

Highlighted words 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 illness is and how it's going to affect you and potentially your family.

Firstly, congratulations on finding us. We are the UK Charity supporting people with Behçet's, together with their families. We were established in 1983 and have a great deal 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 illness. This is not something to take lightly, as many of our members have waited several years to obtain a diagnosis. However, rest assured that we have in England three national Centres of Excellence for Behçet's (in London, Birmingham and Liverpool) where you can choose to be treated. If you live in Wales, [The Welsh Health Specialised Services Committee](#) (WHSS) approves a referral to the Centres of Excellence and must be approved by the patient's consultant. In Scotland, the (NSD) [National Services Division](#) approves funding to individual patients on behalf of Health Boards. You have to be referred by both your GP and a consultant. A Managed Clinical Network for patients with Vasculitis is being set up to offer more specialist support for patients with Behçet's and other vascular diseases across Scotland. This has recently been approved by the Scottish Government and will be available from April, 2020.

What is Behçet's and how is it pronounced?

You will hear many different pronunciations of the illness, but Hulushi Behçet, who gave his name to the illness, 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 illness. 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 the newborn 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 2000 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 elongated 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 – 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 and affects different areas of the body, which unfortunately can be any organ, but you would be very unlucky to have all of these symptoms. Behçet's seems to affect patients differently both in the symptoms they first present with and also 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 Centres of Excellence for Behçet's in the Royal London Hospital, London, the Birmingham and Midland Eye Centre, part of Sandwell and West Birmingham Hospitals NHS Trust, and Aintree University Hospital, Liverpool. You can choose to enrol at one of these Centres where you'll be seen by a team of consultants including a [rheumatologist](#), [ophthalmologist](#) and oral specialist, with other specialists being available at specific clinics.

You can ask to be referred to one of the centres in England. Please refer to [previous section](#) above on how you can be referred to the Centres if you come from Scotland, Wales or Northern Ireland. How this is done is summarised on our website – under the header Patient Support.

At each of these 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 illness.

The advantage of these Centres is that all the consultants have a specific interest in Behçet's and they provide **holistic** care with all the specialists discussing your care 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, or alternatively the Society can help you to find a consultant with experience in Behçet's close to you, although we cannot make a recommendation. 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 illness. 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 clinic 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. The Centres have a phone number you can ring for advice - **if you are registered with them**. 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.

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, can have a positive effect on controlling the symptoms.

The course of the illness 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 prevent any 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.

Unfortunately, Behçet's doesn't qualify you for free prescriptions from the NHS in England, Wales or Northern Ireland. However, all prescriptions are free in Scotland. 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 for your prescriptions.

These can be bought quarterly or annually and can work out more economical depending on how many medicines you take regularly.

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.** A Behçet's Medical Factsheet order form is enclosed in this pack, in case you do not have access to a printer and/or our website, which contains all this information ready to be downloaded, as and when required. These briefs have been written and validated by medical professionals who have an expertise in Behçet's.
- **Newsletters.** We issue a quarterly Newsletter to all our paying members to keep them up to date on what the Society is doing and on current research into Behçet's. You can opt to receive this either in print or by email. Please let us know if you ever change your address or email.
- **Website.** This can be found at www.behcetsuk.org We keep the site up to date with news and information as we receive it and we also have a chat forum where you can discuss Behçet's related

issues anonymously with other people – called Health Unlocked. We are keen to achieve more interaction with patients diagnosed with Behçet's, so I encourage you to use this facility.

- **Annual Conference.** This is open to any member and their family and ordinarily occurs in October, using different locations around the country. It's a chance to meet other people with Behçet's and also to hear the latest information about treatments from our supporting medical teams.
- **Family Day.** Each year we hold a family day at an outdoor activity centre in a different location in the UK. The day is free to members on a first come, first serve basis, and is a great opportunity for members to meet each other, try new activities and spend time with their families, and our trustees and staff.
- **Local Support Groups.** We are currently in the process of establishing more local support groups. In the locations where they currently exist our members find them very helpful.
- **Facebook Peer Support Groups.** We recently created new peer support groups on Facebook which are exclusive to our members and give them the chance to connect online with others in their local area who are affected by Behçet's. Find them here: <https://www.facebook.com/BehcetsUK/groups/>
- **Social Media.** We are active on Facebook, Twitter and have recently joined Instagram and you are welcome to contact us via any of these platforms if you have any queries. Find us @BehcetsUK
- **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.
- **Patient Alert Card.** This card should be used to include your contact details, medication information and the basics about Behçet's. Only issued to Behçet's patients, its use is encouraged.

Can you help the Society?

You may think that you're new to this illness 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.

Version	Last Review Date	Author
3.0	15th April 2019	Catherine O'Hara