

Living with Hidradenitis Suppurativa (HS)

This leaflet is a guide to coping with the emotional and practical effects of Hidradenitis Suppurativa (HS). If you have any further questions, please speak to a doctor or nurse caring for you.

Contents

1. Introduction..... p.2

- What is Hidradenitis Suppurativa (HS)?
- What causes HS?
- Why am I struggling?

2. The effects of HS..... p.2

- Physical effects
- Emotional effects
- The effect of HS on the things you do
- The effect of HS on thoughts and beliefs
- Vicious and virtuous cycles

3. Coping with HS..... p.5

- Looking after yourself physically
- Looking after yourself emotionally
- Mindfulness
- Managing your mind
- Balancing your awareness
- Deciding what to do

4. Communication and relationships..... p.10

- Improving communication with people around you
- Improving communication with your partner
- Improving communication with healthcare professionals

5. Summary and conclusions..... p.11

6. Further reading..... p.12

1. Introduction

Hidradenitis Suppurativa (HS) is a chronic skin condition that can affect people physically, emotionally and socially. This leaflet is for people whose daily lives are affected by HS. It may be particularly helpful for people when they are feeling upset or distressed by the condition.

The first part of the leaflet describes some of the common reactions to HS and how it can affect different parts of your life. Not all of these will apply to everyone. From page 5 onwards, it goes on to offer some ideas on how to manage the difficult thoughts and feelings that can accompany living with HS, and will help you think about how to make choices that may improve your quality of life. It is quite a long leaflet, so you might want to read it a page or two at a time.

What is Hidradenitis Suppurativa (HS)?

HS is a skin disease that causes abscesses and scarring on the skin, commonly around the groin, buttocks, breasts and armpits, although it can affect other areas as well. The HS Trust believes that between 1% and 4% of the population has HS. It is possible that many more may have the condition, but have not felt able to tell their doctor about their symptoms.

What causes HS?

We do not know for sure what causes HS. Some doctors and researchers believe it is probably linked to inflamed sweat glands and blocked hair follicles. There is also some research being carried out to see whether HS may be a type of 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.

Why am I struggling?

Living with a chronic skin condition like HS is not just about managing physical symptoms and flare-ups. Living with a recurring, painful and sometimes visible condition can have emotional, social and interpersonal effects. It can also affect the way you see yourself, the world and the future.

Below are some of the more common experiences and reactions that people living with HS might have. Some may be familiar to you, while others may not.

2. The effects of HS

Physical effects:

HS is associated with a number of uncomfortable and unpleasant symptoms. The frequency and intensity of these will vary from person to person and from flare-up to flare-up. Symptoms include:

- visible lumps and abscesses
- pain and discomfort
- discharge (pus) from the lumps, sometimes with an unpleasant odour
- infection (but remember that not all abscesses with discharge are infected)
- visible scarring
- unwanted side effects of the medications used to treat HS – steroids may cause weight gain and fluid retention, for example, whilst 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.

Emotional effects:

- **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 see your GP, tell a healthcare professional or attend A&E, 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 surgery and followed all of the medical advice given to you, but are still suffering recurrent symptoms of HS, you may feel disappointed and disheartened, and may begin to feel helpless.

The effect of HS on the things you do

Having HS may mean that you stop doing the things you used to do, or the things you enjoy doing, like socialising and engaging with hobbies. In the short term, this can work well because you do not have 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 odour
- physical intimacy with sexual partners
- 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.

The effect of HS on thoughts and beliefs

The way we make sense of our experiences depends a lot on what we think about them. Positive, 'glass half full' thoughts may be really helpful in allowing us to get through difficult times. In times of stress, however, our minds often come up with worst case scenarios and we see things in very black and white ways.

Below are some examples of thinking styles, which we all fall into at times, and which are usually unhelpful.

