



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



# How to manage Behçet's at school and college

A guide for teachers, staff, parents, and carers

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## Acknowledgements

A special thank you to the inspiring young people and their families who gifted us their insights, experience and artwork to enable us to develop this booklet.

Additional thanks to the Paediatric Behçet's Team at Alder Hey and EATC4Children, who made this possible by offering their time to facilitate the workshop and produce the booklet and to the British Association of Dermatologists for funding the project.



# About this booklet

Behçet's is very rare; most people have not heard of it and would not know what it means for a child or young person affected by the condition.

There is no doubt that Behçet's in children and young people can adversely affect their learning, but the good news is that with the right treatment and support, children and young people can participate in school and college life, and achieve their ambitions.

This booklet has been developed with medical professionals and input from young people affected by Behçet's. We hope that it will provide a useful tool for teachers of students with Behçet's, to explain what the condition is and how having Behçet's might affect a child or young person whilst at school or college.

It is also useful for parents and carers of children and young people with Behçet's if they have any school, college or education related problems.

*Please note that the information in this booklet is a guide only, and is not intended as a substitute for individual guidance from appropriate agencies. While we have made every effort to ensure this information is accurate at the time of going to press, please be aware that details may change. We strongly recommend you seek advice according to your individual circumstances, as we cannot be held responsible for any consequences arising from reliance on the information in this booklet.*

“On a good day; I can walk without joint pain, eat what I want because I am mouth ulcer free and I have enough energy to tackle exercise and going outside with friends and having fun, a day where I can almost forget I have Behçet's disease is a good day.

On a bad day; I lie in bed with insufferable mouth ulcers, joint pain makes walking too painful, my stomach will become inflamed, my eyes will be swollen and I'll have skin lesions all over my legs.”

# What is Behçet's?

Behçet's (pronounced 'bet-jets') is a rare, chronic, lifelong, multi-system disease caused by disturbances in the body's immune system. It is known as both Behçet's disease and Behçet's syndrome.

## Key facts about Behçet's

- It is a lifelong condition.
- There is no obvious pattern to symptoms and everybody's condition is different. Behçet's causes 'flares', a period when symptoms are much worse, which then subside. There can also be times when the disease is quiet and causes no problems.
- It is an 'auto-immune disease' – that is, it results from a problem with the body's immune system. Behçet's is not contagious.
- The main symptoms are oral and genital ulceration and eye inflammation. It can also include skin lesions, arthritis and bowel inflammation. Headaches and extreme fatigue are often experienced.
- Behçet's is a multi-system condition, and symptoms occur wherever there is a patch of inflammation; this can be anywhere where there is a blood supply – from the brain down to the feet.
- It is treatable but not currently curable. By suppressing the immune system, inflammation can be reduced and symptoms relieved.

## What is a rare disease?

A disease is defined as rare in Europe when it affects less than 1 in 2,000 people. Behçet's in children and young people is extremely rare, affecting around 4 in a million children in the UK.

Rare diseases can be life-threatening and healthcare needs are often complex. The impact of rare disease can become a source of discrimination and reduce educational, professional or social opportunities.



“ Just because I could do it yesterday doesn't mean I can today ”

