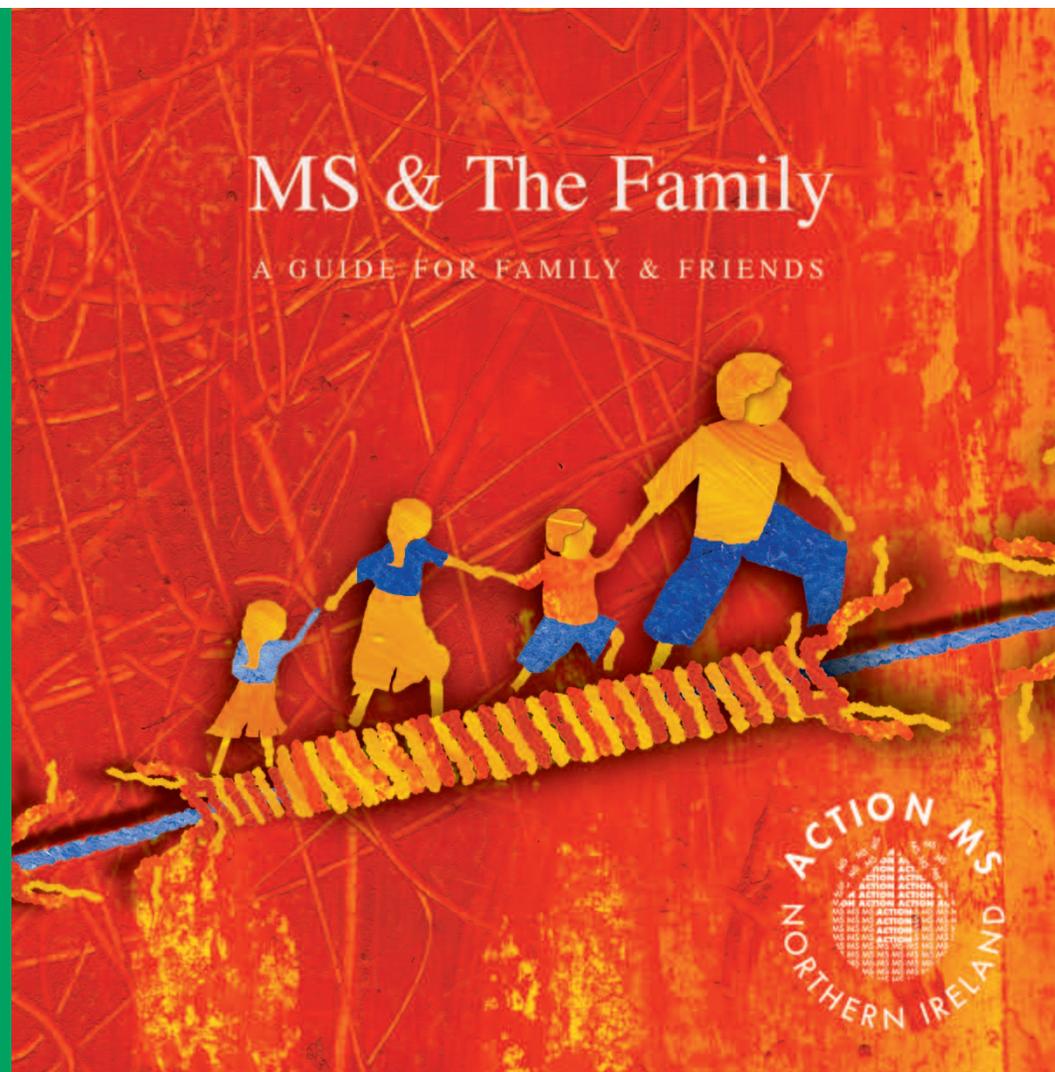


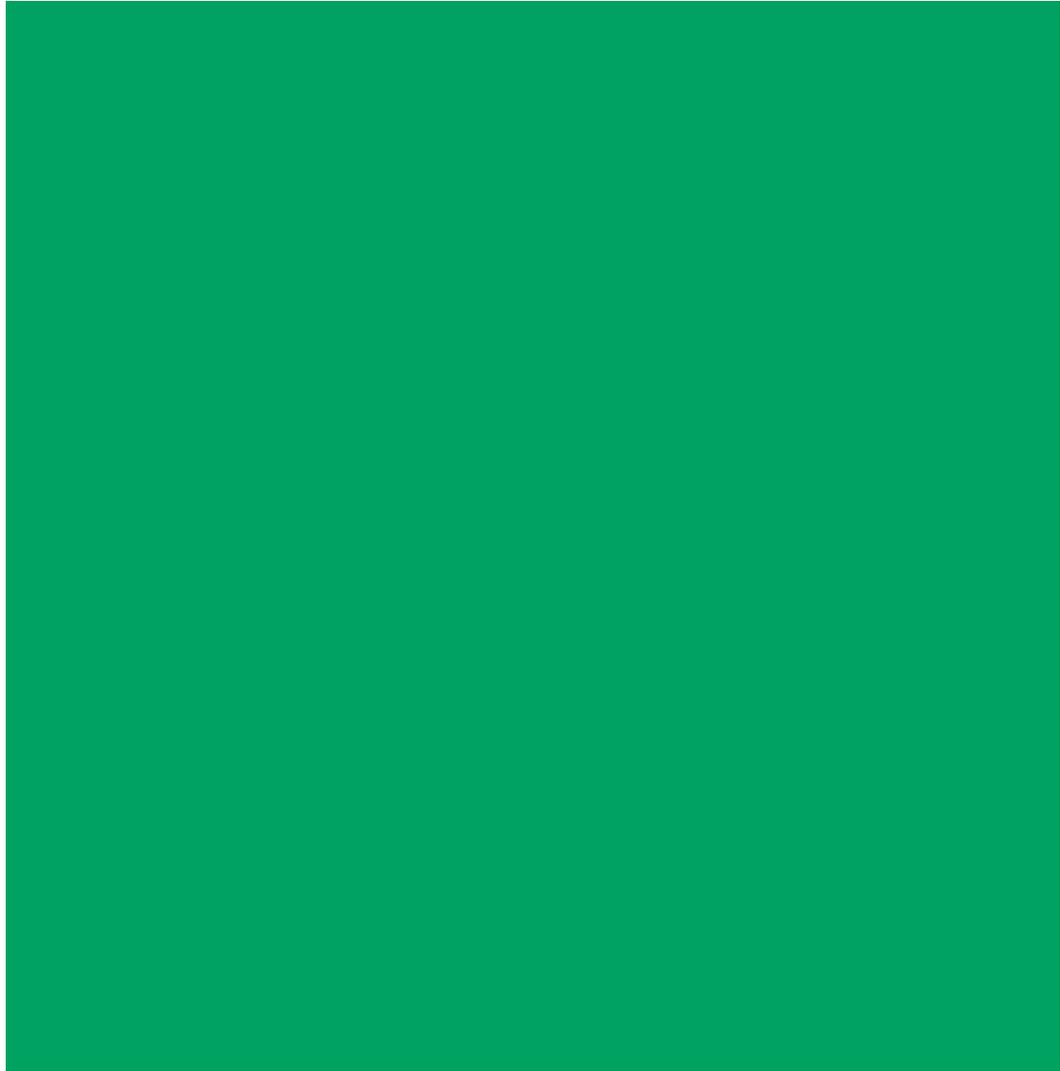
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MS & The Family



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 lives 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.

MS & The Family

Multiple sclerosis affects the whole family. It is something which shocks parents, sisters, brothers, children and friends. It is hard to accept but it is something the family has to learn to live with.

■ *Relationships*

One of the problems in relationships is communication. It becomes an even greater problem when we bottle up feelings of anger, frustration, fear and anxiety. So in coping with MS we need to “let fly” now and again and open up our hearts, share the burden and thus prevent emotional barriers from cutting us off from those who care.

People with MS do have mood swings. But the person is still the same person. People with MS may suffer depression. The need to talk remains. People with MS will change with the passing of the years. But then we all do that.

