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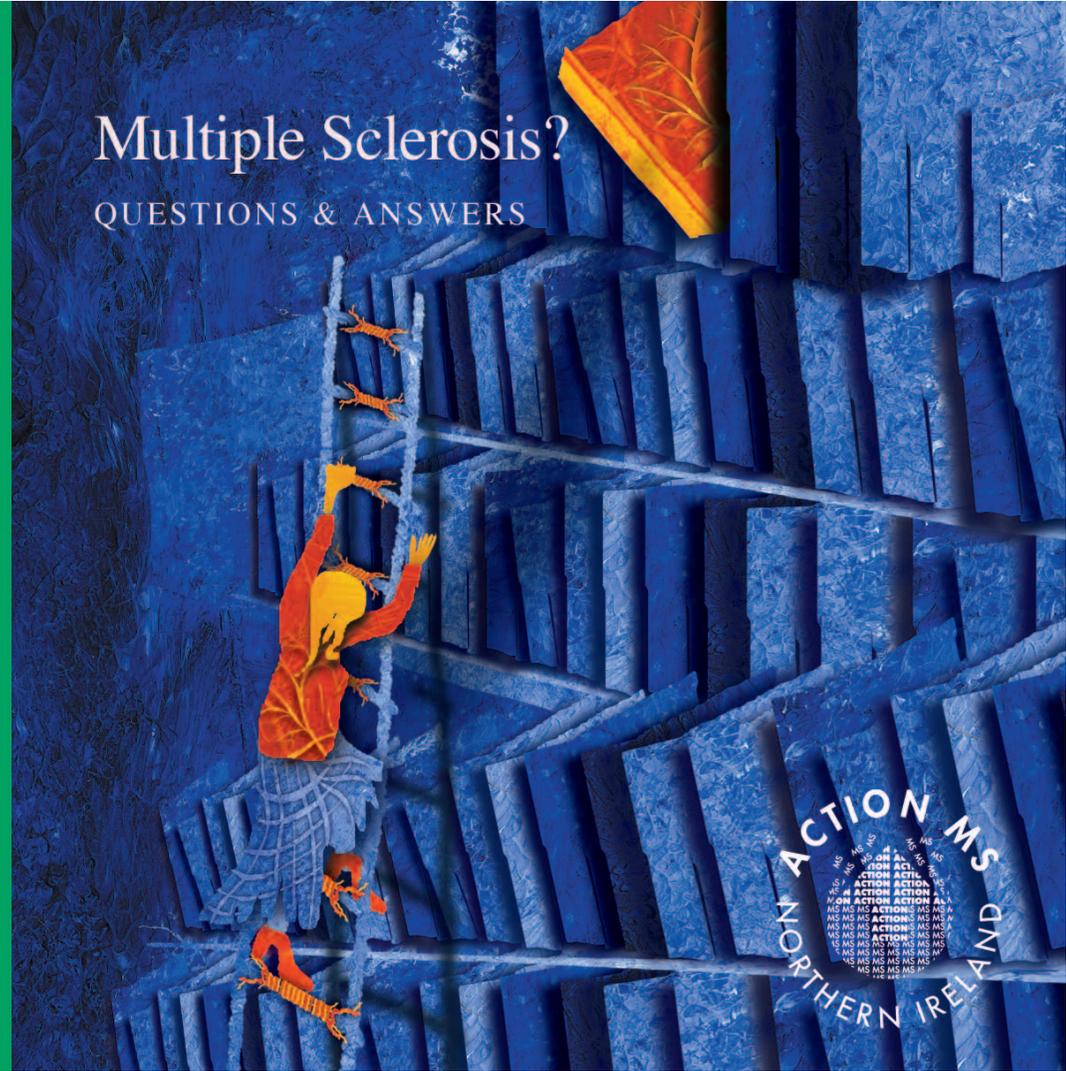
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