



International Association of
Hidradenitis Suppurativa Network, Inc.

The Physical Effects Bringing Awareness to the Forefront

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WHAT IS THE PURPOSE OF THIS PAMPHLET?

This pamphlet 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 effects that you may endure as a patient. The information in this pamphlet is not intended to replace the advice of your doctor.

Introduction

There are many ways that Hidradenitis Suppurativa (HS) can affect a patient physically. These physical effects can often have a detrimental effect of the day-to-day living of a patient, particularly when the condition is at an advanced stage. It is worth noting that, as HS affects each patient differently, some patients may find it easier to cope with these effects than others.

Some common physical effects may include:

- Aches, pains and itching in affected areas (1)
- Discharge from abscesses, often prolonged
- Visible lumps and/or abscesses
- Visible scarring
- Fatigue (2), and difficulty sleeping
- Unable to sit comfortably
- Difficulty walking without experiencing pain and discomfort
- Difficulty with physical intimacy (3)
- Fulfilling employment obligations (4)
- Driving (due to pain when seated and moving, or because of medication side effects)
- Other side effects caused by required medication
- Pain and discomfort after surgery

Below we will discuss some of the most common physical issues faced with HS, including suggestions on how to deal with these.

Pain

The pain associated with the condition can be intense and chronic, and

has been reported to be the most significant factor contributing to a patients' impaired quality-of-life (5). In fact, quality of life is poorer in patients with HS, than that of patients with many other dermatological conditions and serious medical conditions. Pain can be different for each individual, from the type to the intensity, and can often be described in many ways, such as:

- Hot or burning
- Build-up of pressure
- Sharp or cutting
- Throbbing
- Aching

People with chronic pain may be able to attend a specialist Pain Clinic for assessment and possible pain management, and for some, a Pain Management Programs may be beneficial. Pain Management Programs (PMPs) can help people to live with chronic pain by helping them to learn ways of dealing with the disabling effects and distress caused by being in pain, by teaching physical, psychological and practical techniques to improve quality of life.

There are of course other methods of treating pain, including over the counter and prescription painkillers. Stronger pain medications are available, however, these will only be prescribed after consultation with your PCP or a pain specialist. The dose and your response will be closely monitored. These drugs should only be used as part of a long-term plan to manage your pain.

Itching

Itching (or pruritus) can be extremely irritating and uncomfortable for a patient, and can often lead to restlessness, sleep deprivation and sometimes depression. If left untreated, persistent scratching may also lead to further irritation, and possible skin infection. There are

many reasons why your skin may become itchy, the most common reason is due to the fluid releasing onto the skin from the abscess, but other causes could include infection, allergy, dry skin or a reaction to medication. It is important to find and treat the cause of the itch, and persistent itching should be spoken about with your consultant or PCP.

There are a few treatments that can soothe and relieve the itching, with antihistamines being the most commonly used. However anti-depressants, steroids and various lotions and creams may also be prescribed.

Some ways to cope with the itch include:

- Use a pH-neutral soap substitute or lotion, and avoid scented or colored products
- Limit the time spent in the bath, and use lukewarm water
- Thoroughly dry your skin, but pat your skin dry with a towel rather than rubbing
- Wear loosing-fitting cotton or linen clothes
- Keep cool and reduce the room temperature
- Drink plenty of water to hydrate your skin
- Avoid shaving irritated areas
- Ensure you keep your finger nails short.

Sweating

Sweating is the body's way of keeping itself cool. It originates from the sweat glands in the skin. The most common places to sweat are in the armpits, groin and skin folds, and these are the areas that contain the apocrine sweat glands that are affected by HS.

Excess sweating can be caused by a variety of factors, these could include:

- Being in a hot environment
- Movement or exercise
- Changes in mood
- Changes in hormones, either naturally or through medication
- Infection
- Medication

It is always best to seek medical advice if you experience excess or unusual sweating, as diagnosing and treating the cause will often stop or reduce the sweat. There are a few treatment to prevent the body from sweating, and these can be discussed with your consultant or PCP.

There are a few things you can do yourself to reduce sweating, these can include:

- Reduce room temperature and stay cool
- Wear loose-fitting cotton clothing
- Have a fan or air conditioner (AC) blowing on you at night
- Bath regularly
- Avoid eating spicy or large meals
- Avoid excess alcohol
- Drink plenty fluids/water to keep hydrated

Some medication may also produce discolored sweat, most commonly experienced by those prescribed the Rifampicin and Clindamycin combination treatment.

