

Carers

“The realisation that I would need help from other people only dawned slowly. At first I wanted to be completely independent. I also felt that by doing everything myself, in relative secrecy, I could somehow pretend to the outside world that things weren’t so bad. However, as he began to require more attention I had correspondingly less time for other things and was soon very glad of any help offered.”



Here’s a simple question: are you helping to look after a relative, friend or neighbour with MND who could not manage without help? If the answer is yes, then you are a carer, although you probably wouldn’t describe yourself as such. In fact, most people don’t recognise themselves as ‘carers’ - they see themselves as people - including children - trying to do the best they can in a difficult situation.

Who is a Carer?

- You might be any age - young, old, adult or child
- You could spend anything from a couple of hours a week to 24 hours, seven days a week, caring for someone
- The type of care you provide could involve checking the person with MND is okay, shopping or household tasks, helping with personal care, feeding and night care
- You might not live with them
- You might not be related to them
- You might not be the next of kin

“A carer is someone of any age whose life is restricted because they are looking after a relative, friend, partner or child who cannot manage without help because of illness, age, or a disability of any kind.”

The topics covered in this section are:

- Looking after yourself
- Your emotions and feelings
- The different types of carers
- Practical advice and benefit entitlement

Looking after yourself

“When I speak to carers, I always ask how they are getting on...are you getting all the help you really need? Because, whatever else happens, you the carer are the one who needs to keep going.”

It cannot be over-emphasised just how important it is that you look after yourself as well as looking after the person you are caring for. You need the emotional and physical strength to cope and if you allow yourself to get run down you won’t be able to care for anyone. Here are a few important things to bear in mind:

Eat well

Carers sometimes get so overwhelmed by providing the right food at the right times for the person they are caring for that they have no time, energy or inclination to feed themselves properly. A healthy, well-balanced diet for you is essential. If the person you are caring for is no longer eating and drinking it becomes even more important to make the effort.

Making the most of your health care team

- Does your GP know that you are a carer? If not, it's important that they and the practice in general do – they will know you are under pressure and try to give you the help you need
- Don't try to 'tag on' any concerns about your own health at the end of an appointment for the person you are caring for – you and your doctor both need to be focussed on what's bothering you
- Your local GP's surgery is a good place to find information about local support groups and carers' centres
- Make sure that the person you are caring for has informed the doctor that they are happy for medical information to be shared with you
- Make sure that everyone involved in looking after the person you are caring for – health workers and Social Workers – clearly see you as an equal partner in the overall care team. Don't let yourself be sidelined or be afraid to speak up if something's worrying you
- Prepare for any appointment so that all involved know what problems you are facing and what help you need, for example:
 - Is your health worrying you?
 - Are you getting enough sleep?
 - Do you have any aches and pains (such as back ache)?
 - Are you stressed or depressed?
 - Do you need help with any of the caring tasks?
 - Are you isolated or lonely?
 - Are you worried about money?
 - Is your sex life affected?
 - Do you know how to get emergency help if needed?
 - Do you have a plan with your GP covering what needs to happen if you fall ill or have an accident?

Stay fit

Try to do some sort of exercise every day. Some of the things you could consider are:

- Going for a walk – it's cheap, easy and effective
- Using one of the many exercise videos now available – particularly helpful if you find it difficult to leave the person you are caring for
- Joining a club – not always the cheapest option but the good ones have qualified staff on hand to help and advise you

Remember, though, that you should talk to your GP before starting any new exercise, particularly if you are older or unfit to start with. It wouldn't do any good to injure yourself!



Relax

We all need time to ourselves but this is particularly true if you are spending a lot of your time caring for someone else. Some ideas to help you relax include:

- Aromatherapy
- Yoga
- Reflexology
- Massage
- Listening to music

Train

No one was born to be a perfect carer so it can make a real difference to learn various skills or coping strategies

through books, carers groups or training courses. More information can be obtained from the IMNDA office or the Carers Association, Tel: 057 9322920 / 057 9322664.