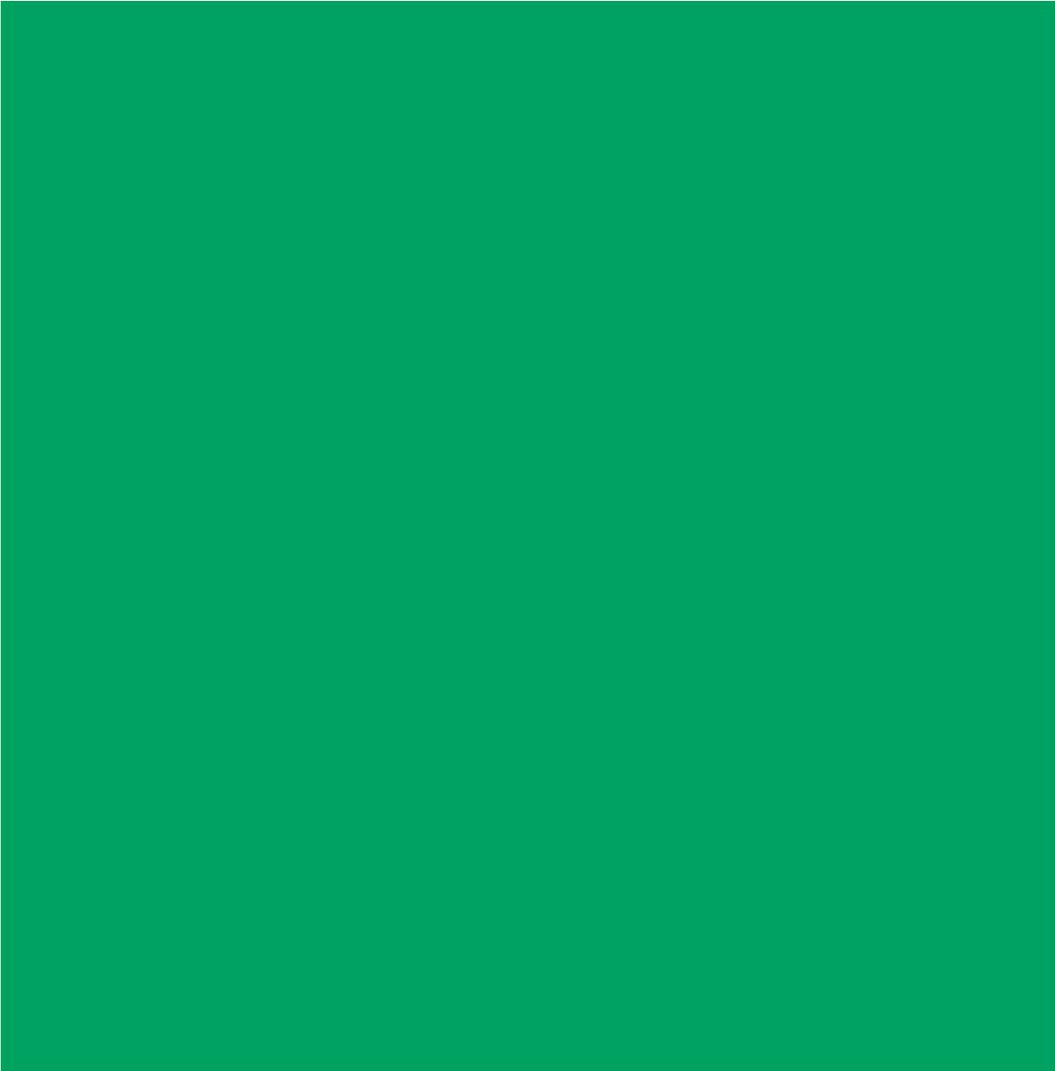
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Multiple Sclerosis?

