

The logo for Behçet's UK features a stylized red flower icon on the left, composed of several overlapping petals. To the right of the icon, the word "Behçet's" is written in a large, bold, blue sans-serif font. Below "Behçet's", the letters "UK" are written in a smaller, bold, red sans-serif font.

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



“I want to work”

A self-help guide for people with Behçet's

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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



“ I enjoy the routine of being at work, and not feeling like I'm defined by my Behçet's ”

Foreword

Professor Robert Moots

Chair of Behçet's UK Medical Advisory Panel

If you have Behçet's and you want help to remain in work or to return to work, then this booklet is for you. In it you'll find advice and information, to make sure you can find the help you need to stay in your job. If you're worried about your career following a recent diagnosis of Behçet's, you can find more information about what kind of support you are entitled to.

For people with rare diseases in employment, the picture is often one of slowed career progression, changes in employment to accommodate their condition and uncertainty about the future, as they face the possible loss of income and pension contributions. It is also clear that 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 many of the barriers people experience in the workplace are not impossible to overcome. Several



factors are important in helping people to remain at work. These include: awareness and understanding from employers; help with travel arrangements; help with specific adaptations or equipment.

As a rare disease, Behçet's is a poorly understood condition. Treatments have improved a great deal. Today people who are diagnosed with Behçet's have far more effective treatments than they did in the past and with understanding and support from employers and healthcare teams, it is possible for most people with Behçet's to remain in work for as long as they wish.

This booklet also discusses the options of re-training or moving to different types of job within an organisation. These can be worth thinking through if you're feeling that you may have difficulties continuing in your current role, due to physical limitations for example.

How can Behçet's affect my work?

The effects of Behçet's are different for everyone; some people are more severely affected than others. You may find it more difficult to cope with work at some times than at others, because of your changing symptoms.

The most common symptoms that can affect whether you can continue to do your job normally are:

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

How you manage your symptoms can depend on the type of work you do and it also depends on having good medication to control your Behçet's, effective pain control and the right support from your consultant and/or GP. Some people with well controlled Behçet's can continue working normally with very few problems, but many people face some challenges in the workplace at some point.

The most serious problems people with Behçet's face in the workplace are:

- taking time off when they are having a flare or unwell
- getting to and from work
- a lack of understanding from their employer
- employers' reluctance to make adjustments
- a lack of understanding from their colleagues

The good news is that many of the problems can be overcome. With the right support many people find that problems in the workplace can be successfully managed so that they can remain in their job. Some manual jobs may be more difficult to manage, particularly if they require heavy physical work.

It may be necessary to consider other options, such as changing your duties, having additional training or seeking an alternative type of work.



Tip: take time to make decisions

Remember: it can be difficult in the early days, when you are experiencing flares and symptoms, you may not have a definite diagnosis and you've not yet started on treatment.

It can take some time (several weeks or even months) for treatment with disease modifying drugs to take effect. However, once your treatment takes effect and your disease is better controlled, you should notice an improvement. So don't rush to make decisions about the future during that early period.

What are the benefits of working?

Staying in work is likely to be one of the most important goals for you and your family. For many patients with Behçet's, treatments can suppress the activity of the condition so that you feel well, you have energy and you can continue to work.

Work isn't only about the money. Of course it is better financially if you can

stay in work, but there are other important benefits of working. Research has shown that people with long-term conditions who are able to work are more likely to have:

- better self-esteem – leading to less depression
- less pain
- less isolation, because of their social interaction with colleagues or workmates.



“I love my work and would be lost without it. It boosts my self-worth and self-confidence to know I'm making a valuable contribution and it pays the bills! It's also my favourite form of distraction therapy for pain management. Being totally engrossed in my work means I'm not paying that much attention to painful joints or ulcers and means I cope better.”

Whom should I tell and when?

There is no 'one size fits all' answer: you will need to make a judgement about the best time to tell your employer. Your decision will of course be influenced by the type of work you do and whether, or how much, your Behçet's affects your ability to do the job.

If you're currently employed

It is particularly important to consider telling your employer if you think you may need some help to continue to do your job to a reasonable standard, now or in the future. This may help avoid the possibility of your employer treating any future problems with your work as a disciplinary issue. You are protected against unlawful discrimination on the grounds of disability from the first day of your employment, as long as your employer knows or can be reasonably expected to know about your condition. There is no qualifying period for discrimination, unlike other employment rights (for example, the right not to be unfairly dismissed where there is a two year service requirement). So it is generally good practice not to delay telling your employer.

Large employers normally have their own human resources (HR)

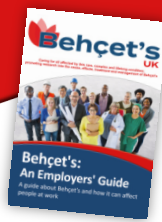
department and many have access to an occupational health practitioner. They may ask you to have an assessment so that they can fully understand your ability to do your work and provide appropriate support. It is important that the HR department works with your line manager so that he/she knows about the process – and ideally is supportive of it – or you may find there is a difference between corporate promises and the 'real world' of the business day to day.