Pressure Sores

Pressure sores can occur when friction and pressure is being applied to the same area of skin constantly, and therefore damages the skin. It is commonly experienced by those with limited mobility who are bedridden or in a wheelchair. There are a variety of factors that can increase the risk of developing pressure sores, these are:

- Sliding on/off chairs or beds
- Friction from sheets or blankets
- Poor hydration
- Moist sweaty skin
- Treatments vary, and can be discussed with your PCP. Common medical treatments will consist of applying special pressure relieving dressings, or occasionally surgery. In order to reduce the risk of producing pressure sores, you could try the following:
 - Change position every 1-2 hours
 - Do not slide or drag joints when moving about
 - Use special pressure relieving pillows or cushions
 - Regularly check for signs of pressure sore development. Look for blisters, swelling, and dry/cracked areas on the skin.
 - Keep your skin well moisturized and hydrated
 - Ask your consultant for specialized lifting equipment, such as grab handles, to assist getting in and out of bed or chairs.

Sleep Deprivation

Pain is a very common reason for patients being unable to get a good night's sleep, and as sleep deprivation can lower your pain threshold,

this can make it much harder to deal with the pain. This is very much a vicious cycle, one that, for many patients can go on for years, causing extra stress, which can in turn worsen the condition.

Prescription sleep medications are available from your doctor, however these may then affect you the following morning, affecting your ability to wake up in time for work, or even safely drive your car.

Thankfully there are a few tips that you can try to help aid a good night's sleep:

- Try to set regular bedtime hours, as this can help the body fall into a better sleep routine.
- Avoid caffeine and alcohol in the evening.
- Take antihistamines to help stop itching that maybe keeping you awake.
- Try wearing cotton gloves in bed, and/or keep the affected areas covered, this may to help to stop you from being woken by scratching.
- Try to relax before bed, listening to soothing music, or having a warm bath can relax the body and mind.
- If you cannot sleep, get up and do something else for a bit until you feel tired, then return to bed and try again. Laying there trying to get to sleep can actually stimulate the mind and keep you awake.
- Make sure you have a comfortable mattress. If it's too hard or soft or old, it may stop you from drifting off.
- There is evidence that therapies such as counseling and Cognitive Behavioral Therapy (CBT) can help.

Intimacy And Relationships

Having a chronic illness can take its toll on a relationship, and the partner who's sick may not feel the way he or she did before the illness. At the same time, the person who's not sick may not know how to handle the changes.

With a little patience and commitment, you and your partner can learn to deal with the strain that the condition can impose on your relationship. The most important things to remember are:

- Communication is key - Discuss the condition openly, and talk about the problems that you are both facing. Lack of discussion can lead to feelings of distance and a lack of intimacy.
- Be open about what help you need – On a good day, you may want to do things on your own, but then become resentful when others don't step up to help when you are not feeling as well. If you're the person with the condition, be clear and direct about what you want because your partner isn't a mind reader.
- Look after each other – If your partner is also your caregiver, you need to keep an eye on how they are coping as well. Look out for changes in their behavior and well-being, as caring for someone with a chronic illness can be hard.

When it comes to intimacy, having HS doesn't necessarily have to mean the end of sex. Using flexibility, experimentation and good communication, couples can continue to enjoy sex and may be able to strengthen their relationship. But for those who decide that sex will no longer be a part of their relationship, either due to excess pain or loss of sexual desire, a focus on other aspects of the relationship can foster closeness and caring.

Treatment Related Side-Effects

Side effects from treatments will vary, and not everyone will experience side-effects at all. While taking your medication, you may find that your PCP will conduct regular blood tests, this is done to ensure that the medication is not affecting you in a negative way. The most common side effects to look out for when trying new treatments are:

- Diarrhea or constipation
- Nausea and/or vomiting
- Rashes
- Weight gain, especially when taking steroid based drugs
- Fluid retention
- Mood swings

Some people may experience an allergic reaction to medication. In most cases the allergic reaction is mild to moderate and can take the form of:

- A raised itchy skin rash (urticaria or 'hives')
- Coughing/wheezing

However, if you experience tightness of the throat, and difficulties breathing, stop your medication and seek medical assistance straight away. When starting new treatments, it is also important to discuss the limitations that certain medication will impose on your day-to-day activities, as some may prevent you from driving, becoming pregnant, breast-feeding, etc. If you start to experience any adverse effects from your medication, become concerned about possible allergic reactions, or have any doubts about what you can and cannot do when taking certain medications, please seek the advice of your PCP or pharmacist as soon as possible.

The International Association of Hidradenitis Suppurativa Network, Inc. is a publicly funded charity, providing reliable information and support to both patients and professionals.

www.iahsn.org

International Association of Hidradenitis Suppurativa Network, Inc. is a registered charity in Brockton, MA (46-1181948).

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

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