



Your personal guide to Motor Neurone Disease



This publication has been kindly supported by:



Support

*This guide is yours to make your own.
Each person's journey is different and
the MND Association exists to help
you find your own way*

Your name _____

Address _____

Tel _____

Key contact _____

Tel _____

MND Association contact _____

Tel _____

In case of emergency please contact _____

Tel _____

information

practical help

**MOTOR
NEURONE
DISEASE**
ASSOCIATION



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Please use the order form at the back of this guide to order any you would like to receive.
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Foreword

To the people who have MND and to their families,

My late father, David Niven, succumbed to MND on 29 July 1983. He began limping in early 1980 and was told by a doctor that he had pulled a muscle. The limping got worse and then he started to lose strength in his hands. Eighteen months before he died he began to slur his words and he was told that was just part of the ageing process.

Finally, he went to the Mayo Clinic in Minnesota and was told that he had MND and that he would not live beyond two years. He was told there was nothing he could do to change the events coming his way and that no one knew very much about the disease anyway. The best advice they could give was to go and buy a button hook, to help him do up his buttons.

So there you have it. Repeated misdiagnosis, lack of information about the disease, and despair.

Today, the Association has put together this new literature about MND that is accurate and to the point. The information has been carefully researched from people with MND. We had none of that in 1980. Think of the difference this would have made to my father and to his family.

My father did his best of course. He told me that he tried to have little victories each day. Things like not losing another pound, or walking a little quicker, or dressing a little faster, all became moments of glory.

He gave the thumbs up symbol before he died.

He was quite a man.

James G. Niven

Testimonial

This literature is a must for useful, practical and down to earth advice. They can't cure MND but in this 'help pack' is all the information you need to make things a little easier. Every aspect of day-to-day living is covered as well as tips about planning for the future. The information is presented in 'bite size' chunks because not everyone needs to know everything all at once, but it is all there when you need it.

Living life to the full is so important. Thanks to this pack, perhaps those of us affected by MND can make life and living a bit more comfortable.

LYN NEWMAN, LIVING WITH MND


How to use this guide

The Motor Neurone Disease Association represents those people who are living with or have lived through the experience of motor neurone disease (MND). In putting together this Personal Guide, we have involved a wide cross-section of people. They have helped us provide this essential information from the perspective of every person who may benefit from it.

We are all unique. Some of us need to know the big picture all at once; others are content to cope with today and let tomorrow look after itself. In fact, anyone who is affected by motor neurone disease, either directly or indirectly, will want or need different information at different times. So we have staged the information in this guide to allow you to absorb it at your own pace and in your own time.




The Personal Guide itself only comes with a few sections. This is because MND affects everyone differently and the additional sections available may not be relevant to or welcomed by each individual. You can pick and choose which of the remaining sections you need or feel would be helpful whenever you want.

In each section, you will be signposted to where more information about a particular topic can be found. This is shown by the signpost symbol . Some of these topics are covered in more than one section. However, in the Index you can find the section with the most detailed information listed in red type.

In other words, it is completely up to you what information you receive and when you receive it. The main purpose of this Personal Guide is to provide information and advice that we hope will guide you through the challenge of living with motor neurone disease – whether you are the person who has it or are supporting someone who has.

 **For information on ordering further sections see *How to get more information from the MND Association*.**

We would also encourage you to keep any of our requested Information Sheets and information that you find from other sources in this guide. This will ensure that you have all the information that is important to you in one place.

Additional publications available from the Association are indicated by the page symbol . These can be ordered using the Publications list order form found in the pocket at the back of this guide.

A stylized, low-poly illustration in shades of orange and white. It depicts a group of people in a park-like setting. In the foreground, there's a man in a white shirt and dark pants, a woman in a white dress, and a child in a white shirt and dark pants. In the background, there's a man in a white shirt and dark pants, and a woman in a white dress. The background is a solid orange color with white, stylized clouds or foliage. A thick, dark blue vertical bar is positioned on the right side of the page, partially overlapping the illustration.

Your home pages

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How to use your home pages

Keeping track

The aim of this section is to help you keep a track of your involvement with Health and Social Care professionals. The forms included here are designed to help you keep a record of what is happening and may avoid unnecessary duplication.

It's up to you which forms you use. Whichever you choose, you will find it helpful to keep all your documents in one folder and take them with you to every appointment.



The forms included here are:

Personal details

Every professional you come into contact with will probably make his or her own notes about you. It can become wearing to be repeating your details over and over again. To save you time and energy, especially if your speech is affected, you can complete this sheet and give a copy of it to each service.

About me

You can use this to let people know about your individual needs and how MND affects you. This may be particularly helpful for nursing staff if you have a stay in hospital.

Communication record

Possibly the simplest sheet but perhaps the most useful! With several people potentially visiting you, it is easy to forget who was who and what they said they would do for you. It is perfectly reasonable to ask any visiting professional to write on this form why they visited and what they are able to arrange for you. This will also help each professional to be aware of what someone else is doing so that referrals are not duplicated.

Professional contact sheet and card holder

One of the most important and useful things to do is to keep a record of every Health and Social Care professional who visits you, or who you meet in the hospital environment and how you can contact them again. All of them will be happy to give you their contact details and keeping them in one place, on a simple form like this, or in the PVC business card holder, will avoid confusion and distress if you need advice quickly.

Equipment record

Some pieces of equipment will prove extremely helpful. The problem is that they come from several different sources, so keeping a record of what comes from where will be very helpful – particularly if you need something repaired or replaced.

Medication list

You can list any prescribed treatment here. Whenever you visit your doctor, you can take this with you and ask them to note down what different medications are for and any side effects to look out for.

Appointments

Keep track of your appointments and avoid duplication.

Notes

It's really up to you how you use this. You may want to record your thoughts and feelings or simply what each day brings, or note down any questions that you may want to ask professionals when you see them.

Extra copies of these forms are available on request.

Personal details

Personal details		
Name:		
Address:		
D.O.B:		Lives alone <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
Lives with:		Relationship:
Name/s:		
Postcode:		Relationship:
Telephone Number:		
NHS Number:		
Informal carer/s (friends relatives, neighbours):		Form of MND:
Name/s:		ALS <input type="checkbox"/>
Address:		Bulbar Palsy <input type="checkbox"/>
		Other <input type="checkbox"/>
		Type of MND:
		Sporadic <input type="checkbox"/>
		Familial <input type="checkbox"/>
		Don't know <input type="checkbox"/>

Communication record

[illegible]

Professional contacts

Professional contacts						
Title	Name	Address	Tel No (day)	Fax No	Email	
Consultants/s:						
GP:						
Neurological Specialist Support Nurse:						
District Nurse:						
Physiotherapist:						
Occupational Therapist:						
Speech & Language Therapist:						
Dietitian:						

Equipment record

[illegible]

Medication list

[illegible]

Appointments

[illegible]

Notes



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2

Starting out with MND

**Who to contact when you
are first diagnosed**

**What is Motor Neurone
Disease?**

**How the MND Association
can help you**

Who to contact when you are first diagnosed

Where will the help come from?