Smaller companies often do not have a professional HR person or use occupational health resources, and may not be familiar with working with employees with a disability. However, such companies are perhaps more likely to treat you as an individual. It is important to tell them what you can do now and explain how your Behçet's may impact on your role.

It may be a good idea to give your manager a copy of the Behçet's Employer's Guide so that they better understand the impact of Behçet's on the individual and the employer's legal responsibilities.

You may wish to tell colleagues about your Behçet's. Again this is a decision only you can make, but it may be in your interests. If you've had adjustments made to your job, telling colleagues can help them to

Behçet's UK has published a guide for employers, with information about Behçet's and how they can support employees who have Behçet's.



understand your abilities and have an appreciation of what living with Behçet's is like, including the impact of pain. However, you can ask your employer to keep the information confidential, if you prefer.

If you're applying for a job

As a general rule, you should be upfront with a prospective employer about the fact that you have Behçet's. However, it is not a requirement and some people choose to wait and see how the recruitment process goes before deciding whether to tell them or not. Many organisations have previously used health screening processes as part of their recruitment process, but, as part of the Equality Act, employers should, generally, not ask candidates to complete any health questionnaire, or attend a medical, until they have made a formal job offer.

Employers may still ask candidates if they have any disabilities that would require reasonable adjustments being made to the recruitment process. Employers may also ask specific questions to establish whether or not an applicant will be able to carry out an "intrinsic" (or absolutely fundamental) function of the work; however, such questions should be

clearly relevant to candidates. If, after a job offer has been made, you are asked specifically about your health, you must of course answer truthfully, and discussions at this point in the process should include reasonable adjustments that may be made to enable you to do the role. If you voluntarily disclose information about your health or disability before the employer has made any job offer, the employer should still not get involved in a conversation with you that is outside the exceptions set out above.

If your Behçet's means that you will need reasonable adjustments to enable you to do the job you have applied for, you should discuss this with the employer before you start work. This is particularly important if there are health and safety considerations. (This could range from your Behçet's affecting your ability to leave a building easily in case of fire, to doors with knobs which are difficult to turn.) In practice it is very rare for employers not to be able to make adjustments to comply with health and safety legislation and only rarely should this be a barrier to you continuing in your job. For more details on available funding see pages 16-17.

What can I do to cope better at work?

Everyone copes with the effects of their Behçet's in different ways. It's worth thinking about how to make full use of help available. There are some practical things you can do yourself and there is help available in the workplace.

Practical tips

- It helps to be proactive. Find out as much as you can about Behçet's and how it affects you. The more you understand your condition, the more you will feel in control about the decisions you take.
- Give a copy of the Behçet's UK Employers Handbook and Behçet's medical factsheets to your employer and ask them to read them.

- Remember your consultant and/or GP are there to provide support. If your condition changes or you feel it is not well controlled, ask for help quickly.
- An occupational therapist/physiotherapist usually takes the lead on workplace issues. They can help with: joint care; ergonomic advice (that is, advice on the interaction between people and environment); advice on gadgets. They can also carry out workplace assessments. For more details of how they can help, see page 15.
- If your company has its own occupational health adviser you may prefer to approach them first. Their role is to support the health of employees at work.

Speaking from experience...

"I manage my Behçet's better by managing my stress levels"

"I communicate with my colleagues about how I am really feeling and whether I need help with anything"

"The most important thing is to pace yourself and not feel pressured to get something done"

"If you need to, take a small break whenever you can"

"Be upfront with any problems without going over the top, and let people help. It's all too easy to say 'I can manage', especially at first"

"If you work at a desk, get away whenever you can, particularly at lunch time – go for a walk"

Self management

Two of the main challenges to remaining in work are pain and fatigue. Learning how to cope with these is one of the best investments of your time you can make.

There are effective self-management strategies that you can learn and use, including joint protection, pacing, sleep management, exercise, relaxation and stress management. If you can learn these early and use them sufficiently in your daily life, you will see the benefit. Research shows that these strategies help to prevent or slow down problems in the future, if people change their habits and use them enough. This means you can

stay in work for longer

The NHS promotes support self-management through peer support and self-management education.

Speak to your GP/consultant or visit your local NHS healthcare trust website to see if they run self-management programmes in your area.

In Northern Ireland you may be eligible for the Condition Management Programme to help you manage your health condition and stay in employment. Visit www.nidirect.gov.uk to find out more.



Visit behcetsuk.org/support for more information on peer support and self-management.



