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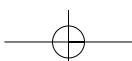
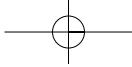
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More About MS Symptoms

ACTION MS
NORTHERN IRELAND



More About MS Symptoms



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 been listening to find out what is most needed by those who live with MS and as a direct result we have developed tailor made services to meet those needs.

More About MS Symptoms

IMPORTANT: This leaflet describes many symptoms associated with multiple sclerosis. However it is important to remember that with MS most people may experience only a few symptoms. Moreover the effects of the illness will vary from person to person.

■ Introduction

Multiple Sclerosis (MS) attacks the nervous system. It is a physical disease which disrupts communication between the brain and nerves in the body. It is not a case of "being bad with your nerves" but rather that motor nerves, which operate muscles, and sensory nerves, which convey sensation such as touch, may not work properly. This may mean for example difficulty in walking or a failure to sense a very hot object.

But not all nerves are affected by MS. Some, such as the nerves working the heart and lungs, are not directly affected by MS.

What happens when MS attacks? The nerve covering known as the myelin sheath becomes inflamed and messages travelling to

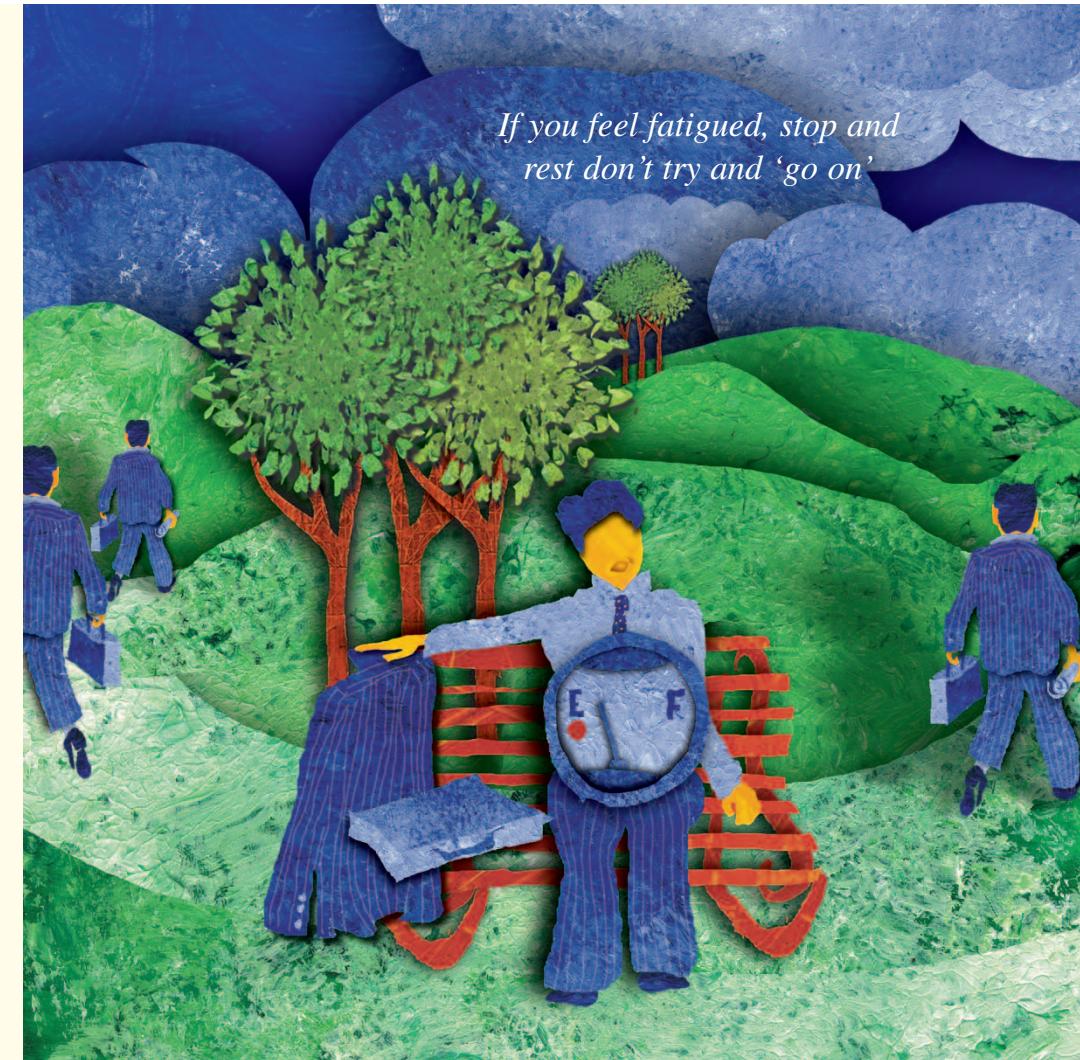
and from the brain to various parts of the body are either altered or interrupted. This may be a frightening experience not only for the sufferer but also for family and friends. Such an attack may be disabling and make the person feel very unwell. But fear of MS is compounded by not understanding the nature of the disease and anxiety over unpredictable outcomes.

