

I Want to Work

A self help guide for people with lupus



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LUPUS UK is the national charity caring for those with systemic lupus erythematosus (SLE) and discoid lupus erythematosus (DLE) supporting our members through the Regional Groups and advising others as they develop the symptoms prior to diagnosis.

You can help by taking up membership
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Reg. charity nos 1051610, SC039682

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.



LUPUS UK is certified under the requirements of the Information Standard.

Our thanks go to the National Rheumatoid Arthritis Society (NRAS) for allowing us to create this booklet by adapting their booklet 'I want to work - a self help guide for people with rheumatoid arthritis'. Thanks also go to those who kindly submitted their case studies for inclusion within this guide.



About this booklet

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

We hope that this booklet will be helpful for employees, health professionals and organisations who advocate for the rights of people with long term conditions.

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How can lupus affect my employment?

Lupus affects everyone differently, with some people more severely affected than others. Due to the fluctuating nature of lupus, the symptoms can vary day-to-day. This can make it difficult to maintain a consistent level of working.

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

- Fatigue and weakness
- Pain
- Problems with mobility or functioning as a result of inflammation in the joints/muscles.
- Sensitivity to strip lighting

How you manage your symptoms can depend on the type of work you do, how well you can pace yourself and it can also depend on having a good treatment plan and the right support from your healthcare professionals. Some people with mild or well controlled lupus can continue working normally with very few problems, but most people will probably face some challenges in the workplace at some point.

Some of the most serious problems you could face in the workplace are:

- Taking time off when having a flare or unwell
- Getting to and from work
- A lack of understanding from your employer
- Employer's reluctance in making adjustments
- A lack of understanding from your colleagues



The good news is that many of these problems can be overcome. With the right support from your employer and healthcare professionals you should find that problems in the workplace can be successfully managed so that you can remain in your job. Some manual jobs may be more difficult to manage, particularly if they require heavy physical work, standing or lifting. It may be necessary to consider other options, such as changing your duties, having additional training or seeking an alternative type of work. Sometimes you may need to consider adjusting your hours or responsibilities to ones that are more manageable.

Tip: take time to make decisions

Remember: it can be difficult in the early days, when you are experiencing symptoms, you may not have a definite diagnosis and you've not started on treatment. It can take some time for drugs such as DMARDs (which reduce the activity of the lupus by suppressing the immune system), such as hydroxychloroquine,

azathioprine, or methotrexate to take effect. However once your treatment takes effect and your condition is better controlled, you should notice an improvement.

"Since receiving a diagnosis of SLE and correct medication, things have improved. I have totally adjusted my life and developed coping mechanisms. I now work part time which allows me flexibility. I work as an assistant for a disabled lady and am very lucky to work in a job share role. We work as a team and have open friendly communication. Regular feedback sessions allow us to work through employment-related issues or concerns. Things are addressed in a positive way - finding solutions and trialling new ways of working."

Farzana (Assistant for a disabled lady)

What are the benefits of employment?

Staying in work is likely to be one of the most important goals for you and your family. Lupus is a condition that can be controlled for many by using appropriate medication to reduce the activity of the disease on the immune system. Many people with lupus can have work aspirations and continue in work as they wish with only minor adaptations.



Work isn't just about money. Of course it is better financially if you can stay in work, but there are other important benefits in working. Consultant Lupus Nurse, Sue Brown, says; 'Work is an important part of life and is known to improve health by increasing self-esteem and wellbeing. Returning to work after any illness can be a challenge, and is an essential part of rehabilitation and recovery. For those who can continue in work with lupus, there is a beneficial effect on all aspects of home and work life, including less depression and isolation.'

"Working provides me with a sense of purpose and structure each week. I did switch from a full time, stressful job to a part-time more straight forward job not long after diagnosis, which allows me more time and energy to participate in other things outside work too, but working distracts me from any on-going symptoms and gives me something else to focus on."

Lynne (Contract Administrator)

"For many years following diagnosis I was unable to work and I became extremely depressed. I have managed to achieve a lot in my career becoming a CEO of a charity and this has given me a great deal of purpose and motivation in my life. It

is not easy as I deal with daily symptoms (a new one every day) and the unpredictability of the disease which makes it hard to set up meetings. However I reckon work kept me going over the past 14 years and stopped me giving up. I know I can make a difference and therefore don't just feel defined by being ill. The downside is the daily paranoia about the understanding of others as I don't look ill."

