

When an employee has lupus An employer's guide

LUPUS

UK

The Information Standard Certified Member

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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 For more information contact:

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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 recomment 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 'When an employee has rheumatoid arthritis - An employer's guide'.

Thanks also go to those who kindly submitted their case studies for inclusion within this guide.

## **About this booklet**

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

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

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## What is lupus?

Systemic lupus erythematosus, or lupus, is an illness of the immune system, a condition in which the body's defence mechanism begins to attack itself through an excess of antibodies in the blood stream causing inflammation and damage in the joints, muscles and other organs.

### **Key facts about lupus:**

- · It is a lifelong condition.
- · It is seen in more women than men.
- People can develop it at any age, even as children. The most common age
  of onset is between 15 and 55.
- There is no obvious pattern to symptoms and everybody's disease is different. People get 'flares', or periods when symptoms are much worse, which then subside. They can have periods when the disease is quiet and causes them no problems.
- It is an 'auto-immune disease' that is, it results from a problem with the body's immune system. It is neither infectious nor contagious.
- The most common symptoms are extreme fatigue and weakness, joint/muscle aches and pains, sensitivity to UV light, flu-like symptoms, depression, headaches, migraine and oral/nasal ulcers.
- Those diagnosed usually receive on-going treatment to lessen the impact of the many symptoms but there may be side-effects. Lupus in its most active form can cause damage to many parts of the body and sometimes without treatment the disease may not be contained and could potentially cause damage to the kidneys, heart, lungs or brain.

There have been great advances in the treatment of lupus. It is important that people are diagnosed early and treated early. It is often medication that helps to keep the disease controlled. These medications work by reducing the activity of the disease and need to be discussed in detail with the team before starting. Once the disease is well controlled, the signs and symptoms of lupus can be managed, allowing them to remain active and continue to enjoy satisfying and productive working lives.

"In the past decade the treatment of SLE has improved in several ways. Plaquenil (or Hydroxychloroquine) is now more widely used as it has benefits in nephritis and lowers cholesterol. The use of a lower dose regime of cyclophosphamide (six fortnightly injections) and the widespread use of mycophenolate has given us more 'big guns' to combat nephritis (kidney disease). The more judicious use of steroids has proved valuable in reducing side effects and recent studies have shown that the biologic drug rituximab may be useful both in long established disease and at the time of diagnosis in an attempt to avoid using steroids altogether. Finally, another biologic drug, Benlysta which blocks a B cell activating factor known as BLyS has been approved by the Federal drug



administration in the USA and the European Medicines Agency for use in skin and joint lupus. As a consequence of these improvements more patients are able to stay at work."

### Prof David Isenberg, Consultant Rheumatologist, UCLH

"If I hadn't received the treatment, there is no way I would have been able to work. Within a week the steroids made a huge difference and now everything is under control and my last blood results showed no lupus activity. About 8 to 12 weeks after starting Hydroxychloroquine, the feeling of complete exhaustion everyday was not as bad. Now I only feel exhausted at the weekend after working, studying and looking after my family and house all week. Otherwise, I generally cope well with it all."

Sharon, Dispensing Manager in an Optometrists

## Managing lupus in the workplace

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

Lupus can be a difficult disease to manage, both for individuals and for employers, as it often begins when people are in the prime of their working lives. However, there can be straightforward and inexpensive strategies to minimise the effects of lupus on employment, from which both the employers and employees benefit. If people are absent from work for long periods of time it becomes extremely difficult for them to return - which argues strongly for

focussing efforts on enabling people to remain in work.

One of the greatest difficulties employers often have is understanding the nature of the disease itself. Lupus is a complex and fluctuating condition, which varies greatly between individuals. It can be severe and at the same time almost invisible; there are often no physical changes in somebody diagnosed with lupus.

There is a real need to increase the understanding about lupus and the needs of people at work who have it. Many patients feel that more knowledge and flexibility on the part of employers could be important in enabling them to remain productive members of the workforce.



## How lupus may affect people at work

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

Some people with relatively mild or well controlled lupus can continue to be able to work normally with few problems. However, the majority do face some challenges in the workplace at some time.

