

Behçet's: An Employer's Guide

A guide about Behçet's and how it can affect people at work



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

Contents

About this booklet.....3

What is Behçet’s?.....4

Valuable assets: skills and experience.....5

How Behçet’s may affect people at work.....6

Communicating about the situation.....8

Supporting an employee who has Behçet’s.....10

Support and resources.....15

Useful addresses.....19

Access to Work Contact Centre.....22

About Behçet’s UK.....23



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.

About this booklet

If you're an employer of someone who has Behçet's disease (also known as Behçet's syndrome), we hope you find this booklet useful. In it there is information about the disease and how it can affect people at work, the kind of difficulties it can cause and how these may be overcome. It also includes up-to-date details of where employers can go for help and advice on the law relating to disability, on best practice and on making adjustments for employees at work and the possible financial help that is also available.

Behçet's is still a poorly understood condition but treatments have improved a great deal. The time to diagnosis for Behçet's patients has reduced from an average of 12 years down to 6 years. The goal is now to diagnose the condition at an early stage. With understanding and support from employers and healthcare teams, it is possible for some people with Behçet's to remain in work for as long as they wish.

However, for those in employment, the picture is often one of slowed career progression, changes in employment to accommodate their condition, uncertainty about the future and concern over the potential loss of income and pension contributions.

When people experience problems at work, it can have a major impact on their social life and their relationships with their partners and families.

What is encouraging, however, is that the barriers people experience in the workplace are often not impossible to overcome. There are several factors which are important in enabling people to remain productively employed. These include: awareness and understanding from employers; travel arrangements; specific adaptations or equipment; and access to medical teams when people need help.

We hope that this booklet will be helpful for employers and organisations who advocate for the rights of people with long-term conditions.

What is Behçet's?

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

Key facts about Behçet's

- It is a lifelong condition
- Although Behçet's can affect people of any age, it is most commonly diagnosed in those between the ages of 20 and 40.
- There is no obvious pattern to symptoms and everybody's condition is different. People get 'flares', or periods when symptoms are much worse, which then subside. They can have periods when the disease is quiet and causes them no problems.
- It is an 'auto-immune disease' – that is, it results from a problem with the body's immune system. It 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, which can potentially involve any organ in the body. It can affect the central nervous system, causing memory loss and impaired speech, and problems with balance and movement.
- 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. The number of Behçet's patients in the UK is unknown, but is estimated to be about 1 in 100,000.

Rare diseases are life-threatening or chronically debilitating with a low prevalence and a high level of complexity. Many have disabilities that become a source of discrimination and reduce educational, professional or social opportunities.

Valuable assets: skills and experience

Ask employers what their most valuable asset is and they invariably reply ‘my employees’. They place a high priority on retaining the skills and experience of valued members of staff, particularly given the high costs of recruitment, induction and training for new staff.

Behçet’s can be a difficult condition to manage, both for individuals and for employers, as it often begins when people are in the prime of their working lives. However, there can be straightforward and inexpensive strategies to minimise the effects of the condition on employment, from which both employers and employees benefit. If people are absent from work for long periods of time, it becomes extremely difficult for them to return – this argues strongly for focusing efforts on enabling people to remain in work.

Part of the difficulty is the nature of the condition itself. Behçet’s is complex and fluctuating, and also varies greatly between individuals. It can be severe and at the same time almost invisible; to non-medical eyes there are often no physical changes in a person diagnosed with the condition. There is a real need to increase understanding about the condition and the needs of those who have it.



How Behçet's may affect people at work

It is natural for employers to be concerned about the possible impact of any long-term health condition on their employees' performance and reliability, and consequently on their business. In addition to concerns about the welfare of employees, there may well be other issues – for example, the additional management requirements such as arranging cover for sick leave, or possible additional costs, such as new equipment.

Many people with Behçet's can continue to be able to work normally with few problems. However, there are those who do face challenges in the workplace at some time.

The impact of the condition at work can very often be successfully managed, and may be less disruptive than many employers fear. There really is no 'typical' scenario, owing to its fluctuating nature and it affecting each person differently. However, the following pages give a very broad outline of what to expect.

When someone has been diagnosed

When someone is newly diagnosed, they are usually prescribed one of the many drugs that are available to control the condition. These disease-modifying drugs are effective, though they take a while to 'kick in' – usually a matter of weeks, but in some cases longer as what one patient can tolerate and feel better using, another patient may reject.