Janine (Charity CEO)

Whom should I tell that I have lupus and when?

There is no 'one size fits all' answer: you will need to make a judgement call 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 lupus affects your ability to do the job. You may think of yourself as ill rather than disabled, but having a long-term fluctuating illness which adversely affects daily life may be regarded as a disability under the Equality Act 2010.

If you're currently employed

It is particularly important to consider telling your employer if you think you may need some help, now or in the future. This can avoid the possibility of your employer treating any future problems with your work as a disciplinary issue. You are legally protected against discrimination on the grounds of disability from the first day of your employment,



provided that you have told your employer about your condition¹. So there is no need to delay telling your employer until you have two year's service (the point at which most other employment protections apply).

It is therefore advisable that you disclose your illness to your employer. Under the Act it is unlawful for an employer to discriminate against a person with a disability. Failing to notify your employers of your illness could affect any future adjustments you may need within the work space to enable you to fulfil your role.

Some people can feel guilty about not being able to fulfil their role as well as they used to. This is a perfectly normal reaction, but it is also important to adapt. An employer's obligation to make reasonable adjustments (more details about this on page 11) is an on-going one, so it can be reviewed if your condition changes.

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 your line manager knows about the process - and ideally is supportive of it - or you may find there are differences 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. However, such companies are often more likely to treat you as an individual. It is still important to tell them what you can do now and explain how your lupus may impact on your role.



You may wish to tell colleagues about your lupus. 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 understand your abilities and have an appreciation of what living with lupus is like. However, you can ask your employer to keep the information confidential if you prefer.

As an employee you have a duty to disclose details of your lupus to your employer if it could cause health and safety problems e.g. If your lupus causes cognitive problems, there would be an issue if you couldn't concentrate and your safety or someone else's might be at risk as a result.

LUPUS UK has published a guide for employers, with information about lupus and how they can support employees who have lupus².

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 lupus. 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 used health screening processes as part of their recruitment process, however, as part of the recent changes in 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 adjustments being made during the recruitment process. Employers may also ask specific questions to establish whether or not an applicant will be able to carry out an “intrinsic” 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 the role. A new requirement for employers to make reasonable adjustments is for them to provide an auxiliary aid* in circumstances where a disabled person would, but for the provision of the auxiliary aid, be put at a substantial disadvantage in comparison with people who are not disabled.

If your lupus means that you will need adjustments to the job you are applying for, you should discuss this with the employer and in advance consider any reasonable adjustments or auxiliary aids you may require. This is particularly important if there are health and safety considerations. (This could range from your lupus affecting your ability to leave a building easily in case of fire, to door 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 for adjustments see page 16.

“I’ve found being honest with my line manager has been the best thing to do and this has then helped both my organisation and myself. In my experience, if you don’t ask you don’t get and this is so important with the invisible condition that is lupus, so if you need help ask! Colleagues and managers will surprise you!”

Jane Robinson

¹ Equality Act 2010 - more information available from the Government Equalities Office www.gov.uk/government/policies/equality - Public enquiries: 0207 211 6000

² When an employee has lupus - a guide for employers. Available free from LUPUS UK

*An auxiliary aid is considered to be a device/thing that can be used so that the disabled person is not put at a substantial disadvantage when compared with other workers eg the introduction of automatically opening doors, Type Talk software etc.

What can I do to cope better at work?