# How Behçet's may affect a child or young person in school or college

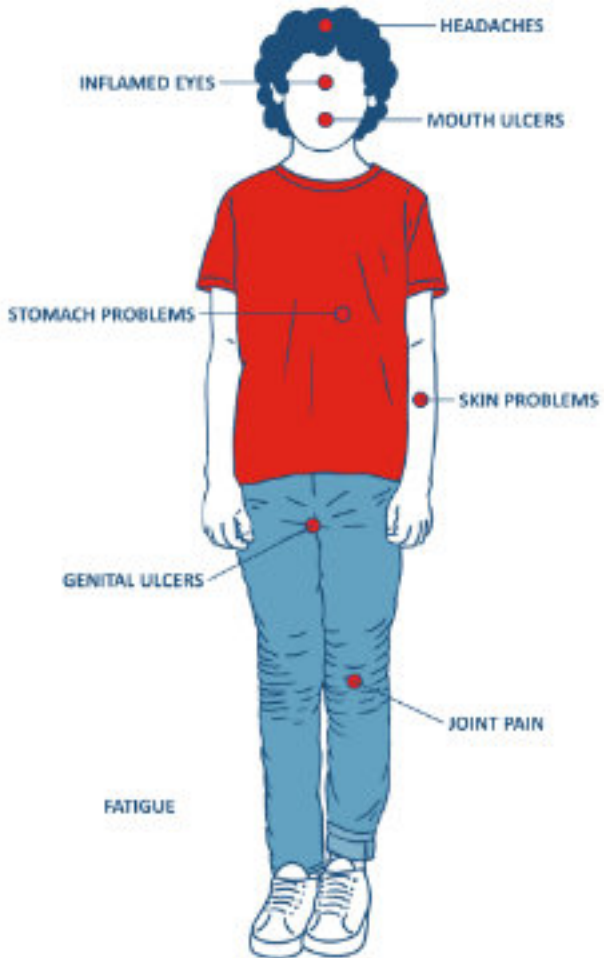
Behçet's is very variable and can affect different children and young people in very different ways. It can also affect individuals differently each day; for example, on a good day, a child may have no symptoms, but a flare can come out of the blue.

Depending on symptoms, a child or young person may not be able to attend school or college. If this is happening regularly the medical team will liaise with the family and school/college to make plans to ensure the child or young person's educational and medical needs are met.

Because of the variety of ways Behçet's affects children and young people, they need to attend hospital appointments, often with different specialists and may need to attend hospital for regular treatments. This can impact on school attendance.

Behçet's is an invisible illness; children and young people may not look unwell. Many symptoms are not visible. This includes extreme tiredness (fatigue) which can also affect mood.

Having a chronic unpredictable condition like Behçet's can affect a child or young person's mood, confidence and self-esteem. Every child and young person is different, and an individual approach is key.



## Considerations in school and college

- Mouth ulcers may impact a child or young person wanting to speak or eat and can also impact their ability to wear a mouth guard for sports, or play a wind instrument. They may need a different softer and plainer diet during a flare or need to use mouthwashes and sprays before meals.
- Genital ulcers and gut symptoms may mean children and young people need a toilet pass and may need to visit the toilet more regularly.
- Joint pain and stiffness may impact on mobility (for example moving between classrooms) and ability to take part in PE. They may need to sit on a chair rather than the floor and may struggle with writing or carrying bags.
- Pain (headaches, joints, tummy, skin, ulcers) may mean a child or young person is quieter than normal or not able to concentrate to their normal level.
- Fatigue can be a big issue for children and young people with Behçet's, and can impact on ability to access school or college full time and/or affect concentration.
- Eye inflammation, while thankfully uncommon in UK children, can lead to impaired vision or blindness.



# Behçet's treatment and therapy

It is important for schools and colleges to understand what treatment and therapy children and young people diagnosed with Behçet's may be receiving and how it can affect them both physically and mentally.

## Medication

A variety of anti-inflammatory or immunosuppressant medicines are used in the treatment of Behçet's in children and young people. These are also used in adults. Treatment is tailored to the individual patient and may include medications to reduce symptoms during a flare (taken intermittently) or medications to prevent flares which are taken regularly.

Generally speaking, mouth and genital ulcers are treated where possible with topical agents including steroid pastes, creams and/or sprays. Mild disease can be treated with colchicine, and simple painkillers such as ibuprofen or paracetamol.

Where the disease is more severe immunosuppressant medicines such as azathioprine, mycophenolate mofetil, adalimumab and infliximab are used. Some of these are taken as tablets or liquids and some as injections.

### Ibuprofen and paracetamol

- Used as painkillers during a flare. Ibuprofen also has anti-inflammatory effect.
- A child or young person with Behçet's may need to use these during the school/college day.

