

MANAGING YOUR EMPLOYER

When you are first diagnosed with MND, there are many things to consider. One is when and what to tell your employer. This is very much a personal decision depending on the stage and speed of progression of your condition, your own personality, as well as your employment situation.

Checking out the benefits in any health insurance scheme operated by your employer is certainly a first step, though at this stage you may not yet be aware of the full range of your potential needs. Be careful about doing anything that might restrict your access to these benefits where they exist as they are usually only available to you while you are still on the payroll. Your pension plan may be another area worth checking into. All of this can be done before telling your employer you have received a diagnosis of MND.

Your local Job Centre can advise of schemes and benefits to support people with disabilities in employment. These can be as simple as providing the costs of a taxi to and from work to having someone to actually help you with some tasks.

When Do You Tell Your Employer?

Some things to consider include

- Do your symptoms affect your ability to do your job? Despite

provisions of the Disability Discrimination Act (DDA) there are clearly some jobs someone with MND cannot do. For example, a bricklayer with paralysed arms is unlikely to find a DDA compliant solution that can keep them building walls.

- Are you working on a project that you want to finish, before telling your employer?
- Should you tell your employer so that they have adequate time to plan how to accommodate you in the work place or plan for your replacement? (The DDA makes it a requirement not to discriminate against a person with a disability such as MND.)
- Do not sign anything regarding termination of employment without first getting legal advice. Notice and redundancy payments usually increase with your number of years of service.

What Protections Do You Have Under Legislation?

UK employment law becomes more complicated with each passing year. In general you can claim "Constructive Dismissal" if you feel your employer has contrived circumstances to force you to resign. You can claim "Unfair Dismissal" if your employer dismisses you without due cause. You can use both of these complaints plus the provisions of the DDA if you feel that your disability is underlying your loss of employment. If necessary, consider taking advice from a lawyer who

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

specialises in human rights and employment legislation. Union representatives are not lawyers, so the quality of their advice is probably going to be limited by their experience. To raise a grievance under any of the above headings you need to consult with ACAS, the advisory, conciliation and arbitration service. If they feel your case is sound they will pursue it and call your former employer to account for their actions in a legal setting.

Understanding Any Health Insurance Coverage Provided By Your Employer

In order to access any benefits of an insurance plan, it is important for you to keep a record of the name, phone number, identification, and group number of your insurance plan. You should also note who the subscriber is (you or your spouse), his/her date of birth, and national insurance number. Be warned, though, very few UK health insurance plans apply the expected coverage to chronic, long term, conditions. It is fair to say that anything "long term," "chronic" or "costing them too much," will generally be excluded from the policy.

Contact your health insurance company directly, and ask specific questions about your entitlements.

Always note the date and the person who provided the information. Remember, having any entitlements described over the phone does not guarantee coverage. Your doctor may be asked to write a letter of medical necessity and complete specific forms to verify your medical condition and eligibility for whatever item or service is being requested.

Driving and Property Insurance

If you don't report your disability to your insurance company, your car insurance coverage may not be valid. Driving can

sometimes require fast foot and hand reactions to avoid an accident. Ask your clinician or MND Care Team Specialist about a driving test service that **can** certify your current abilities for insurance purposes. Also, you may need additional home contents and property insurance regarding assistive equipment you have purchased, or renovations that have been done in your home to accommodate your condition.

PENSION PLANS

Group Pension Plans

If you are in a company or other group pension plan, find out what will happen as a result of an MND diagnosis. To ensure that you get your full entitlement, have these questions answered by someone you trust.

- Can you receive some of your pension before age 65, if you are disabled, and unable to work?
- Will payments be made to your spouse if you are no longer alive?

If problems occur, you may need advice from a lawyer with experience with group pension plans.

To minimise tax on death, you may want to make sure that your spouse is the named beneficiary of any pension plan; otherwise your pension plan's value will be part of your estate, and possibly subject to assessment for inheritance tax.

Additional Expenses

Having MND can bring extra expenses, whether you live at home or in a care setting. Although home care is usually much less costly, the expense falls principally on the family, and can become a major consideration in budgeting. This is true even though various agencies and groups provide some forms of help. The

various forms of assistance provided by MND Scotland become, for many people, a critical factor in remaining at home.

Equipment Costs

A person with MND may need some form of assistive device at the time of diagnosis, and in some cases, will proceed through a variety of equipment: - walking sticks, strollers, manual and powered wheel chairs, not to mention home adaptations such as changing the use of rooms, e.g. converting a downstairs family room into a bedroom, fitting ramps and hoists or creating a wet room in place of a family bathroom and the fitting of other specialist aids... The list can go on and on. It is arguable that no other condition requires so much equipment or care. While essential equipment above a certain cost is usually provided for free by local authorities or the NHS there are some low-cost items the person or family are expected to provide themselves, and some occasionally purchase higher cost items too if they consider the need to outweigh the NHS or council waiting times for the equipment.

