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I wish I'd known that a year ago – Republic of Ireland

If you have been diagnosed with MSA recently there are a number of things that it is important you know about, even if they are not relevant at the moment. This factsheet aims to provide basic information along with links to more detailed guidance. We are here to offer information and support so please don't hesitate to contact us if you need more information, have questions or are worried about anything related to your MSA diagnosis.

Getting out and about

If your ability to walk reasonable distances is limited or deteriorating, you may be considering getting a mobility scooter. Before getting one it is important to consider a number of factors. Before buying it is strongly recommended that you seek the advice of an Occupational Therapist on the suitability of the scooter to your needs. It is recommended you try out and compare a range of vehicles from different suppliers if possible.

If the scooter is being provided by the health services, the Occupational Therapist and wheelchair service provider will be able to assist you in selecting the most suitable vehicle for you.

The Irish Wheelchair Association also provides a range of services including the loan of wheelchairs, the provision of home care, day care and respite/holiday care and advice on motoring and housing amongst other things. Telephone: 01 818 6400. Website is www.iwa.ie.

Taking holidays, in Ireland or abroad, can be important and we have a specific factsheet about this including details of companies who may offer travel insurance to people diagnosed with MSA. It also lists specialist travel agents and advice services. You can download it here - <https://www.msatrust.org.uk/support-for-you/factsheets/>.

There are keys (known as Euro Key) which unlock disabled toilets in many public places in Ireland and Europe. They are available from J. Williams Locksmiths, 8 Whitefriars, Aungiers Street, Dublin 1. Tel: 01 4756307. Mobile: 087 2438053. The key costs €20 and can be sent by registered post for an extra €14.50.

'Just can't wait' cards are available from <https://www.bladderandbowel.org/>. These cards can be used discreetly when you urgently need to use a toilet when out and about. There is also a phone app (Wheelmate) which can be downloaded and used to locate the nearest toilet facilities.

Driving

A Primary Medical Certificate can be issued by the Health Service Executive and certifies that a person is severely and permanently disabled for purposes of the Disabled Drivers and Disabled Passengers Regulations 1994. Holders of a Primary Medical Certificate may qualify for tax relief under The Disabled Drivers and Disabled Passengers Scheme. Certificates can be applied for through Local Health Boards.

A Disabled Persons Parking Card (also known as a European Parking Card) is available from either the Disabled Drivers Association (www.ddai.ie), telephone 094 930 4054 or the Irish Wheelchair Association, www.iwa.ie or telephone 353 45 893094. Holders of Primary Medical Certificates have an automatic entitlement, other people will need to complete an application form explaining the nature of their disability. Cards cost €35 and are valid for 2 years. They can be used within the European Union.

Relief in respect of Vehicle Registration Tax (VRT) and Value Added Tax (VAT) may be obtained on the purchase of a vehicle up to a specified limit. A Primary Medical Certificate will be required. For detailed information about tax relief in respect of driving and vehicles please see:

https://www.citizensinformation.ie/en/travel_and_recreation/transport_and_disability/.

We also have a factsheet on driving. Please see- <https://www.msatrust.org.uk/support-for-you/factsheets/>.

Benefits

Disability Allowance

This is a weekly allowance of €232 for people aged 16-65 years who have a disability. To qualify for Disability Allowance (DA) you must be substantially restricted in undertaking work as a result of your disability. This is a means tested benefit, and it takes into account income for both you and your partner, but not the value of your home. The first €50,000 of any savings is disregarded.

Up to €165 a week from a disabled persons employment is disregarded and 50% of the earnings from €165-375 a week is disregarded.

For more information, and to apply: <https://www.gov.ie/en/service/df6811-disability-allowance/#apply>

Illness Benefit

This is a taxable benefit that is paid to people who are ill and who satisfy the social insurance requirements. It is not linked to benefits paid by an employer. It is paid for up to one to two years depending on a person's contribution record. You cannot work and get Illness Benefit. The amount paid is linked to your average weekly earnings.

