied at intervals to a nodule, to help with pain relief.

Pain medication may also be prescribed if required.



Localised anti-inflammatory therapy

Corticosteroid injections, also known as **intralesional steroids**, are sometimes administered for the treatment of localised disease. A steroid called triamcinolone may be injected into the nodules to decrease the inflammation and reduce the pain.

Surgery

In certain cases, surgery can be very helpful for HS. If necessary, your dermatologist will refer you to the appropriate specialist surgeon.



Self care tips: The following general measures can also be very helpful in the management of HS

1. Stop smoking

Research has shown that people with HS are far more likely to be smokers. Smoking is thought to worsen HS, and stopping smoking may improve symptoms.



The HSE provides tailored quit plans to help people quit smoking, see:
***www.quit.ie or
Freephone
1800 201 203***

2. Maintaining a healthy weight

Obesity is identified as a risk factor for the severity of the condition and weight loss may improve symptoms.

Maintaining a healthy weight is important, for example, please see body mass index online calculator: www.bmicalculator.ie



People with HS are at an increased risk for heart disease and should have their 'risk factors', including blood pressure and cholesterol checked.

3. Skin care

Wound care/dressings

You may require specific types of dressings, or the dressings may need to be customised, depending on the location of the wound, the stage of wound healing and the quantity of fluid that is produced.

Maceration is the softening and breaking down of the skin which occurs when there is prolonged exposure to moisture, such as from the fluid/pus that may be released from wounds in HS.

Therefore, it is important to draw excess fluid away from the skin and to change dressings regularly, in order to keep the skin surface dry and avoid maceration.

The chosen dressing should be **absorbent, non-irritant and non-occlusive (breathable)**. Some dressings also absorb odours. Discuss options with your health care professional.

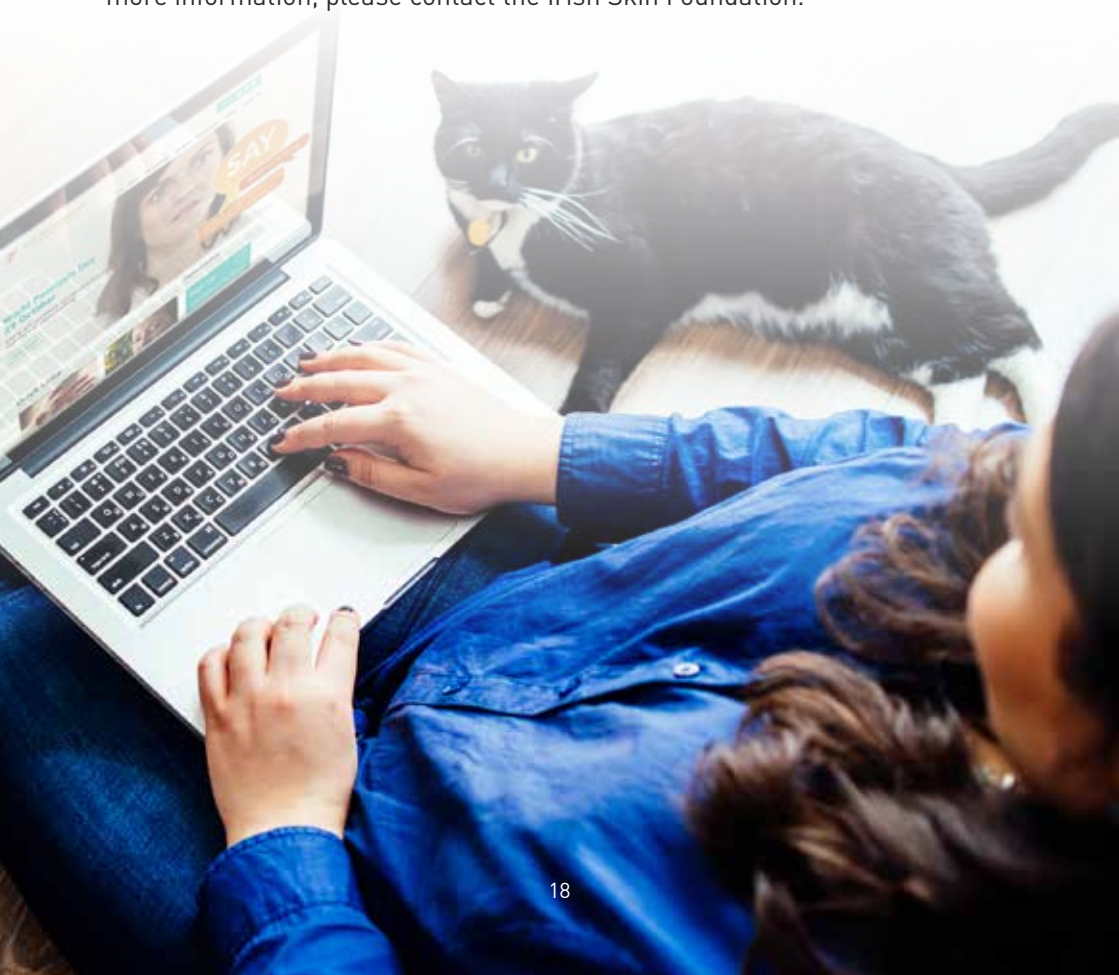
4. What is the best clothing to wear?

Choice of clothing is influenced by what works best for each individual, based on the site and severity of their condition. Typically, loose-fitting cotton clothing is the most comfortable and is preferable to synthetic, wool or slim-fitting garments.

