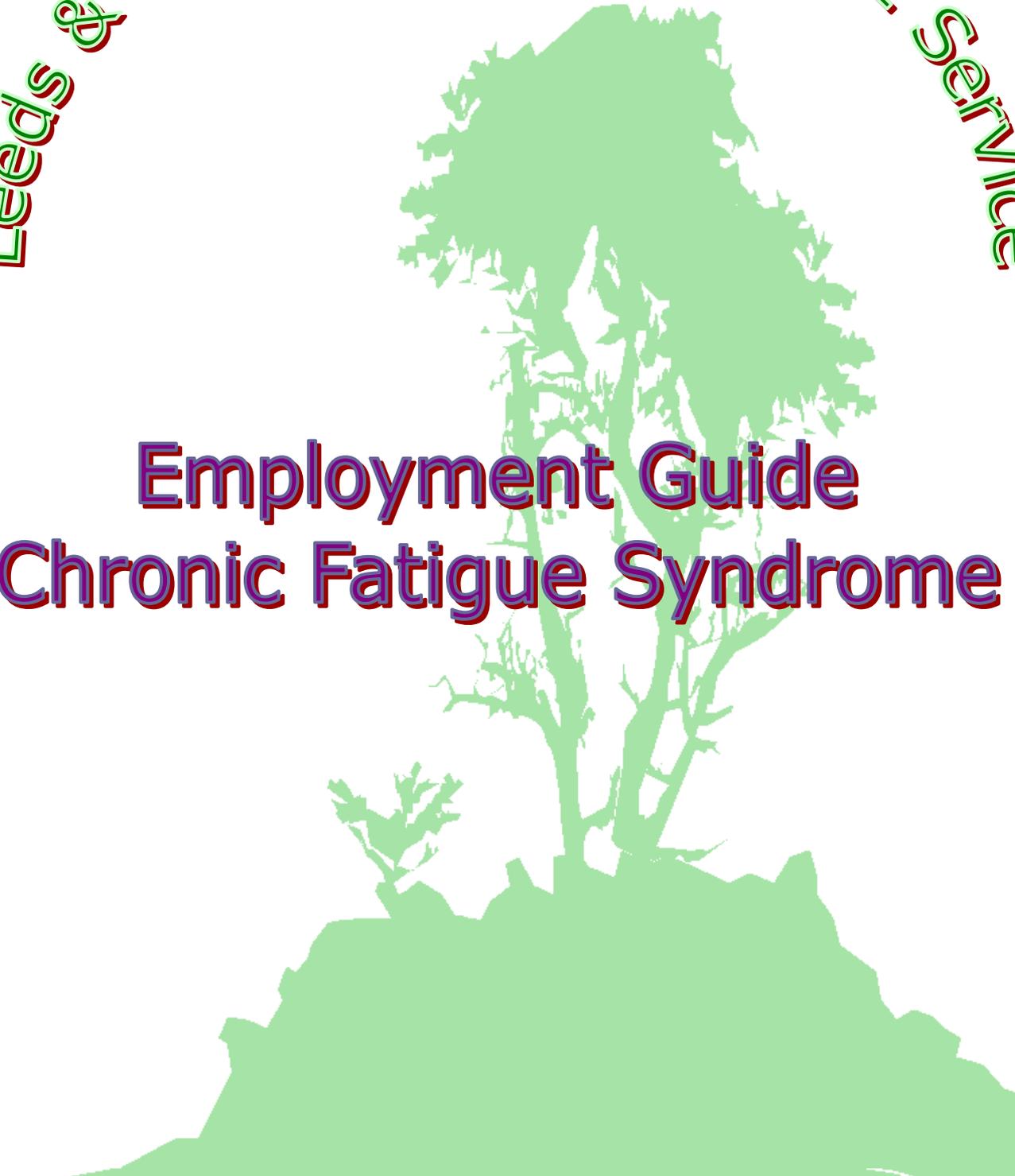


Leeds & West Yorkshire CFS/ME Service



Employment Guide Chronic Fatigue Syndrome

Leeds Teaching Hospitals NHS Trust
Leeds Partnerships NHS Foundation Trust

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**IF YOU HAVE PROBLEMS WITH MENTAL FATIGUE
THAT MAY MAKE READING THIS BOOKLET DIFFICULT**

In CFS/ME it is common for people to have problems with mental fatigue. Often they have difficulty reading for long periods. They tend to lose concentration after a while and stop being able to take in the information they are reading. If this applies to you the following technique could help you to read this booklet.