Some carers' centres run courses on:

- Looking after your back – essential in safe lifting and moving
- Basic first aid
- Handling stress
- Coping with guilt
- Information needs
- Benefits information
- Medicine 'Matters'

Short breaks

“One of my failings was the desire to do everything for him myself. It made him completely dependent on me and he never really trusted anyone else to get it right. This meant leaving him for any time was fraught with difficulties.”

It really is a good idea to give yourself a short break away from caring – and the sooner you start this the better. Carers often feel guilty about needing, wanting or indeed taking a short break but the benefits to both you and the person you are caring for will far outweigh any negatives. Breaks away from each other will also give you the opportunity to have different experiences, just as you would in normal life.

Short break care can mean either someone coming to you or the person you are caring for going somewhere else:

- A person coming to your home, usually for a few hours each week, to let you shop, see friends, pursue some leisure activity or even get a few hours of undisturbed sleep
- The person you are caring for going on some form of residential break, either day care or residential care, to let you go on holiday or simply have a rest
- There are several schemes around the country catering specifically for the needs of **young carers** - ask at your local carers' centre for details

→ See 'How The IMNDA And Other Organisations Can Help' section for useful contact details.

Holidays

Even though you may think a holiday is out of the question or even a selfish desire on your part, they can make a real difference to your ability to cope. You may want a holiday away from the person you are caring for, in which case cover will need to be arranged. Alternatively, you may both want to go on holiday together and there are several places that offer special facilities and support.

→ See 'Movement and Mobility' section for more information on Travel.

Some information on adapted holiday accommodation is available from the IMNDA office.



Finding out what's available

Carers often feel isolated from the 'outside' world and this can be made even worse by any difficulties in finding out about the range of services available to them. At the same time, some carers don't have anyone close by simply to talk to, discuss things through with or to help with making plans. Remember that the MND Nurse Specialist is a phone call or email away. Remember too that by keeping up with your friends, even by quick calls, and any interests or hobbies will keep you anchored in that 'outside' world that can seem so remote from time to time.

Be constructive

Caring for someone with MND does mean a lot of waiting – in the doctor’s surgery, for home visitors, for results of tests and so on. Use this time constructively with your loved one. Learn something new together, do quizzes, read aloud - whatever you like.

Live for today

It is a cliché but take each day as it comes. Try to stop worrying about the ‘what ifs’ or the ‘whys’ – worrying about the future will not change what is going to happen. At the end of each day, look back and recognise two things, however small, that went well. You need it for your self-confidence so never, ever underestimate your ability to cope.

Laugh and cry

Anyone in a stressful situation will go through a whole range of emotions – anger, guilt, frustration, sadness and despair. All are normal and you are likely to experience all of them at some points over the coming months or years. Accept that it is all right to feel this way, so don’t feel guilty and don’t try to bottle up the feelings. Keep your sense of humour and enjoy the funny side of things, you have to find a balance.

Other useful ideas

Many carers find it useful to keep a card giving information about the person they are caring for in their car, wallet, bag or jacket. This can give piece of mind in an emergency. Record the name and contact details of their doctor and someone close by. In case of theft, it is not advisable to leave their direct contact details.

Your emotions and feelings

“I used to feel guilty that I could still go for a walk, chat with friends, prepare and eat a meal. I could still do those things but they gave me no pleasure knowing that my partner would never again be able to enjoy them”. When someone you love has MND, the chances are that you will experience a whole range of emotions at different times. All are perfectly normal and should not be suppressed or allowed to overwhelm you. You may feel ‘bad’ or ‘selfish’ about some of the feelings you have but if you talk to anyone caring for someone, you will find out very quickly that you are not alone.



Some common reactions are:

Grief and despair

When someone we love is diagnosed with MND, it is a major shock. Most of us expect to live long, healthy and fulfilled lives, often with a long-term partner with us through to old age.