Tight fitting clothing may cause chaffing - this is where the skin becomes irritated by continuous friction caused by skin rubbing against skin or clothing, and can contribute to discomfort.

Consider garments with smooth seams to avoid friction.

Specialised undergarments are available for those living with HS. For more information, please contact the Irish Skin Foundation.



HS: Overview

About HS

Age of onset **usually after puberty**



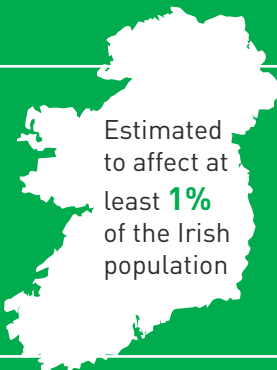
Presents as nodules or abscesses **under the arms**, in the groin or under the breasts



Women are **three times** more likely to be affected



Estimated to affect at least **1%** of the Irish population



Impact on quality of life

Pain and scarring



Areas **leaking** fluid/pus

Difficulty performing daily **activities**



Embarrassment and psychological strain

Impact on **personal** and **work life**



Depression

Associated conditions (comorbidities)

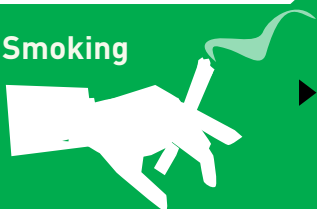


1. Inflammatory bowel disease

2. Arthritis

Risk Factors

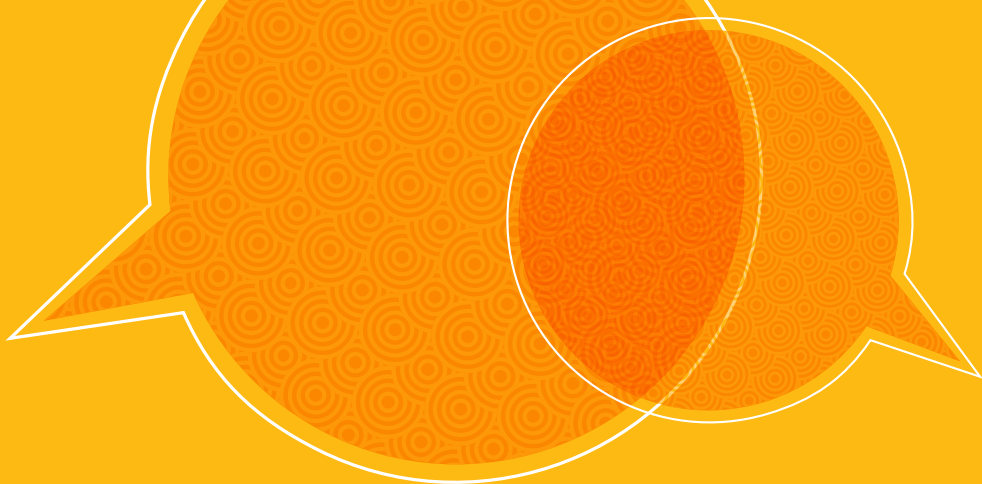
Smoking



Obesity



Family history



Suggestions for talking with your doctor

Be sure to talk with your doctor about your symptoms and progress, and if necessary, alternative treatment options.

Do not be embarrassed about asking your doctor questions. Often, the time you spend with your doctor is limited, so it can be useful to make a list of questions beforehand so you don't forget, and take them with you to your appointment.

Acknowledge your feelings and emotions about your condition. If you are feeling anxious or down, it's important to share your feelings with your doctor.

Make sure you understand the information your doctor is giving you. It is acceptable to say 'I don't understand'.

Learn more about HS. This will make it easier to have a conversation with your doctor about treatment options and your progress.

Keep a diary of your symptoms and how you feel, and note any times that you forgot to take your medication.

Know that you are not alone

While HS is still a hugely overlooked condition, it is not uncommon, with research indicating that it affects at least 1% of the Irish population.

Support

Finding a friend or family member that you can talk to can be beneficial. If you find it difficult, connecting with people who understand your condition and feelings may be comforting and useful, for example:

- Hidradenitis Suppurativa Ireland Facebook Support Group (and also on twitter: @hsireland1)

Where can I get more information about HS?

Reliable sources for patient information are available, including those listed here:

Irish Skin Foundation: www.irishskin.ie

British Association of Dermatologists:

<http://www.bad.org.uk/for-the-public/patient-information-leaflets>



***Irish Skin
Foundation
Nurse Helpline:
01 486-6280
info@irishskin.ie
www.irishskin.ie***

Notes

[illegible]



What you **need to know** about

HS HIDRADENITIS SUPPURATIVA



This booklet has been prepared by the Irish Skin Foundation in consultation with people with HS, dermatology nurses and consultant dermatologists.

Brought to you by the



Irish Skin Foundation

Supporting people with skin conditions in Ireland

Irish Skin Foundation
Charles Institute UCD
University College Dublin, D04 V1W8
tel: 01 4866280 email: info@irishskin.ie
www.irishskin.ie

Charity Regulatory Authority Number: 20078706

The printing costs of this booklet were kindly supported by

abbvie

The views expressed in this booklet are those of the Irish Skin Foundation and are independent of our corporate sponsors.

Date of preparation: February 2017

© Copyright Irish Skin Foundation 2017. All rights reserved.