You must apply for Illness Benefit within 6 weeks of becoming ill. To claim online you will need a MyGovID account: <https://services.mywelfare.ie/en/topics/health-disability-illness/illness-benefit/>

You will also need a medical certificate completed by your GP, which they can complete electronically.

For more information call 01 704 3300 or email illnessbenefit@welfare.ie.

Invalidity Pension

This is a taxable benefit paid to people who are unable to work because of a long-term illness or disability. It is only payable to people who have sufficient social insurance contributions. The current rate is €237.50 a week for the claimant with additions for some other family members.

For more information, and to apply: <https://www.gov.ie/en/service/d148b9-invalidity-pension/>

Partial Capacity Benefit

This is a benefit which permits someone to work part time and still receive some support. Individuals are assessed as having a mild, moderate, severe or profound level of restricted capacity for work and the level of support reflects this assessment. A Medical Assessor will examine your claim and determine your entitlement based on the qualifying conditions outlined. You may be required to attend a medical assessment.

Participation in the Partial Capacity Benefit scheme is voluntary and you can return to Illness Benefit or Incapacity Benefit if, for example, your condition worsens or your job comes to an end.

You may not work until you have received written approval to do so from the Department of Employment Affairs and Social Protection. You should also get the approval of your doctor before taking up employment.

There is no restriction on earnings or number of hours you can work. You can work in a self-employed capacity while getting Partial Capacity Benefit. You cannot get Partial Capacity Benefit and Working Family Payment (formerly known as Family Income Supplement) together. You can get Partial Capacity Benefit and a half-rate Carer's Allowance together.

Further information, including how to apply, can be found here: <https://www.gov.ie/en/service/c79268-partial-capacity-benefit/#apply>

Workplace Support

Practical supports and allowances are available to employers of people with illnesses/disabilities to assist their participation in the workplace. Further details are available at www.welfare.ie/en/pages/workplace-supports_holder.aspx.

Carers Allowance

This is a means tested benefit for people who care full time for someone that requires constant supervision. Payment is made up of a personal rate of €248 per week if you are under age 66, or €286 per week if you are over age 66, plus extra amounts for any child dependants, or if you care for more than one person.

To qualify for Carers Allowance the carer must be 18 or over, must live with the person in need of care (or be in a position to provide this care) and must not be in employment or study for more than 15 hours each week. The means test looks at the carers income and disregards all Department of Employment Affairs and Social Protection benefits, as well as the first €350 a week of a single carer's income or the first €750 of a couple's weekly income. People in receipt of Carers Allowance may also be entitled to the Household Benefits Package (if they live with the person they care for) and free travel.

Carers getting certain social welfare payments may be entitled to retain these and get a half rate Carers Allowance. Two people may share one Carers Allowance as long as each person cares from Monday to Sunday – this can be on alternate weeks.

A Carers Support Grant is paid to everyone in receipt of Carers Allowance, Carers Benefit and Domiciliary Care Allowance (a benefit for people caring for people under 16) annually. It is paid automatically to those receiving Carers Allowance but other carers may be entitled. If a carer cares for more than one person a Carers Support Grant is paid for each person they care for.

An application form plus further information is available here: <https://www.gov.ie/en/service/2432ba-carers-allowance/>

Carers Benefit

This is a benefit paid to people aged 16-65 years who give up work to care full time for one or more people who require constant supervision. It is based on insurance contributions and is taxable, and the current rate is €249 per week when caring for one person. The carer must live with the person they care for (or be in a position to provide this level of care). Carers Benefit does not entitle people to the Household Benefits Package or to free travel.

For further information see: <https://www.gov.ie/en/service/455c16-carers-benefit/>

Carers Leave

Subject to certain conditions employees are entitled to take up to 104 weeks of unpaid leave from their employment and have their jobs kept open for them for this period.

You can get more information from the [Workplace Relations Commission's Information and Customer Service](#).