The onset of MND changes that picture dramatically and many will experience real grief at its passing. Grief brings about a whole range of reactions from shock, denial and anger through to bargaining and, eventually, gradual acceptance.

Accepting a situation doesn’t mean giving up; it means learning to let go of what can’t be changed and to live and make the most of one day at a time.

Frustration and resentment

Caring for someone who is physically deteriorating can be enormously frustrating. Whatever you do, nothing will ever be the same again. You may feel that your efforts are not enough; that your life has changed forever, that you have no time to yourself and sometimes, that nothing you do is actually appreciated.

It is vital that you remember that you are not, and are not expected to be, super-human. You are a person who is doing your best in circumstances that neither you nor the person you are caring for could have anticipated. Your life has changed and it is perfectly normal to feel frustrated or resentful from time to time.

What's important is that you and the person you are caring for take the time to talk to each other and, if necessary, to others about your feelings.

“Bitterness and anger are very draining...life was bad enough – why make it worse? Besides, certain friends had drifted away. Those who stuck it out would have found it much harder if I had appeared antagonistic, embittered, depressed.”

Anger

If feelings of frustration and resentment are not dealt with, it is quite possible that they will develop into anger. There may also be times when you simply have a ‘bad day’ – we all have them and we all get angry when we do.

The important thing is to recognise anger and find ways both of dealing with it and avoiding similar situations in future. You may feel angry with yourself or, equally possible, at the person you are caring for. If you are tired, anger has more of a chance to take control, so try to ensure that you get enough rest and sleep (see below, Avoiding tiredness).

Fear

In many cases, fear stems from feeling you have lost control. With an illness like MND, it is very easy to feel that any control you once had has gone. You may also fear the future or your ability to cope. Again these are natural reactions and talking about your fears will help.

Guilt

It is quite common to feel guilty, either because it is your loved one who is sick while you are healthy or because of some of the more negative emotions you may be feeling. Learning to accept your situation and that there is nothing you could have done about it will help, as will talking about and sharing your feelings – positive and negative – with others.

Avoiding tiredness

Anyone who is tired finds it far more difficult to cope and carers in particular need to ensure that they have as much energy as possible. It's all part of taking care of yourself so that, in turn, you can effectively care for someone else. Here are a few suggestions of how you can avoid getting too tired to cope:

- **Prioritise:** Make a list of the tasks you usually do: then divide these into the most important, those that need doing but not immediately and, most importantly, those that don't really need to be done at all. If you're honest with yourself, there will almost certainly be jobs that aren't vital!
- **Delegate:** Have a close look at your list – what could easily be done by someone else? Jobs like the ironing, Hoovering or shopping are ideal to delegate to family or friends. Some people will have offered to help; others will want to do something but don't know what would be useful. Now is your chance to tell them!
- **Rest:** No one can be on the go 24 hours a day, seven days a week. Look for times when you can have a rest

The causes and symptoms of stress

No one is super-human, no matter how hard they try. People in all walks of life feel stress at some time or another. For people who suddenly find themselves re-evaluating their lives, their roles and their futures by caring for someone diagnosed with MND, the reality of coping with stress will become a priority – because it is only by learning to manage stress that you will begin to be able to take back control of your life.

Signs of stress come in many forms but in general you should look out for:

- Tiredness
- Irritability
- Difficulty sleeping
- Headaches
- Muscle tension
- Unexplained aches and pains

The different types of carers

Many people assume that a carer is a husband or wife, but, as we said in the introduction, there are many different types of carer each with their own particular needs.