Ideally your Consultant Neurologist or GP will refer you to local services provided by the NHS or your local authority. Services vary from area to area; you may be referred to a multi-disciplinary team, MND Care Centre or in some cases to individual services.



What if I have problems?

Some people are not offered a key point of contact when they are diagnosed and are left to find their own way around a rather complex system for help and advice. If this is the case, talk to your GP – they should be able to guide you and ensure you can access the services you need. It will also help to talk to one of the Association's Regional Care Advisers, particularly if you

are experiencing difficulties or finding that your needs are not being addressed as quickly as they should. They will be able to advise you and, if necessary, act on your behalf to secure the care you need, when you need it.

How MND affects you personally will determine which professionals can help. The following is a quick guide.

I am having difficulties with:	Who can help me?	How do I contact them?
Everyday activities (e.g washing, using the toilet or bath, using cutlery, climbing stairs)	Occupational Therapist	Social Services
Personal care (e.g washing)	Social Services	Social Services
Support for you and your family (e.g financial, getting a break)	Social Worker	Social Services
Mobility (e.g walking, climbing stairs, balance, exercise)	Physiotherapist	Through your GP
Employment	Specialist adviser	Job Centres
Stiffness and cramp	GP	Local Surgery
Swallowing food and drink	Speech Therapist	Through your GP
Nutrition (including lack of appetite and weight loss)	Dietitian	Through your GP
Speaking	Speech Therapist	Through your GP
Coughing	GP/Physiotherapist/ Speech Therapist	Through your GP

Remember that most services require a referral from your GP. Anyone can refer themselves to Social Services (see your phone book for numbers – under local councils) but it does help to be clear about the diagnosis and the specific difficulties you are having.



What is Motor Neurone Disease?

Glossary

 Additional Publications available – see Publications list order form

 Further information available in other sections

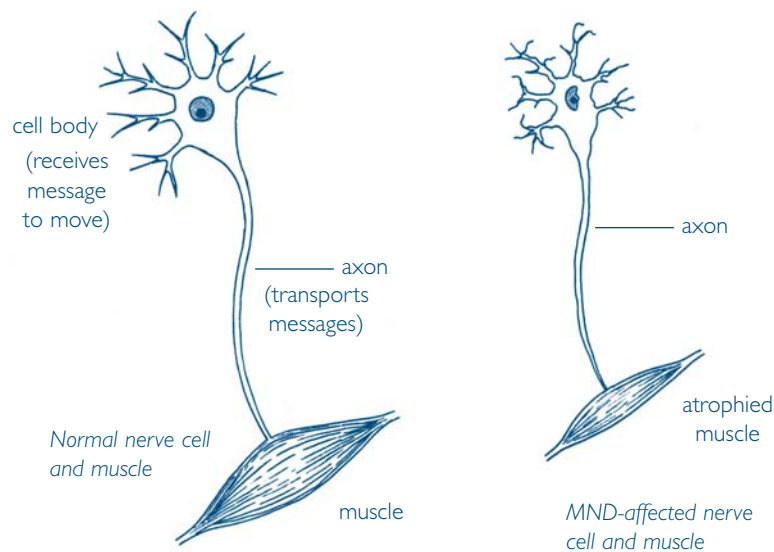
French physician, J M Charcot, first identified motor neurone disease (MND) in 1874. Despite intensive research, the cause remains unknown.

WHO DOES IT AFFECT?

- About two people in every hundred thousand are diagnosed
- There are over 5,000 people living with MND at any one time in the United Kingdom
- It usually affects those over 50 but can occur in people much younger.

WHAT DOES IT DO?

The term, motor neurone disease, actually describes a group of related diseases affecting the nerves in the brain and spinal cord, which tell your muscles what to do. These nerves are known as motor nerves or motor neurones; the words 'nerves' and 'neurones' mean the same thing. As the nerves become damaged, the muscles they control weaken and waste.



Picture of motor nerve

The muscles first affected tend to be those in the hands, feet or mouth and throat, depending on which type of the disease it is. It does not generally affect the senses so sight, smell, touch and hearing tend to remain intact, as do the sphincter muscles that control the bladder and bowel. Other areas that are not usually affected are sexual function and intellect. It is not contagious.

Motor neurone disease is a progressive, life limiting disease and the rate of progression varies greatly from one person to another.

SECTION TWO

3 WHAT IS MOTOR NEURONE DISEASE (MND)?

IS THERE ANY TREATMENT?

There is no specific treatment that will halt the progress of the disease. There have been some promising lines of research and one drug in particular, riluzole (Rilutek™), has been shown to have a modest benefit.

Some people with MND are reluctant to ask for or accept help and advice. "What is the point if I can't be cured?"

Actually, there is a great deal of point. Much can be done to overcome and manage symptoms and there is a range of Health and Social Services professionals who can help you and your family live with the condition. At the same time, some symptoms can be prevented with the right help. A lot can also be done to overcome practical problems and help you maintain your independence for as long as possible.

 **See Who to contact when you are first diagnosed.**



Your GP will continue to provide your medical care and guide you to other people that can help. Try to see the same GP every time you visit the surgery. This will help them to keep track of how you are getting on.

HOW IS IT DIAGNOSED?

“I became more and more convinced I was developing some sort of problem. Almost a year after the first signs I began falling over my feet on the tennis court and enough was enough. When I was told, after two days of tests, that it was probable I had MND, the news came as something of a relief.”

Some of the early signs of MND may be difficult to identify because many other conditions start in a similar way. Your GP will have referred you to a consultant neurologist who will have used various tests to eliminate other possible causes of your symptoms. As there is no specific test for motor neurone disease, your consultant may well have waited to see how your condition progressed before giving you the diagnosis. This can be a frustrating and draining time for everyone concerned.

Motor neurone disease can be very difficult to diagnose for several reasons:

- It is not a particularly 'common' disease
- The early symptoms may be quite slight, such as clumsiness, weakness in the legs or mildly slurred speech. Indeed, it may be some time before someone even considers the changes worthy of visiting their GP about
- In the early stages, many of the symptoms are similar to those of other, more common, medical problems that will need to be eliminated. A number of tests are likely to be used. (See table opposite.)
- The nature of the disease is that it affects different people in different ways. In other words, there are no clear-cut, definitive symptoms that immediately indicate diagnosis
- MND is a serious disease that has many implications, so the consultant needs to be certain of diagnosis.

SECTION TWO

4 WHAT IS MOTOR NEURONE DISEASE (MND)?

Likely tests:

- **Blood test**
- **Lumbar puncture**
- **Myelogram**
- **Electromyography (EMG)**
- **Muscle biopsy**
- **Brain scan**



How individuals react to the final diagnosis varies greatly from person to person. For some, the fact that there is a clear cause of their symptoms comes as a relief; for others, it can come as a thunderbolt out of the blue.