During this early phase people are often distressed and overwhelmed. They are in pain; they are coming to terms with the fact that they have a lifelong condition for which there is no cure and that may have taken many years to diagnose; they are anxious about how this will affect their future, including their ability to remain in their job. Having an employer who understands the nature of their condition and its treatment in these early stages makes a huge difference.



Once the drugs take effect and the condition becomes controlled, some people are able to continue to work as normal. Others may need some adjustments to their working environment, working hours, or to the job itself. There is more information about adjustments on page 12.

Symptoms

The most common ways in which symptoms affect a person's ability to work are:

- problems with mobility and strength
- pain
- fatigue
- reductions in concentration and memory, and physical and mental stamina

However, today people can manage their symptoms more effectively than in the past.

'Flares'

Even when Behçet's is well controlled, people can experience a 'flare' in their symptoms. Flares can sometimes occur suddenly and without any warning signs: a person can be at work one day and be physically unable to get out of bed the next. Flares usually subside within a couple of days, but their frequency and severity varies greatly between individuals. Stress aggravates the condition, so any reassurance you can offer your employee will help considerably.

Flares may be managed without medical help but when they do require medical support, rapid intervention can minimise the severity of the flare.

Time off

To manage their condition people with Behçet's will need some time off for hospital or GP appointments. This does not have to be disruptive; often people can arrange routine appointments on the way to or from work.

People whose disease is not yet effectively controlled are more likely to need some time off before drugs stabilise their condition, though this varies according to each individual.

Fit for Work allow the employee's GP to identify whether they may be fit for work with support. They provide information on how the employee's condition may affect what they do at work and suggestions for common ways to help support the person at work. These may include a phased return to work, flexible working, amended duties and/or workplace adaptations.

More details can be found at: www.gov.uk/government/collections/fit-note which also has useful links for employers including a guide entitled '*Getting the most out of the fit note*'.

Communicating about the situation

People who have their Behçet's very well managed may decide not to tell their employers. Some people will tell their employer as soon as they are diagnosed, while others prefer to take their time and come to terms with the news. Some will effectively have no choice, if their symptoms are severe and they are facing difficulties at work that they need to discuss.

Whatever the circumstances, for most people, this will not be an easy conversation and it makes all the difference to have the understanding of their employer. As well as the difficulties of coping with a life-changing diagnosis, people may have feelings of guilt if their performance at work has recently been affected. They will be uncertain about their future health and perhaps about their rights at work. Employers can help greatly by taking a supportive approach at this difficult time.

- **Follow normal good people management practice in communicating with your employee, particularly ensuring that they have and understand all the relevant company policies and how these apply to their situation.**
- **When an employee has told you that they have Behçet's they may want to inform their colleagues or they may prefer to keep it confidential. If they wish their colleagues to be informed, discuss and agree jointly the best way to go about this.**
- **Agree a series of review meetings with your employee that enable you to discuss any support or adjustments they may need. You can, of course, use your normal review meetings that you have with your employees to discuss these matters.**
- **Let the employee know who they can talk to if they need support or if their situation changes.**
- **If any employee has an extended absence, keep in touch. It will give you information to help manage workloads, and ensure that suitable support is given to an employee on their return. Aim to agree with the individual what frequency of communication is appropriate, which may include home visits, visits to work and/or regular phone calls. Agree who contacts whom, and when to ensure you meet your company attendance policy.**

Finding out what your employee needs: a checklist

- Explore the situation with your employee. Identify with them the aspects of their role that they can complete without a problem and those that they know or think that they may struggle with. Then identify how these could be done differently, including all aspects such as travel to work (missing the rush-hour) and location of parking space in relation to the office/workplace.
- Decide what actions are needed and who will be responsible.
- Examine the working environment and accessibility including workplace location, heavy doors and the need to use stairs. If you do not have an occupational health nurse then arrange a work assessment with an occupational therapist, occupational health physiotherapist or the Access to Work scheme. For more information see pages 15-17.
- Assess the potential for the employee to continue with their current role. Consider whether adaptations, changes to their working hours, or additional training are necessary.
- Identify any trial adjustments needed to their role, or identify a (temporary or permanent) potential alternative job. Examine re-training options.
- Agree on what information colleagues should receive and who is responsible for telling them.
- Agree on a communication and review process.



Supporting an employee who has Behçet's

The type of support an individual needs will of course depend on the type of work they do and how physical it is. Some occupations with heavy labouring are more difficult to accommodate than less physical jobs. However, in some circumstances, there are options for transferring people to less physical work that still uses their skills or allowing some flexibility in the time they spend at specific tasks.