### Mouthwashes for mouth ulcers

- Some numb the mouth and are useful before eating, while others are antiseptic to prevent infection. Steroid mouthwashes help treat mouth ulcers.
- A child or young person with Behçet's may need to use these during the school/college day.

### Steroid creams for skin and genital ulcers

- Reduces inflammation during a flare.
- A child or young person with Behçet's may need to use these during the school/college day.

### Steroids (e.g. prednisolone)

- Helps 'switch-off' inflammation during a flare.
- If used long-term, this can make the child susceptible to infection. It can also cause weight gain and affect behaviour.





“ The pain is not in my head  
– I’m not lying or making  
it up – we need teachers  
to believe us more

”



“ We are people, not just an illness; we want to know we have a future ”

## **Colchicine**

- Milder immunosuppressant that helps 'switch-off' inflammation and is useful for preventing flares of ulcers, and joint and skin disease.
- This does not make a child or young person more susceptible to infections. It can cause a tummy upset and diarrhoea, especially when first started.

## **Azathioprine**

- Used for more severe Behçet's and works on the immune system to 'switch-off' inflammation. Used more long term to prevent flares.
- This medication can make the child or young person susceptible to infection and they will need regular blood tests for monitoring. Children and young people cannot have live vaccines but will require annual flu vaccination.

## **Biologic drugs such as infliximab and adalimumab**

- Used for more severe Behçet's and works on the immune system to 'switch-off' inflammation. Used more long term to prevent flares.
- Adalimumab is given as an injection under the skin and infliximab is given via a drip and requires attendance at hospital every 4-8 weeks for infusion.
- These drugs can make the child or young person susceptible to infection and they will need regular blood tests for monitoring. Children and young people cannot have live vaccines but will require annual flu vaccination.

## **Lead consultant and National Behçet's Centres of Excellence**

Often a child or young person's lead consultant, who manages their treatment, will be a paediatric rheumatologist.

Children and young people (primarily those living in England) may attend one of the three Behçet's Centres of Excellence which are based in Liverpool, Birmingham and London.

These centres run multi-disciplinary clinics where children and young people may be seen by a range of specialities such as paediatric rheumatology, oral medicine, dentistry, and gastroenterology with access to nurse specialists, physiotherapists, occupational therapy and clinical psychology. Behçet's support coordinators help support the families attending these centres

## **Physiotherapy**

Physiotherapists provide therapy to help increase the child or young person's movement and help them manage the pain in their joints. They provide guidance on sports and activities and will also advise on what exercises the child or young person can do between appointments.

## Occupational therapy

Behçet's can lead to difficulties carrying out day to day activities: anything from brushing their teeth to completing school or college work.

Managing with fatigue can be challenging and occupational therapists help develop strategies to help children and young people minimise the impact on their day to day activities. They can also support children and young people to explain the impact of Behçet's to places such as school and college.

## Nurse specialist

A rheumatology clinical nurse specialist (CNS) is a nurse who specialises in looking after children and young people with Behçet's. They work very closely with all of the team who look after the child or young person. They help the child and family learn about Behçet's, the treatments and managing the treatments. The nurse can also talk to teachers and other people that the child or young person may be involved with and may be contacted either in clinic or on the telephone or by email.

The nurse is there to talk to about any worries the child, young person or families may have about the condition or the treatment. Sometimes children and young people need a bit extra support to cope with the condition and often when a child becomes an adult, they can have lots of questions. They also help with the transition to the adult rheumatology team.

## Clinical psychology

Being diagnosed and living with Behçet's can cause children or young people and their families to have lots of different feelings, such as feeling sad, angry or worried.

Lots of children and young people also say that having to come to lots of hospital appointments, experiencing pain and taking medication can sometimes be tricky to manage. All these feelings are normal, and it can be helpful to speak to someone about it.





“ We should not be told how to feel ”

# Disability discrimination in education

If a child or young person's Behçet's affects them in such a way that they meet the definitions of having a disability they are protected from discrimination by law.