QUESTIONS & ANSWERS





Multiple Sclerosis?

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WHO'S WHO in the BACK-UP TEAM



Action MS - fighting MS since 1976

Action MS Northern Ireland was formed in 1976 when a small group of people with MS, families and friends decided to do something to fight multiple sclerosis, a disease of the central nervous system for which there is as yet no cure.

Medical Research

The most obvious starting point was to raise funds for medical research. Over the years with the support of the whole community Action MS has raised thousands of pounds for research work at the Royal Victoria Hospital and the Belfast City Hospital. MS is still a puzzling disease but advances have been made in developing treatments and enhancing quality of life.

Caring Services

Action MS tries to live up to its name. That means offering support to people with MS and to those who care for them. We have over the years learnt to listen and to find out what is most needed by those who live with MS.

Multiple Sclerosis?

QUESTIONS & ANSWERS

■ *What is Multiple Sclerosis?*

Multiple Sclerosis is a medical condition that affects the nerves in the body. It is not a question of being “bad with your nerves”.

During an MS attack the myelin sheath, which covers the nerve, becomes inflamed and this disrupts the messages passed along the motor and sensory nerves.

Motor nerves carry messages from the brain to make parts of the body work. Sensory nerves carry messages to the brain to give information. Consequently some parts of the body may not work as efficiently and sensitivities such as touch may be altered.

Not all nerves will be affected by MS. Some, such as the nerves affecting heart and lungs function will not be directly affected. These belong to the “autonomic system”.

MS is individual, no two people will be exactly the same. There are different types of MS: benign, relapsing/remitting and progressive.

■ *How is MS diagnosed?*

There is no single test. Diagnosis will take account of a number of things such as

- Medical history,
- Eye evoked response test;
- Spinal fluid extracted by lumbar puncture;
- Any damage in the central nervous system identified by an MRI body scan.

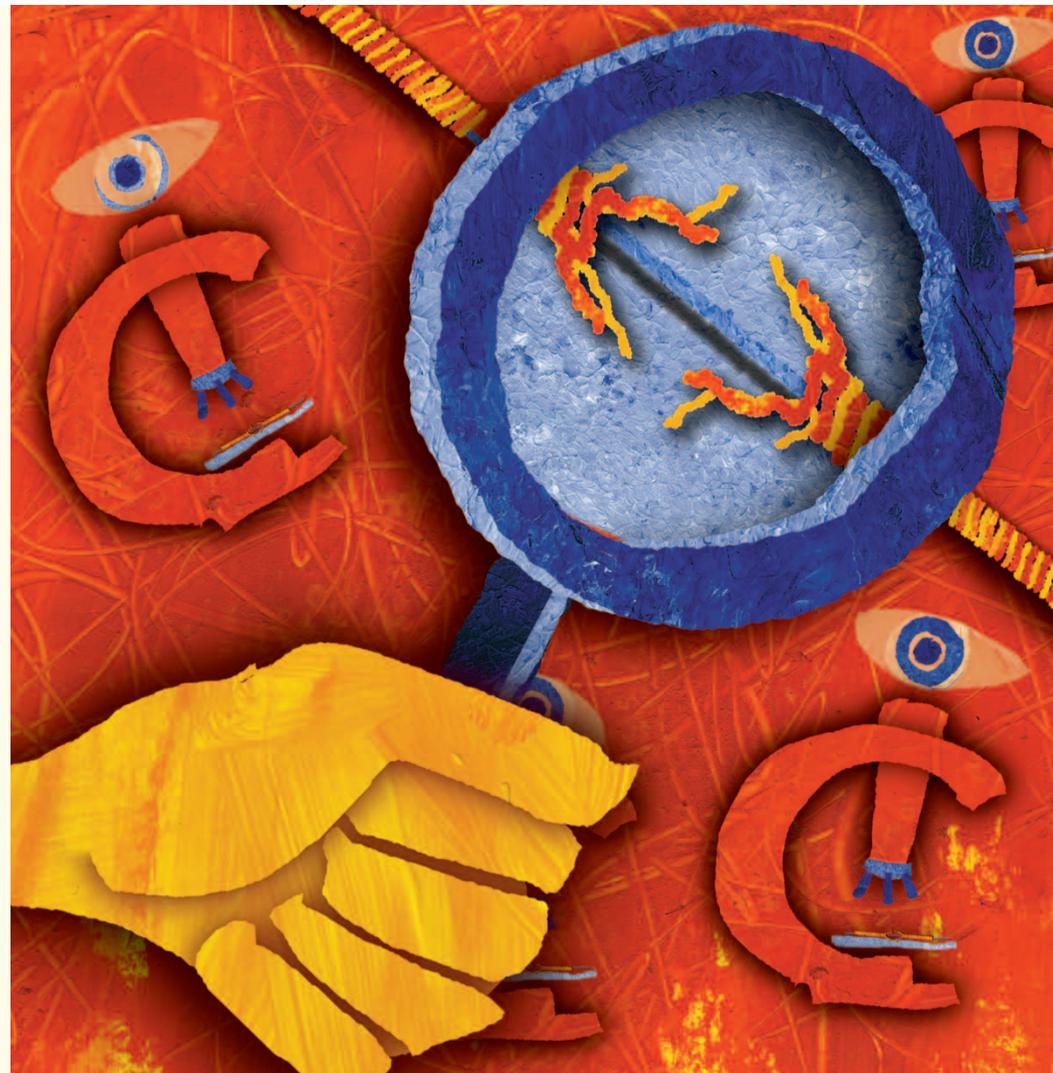
These factors along with at least one previous MS attack and the elimination of other medical conditions usually allow a neurologist to make a definite diagnosis.