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

#### When someone has been diagnosed

When somebody is newly diagnosed with lupus, they are usually prescribed one of the drugs that are available to control the disease process. These disease modifying drugs are effective, though they take a while to 'kick in' - usually a matter of weeks, though in some cases longer.

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



Once the drugs take effect and the disease becomes controlled, some people are able to continue to work as normal. Others may need some adjustments to their working environment, working hours, or to the job itself. There is more information about adjustments on page 10.

## **Symptoms**

Lupus is a complex condition that can affect any part of the body and can cause



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

- Fatigue lupus fatigue can be very different from ordinary tiredness.
   Simple physical and/or mental activities can leave somebody with lupus feeling exhausted and struggling to function. The impact may be felt straightaway or it can take a day or two to take effect.
- Pain pain can manifest in many different ways such as; aching muscles or joints, headache or migraine, nerve pains, abdominal or stomach pain, twitching muscles or cramps.
- Cognitive difficulties this is often described as 'brain fog' and can include short-term memory problems, word-finding difficulties, slurred speech, inability to plan or organise thoughts or loss of concentration.
- Problems with mobility or function
- Sensitivity to UV light About 60% of lupus patients get sun-induced rashes and a further 10-20% complain of other clearly sun-induced problems. Some may need to avoid sunlight, others can also react badly to fluorescent strip lighting.

However, today people can manage their symptoms more effectively than in the past. This is due to a combination of drug treatments (including disease modifying drugs, non-steroidal anti-inflammatory drugs and pain killers) and other, non-pharmacological management strategies. These can range from wrist splints and other supports, to self-management techniques such as pacing and energy conservation.

#### 'Flares'

Even when lupus is well controlled, people can experience a 'flare' in their symptoms. Flares can sometimes occur suddenly and without any warning signs: a person can be at work one day and be physically unable to get out of bed the next. The frequency and severity of flares varies greatly between individuals.

Over time, some people with lupus may possibly learn techniques they can use to help manage their flares. Occasionally, some lupus patients may also find that

early medical intervention can prevent a flare's progression and limit its effect on them.

Flares are often a difficult aspect of lupus for colleagues to understand, particularly as a person experiencing a flare can look exactly the same as usual.

#### Time off

People with lupus need some time for hospital or GP appointments to manage their disease. Once stabilised on treatment, most people see





their consultant rheumatologist every three to six months. Some drug treatments require blood tests for safety reasons, which involves people giving a sample for regular monitoring usually once a month at their GP surgery. This does not have to be disruptive; often people can arrange to do this on the way to or from work.

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

In April 2010, sick notes were replaced with Fit For Work notes. This allows the person's GP to identify if they may be fit for work with some support, information on how the employee's condition may affect what they do at work and suggestions for common ways to help support the person at work. These may include a phased return to work, flexible working, amended duties and/or workplace adaptations. More details can be found at: <a href="http://www.dwp.gov.uk/fitnote/">http://www.dwp.gov.uk/fitnote/</a> which also has useful links for employers. "A Statement of Fitness for Work: guide for employers" is available via this site at <a href="http://www.dwp.gov.uk/docs/fitnote-employer-guide.pdf">http://www.dwp.gov.uk/docs/fitnote-employer-guide.pdf</a>

Health professionals often describe people with lupus as 'can do' people. Because lupus can be such a painful disease, people can become accustomed to dealing with pain and may ignore minor health issues that are unrelated to their lupus.

"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)



## **Understanding individual needs**

People with relatively mild lupus or whose condition is very well managed may decide not to tell their employers, but most people do.

Some people will tell their employer as soon as they are diagnosed, while others prefer to take their time and come to terms with the news. Some will effectively have no choice, if their early symptoms are severe and they are facing difficulties at work that they need to discuss.

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

• Follow normal good people management practice<sup>1</sup> in communicating with your employee, particularly ensuring that they have and understand all the

relevant company policies and how these apply to their situation.

 When an employee has told you that they have lupus, they may want to inform colleagues or they may prefer to keep it confidential. If they wish their colleagues to be informed, discuss and agree jointly the best way to go about this.