A person is defined as having a disability if they have **a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities**. They are entitled to protection under the Equality Act 2010 in England, Scotland and Wales. In Northern Ireland they are protected by the Special Educational Needs and Disability Order (SENDO) and the Disability Discrimination Act 1995.

A substantial effect on your day-to-day activities means one that's 'more than minor or trivial' and can include:

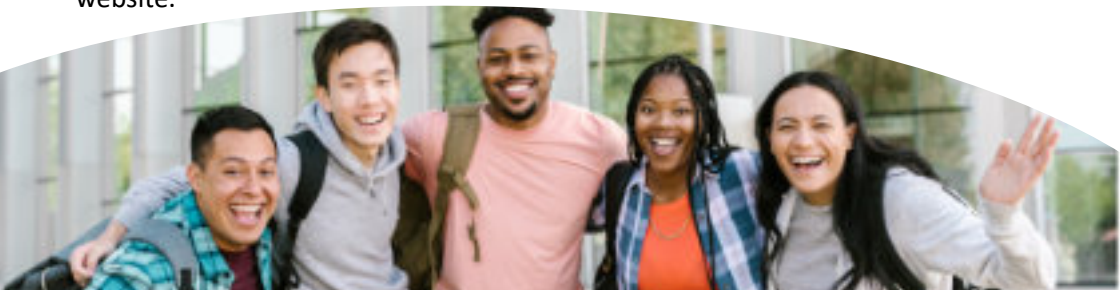
- physical impairments, such as mobility difficulties
- sensory impairments, such as those affecting sight
- a condition which is characterised by a number of cumulative effects such as pain or fatigue

Life-long fluctuating conditions such as Behçet's are specifically included in the definition of a disability.

## Removing barriers for disabled children and young people

In England, Scotland and Wales, under the Equality Act, schools and colleges must remove the barriers children and young people face because of their disability so they can access and participate in education in the same way, as far as this possible, as someone who's not disabled. This is the duty to make 'reasonable adjustments'.

In schools in Northern Ireland, under SENDO, there is a duty to work towards making the education experience more accessible to disabled students and prospective students in terms of premises, the curriculum and information. More information can be found on the Equality Commission for Northern Ireland website.



# Schools and colleges' responsibilities

Schools, nurseries and colleges have to support children and young people and treat them fairly, which is protected in UK Law.

They must also support children and young people with health conditions, including support to manage medications\*, and personal care and to catch up after a period of absence.

Terminology, guidance and process vary between the four UK nations, and you will find more details of organisations that provide comprehensive help and guidance for your nation in the support and resource section starting on page 20.

Most schools have at least one dedicated teacher who is responsible for ensuring the child or young person's educational needs are met. In England and Northern Ireland this teacher is called a Special Educational Needs Coordinator (SENCO), in Scotland an Additional Support for Learning Teacher (ASL), and in Wales an Additional Learning Needs Coordinator (ALNCO).

Colleges don't have to have a SENCO/ASL/ALNCO but they should have a named person who makes sure the student's educational needs are met.

It is advised that parents or guardians make the school's SENCO/ASL/ALNCO aware as soon as possible when Behçet's is diagnosed (or suspected) and how it may affect the child or young person's education. This will ensure that an appropriate support plan is put in place and that everyone has opportunities to regularly review the progress made. Support should continue from the early years through to further education if required, depending on when the child or young person develops Behçet's.

A child or young person with Behçet's may need an healthcare plan, extra learning support or additional support.

*\* In Northern Ireland guidance is primarily around supporting medication needs, but there is no legal duty that requires school or college staff to administer medication; this is a voluntary role.*

## Individual Healthcare Plan (IHP)

In England, Scotland and Wales, if a child or young person has complex health needs, the school may decide to provide an individual healthcare plan (IHP). IHPs are considered appropriate for long-term, complex, recurring and fluctuating conditions.

As Behçet's meets these criteria, children and young people with Behçet's may need an IHP. However, Behçet's is different for every child and young person, so

their needs should be assessed individually.