Everyone copes with the effects of their lupus in different ways. It's worth thinking about how to make full use of the 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 your lupus. The more you understand your condition, the more you will feel in control about the decisions you take.
- Give **information leaflets** about lupus to your employer and ask them to read them.
- Remember that your rheumatology team is there to provide support. If your condition changes or you feel it is not well controlled, **ask for help quickly**. Don't just put up with it – you may be able to change your treatment regimen to help keep your lupus reasonably controlled.
- A **physiotherapist** can help with pain management and simple exercises, such as stretching and keeping mobile at work.
- A **podiatrist** can help with problems with your feet or ankles. They can give advice and treatment to help reduce your pain. It can make all the difference at work to have comfortable feet.
- An **occupational therapist** usually takes the lead on workplace issues. They can help with: joint care; ergonomic advice (that is, advice on the interaction between people and equipment); advice on gadgets and splints. They can also carry out workplace assessments. For more details of how they can help, see page 13.
- 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.
- Sue Brown, Consultant Nurse in Rheumatology, suggests; 'Recognising how lupus affects your body is the first step to coping with an active working life. People tend to think that lupus stops you doing things but in reality it is the way that you approach your work that results in success. Responding to your body and knowing when it is time to stop is important and not doing so can lead to more time off sick from work. Even by just adjusting your levels of activity according to your symptoms that come and go, can help you remain independent. It is important to look at your own work life pattern and consider if that causes any increased symptoms. It may also be advised to keep in close contact with your health professional and assess medications to control/manage pain adequately. By developing the skills of pacing and planning and managing exercise and rest, a rewarding work experience is possible and is an important way of effectively improving your quality of life.'



Self-management

Two of the main challenges to staying 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 pacing, joint protection, 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. Hopefully these strategies will help to prevent or slow down problems in the future, meaning you can stay in work for longer.



Most lupus patients will be likely to find pacing one of the most useful strategies they can learn. Pacing is an energy management technique which allows you to successfully manage activity and rest by being more aware of your own limitations. Pacing involves:

- Taking short regular breaks throughout the day
- Acknowledging which activities use (physical, mental or emotional) energy
- Establishing a baseline for each activity
- Increasing the energy spent on an activity by no more than 10% until a new baseline is achieved.

Some NHS services can offer a treatment package that draws on the key elements of pacing, cognitive behavioural therapy (CBT) and graded exercise therapy (GET). Depending on where you live, your GP may be able to refer you to a structured NHS programme in your area.

Another programme that you might find helpful is provided by Self Management UK. Their FREE self-management courses provide tools and techniques to help you to take control of your health and manage your condition better on a daily basis. For details and to find a programme near you, visit www.selfmanagementuk.org.

Speaking from experience

LUPUS UK members give these personal tips:

'Try to get a job doing something you enjoy so it feels less like work.'

'My job involves some evening and weekend work, so I plan my diary and try to take time back when I know I will need it.'

'Contact Access to Work, who give you a very stress free assessment to see what help they can provide. They pay for me to have a classroom assistant for 7 hours a week, so it doesn't affect the school budget'

'Get as much sleep as possible. Early nights make all the difference!'

'Detach from old expectations. Delegate whatever you can. Reset priorities. Accept help. Be realistic. Rest as often as you can, even before you are tired.'

'I made sure everyone I work with is aware of my condition. If I'm having a bad day, I usually mention this when I get into work and they know that I need some support - they keep me motivated'

'It is important to pace yourself and not feel too pressured to finish tasks.'

'Take small breaks whenever you can.'

Am I covered by the Equality Act 2010?

The Equality Act (EA) 2010 replaced the Disability Discrimination Act 1995 with effect from 1st October 2010. The EA is a law that provides protection to disabled persons; it covers discrimination against both employees and applicants for employment. Disabled persons are, therefore, protected when applying for employment, during employment (including in relation to terms and conditions and benefits offered) and when their employment is terminated. The EA also imposes a duty on employers to make reasonable adjustments¹.

Many people with lupus and other long-term conditions do not think of themselves as disabled. You may prefer to think in terms of being disabled in your ability to do your job. You have protection under the Equality Act if you can demonstrate that you are disabled according to its definition - a person who has a *“physical or mental impairment which has a substantial and long-term effect on his/her ability to carry out normal day-to-day activities”*²

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

- **Does the individual have a physical or mental impairment?**

Lupus is almost always likely to fall within the definition of a physical impairment, whilst many lupus patients also experience brain involvement, which could also fall into the definition of a mental impairment. There is no exhaustive list of conditions which amount to impairments, however lupus is considered to fall within the definitions of progressive conditions.

