



The Scottish MND Association was founded in 1981 by John MacLeod and is the only charity providing care, information and funding for research to improve the lives of people affected by Motor Neurone Disease (MND) in Scotland.

The Association aims:-

- To ensure that the right help, care and support is available to everyone with MND and their families in Scotland
- To inform, educate and support health and social care professionals working with people affected by MND
- To raise awareness of MND
- To promote research into all aspects of MND

### Providing Information

The Association now works under the name of MND Scotland and provides comprehensive, accurate, and timely information about MND to those with MND, those affected by MND, the research and healthcare communities, the media, our donors, and volunteers.

We communicate through several publications such as our newsletter, *Aware*, our research publication, brochures, fact sheets, and our extensive web site [www.mndscotland.org.uk](http://www.mndscotland.org.uk). In addition to being a source of on-line educational materials, MND Scotland web site is a great place for you to find current, trustworthy information about key MND research, MND and Association news, advocacy initiatives, links to other

Associations world-wide, other useful resource sites, and much more. "Knowledge is power", so learn as much as you can!

### Providing Support

MND Scotland provides support through the following services:-

MND Care Team,  
Equipment Loan Service  
Counselling Service  
Library and Information Service  
Benefits and Welfare Service  
Education Service and  
Befriending Scheme (Tayside and Fife)

In addition to the above we also offer practical information and support via family information evenings, a small grants scheme, study days, local branches and opportunities for holidays at our caravan, specially adapted for disabled access, in St Andrews.

MND Scotland produces several publications and factsheets that are available to you. Contact our head office to find out what's available, or go to [www.mndscotland.org.uk](http://www.mndscotland.org.uk) where most of them can be downloaded and printed from the "Information" section.

### MND Care Team

MND Scotland provides the services of an MND Care Team who are linked to hospital neurology departments at Glasgow, Edinburgh, Dundee and Aberdeen. The MND Care Team Specialist is a highly qualified health

**MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.**

professional who has specialised in dealing with patients with MND. They are very experienced in the problems that MND can cause. People with MND can arrange for an MND Care Team Specialist to visit them, their carers and their family at home. The main aspects of their role are to:-

- Visit people with MND and their families at home to give support and advice.
- Support health and social care colleagues e.g. occupational therapists etc.
- Determine future needs and arrange loan of specialist equipment for people with MND.
- Co-ordinate the services provided to people with MND

### **Equipment Loan Service**

As MND progresses it is probable most people may need access to specialised equipment. Most larger more expensive equipment is ordered as required by the professionals responsible for assessing your needs in that area, e.g. a District Nurse might order a specialised bed, an OT might order a riser recliner arm-chair. Our equipment loan service was created to fill the gap between a need being identified and the supply of your own equipment. Your MND Care Team Specialist can arrange for loans and delivery of most common pieces of equipment at no charge.

### **Counselling Service**

MND Scotland offers emotional support and professional counselling for people affected by MND and relatives bereaved by the loss of someone to MND. Counselling normally takes place in a neutral setting close to your home and is carried out by trained volunteers. For

those who are housebound or living in remote areas with no nearby counsellor a confidential telephone counselling service is also available.

### **Library and Information Service**

“Knowledge is power,” is a frequently quoted phrase, but is all the truer when faced with a little known disease like MND. If you do not know what is available to you in the way of specialist services and equipment you do not know what help to ask for. Our library contains books and periodicals on all aspects of MND which are available to borrow by post or in person. Our information officer/librarian is also able to research any aspect of MND on which you need more information. Recent enquiries have included the best way someone with MND can travel from Scotland to Australia unaccompanied, disabled access holidays in the Norfolk Broads and the translation of one of our documents into Urdu.

### **Benefits and Welfare Service**

As Scotland’s social and health policies diverge from those of the rest of the UK entitlement to benefits becomes ever more complex. Free personal care for the elderly and the phased reduction of prescription charges are further factors which complicate the calculation of benefit entitlements. MND Scotland has a Benefits & Welfare Officer who can offer advice and information about benefit entitlement to people affected by MND. Claiming benefits is not always a straightforward process and we aim to help make it as easy as possible. The services offered range from providing basic advice to helping complete application forms, liaising with various agencies on your behalf and finding different sources of financial help.

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.

### Education Service

Family information evenings are held at regular intervals across Scotland to provide an opportunity for families and friends of people with MND to learn more about the condition and the support services we offer. Families of those who have been recently diagnosed will be invited to the next available meeting in their area. If you have not been invited within six months of diagnosis please contact our education officer.

### Befriending Scheme

A befriending scheme operates in Tayside and Fife. The scheme aims to provide help and support to those affected by MND in exactly the same way as a friend might help out.

MND Scotland is also involved in special events, public awareness, and advocacy activities in which you and your friends and family members may wish to participate such as *MND Awareness*

*Week* in June, fundraising walks, or lobbying efforts that focus on making changes to public policy to benefit persons affected by MND. Lobbying activities may involve anything from letter writing campaigns to strategic visits to the Scottish Parliament in Edinburgh. Participation in Association activities can be very empowering. Contact our head office on 0141 945 1077 for information on any upcoming events in your area.

### Supporting Research

MND Scotland is dedicated to finding the cause of and cure for MND through promoting and funding quality research. Attracting new researchers to the MND field is an important strategy in meeting the mission and for this reason a five year rolling programme of PhD studentship awards has been put in place. For more information on the specific research that is currently being supported by MND Scotland, please see Factsheet 26 Current Research.

### Further Reading

Factsheet 1  
Factsheet 26  
Factsheet 20

What is MND?  
Current Research  
Library and Information Service