IHPs should be reviewed annually and typically cover:

- the medical condition, its signs, symptoms and treatments
- precisely what help the child or young person needs to manage their condition
- who needs to be aware of the child or young person's condition
- specific support needed around the child or young person's educational, emotional and social needs .

Healthcare plans for individual children and young people should be drawn up in consultation with the child/young person's parents or guardians

## Extra learning support

If a child or young person's Behçet's diagnosis impacts directly on their learning, they may require targeted support for short or longer periods of time to help them overcome some of the barriers to learning that may occur as a result of their illness such as periods of hospitalisation, fatigue and the effects of medication etc.

In England and Northern Ireland, a child or young person who needs extra support is said to have Special Educational Needs (SEN); in Scotland, this is called Additional Support Needs (ASN), and in Wales, Additional Learning Needs (ALN).

Parents, carers and young people themselves should be involved at all stages of the process of targeted support and creation of an IEP.

## Additional support

If SEN/ALN/ASN is not enough to meet a child or young person's special educational needs and they require more help than would normally be provided by a school or college's own resources then it would be appropriate to request that an Education, Health and Care (EHC) plan in England, a Statement of Special Educational Needs (SSEN) in Northern Ireland, a Co-ordinated Support Plan (CSP) in Scotland or an Independent Development Plan (IDP) in Wales should be considered for that child or young person.

### Individual Education Plan (IEP)

IEPs are written by the school and used to outline and monitor the support they provide to a child or young person. It is a non-statutory document, meaning that schools can choose if and how they use it. Depending on where you live, the IEP may be called something different, such as: SEND Support Plans, Additional Support Plan, Pastoral Support Plan, Pupil Passports or One Page Profiles.

It is advisable for parents and carers to keep copies of IEPs because they will be a source of important evidence should you want to make a case for additional support.



# How else can schools and colleges help?

Behçet's can affect children and young people chronically for years. A caring and friendly school or college environment, with supportive teachers and staff who have positive, understanding and compassionate attitudes, will make a huge difference.

The key is a genuine ethos of inclusion so that a young person with Behçet's has an equal opportunity to participate fully in school and/or college life and reach their full potential.

## **Communicate**

Discuss the condition with the child or young person and their parents or guardians, particularly if there are concerns about attendance or concentration, and ensure communication is regular.

Educate all teachers and members of staff on the condition; this is especially important in secondary schools where a young person can have in excess of 12 teachers. Most importantly, keep communicating.

## **Inclusion**

If they feel well enough, most children and young people want to be included in all the normal activities of school or college including sport, day trips, residential and special occasions. Sometimes a bit of forward planning is needed and the school or college should always do its absolute best not to exclude a child from an activity. In rare cases where they have to, consider what you could do to make the student feel less left out.

Schools and colleges cannot exclude children and young people from trips on the basis of medical conditions, nor can they require parents to accompany them. Children and young people should be allowed to participate fully in out-of-school/college activities, if they feel well enough, and their specific needs should be considered as part of the normal risk assessment for trips.





“ Chronic fatigue is different to tiredness; I am not tired like 'everyone else' ”

## Attendance

Children, young people and parents should not be penalised if a student's absence from school or college is related to their health condition, but parents and young people should still follow the school or college's attendance procedures for notifying absence.

Ensure the schools attendance policy doesn't penalise poor attendance as this can be devastating to students with medical conditions who have really tried to be in school despite the challenges of their condition. Examples include awarding school trips or end of term parties for students with high attendance records. The statutory guidance states that it is not acceptable to penalise children if their absences are related to their medical condition.

If an absence is longer than 15 days, the local authority is under a duty to ensure a student receives as normal an education as possible. The local authority should provide a written statement on how education is to be provided. A full-time education should be provided unless the child or young person's health needs mean a part-time education is more appropriate.