When an employee tells you that they have Behçet's, take the earliest opportunity to ask about any problems they are experiencing and explore ways to overcome them. Often they can be resolved easily and with little effort. Making modifications sooner rather than later may well be cheaper too, as you can make changes before the problem becomes costlier. You may need to arrange a workplace assessment to identify problems and potential solutions. There is more information on pages 13-14.

With the right support and adjustments, people with Behçet's can usually continue in employment.

Legal responsibilities

The Equality Act 2010 protects disabled people in England, Scotland and Wales. The Disability Discrimination Act 1995 protects disabled people in Northern Ireland.

Both acts protect disabled people against discrimination when applying for employment, during employment, when their employment has ended and impose a duty on employers to make reasonable adjustments.

The Equality and Human Rights Commission provides guidance for employers on the Equality Act 2010. The Equality Commission for Northern Ireland provide guidance for employers on the Disability Discrimination Act 1995.

Many people with Behçet's do not consider themselves to be disabled. However, they may be entitled to protection at work under the Equality Act or Disability Discrimination Act if their Behçet's affects them in such a way that they meet the definitions of having a disability; i.e. 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. This can include limitations in:

- mobility
- manual dexterity
- the ability to lift, carry or otherwise move everyday objects
- memory or the ability to concentrate, learn or understand.

Long-term and fluctuating or progressive conditions are specifically included in the definition of disability in the Equality Act and Disability Discrimination Act.

Protection against discrimination

Under the Equality Act and Disability Discrimination Act, an employer may not unlawfully discriminate against a disabled person. There are various types of discrimination – visit www.equalityhumanrights.com or www.nidirect.gov.uk for more details. In particular, an employer must not treat an employee less favourably because they have Behçet's than a similar employee without such a disability, for example in opportunities for promotion and training.

There is also a requirement for employers to not treat a disabled person unfavourably because of something arising from their disability where this cannot be justified. Disability related sickness is an example of this. If an employee needs to take leave because of their Behçet's, it is good practice for the employer to distinguish between such 'disability leave' and general sick leave. The employer may then discount some or all of the disability leave when considering any disciplinary issues, performance measures or selection criteria for promotion or redundancy. However, the employee will be subject to the company's normal sick pay policy. An employer does not have to pay more sick pay to a disabled person (although they can choose to).



‘Reasonable adjustments’

The Equality Act and Disability Discrimination Act require employers to make ‘reasonable adjustments’ - i.e. to make sure that, as far as is reasonable, a disabled employee has the same access to everything that is involved in doing and keeping a job as a non-disabled person

What kind of adjustments should an employer consider and what is considered reasonable?

Many adjustments can support a person with Behçet’s, some of which cost very little to implement. These include:

- adjusting working hours, making these more flexible, allowing additional breaks to help overcome fatigue or working from home for all or part of the time
- adjusting duties, possibly transferring some to other people and allowing an employee to take on others that are more suitable
- acquiring equipment, such as telephone headsets, ergonomic keyboards, adapted handles or a supportive chair
- support from someone else to do part of the job (e.g. help with lifting or transferring necessary equipment)
- improvements to access – e.g. a disabled parking place near to the workplace; ramps; rails and stair lifts; widening doors; positioning of light switches and door handles
- assigning to a different place of work or transferring to fulfil an existing vacancy
- adjusting company policies, such as modifying disciplinary or grievance procedures, redundancy selection criteria or absence management procedures to discount some or all of periods of disability-related absence.

The Equality Act 2010: Employment Statutory Code of Practice and *Disability Discrimination Act 1995: Disability Code of Practice on Employment and Occupation* lists some of the factors that may be taken into account when deciding what steps it are reasonable for an employer to take. The factors are:

- whether or not taking a particular step would be effective in preventing the substantial disadvantage
- the practicality of the step
- the financial and other costs of making adjustments and the extent of any disruption caused
- the extent of the employer’s financial and other resources

- the availability of financial or other assistance to help the employer make an adjustment (such as the help available through Access to Work)
- the type and size of the organisation.

It would be reasonable to expect all employers to provide ramps, rails and simple ergonomic equipment for computers and telephones or minor adaptations to machinery.

But if a building has awkward stairs, for example, it may not be physically possible to install a stair lift without extensive additional building work, which might then make such an adaptation unreasonable.