Thinking style	Examples commonly associated with feeling anxious or worried
Thinking the worst	'This flare-up is so bad that I'll have to take time off. If I take time off, I'll definitely lose my job.'
Mind reading	'That person thinks I don't wash properly or that I don't take care of myself.'
Over-generalising	'I've got a new abscess and I haven't had one in ages. That means I'll definitely get loads of abscesses this month.'
Jumping to conclusions	'The doctor raised her eyebrows and I think she looked shocked when she examined me. That means I'm untreatable.'

Thinking style	Examples commonly associated with feeling low or depressed
Discounting the positive	'My symptoms haven't been so bad since I stopped smoking, but it's probably a fluke and soon they'll be back.'
Self-criticism	'I can't do anything right.'
Pressurising language (shoulds, musts, oughts)	'I should be able to cope with this by now. I must get on top of this.'
Black and white thinking	'I can only get on with life when I get rid of this condition completely.'
Wishful thinking	'If only this didn't run in my family.'

As well as these unhelpful thinking styles, people with HS say that they have other upsetting thoughts and beliefs. Perhaps you recognise some of them:

- Thinking that you aren't in control.
- Thinking that you are helpless or that the situation is hopeless.
- Thinking negatively about how you look and about your body.
- Believing you cannot cope with the condition.
- Assuming that you are going to get negative reactions from others, even before it happens.

Vicious and virtuous cycles

The section above described the ways that your body, thoughts, feelings and choices can be affected by HS. These experiences are all linked, so a change in one area can have a knock-on effect in another area. For example, the way we think about situations affects how we feel physically and emotionally, as well as affecting what we choose to do. Some of these thoughts, feelings and choices can help us (virtuous cycles) and some can keep us stuck (vicious cycles).

Example of a vicious cycle:

Amy has been living with HS for 10 years. Early on, some insensitive people at college made rude remarks about a visible scar and made fun of her when an abscess leaked through her t-shirt. Since then she has socialised very little, except with people she knows very well, and waits until she is symptom-free before trying new things. As a result, she does not get to try new things very often and has never had the chance to find out whether new people she meets will be just like her old classmates at college or not. She often feels fed up and sometimes very low in mood. When she feels low, she often thinks 'I can't be bothered. What's the point anyway?' and decides to stay at home.

3. Coping with HS

Below are some areas of day-to-day life where you could experiment with making changes that enable you to live your life more fully.

Looking after yourself physically

- **Eating well and exercise:** Eating well and keeping active can help to reduce stress and physical tension, and can help with maintaining a healthy weight, which is particularly important for people with HS. Try to eat a well-balanced diet and take regular exercise if you can. Think of an activity that is manageable for you and that you might enjoy. If you have not been active for a while, you might need to take this quite slowly. If you are having a particularly bad flare-up which affects your ability to move about more than usual, you may need to reduce your activity for a short time, building up again as the symptoms start to improve.
- **Sleep and rest:** Allow yourself enough time for sleep and rest, but try not to worry if you are not sleeping well. Having a regular bedtime, and allowing time to wind down before bed can help. Try to resist any temptation to have a few alcoholic drinks at bedtime or to rely on caffeine during the day. This will only make you feel worse in the long run.
- **Changing smoking habits:** For some people with HS, quitting smoking can help with their condition. While smoking is not a cause of HS, it may make the symptoms worse. Quitting smoking can be very challenging and you may wish to seek some support from your GP (doctor). As a first step, you might consider cutting down on the amount you smoke.
- **Designing a self-care routine:** There may be certain things you can do to ease the discomfort of HS and manage the symptoms. These include applying a hot flannel to the affected area, taking any medications as prescribed, using any recommended treatments such as antibacterial washes, or making adjustments to your clothing. There may also be things to avoid, like certain lotions and skin creams, which may make your HS worse. Try to figure out which of these strategies works best for you. Take advice from your healthcare professionals and learn from your own experience. Using this information, draw up your own HS self-management plan. This may help you feel more on top of your HS and better able to manage.

