



In order to remain as independent as possible for as long as possible, you will need a supportive, patient-centred healthcare team who understand MND, your personal situation, and the options open to you. With time you may need to work with your care team to treat various symptoms of MND and adapt to the limitations it imposes on you.

Access to healthcare professionals who work together with you as a team and are knowledgeable about MND is a very important factor in managing MND effectively. Neurology centres in Scotland care for patients who have MND through a multidisciplinary approach.

As well as visiting an MND clinic for periodic follow-up and assessment, you will still need services from community-based healthcare professionals. It is important that all of your primary or family

carers meet with members of your healthcare team to be shown the various helping techniques you might need. Effective communication between healthcare professionals, your carers and you is a key factor in getting the best care. This factsheet attempts to set out, in general terms, where you should look for support for particular problems.

Even if your diagnosis is not yet confirmed you do need to consider who is the best health or social care professional to meet the needs imposed on you by your illness today. Although your MND Care Team Specialist should make contact very soon after diagnosis (and can act as a source of referral to all of these professionals,) the table below can be a useful guide to where you start to find support in the meantime. The rest of this factsheet gives more detail about what these different professionals can do.

Your Problems	Who Can Help	How to get in touch
Everyday activities, e.g. using the toilet, washing, using cutlery, climbing stairs.	Occupational Therapist (OT)	Local Social Work Department
Personal Care e.g. getting in and out of bath or shower	OT or Social Worker	Social Work Department
Support for you and your family, e.g. finances/ respite care	Social Worker	Social Work Department
Mobility e.g. walking, stair climbing, balance or exercise	Physiotherapist or OT	Via your GP or Social Work
Employment	Disability Advisor	Local "Job Centre Plus"
Stiffness and Cramps	GP	Local Surgery
Swallowing food and drink	Speech Therapist	Via your GP
Nutrition, e.g. loss of appetite or weight loss.	Dietician	Via your GP or via your Speech Therapist
Speaking	Speech Therapist	Via your GP
Coughing	GP/Speech Therapist/Physiotherapist	Via your GP

**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.**

### General Practitioner (Family Doctor)

Your GP's tasks may include the following:

- Prescribing appropriate prescription drugs, sometimes recommended by others such as your MND Care Team Specialist;
- Explaining the implications of the diagnosis and possible progression of MND;
- Making necessary referrals to, and consulting with, other health and social care professionals to best manage your care;
- Discussing any treatment options you might wish to take or avoid.

### Neurologist

Your GP will probably already have referred you to a neurologist, a specialist in diseases of the nervous system, who can confirm a diagnosis of MND. Between them they will:

- Outline types of treatment options available;
- Encourage the setting of short-term goals;
- Help you preserve a positive self-image and maintain your morale;
- Work with you to identify specific needs and concerns and
- Refer you to therapists who may be able to find solutions to specific problems or complications.

### MND Care Team Specialist

Your MND Care Team Specialist is a highly qualified health professional who has specialised in dealing with patients with MND. She is very experienced in the problems that MND can cause for those with this diagnosis and has a wealth of

knowledge and experience that will be of great value to the person with MND and their family. Your MND Care Team Specialist is a member of a neurology team at one of the Neurology Centres in Scotland and will feed back to your Consultant any important information about changes to your condition between hospital appointments.

If you have not yet met your MND Care Team Specialist at the neurology clinic she will make contact with you within a few weeks after your diagnosis and will usually arrange to visit you at home in order that she can make an assessment of your needs from your own perspective. As MND progresses most people with your own diagnosis experience similar changes to their abilities to do certain things. The MND Care Team Specialist will recognise what kinds of challenges your own home is likely to pose you in the future and can involve a range of other professionals who can help you to meet any challenges posed by your condition.

