

Many people with MND will feel torn between keeping a positive attitude to keep illness away and knowing that at some time they have to accept they do have a serious disease. When the existence of disease is known, "fighting it" is another approach taken by others. Many, on the other hand, prefer instead to deal with things day by day.

A diagnosis of MND has the power to strengthen healthy family relationships, or shatter already weak ones. It can unpredictably bring out the best in some people and in others can awaken emotions they cannot manage. However the diagnosis affects your family MND Scotland is here to offer support, (See section 3).

This factsheet is intended to give you suggestions to help you cope, as well as tips for others around you who will also be going through changes with you. Factsheet 8 "Care Planning and End-of-Life Issues," and Factsheet 36 "Financial and Legal Considerations" also provide information that may help you and your family to cope with changes now and to plan for the future.

COPING STRATEGIES FOR PEOPLE WITH MND

Social workers, psychologists, counsellors, and support groups can be very helpful. You can learn from those who are familiar with what you are going through, share understanding with others who have the same challenges as you, and learn how people with more advanced MND are dealing with issues you might face in the future.

MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.

CHANGES...

Changes will take place for everyone.

Relationships with family and friends, children and colleagues, will undergo a transition period. Close friends and relatives, including children, should be told the truth about your MND. For most people, not knowing what is happening is worse than knowing the truth. Children in particular imagine frightening things if they can see that someone is sick and no one talks about it in front of them. Knowing what is happening also makes it easier for people to offer support and to help. Don't be afraid to ask for help when it is not offered; people often don't know what to say or what would be helpful. Most people, especially relatives, are glad to be of assistance.

Telling others about your situation often means that you will discover who your true friends are. Some people find it very hard to be around sickness at any time, and others simply do not want to commit themselves to helping in a serious situation. Expect that some people may break off relationships. Although this is hurtful, it should not be taken personally. Most people will try to help and be supportive.

- ALS: Strategies for Living ALS Society of British Columbia, 1993

MND Scotland organises local support groups while local hospices and other organisations often provide opportunities to meet others in a similar position to try

to provide social and emotional support throughout the course of the disease.

Life with MND can be looked upon as a series of progressive losses, but it can also be a unique opportunity for enrichment. The choice is yours. If you choose enrichment, it can take many forms. The choices are very personal.

For example, you may decide to try some of the following:-

- develop closer relationships with family and friends;
- make new friends, either with others who are sharing your experiences or with many other people who are involved with MND, or both;
- learn about computers and how to communicate with others through the Internet and other similar services;
- learn to appreciate other things in the world around you, things that you previously took for granted;
- take time to read and listen to music and learn more about spiritual awareness.

The list can go on and on. It probably won't include everything you've always wanted to do, but it can include enough to give you a full and satisfying life. It all depends on your attitude and your imagination.

Hope, faith, love, and a strong will to live offer no promise of immortality, only proof of our uniqueness as human beings, and the chance to continue to experience growth, even under the grimmest of circumstances. The clock provides only a technical measure of how long we live. Far more real than the ticking of time is the way we use the minutes and invest them with meaning.

Meeting the Challenge

Acceptance of MND does not mean giving up. It should be the first step in making the most of your life with MND. There is much that can be done to help you live a productive and enjoyable life. Be positive, but do not trivialise the situation. It isn't helpful to pretend that everything will be fine or that MND is not a very serious condition.

On the other hand, there is no need to dwell on the negative aspects of the disease. Twenty percent of people with MND live more than five years and nearly 10% live ten years or more. You could be one of those people. Thankfully, neurological research is moving steadily ahead, so no one knows when a breakthrough may occur...it could be sooner than later. These facts give hope and hope is a crucial part of life. Achieving a balance between hope and realism is difficult at times, but something we must all try to do.

If you are a person with MND who has decided to take charge of your condition, here are a few practical things you should consider doing without delay.

1. Stay in Contact with your care team specialist

While there is no cure for MND, your Care Team Specialist is expert in the management of the disease and he or she can bring in much valuable help and support in other areas. Along with your GP your care team specialist will also be able to help you in the future, such as involving other health and social care professionals who can provide specialist help to deal with specific problems you may have.