- **Does the 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; carrying normal objects, reading and taking part in social interaction. They can also encompass activities relevant to working life (necessary for participation in professional life). Depending on the aggressiveness of the condition, most people with lupus 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 (rather than on what you can do). Even if you are able to carry out a number of normal day to day activities this does not mean that any impairment does not adversely and substantially affect

your ability to carry out other normal day to day activities. Importantly, whether an effect is considered substantial is done so ignoring the effects of any medication or treatment, it also takes into account such things as time taken to carry out an activity, the way in which it is carried out; environmental factors etc. Where a person has lupus 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 lupus has on their ability to carry out day-to-day tasks at the moment is not substantial, this effect could become substantial in the future if their condition develops.

- **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, or is likely to recur if it is in remission. As lupus is a long-term condition, people with lupus are likely to be able to satisfy this element of the definition.

Reasonable adjustments

If you meet the Equality Act's 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 considering reasonable adjustments by an employer is to allow a person with a disability to continue working, or return to work if currently on long-term sick absence.

Possible adjustments in the context of people suffering from lupus 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 draft Equality Act Code of Practice lists some of the factors that may be taken into account when deciding what a reasonable step for an employer to have to take is. The factors are:

- Whether or not taking a particular step would be effective in preventing the disadvantage
- The feasibility of this step
- The financial and other costs of making the adjustment 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; and
- The type and size of the organisation

For example, it would be reasonable to expect all employers to provide ramps, rails and simple ergonomic equipment for the computers and telephones or minor adaptations to the 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 page 16.

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 to any proposed adjustments. This is likely to include seeking advice from the individual's GP and/or an occupational health adviser.

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 25 for address) should be able to give you advice.

Protection against discrimination

The Equality Act states that you should not be discriminated against in any way because of your disability. This applies not only to your existing role, but to all aspects of employment, including recruitment processes, training opportunities, promotion and redundancy.

For example, if you need to take leave because of your lupus, it is good practice on the part of the employer to discount this in any calculations on performance

related pay or enhancements, or in counting total sickness absence when starting disciplinary procedures relating to sickness absence. Such absences would be regarded as disability leave (which falls within a reasonable adjustment), and not sick leave, although they may be included in your employer's calculations of your entitlement to sick pay.

¹ A practical guide to the law and best practice for employers, published by the Disability Rights Commission. Available from the Commission for Equality and Human Rights www.equalityhumanrights.com

² For full details on the EA definition of disability and the employment rights it protects, visit www.equalityhumanrights.com

When should I get help with my job? What kind of help is available?

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 help with balancing lifestyles. They can also assess the impact of your lupus across all aspects of your daily life, to help reduce pain and fatigue in non-work activities too. This can help you get a good work/leisure 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 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 such as splints; changes to your work environment; and changes in how you perform your 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 stretch your joints and relieve pain between tasks, e.g. hand exercises
- Splints to relieve pain in the wrists and increase the strength of your grip, changes to your footwear, including insoles in your shoes to reduce lower limb pain
- 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 ergonomic keyboards, an ergonomic mouse and voice-activated software
- better ergonomic seating
- better positioning of office equipment and furniture to reduce strain on joints
- equipment to help with driving to and from work, for example adapted controls, specialist car seats, blue badge

Changes to the physical environment, including:

- 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 and protect your joints 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 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 College of Occupational Therapists www.cot.org.uk has specialist sections for work OT practitioners and OT in Independent Practice (OTIP)

(www.cotss-ip.org.uk). They can provide work (vocational) assessment and rehabilitation. The website has a directory of private practitioners

- The Chartered Society of Physiotherapists www.csp.org.uk
- The Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) www.acpohe.org.uk The website has a directory of private practitioners.
- Access to Work adviser

What is a Disability Employment Adviser?

A Disability Employment Adviser (DEA) provides specialist support to people who are recently disabled or whose disability or health condition has deteriorated, and who need employment advice. DEAs can be found at your local Jobcentre Plus.

The DEA can also put you in touch with the **Access to Work** scheme (AtW) (this is called the Disablement Advisory Service in Northern Ireland). This scheme provides 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. 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:

- Special aids and equipment
- Travel fares to and from work if you can't use public transport because of a disability
- a support worker or job coach to help you in your workplace
- a support service if you have a mental health condition and you're absent from work or finding it difficult to work
- disability awareness training for your colleagues

If you make a claim during the first six weeks of starting a new job, AtW will pay 100% of all approved costs. It is therefore very important that if you need help in work, you contact AtW as soon as you can so that your employer does not have to share any costs. This time restriction does not apply if you are self-employed.