Young carers

Young carers may be looking after a parent, brother, sister, grandparent or close family friend with MND. They may be helping with:

- Washing and dressing
- Shopping and cooking
- Cleaning
- Giving medicine
- Looking after younger brothers and sisters
- Dealing with money and bills
- Interpreting - communicating for a parent

If you are a young carer

Helping to care for someone can make you feel really tired and under pressure. It may mean you have less time to finish school homework and less time to play with friends or do sport and other activities. In fact, young carers can feel that they are different from all their friends and that no one understands their experience. They may feel:

- No one at school understands why they have to put caring and family ahead of everything else
- No one listens to them
- Their contribution isn't properly recognised
- They are obliged to care
- Resentful of the demands made of them
- Afraid that if they fail in their caring, their family may be split up

Helping to care for someone doesn't just mean losing out in various ways. There are many positive aspects to being a young carer:

- Learning to build a strong relationship with someone
- Gaining maturity and understanding
- Learning about caring issues

Who can help

Young carers often choose to remain hidden, worried about what may happen to them and their families if people find out they are caring for someone. The most important thing is to talk to someone. It might be a neighbour, relative, friend or perhaps a youth worker from your local youth club. Some other suggestions include:

- School staff - teacher/tutor; school nurse or counsellor
- Young carers services
- Social Services
- Childline or Samaritans – Childline Tel:1800 666666, Samaritans Tel:1850 609090
- National Carers Association - Tel: 057 9322920 / 057 9322664

Carers with additional needs

Caring for someone with MND can be stressful and tiring even if you are fit and well yourself. Many carers have health problems of their own and these can be made worse by the strains of caring. Indeed, some carers may be looking after a person with MND as well as others, perhaps an elderly relative or child with special needs.

So if you are frail, elderly or have a physical/mental health problem, it is imperative that you have your own needs recognised and assessed. Do not be left feeling that there is no help available.

Caring from a distance

What do we mean by caring from a distance? You may simply not live in the same house, be a bus ride away or 300 miles away. Whichever, caring at a distance has its very own set of problems and stresses? These may be a mixture of time, finances or other commitments.

Planning

Whatever your personal circumstances, planning carefully really can help to minimise potential problems when trying to care at a distance. A few tips:

- Plan your visits carefully - take into account the needs of the person with MND, all your various commitments and decide how many visits are realistic and what you can do while there
- Get the agreement of the person with MND - sit down together and decide on what's important and what steps you need to take
- Be realistic about how often you can afford to visit
- Don't wait for problems to occur

What to look for when you visit

Much of your visiting time will undoubtedly focus on checking the welfare of the person with MND and their health in particular. Recognising any signs of new physical or mental problems is particularly important.

Contacting the healthcare professionals

You may need to contact particular healthcare professionals in the area but be unsure as to how to proceed. Getting the right information in a strange area can seem impossible. The standard help points of your Public Health Nurse (found at your Local Health Centre), Citizens Information Centre and the IMNDA Nurse Specialist remain the best source of impartial information.

If you experience difficulty in contacting any health or social care professionals, the IMNDA will be happy to try and help.

Sharing care

You may be sharing some care tasks and supporting the person who has the main responsibility for caring. This extra source of help is invaluable to the main carer, but watch out for tensions. Good communication is the key to success, so:

- Always keep in touch
- Provide financial help where appropriate
- Recognise the invaluable support of the main carer and remind others of this where appropriate
- Try not to criticise the main carer
- Provide practical help on your visits - ask the main carer what help they would like
- Check for signs of stress on main carer - this is a very difficult role which they are undertaking

Carers who work

Not everyone wants to be a carer or has the option to stop working. It is important not to feel guilty or let others influence your decision to continue or indeed start working. You do have a choice. Talking to the person with MND and deciding what is right for you both is of vital importance.

Talk to your employer about your situation. They may be able to help in a number of ways e.g:

- Flexi-time
- Allowing personal phone calls
- Longer lunches
- Part time hours
- Unpaid or extended leave



As a working carer it can be even more important for you to look after yourself as you may be working and taking on some caring tasks.