- Think about how much you can read before your fatigue level starts to increase. For some people it is 1 page (or just a paragraph), for others it is 20 pages or more.
- Stop reading when you have read the number of pages you can read without increasing your mental fatigue. Mark the point you have reached. Put the booklet down at this point and take a break from reading for a significant period of time.
- Come back to the booklet. Only read the number of pages or paragraphs you can read without increasing your mental fatigue.

By using this technique you will be able to complete reading the booklet in stages and be able to concentrate and retain the information more easily.

EMPLOYMENT AND CHRONIC FATIGUE SYNDROME

THE IMPACT OF CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) is a condition that may occur after many common triggers, especially viral infections. By definition the diagnosis of CFS/ME is only made after having the symptoms for at least 6 months. A person diagnosed with CFS/ME experiences significant fatigue that is not substantially alleviated by rest. The fatigue is both physical and mental.

The condition is variable, and due to the nature of payback fatigue, a person with CFS/ME may be able to do a task one day but may not be able to do this same task the next day, or days, following this exertion. This lack of certainty, along with the variety of different jobs that people do, can raise quite complex issues for people with CFS/ME in the workplace. Therefore, choosing a suitable job or making appropriate adjustments in the workplace will be very important.

GENERAL ADVICE ON WORKING WITH CHRONIC FATIGUE SYNDROME

The following advice is useful for an individual who is trying to maintain employment or return to work:



- It is very important to apply the grading principles at work, so activities should be broken down into small manageable blocks, for example 30 minutes
- Periods of work need to be interspersed with rest/relaxation breaks
- If undertaking a primarily desk based job, it is important to walk around regularly during the day to maintain circulation and muscle strength
- Energy comes from activities that are varied, interesting and satisfying. Therefore, mundane routine tasks can be more draining and increase fatigue
- If you do have to do mundane tasks at work then try to mix and match different types of activities within your day. By changing between physical, mental and social activities and rest/relaxation periods, it can maximise the energy that you have or prevent increasing your fatigue levels
- Consistency is important, so a regular pattern of work is needed
- Maintain fluid intake and food throughout the day to ensure the body has the fuel to do the job
- Tasks requiring concentration can be as demanding of energy as physical tasks. Specifically, optimum concentration in a healthy adult lasts approximately 15 minutes, so the quality of work will deteriorate over long periods
- When increasing working hours, this needs to be done gradually. Any change should initially be sustained before further increases are made. Each level must be stabilised and the time required for this will be different for each individual.

THE DISABILITY DISCRIMINATION ACT (DDA) 1995



DISCRIMINATION

The Disability Discrimination Act (DDA) 1995 applies to all employers whatever their size*. It protects unlawful discrimination in the field of employment - including recruitment, selection, training, promotion, redundancy and dismissal. As part of this protection employers may have to make 'reasonable adjustments' if their employment arrangements or premises place disabled people at a substantial disadvantage compared with non-disabled people. It rules out discrimination in two ways:

- Where a disabled person is treated less favourably than others because of their disability
- Where the employer fails to make reasonable adjustments to the workplace or working arrangements

Discrimination by way of less favourable treatment can be either:

- **Direct** - where, for example, an employer refuses to employ someone when they declare their disability or
- **Disability-related** - where, for example, an employer dismisses someone because they have taken a long period of sick leave after a relapse and are unable to say when they will be able to return to work

An employer cannot try to justify direct discrimination but may attempt to justify disability-related discrimination. This would depend on the nature of the job, the size of the company and the impact of the disability on the person's ability to do the job. However, less favourable treatment cannot be justified if a reasonable adjustment would have prevented this treatment.