When absences are under 15 days, many children and young people still want to keep up with key subjects, particularly if they are well and at home during an outbreak of infectious disease. Providing children and young people with some work to do at home helps them keep up with the rest of the class. Sending work by email via parents or guardians allows the school or college, child or young person and parent/guardian to work out what can be managed.

## Medication

Familiarise yourself with the medications the child or young person takes, how they are taken and their side effects such as changes in behaviour or mood when taking steroids. Keep young people and parents or guardians aware of significant outbreaks of infectious diseases if the child or young person is on steroids or immune-suppressing medication.

## Timetable adjustments

Depending on the severity of the child or young person's Behçet's, adjustments to their timetable may be considered, such as flexibility around deadlines, reduced timetable, dropping some exam subjects or avoiding PE. These types of adjustments result in a reduction in stress and an improvement in attendance.

## Tests and formal exams

Children and young people often find tests stressful, and stress can cause Behçet's to be more active.

During exams, children and young people with Behçet's may be disadvantaged by being too tired to revise as much or effectively as they would like and feeling considerably stressed and unwell on the days of examinations.

Children with Behçet's may need special arrangements for external examinations. It is recommended that schools meet with parents to discuss arrangements to support children with Behçet's at the point at which options are chosen. Stress does not cause Behçet's, but it can make the disease more active.

### **Friendships and bullying**

Some children and young people don't want their peers to know about their condition so withdraw from social activity.

The symptoms of Behçet's mean some may not feel confident in joining their friends for normal social activities like birthday parties, sleepovers, swimming or going for food. This can make them feel socially isolated, as can hospital stays.

Some of the physical side effects of treatments (like the puffy face associated with steroids) can make children and young people targets for teasing and bullying.

For some, Behçet's may be considered 'invisible' when there are no outward physical symptoms, which can result in the perception that a child or young person has special privileges (for example, coming in late or not having to take part in sports), and this can cause resentment among peers. Teachers and staff should support children with the emotional difficulties of Behçet's.





“ Being comfortable is key, we aren't wearing certain things as a fashion statement, certain clothes make us feel comfortable, we want to wear comfortable things that don't increase pain ”

# Support and resources

## For teachers and staff in education

### Alliance for Inclusive Education (ALLFIE)

A national network led by disabled people to promote inclusive education for all students. It provides a range of resources and training for educators and parents.

**020 7737 6030**

**[www.allfie.org.uk](http://www.allfie.org.uk)**

### Children's Legal Centre Wales

Offer training and other help to schools, community groups and professionals.

**[childrenslegalcentre.wales](http://childrenslegalcentre.wales)**

### Council for Disabled Children

Provides an information service to parents and professionals on the needs of disabled pre-school children, pupils and students.

**[councilfordisabledchildren.org.uk](http://councilfordisabledchildren.org.uk)**

### Education Authority - Northern Ireland

Responsible for ensuring that efficient and effective primary and secondary education services are available to meet the needs of children and young people.

**028 9056 4000**

**[www.eani.org.uk](http://www.eani.org.uk)**

### Enquire

Scottish advice service for additional support for learning for families and professionals.

**0345 123 2303 (Helpline)**

**[enquire.org.uk](http://enquire.org.uk)**

### Equality and Human Rights Commission (EHRC)

Provides advice and guidance covering a range of equality and diversity issues in England, Scotland and Wales.

**[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

### Equality Commission (Northern Ireland)

Provides free general advice to schools and education providers on recommended good practice

**028 90 500 600**

**[www.equalityni.org/Schools](http://www.equalityni.org/Schools)**

### Government – Education Departments

England: **[www.gov.uk/government/organisations/department-for-education](http://www.gov.uk/government/organisations/department-for-education)**

Northern Ireland: **[www.education-ni.gov.uk](http://www.education-ni.gov.uk)**

Scotland: **[www.gov.scot/education](http://www.gov.scot/education)**

Wales: **[gov.wales/education-skills](http://gov.wales/education-skills)**

## Health Conditions in Schools Alliance

Offers guidance and tools to schools who are looking after children with health conditions.