■ *What causes MS?*

The cause of MS is not yet known.

■ *Is MS infectious?*

No. MS cannot be passed onto someone else. Moreover it is not directly inherited although individuals who have a family history of MS have a slightly higher chance of developing the condition. Women are more likely to have MS than men.



■ *What are the symptoms?*

There are a range of symptoms, but it is important to remember that these will vary in number and severity. They may be experienced acutely during an attack and then ease considerably.

The most common symptoms include fatigue, weakness, tingling, numbness, poor co-ordination, unsteadiness and problems with balance, eyesight problems, tremors, spasticity or muscle stiffness, slurred speech, swallowing problems, bladder or bowel problems, sexual problems, sensitivity to heat or cold, short-term memory loss, mood swings, euphoria and depression.

■ *What is an MS attack?*

An MS attack, also known as relapse, flare-up or MS exacerbation, occurs when part of the myelin sheath covering a nerve becomes inflamed. Consequently the messages passing along the nerve are disrupted. This may be disabling, give a sensation of being very unwell and can be very frightening.

Such attacks may strike at different areas of the nervous system. Some people may experience a similar pattern of attacks while others will find that each attack causes different problems.

Fortunately, as the inflammation dies down many of the symptoms clear away or ease considerably. Sometimes people will appear to return to how they were before the MS attack.

The time between attacks is known as remission.

■ *What is the effect of an MS attack?*

Inflammation of the myelin sheath may damage it and this can result in scar tissue. This only affects a tiny area of the nerve.

The body has a wonderful ability to recover and the scarred areas may not cause a change in a person's capabilities. However if the number of scar is concentrated along a particular nerve pathway then some disability may occur.

An MS attack may last for some days or weeks.

■ *Does MS always cause disability?*

Many people with MS have a mild form and are only slightly affected throughout their life while others experience no great level of disability for 10, 20 or more years. However some people may have attacks more often and a small number may deteriorate more dramatically becoming progressively disabled.

Only the minority of people with MS may need to use a wheelchair.

■ *What is the treatment for MS?*

MS symptoms can be relieved by medications and therapy or both. As yet there is no cure.

Medication can help ease symptoms such as pain, tremors, muscle cramp and depression.

Steroids may be given orally or by intravenous infusion (a drip) to help reduce inflammation, usually during an attack.

Disease Modifying Therapies (DMT's) are available in various formats: Injection able, oral forms and infusions. Further information relating to the most suitable format can be discussed with your MS specialist Nurse.

Professionals such as physiotherapists, speech therapists and occupational therapists may all help make the most of capabilities, rehabilitation and learning to live with multiple sclerosis.

Physical exercise, a good diet and periods of rest will help and these should be discussed with appropriate professionals.

■ *What does the future hold?*

MS is not predictable. It is unique in its effects. There are many symptoms but not everyone will be affected in the same way. Consequently it is impossible to predict what may happen over five years or ten years. Some people may have little physical disability after 30 or 40 years.

Within five years of diagnosis it may be possible to identify the type of MS.

■ *Does MS affect the mind?*

The uncertainty surrounding MS is a worry to say the least. It can lead to severe stress, especially during attacks and any subsequent reduction in function. Powerful emotions accompany this long term condition and the mental pain, like physical pain, needs to be recognised and understood by both the person with MS and those who care.