**excludes the armed forces; prison officers; fire fighters; Ministry of Defence Police; British Transport Police; Royal Parks Constabulary; United Kingdom Atomic Energy Authority Constabulary; employees who work wholly or mainly outside Great Britain; or employees who work on board ships, aircraft or hovercraft.*

DEFINITION OF DISABILITY

The DDA defines disability as a 'physical or mental impairment, which has a substantial or long-term effect on a person's ability to carry out normal day-to-day activities'. The impairment must have lasted, or be likely to last, for twelve months or more to be viewed as long-term. A short-term impairment, for example, an illness, will not fall into this definition.

People with CFS/ME may not consider themselves to be disabled but should do so for the purposes of the Disability Discrimination Act. This is because people with CFS/ME are covered by the Act and the term 'disabled' has a specific meaning under that Act. Obviously, your entitlements and benefits cannot be established until you have disclosed that you have CFS/ME.

Information about general employment rights can be obtained from the following sources, for which contact details are given on page 15:

- Advisory, Conciliation and Arbitration service
- Department for Work and Pensions
- Citizens Advice Bureau

Details specific to your organisation should be in your contract and other employment documents, such as the employee handbook, and available from your Human Resources department.

DO I HAVE TO DECLARE MY DISABILITY?

Under the DDA it is unlawful for employers to discriminate against disabled people in their recruitment and selection procedures. Whilst it is not unlawful to ask questions about health or disability on an application form, or to issue a separate health questionnaire, it is unlawful to use the responses in a discriminatory way. However, it is up to you whether you wish to tell your employer about your health condition if it develops after starting your job. If your disability actually affects your way of working then it is advisable to talk to your employer and to your colleagues about it if you want a reasonable adjustment to be considered. If your employer does not know that you are disabled, they may not have to make changes that would help you. However, if, for example, your condition gets worse and you feel that you may need a reasonable adjustment, you can change your mind and tell your employer at a later date. From that time onwards your employer will have to take some action.

REASONABLE ADJUSTMENTS IN THE WORKPLACE



A key provision of the Disability Discrimination Act is that a person with a disability or a health condition, such as Chronic Fatigue Syndrome, can ask for reasonable adjustments from their employer if any aspect of their working arrangements, including the building or place of work, makes it more difficult for them than for a person without a health condition or disability to do their job.

The employer should discuss with the employee whether any reasonable adjustments would:

- Enable the employee to return to work, or
- Reduce the number or length of periodic absences, or
- Help the employer to accommodate the periodic absences

Disability employment advisors can be very helpful in giving practical advice tailored to your needs (see page 16 for contact details).

Occupational health physicians may also be helpful in terms of reviewing the employee's duties at work against the job description and offering recommendations on any possible adjustments.

Many helpful adjustments at work are not expensive

For example:

- Flexible or altered working hours to help you in terms of getting ready for work, travelling, or attending appointments - for example, part-time working, job-sharing or working from home for some or all of the time
- Providing for you to take more regular breaks
- Re-arranging responsibilities/tasks - for example, exchanging a single demanding project for a job consisting of a number of smaller tasks
- Moving your work station nearer to a toilet or on the ground floor to avoid frequent use of stairs
- Distancing your work station from sources of heat
- Providing room-dividers, partitions or other soundproofing or visual barriers to aid concentration
- Reducing noise in the work environment
- Providing an electronic organiser with an alarm may help someone with memory difficulties to recall important dates, appointments and phone numbers

- Allowing paid time off for medical appointments during working hours. If appointments go on for a long time or affect the financial viability of the organisation then other arrangements should be considered, such as unpaid time off, time-in-lieu or allowing a longer lunch break for which time can be made up later
- Flexibility in the rules applying to annual holidays - for example, allowing someone to use unscheduled annual holiday entitlement at short notice
- Assigning you to a different workplace
- Transferring you to fill an existing vacancy
- Providing training or supervision
- Modifying instructions or assessments
- Arranging for meetings to be held in a location or at a time to suit you
- Designating a car parking space by your nearest entrance into work
- Providing supervision
- Improving accessibility - for example, by providing handrails or a ramp

Other adjustments may involve the use of equipment.