If you have been in your job for 6 weeks or more when you first apply for help, AtW will pay a proportion of the costs of support as follows:

- Employers with less than 50 staff – AtW can pay 100% of the approved costs.
- Employers with 50 to 249 staff – employer will have to pay the first £500 and AtW can then pay 80% of the approved costs up to £10,000.
- Large employers with 250 or more staff – employer will have to pay the first £1,000 and AtW can then pay 80% of the approved costs up to £10,000.
- Access to work would normally cover all additional costs over £10,000.

For a list of Access to Work regional centres, see page 28.

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, some of which specialise in musculoskeletal conditions.

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

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

Commercial Occupational Health Providers Association COHPA will assist and advise on suitability of different providers in your area - 0333 772 0401 or info@cohpa.co.uk

The 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 work place. You can look at the detailed information about their specialist services 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 using the search term 'vocational rehabilitation'.

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).

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 Freephone 0800 269545, or visit www.abilitynet.org.uk.

Forum of Mobility Centres provide specialist advice and assessments for driving and for car adaptations. For more information and to find your nearest centre, Freephone 0800 559 3636 or visit www.mobility-centres.org.uk.

"I spoke to my line manager at work, my Head of Department and then Occupational Health. The difference these conversations made to my ability to manage my condition has been outstanding.

I originally worked in a classic open plan office with windows all round, skylights, fluorescent lighting and air conditioning. The car park is a large open air space; though not a great distance from the office entrance it can be difficult to park nearby.

After I explained the problems these elements cause lupus sufferers, my line manager and Head of Department arranged for me to move into a small corner

office with blinds and an option of none or reduced lighting, with no air conditioning. The site security and local SHE (Safety Health & Environment) manager provided a reserved car parking space adjacent to my new corner office, in the shade of trees and bushes.

It is amazing what these relatively simple measures have meant for me. I can reach the office in the shade and it is a short distance to walk, vital on the days when my joint pains are worse and it also limits my exposure to lights and reduces lupus flares.

Other assistance that BAE Systems has provided includes supplying me with a new lightweight laptop, allowing me to work at home when necessary, and giving me the flexibility to go home and rest if I get a flare up while at work. Through a recent risk assessment, the company has also suggested that I try a new footstool and a joystick mouse for my computer."

Diane (Import/Export Controls Lead Practitioner)

Am I entitled to time off for medical appointments?

The Equality Act imposes a strict duty upon 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 many organisations do pay it.

If you take sick leave due to your lupus, your employer should disregard 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).



The nurse said my illness was under control as long as I took my tablets. She also advised management not to expect me to work longer than my weekly hours. When I developed CNS Lupus they were very supportive allowing time for appointments and investigations.

Mandy, Clinic Co-ordinator

Should I consider a different type of work, or reduce my hours?

Some jobs can be particularly difficult to cope with when you have lupus, such as jobs that involve heavy manual work or lifting.



Before you make any decision about stopping work, talk to your rheumatology team to find out if they think your disease is adequately controlled. If they feel it is, this can help you 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. Employers are not required to redeploy workers if there are no vacancies, it is however something that they may need to consider in making reasonable adjustments. You may also want to consider the possibility of adjusting the number of hours you work to make it more manageable. This may have financial implications for you, in which case you may want to enquire about any benefits you may be eligible for (see

page 24). You can consider asking for help from your employer, their Occupational Health Service, HR team, NHS Plus (contracted OH services) or your Disability Employment Adviser. See information starting on page 15.

" I was self-employed at the start having my own hairdressing salon, when that became too much I gave it up I then went on to working a part time job that gave me enough time to rest in between but with the ability to make good commission"

Rona (Sales Consultant)

What can I do if my employer treats me unfairly?

If you feel you are being treated unfairly because of your lupus, you should first discuss this informally with your manager. If necessary you can then register a formal grievance 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 disability discrimination through an employment tribunal. You **MUST** notify ACAS of your potential claim before you can make a claim to an employment tribunal.

The Advisory, Conciliation and Arbitration Service (ACAS) have a process of trying to resolve a dispute before it goes to an employment tribunal. This process is free and confidential and is called early conciliation.