“ Exercise definitely helps me manage my fatigue, but it’s also important to find time to relax. ”

Am I protected from discrimination?

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

Both the Equality Act and Disability Discrimination Act protect disabled people against discrimination when applying for employment, during employment and when their employment is terminated, and impose a duty on employers to make reasonable adjustments.

Many people with Behçet’s and other long-term conditions do not think of themselves as disabled. However, you have protection under the Equality Act or Disability Discrimination Act if you can demonstrate that you are disabled according to the definition – a person who has 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.

In the context of people who have been diagnosed with Behçet’s, this test can be broken down into four elements as follows:

Does the individual have a physical or mental impairment?

Behçet’s can fall within the definition

of both a physical and a mental impairment and, therefore, it could satisfy this element of the test.

Does that impairment have an adverse effect on the individual’s ability to carry out day to day activities?

Day to day activities are those which are carried out by most people on a fairly regular or frequent basis - for example, walking, carrying normal objects, reading and taking part in normal social interaction. They can also encompass activities relevant to working life. Depending on the aggressiveness of the condition, most people with Behçet’s are likely to be able to satisfy this definition.

Is that effect substantial?

This is the more difficult element of the definition to satisfy and will require an analysis of what the individual cannot do or can only do with difficulty as a result of the condition. Importantly, the effect is considered ignoring the effects of any medication or treatment. Where a person suffers from Behçet’s as a progressive condition (one which is likely to change and develop over time), they will be able to satisfy this definition if they can show that although the effect that the Behçet’s has on their ability to carry out day to

day tasks at the moment is not substantial, this effect is likely to become substantial in the future.

Is that effect long-term?

Long-term is defined as having lasted at least 12 months, or being likely to last 12 months or for the rest of the affected person's life. As Behçet's is a life-long condition, people with Behçet's are likely to be able to satisfy this element of the definition.

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 the Equality & Human Rights Commission (EHRC) www.equalityhumanrights.com or the Equality Commission for Northern Ireland (ECNI) www.equalityni.org for more information. In particular, your employer must not treat you less favourably because you 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 not to 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 you need to take leave because of your Behçet's, it is

good practice for your employer to distinguish between such 'disability leave' and general sick leave. Your 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, you 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).

It is also discrimination if an employer does not make a 'reasonable adjustment' where a disabled worker would be at a substantial disadvantage compared with their non-disabled colleagues. This is covered in more detail in the following section.

'Reasonable adjustments'

If you meet the Equality Act's (or Disability Discrimination Act in Northern Ireland) definition of disabled you can discuss with your employer how reasonable adjustments can be made to your job, equipment or workplace to help you, including the provision of auxiliary aids. The purpose of making reasonable adjustments is to overcome any substantial disadvantage caused by a person's disability and thus enable them to continue working, or return to work if currently on long-term sick absence. An employer's obligation to make reasonable adjustments is an

ongoing one, so it should be reviewed if your condition changes.

Possible reasonable adjustments in the context of people suffering from Behçet's could include:

- making adjustments to premises - e.g., easier door opening
- allowing the individual to be absent during working hours for assessment or treatment
- acquiring or modifying equipment
- modifying the work area
- allocating some of the disabled person's duties to another person
- altering hours of work or training
- assigning to a different place of work or transferring to fulfil an existing vacancy

For more details about adjustments see 'What kind of changes can be made at work?' on page 14.

What is considered 'reasonable'? The

EHRC and ECNI both publish their own Code of Practice which list some of the factors that may be taken into account when deciding what is a reasonable step for an employer to have to take. The factors are:

- whether or not taking a particular step would be effective in preventing the substantial disadvantage
- the practicality of this step
- the financial and other costs of making the adjustment and the extent of any disruption caused to the employer's financial and other resources
- the availability of financial or other assistance to help the employer make an adjustment; and
- the type and size of the organisation.

“ I have recently had a change to my working pattern by working half of the day doing the physical side of the job and the other half doing desk-based duties which really helps me manage my fatigue. This was all made easier to implement with the help of an amazing occupational health doctor who really went the extra mile to ensure I wasn't running before I could walk! ”



For example, 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. However, if a building has awkward stairs, it may not be physically possible to install a stair lift without extensive additional building work, which might then be considered unreasonable.

Some larger companies with a large workforce may be able to afford to allocate another employee to provide assistance as necessary, whereas a small company with only a few employees may not be financially able to do so. For more information about financial help, see pages 16-17.

As a matter of good practice, it is advisable for employers to consult with employees regarding the steps taken to ascertain which adjustments

should be made and to agree any proposed adjustments. This is likely to include seeking advice from the individual's GP and/or an occupational health adviser; be proactive and seek a letter of support from your therapist.

It is also good practice for both the employer and employee to keep a written record of all agreed reasonable adjustments.