GETTING MORE INFORMATION

The moment of diagnosis does tend to stun people, with the result that they find it difficult to take on board all the other information immediately. So don't be afraid to ask questions every time you see your doctor. As MND is fairly uncommon, your GP may not have much experience of helping someone who has been diagnosed. The Motor Neurone Disease Association can and does provide GPs with as much information as they need.

Almost certainly, anyone diagnosed with MND will want to find out more about it – whether from professionals, the library or the internet. It is vital, however, that wherever someone goes for this information, it is a reliable source. The internet, particularly, can be the source of much unreliable and unprofessional information that could only serve to either increase anxiety or give unfounded hopes of a 'cure'. The list of recommended sources of further information provided at the back of this folder will offer a starting point.

One of the key things a lot of people want to know – how and at what rate the disease will progress – is something that is almost impossible to answer.

REVIEWING YOUR PLANS



The fact that you have motor neurone disease may well mean that the plans you had made and the lifestyle you led before diagnosis will need to be reviewed and, if necessary, changed. These could relate to work, home or leisure pursuits.

 **See *Work, benefits and finance*.**

The choices we all make about our lives are very personal ones but it's important that they are made for the right reasons and in the right frame of mind. You could see this as an opportunity to make changes for the better – you can develop closer relationships with family and friends, make new friends with others sharing your experiences, learn about computers and how to communicate through the internet, and so on. What you can do may not include everything you've always wanted or planned to do but you can still lead a full life. It all depends on your attitude and imagination!

TAKING A POSITIVE APPROACH

Living with MND means continuous change and personal challenge. Accepting the fact that you have a serious, disabling illness that is not yet curable does not mean giving up and doing nothing. Rather, it means continuing to do as much as you can and channelling your time and energy into maintaining the best quality of life and independence.

The physical effects of motor neurone disease vary from one person to another, as does the rate of progression. So there is little to be gained from worrying about the future, over which none of us has any control, and much to be gained from enjoying today.

Clearly there will be times when you feel frustrated if you can't do all the things you used to but it does help to keep as normal a lifestyle as possible. Particularly important is to ensure that everyone in the family maintains their individual roles, even if everyday jobs need to be shared out differently.

FEELINGS AND CONCERNS

You may find it helps to talk through any feelings or worries with someone outside the immediate family. A close friend, an understanding relative or your GP could all be useful support. Social Workers are also available to help, both in hospitals and through your local Social Services department. You may also like to talk to the Association by contacting the RCA, Association Visitor, local Branch or MND Helpline.

Notes



MND Association, PO Box 246, Northampton NN1 2PR
Tel: 01604 250505 Fax: 01604 624726 Website: www.mndassociation.org
Registered Charity No. 294354
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How the Motor Neurone Disease Association can help you

The Motor Neurone Disease (MND) Association is the only organisation of its kind in England, Wales and Northern Ireland dedicated to working on behalf of people living with MND and their families.

We have two key aims:

- To ensure that people affected by MND can get the care and support they need
- To promote research into the causes and treatments of MND.

SO HOW CAN WE HELP YOU?

Whether you have been diagnosed with MND yourself or you know someone who has, our services can make a real difference to how you cope in the weeks and months ahead. MND is a life-changing illness and we are dedicated to making each change as smooth as possible for all those directly or indirectly living with it.

PROVIDING INFORMATION

The first step to living positively with motor neurone disease is information: what support is available; what to expect; how to cope, and so on. The more you know, the better you will be able to take control of what is happening to you and the care you get. That's why we place so much emphasis on providing as much, or as little, information as you need.

It may be that you simply want someone to talk to. You might be concerned about a particular aspect of the disease and want to know more. You may be worried about the effect on your family. Or you might want to know as much as possible about MND, its causes, progress and treatment.

Whatever you need to know, we will do our best to help you:

- Our national **Helpline** (08457 626262) is open seven days a week, offering information, support and advice
- Our **publications** cover a whole range of related issues, from specific aspects of MND to treatment advice to research developments
- Our **website** (www.mndassociation.org) can give you up-to-date news of developments alongside practical information on all aspects of living with MND.

INDIVIDUAL SUPPORT

MND affects people in different ways and we never forget that everyone is an individual with unique needs, fears and problems.

What your Regional Care Adviser (RCA) can do for you

- Visit you in your own home
- Is available via telephone and email for advice and support and information
- Link you to local services
- Chase up loose ends
- Link you to Association Visitors and Branches
- Provide training and support for professionals who may be involved in your care
- Listen to you.

Just what level of help you get from the statutory services is heavily influenced by our team of **Regional Care Advisers (RCAs)**. These trained Health and Social Care professionals have expert knowledge of the care and management of MND and work closely with local service providers to ensure you get the best possible care and support at the right time – support that matches our own Standards of Care.

Standards of Care

- Access to information when you need it:
 - Written and verbal information related to the disease and how it may affect your life, and services available locally
 - Details of the support and services of the MND Association on a continued basis.
- Flexible, co-ordinated professional support:
 - A single point of contact, who can refer you to other services, as appropriate
 - Referrals to professionals in a co-ordinated way, so that any difficulties can be addressed promptly
 - Regular review of your situation
 - Opportunities to take advantage of the support offered by palliative care services.
- Opportunities to discuss your needs
 - Regular appointments with the MND team, to help support you and your carer both emotionally and practically
 - A recognition and regular review of the needs of the carer
 - Opportunities to discuss issues that are important to you, whether practical, emotional or spiritual.




These Standards of Care are vital in ensuring not only that the right services are available at the right time but also that you as an individual are actively involved in any decisions. With several different services likely to be involved at the same time, it is vital that you and your family feel able and confident to work in partnership with the professionals. We have already established ten **Care Centres** across

the country where this partnership of care and support can work smoothly. More are planned, and the network is growing.

For many people living with MND, one of the most important sources of help is the **Association Visitor (AV)**. We have trained men and women based throughout the country who can give you one-to-one support and advice. Our Visitors are more than simply someone to talk to. They have the experience and the knowledge to provide caring, practical support to people with MND and their families.

We have a network of over 80 **Branches** nationwide which provide a warm welcome, friendship, and the opportunity to meet with other people in your local community. Branches produce newsletters and organise regular meetings where people affected by MND offer each other emotional and practical support and exchange information. Local fundraising events and activities also take place.

PRACTICAL SUPPORT

As MND progresses, everyday tasks may become more difficult. It could be something as simple as getting out of a chair or problems with communicating. There is a whole range of equipment that can make a real difference to maintaining your independence and quality of life. Some of the key items are available through our **Equipment Loan Service** , and can be requested by an appropriate Health or Social Care professional, e.g. Occupational Therapist or District Nurse.