[www.medicalconditionsatschool.org.uk](http://www.medicalconditionsatschool.org.uk)

## IPSEA

Provides training for schools and local authorities on SEND.

[www.ipsea.org.uk](http://www.ipsea.org.uk)

## Well at School

A resource helping schools support students with medical and mental health conditions so they can fully engage in education.

[www.wellatschool.org](http://www.wellatschool.org)

## Whole School SEND

An online portal developed by Nasen, offering education professionals free, easy access to high quality information, resources and training for meeting the needs of children with special educational needs and disabilities (SEND).

[www.wholeschoolsend.org.uk](http://www.wholeschoolsend.org.uk)

## Young Minds

UK's leading charity fighting for children and young people's mental health

[www.youngminds.org.uk](http://www.youngminds.org.uk)

## For parents, carers, children and young people

### Alliance for Inclusive Education

A national network led by disabled people to promote inclusive education for all students. Provides a range of resources and training.

**020 7737 6030**

[www.allfie.org.uk](http://www.allfie.org.uk)

*England, Northern Ireland, Scotland, Wales*

### Children in Scotland

Provides practical support, advice and representation for children, young people, parents and families throughout Scotland.

[childreninscotland.org.uk](http://childreninscotland.org.uk)

*Scotland*

### Children's Legal Centre Wales

A Wales-wide, bilingual service providing information and access to legal advice for children and young people.

[childrenslegalcentre.wales](http://childrenslegalcentre.wales)

*Wales*

### Contact

Provides direct advice and support services to parent and carers

**0808 808 3555 (Helpline)**

[contact.org.uk](http://contact.org.uk)

*England, Northern Ireland, Scotland, Wales*

## Disability Rights UK

Works to influence regional and national change for better rights, benefits, quality of life and economic opportunities for disabled people. Provides education factsheets and guides

**0330 995 0414 (Disabled Students Helpline)**

**[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)**

*England, Northern Ireland, Scotland, Wales*

## Education Authority - Northern Ireland

Responsible for ensuring that efficient and effective primary and secondary education services are available to meet the needs of children and young people

**[www.eani.org.uk](http://www.eani.org.uk)**

*Northern Ireland*

## Education Scotland

Education Scotland is a Scottish Government executive agency. Includes useful section Parentzone

**0131 244 4330**

**[education.gov.scot/parentzone](http://education.gov.scot/parentzone)**

*Scotland*

## Enquire

Scottish advice service for additional support for learning for families and professionals.

**0345 123 2303 (Helpline)**

**[enquire.org.uk](http://enquire.org.uk)**

*Scotland*

## Equality and Human Rights Commission (EHRC)

Provides advice and guidance covering a range of equality and diversity issues

**[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

*England, Scotland and Wales*

## Equality Advisory & Support Service (EASS)

Aims to provide bespoke advice to those facing discrimination issues via the helpline

**0808 800 0082 (Helpline)**

**[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)**

*England, Scotland and Wales*

## Equality Commission (Northern Ireland)

Provides advice and assistance for people who feel they have been discriminated against.

**028 90 500 600**

**[www.equalityni.org](http://www.equalityni.org)**

*Northern Ireland*

## Family Fund

Family Fund is the UK's largest charity providing grants for disabled children and their families.

**[www.familyfund.org.uk](http://www.familyfund.org.uk)**

*England, Northern Ireland, Scotland, Wales*



## Independent Parent Special Education Advice (IPSEA)

IPSEA offers free and independent legally based information, advice and support to help parents get the right education for children and young people with all kinds of special educational needs (SEN) and disabilities.

**[www.ipsea.org.uk](http://www.ipsea.org.uk)**

*England*

## Information, Advice and Support Services (IAS)

IAS services in every local area in England provide dedicated and impartial advice to young people and parent carers.