If you cannot reach an agreement on reasonable adjustments and you feel that your employer is being unreasonable, you should raise the matter as a formal grievance. If this does not improve matters you should get some further advice before taking any further action. Your local Citizens Advice Bureau or ACAS (see page 21 for address) should be able to give you advice.



“ Don't let Behçet's stop you going for anything; always give anything you are able to a try. Also be honest with your employer about your condition from the start. Others around you may not always understand as it is an invisible illness, but you can tell those you trust and know well what you feel able to share; they are often very understanding. ”

When should I get help with my job?

It's best to seek help at an early stage. Many people put off getting help about work until there is a crisis or they are forced to take more sick leave. Once people go on extended sick leave, they are more likely to lose their job within a few years.

Making changes to how you do your job sooner rather than later may keep you in work for longer. It may well also be cheaper as your employer can put changes in place before the problem becomes more costly.

Where do I start? Who can help?

- Occupational therapists specialise in enabling people with illness or disabilities to perform work, leisure, daily activities and social roles more easily. They can provide both physical and psychological interventions (e.g., stress management) and information. They can also help with balancing lifestyles and assess the impact of your Behçet's across all aspects of your daily life, to help reduce pain and fatigue in non-work activities too. This helps you to get a good work/life balance and therefore helps you to continue working.

- Occupational health physiotherapists also specialise in work problems.
- Occupational health nurses specialise in work-related health issues.

Any of these professionals can provide workplace advice and/or job analysis and assessments. Assessments can be carried out by visiting you at work or by a structured interview.

If the therapist can visit you at your workplace, they can see your physical environment and what you do. They can evaluate job tasks and advise how you might simplify or modify them to reduce the effort needed. They may suggest: changes or adaptations to equipment; 'assistive technology' (meaning gadgets to help you in using equipment); other devices; changes to your work environment; and changes in how you perform the job. The therapist can analyse how fast you do things, your movements, the positions you're in, and the order of your tasks. Based on this, they can recommend changes to these to make your work easier.

Therapists can also: discuss issues with colleagues and employers sensitively; advise you on how to negotiate with employers about adjustments; help

you to think through how you liaise with others at work; and provide advice to help them appreciate your difficulties.

If you do not want or need a workplace visit, the therapist can use a structured interview assessment to help identify the problems you have or may have in doing your job. These

might be, for example, problems with: transport; access within the workplace; a specific ability or task you need to do the job; your physical and social working conditions. They can help you to prioritise these, come up with acceptable solutions and draw up action plans to make the changes you need.

What kind of changes can be made at work?

Therapists may suggest

Ways to help relieve pain at work, including:

- exercise programmes to relieve pain between tasks
- use of heat or ice packs in the workplace to reduce pain and inflammation
- regular taking of analgesia – including as a preventative measure

Changes to equipment, including:

- adapted computer equipment, such as larger screen, ergonomic keyboards, ergonomic mouse and voice-activated software
- better ergonomic seating and footrest
- better positioning of office equipment and furniture to reduce strain

Changes to the physical environment, including:

- lighting, ramps, rails, changes to door handles, automatic opening doors
- stairlifts to improve access, parking space nearby, change in working location to reduce distance walked or to avoid stairs

Training in new skills, including:

- how to keep the correct posture by using different movement patterns
- how to conserve energy by pacing yourself, so that you reduce pain and fatigue and increase your endurance
- training in communication skills, to help you negotiate support from your colleagues and employer

Alterations to your hours, including:

- reduced hours, more flexible hours
- working from home for part of the time
- a temporary restriction from shift or night work

How do I find an occupational therapist?

Your local rheumatology department may have an occupational therapist (OT) in the team or in a separate unit in the hospital. You can ask to be referred to an OT.

Some NHS therapy services have occupational therapists and physiotherapists who specialise in work assessment. You can ask your GP to refer you to a local occupational therapy or physiotherapy department to find out if they have this kind of service or can refer you on to another department elsewhere.

If these services are not available locally, the following are organisations of specialist practitioners:

- The Royal College of Occupational Therapists www.rcot.co.uk has specialist sections for OTs

specialising in Work, Rheumatology, and Independent practice. They can provide work (vocational) assessment and rehabilitation. A list of independent practitioners can be obtained from rcotss-ip.org.uk.

- The Chartered Society of Physiotherapists www.csp.org.uk. Use the Physio2U section to find a private physiotherapist.
- The Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) www.acpohe.org.uk. The website has a directory of private practitioners in their Physio Near You section.
- Vocational rehabilitation (VR) practitioner vrasociationuk.com.
- Access to Work adviser.

“ They did a workplace assessment. I had a new, bigger screen that is better for my vision and an ergonomic chair that is more appropriate for my joint issues. They changed the absence management process to allow me more sick leave. ”



What occupational therapy can offer

Nicola Briggs, NHS occupational therapist.