You must contact ACAS to tell them that you intend to bring a claim before you can present a claim to an employment tribunal. This does not mean that you actually have to take part in conciliation. You only have to notify ACAS of your potential claim.

Early conciliation applies to most employment disputes, including claims for:

- unfair dismissal
- workplace discrimination
- redundancy payments or disputes over selection procedures
- deductions from wages or unpaid notice or holiday pay
- rights to time off or flexible working
- equal pay.

There are a number of steps to the early conciliation process:

Step one: You contact ACAS either by completing an online form or by telephone. A conciliation officer will contact you within two working days to confirm basic information about your case and explain the early conciliation process.



Step two: If you say that you would like to try to conciliate the dispute about which you want to make a claim, ACAS will contact your employer. If you and your employer agree to take part in conciliation, an ACAS conciliator will contact you both. If you resolve your dispute, ACAS will prepare an agreement for you both to sign. This is referred to as a COT3 which is the name of the form used.

Step three: If you do not resolve your dispute, or if you or your employer do not want to take part in conciliation (see next step), ACAS will issue an early conciliation certificate. The certificate has a number which you must include on your ET1 claim form. If you do not include this number, the employment tribunal will reject your claim.

Step four: Taking part in conciliation is entirely voluntary so neither you nor your employer actually has to take part in conciliation. The only thing you must do is notify ACAS that you intend to bring a claim. ACAS will issue a certificate and you can proceed with your claim.

The normal time limit for making a claim in most employment cases is three months minus one day. In redundancy pay and equal pay cases, the time limit is six months minus one day. If early conciliation applies to your case, this will affect the time limit for presenting your case to an employment tribunal.

Early conciliation (EC) can last up to one calendar month starting on the date on which you notify ACAS of your potential claim. This one-month period can be extended by up to 14 days if, towards the end of the month, ACAS thinks that there is a reasonable prospect of settling the case within those extra 14 days. You (or your representative) can also ask for an extension.

Useful organisations

- Advisory, Conciliation and Arbitration Service (ACAS)
www.acas.org.uk or telephone 0300 123 1100
- Citizen's Advice Bureau (CAB)
www.citizensadvice.org.uk or telephone local CAB office
- Specialist legal advice can help to find a speedy and satisfactory resolution to your concerns and help to avoid tribunal proceedings. (see useful addresses on pages 25-28)
- Equality Advisory Support Service (EASS) publish excellent resources relating to your employment rights.

For more information visit **www.equalityadvisoryservice.com**

Now my lupus is under control I would like to return to work. Where should I start?

The Disability Employment Adviser (DEA) at your local Jobcentre Plus (see page 25 for how to find them) can help you with retraining, seeking appropriate work and practical support to get you 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 DEA includes:

- **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
- Information on the **Work Choice** scheme which helps people with disabilities whose needs cannot be met through other work programmes, Access to Work or workplace adjustments. This is made up of 3 modules:

Module 1: Work Entry Support

This will last for up to six months. You will receive help with personal skills and work-related advice to get you into supported or unsupported work.

Module 2: In-Work Support

This will last for up to two years. You will receive help to start work and stay in your job.

Module 3: Longer-term In-Work Support

You will receive help to progress in your job and where appropriate, help you move into unsupported work.

- Information on the **Disability Symbol**. This is a symbol of recognition given by Jobcentre Plus to employers who have agreed to meet five commitments about the recruitment, employment, retention and career development of disabled people

Other sources of help and advice include:

- Your occupational therapist
- **Remploy**, a specialist employment services group, provides a range of services to help people get the right job. www.remploy.co.uk or telephone 0300 456 8110
- **Shaw Trust**, a national charity that provides training and work opportunities for people who are disadvantaged in the labour market due to disability, ill health or other social circumstances. www.shaw-trust.org.uk or telephone 01225 716300 or information on Work Choice 0300 30 33 111
- There may be a local scheme or charity that can help. Ask at your local Citizens Advice Bureau or Jobcentre Plus
- If you are on long-term sick leave meet with your manager, HR or occupational health nurse to discuss your return to work

Can I apply for any state benefits while I am working?

There is a range of benefits that you may be eligible for, depending on how much you earn, how many hours you work a week, or if your condition limits your ability to carry out certain tasks or results in extra costs of living.