- Listen to you and to try to understand your needs,
- Provide information about MND when you have been newly diagnosed and as your condition progresses,
- Help you to understand information and apply it to your circumstances,
- Help you to understand the health system and to identify and access services you may need now and in the future,
- Act as a source of expertise and advice to patients and their families on what help is available to deal with difficulties caused by MND,
- Liaise with health and social care professionals to secure the specialist help needed by a person with MND,
- Provide information and support to general practitioners and district

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nurses who may have limited experience of treating people with MND,

- In conjunction with other professionals, help you to understand your entitlement to funding, grants and welfare benefits,
- Maintain contact with the person with MND and the family on a regular basis,
- Promote communication and cooperation between the individuals and agencies involved in your care,
- If you want, offer you the opportunity to meet or be in contact with others with MND

### **Getting the best from the Care Service**

For your MND Care Team Specialist to be effective it is important that you feel comfortable, are able to exchange information freely, and understand the written information which you receive. Please feel free to have support people with you when you meet with your MND Care Team Specialist. MND can cause a wide range of symptoms, which you might not immediately think are related to your condition, therefore if there is anything concerning you please mention it to your MND Care Team Specialist.

If English is not your first language, or you have specific cultural needs, your MND Care Team Specialist will be happy to have someone present who can translate or otherwise assist. If you don't know a person who can do this, your MND Care Team Specialist will work with you to find someone.

### **The MND Care Team Specialist & Client Relationship**

The MND Care Team Specialist's relationship to you is a professional and confidential one, and as such is different to relationships you may choose to have with other people you meet through the

Association. Your MND Care Team Specialist works for the NHS but is paid for by the Association. Any information that you give the MND Care Team Specialist can only be passed to the Association if you give your consent.

### **Confidentiality of Information**

Your MND Care Team Specialist will need to collect and keep information about you in order to provide effective support. Safeguarding your privacy is a priority for your MND Care Team Specialist, and your information will be kept securely.

- You have the right to access information which the NHS holds about you and to request that it be corrected if necessary.
- Your MND Care Team Specialist may need to share information about you with health professionals involved in your care to assist you to receive the services you need. She may also seek your permission to refer you to another health professional or agency.
- The MND Care Team Specialist may need to share information relating to her work with you with a professional supervisor and/or with her line manager.

### **What the MND Care Team Specialist won't do.**

- Your MND Care Team Specialist may have trained in a health discipline but will not be working with you in that role and will not provide 'hands on' care.
- MND Care Team Specialists do not provide an emergency service. It is important that you know who to contact in an emergency. You can discuss this with your Care team member and with others on your health-care team.
- Your MND Care Team Specialist is

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not a counsellor. If your need for support goes beyond your MND Care Team Specialist's role and skills, she may suggest that you contact our counselling service at headquarters.

- Your MND Care Team Specialist will not always be there when you call. She may work part-time, and will often be out visiting clients. You can contact your MND Care Team Specialist by calling the number at the end of this pamphlet. If she is not there, leave a short message with your name and telephone number. Your MND Care Team Specialist will return your call as soon as possible.
- Your MND Care Team Specialist is committed to visiting or contacting you at least once every three months.

### **Occupational Therapist and Physiotherapist**

The occupational therapists (OT) and physiotherapists (PT) you are likely to meet if you are not in hospital are usually employed by your local council's social work department. The local council has a statutory duty to carry out an assessment of your needs when asked and most will take steps to make what they consider reasonable provision based on that assessment. Their role is to develop strategies that enable people with MND to continue to carry out daily activities in a safe and efficient manner. This is accomplished through the following:

- Teaching by demonstration;
- Ongoing assessment/evaluation;
- Ordering appropriate equipment in a timely manner;
- Preventing complications;
- Utilising community resources;
- Providing psychological support.

**The Occupational Therapist (OT)** is generally more concerned with fine-motor control and how movement will affect function. The OT will visit you at home and will make an assessment of the problems MND is causing for you. Some suggestions will be very low cost and you might be expected to make arrangements to provide these solutions for yourself, for example replacing fasteners that give you problems, such as buttons or zips, with Velcro-type fasteners. More expensive items, such as the provision of handrails, might be provided free by the council.

Other suggestions might have no cost at all, for example if you are weaker on one side than on the other dressing is often easier if you put clothes on starting with the weak side, or if you have trouble with your legs it might be easier to pull trousers on while lying down.