- **Learning to relax:** Learning how to relax can help the mind and body. You can try out different things until you find one that works for you. For example, you could try:
 - listening to relaxing music or recordings of ambient sounds, like waves crashing or rain falling. You can download free apps to your smart phone or use Google to find audio files to download to your PC or MP3 player. Alternatively, CDs of white noise or other relaxing music are widely available.
 - spending five minutes focusing your attention on the rhythm of your breath.
 - using meditation practices, or prayer if you are religious, to relax.
 - imagining being in a peaceful scene, such as a beach or woodland – notice what you can see, hear, touch, taste and smell.
 - gently tensing and relaxing different muscle groups in your body until your body feels physically relaxed – for detailed instructions, search for ‘Progressive Muscle Relaxation (PMR)’ online.
 - not rushing around during the day and leaving plenty of time for your planned activities.

Looking after yourself emotionally

Living with a chronic illness can have emotional as well as physical effects. This is common and understandable. If you are experiencing some or all of the emotional effects described earlier, you are not alone. Being frustrated, anxious or low is not a sign that you are not coping or are not a strong person. Many people feel this way when they are managing a condition day after day. Remember, looking after yourself emotionally is as important as looking after yourself physically. Below are some suggestions that may help you cope.

What am I feeling?

- Try to become aware of the particular feelings or emotions you are experiencing. Noticing them and being able to name them (sad, grumpy, irritable, anxious, overwhelmed, stressed, happy, excited, and so on) is a good first step. There is no need to try to change them. Just feel your emotions exactly as they are.
- Next, ask yourself what triggered the feeling. Was it a thought, a memory or an image? Maybe it was something someone said or did, or a physical sensation. Once you know the triggers, it can be easier to understand and manage your feelings.
- Finally, write them down, exactly how you felt them.

What can I do about it?

- Talk to a trusted friend or healthcare professional about how you are feeling. They may have suggestions about how to cope.
- Join a support group for people with HS, such as the online group run by the HS Trust (<https://uk.groups.yahoo.com/neo/groups/hs-uk/info>).
- Think about times in the past when you have managed difficult feelings during tough times. What strategies did you use? Were they helpful (in the short term or the long term)? Could you use them now?
- If these emotions make you feel bad, you may wish to get rid of them. Sometimes people try to get rid of unwanted feelings by using food, drugs or alcohol, or by using other strategies, such as keeping very busy. While these strategies may help in the short term, they often have unhelpful consequences in the long term.
- Getting rid of feelings – positive or negative – is actually very difficult, so using your energy in this way may not help you. Instead, try just noticing your feelings without trying to change them. This is part of a practice called **mindfulness** (see below).

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.

Being mindful of your experiences is a very different way of paying attention and it takes practice. There are many good books, CDs and apps about mindfulness and about how to apply it if you think this approach might be helpful for you.

You can listen to a mindfulness exercise on the IMPARTS website. You can also find a mindfulness exercise specifically for patients with HS.

w: www.kcl.ac.uk/iop/depts/pm/research/imparts/Self-help-materials.aspx

Managing your mind

Thoughts pop into our minds all through the day. They can be pleasant, unpleasant or neutral. The mind is a bit like a storyteller or a narrator, commenting on what is going on. Sometimes the mind comments in helpful ways, drawing our attention to interesting or pleasant things, reminding us of happy memories from the past, or alerting us to things we have planned to do in the future, like phoning a friend or going to the post office. During times of stress, however, the mind can be less helpful. It might butt in with unpleasant memories from the past or scary predictions about the future. Confusingly, these thoughts are not always facts, even though they may seem convincing.

Below are some suggestions about how to respond to your thoughts:

- First notice your thoughts. What is your mind saying?
- Once you have identified the thought, you have a couple of choices – you can challenge the thought, or you can be mindfully aware of it.

Thought challenging:

Amy was invited on a holiday in the sun with some close friends, as well as some people she didn't know well. She immediately had the thought, 'As soon as they notice my scars and abscesses, they'll think I'm disgusting and avoid me. The holiday will be ruined.'