 Agree a series of review meetings with your employee that enable you to discuss any support or adjustments they may need. You can, of course, use your normal review



meetings that you have with your employee to discuss these matters.

- Let the employee know who they can talk to if they need support or if their situation changes.
- If the employee has an extended absence, keep in touch. It will give you
  information to help manage workloads, and ensure that suitable support
  is given to an employee on their return. Aim to agree with the individual
  what kind of communication they prefer whether that means visits,
  phone calls or an occasional email.



#### Finding out what your employee needs: a checklist

- Explore the situation with your employee. Identify with them any aspects of their role that cause problems. Include travel to work and parking.
- Decide what actions are needed and who will be responsible.
- Examine the working environment and accessibility. Arrange a work assessment with an occupational therapist, occupational health physiotherapist or the Access to Work scheme. For more information see page 11.
- Assess the potential for the employee to continue with their current role. Consider whether adaptations, changes to their working hours, or additional training are necessary.
- Recommend any adjustments needed to their role, or recommend an appropriate alternative job. Examine re-training options.
- Agree on what information colleagues should receive and who is responsible for telling them.
- · Agree on communication and review process.

"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

<sup>1</sup>E.g. management standards **www.management-standards.org.uk**; Investors in People (liP) standards,

www.investorsinpeople.co.uk/Documents/IiP\_StandardOverviewI.pdf; and the EFQM Excellence model,

www.efqm.org/Default.aspx?tabid=40



## Supporting an employee who has lupus

The type of support an individual needs will of course depend on the type of work they do and how physical it is. Some occupations with heavy labouring are more difficult to accommodate than less physical jobs. However, in some circumstances, there are options for transferring people to less physical work that still uses their skills or allowing some flexibility in the time they spend at specific tasks. There is more information about this on page 10.



When an employee tells you that they have lupus, take the earliest opportunity to ask them about any problems they are experiencing and explore ways to overcome them. Often they can be resolved easily and with little effort. Making modifications sooner rather than later may well be cheaper too, as you can make changes before a problem could become

more costly. You may need to arrange a workplace assessment to identify problems and potential solutions. There is more information on page 11.

With the right support and adjustments, many people with lupus are able to continue in employment.

## Legal responsibilities

'The Equality Act (2010) provides disabled people with rights and it also places strict duties on employers. It helps encourage employers and employees to work together to break away from the rigid employment practices, to identify what adjustments and support might be needed, and find flexible ways of working that may benefit the whole workforce.'

Many people with lupus do not consider themselves to be disabled. However, they can be entitled to protection at work under the Equality Act (2010), as lupus is defined as a type of impairment being a progressive condition that can affect people in such a way that they meet the Act's definition of disabled. The Act recognises that some diseases are of a fluctuating nature and that people may be impaired more at certain times.



There is reliable and useful information available for employers about the Equality Act and about best practice.<sup>2</sup> In summary, the Equality Act defines a person having a disability and is applicable to employees in the UK who have a physical or mental impairment which has a **substantial** and **long-term** adverse effect on their ability to carry out **normal day-to-day** activities. This can include limitations in:

- Mobility
- Manual dexterity
- The ability to lift, carry or move everyday objects

## 'Reasonable adjustments'

The Equality Act states that 'reasonable adjustments' must be made by the employer to allow a person with a disability to continue working and to meet the requirements of the Act. What kind of adjustments should an employer consider and what is considered reasonable?

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

- Adjusting working hours, making these more flexible or allowing work from home for part or all of the time.
- Adjusting duties, possibly transferring some to other people and allowing an employee to take on others which are more suitable.
- Equipment, such as telephone headsets, ergonomic keyboards, adapted handles
- · A supportive chair.
- Support from someone else to do part of their job (e.g. help with lifting or transferring necessary equipment).
- Improvements to access, e.g. a disabled parking place near to the workplace, ramps, rails and stair lifts.

It may also be reasonable to exclude absences that are directly related to a person's disability when monitoring sick leave. However, it is not a requirement to pay higher levels of sick pay to disabled employees than others.<sup>3</sup>

The Equality Act states that what is 'reasonable' can vary depending on:

- The size and type of the organisation.
- The turnover of the company.
- The practicality of the adjustment.
- The costs and disruption while any work is being carried out.
- The potential benefit to employees and customers.