Undoubtedly the impact of MS can contribute to depression associated with MS and this, like any medical illness, needs treatment, support and healing time.

MS is not directly associated with any form of dementia. A few people may have difficulties with short term memory loss but this

does not reduce their intelligence.

The character of speech may be affected but this does not mean that the person cannot think quickly and accurately. Only a few experience confusion in understanding words and grammar.

■ *Will children inherit MS?*

If there is a family history of MS then there is a slightly higher chance of children developing the condition.

■ *Will pregnancy affect MS?*

There is no proof that pregnancy will change the overall progress of MS although if planning a pregnancy it is advisable to discuss this with the doctor.

■ *What about the man's fertility?*

MS does not affect a man's usual sperm count.

■ *Is MS painful?*

Most people with MS will experience physical pain to a greater or



lesser degree. For some it may be an ongoing problem and for others it may occur only during attacks.

This may take the form of shooting or burning pains in the area of the body affected. Stiffness associated with MS or strain due to reduced mobility may cause some pain or a sensation of cramp.

Medication or therapy can help reduce pain. There is a wide range of drugs and the most suitable can be discussed with the doctor.

■ *Who can help?*

Professional staff in the Health and Personal Social Services offer a wide range of services. The GP can advise and refer patients to the appropriate specialist or agency.

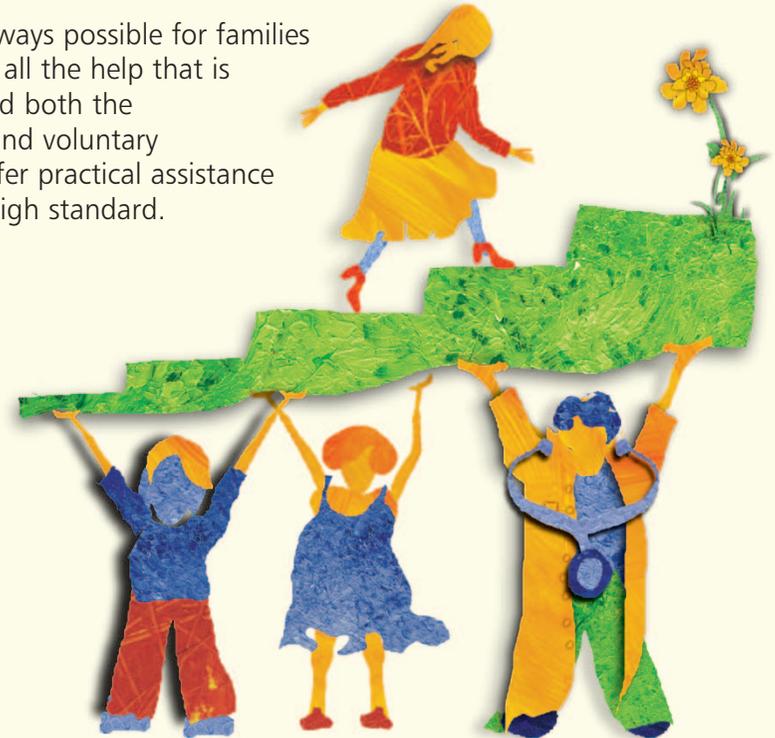
Community Care Teams are made up of professionals from various disciplines. In particular the Social Worker can be a useful contact in providing information about helpful agencies.

For people at home a list of contact telephone numbers and information on where assistance is available is useful before a relapse occurs or some difficulty arises.

If in hospital it is normal practice to be given the names and contact numbers of all those referred to, such as physiotherapist or occupational therapist, on discharge.

Voluntary organisations can provide various kinds of help from straightforward information to counselling and much more. These include Action MS, Crossroads and Carers Northern Ireland. Additional information is available from Action MS, the local library or advice centre.

It is not always possible for families to provide all the help that is needed and both the statutory and voluntary services offer practical assistance of a very high standard.



Help is at hand

WHO'S WHO in the BACK-UP TEAM

The Neurologist is usually involved at the time of the diagnosis of MS. He evaluates the patient's symptoms, examines him or her and organises tests like lumbar puncture or scans which should show confirmatory evidence of MS and exclude other conditions which might be confused with MS.