Homemakers Scheme

People who take time away from work to care full time for children aged under 12 years and/or a disabled person may be eligible for social insurance credits under a Homemakers Scheme. Further details on this scheme are available here:

<https://www.gov.ie/en/service/e216c5-homemakers-scheme/>

Supplementary Welfare Allowance

This is a means tested benefit for people who do not have enough income to meet the needs of themselves and their family. It is *not* a taxable benefit. It may be paid to people out of work or whose earnings need topping up because they are below the Supplementary Welfare Allowance rate. It can be paid whilst waiting for other benefits but monies paid in these circumstances will be recovered. The current rate payable is €240 per week. To apply, contact the Department of Social Protection's Community Welfare Service at your local Intreo Centre or Social Welfare Office, or you can find further information [here](#).

Household Benefits Package

Everyone aged over 70 years is entitled to help with gas and electricity and to a free TV licence. Some people aged under 70 are entitled to the Household Benefits Package including those in receipt of disability and means tested benefits.

You can now apply on www.MyWelfare.ie using this [link](#).

Free Travel

Free travel is available to everyone aged 66 years and over. It may also be available to people under 66 years who are in receipt of some other benefits including Incapacity Pension, Partial Capacity Benefit and Carers Allowance.

For further information and to apply, please see: <https://www.gov.ie/en/service/9bba61-free-travel-scheme/>

Living Alone Increase

This is an extra payment (€22 a week) for people in receipt of social welfare payments who live alone. It is payable to people aged 66 years and over who have a state pension (contributory or non-contributory) and/or certain other benefits. It can be paid to people who live independently in a granny annexe (with its own dining and sleeping facilities) and in sheltered accommodation. It can also be paid to elderly or frail people who have a friend/relative to stay at night or who go to a friend/relatives house at night.

To apply complete the LA1 online form or contact your local Intreo or Social Welfare Office.

Managing Financial and Other Affairs

If you become unable to deal with your affairs, there are various legal arrangements you can make to have someone do these things on your behalf. The choice of legal arrangements open to you depends on your precise circumstances. Some of the arrangements are very simple to make and have limited effect, for example, appointing an agent to collect your social welfare payment. Others are complex and require the help of legal and medical professionals, for example, executing an enduring power of attorney. It is advisable to take legal advice before entering into the more complex arrangements. You can find more information here:

https://www.citizensinformation.ie/en/health/legal_matters_and_health/legal_arrangements_f_or_incapacity.html.

Medical cards

Unless you have a medical card or GP visit card, visits to GP's are not free. If you have a medical card you don't have to pay to see your doctor or for the medicines they prescribe. A medical card also covers public outpatient and inpatient services, eye and ear tests and dental checks. A GP visit card only covers GP visits and blood tests to diagnose or monitor a condition.

Anyone can apply. A small group qualify automatically. It is means tested. When applying you need to include details of income (from all sources) and expenses. Details of the exact income levels for medical cards is available on: <https://www.hse.ie/eng/cards-schemes/>.

Cards can be applied for online. To apply or renew go to www.medicalcard.ie. Paper forms can be downloaded or can be obtained by ringing 1890 252 919.

If you are aged 70 or over you also qualify for a GP visit card. To apply go to: www.gpvisitcard.ie or call 1890 252 919.

People who are terminally ill can have an Emergency Medical Card. The application is made by a health professional and contains a detailed medical report. There is no means test. Speak to your GP, specialist or hospice for more information and to request that the card is applied for. It seems not to be well known about and is not mentioned on websites that relate to medical cards.

If you have certain medical conditions (including 'Parkinsonism') you can apply to join the Long-Term Illness Scheme. This scheme is not means tested. It allows people to obtain medicines and surgical appliances that are related to their condition free of charge. See: <https://www.hse.ie/eng/services/list/1/schemes/lti/> for more information and to apply. Forms are also available from local health offices.

Help with Managing at Home and in the Community

Community Care Services, provided by the HSE cover: Physiotherapy, Occupational Therapy, Chiropody, Social Work, Speech and Language Therapy and Dietitian support. Therapy services are free to holders of medical cards. Community Care Services also include day centres and home help. Further information about your local services can be obtained from your GP or Local Health Office.

