

Highlighted words (in blue) are explained in Common Terms and Definitions sheet

So, you have Behçet's?

So, you've just received a diagnosis or a 'potential diagnosis' of Behçet's *syndrome* (or Behçet's *disease*). You're probably feeling a mixture of emotions now, but this may include relief at receiving a diagnosis and also fear about what this condition is and how it's going to affect you and potentially your family.

Firstly, congratulations on finding us. We are the primary UK Charity supporting people with Behçet's, together with their families; established in 1983, we have over 40 years of experience in helping people with this condition. By finding us, you've also found comprehensive medical information prepared by leading experts on Behçet's in the UK.

Also, receiving a diagnosis or a suspected diagnosis of Behçet's is a real step forward. It means you must have found a medical person who could recognise the symptoms and was aware of this rare condition. This is not something to take lightly, as many of our members have waited several years to obtain a diagnosis. Behçet's patients living in England can request a referral to one of the three National Behçet's Centres of Excellence (in London, Birmingham and Liverpool). If you live in Wales, Scotland and Northern Ireland you may be able to request a referral, more information about the referral process from the four UK nations can be found here behcetsuk.org/national-behcets-centres-of-excellence/#referral

What is Behçet's and how is it pronounced?

You will hear many different pronunciations of the condition, but Hulushi Behçet, who gave his name to the condition, pronounced his name "Bet- Jet". To add further complication, it is also referred to as both Behçet's syndrome and Behçet's disease. The two are legitimately used, often interchangeably, though it does not help clarity when trying to 'champion our cause'. Over 80% of research publications use the term disease.

Behçet, a Turkish Professor of *dermatology*, described the *main* features of it in 1937. It had previously been described as long ago as the 5th century BC by Hippocrates, a Chinese physician in the 5th century AD, and by a number of European physicians in the late 19th and early 20th century, particularly Benediktos Adamantiades who was Greek.

The cause of the condition is not known. It's been proved that there is a disturbance of the *immune* system, but this isn't thought to cause the condition. Current theories are that it is potentially a *genetic* weakness that is triggered by an infection or virus, but this has still to be proved. It usually starts during a person's 20s and 30s but it can affect any age group from new-borns to the elderly. In recent years, many more children have been diagnosed.

It is known that the condition is most prevalent in Turkey, North Africa, the Middle East and South East Asia – the old Silk Route, which gives the condition its other name – the Silk Route disease. It is rare in Western Europe, with perhaps up to 3-4000 people in the UK having a diagnosis. It seems to be more common among women in Europe, but men are more frequently affected in other regions, and men also tend to have more severe disease activity.

How is it diagnosed?

There is no diagnostic test for Behçet's, which is partially the reason for the protracted diagnosis period – or 'diagnostic odyssey' as it is often termed. A clinician who has experience of Behçet's would be able to make a diagnosis based on a collection of the following symptoms presenting themselves (other clinicians may have a high index of suspicion and refer you to an expert).

- Ulcers – multiple recurring ulcers in both the mouth and genital region.

- Skin lesions – acne-like or red tender swellings known as erythema nodosum – Pseudofolliculitis - raised red or white spots that resemble a shaving rash.
- Eye involvement – including inflammation of the front or back of the eye (uveitis) or around the retina (retinal *vasculitis*).
- Arthritis or arthralgia (joint pain) – particularly in the knees, hands and wrists.
- Thrombophlebitis – inflammation of veins, usually in the lower legs, resembling *deep vein thrombosis*.
- Pulmonary lesions – arising from inflammation around the heart.
- Central nervous system involvement – arising from inflammation around the brain.
- *Gastrointestinal* ulceration – affecting the small intestine or the colon.
- Pathergy reaction – a red lump appearing 48 hours following a sterile needle pricking the skin. (Not everyone with Behçet's will have this reaction).
- Chronic fatigue.