For example:

- A different computer screen for those who are experiencing sight problems
- Voice-recognition software or an adapted keyboard or mouse for those who find typing difficult
- A special chair if you cannot stand for long periods

When considering whether or not an adjustment is 'reasonable', the employer should consider:

- How effective it would be in improving the situation or preventing the disadvantage
- The practicality of the adjustment
- Financial and other costs of the adjustment and the extent of any disruption caused
- The extent of the employer's resources - money, equipment and people, as well as the type of activity a business undertakes.

It is important to note that there is no limit to the number of adjustments that you can request or the frequency with which you can request them.

EMPLOYMENT OPTIONS



If you feel that your current employment is not suitable then you may consider the following alternative options:

ADJUSTMENTS TO YOUR CURRENT JOB

- A change in your working pattern - for example, altering your working hours, working part-time or a job share
- Moving location - if travelling is more difficult for you now, a change of location may be easier
- Working from home - with the advances in IT, this is an increasingly popular option for many people. Even if you do not want to work at home the whole time, being able to do so on occasions can be useful.

[See section on 'Reasonable Adjustments in the Workplace', page 8 for further information]

A NEW JOB

- A change of job within the organisation
- You may choose to stay in your current field but to take up employment with another organisation, perhaps one more suited to your requirements. If you choose to do this, make sure that you are always honest about your health. Withholding information or failing to tell the truth could cost you your job. (That is not to say that you have to 'volunteer' any information you are not asked for).

A CHANGE OF DIRECTION

- Voluntary work - this can provide you with a challenge whilst allowing you to give something to others. Voluntary work can also be a good way to ease yourself back into the working world. Arrangements are likely to be more flexible, including shorter hours, in comparison to paid employment. It is a good way to discover how much you are able to manage and then perhaps you can gradually build this up as a stepping stone to paid work.
- Becoming self-employed - if you have the appropriate skills, this may be an option. Generally, a self-employed person has more control over how much work he or she takes on, and when
- A different career - you could consider moving into a role, which has more of a coaching or training focus. Another option might be to retrain

- Retirement - if retirement is an option for you, it may give you freedom to pursue other interests. It is important to be aware that in most pension schemes, once you opt to take your pension, you will not be able to change your mind at a later date. As long as this is your choice and not something forced on you by others, you may find it a helpful option. It is important to note that people with CFS/ME can find it difficult to obtain early retirement on the grounds of permanent ill health due to the fact that a key requirement of nearly all pension schemes is that the ill health and disability being experienced will be (or is likely to be) 'permanent'. This involves a level of prognostic insight by a medical professional that is often unrealistic to predict in this illness. 'Permanency' is more likely to be envisaged when the condition has persisted for many years with good management but without any significant improvement.
- Career Break - Some employers will allow you a period of leave to readjust, recuperate, or simply relax - without resigning from employment.

WELFARE BENEFITS



This is a general guide to benefits. Please note that changes in benefits law are frequent and entitlement to benefits depends on a claimant meeting set criteria.

WHILE YOU ARE IN WORK

Disability Living Allowance (DLA)

- Disability Living Allowance is a cash benefit for people under 65 who need help with personal care or for getting around. Disability Living Allowance does not depend on your income, savings or National Insurance contributions.
- There are two components to Disability Living Allowance:
 - the care component, which consists of three rates: high, middle and low, is for help with things like washing, dressing and cooking;
 - the mobility component is for those who cannot walk or have difficulty in walking due to their illness and is broken down into two levels: high rate and low rate.

Working Tax Credit

- The working tax credit is paid to people on a low income who are in work. The level that you are entitled to will be higher if you are disabled or have children. You may be able to claim if you or your partner are in work at least *16 hours per week, and have at least one child, or are disabled. You may also be able to claim if you are aged 50 or over and have started work of at least *16 hours or more, having been out of work or sick, or if you are aged 25 or over without children or a disability and you work at least *30 hours per week.

Statutory Sick Pay (SSP)

- If you work for an employer, pay National Insurance and earn more than *£82 a week you will usually get Statutory Sick Pay when you are off sick for four or more days in a row. Your employer will pay statutory sick pay for up to *28 weeks. Spells of illness with eight weeks or less between them link and count as one spell. If you are sick after *28 weeks of Statutory Sick Pay, or your employer's obligation to pay your Statutory Sick Pay ends before *28 weeks, you may get Incapacity Benefit. In either case, your employer should give you a changeover claim form (SSP1).