**[councilfordisabledchildren.org.uk](http://councilfordisabledchildren.org.uk)**  
and search for

“Find your local IAS service”

*England*

## Joint Council for Qualifications

Established to unite the largest educational and vocational examination boards in the UK. Provides an overview on “Access Arrangements, Reasonable Adjustments and Special Consideration”

**[www.jcq.org.uk](http://www.jcq.org.uk)**

*England, Northern Ireland, Scotland, Wales*

## Learning Disability Wales

A national charity representing the learning disability sector in Wales.

**[www.ldw.org.uk](http://www.ldw.org.uk)**

*Wales*

## National Network of Parent Carer Forums

Over 150 local Parent Carer Forums across England, used by over 52,000 parents every year.

**[www.nnpfc.org.uk](http://www.nnpfc.org.uk)**

*England*

## RAiSE

RAiSE is an organisation inspired by the negative experiences that young people face while studying and living with invisible illnesses.

**[raise.co.uk](http://raise.co.uk)**

*England*

## Reach

Helps you understand children’s rights to be supported and involved in decisions so they have an equal chance to flourish in their education.

**[reach.scot](http://reach.scot)**

*Scotland*

## Resolve:ASL

An independent mediation service for parents and carers of children and young people in Scotland with additional support needs.

07955 788967

**[resolvemediation.org.uk](http://resolvemediation.org.uk)**

*Scotland*

## Right to Participate

Part of Disability Rights UK’s Right to Participate project which aims to increase awareness of the Equality Act.

**[righttoparticipate.org](http://righttoparticipate.org)**

*England, Scotland, Wales*

## SENAC

Independent and confidential service which advises on the Northern Ireland statutory SEN system.

**senac.co.uk**

*Northern Ireland*

## Snap Cymru

Provides information, advice and support for parents, children and young people in Wales who have, or may have, special educational needs or disabilities

**0808 801 0608 (Helpline)**

**www.snapcymru.org**

*Wales*

## SOS!SEN

Aims to empower parents and carers of children with SEN to tackle successfully themselves the difficulties they face when battling for their children's rights.

**0208 538 3731 (Helpline)**

**sossen.org.uk**

*England*

## Working Families

Aims to remove the barriers that people with caring responsibilities face in the workplace. Provides free legal advice to parents and carers on their rights at work.

**workingfamilies.org.uk**

*England, Northern Ireland, Scotland, Wales*

## Young Minds

UK's leading charity fighting for children and young people's mental health.

You will find links to other organisations that help children and young people call, text, chat online, or email about any concerns and problems, including their mental health.

**www.youngminds.org.uk**

*England, Northern Ireland, Scotland, Wales*

# About Behçet's UK

Behçet's UK (formerly Behçet's Syndrome Society) was founded in 1983 by Judith Buckle and is Registered Charity No. 326679.

We represent 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.

## 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.

## Working together

The rare disease patient is the orphan of health systems, often experiencing a lengthy journey to diagnosis, contradictory experiences, and varying levels of treatment and indeed understanding about their symptoms.

Behçet's UK works with others so that its 'collective voice' can be heard. We are a member of:

- **National Voices** [www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)
- **Genetic Alliance** [geneticalliance.org.uk](http://geneticalliance.org.uk)
- **EURORDIS** [www.eurordis.org](http://www.eurordis.org)
- **International Society for Behçet's Disease** [www.behcetdiseasesociety.org](http://www.behcetdiseasesociety.org)
- **The Neurological Alliance** [www.neural.org.uk/](http://www.neural.org.uk/)

For more information please visit our website

**behcetsuk.org**

Email: [info@behcetsuk.org](mailto:info@behcetsuk.org)

Telephone: 0345 130 7328

For all general enquiries

**Helpline: 0345 130 7329**

Our helpline is for anyone over 18 who is affected by Behçet's or wants to know more about the condition. It is run by volunteers who can provide general support, a listening ear and guidance about Behçet's. They are unable to provide medical advice and do not deal with emergencies.

Follow us: [@behcetsuk](https://www.instagram.com/behcetsuk)



**Registered charity in England & Wales (326679)**

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*How to manage Behçet's at school and college - October 2022 v1.0*

