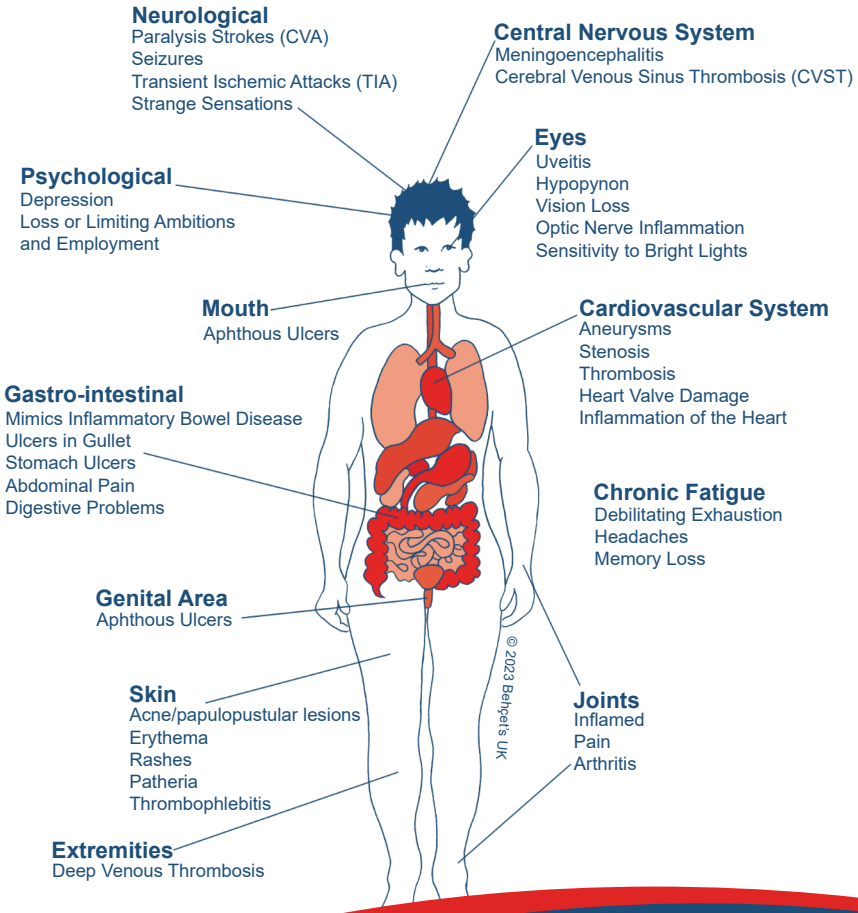
Behçet's UK

Caring for all affected by this rare, complex and lifelong condition; promoting research into the cause, effects, treatment and management of Behçet's

# Behçet's: a short guide for General Practitioners




**Behçet's symptoms can occur anywhere where there is a blood supply - from the brain down to the feet!**

# " It's like having arthritis, LUPUS, MS and Crohn's all at once "

**CK, Behçet's patient**

## What is Behçet's?

Behçet's (pronounced bet-jets) is known as both Behçet's syndrome and Behçet's disease or, simply, Behçet's.

- A multisystem autoinflammatory disorder.
- Potentially any organ can be affected.
- Treatment is a considerable challenge.
- A chronic debilitating type of vasculitides.

Behçet's is unique as it results from small medium and large blood vessels of both arterial and venous circulation.

## Symptoms

Symptoms fluctuate and occur wherever there is a patch of inflammation. The most common symptoms are:

- mucocutaneous - oral and genital ulcerations and skin lesions, including Erythema Nodosum
- eye involvement - anterior uveitis, posterior uveitis and retinal vasculitis
- arthritis and arthralgia
- bowel inflammation.

Most of the symptoms are painful but not life-threatening. However, when the disease affects major parts of the body, such as the eyes or brain, it can cause serious consequences including blindness or strokes.

## When to suspect Behçet's?

When a patient presents with two or three symptoms of:

- painful recurrent mouth ulcers
- painful recurrent genital ulcers
- recurrent eye inflammation
- recurrent skin lesions
- thrombophlebitis.

There is no diagnostic test for Behçet's and similar conditions to rule out are:

- Reactive arthritis
- Stevens-Johnson syndrome
- Sweet syndrome
- Crohn's disease.

## Behçet's in children

Behcet's is extremely rare in children and young people in the UK and most have mucocutaneous disease. Healthcare needs are complex and coordinated care is key.

**Read our medical factsheets, written by Behçet's specialists, which cover symptoms and treatment, on our website.**

**https://behcetsuk.org/behcets-medical-factsheets/**

## Referrals

Clinical diagnosis requires multi-disciplinary assessment.

GPs are advised to refer patients to the National Behçet's Syndrome Centres of Excellence.

Referrals are accepted for those with possible or probable Behçet's as well as confirmed disease.

Patients may not wish to be referred if their Behçet's is already well controlled, or if they do not want to travel to a Centre.

The urgency, or not, of the referral request should be highlighted.

The centres are funded centrally by the NHS, thus saving ICS and NHS Trust resources (and GPs time).

Patients in Wales, Scotland and Northern Ireland can, and should, be referred to these Centres of Excellence .

- Scotland - referred by a GP and a tertiary specialist consultant, and their referral submitted via the National Services Division (NSD).
- Wales through NHS Wales.
- Northern Ireland through Health and Social Care in Northern Ireland (HSC).

Most important principle is that patients need managing by a specialist with expertise in this rare disease.

A lead specialist is needed to coordinate care.

## Treatment

Behçet's is incurable at present, which is a key patient concern but it is treatable to a degree.

Treatment aims are suppress disease activity as much as possible, avoiding unacceptable side effects.

Their lead specialist must choose from a wide variety of drugs, which must be tailored to the patients individual needs – not one-size fits all:

- Therapy may only be needed during a flare-up.
- More severe and persistent disease, will need chronic (long term) therapy to suppress disease and minimise the occurrence of flares.
- When a major organ, such as the eye, is threatened by critical involvement, there is an urgent need for often the most powerful drugs, to prevent or minimise damage.

## What causes Behçet's?

The exact cause is unknown.

A combination of genetic and environmental factors are thought to play a role.

A variation of the HLA-B gene (B*51) is thought to be associated with an increased risk of developing Behçet's for some, however, the mechanism is not well understood.

**"It took 14 years to get diagnosed"**

**Jenny, Behçet's patient**

## Further reading

- **Behçet's UK**
  https://behcetsuk.org
- **National Behçet's Syndrome Centres of Excellence**
  www.behcets.nhs.uk
- **NHS Conditions**
  www.nhs.uk/conditions/behcets-disease

## About Behçet's UK

Behçet's UK (formerly Behçet's Syndrome Society) was founded in 1983 by Judith Buckle and is a registered charity in England and Wales (326679).

We are the UK's primary Behçet's charity; supporting and representing all Behçet's patients in the UK, including those yet to be diagnosed.

We were instrumental in establishing the Behçet's Centres of Excellence in NHS England, which provide the best level of holistic care for patients. We now lobby for proper comprehensive care in Wales, Scotland and Northern Ireland, including the establishment of a Patient Registry and funding a Natural History study in the UK.

### Main aims

Provide information and support for people with Behçet's and for those who care for them.

Provide financial aid for those in hardship caused by Behçet's.

Foster education, collaboration and networking in the medical and allied professions with an interest in Behçet's.

Promote and assist with research into the cause, effects, treatment and management of Behçet's.

Promote the formation of patient support groups and awareness of this rare condition amongst appropriate influential institutions, authorities and decision-making bodies, and provide them with detailed information about Behçet's.

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