Practical advice and benefit entitlement

The benefits system can seem very complicated, long-winded and even contradictory at times. The following is a brief summary. It is essential that you get advice to ensure that you are getting everything you are entitled to. If you are caring for someone – young or old, related or not, living nearby or some distance away – it is important that you know about any ‘official’ help you may be entitled to.

Be prepared

It really helps to think about the sort of help you need before any assessment takes place. Make notes of everything you think of. It may help to use the list below to guide you on the areas to think about:

- **Your home:** Does your loved one need help with any aspect of the home, such as the stairs or the bath? Are there any pieces of equipment or adaptations that would make life easier?
- **Your health:** Are you fully fit? Does your loved one have any specific health difficulties that you cannot cope with? Are you getting enough rest and sleep? Do you have any of the symptoms of stress or depression?
- **Your time:** How much of your time is spent caring (both directly and indirectly such as cooking, ironing or shopping)? Do you get any help? Is there anything you are missing out on because there simply isn't the time or opportunity to do it? Are you getting time to yourself? Would it help if your loved one went into respite care from time to time to give you a break? Do you want a holiday?

- **Your support:** Does anyone else help you with the day-to-day jobs such as cooking, ironing, cleaning or shopping? Is there anyone who can keep an eye on your loved one while you do other things? Do you want more help? Do you need more practical information; for example about lifting and moving another person safely?
- **Your feelings:** Do you feel that you have no choice about providing care?

Moving and handling

It is very important that you seek advice from a healthcare professional, such as an Occupational Therapist, Public Health Nurse or Physiotherapist about the safe ways to move the person you are caring for. This will avoid any unnecessary injury to you or the person you are caring for. As the illness progresses you may also require the help of special aids and equipment to make it safer and easier to move them. These should be provided by an appropriate healthcare professional.



Carer's allowance

This is a means tested benefit available to a carer providing full time care to a qualifying person. The person receiving care is regarded as requiring full-time care and attention where

- He or she is so incapacitated as to require continuous supervision in order to avoid danger to him or herself or continual supervision and frequent assistance throughout the day in connection with normal bodily functions
- He or she is so incapacitated as to be likely to require full-time care and attention for a period of at least twelve months

While claiming Carers Allowance you must not be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week. During your absence, adequate care for the person requiring full-time care and attention must be arranged. If you are getting certain social welfare payments and you are providing full time care and attention to another person, you can keep your main social welfare payment and get half-rate Carers Allowance as well.

For assessment purposes your means are any income you or your spouse/partner have or property (except your home) or an asset that could bring in money or provide you with an income, for example, an occupational pension, pensions/benefits from another country.

If you give up work to care for someone and get Carers Allowance you will be awarded PRSI contribution credits.

For an application form/further information contact the Department of Social and Family Affairs on 1890 662244 or www.welfare.ie or your local Citizen's Information Centre.

Carers benefit

Carers Benefit 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 can get Carers Benefit for a total period of 104 weeks for each person being cared for. This may be claimed as a single continuous period or in any number of separate periods up to a total of 104 weeks. However, if you claim Carers Benefit for less than six consecutive weeks in any given period you must wait for a further six weeks before you can claim Carers Benefit to care for the same person again.

If you are caring for more than one person, you may receive payment for each care recipient for 104 weeks. This may result in the care periods overlapping or running concurrently.

You may be eligible for Carers Benefit if:

- You are aged 16 or over and under 66
- You have been in employment for at least eight weeks in the previous 26 weeks before becoming a carer. You must have worked for a minimum of 16 hours per week or 32 hours per fortnight
- You are resident in the state
- You give up work in order to be a full time carer. Being a full time carer means you must be living with or in a position to provide full-time care and attention to a person in need of care who is not living in an institution
- You meet the PRSI contribution conditions
- The person being cared for is so incapacitated as to require full-time care and attention and is not normally living in an institution. Medical certification is required
- You must not be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week. There is a maximum weekly income limit
- If the person you are caring for dies, payment of Carers Benefit will continue for 6 weeks following the death

If you give up work to care for someone and get Carers Benefit you will be awarded PRSI contribution credits.