It is possible to challenge these thoughts by asking yourself the following questions:

- What makes me think this thought is true?
- Is there anything to suggest that this thought may not be true?
- Is there another way of looking at this?

- Based on the evidence for and the evidence against this thought, what is the most logical or balanced alternative perspective?
- If a friend I cared deeply about, or someone else with HS, had this thought about themselves or their situation, what would I say to them?

While no one can stop unwanted thoughts from coming to mind, challenging your thoughts in this way can help you to see things from a different perspective, which may help you feel better able to deal with them.

When Amy's close friend, Shabnam, heard that she was thinking of dropping out of the holiday because of these worries she suggested trying out some thought challenging. Shabnam had found this helpful when she was trying to overcome panic attacks a couple of years before. Although Amy was unsure, she decided to give it a try. When she noticed the thought, 'As soon as they notice my scars and abscesses they'll think I'm disgusting and avoid me. The holiday will be ruined', she worked through the steps (above), which she kept in her wallet. She came up with a couple of alternative thoughts – a logical one and a compassionate one:

'Even though it is likely that they will notice my scars, it is not necessarily true that they will find them disgusting and I can't know for sure whether they will avoid me until I go there and find out. As well as that, half of the group are people I do know and like, so the trip won't be totally ruined, even if it's not as I had hoped.'

'It's understandable that I'm worried about how other people might perceive me because of the horrible experiences I have had in the past, and it's OK to have a wobble and feel like backing out. But the kindest and best thing I can do for myself is to focus on the people I do like and trust, and think about all the good things I can get from this holiday.'

Mindful awareness:

If challenging your thoughts in this way does not work for you, or if you would like to try something different, you could use a mindful approach to thoughts in the same way that you might use it for feelings (described above). Try these steps:

- First notice the thought that has popped into your mind.
- Try not to judge the thought as good or bad. Just notice it.
- You could even thank your mind, the storyteller, for its contribution to your day.
- Then ask yourself, is this thought a helpful one? If so, perhaps pay attention to it and act on it.
- If it is not a helpful thought and your experience tells you that these thoughts make you feel bad and keep you stuck, just observe the thought instead of reacting or responding immediately.
- It might help to imagine the thought being a headline on the kind of newspaper that prints exaggerated and sensationalised stories.
- Then let the thought pass, like leaves on a stream or cars passing by outside your window.

Balancing your awareness

Being aware of your body can help you to make wise choices, but being over-aware can make it hard for you to focus on other things. This can mean you miss out on fully enjoying the good things in life. Being over-aware can also cause you unnecessary worry and distress, which can make your symptoms feel worse. It can help to put your feet flat on the ground and simply notice how it feels. You can also try focusing on what you can see and hear in the world around you.

Deciding what to do

Planning to lead a fuller and happier life takes work. You will need to establish what your goals are and then think carefully about how best to achieve them. This section gives some hints and tips on how to start planning your course of action.

1. Do what matters

When you're having a hard time physically or emotionally, it can make you feel like opting out of doing things, such as exercise or socialising, for example. Avoiding these things may seem to help in the short term, but can lead to missing out on the things that really matter to you in the long term, like close relationships or good health.

Try to ask yourself what things matter to you most. Perhaps it is family, friendships, your health, your work or your hobbies, for example. Try to do something most days that keeps you moving in the direction of what matters to you most. Usually there is more than one way of doing this, so you might need to try out new approaches if your old strategies no longer work.

2. Do things you enjoy

Look out for opportunities for fun, laughter and pleasure. This could mean meeting a friend who makes you laugh, watching a repeat of a comedy show you know you find hilarious or making time for things you really relish, like an afternoon of watching football or a soak in the bath. Also, try to do things that will give you sense of satisfaction when you are done. Try to notice whether these activities have an effect on how you feel in your mind and body.