Home adaptations may require some financial contribution to the cost of the works from the person with MND or their family, who will also have to bear the costs of interior redecoration on completion of the work.

Prescription Costs

In addition to equipment, people with MND take many medications for symptom management. If you have to pay for your prescriptions it is worth considering purchasing an annual prescription pre-payment certificate. In line with the Scottish Government's policy of reducing prescription charges the cost of this certificate has been reduced from £98.70 to £48, in April 2008, then down to £38

and finally £28, before they are ended in 2011. The quarterly pre-payment certificate has also been reduced pro-rata. The cost for a single prescription was cut from £6.85 to £5 in April 2008, with further reductions by £1 in each of the two subsequent years before abolition.

Home Care

Home care assistance and respite care that can allow your relatives a break from caring can also come at a financial cost to the family. The homecare services provided by local authorities vary in their nature and extent across Scotland with different local authorities offering different levels of support and different charges for the services they do offer. Details of how to contact your own local authority to discover what homecare and respite services they can provide are available to download as a separate file. (*Local Councils 2009.pdf*).

Some families feel it is important to purchase a wheelchair accessible van or make substantial modifications to their home to help the person with MND maintain independence. Obviously, these choices come with rather hefty price tags and are a matter of personal choice and circumstances. Funding assistance for some of the associated costs of MND may be available through local authority and central government schemes. Talk to your social worker or MND Scotland Care Team Specialist for more information and referrals to sources of support.

In some cases MND Scotland can help fill the gap between the need for a piece of equipment being identified and then supplied by an OT or other professional through our *Equipment Loan Service*. Speak to your MND Care Team Specialist for information about how this important

service can help you.

State Benefits

MND Scotland employs a welfare rights and benefits advisor who should be able to give specific advice on benefits and entitlements to people and families affected by MND. This service can be contacted at our head office at 76 Firhill Road, Glasgow, G20 7BA, telephone 0141 945 1077.

A bewildering variety of state benefits are possible for those unable to work due to MND. Those under 65 years of age should apply for Disability Living Allowance (DLA) which can open up entitlement to other benefits that are not available to those not on DLA. If DLA is paid before the age of 65 it carries on after your 65th birthday. New applicants cannot apply after their 65th birthday and should instead apply for Attendance Allowance and Carer's Allowance if that is appropriate. Unfortunately these latter two do not give access to the same range of benefits as DLA. For example, you need to be in receipt of the DLA higher rate mobility allowance to qualify for the Motability scheme. The "Directgov" website (see Further Information) is a useful resource to consult, particularly the pages dealing with financial support for those with a disability and the general section on money and tax.

Estate Planning

Whether you continue to work, or are forced to rely on state benefits it is important to make a will in order to simplify the winding up of your estate after death. See our factsheet 14 "Making a Will and Leaving a Legacy for further information.

What is a Living Will?

A living will, sometimes called an

advance directive, is a document that states your written instructions about your wishes for future health or personal care if you are unable to speak for yourself. Personal care includes choices regarding shelter, nutrition, safety, hygiene, comfort, etc. Some people also include their choices regarding "Do Not Resuscitate" orders (DNRs), being connected to machines to stay alive, having surgery, and donating organs within an advance directive.

The role of living wills is ambiguous in Scotland and not fully accepted, however, you can grant a power of attorney to someone giving them the power to make decisions on your behalf if you are sufficiently incapacitated to be unable to make your own wishes known. Your attorney then gives or refuses permission on your behalf. For protection of the vulnerable the "Adults With Incapacity Act 2000" specifies certain treatments and medical procedures your attorney cannot commit you to.

The Adults with Incapacity (Scotland) Act 2000 was one of the first pieces of social legislation passed by the Scottish Parliament. The Act provides a range of options to help those who are or may become incapable of looking after their own financial or welfare affairs. These options are set out in Part 2 of the Act. "Powers of Attorney", Part 3 "Access to Funds" and Part 6 "Guardianship and Intervention Orders."

Factsheets 24, "Powers of Attorney," 25 "Guardianship and Intervention Orders" and 44 "Advance Directives" summarise how you might use these different options. As ever, it is best to take professional advice regarding your options.

Further Information

<http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/index.htm>

<http://www.direct.gov.uk/en/MoneyTaxAndBenefits/index.htm>

Factsheets

Factsheet 4	Benefits in Brief
Factsheet 14	Making a Will and Leaving a Legacy
Factsheet 27	Coping With MND
Factsheet 20	Library and Information Service
Factsheet 32	MND Scotland
Factsheet 29	Telling Children About MND
Factsheet 31	Sources of Support
Factsheet 23	Tools to Help You
Factsheet 42	Being A Carer
Factsheet 44	Advance Directives