

Behçet's Syndrome National Centre of Excellence

Information and advice for patients

Behçet's Centre

Behçet's syndrome is a rare multisystem disorder. It can affect many parts of the body including bowels, lungs, muscles, joints, bones, nerves and the eyes.

Symptoms can include oral and genital ulcers, inflammation of the eye or veins in your legs, arthritis and skin lesions however it is unlikely you will suffer from all of the symptoms.

The cause is currently unknown. If Behçet's syndrome is left undiagnosed it can eventually cause irreversible damage such as blindness, stroke or death, particularly in young people, so it is important it is diagnosed and treated.

Three specialist Behçet's Syndrome National Centres of Excellence have been set up in the country, in Birmingham, Liverpool and London. These centres offer a service to anyone who has been diagnosed or suspect they could have Behçet's syndrome.

What is the Behçet's Syndrome National Centre of Excellence?

The Behçet's Syndrome National Centre of Excellence in Birmingham is located in the Birmingham and Midland Eye Centre (BMEC) which is at:

Birmingham and Midland Eye Centre

City Hospital
Dudley Road
Birmingham
B18 7QH

Because Behçet's can affect many parts of the body, people with Behçet's often need to see several different consultants. At the centre you can be seen by consultants from different specialties on the same day, instead of having to attend different appointments. However this may mean that your appointment will take longer than usual and you may need to make necessary family/work arrangements.

Doctors from different specialities will be present at the clinic. The clinic is held on Fridays from 8.45am - 1pm, but there are plans to extend this, please call the centre for more information.

The service allows you to:

- Phone the centre for more information
- Phone the centre for support before, during and after any appointments
- Have all of your symptoms managed in one place at one appointment
- Be seen by doctors from different specialties in one visit
- Be seen by the specialist behçet's nurse
- Be tested and diagnosed as soon as possible

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- Receive treatment promptly
- Receive support from our non-medical support workers

How can I be referred to the centre?

You must be referred to the centre by a medical professional such as your GP, dentist or ophthalmologist. We will then send you an appointment for the clinic.

We welcome any enquiries on how to be referred.

The day of your appointment

Please bring the following with you to your appointment:

- Your most recent medical prescription
- Your usual eye glasses, both for reading and general use

On arrival

When you arrive at the Birmingham and Midland Eye Centre you will need to go up the stairs/lift to the Sheldon Block, room D46 on the second floor.

On arrival to the unit please report to reception where you will need to complete some forms. A nurse will then take your blood pressure, weight, height, and test your urine. You will also have an eye (visual acuity) test done. All the tests are done in the unit.

For the eye test, your pupils may be dilated with eye drops so the consultant can see into the back of your eye. The drops will sting, this is normal so do not be alarmed. The drops will cause your eyesight to be blurred for 4-6 hours, so you should not drive during this time.

Further appointments

The number of times you come to the centre will depend on the results of your consultation. Any tests that you have will be examined by the consultant and you will be informed of the results by letter. You may need to attend for further appointments to discuss the conclusion of your tests or to start any necessary treatment.

Refreshments

Hot drinks such as coffee, tea or hot chocolate are available on the unit with a charge of 50p.

Snacks and cold drinks are available at the following locations:

- Sheldon Block 1st floor, 10.30am – 2pm
- Sheldon Block ground floor, 10.30am – 2pm
- Birmingham and Midland Eye Centre (BMEC) Costa Coffee ground floor 8.30am - 3.30pm.

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Meet the team

- Dr D Situnayake, Consultant Rheumatologist and Clinical Lead for the Centre
- Dr D Carruthers, Consultant Rheumatologist
- Professor P Murray, Professor of Ophthalmology
- Miss P Stavrou, Consultant Ophthalmologist
- Mr J Hamburger, Consultant in Oral Medicine
- Miss A Richards, Consultant in Oral Medicine
- Debbie Mitton, Lead Nurse/Centre Manager
- Janine Pugh, Behçet's Society Support Worker
- Vicky Sewell, Behçet's Administration Clerk

What to do if you have a flare of your symptoms

A flare of your symptoms is when your symptoms suddenly get worse. If this happens you may need to be seen urgently. Please phone the Behçet's centre helpline for advice or visit your GP. In extreme circumstances such as vision loss you may need to go to A&E for urgent assessment and treatment.

If you are admitted to hospital please make sure the hospital staff call the Behçet's centre helpline to inform us of this.

Contact us

For more information you can call the centre's helpline. The helpline is for support and advice regarding your disease, problems with medication or general advice. If you need to leave a message, your call will be returned within 24 hours.

Helpline: 0121 507 4243

8.30am - 4.30pm, Monday-Friday, excluding Bank Holidays

Alternatively you can email Behçetsbham@nhs.net. We aim to reply to your email within 24 hours.

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Further information

For more information about our hospitals and services please see our websites www.swbh.nhs.uk and www.swbhengage.com, follow us on Twitter @SWBHnhs and like us on Facebook www.facebook.com/SWBHnhs.

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5420 or email: swb-tr.swbh-gm-patient-information@nhs.net



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