If we don't have something you need and it's not available through Health or Social Services, we may be able to help with a grant from our **Financial Support** fund. This can also help with one-off or on-going costs for specialised care in the home. Again, a request from a Health or Social Care professional is required.

SHARING KNOWLEDGE AND EXPERIENCES

Meeting others who are facing similar problems to your own can make a huge difference to your morale and can often give you fresh ideas of how to cope. We organise regional and national conferences aimed at bringing people together to share ideas and experiences. Here we can also share new developments and bring you up-to-date on the latest research and treatments.

Campaigning on your behalf

Your experiences and those of others living with MND mean that we have first-hand knowledge of the reality of the disease. We use this knowledge to speak out on your behalf and influence decision-makers at local and national level. This ranges from lobbying at Westminster to ensuring that you are able to claim the allowances to which you are entitled.

By becoming a member you will have the opportunity to participate in surveys asking for your experiences of living with MND, which feed into our campaigning work.

To find out more about the MND Association and how we can help you, contact the Care Information Service, your RCA, Association Visitor or local Branch.

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Tel: 01604 250505 Fax: 01604 624726 Website: www.mndassociation.org
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3

Moving on from diagnosis

Living with MND

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*answering their questions***

Everyday activities

**More about MND –
*types, tests and treatments***

Symptoms

Movement and mobility

Speech and communication

Eating and drinking

End of life decisions



Living with MND

“The consultant’s actual words were: ‘Sorry old boy, it’s Motor Neurones.’ He then marched out of the room, followed by his students, leaving his Registrar, who said: ‘I’ll leave you two alone to talk things over.’ So there we were. I hadn’t a clue what motor neurone disease was.”

The one thing that can be certain about anyone’s reaction to a diagnosis of MND is the impact of that news will vary from person to person. The reaction, for example, of a young person with family responsibilities may well be very different to that of an older person looking forward to an active retirement. We are all in different circumstances that influence how we react to crises. Our concern and anxiety may not only be for ourselves but for those around us.



There are two important things to know: first, whatever reaction you have is normal; second, there is a whole range of help and support available. Whatever your circumstances, you need not be alone.

NORMAL REACTIONS

The diagnosis of MND inevitably means the beginning of a new journey – one that, in all likelihood, you did not expect to be making but one that, in fact, you had already begun.

‘Normal’ reactions to learning that you or someone close to you has a serious illness include:

- Shock
- Fear for the future
- Disbelief at the diagnosis
- Anxiety for loved ones and friends
- Grief for the loss of the future you expected
- Anger at the medical profession or family and friends
- Isolation because suddenly you feel ‘different’ from those around you
- Intense sadness
- Relief that you finally know what is happening to you.

Some or all of these feelings may be overwhelming for a while and you need to work through them at your own pace. You may also find that you need to get the reality of the situation straight in your own mind first before turning to people for support. Others may find it easier to involve family and friends immediately. Gradually, though, most people will begin to ‘rethink’ and review their life and plans.

One of the most difficult things at this time is to get a balance between keeping a positive attitude and accepting that you have a serious illness. You may feel

Glossary



Additional Publications available – see Publications list order form



Further information available in other sections

determined to face the disease head-on and fight it, or you may prefer to deal with it one day at a time.

Discussing and acknowledging feelings within the family is vital. Motor neurone disease affects not just the person with it but those close to them as well. Sharing the highs and the lows with your family and close friends, and allowing them to do the same, will mean that you can help each other. Bottling up feelings only leaves them to fester, causing far greater problems in the long term.

Depression

Depression is a natural reaction and it is quite normal to feel low at times. Even so, it is important to be aware of signs such as:

- Insomnia
- Loss of interest
- Loss of appetite
- Lack of energy.

If any of these persist for any length of time or become overwhelming, talk to your GP – they may be normal but that doesn't mean you have to go through them without help.

EMOTIONS

You may find that you are laughing and or crying at what might seem the wrong time and you are unable to control it. This may be due to how you are feeling but commonly it is because a part of your brain that is affected by the disease is causing it to happen. This may seem embarrassing to you and disturbing to those around you; be reassured though, that this is normal and not a sign that your mind is affected. Some people have found that taking certain medication helps with these symptoms so you may want to talk to your GP about it.



SHARING THE DIAGNOSIS WITH OTHERS

Almost certainly, you will have undergone a variety of tests before the diagnosis was made. You may have involved those closest to you in every stage, or it may simply not have been possible for someone to be with you at every doctor's appointment or hospital visit. Either way, those closest to you will have been concerned for you and it is important that, at some point, they know what is going on.

It can be very helpful to make an appointment to see your consultant together so that your partner or close friend can ask their own questions and settle their own concerns as well as sharing the experience with you.

It does not follow that, just because someone is close to you, they will experience the same feelings as you at the same time. It may well be that, when you are feeling anxious and distressed, your loved one is not – and vice versa. Open, honest communication is vital to avoid possible friction or misunderstanding. Never make assumptions about how others are feeling.

Advice for family and friends

While feelings of anger, disbelief and anxiety are normal for someone diagnosed with MND, they are equally normal reactions for those close to them. Family and friends may feel guilty both because they have reacted negatively and because someone they love and care about has been diagnosed instead of them. At the same time, they are trying to offer as much support and understanding as they can.

It may be that the person with MND is rejecting any attempt at support – their anger may be directed at family and friends. It may feel as though any help offered is simply not enough. Equally, they may feel some level of resentment that their lives and expectations, too, have changed.

It is important that friends, family and carers:

- Accept their own reaction as normal and that they, too, find a source of support and help, whether from professionals or friends
- Try not to over-react to any anger or frustration that may seem to be directed at them
- Know that any negative reactions from someone diagnosed with MND are usually temporary. Though there may be periods in the months and years ahead when these negative feelings overwhelm them again, these are natural, normal, understandable and, again, usually transient.



Telling the children

How and what you tell children will depend very much on their age. However, a diagnosis of MND on any member of a family will affect everyone and not knowing what's going on or feeling excluded from discussions is often worse than having some idea of the full picture.

Every family situation is different and every person diagnosed with MND must do what feels right and comfortable for them.

 **See Children and young people.**

Telling other people

How much detail you share with others is a very personal thing. Some people find it helps to 'get it straight' with everyone from the start. Others prefer to keep such information closer to home.

People have no automatic right to know anything about your personal life and you may not want to have to explain the situation over and over again. On the other hand, as the disease progresses, you may want people to understand that, though your body may be becoming weaker, your brain and your mind are not.

The reactions of others

The more people know, the easier it is for them to offer help and support. Having said that, people may feel awkward in coming forward and think it best to wait to be asked. So don't be afraid to ask for help.

Some people, though, find it very difficult to accept or be around illness. They may be frightened, or nervous of committing themselves to helping in a serious situation, and so become distant.