For information about what benefits you may be eligible for, you can complete an online benefits calculator. This provides independent advice about the benefits you can get and how to claim them. www.gov.uk/benefits-calculators.

For assistance with the application process, your local **Citizen's Advice Bureau** or **DIAL** should be able to help. You can see details on finding your nearest centre in the useful addresses section on page 25.

What if I am no longer able to work?

Despite receiving adjustments in the workplace (see page 11), there may come a point where you feel you are no longer able to continue working. This can be a very difficult decision to make and it will potentially have financial and/or emotional implications.

Before making a decision about stopping work, talk to your rheumatology team to find out if they think your disease is adequately controlled. They may be able to make adjustments to your treatment or advise a different type of work (see page 20). They may suggest that a break from working or early retirement would be better for your health.

If you find the transition from working to not-working is difficult, you might find it helpful to request a referral for counselling from your GP. There are also many private counselling services. For further information about counselling services go to: <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/free-therapy-or-counselling.aspx>

For information about what benefits you may be eligible for and how to claim, you can complete an online benefits calculator, details of which can be found in the section above.

For assistance with the application process, your local **Citizen's Advice Bureau** or **DIAL** should be able to help. You can see details on finding your nearest centre in the useful addresses section on page 25.

Useful addresses

AbilityNet

National charity and provider of advice on computing and disability.

Freephone 0800 269545

www.abilitynet.org.uk

ACAS

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

0300 123 1100

Monday to Friday 8am until 8pm

Saturday 9am until 1pm

www.acas.org.uk

Access to Work

Access to Work (AtW) provides advice and practical support to disabled people and their employers to help overcome work related obstacles resulting from disability.

As well as giving advice and information to disabled people and employers, AtW pays a grant, through Jobcentre Plus, towards any extra employment costs that result from a disability.

Contact your local Jobcentre Plus or see list of AtW centres on page 34

For more information please see

www.gov.uk/access-to-work

Association of Chartered Physiotherapists in Occupational Health and Ergonomics

A proactive group, promoting best practice in the field of occupational health physiotherapy. Can help you to find a physiotherapist near you with their online search facility.

www.acpohe.org.uk

Benefit Enquiries

Use the Benefits Calculators to find out what benefits you could get, how to claim and how your benefits will be affected if you start work. These are free to use, anonymous, and have replaced the Benefits Adviser service.

www.gov.uk

<https://www.gov.uk/benefits-calculators>

Chartered Society of Physiotherapists

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

020 7306 6666

www.csp.org.uk

Citizens Advice Bureau

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

<p>College of Occupational Therapists Includes OTs in Independent Practice (OTIP). OTIP has online information about private OT services and can help you find an occupational therapist specialising in work problems near you.</p>	<p>020 7357 6480 www.cot.org.uk www.cotss-ip.org.uk and Search the OT in Independent Practice directory using the search term 'vocational rehabilitation'</p>
<p>Commercial Occupational Health Providers Association COHPA will assist and advise on suitability of different providers in your area</p>	<p>0333 772 0401 info@cohpa.co.uk</p>
<p>Equality Advisory & Support Service (EASS) The new service is directed towards people who think they may have experienced discrimination and will not be available to employers, service providers or educators. The service aims to support individuals referred from local organisations, advisory groups, faith based organisations and other groups working within the community that support people experiencing discrimination.</p>	<p>0808 800 0082 www.equalityadvisoryservice.com</p>
<p>DIAL UK DIAL is run by and for disabled people. It provides information and advice to disabled people and others on all aspects of living with a disability.</p>	<p>0808 800 3333 Monday to Friday 9am until 5pm www.scope.org.uk/support/disabled-people/dial/about</p>
<p>Disability Rights UK Produces the Disability Rights Handbook, a detailed and comprehensive guide to what benefits and services are available to people with disabilities and their carers.</p>	<p>020 7250 8181 not an advice line www.disabilityrightsuk.org For general enquiries email enquiries@disabilityrightsuk.org</p>
<p>Disability Law Service Provides legal advice/representation to disabled people and has useful fact sheets on employment rights</p>	<p>020 7791 9800 Monday to Friday 10am until 5pm www.dls.org.uk</p>
<p>Disability Advisory Service For Northern Ireland: provides advice and practical and financial support to disabled people and their employers to help overcome work related obstacles resulting from a disability.</p>	<p>028 9025 7777 Monday to Friday 9am until 5pm Access the site at www.delni.gov.uk</p>