For an application form/further information contact the Department of Social and Family Affairs on 1890 662244 or www.welfare.ie or your local Citizen's Information Centre.

Carers Leave

The Carers Leave Act 2001 allows employees in Ireland to leave their employment temporarily to provide full-time care for someone in need of full-time care and attention. The minimum period of leave is 13 weeks and the maximum period is 104 weeks (this can be taken as a continuous period or a number of periods).

Carers leave from employment is unpaid. If you take Carers Leave your job will be kept open for you for the duration of the leave. You may qualify for Carers Benefit or for Carers Allowance. You can take Carers Leave even if you do not qualify for either of these payments.

You must have worked for your employer for a continuous period of 12 months to be eligible to apply for Carers Leave.

The person you are proposing to care for must be deemed to be in need of full-time care and attention by a deciding officer of the Department of Social and Family Affairs. The decision by the Department is reached on the basis of information provided by the GP of the person for whom you will be caring.

The person you propose to care for must be so disabled as to require:

- Continuous supervision and frequent assistance throughout the day in connection with their normal personal needs for example, help to eat, drink, wash or dress,
or
- Continuous supervision in order to avoid danger to themselves

You must not be engaged in employment, self-employment, training or education courses outside the home for more than 15 hours a week. There is a maximum weekly income limit.

If you take Carers Leave you will be awarded PRSI contribution credits.

If you wish to avail of unpaid leave from employment for less than the 13 week minimum set down by the Carers Leave Act, it is possible to agree this with your employer. You will need to get in touch with PRSI records section in the Department of Social and Family Affairs to ensure that your social insurance record is preserved during this leave.

For an application form/further information contact the Department of Social and Family Affairs on 1890 662244 or www.welfare.ie or your local Citizen's Information Centre.

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. The person being cared for must normally reside with the married couple or if they are relatives they must reside next door, on same property or within 2 kilometres of the claimant. There are limits applicable to the level of income of the home carer.

The qualifying rules can be complicated, so it is advisable to talk to the experts before filling out a claim. For further information or a claim form contact www.revenue.ie or your Regional Revenue Office.

→ See 'How The IMNDA And Other Organisations Can Help' section for details.

Respite Care Grant

This is a cash payment made to carers by the Department of Social and Family Affairs in Ireland. Carers can use the grant in whatever way they wish. It is not necessary to use it to pay for respite care.

It is automatically paid to those in receipt of Carers Allowance, Carers Benefit, Constant Attendance Allowance or Prescribed Relative's Allowance. If you are not in receipt of one of these payments you may still apply for the grant once

- You are providing full time care to an eligible person
- You are caring for the person for at least six months including the first Thursday in June
- You must live with the person or have a direct system of communication between your home and theirs (e.g. telephone or alarm system)

You do not qualify if you are working more than 15 hours per week outside the home, if you are getting an unemployment payment or if you are signing on for unemployment credits. You also do not qualify if you are living in a hospital, convalescent home or similar institution. If you are caring for more than one person, a grant is paid for each of them.

For an application form/further information contact the Department of Social and Family Affairs on 1890 662244 or www.welfare.ie or your local Citizen's Information Centre.

Disabled Persons Parking Card

If the person you are caring for does not drive, you will be able to use their Disabled Persons Parking Card in your car when you have them with you. This will let you park in more convenient places.

→ See 'Movement & Mobility' section for more information.

Road tax exemption

If the person you are caring for has a Primary Medical Certificate and a vehicle admitted to the Tax Relief for Vehicles Purchased for use by People with Disabilities scheme the vehicle is exempt from the payment of annual road tax. Applications can be made by a disabled driver or passenger. There is a provision for a family member of a person with a disability who purchases a vehicle for the transport of that person as a passenger to apply.

→ See 'Movement & Mobility' section for more information.