TALKING AND LISTENING

One of the most important things is to talk and listen:

- To those who are qualified to give you more information and professional support
- To family and friends – they need to know how you are feeling so that they can support you, and you need to know how they are reacting
- To the MND Association.

It is important to remember that your feelings and those of people around you will change – there will be highs and lows.

CHANGES IN LIFE ROLES

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

How you feel

Family and friends will no doubt be struggling to support you through the emotional roller coaster that is living with MND. People often tell us that their feelings are in such chaos that it is difficult to explain how they feel. The many life adjustments that become necessary can lead to sadness and loss, guilt and frustration, and even fear and resentment. All of these can be mixed in with feelings of hope and optimism, and a bloody-minded, fighting spirit.

Keeping these feelings to yourself can lead to misunderstanding and isolation from those around you. Try to share your feelings with someone, because this will help you to organise your thoughts and banish the chaos. This need not be someone close to you, although it's best if it is. Many of the professionals helping you will have some training in emotional or psychological support, and you can ask them where you can get a 'listening ear' to help you get your thoughts in order. Research tells us that getting the best out of living with MND relies on being open about your feelings and not allowing guilt and resentment to build up.

How other people feel

We know that MND affects the whole family. Normal routines and lifestyles can be turned upside down and lead to significant emotional changes for everyone.

Some may take on tasks that were traditionally yours. Careers may have to be put on hold and resulting money worries may increase. Many will try to hide their own feelings of loss and helplessness to protect you.

As MND progresses, the nature of your usual relationships may shift, bringing you closer together in many cases. Whether you live in a family unit, as a couple, or within a friendship network, hold on to what was unique about those relationships before you had MND. Try to avoid everyone becoming your 'carer' by accepting outside help for some of your physical care. Above all, try to recognise when those you love need to share their feelings and be prepared to encourage it.




INTIMACY AND SEXUALITY

“I enjoy my partner holding me in her arms closely while in bed with our favourite music on.”

Physical intimacy is core to any loving relationship: we need to feel and be close to others. Although MND does not affect sexual ability, when other movements become affected, sexual expression may be more difficult.

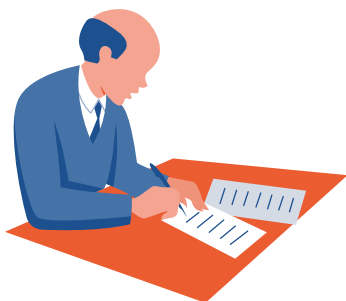
This is the time to talk openly about these changes and discuss alternatives. If you are a man and find movement difficult, try having sex with your partner on top, or vice versa if you are a woman. If sex becomes impossible in any position, there are other ways to show affection and enjoy sexual intimacy such as masturbation or oral sex. Consider talking to a 'Healthcare professional, such as a Sex Therapist, if necessary. Living life to the full with MND is what it is all about.

Sex itself may become less of an issue for some couples, but do show your love in other ways like cuddling and kissing. Some members of your family may be worried about showing they care – if they would normally give you a hug and a kiss, encourage them to do so.  **See Other organisations.**

PLANNING AHEAD

“In my view, mental and physical aspects of MND go hand in glove – if one has the right frame of mind, one can almost achieve the impossible.”

A diagnosis of MND may interrupt the best-laid plans but that does not mean you should stop making any new ones. Rather, you need to become informed about the disease and learn to manage it as best as possible.



Why plan - how it can help

The urge to deny the impact of a diagnosis of MND may be overwhelming, swiftly followed by the thought of “Why me?” It is normal and perfectly understandable to ask, but if you remain focused on this, you put off learning to live with MND and being able to take control of how you manage the illness. It is important to become informed about the types of decisions that you may have to make in the future.

The following coping strategies offer a positive way of dealing with the diagnosis:

Accommodating change

- This means adapting to change, being able to recognise what was, and what now is
- It is proactive – turning “Why me?” into “What I can do?”
- Acknowledging that MND is a real part of your life can take considerable time.

Accepting change

- Takes however long you require – it may be months; for others, it may never happen
- It means, for example, using a walker or wheelchair for safer mobility
- It does not mean giving up or giving in.

Making decisions

- Can be improved if you talk with family and friends - but you have the final decision
- Will be on-going as your symptoms change – decisions will need to be revised or sometimes reversed.

Staying in control

- Remain involved in the world around you
- Organise your own healthcare – choose a GP and Healthcare professionals you like and trust
- Retaining a sense of humour is life-enhancing
- Deal with MND one day at a time.




MND Association, PO Box 246, Northampton NN1 2PR
Tel: 01604 250505 Fax: 01604 624726 Website: www.mndassociation.org
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Work, benefits and finance

Glossary

 Additional Publications available – see Publications list order form

 Further information available in other sections

The information in this section is provided for your guidance and is not intended as a complete and authoritative statement of the law and your entitlements. The overriding piece of advice is to seek help and information. This section will give you a broad picture but each individual and their circumstances is different so use it as a guide to start you off.

It may seem complicated and possibly overwhelming but there are plenty of people and organisations who can give you specific help and advice:

- Welfare Rights
- Citizen's Advice
- Social Services Departments

In addition, you could contact the Benefits Enquiry Line, free on 0800 882200.



STAYING IN WORK

A diagnosis of motor neurone disease 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, are likely to become 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 **Disablement Resettlement Officer** or **Disability Employment Adviser** at your local job centre can work with you and your employer to alter your workplace so that you can continue working.

They may also be able to help through the Access to Work Scheme – this is set up both to help with alterations to work premises and to provide practical help at work, and with getting to and from work.

Benefits/Allowances

Disability Working Allowance

- Available if you reduce your hours or take a less well paid job because of your illness
- You will need to work at least 16 hours a week
- Payments do not affect any Disability Living Allowance (DLA) or Attendance Allowance (AA)
- The qualifying rules are complicated, so it is worth getting advice from the Benefits Agency.

Income Support

- Is paid to top up those on benefits or low income
- Is means tested and does not depend on National Insurance contributions
- If you are awarded Income Support, at whatever level, you may become eligible for a whole range of other benefits, such as:
 - Housing Benefit
 - Council Tax Benefit
 - Free prescriptions
 - Free dental treatment
 - Housing renovation grants
 - Help from the social fund.

Note: Income Support is not the only criterion for obtaining these benefits.

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?

- Statutory sick pay is paid by employers for up to 28 weeks
- Incapacity Benefit is then paid for a further 28 weeks, so long as you have made sufficient National Insurance contributions and meet the qualifying conditions.

If you are self employed or unemployed

If you have paid sufficient National Insurance contributions, you may be paid **Incapacity Benefit** from the outset. The Department of Social Security will need to be satisfied that you cannot continue your work.