Whatever way we look at the impact of MS on a person’s personality it is as well to remember that there are no black and

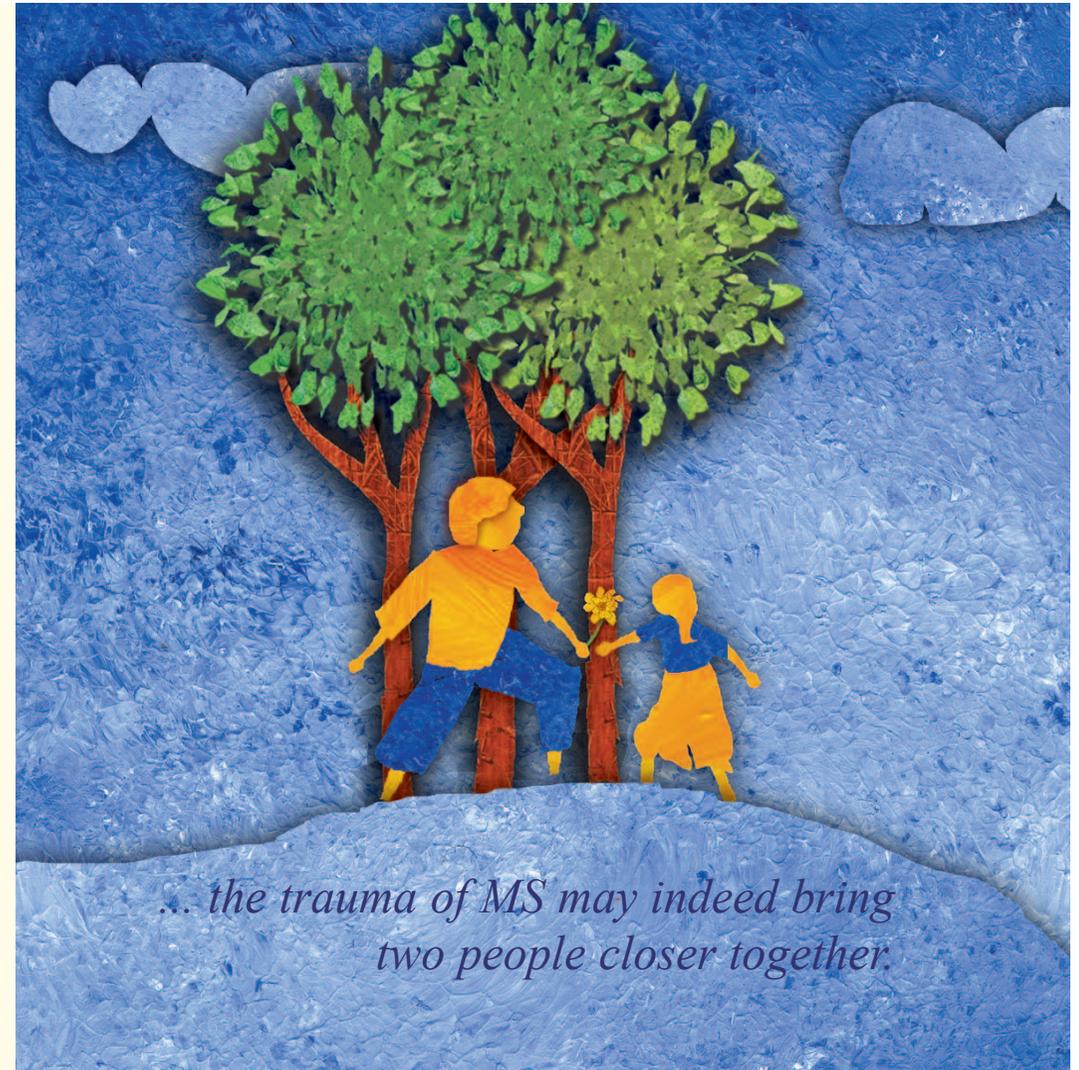
white answers - life is complex. Change of one sort or another comes to us all.

Of course an MS diagnosis can sap a person's confidence. There is a very traumatic sense of uncertainty and this seeps into relationships. The same may be said of people who face unemployment, financial problems and so on. In all of this and more the family has to learn to cope. But tragically, it may sometimes happen that family members use MS as an excuse for not dealing with situations frankly and openly. The disease is blamed for everything and hurt and anger are allowed to fester.