“Very rarely do we have to recommend to anyone that they stop their paid or voluntary work. The team here is aware of what work means to people – not just the financial aspect but the social side, the daily routine and the confidence or sense of achievement work may give.

Some individuals are referred here because they’re already having difficulties with their work, and didn’t know someone could help. For other people, we identify potential difficulties because we’re already working with them. Problems can come up with the layout of someone’s desk or workstation, fatigue, handling small or heavy tools, or completing specific tasks.

Discussions or assessment may take place within the workplace. We offer advice, specific to each person, about their job and any potential difficulties. There are some things that people can implement themselves, while other recommendations may need input from the occupational health team, the human resources department or managers at work. We can liaise with all of these if people want. We can also liaise with the local Access to Work team who may be able to provide funding for equipment.

There are different options people can consider, including planning and pacing their day, adapting job tasks and altering the hours they work – either in total or their starting time. If people want to change their job but are unsure how or which job to do, we can refer them to a Disability Employment Adviser, who can help match their skills and needs to a type of job.

It’s important to us to help people stay in their jobs – because it’s so important to them.”

Access to Work Scheme

In England, Scotland and Wales the Access to Work scheme (AtW) provides practical support to disabled people, people with long-term health conditions and their employers, to help overcome work-related obstacles resulting from a

disability or health condition.

There is a similar Access to Work scheme in Northern Ireland. Visit www.nidirect.gov.uk for more information. You can apply through the Department for Communities or speak to a work coach in your local Jobs and Benefits office.

An AtW adviser can give advice on what is available. 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 you need.

Support and financial help is available for:

- communicator support at interview
- 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.

Access to Work can pay up to 100% of the approved costs if you have a paid job (or are about to start or return to one). A paid job can be full or part-time and can include:

- employment
- self-employment
- an apprenticeship
- a work trial or work experience
- an internship

If you have been employed for more than six weeks your employer might need to contribute towards the cost of things paid for by Access to Work.

If you’re a civil servant your employer will provide support instead of Access to Work.

Access to Work will not pay for

reasonable adjustments. These are the changes your employer must legally make to support you to do your job.

Access to Work funding is available for up to three years. At the end of this period your needs will be reviewed to assess if continued or further funding is required. As long as you need the funding, you should continue to get it.

Information on how to contact and apply for Access to Work can be found on page 25.

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 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 rcotss-ip.org.uk

For physiotherapists: Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) at www.acpohe.org.uk. Their professional body is the Chartered Society of Physiotherapists, www.csp.org.uk

Society of Occupational Medicine (SOM) , which merged with COPHA in January 2024, manages a directory of OH providers www.som.org.uk

The Chartered Institute of Ergonomics and Human Factors also lists some therapists and other ergonomics professionals at www.ergonomics.org.uk

Some consultancies specialise in problems of workers with disabilities, and others provide general ergonomic workplace advice for preventing injuries-in-the-workplace injury. 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 (CMSUK) adhere to the Society's code of practice and standards. To find a practitioner and identify the company they work for search www.cmsuk.org, and select Member Check from the menu to find a case manager.

A Vocational rehabilitation (VR) practitioner is a therapist or other professional who has completed a certified / accredited VR training

course vrassociationuk.com.

The UK Rehabilitation Council's guides "Rehabilitation Standards" and "Choosing a Rehabilitation Provider" (2009) may help you identify good quality private providers www.rehabcouncil.org.uk.

National charity AbilityNet provides advice on computing and disability. They help people with a wide range of disabling or limiting conditions to continue using computers. They provide an advice and information service and individual assessments to help people find the right solution. For more information call 0300 180 0028 or visit www.abilitynet.org.uk

Driving Mobility provides specialist advice and assessments for driving and for car adaptations. For more information and to find your nearest centre, visit www.drivingmobility.org.uk

Workable (NI) in Northern Ireland www.nidirect.gov.uk offers a range of long-term support to help people with disabilities who have barriers to employment to stay in work, including:

- one to one help from a job coach to help the employee and their colleagues adapt to the needs of the job
- extra training for the employer
- disability awareness training for the employer and work colleagues.

Am I entitled to time off for medical appointments?

The Equality Act and the Disability Discrimination Act obliges employers to make reasonable adjustments, one example of which is to allow a person 'to be absent during working or training hours for rehabilitation, assessment or treatment'.

There is no automatic right to be paid for time attending such appointments, though again many organisations do pay it.

If you take sick leave because of your Behçet's, it is good practice for your employer to discount some or all of these absences when considering any disciplinary issues, performance measures or selection criteria for promotion or redundancy. However, you 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 do so).