This list is long, not exhaustive, and affects different areas of the body, which unfortunately can be any organ, but you would be very unlucky to have all these symptoms. Behçet's is unique as it affects not only large and small blood vessels but also veins. Behçet's also seems to affect patients differently both in the symptoms they first present with and in what may develop later. It is best to be aware of the various areas it can affect so that you can discuss any concerns you have with your consultant.

Appointments and your doctors

It may well have been that, before you had symptoms of Behçet's, you may not have had a need to visit your GP and the hospital very much. Unfortunately, that is likely to change and you will need to build relationships with the medical professionals who are providing your care.

The Society was successful in 2012 in working with a medical team (the NHS - Highly Specialised Services) to establish the NHS England, National Behçet's Syndrome Centres of Excellence. At the centres you'll be seen by a team of consultants including a *rheumatologist*, *ophthalmologist* and oral specialist, with other specialists being available at specific clinics.

Patients living in England can ask to be referred to one of the three centres. If you live in Scotland, Wales or Northern Ireland you may be able to request a referral, see behcetsuk.org/national-behcets-centres-of-excellence/#referral for more information.

At each of the centres, there is also a Behçet's Support Coordinator available who can help with a number of non-medical matters such as: providing practical and emotional support; liaison with employers, educational establishments and organisations such as Department of Work and Pensions (Benefits) to ensure a better understanding of Behçet's; signposts to specialist agencies including money and benefits advice services; occupational therapy; physiotherapy; housing; social services and advocacy services. The Centres can also make patients aware of Behçet's support groups operating in different regions of the UK. Other services available are: support for patients in maintaining employment; leisure activities on offer; volunteering opportunities; arranging home visits where appropriate; providing information packs and help with informing friends, family and work about the condition.

The advantage of the centres is that all the consultants have a specific interest in Behçet's, and they provide *holistic*, multi-disciplinary care with all the specialists discussing your case together and sharing their expertise. It will also reduce the number of hospital appointments you'll need to attend.

You can choose to remain with your current consultant in a local hospital, supported by one of the Centres, or alternatively the Society might be able help you to find a consultant with experience in Behçet's close to you, although we cannot make any medical recommendations. With this arrangement, depending on what symptoms you have, you may just be seeing one consultant and your GP or you may have several consultants concentrating on different areas of your condition. The regular medical appointments you will need can become exhausting, particularly when you're unwell, but it is important that you attend all of them or let the clinics know if you are too unwell to attend.

Whichever treatment route you choose, when your symptoms flare, it is very important to seek prompt medical advice. If you are registered with a Behçet's centre, they have a phone number you can ring for advice. For local care, a call to your consultant's secretary or your GP may be required. If you have built up a relationship with your clinician this is far easier.

Since the Covid-19 pandemic in 2020, it has been more difficult for patients to access their consultants in hospitals and you may well have had virtual consultations by either video or telephone. There is no doubt that some virtual consultations will continue and while it is far from ideal for some for others it can be beneficial as travelling a distance to see a consultant can be difficult.

The future

Behçet's is currently incurable, but that doesn't mean it is untreatable. Many drugs are on the market which, although not licensed specifically for Behçet's, have been approved for use by the Medicines & Healthcare products Regulatory Agency (MHRA), and can have a positive effect on controlling the symptoms.

The course of the condition tends to be that it 'flares up' and then subsides. During these flare-ups, the symptoms you already have may become more of a problem or you may present with new ones. It is at this point that your medication may be increased or new drugs added to your prescription. However, during times when your disease activity is minimal, you will still need to take this medication to help reduce the potential of further inflammation.

There are different drugs you may be prescribed depending on your symptoms. Steroids are often used to dampen down the immune system, but *immunosuppressants* may also be required, together with topical treatments for other symptoms. A link to the 'Drugs Pathway' agreed by the MHRA can be found on our website behcetsuk.org/behcets-medical-factsheets/#medication.