■ *Couples*

An MS diagnosis may set in motion feelings of individual loss which can lead to thoughts of worry about losing a partner's love. That worry may be justified for there will be times when the strain of MS stretches to breaking point in a relationship. However the deeper the root the better chance there is of the tree standing firm. A strong and stable relationship will be able to draw on reserves of strength and the trauma of MS may indeed bring two people closer together.

But remember that nowadays one marriage in three ends in



divorce. MS may not be the only cause of difficulty for as someone said: "MS for us was the straw that broke the camel's back."

The early years in a relationship can be hit hard by MS in the sense that the roots have not grown strong enough to cope. And family pressures may demand that a relationship continues in spite of an individual's wishes or the quality of the relationship.

Nevertheless a significant number of couples learn to live with MS and to go on to enjoy a meaningful life together.

■ *Sexuality*

MS can lead to particular physical and emotional problems. These stem from damage to the central nervous system and this may impact on sexual functions. There are many specialist advisers and counsellors available to help when difficulties of a sexual nature threaten to spoil a relationship. But first it is better to talk to each other and then, if necessary, to a counsellor rather than let matters get worse. The family doctor can offer advice, medication and help in finding a special therapist or clinic.



■ *Pregnancy*

An MS relapse often occurs in the months after birth. However, research shows that the long-term clinical condition of women with children is not significantly different when compared to women who do not have children. It seems that over time pregnancy may not have negative consequences for women with MS. There is no justification in advising termination of a pregnancy because of MS.

MS has no effect on a man's fertility.

If you are planning a family it would be worthwhile having a chat with your family doctor or neurologist.

■ *When mummy has MS*

Children will be confused when a parent becomes ill. Their source of emotional security and stability, their invincible mummy or daddy, is suddenly vulnerable. It is then that children need help and support.

The best way to give this support is for the family to talk it over with the children. There is no value in trying to protect them from

the reality of MS. If they are kept out in the cold, with the best of intentions, their imaginations will take over to paint a picture that is both scary and bleak. MS should not be a secret. Allow children to talk it through and express how they feel and how they may cope with the change in their family life.

Plain speaking that is direct and caring and free from jargon is a good start. Questions will flow and they should be patiently answered. But for some children enough information will be enough. There is no merit in force feeding information which is not asked for.

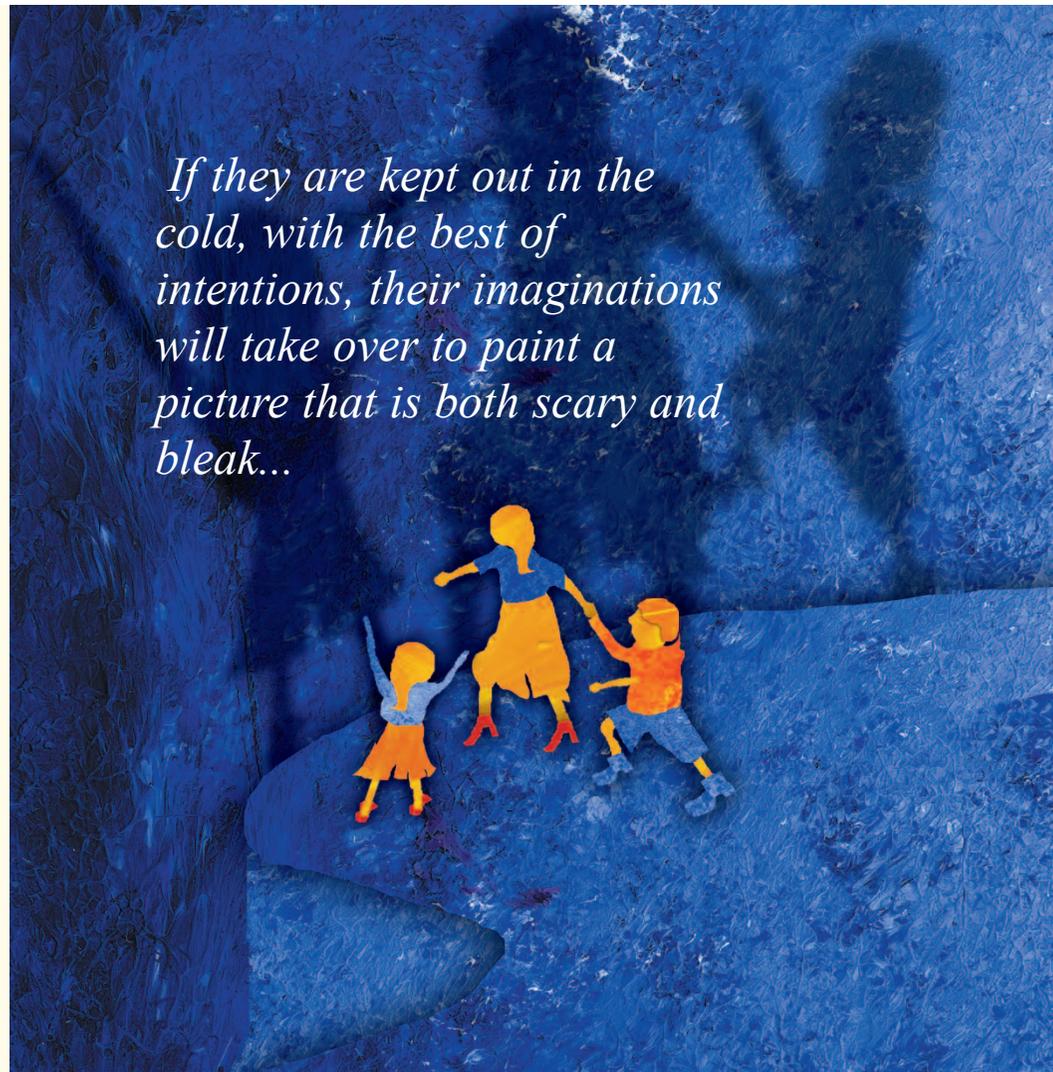
Action MS has a book called A Fishy Tale especially written specifically for children living with MS. It is very colourful and free of charge. Contact us to request a copy