“ I've declared my illness at work which means doctor's notes that link the absence to Behçet's are considered differently than if I was off for random illnesses. I still have to go through the same occupational health processes as everyone else when I've been off a certain number of days, but over the years I've built up a relationship with them and it's more about whether they can help me manage or make any further reasonable adjustments. ”



Should I consider a different type of work?

Some jobs can be particularly difficult to cope with when you have Behçet's, such as jobs that involve heavy manual work.

Before you make any decision about stopping work, talk to your medical team to find out if they think your disease is adequately controlled. If they feel it is, this can help you to think about the next steps. You might

want to discuss the possibility of retraining or transferring to another job within the company - if this is a possibility.

You can consider asking for help from your employer, employer's Occupational Health Service, HR team, or a work coach at Jobcentre Plus or Jobs and Benefits Office (NI). See information starting on page 19.



“ I was offered a three-month trial for another job, very different from what I was used to. My employers gave me full support for this change of direction by opening up training opportunities, mentoring and career coaching. They also offered me designated parking and upgraded existing equipment and minor physical features of the building.

My request to work variable hours, including avoiding rush hour travel and splitting my rest and lunch break really helped me by reducing fatigue.

Believe in yourself! Adjustments allow you to integrate, and put the emphasis on what you can do not what you can't. ”

What can I do if my employer treats me unfairly?

If you feel you are being treated unfairly because of your Behçet's you should first discuss this informally with your manager. If necessary you can then register your grievance by following the company's grievance procedure. If you belong to a trade union your representative can support and advise you. If the grievance procedure does not lead to an acceptable solution, as a last resort you may have the option to take a case of discrimination through an employment tribunal. You may wish to contact the Equality Advisory and Support Service (EASS) or ACAS for advice.

Before you consider putting in a tribunal claim you could consider using a disability discrimination questionnaire. This is a procedure under the Equality Act that you can use to collect evidence about the way you have been treated, to look at the strengths and weaknesses of your claim and to decide whether it is worth pursuing. You complete the first part of this questionnaire

yourself and set out the reasons why you feel you have been discriminated against. You then ask your employer to reply. Your employer's answers – whether or not you agree with them – should help you to decide whether you can settle the dispute or need to make a complaint to an employment tribunal.

Useful organisations

- ACAS www.acas.org.uk
- Citizens Advice Bureau (CAB) www.citizensadvice.org.uk
- Equality Advisory and Support Service (EASS) www.equalityadvisoryservice.com
- The Equality and Human Rights Commission (EHRC) publishes excellent resources for finding out about your employment rights. www.equalityhumanrights.com
- The Equality Commission for Northern Ireland offers advice and assistance to people who think they have been unfairly treated at work. www.equalityni.org
- Specialist legal advice can help you to find a speedy and satisfactory resolution to your concerns and help to avoid tribunal proceedings. See support and resources on pages 25-28.

I would like to return to work

If you have taken time out from work and you would like to return, the work coach at your local Jobcentre Plus or Jobs and Benefits office (NI) can help you with retraining, seeking appropriate work and practical support to get back into work.

They can give you details of suitable vacancies and explain more about the range of programmes available to help you. You may need to consider whether part-time work might be more suitable and could consider looking for a job share or flexible hours.

The type of help you can get through your work coach depends on what you need but can include:

- employment assessment to help you find out how your disability or health condition affects the type of work or training you want to do
- help and advice on looking for a job
- advice and information about training
- information on return to work programmes that you may be eligible for.

Support programmes

In England and Wales your Job Centre Plus work coach may recommend the

Work and Health Programme, a voluntary programme. It will give you personal support to help you identify your employment needs, match your skills to work that's available, get training, find long-term employment, and manage health problems to reduce their impact on work.

Intensive Personalised Employment Support (IPES) is another voluntary programme in England and Wales to support people with disabilities and complex barriers into work. Participants on IPES receive a minimum of 15 months of intensive support to achieve and sustain employment, followed by up to 6 months of in-work support and a further 6 months of transitional support.

Fair Start Scotland is a flexible employment support service to help you get ready for work and achieve your potential.

www.startscotland.scot

Workable (NI) and the **Condition Management Programme** and are available to help you find and stay in employment.

www.nidirect.gov.uk

Disability Confident

When you start looking for work, keep an eye out for Disability Confident symbol. This is a



government scheme designed to encourage employers to recruit and retain disabled people and those with health conditions.

Disability Confident organisations can use the symbol on their websites and job adverts and have committed to offering an interview to a fair number of disabled people who meet the minimum criteria for a job. This does not mean that all disabled people are entitled to an interview. If you want to get an interview under Disability Confident, you will need to say that you are disabled in your job application.