The OT's tasks may include the following:

- Assessing fine-motor functional abilities (for example, hand use);
- Evaluating positioning and seating requirements;
- Assisting in choosing and accessing suitable augmentative mobility and communications strategies\* and any required assistive devices;
- Giving instruction to the person with MND, family members, and carers on exercise, positioning, correct body mechanics for lifting and transferring, and use of assistive devices;
- Teaching energy conservation and time management techniques;
- Providing information about modifications to home and other environments to enhance mobility and safety.

\* The OT is not a specialist in speech and language therapies and will probably involve a specialist speech and language

therapist (SLT) if the need arises.

**The Physiotherapist (PT)** is generally more concerned with gross-motor function and anatomical impairments associated with abnormal movement. The PT's tasks may include the following:

- Providing a detailed analysis of abnormal movement (for example, gait analysis-how you walk);
- Optimising the person's strength, function, and comfort;
- Designing and monitoring a therapeutic exercise regimen when appropriate;
- Assisting with breathing management; providing training in energy conservation and time management techniques;
- Preventing needless purchases of unsuitable equipment;
- Making a home assessment.

### **The Rehabilitation Specialist**

The Rehabilitation Specialist, a medical doctor specialising in physical and rehabilitative medicine, generally evaluates the extent of disability and functioning, and gauges the level of muscle function you still have (residual level). On the basis of these findings, treatment plans may be designed. Other functions may include:

- Recommending preventive and supportive treatment;
- Preventing complications;
- Determining which diagnostic tests are necessary;
- Helping maintain maximum function and quality of life;
- Consulting with other therapists concerning medical devices and equipment that may be of use to you.

### **District Nurse and Health Visitors**

**District Nurses** offer a range of services within the home during the day, evening and night such as changing dressings or giving injections. They can advise you and teach your family how to become as independent as possible and still meet your needs at home. These nurses are often extremely experienced and work within the community attached to a particular GP, Health Centre or Community Health Partnership.

**Health Visitors** are nurses who specialise in health promotion such as smoking cessation. They can offer help with referrals to other agencies. Your GP can organise referrals to a health visitor if it is appropriate.

### **Dietician**

A dietician's primary considerations are to keep your quality of life as high as possible by maintaining safe and adequate nutrition and hydration, in order to prevent life-threatening nutritional deficits from developing. The dietician may assess or evaluate the following:

- Functional abilities (ability to self-feed or to administer tube feedings);
- Nutritional status and present intake.

The dietician may recommend the following strategies:

- Appropriate changes in food texture and consistency;
- Appropriate methods of food preparation;
- Substitutions for hard-to-manage foods;
- Meals of a manageable size and frequency;
- Strategies for maximising nutritional intake.

### **Respiratory Specialist Nurse and Respiriologist**

The respiratory specialist nurse generally devises strategies to optimise remaining muscle function, reduce discomfort and, if necessary, institutes a program of chest care. In some locations, the physiotherapist may be the person who helps you with exercises to promote airway clearance and cough techniques. Other tasks may include:

- Evaluating lung function status;
- Maintaining airway hygiene;
- Providing suggestions for managing decreasing breathing function;
- Offering information on body positioning, energy conservation, relaxation, and compensatory techniques to improve breath support for nutrition and speech;
- Setting up a home ventilation program if appropriate;
- Making suggestions about a course of action to take if respiratory failure occurs.

The respirologist is a medical doctor who specialises in care for the respiratory system. During the course of MND you may be referred to a respirologist in the event of a respiratory infection, or if your chest muscles deteriorate to such an extent that decide you are interested in mechanical ventilation.

### **Speech and Language Therapist (SLT)**

A speech and language therapist provides advice on techniques and strategies to allow the person with MND to continue to communicate throughout life. Some functions of the SLT may include:

- Evaluating the individual's motivation

and potential for learning new techniques;

- Evaluating functional abilities, such as oral motor function, cognitive-linguistic function, augmentative communication function, and swallowing function;
- Determining the most efficient communication function;
- Training people with MND and family members in techniques of effective communication and energy conservation and, often in conjunction with a dietician, safe eating, drinking and swallowing techniques.

SLTs can be involved at an early stage when someone has presented with bulbar symptoms. The role of the SLT is to find ways to help the person maintain verbal communication for as long as possible and to identify alternative methods of communication when speaking is no longer possible.