It would be reasonable to expect all employers to provide ramps, rails and simple ergonomic equipment for computers and telephones or minor adaptations to machinery. But if a building has awkward stairs, for example, it may not be physically possible to install a stair lift without extensive additional building work, which might then make such an adaptation unreasonable.

A larger company may be able to afford to allocate another employee to help, whereas a small company with a few employees may not be able to do so. Note that financial help is available through the Access to Work scheme – there are more details on page 14.



Employee and employer should aim to communicate effectively and openly, to negotiate on both sides what is 'reasonable'. Further advise is available from the Trades Union Council.<sup>4</sup>

If an employee cannot continue in their present role because of their lupus, you should explore all avenues for transferring the employee to

another role within the company. Such a move can also be considered a reasonable adjustment and could include a role at a different work location.

## Workplace assessments

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

- Occupational Health Therapists, whose job is to enable people with disabilities or illness to perform tasks at work and in their daily lives more easily
- Physiotherapists, specifically those that specialise in Occupational Health
- Vocational Rehabilitation (VR), counsellor and case manager
- An Access to Work (AtW), advisor

A therapist, VR counsellor or AtW advisor can visit the workplace to assess the employee's job and their physical environment. They can evaluate job tasks and advise how they can be simplified or modified to reduce the effort needed. They may suggest: appropriate adaptations to equipment; assistive technology; other devices such as splints; and changes to the work environment or how the job is performed. An employee may request that an occupational therapist from their own health team visits to do an assessment. For information about qualified therapists and VR counsellors and how to find them, see Support and Resources on pages 14-18. There are a number of different professionals listed above who are involved in Vocational (work) Rehabilitation (VR). Experienced



professionals should be qualified, members of a professional association and adhere to VR national standards for their profession.

## **Protection against discrimination**

The Equality Act places a strict duty upon employers not to treat an employee with a disability less favourably, which means that employers may not penalise a disabled employee in any way because of their condition. This applies not only to their existing role, but to all employment practices, including recruitment, training, promotion, and dismissal.

If an employee takes sick leave because of their lupus, it is good practice for employers to discount this in any calculations they make about performance related pay or enhancements or in any disciplinary procedures that relate to sickness absence. If this is not the case this may be discriminatory; it is good practice to regard such absences as disability leave and not sick leave.

"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)** 



"Severe UV sensitivity was problematic over the years, until I started on Plaquenil. Once this began to work, I went from paranoid about UV light to just cautious. I was respectful to sunlight and still careful using blocks and clothing.

I started a new job with an office in an old building. It was a small office with just my boss and me. I would go home exhausted and 'fuzzy'. I put it down to going back to work on a more regular basis than I had for some time and though I just needed time to adjust.

I was working at my boss's computer one afternoon and I turned around to look at her and she was shocked. I looked like I had bad sunburn on my face and chest - the penny dropped. The old lights were emitting UV light which was intense in the confined space. I explained to my employer that this had surprised me as much as her and that it now explained the brain fog I had been having. She asked me what we could do and instructed me to source a solution, which I did.

Filming the fluorescent lighting was the easiest and most economical way to overcome the problem. Being a small company within a larger organisation, we started the steps required to have the problem rectified through occupational health and then facilities. Unfortunately, the cogs were not turning and there was disbelief that anyone could be having a problem with the lights! My boss said enough was enough and bypassed the system and we ordered the film directly with financing to be sorted at a later date. This has made a world of difference to me.

I am still cautious and respectful to fluorescent lighting and generally have the lights over my desk off (works in the summer). My colleges think I am a vampire but are very good about it and now view the UV sensitivity as an 'allergy' and are respectful to that."