- In order to claim Statutory Sick Pay, after a seven-day period of self-certification you need to obtain a sick note from your GP and give it to your employer. Your employer will arrange for any appropriate Statutory Sick Pay to be paid to you in the same way as your wages.

BEFORE FINISHING WORK

Occupational Pensions

- Advice is normally available through an employee's human resources or personnel department.

Permanent Health Insurance

- Advice is normally gained through the employee's company or personal provider.

Personal Pensions

- Advice can normally be obtained through the pension provider.

AFTER WORK

Disability Living Allowance (DLA)

(see previous entry under section: 'While You are in Work', page 12)

Attendance Allowance

- Attendance Allowance is a tax-free benefit for people aged 65 or over who need help with personal care or supervision to keep them safe. The rules are almost the same as Disability Living Allowance middle and high rates of care.

Incapacity Benefit

- If you are unable to work because of illness and have been unable to do so for more than *28 weeks without a break; are under state pension age and have paid sufficient National Insurance contributions or you are aged over 16 but under 20 (25 if you were in education or training at least 3 months immediately before age 20) you may be able to receive Incapacity Benefit.
- Incapacity Benefit is paid if your Statutory Sick Pay has ended or you are unable to get Statutory Sick Pay. It can be paid at three different rates dependent on how long you have been unable to work and your qualifying criteria.

Income Support (for people under the age of 60)

- Income Support is for people who are not required to sign on for work and have capital/savings of less than *£8,000, or *£12,000 if your partner is *60 or over, or *£16,000 if you live in a care home. You do not need to have paid National Insurance Contributions to claim this benefit. You will not be able to claim Income Support if your partner works *24 hours or more a week.

Carers' Allowance

- You can claim Carer's Allowance if you are aged 16 or over and spend at least 35 hours a week caring for a person getting Attendance Allowance, or Disability Living Allowance (at the middle or highest rate for personal care), or Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension). You cannot claim Carer's Allowance if you are in full-time education with *21 hours or more a week of supervised study or earn more than *£84 a week after certain deductions have been made (such as Income Tax).

RETURNING TO WORK

Permitted Earnings

- Individuals receiving Incapacity Benefit or Income Support on health grounds are permitted to earn up to *£20.00 per week without their benefits being affected, for an indefinite period. If you are on Incapacity Benefit you can also earn up to *£81.00 per week and work less than *16 hours per week (on average). You can do this for up to *52 weeks. If you want to start work under the permitted work rules, let the DWP know using form PW1 obtainable from them.

Protected Benefit

- Incapacity Benefit claimants can have their benefit protected for a year while they try to return to work. In other words, if you attempt to return to work, but find that you cannot manage, you can return to your benefit within a year at its existing rate, without any medical test. The aim here is to prevent the fear of losing benefits becoming a disincentive to attempting to return to work.

Personal Advisors

- The Department for Works and Pensions (DWP) employ 'Incapacity Benefit Personal Advisors' with whom it is possible to discuss the issues of returning to work and benefits. The DWP ensure that approaching them to discuss your situation will not trigger a medical review.

WHERE TO FIND FURTHER HELP, INFORMATION AND ADVICE



ADVISORY, CONCILIATION AND ARBITRATION SERVICE (ACAS)

Provides up-to-date information, independent advice and high quality training. Aims to work with employers and employees to solve problems and improve performance.

Telephone 08457 47 47 47

www.acas.org.uk

CITIZENS ADVICE BUREAU (CAB)

Offers advice on debt, benefits, housing, legal matters, discrimination and employment

Telephone 020 7833 2181 (to find your nearest branch)

www.citizensadvice.org.uk

DEPARTMENT FOR WORK AND PENSIONS (DWP)

Offers information, advice and support on all aspects of working and pensions

Telephone 020 7712 2171

www.dwp.gov.uk

DISABILITY INFORMATION AND ADVICE LINES (DIAL)

Offers information and advice on all aspects of living with a health condition

Telephone 01302 310123 (to find your nearest branch)

www.dialuk.info

DISABILITY EMPLOYMENT ADVISORS (DEA)

Contact through your local Jobcentre Plus office (see page 17).