A larger company may be able to afford to allocate another employee to help, whereas a small company with a few employees may not be able to do so. Note that financial help is available through the Access to Work scheme – there are more details on page 15.

Employees and employers should aim to communicate effectively and openly, to negotiate on both sides what is ‘reasonable’. Further advice is available from the Trades Union Council (TUC).

If an employee cannot continue in their present role because of their Behçet’s, you should explore all avenues for transferring the employee to another role within the company. Such a move can also be considered reasonable adjustment and could include a role at a different work location.



Workplace assessments

The best way to assess what adjustments are needed may be to carry out a workplace assessment. An assessment can be carried out by:

- **Occupational Health Therapists**, whose job is to enable people with disabilities or illness to perform tasks at work and in their daily lives more easily
- **Physiotherapists**, specifically those who specialise in occupational health

- **Vocational Rehabilitation (VR)**, counsellor or case manager
- **An Access to Work (AtW)** advisor
- **Occupational Health Nursing** advisor, who acts as a link between employer and employee.

A therapist, VR counsellor or AtW advisor can visit the workplace to assess the employee's job and their physical environment. They can evaluate job tasks and advise how they can be simplified or modified to reduce the effort needed. They may suggest: appropriate adaptations to equipment; assistive technology; other devices such as splints; and changes to the work environment or how the job is performed.

An employee may request that an occupational therapist from their own health team visits to do an assessment. For information about qualified therapists and VR counsellors and how to find them, see Support and Resources on pages 15-17. There are a number of different professionals listed above who are involved in Vocational (work) Rehabilitation (VR). Experienced professionals should be qualified, be members of a professional association and adhere to VR national standards for their profession.



Support and resources

If your company has an occupational health nurse advisor, they are the starting point for support. If not, there are many external sources of help, on the law, making adjustments, work assessments and good practice.

The Access to Work scheme (AtW) provides support to disabled people, those with long-term health conditions and their employers to help overcome work- related obstacles resulting from a disability or health condition.

Financial assistance is available from AtW to help employers recruit, retrain or make necessary adjustments in the workplace.

An AtW advisor can give support and information on helping to tackle practical obstacles in the workplace. They may be able to act on an existing report from a therapist, or they may need to arrange for an assessment to determine how much and what type of help an employee needs.

Practical and financial help is available for:

- special aids and equipment
- support workers
- travel to and from work, where extra costs are incurred in travelling to and from work because of a disability
- adaptations to premises and equipment.

For employees starting a new job (i.e. they started less than 6 weeks ago), Access to Work will consider covering up to 100% of approved costs of help. Whatever the employment status, Access to Work will also consider paying up to 100% of the approved costs of help with:

- support workers
- fares to work
- communicator support at interview.

To contact Access to Work directly, see page 22. The employee can also discuss their needs and contact AtW via the Disability Employment Advisor at their local Jobcentre Plus or if they are in Northern Ireland their Work Coach at their local Jobs and Benefits Office .

NHS Health at Work Network

NHS Health at Work is the network of occupational health teams dedicated to ensuring that the NHS has a healthy, motivated workforce that is able to provide the best possible patient care.

NHS Health at Work influences and advises Government and other bodies about occupational health in the NHS. They also provide a gateway for businesses in the broader community who are seeking occupational health advice and support including a section to enable you to find an NHS occupational health (OH) provider.

To find out more about the services offered visit:

www.nhshealthatwork.co.uk/

Workplace Health Advice

Government funded services providing confidential, practical and free advice to small businesses on workplace health and safety, management of sickness absence and return to work issues are available from the following:

England: The Health and Safety Executive
www.hse.gov.uk

Scotland: 'Healthy Working Lives'
www.healthyworkinglives.scot

Wales: 'Healthy Working Wales'
www.healthyworkingwales.wales.nhs.uk

Northern Ireland: Health and Safety Executive for Northern Ireland
www.hseni.gov.uk

Business Disability Forum

The Business Disability Forum (BDF) is a membership and partnership organisation that provides information and advice on disability as it affects business.

Information, support and advice on disability are offered as a proactive or reactive business issue. Examples of advice offered include:

- advice on adjustments and whether they are reasonable
- support for members who are measuring how disability-smart their organisation is against the BDF Disability Standard
- review of documents and policies and feedback from a disability perspective.

For further information contact BDF on **020 7403 3020** or email **advice@businessdisabilityforum.org.uk**

AbilityNet

AbilityNet is a national charity and a leading provider of advice on computing and disability. It provides:

- an advice and information service
- individual assessments to find the right solution for disabled people who have a problem using their computer
- awareness training and advice to businesses.