List of General Benefits	
Non-means tested	Means tested
Incapacity Benefit	Income Support
Statutory Sick pay	Housing Benefit
Invalid Care Allowance	Council Tax Benefit
Disability Living Allowance	Disabled Persons Tax Credit
Attendance Allowance	Working Families' Tax Credit
Child Benefit	

DISABILITY AND CARE BENEFITS

Disability Living Allowance and Attendance Allowance are two of the most important benefits for people living with MND. The amount available for either is paid at rates determined by the severity of the disability.

Disability Living Allowance (DLA)

- Is tax free and not means tested
- Is available to anyone under the age of 65
- Is paid to those who have had difficulties with everyday tasks for at least three months (whether or not you had actually been diagnosed in that time)
- Covers two main areas of disabling illness – Care and Mobility. Both carry different rates:
 - *Care component:* people are often confused by this wording and assume that if they can wash and dress themselves, they do not qualify. We all know that MND can be overwhelming fatiguing, and while personal care tasks may be possible, they take a lot out of you. Weakness in the hands may cause difficulties with, say small buttons and fastenings. Think about those times when you need or could use a hand with everyday tasks. You do not need to have someone looking after or helping you to qualify. To qualify for this component, you will need to think about those times when you need or would find it easier to have help with for example:
 - Washing and dressing
 - Preparing a cooked meal
 - Other basic tasks.

Three different rates (Higher, Middle, Lower) are available.

- *Mobility component:* this is paid at 'Higher' or 'Lower' rates, depending on your individual circumstances. This component will continue to be paid after the age of 65 so long as you originally applied before your 65th birthday. You will qualify if you:
 - Cannot walk at all
 - Have difficulty walking
 - Can walk but need someone with you outside.

You may be eligible for both components, Care and Mobility. If so, and you are applying for both, it is important to make this clear on the form.

Attendance Allowance (AA)

- Is tax free and not means tested
- Is available to people over the age of 65 with a disability
- Is paid to those who have had difficulties with daily living tasks for at least six months (whether or not you had actually been diagnosed in that time)
- Is paid even if you live alone – you don't need to have a carer
- Does not have a mobility component.

How to claim for DLA or AA

Ask the Department of Social Security for the DLA or AA claim pack either by:

- Calling in at your local Department of Social Security office, or
- Phoning the free Benefit Enquiry Line on 0800 882200.

All forms issued are date stamped on the day you request them. If you return the forms within six weeks, your claim can be backdated to then. **Claims will not be backdated to when you were diagnosed, so it is worth applying for either DLA or AA as soon as possible.**

Claiming under 'Special Rules'

When you receive your claim pack you will find notes about claiming under Special Rules. Claiming under Special Rules means that your claim should be dealt with quickly and you will not have to fill in all the long forms. It also means that there is no three or six-month qualifying period. With a progressive illness

such as motor neurone disease you should automatically qualify under Special Rules, however the unpredictable nature of the disease means that not everyone will be eligible for this kind of claim.



If you are unsure whether your claim can be made under the 'Special Rules', talk to your doctor or your Regional Care Adviser. If they agree, your doctor will need to provide the Benefits Office with a form DS1500.

Tips for completing claim forms

- Ensure that what you put down on the form gives a clear picture of your situation
- Imagine your worst day and complete the form from this basis – your worst day is when you really need help
- Remember that fatigue has real implications for what you can or cannot manage. If you can only do something with monumental effort, it should not be listed as something you 'can do' because the very effort of doing it affects your health and quality of life
- Don't underestimate the help you need – rather, imagine how difficult your life would be without someone to help with basic tasks, no matter how small
- Be explicit – for example, answering the question 'Can you wash and dress yourself?' with a simple 'Yes' does not give an accurate picture. A more explicit answer, such as, 'It takes me at least two hours to wash and dress. I must take frequent rests while doing it and someone has to help me with my fastenings', will give a far better idea of what it actually means
- Get help with filling out what can be a daunting form from:
 - Your Regional Care Adviser
 - The MND Helpline
 - Your local Welfare Rights Officer
 - Your local Citizens Advice Bureau (sometimes they can come to you if you have difficulty getting out)
 - Your local DIAL group (available in some areas) or other disablement advice centre
- Get a copy of the Disability Rights Handbook, published by the Disability Alliance.

Finally, some people do not feel that they are 'disabled' and therefore not entitled to make a claim for DLA or AA. 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 – and they are not means tested!

 The Association also provides a booklet for professionals to enable them to help you with your claim.

SECTION THREE

6 WORK, BENEFITS AND FINANCES

FOR CARERS

Invalid Care Allowance is available:

- If you are a carer under the age of 65
- If you are looking after someone who is receiving the 'Middle' or 'Higher' rate of DLA or AA
- If you are spending a minimum of 35 hours a week caring
- You don't have to be related to or living with the person you are caring for.

The qualifying rules are complicated, so it is very advisable to talk to the experts before filling out a claim, by contacting:

- The Benefits Enquiry Line – Freephone 0800 882200
- The Carers' National Association – 08008 808 7777

CARE COSTS

Under 'community care' it is the local authority which is responsible for directly providing or arranging care services for people living at home. Your local Social Services department will assess your care needs and a financial assessment (means test) will be carried out to determine any contribution you may be asked to make towards paying for your care. Most local authorities charge for care services.

Direct Payment scheme

Run by some local authorities, this scheme means that rather than arranging community care services themselves, Social Services provide you with the money to make your own arrangements. While this scheme does provide you with the flexibility to organise your own care, it's vital that you get good advice before employing a carer. Your local Social Services should be able to recommend an advocacy service that can help.

Independent Living Fund

This provides grants for care to people under 65, with severe disabilities, on a low income. A social worker will carry out an assessment and your proposed or existing care services will need to cost at least £200 per week.

Residential care

Funding for residential care is only provided if the social services feel that your needs can only be met out of your own home. If you feel this is the case, they will do an assessment. The cost of such care does worry many people and this is not helped by the complex financial assessment process. Your local Social Services will be able to give you a booklet explaining the procedure.

Nursing home

If you are assessed as needing care from a qualified nurse in either residential care or a nursing home, the Health Authority usually funds this. You would not be financially assessed or charged for this part of your care.

Prescription costs

Prescriptions are free if you are retired or getting Income Support. Otherwise, although MND is not yet listed among the conditions that mean automatic exemption from prescription charges, is it worth talking to your GP. They may be able to put a case for free prescriptions on the grounds that MND is a chronic, enduring condition.

Buying Equipment

If you need special equipment for disability, this will usually be provided by your local Social Services Occupational Therapist. Purchasing your own equipment requires the advice of a specialist; we recommend you get this either from your Occupational Therapist or a local Disabled Living Centre. They show, demonstrate and provide information and advice about aids and equipment. Remember that anything you purchase that is specifically for people with disabilities is zero rated for VAT.



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 motor neurone disease 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.