Other sources of help and advice

- Your occupational therapist
- Your Behçet's Support Coordinator - if you are registered with one of the Behçet's Centres of Excellence behcetpatients.org.uk

- Scope, a disability equality charity, provide comprehensive work and careers advice for disabled people. Including links to specialist job sites for disabled people and sites which offer flexible and part-time vacancies www.scope.org.uk
- Evenbreak provide a career hub which offers support for disabled candidates looking for new or better work hive.evenbreak.co.uk
- Ask at your local Citizens Advice Bureau, Jobcentre Plus or Job and Benefits Office (NI) to see if there are any local programmes, schemes or charities
- If you are on long-term sick leave meet with your manager, HR or occupational health nurse to discuss your return to work.

“Doing a job you like and that motivates you is my key as it can be difficult getting up and turning into work each day when you're battling various symptoms, and I'm not sure how I'd do that if I was bored or unhappy at work and if my only reason to go was the payslip!”



Can I apply for state benefits while I am working?

If you are working you may be able to top up your income with Universal Credit. If you are out of work or working part-time and are looking for work you may be able to claim Jobseeker's Allowance. If you are getting a benefit because you are considered to be incapable of work, such as Employment Support Allowance, you may still be able to do some limited 'permitted work'.

Whether you are in or out of work, you may be able to claim Personal Independence Payment (PIP) in England, Wales and Northern Ireland and Adult Disability Payment (ADP) in Scotland to cover the extra costs that result from your condition. PIP/ADP have replaced Disability Living Allowance for most people. If you are old enough to claim the state pension, then Attendance Allowance may be claimed instead. If you have a carer, they may be able to claim Carer's Allowance.

About PIP and ADP

Personal Independence Payment (PIP) in England, Wales and Northern Ireland or Adult Disability Payment (ADP) in Scotland is an important

benefit for people with Behçet's. It is not paid simply because you have Behçet's but because of the effect that the symptoms have on your daily life and mobility.

PIP/ADP are non-means tested benefits which means that you can still claim if you are working. Payments are not affected by any earnings or savings that you may have, nor treated as income for other benefits which are means tested such as Employment and Support Allowance, Housing Benefit and tax credits.

You can claim PIP/ADP if you meet certain basic qualifying conditions and the disability conditions. You can complete a free online PIP test (which can also be used for ADP) to gauge if you are likely to qualify, at www.benefitsandwork.co.uk.

To be entitled to PIP/ADP you must be aged between 16 (18 in Scotland) and state pension age. If you are state pension age you may be able claim Attendance Allowance.

Other benefits

Speak to the Jobcentre Plus, Jobs and Benefits Office (NI) or Citizens Advice Bureau (CAB), or use the www.turn2us.org.uk free online benefits calculator to see what other benefits you may be entitled to.

Support and resources

AbilityNet

National charity and provider of advice on computing and disability.

0300 180 0028 (Helpline)

abilitynet.org.uk

Able Futures

Supports people in England, Scotland and Wales who are working and living with mental health difficulties.

0800 321 3137

able-futures.co.uk

ACAS

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

0300 123 1100 (Helpline)

www.acas.org.uk

Access to Work - England, Scotland and Wales

For more information or to apply online

0800 121 7479 (Helpline)

www.gov.uk/access-to-work

Access to Work - Northern Ireland

For help through this programme contact your work coach in your local Jobs and Benefits office or contact the Department for Communities

www.nidirect.gov.uk

Advicelocal

Find independent advice organisations in your area who may be able to help answer questions you have in relation to benefits, employment and work issues

advicelocal.uk

Association of Chartered Physiotherapists in Occupational Health and Ergonomics

A proactive group, promoting best practice in the field of occupational health physiotherapy. Online search facility for local physiotherapists.

www.acpohe.org.uk

Behçet's Patient Support

Behçet's Support Coordinators provide detailed non-medical support for patients who attend one of the three NHS England Behçet's Centres of Excellence

behcetpatients.org.uk

Benefits and Work

Provides comprehensive guides on claiming and appealing benefits claims.

www.benefitsandwork.co.uk



Behçet's UK can share these guides with our members, so please contact us if you would like to read any of the guides.

Chartered Institute of Ergonomics and Human Factors

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

0330 135 9833

www.ergonomics.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)

Citizens Advice Bureau (CAB)

The Citizens Advice service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

Telephone your local CAB office

www.citizensadvice.org.uk

Civil Legal Aid

A government funded legal aid service available to those who qualify for legal aid. Can provide legal advice about discrimination issues at work.

0845 345 4345

www.gov.uk/civil-legal-advice

Commercial Occupational Health Providers Association

(COHPA) See Society of Occupational Medicine

Disability Action (NI)

Have a number of projects that help disabled people to find employment and support them in their place of work.

www.disabilityaction.org

Disability Law Service

Provides legal advice /representation to disabled people and has useful factsheet on employment rights.