The HSE Home Support Service (formerly called the Home Help Service or Home Care Package Scheme) aims to support older people to remain in their own homes for as long as possible and to support informal carers. Services include additional home help hours, nursing services, therapy services, and other services which might be needed due to illness or disability - or after a stay in hospital or nursing home. Community services include home help, nursing, physiotherapy, occupational therapy, speech & language therapy, day care services and respite care. Services may be provided directly by the HSE by its own staff, or by other agencies.

You do not need a medical card or a means test to obtain home support services. Any support received will be based on your assessed care needs.

To apply you will need to complete an application form. Details and the form can be found here: <https://www.hse.ie/eng/home-support-services/apply-for-home-supports-services/applying-for-home-support-services.html>.

After you apply, the HSE will carry out a Care Needs Assessment. This will look at your overall health care needs as well as your social circumstances. It will also look at what level of care you are currently receiving and what other supports you may need. To get a Home Care Package, this assessment has to confirm that enhanced levels of service/support are required otherwise it will be refused.

Non-Statutory Services that may help

In every area there will be a range of services provided by voluntary organisations or by private providers. Examples would include day centres or befriending schemes.

Many hospices also have a range of services offering ongoing support to people with progressive neurological conditions. Hospice support is not only for end of life care but is about improving quality of life. Each hospice is different but many offer day hospice support, regular home visits by trained volunteers and access to specialist advice. Your GP can refer you.

Obtaining equipment

Equipment that aids your independence at home, or which assists your carer, can often be obtained via your Occupational Therapist or Public Health Nurse. Walking aids and wheelchairs are usually provided free to medical card holders and people on the Long-Term Illness Scheme. Should you wish, or need, to purchase equipment privately obtain advice from a relevant professional (typically an Occupational Therapist, Physiotherapist or Nurse).

If you require help with obtaining the equipment you need, please contact our Social Welfare Specialist Service by calling (+44) 0333 323 4591 or emailing support@msatrust.org.uk. We do have a small grants budget – please contact us if you would like to apply for a grant. Help can also be given to apply to other organisations that provide grants.

The Mobility Aids Grant Scheme is available to older/disabled people with a household income of less than €30,000 a year. It can help with the cost of purchase and installation of things like grab rails, level access showers or ramps. The maximum grant is €6,000 and this can be for up to 100% of the cost of the work. The grant does not cover VAT on the work. However, you can apply for a VAT refund for any appliances that you need and the cost of installing them. The scheme is administered by your Local Authority.

Housing Grants

A housing adaptation grant is available where changes need to be made to a home to make it suitable for a person with a disability to live in.

The grant can help you to make changes and adaptations to your home, for example, making it wheelchair-accessible, extending it to create more space, adding a ground-floor bathroom or toilet or a stair-lift, or in some cases, the provision of heating.

The scheme is administered by Local Authorities. It is means tested with household income over €30,000 a year assessed. The maximum grant is €30,000 unless your house is under a year old in which case the usual maximum is €14,500. The grant is expected to cover all adaptation needs but a further grant can be applied for in the future if needs change.

Grant applications are prioritised according to need and categorised as 1, 2 or 3 with level 1 being the highest priority. Grants are subject to local authority funding and they may not always pay the full amount. In this case you may be able to get a local authority home improvement loan.

The Housing Aid for Older People Scheme is used to improve the condition of an older person's home. In general, it is aimed at people 66 years of age and older, who are living in poor housing conditions. However, in cases of genuine hardship the local authority may assist people under age 66. It covers essential repairs to make a property habitable, for example, re-wiring. The maximum grant is €8,000 which can cover up to 95% of the cost of the work.

For further information on Housing adaptation grants can be found here – https://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/.

Support for Carers

Carers need support and many carers leave it a long time before asking for help. It is a good idea to request help at an early stage so the risk of a crisis developing is lessened.