SLTs like to get involved as early as possible, and preferably before they are really needed in order to allow them to get to know the person and to work out which of the many possible alternative communication methods are likely to work best for that person.

### **Social Worker**

In addition to other healthcare professionals, you may be referred to a social worker. The social worker's tasks include both practical assistance as well as emotional support to help people with MND and their families cope with everyday life. The social worker offers:

- Emotional support and counselling to the person with MND and to family members and referrals to an appropriate service agency if ongoing support is required;

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- An understanding of the emotional impact of an MND diagnosis and assists with the psychological adjustments that come with this diagnosis;
- Information about available community resources and acts as an advocate to assist people in accessing these resources;
- Information on legal and financial issues and assists people to access these resources in their own communities; and
- Help with setting short-term and long range goals and making plans that will meet future care needs.

### **Pastoral Care Worker**

A minister, priest, rabbi, chaplain or other pastoral care worker may perform the following functions:

- Listening to and empathising with those who want to talk about their concerns;
- Assisting in making decisions;
- Giving spiritual support during emotional or physical crises;
- Acting as an advocate for those who have no voice;
- Reassuring people with MND that their lives have meaning and facilitating spiritual reflection; encouraging people with MND to discover their personal strengths;
- Encouraging people with MND to recapture positive experiences from the past by recall or reminiscence;
- Celebrating the individual's humanity and worth;
- Listening to concerns about death and dying; and
- Arranging for and conducting services when appropriate.

In effect, the pastoral care worker is using

their belief structures, experience and interpersonal skills to counsel people within the context of the religious structures and beliefs to which they themselves subscribe. If you are not religious and have no belief in a "higher power" the same objectives of having someone listen, give support, help in decision making and so-on can be obtained through our counselling service.

### **Other Professionals**

There may be other healthcare professionals on your MND team such as an assistive technology expert, psychologist, or gastroenterologist. The above mentioned professionals comprise the most common members of an interdisciplinary MND care team. A business card holder page has been included at the start of this manual to help you keep the contact information for your healthcare team members handy when you have questions or need to make appointments.

Depending on your circumstances you may need to call on support from other organisations as and when required. Local health and social work services have been brought together in the last couple of years under the umbrella title of "**Community Health Partnership.**"

**Community Health Partnerships (CHPs)** are intended as "one stop shops" for seamless social and health care support. Precise arrangements vary across Scotland as the services transition from their previous arrangements to their new arrangements. Your MND Care Team Specialist can advise you on your most valuable points of contact in your CHP for your current needs.

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### **Department of Work and Pensions (DWP)**

The DWP is the UK service which provides advice and information about entitlement to state pensions and benefits such as Disability Living Allowance and Attendance Allowance. They also handle and process claims, reviews, and appeals and arrange for payments to be made. Additional advice on benefits can be obtained from the Citizens' Advice Bureau (CAB) and MND Scotland's Welfare Rights and Benefits Officer. If you need additional independent advice regarding benefits contact our information officer or welfare rights officer on 0141-945-1077.

**Housing Associations** are independent providers of housing who have taken over in some areas from the local council **Housing Departments**. Together they have a major role in providing public

housing for people with special needs. It is worth contacting whichever of these organisations provides public housing in your council area if you feel you would benefit from re-housing. Check your local council's entry in your telephone directory for a housing department. If none is listed the council should be able to supply you with a list of housing associations operating in their area. Check also "Housing Associations" in the classified section of the BT directory or Yellow Pages.

**Citizens' Advice Bureau (CAB)** is a useful independent source of information and support. Trained staff are knowledgeable about local and national services. Your local Bureau will be listed in your local telephone directory or Yellow Pages or can be located through the Citizens' Advice Scotland website [www.cas.org.uk](http://www.cas.org.uk).

### **Further Information:**

Contact Lynnette Scott at MND Scotland's Headquarters (0141 945 1077, or by email at [lynette.scott@scotmnd.co.uk](mailto:lynette.scott@scotmnd.co.uk)), if you, or a member of your family, would like counselling

### **Factsheets:**

Factsheet	5A	Maintaining Mobility
Factsheet	34	Adapting to Swallowing Problems
Factsheet	36	Oral Health
Factsheet	30	Communication Strategies
Factsheet	35	Breathing Matters