

Changes in life roles

Everything becomes different with MND. Remember, that living with change is part of normal life and we are good at adapting to these changes.

Staying in work

A diagnosis of MND does not automatically mean that you will have to stop working. At the same time, it is better to be realistic about what you will or will not be able to continue doing. Physical jobs like building or decorating, for example, will become more difficult, more quickly, than desk-based jobs. Either way, it is important that you discuss your changed situation with your employer or human resources officer sooner rather than later. It may well be that you could work in a different area, reduce your hours, or modify your existing job.

Where to go for advice

The Employment Services Officer at your local Intreo Office can work with you and your employer so that you can continue working. Intreo offer the disabled worker and their employer a range of schemes and grants to cover workplace adaptation, and employee retention.

For more information and to locate your local office please go to www.welfare.ie

If you decide to stop work

If you feel you cannot continue working, carefully consider the options open to you. Can you take early retirement, or would you be financially better off if you take long-term sick leave for the maximum period possible?

Benefits and allowances

Disability allowance

Disability Allowance is a weekly allowance paid to people with a disability who are between 16 and 66 years of age. Disability Allowance is a means-tested payment. To get the allowance your total means must be below a certain amount i.e. any cash income (both your own and your spouse), capital (savings, investments, shares, etc.) and/or maintenance paid to you will be taken into consideration during the application for Disability Allowance.

If you qualify for Disability Allowance you may also get extra social welfare benefits with your payment and other supplementary welfare payments.

Illness (Disability) benefit

You may get Illness Benefit if you cannot work because you are sick or ill. Illness Benefit was known as Disability Benefit. The name of the benefit changed in 2006.

How illness benefit works

This benefit will vary depending on whether you are entitled to sick pay from work or not. Your employer can decide their own policy on sick pay and sick leave. You will need to check the policy around sick pay and sick leave in your workplace.

If you can receive sick pay from work, your employer will probably require you to sign over any Illness Benefit payment from the Department of Social Protection for as long as you receive sick pay from work. When your sick pay ends, your employer should stop getting your Illness Benefit.

Alternatively, if you are not entitled to sick pay from work you may get Illness Benefit if you have enough (PRSI) social insurance contributions as set out below:

Invalidity pension

Invalidity Pension is a weekly payment to people who cannot work because of a long-term illness or disability and are covered by social insurance.

To be eligible, you must be getting Illness Benefit for at least twelve months before you claim Invalidity Pension. However, it may be possible to get Invalidity Pension after a shorter period if you are unlikely to be able to work for the rest of your life because of your illness or disability, which is fairly common for people with MND.

The Invalidity Pension is taxable and should be reported to your tax office as soon as your payment starts. You can contact the Revenue Commissioners www.revenue.ie for more information. You may be entitled to a free travel pass you may also get extra social welfare benefits.

Finally, some people do not feel that they are 'disabled' and therefore not entitled to make a claim. However, the term 'disabled' simply means that you have an illness that affects your ability to do everyday things. It is your right to claim these benefits if you meet the qualifying criteria.

For Carers

Full time carers may be entitled to support from the Department of Social Protection.

Carer's allowance

This is a means tested benefit available to a carer providing full time care to a qualifying person. The person being cared for must be incapacitated and require full time care and attention and must be likely to require it for at least 12 months.

While receiving the allowance, a carer cannot be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week.

Assessment for the Carers Allowance is based on any income you and your spouse/partner have or property apart from your home or an asset that could provide an income.

If you leave work to become a full time carer and receive the Carers Allowance you will also be awarded PRSI credits.

Carers benefit

This is a payment made to insured persons in Ireland who leave the workforce to care for a person(s) in need of full time care and attention.

You are entitled to Carers Benefit for up to a maximum of 104 weeks either over a continuous period or within a number of separate periods of time.

Income tax - home carers tax credit

A tax credit may be available to married couples who are jointly assessed where one spouse is a home carer for someone who is over 65 or is permanently incapacitated. There are limits applicable to the level of income of the home carer.

The qualifying rules are complicated, so it is advisable to talk to the experts before filling out a claim. For more information and to obtain the IT 66 application form for Home Carer's Tax Credit contact one of the following offices or visit www.revenue.ie.

Medical Card

The Medical Card is something we would recommend all clients with a diagnosis of MND apply for as soon as possible for full access to health services. The Medical Card covers:

- Free GP (family doctor) services
- Prescribed drugs and medicines
- In-patient public hospital services, out-patient services and medical appliances
- Some personal and social care services, for example, public health nursing, social work services and other community care services

For more information on any of these Benefits and Entitlements and to seek help or advice on which benefits are most relevant to you go to: www.citizensinformation.ie or www.welfare.ie

Getting around

Primary Medical Certificate

This Certificate entitles its holder to a number of tax reliefs associated with buying or using an adapted vehicle for drivers and passengers with a disability. The tax reliefs include:

- Remission or repayment of vehicle registration tax (VRT)
- Repayment of value-added tax (VAT) on the purchase of a vehicle
- Repayment of VAT on the cost of adapting a vehicle

Disabled Parking Permit Scheme

This scheme was born out of a basic necessity to maintain independence for people with limited mobility. A person with a disability requires access to a disabled parking bay because of its size (accessible parking bays are larger than the standard parking space) and their proximity to daily facilities. This gives vital access to: work, shops, bank, social events, etc. that would otherwise severely restrict people with disabilities entitlement to participate in society.