To find your local office, look in your phone directory or
www.jobcentreplus.gov.uk

DISABILITY RIGHTS COMMISSION (DRC)

Free advice if you feel you have been treated unfairly

Telephone 08457 622633
www.drc-gb.org

DOVE CENTRE

Offers people living in Leeds practical help, support and guidance regarding employment, training, voluntary work and educational courses.

Telephone 0113 2326057
Email: dove@leedsmind.org.uk

EMPLOYMENT ASSESSMENT

An employment assessment with the Disability Employment Adviser (DEA) in your Jobcentre Plus office or Jobcentre can help you find out how your health condition affects the type of work or training you want to do and help you identify your abilities and strengths. You may also be referred to a Work Psychologist for a further assessment of your employment needs. Both can provide specialist support to help people with health conditions get or keep employment. An employment assessment does not affect your benefits and you'll be able to claim travel expenses. To arrange an employment assessment, contact your Jobcentre Plus office or Jobcentre (see below). They will be able to give you details of the Disability Employment Advisor nearest to where you live.

JOBCENTRE PLUS

A section of the Department of Work and Pensions established to help more people into paid work, help employers fill their vacancies and give people of working age the help and support they are entitled to if they cannot work.

To find your local office, look in your phone directory or
www.jobcentreplus.gov.uk

PENSIONS ADVISORY SERVICE (OPAS)

Provide information and guidance on any aspect of pensions

Telephone 0845 6012923
www.opas.org.uk

PAY AND EMPLOYMENT RIGHTS SERVICE (PERS)

Free service for individuals and employers in West Yorkshire who offer advice on any aspect of pay and employment law

Telephone 01924 439587
Email: mail@pers.org.uk

SHAW TRUST

A national charity that provides training and work opportunities for people who are disadvantaged due to disability, ill health or other social circumstances. This can act as a useful stepping stone by enabling you to engage in pre-employment activities in a supportive environment.

<http://www.shaw-trust.org.uk/>
Telephone: 0800 085 1001

WELFARE RIGHTS UNIT

Free, confidential and impartial welfare rights service that offers advice and information on a range of welfare benefits and can help to fill in forms via the telephone or home visits. They hold advice surgeries around the city.

Telephone 0113 214 9006
Email: Welfare.Rights@leeds.gov.uk

INFORMATION FOR YOUR EMPLOYER

The next section is an information booklet that you can separate and give to your employer. This will help them to think about how they could adjust your work role or environment. The Leeds and West Yorkshire CFS/ME Service can also provide your employer with general information about the condition, but if they wish to have any information specifically related to your difficulties we would need your written consent to release this information.

INFORMATION FOR EMPLOYERS



WHAT IS CHRONIC FATIGUE SYNDROME?

CFS/ME is a variable condition that can affect people of all age groups and socio-economic backgrounds. It is estimated that 1 in 1000 people may be affected by CFS/ME, for example this would mean about 750 sufferers in Leeds. Many people with CFS/ME are working-age when they are diagnosed. Therefore, employment is often a significant issue for many of them.

By definition the diagnosis of CFS/ME is only made after an individual has had the symptoms for at least 6 months. The main symptom of Chronic Fatigue Syndrome is a feeling of unusual tiredness that is characteristically made much worse after any activity and is not substantially alleviated by rest. The fatigue is usually both physical and mental. The physical fatigue lasts longer and is more severe than normal. It often has a fluctuating pattern, which is made worse by activity and is not made better by rest. The mental fatigue leads to difficulty in concentrating or muddled thinking. Slips of the tongue and difficulty finding the correct words may cause considerable embarrassment. Some sufferers have difficulty remembering simple things or doing more than one task at a time. Both types of fatigue will significantly affect how people manage normal everyday activities. There may be good and bad days but characteristically any undue exertion has to be 'paid for' later.

Other common symptoms can include aching in the muscles or joints, which become tender to touch, muscle twitching, recurrent sore throats, feeling hot and cold, sweats, mild fever and painful neck glands. Headaches, dizziness and 'fuzziness' are also common and there may be increased sensitivity to loud noises or bright lights. Some people have visual disturbances with blurred vision at times, although their eyes appear normal, when an optician tests their vision. People with CFS/ME can often feel isolated because, although debilitated, they often look outwardly well and may worry that other people think they are pretending to be unwell.