## Kim (PA to the Executive Officer)

<sup>1</sup> A practical guide to the law and best practice for employers, published by the Disability Rights Commission. Code: EMP14 Publish Date: 18/07/2005 and Employment: A practical guide to the law and best practice for employers (Scotland) Code: SCOTEMP1 Publish Date: 19/10/2006. For full details of the definition of disability and employment rights for the people covered by the Equality Act, see **www.equalityhumanrights.com** Note: From I October 2007 the Commission for Equality and Human Rights (CEHR) took over the work of the Disability Rights Commission (DRC).
<sup>2</sup> ibid

www.bailii.org/uk/cases/UKEAT/2006/0109\_06\_0408.html

<sup>4</sup> For example, see Disability and Work. A trade union guide to the law and good practice. Available at **www.tuc.org.uk** 



<sup>&</sup>lt;sup>3</sup> O'Hanlon v Revenue and Customs

## Available resources and support

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

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

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

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



Practical and financial help is available for:

- · Special aids and equipment
- Support workers
- Travel to and from work, where extra costs are incurred in travelling to and from work because of a disability
- · Adaptations to premises and equipment.

For employees starting a new job (ie they started less than 6 weeks ago) Access to Work will cover up to 100% of approved costs to help. After this period the amount payable by employers varies according to the number of employees:

- Employers with 1 to 9 employees will not be expected to share costs
- Employers with 10 to 49 employees will pay the first £300 and 20 per cent of costs up to £10,000
- Employers with 50 to 249 employees will pay the first £500 and 20 per cent of costs up to £10,000
- Large employers with 250 or more employees will pay the first £1,000 and 20 per cent of costs up to £10,000

After between one and three years, Access to Work will review your circumstances and the support you're receiving.



For a list of Access to Work Regional Business Centres, that can be contacted direct, see page 23. The employee can also discuss their needs and contact AtW via The Disability Employment Advisor at their local Job Centre.

## **Equipment and environment**

Albertina an administrator explains the adjustments her employers made for her. "I got to know about Access to Work through a colleague of mine who was on a contract. She gave me the telephone number, so I phoned them and they took my details, as well as my doctor's address to get confirmation about my sickness.

Once AtW got the confirmation, they rang me to make an appointment to come to my office and also wrote to my manager. When their representative arrived she took some measurements of the type of chair that would be suitable for me and gave me the name and address of the company to contact. When everything was done, ATW paid part of the money and my employer paid the rest.

I had a second visit as I was having problems with my wrists and my feet. She suggested some other equipment for me, which I am still using. It was also recommended by them to ask my employer to get me a fleece jacket when I cover lunch breaks for the receptionist, as the reception area turns very cold. My life at work is much better, thanks to AtW."

#### **NHS** Health at Work

NHS Health at Work is a network of NHS occupational health (OH) departments across England, supplying health and well-being services to NHS staff as well as small to medium sized enterprises (SMEs).

SMEs can get occupational health advice and support through the free advice line and through the network of NHS providers. You can call the free advice line on 0800 077 88 44 or go to http://www.health4work.nhs.uk/

For help in finding a local NHS occupational health provider, go to http://www.nhshealthatwork.co.uk/find-providers.asp

For more information on NHS Health at Work, go to www.nhshealthatwork.co.uk



## **Workplace Health Advice**

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

England: The Health and Safety Executive Infoline on 0845 345 0055 or hse.infoline@connaught.plc.uk

Scotland: 'Healthy Working Lives' on 0800 019 2211 or www.healthyworkinglives.com

Wales: 'Workboost Wales' project on 0845 609 6006 or www.workboostwales.com

**www.health4work.nhs.uk** or **0800 077 8844** - a free advice line for workplace health issues, including supporting employees with health issues effectively.

## **Employers' Forum on Disability**

This is a not-for-profit organisation dedicated to sharing best practice about disability. It is funded and managed by employers who between them employ almost 20% of the UK workforce.

The forum produces a variety of publications including a Line Manager's Guide: a best practice approach to working with disabled colleagues. This includes:

- A 'reasonable adjustment request' form to help identify what adjustments are needed and what is reasonable
- Advice on enabling staff to feel confident working with disabled team members
- · How to get help for people with disabilities
- Understanding the law.

To find out more visit www.efd.org.uk

### **AbilityNet**

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

- An advice and information service
- Individual assessments to find the right solution for disabled people who have a problem using their computer
- · Awareness training and advice to businesses

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



#### NHS rehabilitation services

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

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

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

## Other sources of help

Some private companies also provide workplace assessments. Therapists may be self-employed or employed by health insurance companies, private health companies, or rehabilitation case management companies, some of which specialise in musculoskeletal conditions.