Directgov

Directgov brings together a wide range of public service information and services online. The site also gives you access to government directories, as well as links to relevant third parties who can offer additional trusted support and advice.

www.gov.uk

Employment Tribunals

The Employment Tribunals are judicial bodies established to resolve disputes between employers and employees over employment rights. This website provides information about the tribunal's procedures and gives guidance on how you make or respond to a claim

ACAS 0300 123 1100
0300 123 1024 (England & Wales)
0141 354 8574 (Scotland)
Monday to Friday 9am until 5pm
www.gov.uk/employment-tribunals

Institute of Ergonomics and Human Factors

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

07736 893350
www.ergonomics.org.uk

Jobcentre Plus

A government agency supporting people of working age from welfare into work, and helping employers to fill their vacancies. It is part of the Department for Work and Pensions (DWP).

0345 604 3719
www.gov.uk/looking-for-work-if-youre-disabled/looking-for-a-job

They also employ Disability Employment Advisers (DEA)

Law Centres Federation

Law Centres Federation provide an independent legal advice and representation service. They employ specialists in areas of 'social welfare' law and help individuals and local groups with problems.

0203 637 1330
www.lawcentres.org.uk
You can find a local Law Centre through this site.

Remploy

A specialist employment services group, provides a range of services to help people get the right job.

0300 456 8110
www.rempoy.co.uk

Shaw Trust

A national charity that provides training and work opportunities for people who are disadvantaged in the labour market due to disability, ill health or other social circumstances.

01225 716300
www.shaw-trust.org.uk

Access to Work contact centres

Contact details of the three regional contact centres that deal with claims for Access to Work.

Contact the centre covering the area where you work by telephone, textphone, fax, email or by post. Please note that there are no walk-in facilities; these are postal addresses only.

London

Contact this centre if you work in:

- South East England
- London
- East of England

Jobcentre Plus

Access to Work Operational Support Unit

Nine Elms Lane

London SW95 9BH

Telephone: 0208 426 3110

Textphone: 0208 426 3133

Fax: 0208 426 3134

Email: [atwosu.london@](mailto:atwosu.london@jobcentreplus.gsi.gov.uk)

[jobcentreplus.gsi.gov.uk](mailto:atwosu.london@jobcentreplus.gsi.gov.uk)

Cardiff

Contact this centre if you work in:

- South West England
- Wales
- West Midlands
- East Midlands

Jobcentre Plus

Access to Work Operational Unit

Alexandra House

377 Cowbridge Road East

Cardiff CF5 1WU

Telephone: 02920 423 291

Textphone: 02920 644 886

Fax: 02920 423 342

Email: [atwosu.cardiff@](mailto:atwosu.cardiff@jobcentreplus.gsi.gov.uk)

[jobcentreplus.gsi.gov.uk](mailto:atwosu.cardiff@jobcentreplus.gsi.gov.uk)

Glasgow

Contact this centre if you work in:

- Scotland
- North West England
- North East England
- Yorkshire and Humberside

Jobcentre Plus

Access to Work Operational Support Unit

Anniesland JCP

Baird Street

Glasgow G90 8AN

Telephone: 0141 950 5327

Textphone: 0845 602 5850

Fax: 0141 950 5265

Email: [atwosu.glasgow@](mailto:atwosu.glasgow@jobcentreplus.gsi.gov.uk)

[jobcentreplus.gsi.gov.uk](mailto:atwosu.glasgow@jobcentreplus.gsi.gov.uk)

To find out more about the Access to Work Scheme in

Northern Ireland contact

Department for Employment and Learning

Adelaide House

Belfast BT2 8FD

Tel: 028 9025 7777

(Monday-Friday 9.00am – 5.00pm)

Text Phone: 028 9025 7458

Email: info@delni.gov.uk

Publicity materials, leaflets, posters, a dvd for the newly diagnosed, media releases and more are always available from the charity's National Office for better awareness about lupus in clinics, hospitals and public places.