0207 791 9800

www.dls.org.uk

Disability Rights UK

Aim to provide high quality information to those living with a disability, including factsheets on work and benefits and contact details for many other useful organisations.

www.disabilityrightsuk.org

Employment Tribunals

Judicial bodies established to resolve disputes between employers and employees over employment rights.

England/Wales: **0300 323 0196**

Scotland: **0300 790 6234**

www.judiciary.uk/courts-and-tribunals/tribunals/employment-tribunal

Northern Ireland: **028 9032 7666**

www.employmenttribunalsni.co.uk

Equality Advisory & Support Service (EASS)

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

0808 800 0082

www.equalityadvisoryservice.com

Equality and Human Rights Commission (EHRC)

The EHRC has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine “protected” grounds – including disability. Their website includes information pages on work and work issues.

www.equalityhumanrights.com

Equality Commission for Northern Ireland

Provides advice and assistance to people who think they have been unfairly treated at work.

028 90 500 600

www.equalityni.org

Evenbreak

A specialist job board that helps disabled candidates find work opportunities with employers who will value their skills.

Also providing a ‘hive’ for career support

hive.evenbreak.co.uk

Gov.uk

Information about government services.

www.gov.uk

Jobcentre Plus

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

0800 169 0190

www.gov.uk/contact-jobcentre-plus

Also visit www.gov.uk/looking-for-work-if-disabled

Jobs and Benefits Office (NI)

Supporting people, of working age from welfare into work in Northern Ireland.

0300 200 7822

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

Labour Relations Agency (NI)

Provides advice and support to employees and employers in Northern Ireland.

03300 555 300

lra.org.uk

Law Centres Network

Support a national network of Law Centres that work with some of the most vulnerable and disadvantaged people in society.

www.lawcentres.org.uk

NI Direct Government Services

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

www.nidirect.gov.uk

Royal College of Occupational Therapists

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

www.rcot.co.uk

rcotss-ip.org.uk click 'Find an Occupational Therapist', enter postcode/town, age group and select 'Work/Vocational Support'

Scope

Scope provides information and advice, including comprehensive work and careers signposting, to disabled people and to others on living with a disability.

01302 310 123

www.scope.org.uk/helpline

Society of Occupational Medicine

Provides assistance with finding a provider in your area

www.som.org.uk

Trade Unions Council (TUC)

Brings together 48 member unions.

www.tuc.org.uk

Turn2us

A national charity providing practical help to people who are struggling financially. Their free and confidential benefits calculator can help you find out what benefits you may be entitled to claim

www.turn2us.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

Vocational Rehabilitation Association

Search for a vocational rehabilitation practitioner in your area.

vrassociationuk.com

VoiceAbility (Scotland)

A free social security benefits advocacy service in Scotland if you are disabled.

0300 303 1660

www.voiceability.org/in-scotland/support-to-access-benefits-in-scotland

About Behçet's UK

Behçet's UK (formerly Behçet's Syndrome Society) was founded in 1983 by Judith Buckle.

We represent all Behçet's patients in the UK including those yet to be diagnosed. We provide information and support for people with Behçet's and for those who care for them.

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.

Behçet's UK services and member benefits

- Helpline is a 'friendly ear' offering general support and guidance for anyone affected by Behçet's.
- Local and online support group meetings for peer to peer support.
- Behçet's Medical Factsheets which are written by medical professionals who have an expertise in Behçet's.
- We publish a quarterly Newsletter to all our members to keep them up to date on what the Society is doing and on current research into Behçet's.
- Our website is kept updated with news and information and you can also reach our online forum hosted

on HealthUnlocked where you can discuss Behçet's related issues with other people.

- The Behçet's UK Annual Conference is an excellent opportunity to hear the latest on research and treatments from Behçet's specialists and if attending in person a chance to meet others with Behçet's.
- The Behçet's UK Friends & Family Day is always a day of laughs and happy faces for our members and their friends and families. It's a great chance to meet others affected by Behçet's while trying new activities and having fun.
- Medical Advisory Panel provide guidance on what approach to take with general medical queries.
- Personal Grant Aid Fund for members in financial hardship caused by Behçet's.
- The Patient Alert Card for Behçet's UK members is essential in emergencies to alert medical professionals to your condition and medication.

Join Behçet's UK today!

Scan the QR code or visit behçetsuk.org and click on join.



Call us on 0345 130 7328 to request a membership form by post.

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 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



Registered charity in England & Wales No. 326679

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Information contained within this booklet was originally provided by the National Rheumatoid Arthritis Society (NRAS) in March 2016 and all information contained within the two NRAS booklets "I want to work" and "When an employee has RA" was accurate at that time.

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