To find out more visit www.abilitynet.org.uk or call **0800 269545** or **01926 312847**.

NHS rehabilitation services

NHS rehabilitation services are available. An employee may be able to get guidance or may prefer to have a workplace assessment undertaken by someone with a specialist knowledge of their disease. Employees can ask their consultant or GP what services are available locally.

Occupational therapists specialise in enabling people with illness or disabilities to perform work, leisure, daily activities and social roles more easily. **Occupational health physiotherapists** also specialise in work problems. Either of these professionals can provide workplace advice and/or job analysis and assessments. Assessments can be carried out by visiting employees at work or by a structured interview.

These professionals can evaluate how people perform tasks and help them to simplify or modify job tasks to reduce the effort required. They can do this by suggesting appropriate adaptations to equipment, assistive technology (gadgets) and devices (splints), changes to the work environment, and changes in how a person carries out their job. The therapist can analyse how people carry out tasks, their movements and positions, and the order of tasks. Based on this they can recommend changes to make tasks easier.

Other sources of help

Some private companies also provide workplace assessments. Therapists may be self-employed or employed by health insurance companies, private health companies, or rehabilitation case management companies.

To identify private occupational therapists, occupational health nurses and occupational health physiotherapists, you can search online at the following sites.

- For occupational therapists: The Royal College of Occupational Therapists Specialist Section in Independent Practice www.cotss-ip.org.uk

- For occupational health nurses: The Commercial Occupational Health Providers Association (COHPA) – **www.cohpa.co.uk** – select from ‘OH Providers’ on this page.
- For physiotherapists: Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) – **www.acpohe.org.uk**. Their professional body is the Chartered Society of Physiotherapists – **www.csp.org.uk** – go to the PHYSIO2U section on this page
- The Institute of Ergonomics and Human Factors also lists some therapists and other ergonomics professionals – **www.ergonomics.org.uk** – click on ‘Find an Accredited Consultancy’ on the homepage.

Some consultancies specialise in problems of workers with disabilities, and others provide general ergonomic workplace advice for preventing injuries in the workplace. Look at the detailed information about their specialist services, e.g. on the internet.

Rehabilitation case management companies may provide a range of services covering physical, psychological and social issues. Some specialise in employment-related services (e.g. ergonomic and worksite assessments, stress awareness, promoting wellbeing, rehabilitation, and planning for a return to work). Practitioners who are members of the Case Management Society UK adhere to the Society’s code of practice and standards. To find a practitioner and identify the company they work for, you can search **www.cmsuk.org**, click on Case Management and then select ‘find a case manager’.

A new qualification in the UK has recently been developed as Vocational Rehabilitation (VR) Counsellor; this is for therapists or other professionals who have completed a certified/accredited VR training course. The UK Rehabilitation Council’s ‘Rehabilitation Standards’ and ‘Choosing a Rehabilitation Provider’ (2009) may help you identify good quality private providers – **www.rehabcouncil.org.uk** (select Downloads & Links on this page to access these documents. NB you will need to register before downloading)

Useful addresses

AbilityNet

National charity and provider of advice on computing and disability.

0800 269545 or 01926 312 847

abilitynet.org.uk

ACAS

Provides up to date information, independent advice and can help employers and employees to solve problems and improve performance.

0300 123 1100

www.acas.org.uk

Association of Chartered Physiotherapists in Occupational Health & Ergonomics

A proactive group, promoting best practice in the field of Occupational Health Physiotherapy. Online search facility for local physiotherapists.

01284 748202

www.acpohe.org.uk

Business Disability Forum

Members and Partners of the BDF can contact the organisation for information or advice on disability as it affects business.

020 7403 3020

businessdisabilityforum.org.uk

Chartered Society of Physiotherapists

Can help you to find a chartered physiotherapist that offers private services.

020 7306 6666

www.csp.org.uk (PHYSIO2U section)

Commercial Occupational Health Providers Association (COHPA)

Provides assistance with finding a provider in your area based on your needs.

0333 772 0401

cohpa.co.uk

Equality and Human Rights Commission (EHRC)

Provides advice and guidance for business covering a range of equality and diversity issues.

0808 8000082

(Textphone: 0808 800 0084)

www.equalityhumanrights.com

Equality Advisory & Support Service

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

0808 800 0082

(Textphone: 0808 800 0084)

www.equalityadvisoryservice.com

Equality Commission for Northern Ireland

Provides free general advice to employers on recommended good practice.

