



International Association of
Hidradenitis Suppurativa Network, Inc.

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

HOW CAN HS AFFECT ME EMOTIONALLY?

Living with a chronic illness can have emotional as well as physical effects, and this is very common in many conditions. Some of the common effects that may be experienced by a patient are:

Shame and embarrassment

Because HS is a visible illness with sometimes unpleasant symptoms, there may be times when you feel ashamed or embarrassed. You may have to deal with other people's misunderstandings about the condition (the idea that it is contagious, for example) or be worried about what other people might be thinking (that the condition is in some way your fault because of your lifestyle or your personal hygiene habits). This may even have stopped you from telling your doctor about your symptoms, meaning a delay in getting a diagnosis and treatment.

Anger and irritability

You may feel angry about having this condition and about the limitations it puts on your daily life. You may also feel irritated when a new lump develops or when you have to deal with symptoms such as pain and discharge.

Depression

Living with a chronic health condition can increase your chances of experiencing low mood or depression. You may have opted out of hobbies, social outings or intimate relationships because of HS, and at times you may feel bad about yourself and the future. Perhaps others have not always been kind or understanding about your HS. All of this can contribute to low mood and depression. If you are experiencing depression and have had thoughts that your life is not worth living, it is important to tell a healthcare professional such as your Primary Care Physician (PCP), particularly if you think you might act on these thoughts.

Anxiety

You may experience a range of worries that cause anxiety and stress. You may worry about the next abscess or about the condition getting worse over time. You may worry about how the condition is affecting you now or how it might affect your work life, family life and close relationships in the future. Also, you may feel worried and anxious when you think about what other people might be thinking about you, whether you are right about this or not.

Feeling disappointed or disheartened

If you have had unsuccessful treatment for HS, you may feel disappointed and disheartened, and may begin to feel helpless.

Effects on daily life

Having HS may mean that you stop doing the things you used to do, or the things you enjoy doing, like socializing and engaging with hobbies or exercise.

In the short term, it avoids having to face difficult situations like worrying about what other people think or being faced with the risk of unkind reactions. However, over time this strategy can lead to isolation and boredom. It can make you feel worse physically and emotionally because you are missing out on opportunities for pleasure, fun, activity and achievement. You may have avoided:

- Social situations in case other people notice the abscesses, discharge or odor.
- Physical intimacy with sexual partner.
- Physical closeness with friends and family.

- Workplace opportunities, like giving a talk or taking the lead on a demanding project.

As well as opting out of things, your HS may mean that you have to do things you would rather not do. These might include:

- Avoiding moving about due to painful lumps
- Spending lots of time trying to cover up the abscesses or scars
- Having to choose your clothes carefully (for some people tight clothes can affect their HS symptoms)
- Having to be careful about the products and cosmetics you use
- Missing work, school or college due to flare-ups
- Changing or postponing activities you were looking forward to when the symptoms are bad.

Having to make these changes may lead to lots of different reactions and emotions, such as feeling frustrated, overwhelmed or downhearted. On the other hand, you may have come to accept some of these adjustments over time.

Looking after yourself emotionally

It is important to look after yourself emotionally as well as physically, below is some suggestions that may help you cope.

- Become aware of particular feelings or emotions you are experiencing, try to identify them, i.e. stressed, anxious, etc.
- Ask yourself what triggered the feelings. Once you can answer this, it will be easier to understand and manage your feelings.

- Write them down, this will help you to keep a record of your moods and feelings.
- Talk to someone about these feelings, either a close friend, family member or healthcare or mental health professional.
- Join a support group and speak to others going through the same experiences as you.
- Develop a strategy for dealing with the feelings, but avoid such things as excessive alcohol, over-eating and drug abuse, as these may help in the short-term, but may have a detrimental effect in the long-term.

Mindfulness

When you are upset or feeling physically unwell, it is common for your mind to come up with lots of different, sometimes strong feelings. Your mind may also come up with different thoughts, images and memories. Often we can get caught up in reacting to these thoughts and feelings, or we get stuck trying to get rid of them, often without much success. As an alternative, try taking a curious attitude towards whatever you are experiencing right now, including thoughts, feelings and sensations. Just notice them without judging them or trying to change them. This approach is called mindfulness.

Try these simple steps:

- Focus first on your breath.
- Pay attention to the natural rhythm of your breath.
- Notice the rise and fall of your chest and stomach.
- If the focus of your attention shifts to parts of the body that

are uncomfortable or are affected by HS, gently invite your attention back to the breath, focusing instead on the part of the body in which you feel your breath most intensely.

- Notice how the breath feels coming in and out of your nose.
- Don't be concerned if you notice that your mind has wandered off. Briefly note what grabbed your attention (a thought, feeling or sensation), and then bring your focus back to the breath.

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

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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Helpful Links

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