When the diagnosis had been made it is the duty and responsibility of the neurologist to communicate the diagnosis to the patient and provide information about the condition and likely outcome.

Neurologists help the patient and their family to cope with the disease, by medical treatment of relapses, the treatment of troublesome symptoms, and helping the person to face up to the consequences of the disease.

The MS Nurses are available to those who have been newly diagnosed as well as those who already have multiple sclerosis.

The MS nurses operate an open referral system which means you could be referred by yourself, neurologist, by staff on the hospital ward, by your GP or other healthcare professionals plus organisations such as Action MS and other voluntary agencies.

There are seven MS Nurses, seven based at the Royal Victoria Hospital, two at Altnagelvin Hospital, L'Derry and two at Craigavon Area Hospital . If you are diagnosed in hospital the nurses are available to go and talk to you on the ward, if that is appropriate. If you have been diagnosed in an outlying clinic, the nurses rely on the consultants to pass this information on to them, at which time they will write or phone to introduce themselves and to make initial contact with you. The nurses can discuss specific issues with you such as who to tell, or whether to tell anyone at all, and also what the future might hold.

The nurses can give general advice and support as well as advice about symptom management and life adjustment.

Exercise - Will exercise do me any harm / what sort of exercise can I do? The nurses recommend light exercise as it can help with fatigue;

Relationships - How do I maintain my relationship with my husband / wife / child?

Nutrition - what should I eat / what shouldn't I eat?

Organisations - What organisations are available and how do I get in touch with them?

The MS Nurses can be contacted on the following telephone numbers. You may get an answer phone but leave a message and the Nurse will get back to you. Don't forget to leave a contact telephone number.

Belfast Health & Social Care Trust 028 9063 2757

Royal Victoria Hospital

Glen Cartmill (Team Leader)

Mark Cunningham

Eamon Crossey

Grainne Goldsmith

Brenda Hamill

Fiona Magill

Loreta Delarossa

Western Health & Social Care Trust 028 7129 6132

Altnagelvin Hospital

Fiona Mullan

Karen Hinchcliff

Southern Health & Social Care Trust 028 3861 3863

Craigavon Area Hospital

Heidi Thompson

Jill Patton



The General Practitioner is a key member in the care team and is usually the first to be asked about symptoms and medication and thereafter any subsequent treatment. Referrals may be made to specialists such as community nurses, social workers and neurologists. Medical evidence may be provided to help with applications for benefits, home adaptations, equipment, insurance, driving licenses and other requirements.

At health centres and doctors' practices various leaflets are available on a range of health and personal social services. These are useful and should be kept for easy reference along with surgery times and times when doctors are available to receive telephone calls.

The Physiotherapist is often a member of a hospital or community care team. There are three main aspects to this profession.

- Assessing physical capabilities
- Planning appropriate therapy with the person
- Helping people make the most of their physical capabilities.

Therapy may include exercise programmes and physical education. The aim is to help people adjust to changes in their physical condition and arrangements may also be made for the provision of

aids and other equipment to ensure maximum independence and comfort.

In general the physiotherapist will work with patients to help them keep fit and maintain good reflexes as well as develop skills in the use of any equipment that may be appropriate.

The physiotherapist can give pain relief therapy, emotional support and referral may be made to other professionals or agencies.

The Occupational Therapist works as a member of the hospital or community care team. In coming to terms with changes in lifestyle the occupational therapist offers an invaluable service in helping people to manage day by day in areas often taken for granted such as dressing, personal hygiene, cooking safely, pursuing hobbies and other interests. The professional is also expert in organising specific aids, equipment and, with other agencies, adaptations in the home to ensure maximum independence when for example mobility or eyesight is reduced.