Your GP can help by in ways other than simply prescribing drugs, for example by writing a letter in support of any application you make for a disabled parking permit (see below) or prescribing food supplements. You should also suggest that your doctor access the resources available to GPs and other allied health professionals from MND Scotland by requesting a copy of our **“Problem Solving Approach for GPs and Allied Health Professionals.”** Also, encourage your doctor to rely on your MND Care Team Specialist for consultations and advice. You should also discuss with your family doctor his or her arrangements for out of hours services and availability to do home visits as MND progresses.

2. Become a member of MND Scotland

While you do not have to be a member to access the services provided by MND Scotland – our aim is to provide support to anyone with MND in Scotland – as a non-member you will not receive our quarterly newsletter and will therefore not be kept up to date with the latest developments in our services or news relevant to people with MND. Both in its own right and as a member of the Neurological Alliance, MND Scotland has been an active lobbyist of the Scottish and UK Governments on the rights of people with MND.

3. Apply for a Disabled Parking Permit

The local authority for the area where you live is responsible for issuing a disabled (Blue Badge) parking permit to people with MND. Get the application form through your local authority’s social work department. You can find the details of how to contact your local council in the factsheet section of our website under the heading of “Supplementary Files.”

You do not need to own a car to qualify for one of these permits. The permit is issued to the person with a disability and is displayed on the dashboard of any car in which that person is travelling. This gives complete flexibility to the person who owns the permit and allows any friend or family member to benefit from the special rules applicable to the “Blue Badge” scheme, but **ONLY** while transporting the owner of the permit.

Local authorities and owners of car parks are very aware of the abuses made by able-bodied people of the previous Blue Badge scheme and take special interest in who is present when a “Blue Badge” is used. It is for this reason the badge is now issued only for a limited period and carries a photograph of the user.

4. Obtain a MedicAlert Bracelet

A MedicAlert bracelet can be useful to warn others about your condition in the event that you are unable to speak. This may be particularly useful for those with bulbar symptoms who are unable to speak or have slurred speech. For further information and a membership application form you can either call MedicAlert at 020 7833 3034 or Freephone 0800 581 420. You can also join via their website at www.medicalert.org.uk/

TO DO LIST. . .

1. Contact your Care Team Specialist and family doctor
2. Join MND Scotland
3. Apply for a Disabled Parking Permit
4. Obtain a MedicAlert Bracelet
5. Contact your car insurance provider

5. Contact your car insurance company

If you don't report your disability to your insurance company, your car insurance

may not be valid in the event of an accident. Since driving requires effective coordination and sometimes requires fast foot and hand reactions you might have difficulties if it emerges AFTER an accident that you have MND. If your insurance company wants to change your premiums or insurance in any way that you consider unfair enquire if they subscribe to a driving test service that will certify your current abilities for insurance purposes.

How to help your Family Cope

It is important to be aware that members of your family and your friends are experiencing emotional reactions to your disease. They may feel guilty that you have MND and they are healthy. They may also be short-tempered because of the extra daily responsibilities that they face – running the household, banking, paying bills, raising children with less help from you, more housework - all this in addition to the care they give you. They may feel a sense of grievance at having your previous lifestyle and domestic arrangements disrupted and then feel guilty about reacting this way.

Keeping the lines of communication open is the best way to work out these feelings. Talk openly to your family about how you feel. Encourage them to share their feelings with you. If your spouse/ partner irritates you without knowing, or you get a similar feeling that they do not understand you, you have a communication problem. Neither of you are explaining to the other exactly how you feel nor what you expect from each other. If this is hard to do, it may be useful to talk with a social worker or other member of your MND team. He or she may be able to help you and your family to solve communication problems.

It is most important that you have someone to talk to who will not be upset by what you are saying. The person you need may be one of your healthcare professionals, a friend, minister of religion or a family member or possibly the counselling service offered by MND Scotland.