HOW DOES CHRONIC FATIGUE SYNDROME AFFECT A PERSON'S ABILITY TO DO HIS/HER JOB?

Many symptoms of CFS/ME are not visible, for example fatigue and aching in the muscles or joints, therefore people with CFS/ME are often experiencing a range of symptoms that may not be obvious to others. In addition, the condition is variable, and due to the nature of payback fatigue, a person with CFS/ME may be able to do a task one day but may not be able to do this same task the next day, or days, following this exertion. This lack of certainty raises quite complex issues for people with CFS/ME in the workplace.

Consequently, people with CFS/ME will aim to manage their symptoms as best they can in order to alleviate the impact that their health has on work and therefore will often require assistance from their employers in terms of making changes in the way they work or in the type of work they do. It is important to note that being diagnosed with CFS/ME does not alter the person's knowledge or skills. Therefore, time and resources spent in making any helpful adaptations will be worthwhile, especially when considering past investment in individuals. Many adjustments requested will be inexpensive and cause minimal disruption. It is also important to note that as the severity of CFS/ME varies for each individual, reasonable adjustments in the workplace must be considered on the basis of individual need.

Recovery from CFS/ME can undoubtedly affect people's confidence in their ability to function after a long illness absence from work; they may even doubt whether they can cope with the stresses and responsibilities of working life again. We would support a gradual, phased and negotiated return to work, if and when health improves sufficiently. This can include "stepping stones", such as reduced weekly hours for a negotiated period of time, or allowing flexibility for start/finish times and lunch breaks. Occupational health physicians can offer specific advice based on individual need regarding a phased return to work. Proactive involvement from an occupational health physician can be extremely beneficial for the individual with CFS/ME because by engaging the employee early on in a process of occupational rehabilitation, it can prevent further deterioration and loss of work role through the available therapeutic approaches and suggestions on reasonable adjustments. Occupational health physicians can also elicit cooperation from the employer and encourage active participation from the GP and specialist CFS/ME service.

CHECKLIST FOR EMPLOYERS



Can you offer your employee any of the following adjustments at work?

Consider if the adjustments will be effective, practical and improve your employee's output as well as being cost-effective.

AT WORK

- Allowing more regular breaks
- Allocating some of the employee's work to someone else
- Re-arranging work responsibilities/tasks (*for example, exchanging a single demanding project for a job consisting of a number of smaller tasks*)
- Providing training or supervision
- Modifying instructions or assessments
- Arranging for meetings to be held in a location or at a time to suit the employee
- Providing supervision
- Assigning the employee to a different workplace location

MAKING PHYSICAL ADJUSTMENTS TO THE WORKPLACE

- Moving the employee's workstation nearer to a toilet or on the ground floor to avoid frequent use of stairs
- Distancing the workstation from sources of heat
- Providing room-dividers, partitions or other soundproofing or visual barriers to aid concentration

- Reducing noise in the work environment
- Designating a car parking space for the employee's nearest entrance into work
- Improving accessibility - for example, by providing handrails or a ramp

USE OF AIDS AND EQUIPMENT

- Providing an electronic organiser with an alarm (*can help those with memory difficulties to recall important dates, appointments and phone numbers*)
- Using a Dictaphone, for example when taking meeting minutes, to aid memory
- A different computer screen for those who are experiencing sight problems
- Voice-recognition software or an adapted keyboard or mouse for those who find typing difficult
- A special chair for those who cannot stand for long periods

ALTERED WORKING HOURS

- Part-time working
- Job-sharing
- Working from home for some or all of the time
- Starting work later to allow more time for getting ready on a morning and making up time later in the day

MODIFYING RULES FOR TIME OFF WORK

- Allowing paid time off for medical appointments during working hours
- Considering unpaid time off, time-in-lieu or allowing a longer lunch break for appointments, if more appropriate
- Flexibility in taking annual holidays (*for example, allowing someone to use unscheduled annual holiday entitlement at short notice when needed*)

CHANGE OF WORK

- Transferring the employee to fill an existing vacancy
- A change of the employee's job within the organisation