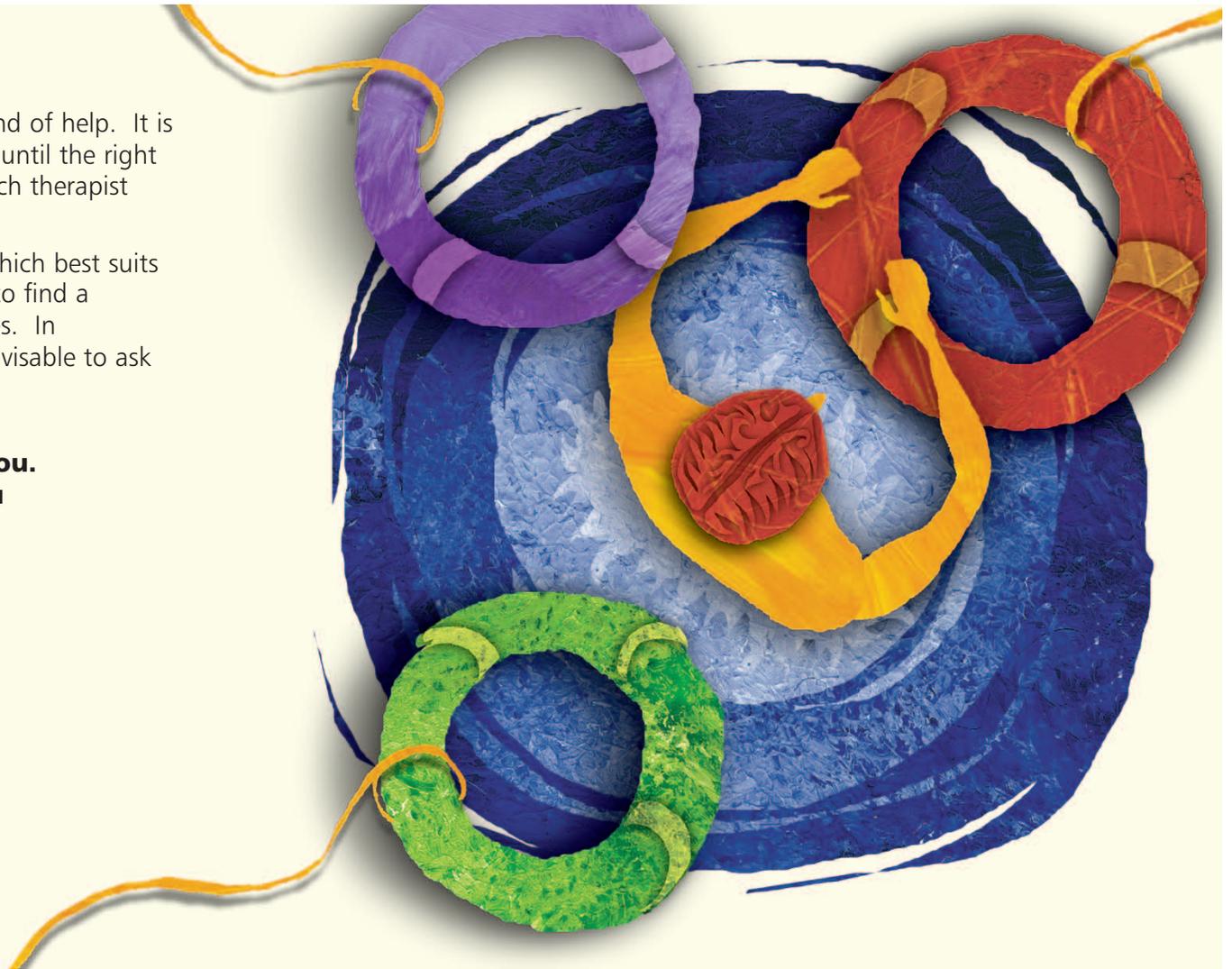
In helping people to live with multiple sclerosis, particularly in the home setting, the occupational therapist takes account of individual needs and also those of the family.

The Speech Therapist works with people who develop difficulties in communicating. This may require speech retraining in a way that is suitable to each individual. Referral to other professionals

may be necessary to ensure the most appropriate kind of help. It is also possible to try various methods and techniques until the right one is found to suit an individual's needs. The speech therapist may also help with swallowing problems.

The Dietician is an expert in advising on the diet which best suits an individual's lifestyle. This aim is to assist people to find a balanced diet that meets both needs and preferences. In considering a major change in dietary habits, it is advisable to ask the dietician for advice.