■ *Reassurance*

Reassurance may be expressed in a number of ways: "MS is not directly passed on from parent to child"; "You cannot catch MS like you can a cold or chicken pox"; "You are not to blame for mummy being sick"; "Daddy loves you but he can't do some things because he is ill"; "Most people with MS live just as long as other people".

It is important not to give false reassurance: "They will definitely find a cure for MS soon"; "Mummy will not get any worse"; "Daddy will never have to go into hospital again".

If they are kept out in the cold, with the best of intentions, their imaginations will take over to paint a picture that is both scary and bleak...



Say what you mean and mean what you say. Of course you get sad and angry sometimes. Children will too. Share these down times and allow them to talk to others in the family, in the circle of friends, in the school.

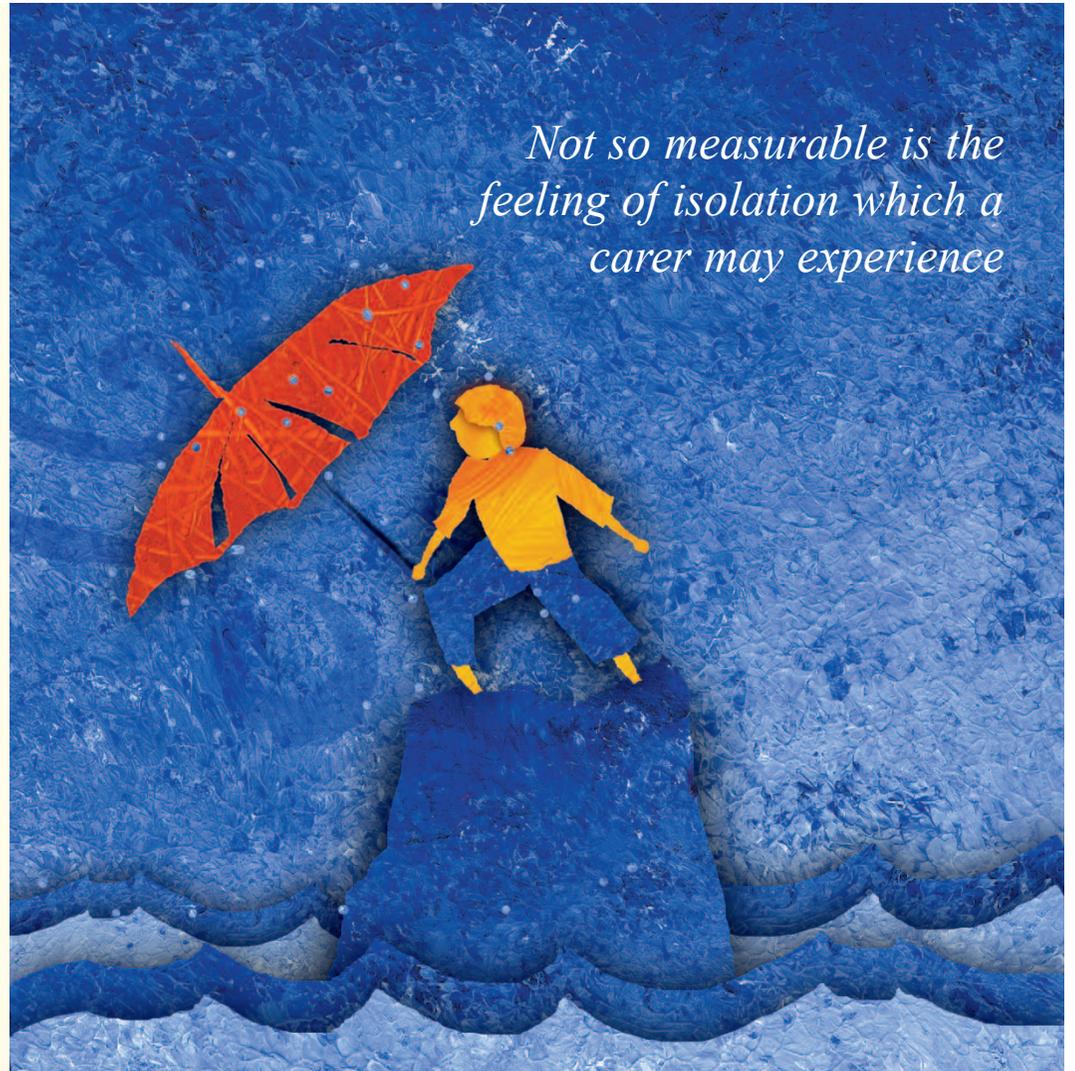
■ *Carers need care*

MS affects the family and members may be required to play their part in caring. This new responsibility may be restrictive and disruptive. Nevertheless what needs to be done to care is often prompted, and indeed inspired, by love, a sense of duty or in a more negative way by a feeling that they have really no other choice.

So someone takes on the role of carer and research shows that most carers do so cheerfully despite the physical demands, the emotional stress and the time consuming nature of the role.

Some of the difficulties facing the carer are practical such as finance. There may be a need for extra heat or accessible transport. Not so measurable is the feeling of isolation which a carer may experience. The restrictions on going out to the shops or attending social events or going to church all undermine a

Not so measurable is the feeling of isolation which a carer may experience



carer's social life. All this may lead to friction and leave the carer in a "no win" situation.

■ *Changes*

MS may demand changes in the role of individual family members. The person with MS may find it difficult to continue with some of the jobs within the family. So other members of the family will have to step in and change their routine. This can be disturbing in more ways than one. It's said that coping with change is the most stressful thing we can experience. This is particularly true in a traditional environment where it has long been accepted that 'mum does that' and 'dad does the other thing'. Moreover in a shared role situation – share and share alike – change may mean shifting the balance with more required of one of the partners. One carer said: "It became difficult being a wife, mother, wage earner and carer but with time I just learnt to cope".

It is important to stress that while a person with MS may find their role changing within the family it does not disappear. Change may mean finding a new role. "In the past when I was working I had little time to spend with the kids. I can do things like help them with their homework now and I can play a real part in their lives".

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.

- Contact your GP for referral to your neurologist, 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:

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Action MS Information Services

Action MS provides various free information leaflets. 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 join please enclose £4 annual subscription. As a member you will receive regular information about various activities, a free copy of the quarterly Action MS Magazine and updates on multiple sclerosis research work.

Send to:

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Tel: 028 907 907 07 Fax: 028 9040 2010

Action MS, North West,

70a Union Street, Coleraine BT52 1QB
Tel: 028 7032 6868 Fax: 028 7032 6668.

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 :