Adapting your home

A **Disabled Facilities Grant** can be made to meet the cost of adapting a property for a disabled person:

- You will need to apply through your local authority
- The award of a grant is based on a means test
- It can be a lengthy process, sometimes taking six to nine months before work can start
- You will need to be assessed by an Occupational Therapist
- They are not paid retrospectively.

If you decide to pay for any adaptations yourself:

- Your Occupational Therapist will advise on the best way to adapt your home
- The OT may be able to supply special equipment and fixtures
- You should be able to claim VAT exemption on materials and costs.

Note: There may be other sources of grants available locally – check with your Occupational Therapist.

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, Citizens Advice Bureau or Regional Care Adviser for advice on available grants to help with the cost of fixtures and fittings you will need if you do move.

COUNCIL TAX

Discount

You may be able to claim for a Council Tax discount. The rules surrounding who is eligible and what discount they may be entitled to are complicated, so it is worth getting advice from your Citizens Advice Bureau.

Reduction

It is possible to get a reduction in Council Tax if anyone in your home is permanently disabled and if your home has:

- A room primarily used by the disabled person because of their disability – e.g. a separate bedroom
- A second bathroom or additional room needed by the disabled person
- Space that is designated as accessible for a wheelchair user.

These do not need to have been specially installed or adapted – simply needed by someone living in the house. If you do qualify, the reduction means that your home will be treated as if it were in the next lower valuation band. For example, if your home is currently Band C, with a reduction it will be treated as a Band B.

A similar Scheme is available in Northern Ireland. This is called Disabled Persons Allowance (DPA) – a reduction in the Rateable Valuation of a domestic property.

Remember, you can apply for both a discount and a reduction. You can also claim a rebate on your Council Tax bill if you are on a low income.




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

- Help the Aged produce a booklet 'Thinking about money' that gives useful advice on how to assess your financial situation and prepare a balanced personal budget  **See Other organisations.**
- There are many charities, such as professional trade and benevolent funds or ex-service organisations, that will help with unexpected expenses - your local Citizens Advice Bureau will have details
- The Motor Neurone Disease Association will consider providing financial support - talk to your Regional Care Adviser.

Debt

Sometimes, getting into debt is unavoidable but that doesn't make it any less stressful and worrying. Your local Citizens Advice Bureau is a good place to go for advice, or you could contact one of the specialist advisory services.

 **See Other organisations.**

Notes



MND Association, PO Box 246, Northampton NN1 2PR
Tel: 01604 250505 Fax: 01604 624726 Website: www.mndassociation.org
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- Natural Death Centre, 20 Heber Road, London NW2 6AA
Tel: 020 8208 2853 www.naturaldeath.org.uk email: rhino@dial.pipex.com
Provides details of green burials.
- Cruse – Bereavement Care, 126 Sheen Road, Richmond, Surrey TW9 1UR, Tel: 0208 940 4818
- Bereavement Trust, Stamford Hall, Loughborough, Leicestershire
Tel: 01509 852333
- National Association of Bereavement Services, 20 Norton Folgate, London E1 6DB Tel: 0207 247 1080
- Way Foundation, PO Box 74, Penarth, Cardiff CF64 3YX
Tel: 029 2071 1209 www.wayfoundation.org.uk email: info@wayfoundation.org.uk
Bereavement support for people under 50 – particularly with young children.

Living with MND

- SPOD (Sexual and Personal Relationships of Disabled People), 286 Camden Lane, N7 0BJ Counselling Hotline: 0207607 8851
www.spod-uk.org, email: info@spod-uk.org

Equipment suppliers

(inclusion should not be taken as a recommendation)

Communication/Switches/Alarms/Environmental controls

- Toby Churchill Tel: 01223 576117 www.toby-churchill.com
- Possum Tel: 01296 481591 www.possum.co.uk
- QED 2000 Ltd Tel: 023 9271 8719 www.QEDLtd.com

Range of products for making life easier

- Boots - see catalogue in store
- Keep Able Tel: 08705 20 21 22 www.keepable.co.uk
- Functional Solutions Tel: 0845 330 2220 www.promedics.co.uk

Specialist clothing suppliers

- JD Williams Tel: 0161 238 2619
- Wearable Clothing Ltd Tel: 0141 774 9000 www.wearableclothing.com

Other organisations that can help

Work, finances, benefits

- Consumer Credit Counselling Service, Wade House, Merrion Cross, Leeds LS2 8NG Freephone: 0800 1381111
- Money Advice Association, First Floor, Gresham House, 24 Holborn Viaduct, London EC1A 2BN Tel: 0207 236 3566
- National Debt Line, Birmingham Settlement, 318 Summer Lane, Birmingham B19 3RL Free Helpline: 0645 500511 (also provide a free 'Dealing with your Debts' self-help pack)
- Disability Law Service, 2nd Floor North, High Holburn House, 52-54 High Holburn WC1V 6RL Helpline 0207 8318031 Offers free confidential legal advice for people with disabilities.
- Disability Alliance, Universal House, 88-94 Wentworth street, E1 7SA www.disabilityalliance.org Rights Advice Line 0207 247 8763 Offers advice on benefits to disabled people.
- Help the Aged, 207 – 221 Pentonville Road, London N1 QUZ Tel: 0207 278 1114 www.helptheaged.org.uk info@helptheaged.org.uk
- Benefits Enquiry Line – 0800 882200

Movement and mobility and Everyday activities

- Motability Scheme, Goodman House, Station Approach, Harlow, Essex CM20 2ET Tel: 01279 635666
- Community Transport Association (CTA) Tel: 0161 367 8780 email: cta.man@dial.pipex.com Offers free information and advice on all aspects of minibus and accessible community and voluntary transport operations
- Disability Handbook (available from Disability Alliance see above)
- Disabled Living Centres Council, Redbank House, 4 St Chad's Street Manchester M8 8QA Tel: 0161 834 1044 – for details of your local Disabled Living Centre
- Disabled Living Foundation, 380-384 Harrow Road, W9 2HU Tel: 0207 289 6111 www.dlf.org.uk Information and advice about daily living equipment for people with disabilities.