3. Making changes: Goal setting

Making changes, such as quitting smoking or taking steps towards losing weight, can be difficult. Many people don't know where to begin. If you are in this situation, try to set a specific goal. Goals are easier to achieve if they are SMART:

- **Specific** – What exactly do you plan to work towards? When, where, how, with whom?
- **Measurable** – How will you know you have achieved it?
- **Achievable** – Try not to set goals that are so ambitious that you set yourself up to fail. This is usually unhelpful and disheartening.
- **Relevant** – Is this goal meaningful and important to you?
- **Time-limited** – Decide when you want to have achieved the goal by. Is it a short-term, medium-term or long-term goal?

Write your SMART goal down. Share your intention to work towards this goal with a trusted friend, family member or healthcare professional. When you achieve your goal, give yourself a reward – something you would enjoy, like a cinema trip or a favourite meal. If you have a setback and do not manage to achieve your goal, try not to give yourself a hard time. Think about what got in the way so you can be prepared if you encounter this barrier next time. If you think you may have set an unrealistic goal (one that was too difficult), reset your goal, making it more achievable. Then re-commit to the goal, rather than giving up on it.

If you notice that you keep on encountering barriers to your goals, and are struggling to overcome them, it may help to use a problem solving approach (see next section).

4. Problem solving

Problem solving is a step-by-step way of overcoming barriers to your goals, and can work in many situations. Using these steps can help when you feel overwhelmed and do not know where to begin. They are particularly useful if you are facing multiple problems. You may find it helpful to do this together with your healthcare professional, who may have some helpful ideas from their professional experience to add to your own thoughts. Below are the key steps:

1. **Define the problem(s).** What exactly are you up against? Try to complete this sentence: 'The problem I am facing is_____'.
2. **Prioritise.** If you have several problems, write a list. Choose two or three problems from the list and order them from least important to most important. Put a circle around the one you have chosen to work on. If you find your mind wandering to the other problems, gently remind yourself that for now you are focusing on just one problem at a time.
3. **Ask yourself, 'Is this a problem I can do something about, or is it outside of my control?'** Some problems cannot be solved by individuals, despite their best efforts. Public transport being on time, the weather or the choices and behaviours of other people are examples of things that are outside of your control. If you believe that there is something you can do about the problem you are facing, continue following the steps below.
4. **Brainstorm.** List as many possible solutions to the problem as you can. Write down everything from the most simple to the most farfetched and funny. This will help you to start thinking flexibly and considering lots of options.
5. **Choose one.** Take a step back and review the solutions you have come up with. Which one do you believe will help you to move closer to solving the problem? Try to choose something from your list that is both manageable and realistic.
6. **Make a plan.** Decide when, where, and how you will carry out the solution you have chosen. Try to be as detailed as possible. Write it down and put it somewhere you can see it.
7. **Beware of jumping ahead or getting side-tracked!** It is common to start off enthusiastically with these steps and then get distracted by other things. To give yourself the best chance of success, put a reminder in your phone or tell a friend what you are planning to do. Also, it is common to unintentionally skip some steps and jump into doing things. Try not to fall into this trap. The steps are an important tool for helping you approach problems effectively and for helping you learn from what went well and what did not go so well.
8. **Now do it!**
9. **Review how it went.** Did it go to plan? Did it move you closer to solving the problem? If it did not go to plan, perhaps you can break the solution down into smaller, more manageable parts, or go back to the list to choose another option.
10. **Repeat.** If the problem is not yet solved, go through these steps again.