**Remember Action MS is here for you.
We would love to hear from you**



The Social Worker is often called “the gate keeper”, a reference to their role of organising services across a wide span of social care. These services may include help in the home, child care in the home, provision of aids, adaptations in the home, specialist counselling, the use of facilities such as day centres, short or long term respite care and ongoing social work support.

A social worker can provide information about benefits, suggesting which benefits you may be entitled to and helping you to fill in application forms, for example to claim DLA. If they are unable to answer any of your questions you will be referred to an agency such as the Citizens Advice Bureau (CAB).

There are a number of ways to make contact with a social worker. These include referral by a hospital social worker, by your GP, by a family member, by a voluntary organisation or self-referral.

Normally you will arrange a visit with the social worker for an assessment of your needs. A carer’s assessment is also carried out.

The District or Community Nurse is a registered nurse who may have additional qualifications and usually works as a member of a community care team based in a health centre or doctor’s practice.

The nurse plans nursing care in the home which may involve assistance with personal hygiene, dressings, management of medication, care of pressure sores and advice on other aspects of

care and support for those living with MS. Referral may be made to other agencies and services to help the individual and the family.

The Community Psychiatric Nurse (CPN) is a title which is often misunderstood because of the association of the word ‘psychiatric’ with mental ill health.

Someone who has MS may experience stress or even become depressed. Very often this accompanies the diagnosis and the fear of how life may change. What course will my illness take? Will I remain mobile? Will it affect my chances of employment or promotion or my status within the family?

CPN says: “The most important contribution to the patient’s well-being at a difficult time may be giving them time and reassurance, support and monitoring.”

The CPN is linked to the GP surgery and identifies people with mental health problems. Referral for an assessment is usually made by a GP, with the patient’s consent, or by other members of the community multi-disciplinary team. The CPN can provide: counselling, health education, mental health advice, recreation therapy, stress management, cognitive therapy, post natal advice and family support/therapy. A holistic approach is adopted to guide the patient through their illness. Counselling may be used in addition to anti-depressants and complementary therapies.

The Care Assistant and Auxiliary Nurse are trained in a range of duties that include assisting with toileting, personal hygiene, dressing, feeding. As member of the hospital and community care teams they are not trained to registered nurse standards but may carry out a variety of care tasks either alone or under supervision.

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We would love to hear from you**



Learning to live with MS

Some Suggestions

- Join an MS support organisation such as Action MS. It helps to share problems and exchange information with others.
- Be patient and don't expect too much from yourself or others. Perfection is not always possible.
- Eat a healthy, balanced diet.
- Learn some useful exercises and keep practicing!
- Live one day at a time.
- Get adequate rest and sleep.
- Be informed - ask questions, know where to get answers.
- Seek advice - understand the symptoms of MS.
- Use the Health and Personal Social Services.

- Use GPs, neurologists, MS Nurses, physiotherapists and other professionals.
- Use specialist agencies as necessary such as Relate and Citizens Advice Bureau.
- Claim your right to benefits and allowances.

Everybody Needs Help Sometime!

For more information contact:

Action MS

Actionville, Knockbracken Healthcare Park,
Saintfield Road, Belfast BT8 8BH

TEL: (028) 907 907 07 FAX: (028) 9040 2010

info@actionms.co.uk www.actionms.co.uk

www.facebook.com/ActMS.

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Action MS Information Services

Action MS provides various free information booklets. If you would like to receive more information please tick the appropriate box on this request card and send it to Action MS at the address below.

Information is also available on the Action MS website at
www.actionms.co.uk.

Action Ms invites new members. If you would like to avail of our services and learn more please enclose £4 annual subscription and you will be entitled to our free MS professional support services and updates on our work.

Regular updates are available on our web site, facebook and twitter

Send to:

Action MS, Actionville,

Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH

Tel: 028 907 907 07 Fax: 028 9040 2010

E Mail: info@actionms.co.uk

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Booklets List (please tick)

- Action MS Northern Ireland
- Multiple Sclerosis? Questions and Answers/Help is at Hand
- More About Symptoms
- MS and the Family
- Coping with MS/Diet & Exercise
- I wish to become a member of Action MS
- I enclose £4.00 annual membership subscription

Name:

Address:

Postcode:

Telephone number:

Email :