Not everyone with MS is affected in precisely the same way. Also MS attacks follow no uniform pattern. Some people may experience repeat attacks which are very similar while others will find that each attack affects them in a different way.

Multiple Sclerosis - The Symptoms

■ Fatigue

This is one of the most common symptoms yet the most difficult to explain to families and friends. It can come on quickly - "out of the blue" - and there is no way to shake it off. Unlike the marathon runner at the 20-mile "wall", the person with MS is unable to grit his teeth and press on. Moreover it is not a matter of "digging deep" into a resolute character and finding fresh



reserves of energy. Fatigue in MS simply leaves a person drained and overcome by a sensation of physical weakness.

In order to cope with such fatigue people with MS learn to pace themselves and to organise their daily routine.

Some people may find for example that fatigue will occur at certain times of the day or night or certain conditions such as hot, humid weather or having a hot bath make fatigue harder to handle.

It is helpful to talk about this "unseen" symptom so that those around you either at home or at work will understand what is wrong. This may be true in relation to sexual drive when a partner may misunderstand. Also talking it over with children helps them to understand that, for example, not attending school events is not indicative of a lack of interest in them or what they are doing.

■ *Eyesight*

Some people may suffer from symptoms such as double vision, blurred vision, a partial squint, rapid eye movements or pain in one or both eyes. This visual disturbance is often worse or only apparent during MS attacks. It can prompt a fear of blindness. But extremely few people with MS will lose all of their sight or be registered blind and for most this symptom will be either temporary or so mild as to be managed in day to day life.

■ *Sensations*

When the sensory nerves are affected the result can be a range of sensations which are difficult to describe. "Pins and needles", numbness or a heaviness in the hand, leg or arm, one section of the body or even one side of the body.

These sensory symptoms occur mostly during MS attacks and few people will experience them regularly and even fewer continuously.

The numbness may be similar to the kind which follows a dental injection but with MS there is no certainty that it will wear off - this can cause anxiety.

Sensitivity of touch may be affected or a degree of pain or "burning" sensation may be felt in any area of the body. This may be worse during an attack but it is often temporary and if these symptoms persist they often become less severe. Medication can help.

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

■ Movement

When MS affects the motor nerves the experience can be devastating. "Movement" messages from the brain to the body are simply not getting through correctly. The result may be clumsiness, weakness and stiffness. Spasms or tremors may occur. Understandably people fear that they will lose their mobility and independence.

These symptoms are at their worst during attacks and will often reduce markedly afterwards.

The degree of disability associated with this symptom varies widely. A minority of people with MS may end up using a wheelchair, if only to manage outside of the home or to get along to the shops. The majority however never reach this level of disability even after thirty to fifty years with MS. A small proportion of people with MS do deteriorate more quickly.

■ Bladder Problems

These symptoms can be embarrassing, are rarely discussed in public, and can occur for different reasons. Wanting to pass water frequently is one symptom. This may happen because sensory messages to the empty bladder keep recurring. The bladder may not completely empty and therefore fills up more quickly.



MS can reduce the efficiency of the muscles that control the bladder and this can lead to leakage or retention. Many people with MS learn some simple pelvic floor exercises, the kind familiar to pregnant women. These are easily taught by a physiotherapist and practiced daily at home.

Of course a frequent urge to pass water can be a nuisance. There never seems to be a loo when you want one! This can persuade people to reduce their social life or not to travel. It may also be a dominant influence in planning daily routines.

Do not be tempted to drink less. It will not solve the problem and worse, problems of dehydration (an abnormal lack of fluid in the body) could develop. A normal fluid intake is important.

It is also worth remembering that there are specialist continence nurses available to help manage these symptoms. Much can be done, including prescribed drugs and techniques for emptying the bladder as appropriate.