- Talking Newspapers National Recording Centre, Heathfield, East Sussex TN21 8DB Tel: 01435 866102 www.tnauk.org.uk email: info@tnauk.org.uk
- MAVIS (Mobility Advice and Vehicle Information Service)
Tel: 01344 661000
www.mobility-unit.detr.gov.uk/mavis.htm email: mavis@detr.gov.uk
- THRIVE The Geoffrey Udall Centre, Beech Hill, Reading RG7 2AT
Tel: 0118 988 5688 www.thrive.org.uk email: info@thrive.org.uk
Gardening solutions for people with disabilities
- Tripscope The Vassel Centre Gill Avenue Bristol BS16 2QQ
Tel: 08457 585 641 www.tripscope.org.uk email: tripscope@cableinet.co.uk
Transport advice for people with disabilities
- REMAP JJ Wright National Organiser, Hazeldene Ightham, Sevenoaks Kent TN14 9AD Tel: 01732 883818
Makes or adapts aids when not commercially available.
- RADAR (Royal Association for Disability and Rehabilitation), 250 City Road, London EC1V 8AF Tel: 020 7520 4119 www.radar.org.uk
email: radar@radar.org.uk
National disability campaigning and information service.
- Listening Books, 12 Lant Street London SE1 1QH Tel: 0207 407 9417
www.listening-books.org.uk email: info@listening-books.org.uk
- Holiday Care, 2nd Floor Imperial Buildings, Victoria Road, Horley, Surrey RH6 7PZ Tel: 01293 774535 www.holidaycare.org.uk
email: holiday.care@virgin.net
Holiday information for people with disabilities

Speech and communication

- Abilitynet, PO Box 94, Warwick CV34 5WS Tel: 0800 269 545
www.abilitynet.co.uk email: enquiries@abilitynet.co.uk
Provides information, advice and assessments in computer solutions (hardware and software) for people with disabilities.
- Typetalk Tel: 0151 709 9494

Communication Aid Centres (CACs)

Belfast Musgrave Park Hospital, Stockmans Lane, Belfast BT9 7JB
Tel: 01232 669501

Birmingham Oak Tree Lane Centre, Oak Tree Lane, Selly Oak, Birmingham, B29 6JA Tel: 0121 627 8235

Bristol Speech Therapy Dept, Frenchay Hospital, Bristol BS16 1LE
Tel: 01272 701212 ext. 2151

Cardiff Rookwood Hospital, Llandaff, Cardiff CF5 5TN
Tel: 01222 566281

Glasgow Scottish Centre of Technology for the Communication Impaired,
Victoria Infirmary, Langside Road, Glasgow G42 9TY
Tel: 0141 649 4545

London GN05, Charing Cross Hospital, Fulham Palace Road, London
W66 8RF Tel: 0181 846 1057/8

Newcastle The Dene Centre, Castle Farm Road, Newcastle-upon-Tyne
NE3 1PH Tel: 0191 248 0480

Carers

- Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT Tel: 08457 573369
www.carersuk.demon.co.uk email: info@ukcarers.org
- Childline, Studd Street, London N1 0QW Tel: 0800 1111
www.childline.org.uk email: info@childline.org.uk
- Crossroads – Caring for Carers, 10 Regent Place, Rugby CV21 2PN
Tel: 01788 573 653
Promotes, offers, supports and delivers services for carers.

Symptoms

Alzheimers Disease Association – Gordon House, 10 Greencoat place
London SW1P 1PH Tel: 020 7306 0606 Email: info@alzheimers.org.uk
www.alzheimers.org.uk

Children and young people

- Childline – As above
- The Disabled Parents Network Helpline. Tel: 0870 241 1450
Email: information@disabledparentsnetwork.org.uk
Gives advice on how to approach Social Services and obtain the appropriate support; custody and legal issues and requests for contact with other members.
- DPPi (Disability, Pregnancy and Parenthood international) UK Information Service
Tel: 0800 018 4730 Text-phone: 0800 018 9949
Fax: 020 7263 6399
Email: info@dppi.org.uk website: www.dppi.org.uk
Welcomes calls from disabled people who are concerned with disability and/or pregnancy and parenthood.

End of life decisions

- Funeral Standards Council, 30 North Road, Cardiff CF1 3DY
Tel: 029 2038 2046
- National Association of Funeral Directors, 618 Warwick Road, Solihull,
West Midlands B91 1AA Tel: 0121 711 1343
- Society of Allied and Independent Funeral Directors, Crowndale House,
1 Ferdinand Place, London NW1 8EE Tel: 0207 267 6777 www.saif.org.uk

How to get more information from the MND Association

There is a Publications List Order Form enclosed in the back pocket of this guide, which details the range of information we have available to order. In addition sections from the Personal Guide are available for download from our website www.mndassociation.org

If you are unsure what publications would be useful or whether you wish to receive further information, please contact your Regional Care Adviser (RCA) or the Care Information staff at National Office on 08457 626262.

You may also wish to talk to someone after you have received and read the information; again, please contact the people above.

In addition to our printed publications we have a large library of information covering all aspects of MND. So if you cannot find what you want or need to know more about a particular subject we can usually help. Contact the Care Information Service, using your preferred method of communication at:

Motor Neurone Disease Association
PO Box 246
Northampton
NN1 2PR
Tel: 08457 626262
Fax: 01604 638289
helpline@mndassociation.org
www.mndassociation.org

To ensure appropriate care and support for people affected by MND we also produce a range of information for GPs and Health and Social Care professionals. If a professional caring for you would like more information please ask them to contact us on 01604 611870.

Useful publications

Books

Title: Motor Neurone Disease: A family affair
Author: D Oliver
References: London, Sheldon Press, 1995, 1st Edition, 84pp
ISBN 085969 705 3, £5.99

Aimed at people with the disease, their carers and families, this book conveys the wide range of positive support and assistance available in the UK to ensure quality of life is maintained, even though there is as yet no cure. Dr Oliver tries to answer honestly the questions many people have, stressing always the very individual nature of the disease, making sense of the range of health and social care professionals involved and emphasising the importance of involving the whole family in the adjustments necessary to live with ALS/MND. Above all this is a sympathetic, but practical guide to ensuring life is lived as fully and with as much independence as possible.

Title: Amyotrophic Lateral Sclerosis – a guide for patients and families
Author: Mitsumoto, MD. Munsat, TL.
References: New York, Demos, 2001, 2nd edition, 451pp
ISBN: 1-888799-28-5

The first edition of this book, published in 1992, was intended for health and social care professionals. However, patients and families (in the USA) were frequent readers of the book because no comprehensive book on ALS was available to them. Hence the current edition has been extensively revised and rewritten to address the concerns of everyone living with MND. There is a huge amount of text which some people may find a little daunting and in addition as it is written from the perspective of American health care systems some of the content may not be applicable to people living in the UK.

If you would like further information on Motor Neurone Disease or any aspect of research into the disease, the MND Association maintains a bibliographic textbase of journal articles and detailed entries on books on which searches can be made, and a printout of the references supplied.

Contact: The Care Information Service,
Motor Neurone Disease Association,
PO Box 246, Northampton NN1 2PR.
Tel: 01604 611870 (direct dial)
Fax: 01604 624726
Email: helpline@mndassociation.org

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MND Helpline & Information

for people with MND and their carers

08457 626262 (calls charged at local rate)

email: helpline@mndassociation.org

website: www.mndassociation.org

For Care Professionals:
(Information Team) 01604 611870



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MND Association, PO Box 246, Northampton NN1 2PR
Tel: 01604 611870 Fax: 01604 638289
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