The parking cards are issued by the Irish Wheelchair Association and the Disabled Drivers Association. Application forms are available from either organisation.

Nursing Home Support Scheme

The Nursing Home Support Scheme, also known as the 'Fair Deal', provides financial support to people who need long term nursing home care. The scheme is operated by the Health Service Executive (HSE) and replaces the Nursing Home Subvention from 27 October 2009.

Under this scheme you make a contribution towards the cost of your care and the State pays the balance. The scheme covers approved private nursing homes, voluntary nursing homes and public nursing homes. You can get the list of approved nursing homes from the HSE - visit: www.hse.ie click through to Find Health Service then click on Older People Service then click on Nursing Home Support Scheme.

Anyone who is ordinarily resident in the State and is assessed as needing long-term nursing home care can apply for the scheme. For more information on nursing homes in Ireland contact your local HSE health office or visit www.hse.ie or contact Nursing Homes Ireland and ask about their guide on how to choose a nursing home www.nhi.ie

For information on how to apply, contact your local HSE health office or visit their website at www.hse.ie or alternatively visit www.citizensinformation.ie

Prescription costs

Under the Drugs Payment Scheme an individual or family, who reside in Ireland, are expected to pay a maximum of €120 (current rate) per month for approved prescribed drugs, medicines and certain appliances.

Anything over this amount can be reclaimed using the Drug Payment Scheme.

Contact local HSE health office for more information on this or visit www.hse.ie website.

Medical card holders are entitled to approved prescribed drugs and medicines free of charge so they are not eligible for this scheme. Applications for a medical card are subject to a means test.

Housing

“Was our house suitable? If not, what would we need to do to be able to live as normal a life as possible? Should we move to a bungalow? We decided to stay put and have alterations made to the home...”

Something many people think about when they are diagnosed with MND is whether their home is going to be suitable in the longer term. It is worth remembering that there is often a great deal you can do to adapt your home to your needs. Moving house is also an option. Both are a huge step, fraught with physical and emotional upheaval, not to mention the expense. Whatever your decision the Occupational Therapist is the best person to speak to for advice.

The community HSE Occupational Therapist cannot complete your adaptation report. Your local authority may be able to arrange for an Occupational Therapist to visit your home but under the Housing Adaptation Grant for People with a Disability, you can employ an Occupational Therapist to carry out an assessment and recoup up to €200 as part of the total grant.

Refer to the listings from the Association of Occupational Therapists of Ireland www.aoti.ie

Adapting your home

The Housing Adaptation Grant for People with a Disability can be made to help meet the cost of adapting a property for a disabled person. The grant can help toward the cost of changes and adaptations to your home, allowing you to make it wheelchair accessible, or allowing the addition of a ground floor bathroom or toilet or stair-lift.

Your application will be based on medical need. There are three levels of need. Priority will be given to a person based on medical grounds. Ordinarily, a person with MND will fall into priority level 1.

If you only require minor work you can apply for the Mobility Aids Grant Scheme instead. You must satisfy the means test to be eligible for the scheme and it is worth noting that you cannot receive both the Housing Adaptation Grant for People with a Disability and the Mobility Aids Grant Scheme.

For more information, visit www.citizensinformation.ie or contact your Local Authority.

Council tenants

Your local council may consider moving you to a more suitable property. Remember though that these are often in short supply and there is likely to be a waiting list. It is also worth talking to your Social Worker or Citizens Information Centre for advice on available grants to help with the cost of fixtures and fittings you will need if you do move.

Financial advice

Anyone can find it difficult to manage their money even in ordinary circumstances. It can be particularly difficult and worrying, however, if you unexpectedly find you cannot work and your income falls sharply.

Getting advice

If you get into difficulties and are faced with bank charges for being overdrawn, arrange a meeting with your bank or building society. They are a good source of general advice about managing your money and can help you set a realistic amount to be paid back in instalments - but they can only help if you talk to them.

If you have a mortgage, tell your mortgage lender about your changed circumstances and let them help you - again, they can only do so if you talk to them.

There are many charities, such as professional trade and benevolent funds or ex-service organisations that will help with unexpected expenses - your local Citizens Information Centre will have details.

Debt

Sometimes, getting into debt is unavoidable but that doesn't make it any less stressful and worrying. Your local Citizens Information Centre is a good place to go for advice, or you could contact one of the specialist advisory services such as MABS (Money Advice and Budgeting Service) Monday to Friday 9am – 8pm, www.mabs.ie

Conclusion

For information, advice and advocacy on services to people with Motor Neurone Disease, their families and carers please contact Freephone 1800 403 403 or email services@imnda.ie