Family Carers Ireland is a charity which offers information and support to carers. They have a Careline – 1800 240 724 staffed Mondays to Fridays 9am until 8pm and Saturdays 10am until 12pm. Outside these hours callers can choose to stay on the line to talk to someone from the Samaritans. Family Carers Ireland provides information on local carers services as well as training and respite break weekends amongst other services. They have a guide called The Carers Companion which can be downloaded from their website - www.familycarers.ie.

Many carers also find the online forum HealthUnlocked a convenient and helpful way of asking questions of other carers and people living with MSA. You can access this by going to <https://healthunlocked.com/msa-trust>. Our Support Groups are also a helpful and supportive way for carers to get together, both online and in person. You can read more about this at <https://www.msatrust.org.uk/support-for-you/local-support/>

Voice Banking

Many people living with MSA notice that their voice becomes softer or quieter over time making speaking difficult and their speech possibly unintelligible. This can cause frustration, both for the person living with MSA and their family. Because of this, the MSA Trust has entered into a contract with a company who support voice banking. Through voice banking a version of your voice can be banked whilst it is still reasonably clear and used with various devices to aid communication in the future. It is important that this is considered at an early stage and that you discuss it with your Speech and Language Therapist. Where the therapist recommends it we can provide the service free of charge. Please see:

<https://www.msatrust.org.uk/support-for-you/for-people-affected-by-msa/voicebanking/>.

Vulnerable Person Scheme (Electricity supply)

If you rely on electrically operated/powered medical equipment ask your electricity supplier to put your name on the vulnerable customer list. See <https://www.esbnetworks.ie/who-we-are/customer-service/vulnerable-customer-policy> for more information.

Nursing Homes Support Scheme/Fair Deal Scheme:

You can apply for financial support to help pay for the cost of care in a nursing home through the Nursing Homes Support Scheme (NHSS), also known as the Fair Deal scheme. This scheme is managed by the Health Service Executive (HSE).

Under Fair Deal, you pay a certain amount towards the cost of your care and the HSE pays the rest.

You need to be approved before you can receive funding for a nursing home. There is a three stage process:

1. Care needs assessment
2. Application for means tested state support
3. The option to apply for the Nursing Homes Loan (Ancillary Support)

The means test covers income and savings and does include property but there are upper limits to the amount that is contributed from the value of your home. People pay a 7.5% contribution based on their principle residence for each year – for a maximum of three years. If you opt for a Nursing Homes Loan these payments can be deferred until after your death (and after the death of any partner you may have who lives in your home). The first €36,000 of a single persons assets are not counted when the assessment is made. For a couple the figure is €72,000.

If you are in hospital, but no longer need acute care, then you can be charged for long-term care in that hospital. If, for example, you are waiting to move to long-term care, then you should apply for the NHSS scheme as soon as possible.

There is a set level of funding for the scheme each year, so there may be situations where a person's name goes onto a waiting list until funding becomes available. If this is the case the HSE will let you know when it writes to advise you whether you are eligible for State support.

There is detailed advice on www.hse.ie and on www.citizensinformation.ie Citizens Information can also provide telephone advice. Their number is 0761 07 4000 and they are open Mondays to Fridays 9am until 8pm.

Six Things... If you do just six things do these...

1. Get a benefits check
2. Have a care needs assessment (and ensure your carer has a carers assessment) and accept care support if needed
3. Look into arranging Enduring Powers of Attorney
4. Plan ahead with respect to housing and adaptation needs
5. Maintain your network of family and friends and accept their help
6. Do things you enjoy.

Further information

The MSA Trust offers information and support in a number of ways.

Please call (+44) 0333 323 4591 for our main office support line or email support@msatrust.org.

If you have questions relating to your diagnosis or your care needs you can contact one of our MSA Health Care Specialists.

You can visit our website at www.msatrust.org.uk.

The HSE information line is 1950 24 1850 and they are open Monday to Saturday 8am until 8pm. Website: www.hse.ie

Citizens Information can also provide telephone advice. Their number is 0761 07 4000 and they are open Mondays to Fridays 9am until 8pm. Website: www.citizensinformation.ie

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References for this information sheet are available by contacting support@msatrust.org.uk.

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