To identify private occupational therapists and occupational 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
- 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-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 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 developed as Vocational Rehabilitation (VR) Counsellor; this is for therapists or other professionals who have completed a certified/accredited VR training course.

'Available from http://businessdisabilityforum.org.uk/our-offer/advice/publications



## 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.

08457 474 747

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**

Confidential advice and information for people with disabilities, and their carers and representatives, about social security benefits and how to claim them.

#### 0800 882200

Monday to Friday 8.30am until 6.30pm; Saturday 9am until 1pm www.dwp.gov.uk

# 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.adviceguide.org.uk



## 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.

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

#### **Commercial Occupational Health**

Providers Association COHPA will assist and advise on suitability of different providers in your area 01933 232 373

rehabilitation'

Fax 01933 232 374 info@cohpa.co.uk

## 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.

0800 444 205

www.equalityadvisoryservice.com

### **Community Legal Advice**

A government funded legal advice service. It has been set up to help you find the right legal information to help with problems including work issues.

0845 345 4345

Monday to Friday 9am until 8pm Saturday 9am until 12.30pm www.gov.uk/legal-aid

#### **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.

01302 310 123

Monday to Friday 10am until 4pm www.dialuk.info

#### 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.

020 7250 3222 not an advice line www.disabilityrightsuk.org

For general enquiries email enquiries@disabilityrightsuk.org

#### **Disability Law Service**

Provides legal advice/representation to disabled people and has useful fact sheets on employment rights 020 7791 9800

Monday to Friday 10am until 5pm www.dls.org.uk



#### **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.

028 9025 7777

Monday to Friday 9am until 5pm
Access the site at www.delni.gov.uk

#### **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.direct.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

0845 795 9775 or ACAS 08457 474 747 Monday to Friday 9am until 5pm www.employmenttribunals.gov.uk

## Institute of Ergonomics and Human Factors

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

01509 234904

www.ergonomics.org.uk

#### **Jobcentre Plus**

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).

0800 055 6688

www.gov.uk/looking-for-work-ifyoure-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.

0207 842 0720

#### www.lawcentres.org.uk

You can find a local Law Centre through this site.

#### **RADAR**

A campaigning organisation for people with disabilities. With useful information sheets.

020 7250 3222

www.radar.org.uk



Remploy A specialist employment services group, provides a range of services to help people get the right job.	0845 155 2700 www.remploy.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 is you work in:

- South East England
- London
- East of England

#### **Jobcentre Plus**

Access to Work Operational Support Unit

Nine Flms Lane London SW95 9BH Telephone: 0208 426 3110

Textphone: 0208 426 3133 Fax: 0208 426 3134 Email: atwosu.london@ jobcentreplus.gsi.gov.uk

#### Cardiff

Contact this centre if you work in:

- South West England
- Wales
- West Midlands
- Fast Midlands

#### **lobcentre Plus**

Access to Work Operational Unit

Alexandra House

377 Cowbridge Road East

Cardiff CF5 IWU

Telephone: 02920 423 291 Textphone: 02920 644 886

Fax: 02920 423 342 Email: atwosu.cardiff@ jobcentreplus.gsi.gov.uk

#### Glasgow

Contact this centre if you work in:

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

#### **Iobcentre Plus**

Access to Work Operational Support Unit

Anniesland ICP **Baird Street** 

Glasgow G90 8AN

Telephone: 0141 950 5327 Textphone: 0845 602 5850

Fax: 0141 950 5265

Email: atwosu.glasgow@ jobcentreplus.gsi.gov.uk To find out more about the Access to

Work Scheme in

Northern Ireland contact

Disablement Advisory Service (DAS)

Headquarters

Disablement Advisory Service

5th Floor

Gloucester House

Chichester Street

Belfast BTI 4RA

Tel: 028 9025 2085 or

028 9025 2279

(Monday-Friday 9.00am - 5.00pm)

Answer Machine: 028 9025 2268 (outside

office hours)

Fax: 028 9025 2330

Text Phone: 028 9025 2228 **Email: das@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.

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