Many people, not just those with MS, suffer some degree of incontinence. It may not always be curable but it can always be helped and managed.

■ Sexual Problems

MS affects the sensory nerves and reduces sensitivity. This may cause sexual problems for both men and women.

The impact of other MS symptoms on sexual relations – fatigue, depression, low self esteem and stress - can reduce the sex drive and undermine confidence in participating in sexual activity.

Men may experience difficulty in achieving or maintaining an erection and complete or periodic impotence may also occur as well as changes in the timing and sensation of ejaculation.

Women may experience a lack of vaginal lubrication as well as a lack or absence of clitoral arousal.

These problems may be most acute during an MS attack but they are usually temporary. There are professionals, clinics, agencies and counsellors who specialise in sexual problems on a daily basis.

Medication, such as Viagra, can also be prescribed. The GP or Neurologist can discuss these symptoms and arrange referral for the person, and partner, if appropriate.

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■ *Difficulties in swallowing*

Many people with MS will never have difficulty in swallowing. But it can be experienced during an attack and how much this can be an ongoing problem will vary among individuals.

Food and drink are of course essential to health and may also be an important part of social life. Therefore any difficulty in swallowing must be dealt with quickly and efficiently. The thought of choking is scary. It can soon put people off their normal diet.

So it may help to overcome this symptom by practising sitting straight with head up, not talking when eating, taking time to chew and keeping calm. These tips should make milder swallowing problems manageable. A specialist speech/swallow therapist can help.

■ *Constipation*

People with MS may experience a reduction in bowel function. This can lead to constipation. This is particularly common with reduced mobility. However a balanced diet that contains plenty of fibre can help maintain bowel function. If the symptom persists laxatives may be required occasionally and these should ideally be prescribed to ensure they are suitable.

■ *Speech*

Any difficulty in speaking can be embarrassing and highly frustrating. People with MS may find difficulty in physically forming and projecting words. This is known as dysarthria and while the person may think as well and as fast as usual, the words just will not come out properly. This manner of speaking will vary. The volume and tone may alter and speech may be slurred.

The thinking aspect of speech in understanding what is said or getting muddled with grammar is known as dysphasia and is only experienced by a small minority.

Speaking difficulties may only be a slight problem or occur only at times of fatigue. But for some people with MS this symptom is more permanent.

Practical help in the form of speech therapy is now widely available. Self-help is possible through practicing simple things such as sitting upright to ease breathing, and speaking slowly which may be difficult when you are trying to form words.

A useful rule is to make the most important points first and try to eliminate any background noise. And keep talking even when alone by saying words. It may help to stress the first or last letter or to take a deep breath before beginning to speak.

■ Physical Pain

Pain is real. It may occur because of strained muscles or bad posture or sensory problems. Whatever the cause it is important to seek help in easing pain. Some people feel they might be considered "moaners" or "neurotic" if they consult a doctor. That is wrong. Pain soaks up precious energy, distracts concentration and is very unpleasant.

Medications are available for pain relief but not all suit everyone. The doctor will discuss with you and prescribe what is suitable.

■ Mood Swings, Depression & Euphoria

Some people with MS may experience mood swings and the frequency and distress this causes will vary between individuals.

Associated with MS is depression, a feeling of great sadness and bleakness. It is not uncommon in anyone who has a chronic life altering condition. It has different forms. It may occur for example after diagnosis or as a reaction to change after an attack that results in some level of disability. Depression may be influenced by other life changes and like fatigue it is not a matter of "pressing on" or "getting a grip on things". It is a medically recognised condition and should be treated as such.



In the darkness of depression it is difficult to seek help. But help is available. The doctor will help. Depression can go away.

A small percentage of people with MS may experience euphoria - an unrealistic feeling of happiness.

■ Conclusion

It is important that the symptoms outlined above are not mistaken for other ailments. For example frequency in passing urine, especially if it is painful, should be checked by the doctor in case it is due to another condition such as cystitis or a urinary infection.

Similarly pain may be caused by something straightforward and may be easily dealt with.

People with MS should be aware of these symptoms and understand how they may change. MS for example may cause backache but so does bad posture!

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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 GP's, 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:

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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 join please enclose £4 annual subscription. As a member you will receive regular information about our services and updates on our work.

Send to:

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Leaflets 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
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Name:.....

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Telephone number:.....

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