028 9050 0600

(Textphone: 028 9050 0589)

www.equalityni.org

Gov.uk

Information about government services.

www.gov.uk

Employment Tribunals

Judicial bodies established to resolve disputes between employers and employees over employment rights. These websites provide information about the tribunal's procedures and gives guidance on responding to a claim.

England/Wales: 0300 1231024

Scotland: 0141 354 8574

www.justice.gov.uk/tribunals/employment

Northern Ireland: 028 9032 7666

www.employmenttribunalsni.co.uk

Fit for Work

Free service offering support to GPs, employers and employees to help those in work and off work sick.

0800 032 6235

fitforwork.org

Health and Safety Executive

Practical and free web-based advice to small businesses on workplace health and safety, management of sickness absence and return to work issues.

www.hse.gov.uk

Health and Safety Executive for Northern Ireland

Responsible for the promotion and enforcement of health and safety at work standards in Northern Ireland.

0800 0320 121

www.hseni.gov.uk

Health4Work

Provides website information on all health issues affecting your business.

www.Health4work.nhs.uk

Healthy Working Lives

For small businesses in Scotland. Confidential, practical and free advice to small businesses on workplace health and safety, management of sickness absence and return to work issues.

0800 019 2211

www.healthyworkinglives.scot

Healthy Working Wales

Supports employers and working age people to stay fit and healthy so they can remain in employment or return to work following a period of ill health.

Helpline: 02921674966

www.healthyworkingwales.wales.nhs.uk

Institute of Ergonomics and Human Factors

Advice on how to choose and where to find an ergonomist.

01509 234904

www.ergonomics.org.uk

Jobcentre Plus

Supporting people of working age from England, Scotland and Wales, from welfare into work, and helping employers to fill their vacancies. Part of the Department for Work and Pensions (DWP).

0800 055 6688

(new benefit claims only)

0345 604 3719

(to cancel/change appt.)

www.gov.uk/contact-jobcentre-plus

They also employ Disability Employment Advisors (DEA).

www.gov.uk/looking-for-work-if-youre-disabled

Jobs and Benefits Office (NI)

Supporting people, of working age from welfare into work, and helping employers to fill their vacancies in Northern Ireland.

0300 200 7822

To find your local office visit

www.nidirect.gov.uk/contacts/jobs-benefits-offices

NI Direct

A Northern Ireland government website managed by the Executive Information Service.

www.nidirect.gov.uk

NHS Health at Work

Provides a gateway to advice and support on occupational health to businesses.

www.nhshealthatwork.co.uk

Remploy

Offers recruitment and retention services designed to support employers to recruit and retain employees who may be facing difficulties at work due to a disability.

www.remploy.co.uk

Royal College of Occupational Therapists

Provides online information about private OT services and can help find local occupational therapists specialising in employment.

020 7357 6480

www.rcot.org.uk

To find a private OT

www.cotss-ip.org.uk to find a private OT enter postcode/town and select “Work/Vocational Support”

Trade Unions Council (TUC)

TUC bring together 48 member unions.

www.tuc.org.uk

UK Rehabilitation Council

Consists of a community of rehabilitation associations to ensure access to high quality services in the UK.

rehabcouncil.org.uk

Access to Work Contact Centre

England, Scotland and Wales:

For more information or to apply online visit: www.gov.uk/access-to-work

Helpline : 0800 121 7479

Textphone: 0800 121 7579

Monday – Friday, 8am – 7.30pm

Northern Ireland:

If you want more information or wish to apply for help through this programme, contact 'Preparation for Work Programmes Branch'.

Tel: 028 9072 6756

Visit www.nibusinessinfo.co.uk/content/disability-employment-service

Or you can contact the Work Coach in your local Jobs and Benefits office.

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 to 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
- **Rare Disease UK** www.raredisease.org.uk
- **EURORDIS** www.eurordis.org
- **Behçet's Forum** behcets.org.uk/behcets-forum-meetings
- **International Society for Behçet's Disease** www.behcetdiseasesociety.org
- **RAIRDA** rairda.org

For more information please visit our website

behcetsuk.org

Email: info@behcetsuk.org

Telephone: 0345 130 7328

For all general enquiries

Helpline: 0345 130 7329

Our helpline is run by volunteers who can provide general support and guidance about the condition. They are unable to provide medical advice and do not deal with emergencies.

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