With time members of your immediate family may become involved in your daily care and assistance. Most people with MND remain in the home for as long as possible. As a result the demands upon family members can be great. Your primary "informal" caregivers, such as your spouse, partner or grown children, may find that your care, especially in the later stages of the disease, is taking up most of their lives. It is natural for them to want to give all that they can to help you, but there should be limits to self-sacrifice that you need to acknowledge to them.

Your principal carer might, intuitively, know exactly what to do and how to do it to your best satisfaction. For this you will naturally hold them in highest regard. It is only natural that if other people do not come up to that standard you will want your principal carer to be there all the time.

However, carers must continue to have lives of their own and to take care of themselves. Spending time in the company of friends or family who are not sick, or taking part in outside hobbies or activities gives them a chance to re-charge their batteries. For some carers quiet time alone can be an important refresher. All of these allow the carer opportunities to unburden themselves about their fears and worries and to seek the help and support they might require. Above all carers need time to themselves to set aside the stresses of caring, put things into perspective and recharge

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themselves mentally. Only if they can do this can they become more effective, balanced helpers. It is for this reason that it is essential that you start to involve other family members and friends and teach them the best way to do things for you as early as possible. As their knowledge of how best to care for you grows the stresses on your primary carer will lessen as they know they can safely leave you in the care of certain others who are equally skilled in meeting your needs.

Do not hesitate to ask other family members to fill in for your main carer while he or she takes regular breaks or, if possible, arrange for voluntary or paid help. A social worker or MND Scotland Care Team Specialist may be able to help you identify respite services that work in your area such as "Crossroads Caring

Scotland," whose members will sit with someone to allow the carer time off to do other things. Other organisations such as the Leonard Cheshire Foundation and Shared Care Scotland can guide carers to short break opportunities and MND Scotland offers funding under our "Time Out" grants scheme to help fund breaks directly of to fund other activities that can offer carers respite.

The needs of a carer tend to take a back seat to the needs of the sick person. It is hard to have a serious illness, but it is also difficult to care for someone with one. Most people, sick or well, feel a combination of some or all of the emotions listed in the following table at different times when dealing with illness. Most importantly, no one should feel guilty about any of these feelings. They are perfectly normal and to be expected.

Commonly experienced emotions in both the initial and longer terms are:

Initial emotions:	Long-term emotions:
<ul style="list-style-type: none"> • Curiosity • Love • Closeness and openness to others • Hope • Disbelief • Loss • Anticipatory grief • Guilt • Erosion of trust • Denial • Responsibility 	<ul style="list-style-type: none"> • Persistence • Hope • Love • Appreciation of the value of life and of others • Sadness • Guilt • Loneliness • Jealousy • Annoyance • Feeling trapped • Feeling overwhelmed

Remember, everyone has the right to:

- put themselves first
- sometimes make mistakes
- have their own opinion and convictions
- change their mind or decide on a different course of action
- protest against unfair treatment or criticism

The information in this leaflet is believed to be accurate at the time of production, MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

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Being a patient is never easy, particularly when the future contains as many uncertainties as MND. Caring for someone with MND is just as hard, and for some harder, than if they had the disease themselves. Patients and carers need to have regard to each others rights and preferences and the sensitivity to acknowledge that the indignities brought

by the illness can be equally embarrassing to both the carer and the person affected. Both need to support each other through the “downsides” as well as actively looking to find opportunities for pleasure and happiness during the lighter moments when the disease is forgotten.

Further Information

Factsheet 20 Library and Information Service

Book The Selfish Pig’s Guide to Caring by Hugh Marriott, Published by Polperro Heritage Press

Carers Scotland Tel 0808 808 7777 <http://www.carersuk.org/scotland>

Princess Royal Tel 0141 221 5066
Trust for Carers <https://www.carers.org/>

Crossroads Caring Scotland Tel 0141 226 3793 www.crossroads-scotland.co.uk

Leonard Cheshire Foundation www.lcdisability.org/

Shared Care Scotland Tel 01382 622 462 www.sharedcarescotland.org.uk

Medic Alert Tel 020 7833 3034 or 0800 581 420 www.medicalert.org.uk/