Unfortunately, Behçet's doesn't qualify you for free prescriptions from the NHS in England and Northern Ireland (something we are lobbying to change, as members of the Prescription Charges Coalition). All prescriptions are free in Scotland and Wales. If you do not qualify for free prescriptions, due to another condition or your financial circumstances, it may be beneficial to consider a Prepayment Certificate (PPC) for your prescriptions. PPCs can be bought quarterly or annually and can work out more economical depending on how many medicines you take regularly.

Check what help you can receive for NHS costs, including prescriptions here: check-for-help-paying-nhs-costs.nhsbsa.nhs.uk

What can the Society do for you?

The Society offers many services including:

Helpline

0345 130 7329 for general support and guidance about Behçet's – a 'friendly ear'.

Behçet's Medical Factsheets

These briefs have been written and validated by medical professionals who have specific expertise in Behçet's and can be downloaded from on our website at behcetsuk.org/behcets-medical-factsheets. If you don't have access to a printer and would like a printed copy, please contact our admin team by email at info@behcetsuk.org or call on **0345 130 7328**.

Newsletters

We publish a quarterly Newsletter for all our members to keep them up to date on Society news including current Behçet's research and treatments. Members can opt to receive this either by post or email.

Annual Conference

Our conference is ordinarily held in October. It is a hybrid event, held in different towns and cities around the UK and also streamed online via Zoom webinar. It's an informative day giving patients and medical professionals the chance to hear patient journeys, the latest on research and treatments from our supporting

medical teams and for those attending in person an opportunity to meet the experts and other people with Behçet's behcetsuk.org/conference.

Friends and Family Day

Each year we hold a friends and family day at an activity centre in a different part of the UK. The day is free to members on a 'first come first served' basis, and is a great opportunity to meet others affected by Behçet's, have fun, try new activities and spend time with friends, family, our trustees and staff behcetsuk.org/ffdays.

Behçet's Support Groups

Our support groups have always proved very helpful for anyone affected by Behçet's. We host regular online support groups via Zoom and also have a few local support groups who meet in person behcetsuk.org/support-groups.

Online Peer Support

We host an **online patient forum** on HealthUnlocked (linked from our website) where you can discuss Behçet's related issues anonymously with your peers. We also have peer groups on Facebook for Behçet's UK members www.facebook.com/BehcetsUK/groups.

Social Media

We are active on **Facebook**, **X (formerly Twitter)** and **Instagram** and we encourage you to follow us and feel free to contact us via any of these platforms if you have any queries.

Medical Advisory Panel

The Society has a team of medical professionals who advise and help with medical queries. They are not allowed to offer specific diagnosis or individual patient advice about medication (medical protocol dictates this is conducted by your own GP or clinicians who treat you) but if you have a general query, you can email us at info@behcetsuk.org and you will receive guidance about what approach to take.

Personal Grant Aid Fund

The Society manages a grant aid fund for eligible members to improve their quality of life if they are experiencing financial hardship as a result of their Behçet's behcetsuk.org/personal-grant-aid-fund.

Patient Alert Card

The alert card is issued to Behçet's UK members who are patients, and we encourage it's use, especially when seeking medical treatment from clinicians who are not aware of Behçet's. It contains information about Behçet's and has space for you to include your contact details and medical information.

Can you help the Society?

You may think that you're new to this condition and that you have nothing to offer the Society, but you will be best placed to let us know what services are most needed. A fresh viewpoint is always welcomed. If you're refreshing your knowledge with this factsheet, maybe you're at a stage now when you could bring your experience to the Society?

You can help in many ways, whether this be joining the Board or volunteering for the Helpline or whether you'd like to help with fundraising. This can involve selling our Christmas cards or encouraging friends and family to help. Maybe they'd like to jump out of a plane, run a marathon or even undertake a challenge event such as walking the Great Wall of China! Contact info@behcetsuk.org for more information.

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