



PATIENT INFORMATION LEAFLET

BEHÇETS

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about Behçets. It tells you what it is, what causes it, what can be done about it, and where you can find out more about it.

WHAT IS BEHÇETS?

Behçets (also known as Behçets syndrome or Behçets disease) is a rare condition that affects blood vessels, including arteries and veins, throughout the body. In the UK there are approximately 1000 people living with Behçets. It can affect various parts of the body, including the skin, eyes, mouth, genitals, the nervous system and other organs. This explains why the symptoms can be quite varied. Most people with Behçets only experience some of the symptoms. These symptoms can come and go at different times. Flare ups do not always have a trigger.

WHAT CAUSES BEHÇETS?

The exact cause of Behçets is unknown. It is believed to involve a combination of genetic and environmental factors. It most commonly affects people from Turkey, North Africa, the Middle East and Southeast Asia. There are only about 1000 people with this rare condition in the UK. While genes play a significant role in predisposing some individuals to Behçets, the precise environmental triggers remain unknown. Behçets is sometimes referred to as an auto-inflammatory condition. This means the body's immune system is reacting to itself and causing inflammation.

IS BEHÇETS HEREDITARY?

There are certain genes that make individuals more likely to develop the condition. These genes are not always inherited from parents so there may not be a family history. Our

genes can be affected by things in our environment.

Behçets typically affects adults between the ages of 20 and 40, however children can also develop the condition.

IS BEHÇETS CONTAGIOUS?

No, this condition is not an infection so it cannot be passed onto others.

WHAT DOES BEHÇETS LOOK LIKE AND FEEL LIKE?

The symptoms can be quite varied. Most people only experience some of the symptoms listed below.

Oral (mouth) and/or genital ulcers:

Repeated attacks of mouth ulcers are a very common symptom of Behçets disease. They are not necessarily the first symptom people experience. Ulcers can be single or multiple and are often very painful. Sometimes it can be difficult to eat or brush your teeth. They can take 1-3 weeks to heal.

Genital ulcers are another common feature. They are also usually painful. In males, they can be found on the scrotum, less so on the penis. In females, they appear on the vulva and vagina.

Skin:

Acne-like skin changes can sometimes be seen. Other skin changes include sore swellings usually on the legs called erythema nodosum.

Thrombophlebitis:

Blood clots can form within veins and cause them to block. This blockage can cause pain and sometimes skin redness along the length of the vessel. If deeper, larger, veins are involved, this can lead to a deep vein thrombosis.



Eye involvement:

About half of patients experience eye symptoms. Typical symptoms include painful red eyes, blurred vision and floaters (small shapes that float across your vision). This can be serious resulting in blindness. Such symptoms should be promptly reported to your doctor as quick treatment is required.

Arthritis:

Half of patients will experience joint pains. Sometimes joints can be red and swollen. Typical affected joints include the knees, ankles, small joints of the hands/wrists, shoulders and hips.

Arteritis:

Less commonly there can be inflammation and damage of the main blood vessels in the body. This can result in generally feeling unwell and in severe cases, arteries can weaken and rupture.

Central nervous system:

Inflammation of the brain and spinal cord can result in a variety of symptoms. These include persistent headache, drowsiness, double vision, loss of balance, slurred speech, limb weakness and fits. Such symptoms require urgent medical attention. Less than 10% of people with Behçets will experience involvement of the nervous system.

Gastrointestinal effects:

Inflammation of the gut can cause a variety of symptoms. These include severe abdominal pain, bleeding from the anus and weight loss. In severe cases the intestines can ulcerate requiring urgent medical treatment. Signs of this can include severe abdominal pain, fever and weakness.

Ulcers can also occur around the anus. This can be very uncomfortable particularly when opening the bowels. Don't hold back from telling your doctors about such symptoms.

Fatigue:

General tiredness can be a common symptom. In many cases tiredness can be severe. As a result, it can have an impact on all daily activities. Don't be afraid to discuss this important symptom with your doctors.

Other:

Headaches can be another complaint. These can be severe and last longer than an average headache.

HOW IS BEHÇETS DIAGNOSED?

There is no single test for Behçets disease so it can be difficult to diagnose and there is often a delay in its diagnosis. Each individual patient can have a variety of symptoms. These symptoms can be present at different times of their life and not all at once.

If your doctor suspects this rare disease, they will refer you to a relevant specialist. There are three highly specialised Behçets disease centres in England. If your symptoms are difficult to control you may be referred to one of these NHS Centres of Excellence.

CAN BEHÇETS BE CURED?

There is no cure for this condition. However, the symptoms can be controlled or improved with medications.

HOW CAN BEHÇETS BE TREATED?

Treatment is very much tailored to each individual and their symptoms. Pain relief is often a high priority.

For oral and genital ulcers, treatments include steroids - usually in the form of a [cream](#) or inhaler that is squirted onto the ulcers. Special mouth and genital washes that contain steroids, antibiotics/antifungals and pain killers can also be helpful.

If you have repeated severe ulcers, you may be prescribed an oral medication called [colchicine](#). It should reduce the number and severity of the ulcers. A common side effect is upset stomach. If this is the case, you should seek advice from your doctor who may reduce the dose.

If the ulcers are very troublesome or they do not respond to the above treatments other medications may be needed. These include [oral steroids](#), [azathioprine](#) or biologics such as [infliximab](#) or [adalimumab](#).

For many of the other Behçets symptoms, tablet or injection medications are often required. These options will be discussed with



you to find the most suitable treatment for your symptoms and circumstances.

SELF-CARE (WHAT CAN I DO?)

In the case of oral ulcers, it is very important to maintain good oral hygiene. Brushing your teeth twice daily as well as regular visits to a dentist are important in the long term. Also avoid chemicals that can irritate the mouth particularly sodium lauryl sulfate found in some toothpastes.

Behçets can result in 'pathergy'. This means that relatively minor skin injury can result in an exaggerated skin reaction that is difficult to heal. This could occur with surgery, so it is important you tell all health professionals of your condition. It is also best to avoid tattoos and take extra care to avoid skin injury during contact sport.

If you are planning pregnancy, always speak to your doctor first to discuss your options. This will help ensure you are well prepared for a safe pregnancy.

Behçets can be a difficult condition to live with. It can have an impact on your daily life, relationships, school and work. If you are struggling do ask for help. Your GP may be a good person to start with. It can also be helpful to inform your family/friends, school and employer of the condition. This is particularly important for flare ups as rest is often needed. There are also online resources and support groups where you can contact other people with this rare condition.

WHERE CAN I GET MORE INFORMATION ABOUT BEHÇETS?

Patient support groups providing information:

<https://behcetsuk.org/>

<https://www.behcets.nhs.uk/>

Web links to other relevant sources:

<https://www.nhs.uk/conditions/behcets-disease/>

Jargon Buster:

<https://www.skinhealthinfo.org.uk/support-resources/jargon-buster/>

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

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