For more detailed advice, see the IMPARTS leaflet, **Problem Solving for People Living with Health Conditions**, which can be found at:

w: www.kcl.ac.uk/iop/depts/pm/research/imparts/Self-help-materials.aspx

4. Communication and relationships

Living with HS can be difficult to explain to others. This could cause difficulties with work colleagues, with friends or in intimate relationships. However, trying hard to avoid talking about your HS can be a source of further stress for you, as well as a source of confusion for others. Remember, even though your mind might be trying to convince you that people would be unkind, or reject you if they knew, this may not be true. Below are some suggestions which may help you communicate effectively about your HS:

Improving your communication with people around you

As a first step, consider finding ways to explain your condition to people that you feel comfortable with. Practice saying the sentences in advance with a friend, family member, healthcare professional or someone else with HS. Keep your explanation short and to the point. This will help to dispel any myths people might hold about your condition, such as ideas that it might be contagious or due to poor personal hygiene. It will also make it easier to explain your condition to people you are not as close to, such as work colleagues.

Andrew is a 32 year old man who has been living with HS for about 15 years. He has a particular difficulty managing the odour related to his HS. Despite his best efforts, there are times when this odour is noticeable to others. For many years, Andrew was so embarrassed by this that he would try to get out of the situation as quickly as he could. However, after many missed opportunities, he came up with another way of managing. When the odour became noticeable and other people were around, he would say with a grin, 'Before you give me a bar of soap, I know I don't smell of roses. I have a medical condition'. He discovered that most times people reacted with a nod and a smile. But there were sometimes a few who didn't know how to react, or were rude and unfriendly.

Improving communication with your partner

People with chronic skin conditions can and do form and maintain close, intimate relationships even though at the outset they might have believed that this was not possible. Even though it may seem difficult at first, try to be open about your condition and how it affects you physically and emotionally.

If you are worried about your partner discovering that you are having a flare-up, and being shocked or put off by it, try to be upfront and tell them about it. This may take some of the pressure off. Being upfront in this way will also allow you and your partner to make adjustments in your physical relationship for your comfort and wellbeing. This might include changing the position in which you have sex or postponing sex until your flare-up has subsided.

Try to think broadly and flexibly about what intimacy means for you and your partner. There may be times when cooking a special meal together or curling up on the couch with a favourite film can create intimacy and closeness when you are bothered by pain or inflammation.

Try not to make guesses about what your partner may be thinking or feeling. If you are unsure, perhaps you could ask them.

Improving communication with healthcare professionals

You also may wish to improve communication with your healthcare professionals. For some people, going to see their GP, nurse or consultant can be anxiety-provoking or embarrassing. Other people feel so bad about taking up too much of the doctor's time that they don't bring things up or they say that everything is fine when it may not be. This can mean that you don't get what you need from the meeting and it also prevents your healthcare professional from having a full understanding of your needs. Try to prepare for your consultations in advance. Write down the things you would like to discuss. Remember that you can bring up the impact of the problem on your life as well the medical side of things. When you arrive at your consultation, it is a good idea to look at the list with your doctor or nurse so you can decide how best to use the time. They may invite you back for a second consultation if all of the topics cannot be covered in one slot.

5. Summary and conclusions

Living with HS can be a challenge. The effects of HS are not just physical – HS can affect your emotional, social and interpersonal wellbeing. How you think about your HS, how you feel about it and what you choose to do or not do because of it, are all linked and contribute to how much HS impacts on your life. This means that understanding your thoughts, feelings and reactions can help you to make choices that will keep your life moving in the direction you want it to go. This is not always easy. This leaflet has offered some suggestions about how to manage life with HS. Some may suit you better than others.

You may wish to choose a few strategies to try out, perhaps with the support of someone you trust. If, after trying some of these suggestions, you continue to feel stuck or very distressed by your experience of HS, talk to your healthcare professional about getting some additional support.

6. Further reading

- The HS Trust website is an excellent source of information and advice about HS, and includes an online support group
w: <https://uk.groups.yahoo.com/neo/groups/hs-uk/info>
- **Living with Confidence**, by Changing Faces, is a booklet for people who live with a visible difference.
w: www.changingfaces.org.uk
- **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.
w: www.changingfaces.org.uk

Contact us

If you have any questions or concerns, please contact your clinical nurse specialist (CNS) using the details given on your CNS contact card and/or medicine booklet. These details can also be found at the top of your clinic letter.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953