

 $\bigcirc$ 

# Fatigue

#### Practical living for everyday life with MS

#### Contents

- **02** What is fatigue?
- **03** What causes fatigue?
- 05 Analyse your fatigue
- **07** Sample fatigue diary
- **09** Deal with factors that contribute to fatigue
- **10** Manage the fatigue that remains
- **16** Self-management programmes
- **17** Drugs for MS fatigue
- **18** Research into fatigue
- **19** Further information

#### This booklet suggests practical ways to analyse fatigue and then minimise its effects on daily life.

Fatigue is one of the most common symptoms experienced by people with multiple sclerosis (MS) and, for some, it is the symptom that affects them most.<sup>1</sup> Different people have different experiences of fatigue and it can impact on all aspects of life. It can come and go, or change over time and could be one of the first symptoms you experience, or something that appears years later.

Fatigue is difficult to explain. In MS, it is not just an ordinary tiredness that people might experience after a hard day's work or strenuous exercise. Many describe it as an overwhelming sense of tiredness with no apparent reason. Some people become tired after very little activity, or rarely wake up feeling refreshed in the morning. While there is still much to learn about the exact causes of fatigue in MS, many people have found ways to minimise its effects.

Health care professionals can help with managing fatigue, but because fatigue in MS may have a variety of causes, and affects each person differently, there is no 'one size fits all' treatment. Some people may be prescribed drugs that help. But for many, a combination of self-management strategies, physiotherapy and exercise helps reduce the impact of their fatigue.

### What is fatigue?

Fatigue in MS is more than the tiredness everybody feels after exertion.<sup>2</sup> This type of tiredness can still affect you, but fatigue in MS goes beyond that. Some people say they feel like their power plug has suddenly been pulled out – a feeling of complete tiredness that arrives without warning, which can leave just as suddenly. Others notice a constant fatigue that makes everything more of an effort. It may be a frustrating, but tolerable, fatigue that saps your spare energy but lets you work around it. When at its worst, it can be the sort of ongoing exhaustion people get with flu, stopping you from doing even the smallest tasks.<sup>3</sup>

Some people find that when they are fatigued, their limbs feel heavy and it becomes harder to grasp things or to write. Other symptoms, like difficulties with balance, vision or concentration, may also get worse temporarily.

#### Heat

Very often, heat makes fatigue worse for people with MS. Changes in the weather, an overheated room or physical exertion can all have a temporary effect. Infections can also raise the body's temperature and make fatigue worse until your temperature returns to normal.<sup>4</sup>

#### **Everyday activities**

Fatigue can have both a physical and mental impact. It can influence both how and when you get things done – things you need to do and things you like to do.<sup>5, 6</sup> All kinds of activities can be affected: from going to work, to going

to the pub, cooking a meal or playing with your children. Balancing these activities can become a daily issue when you've got limited reserves of energy. Getting the understanding and involvement of others sometimes makes all the difference, so let your friends and family know how fatigue affects you.

#### **Explaining fatigue in MS**

Although it is given one name, fatigue affects people in different ways. It may change from week to week, day to day, or hour to hour. This can make it complicated to explain your fatigue to friends, family, colleagues and health and social care professionals. Many people find it a relief to discover it is a recognised symptom of MS, though they still find this 'invisible' symptom hard to describe.

#### Those around you

There will be times when your fatigue is not obvious to others – without understanding the issue, they may unhelpfully ask you to 'make a bit more effort' or 'stop being lazy'. On the other hand, people close to you can sometimes notice effects of fatigue that you perhaps have grown used to and adapted to without realising. For example, a partner might notice you are walking more slowly later in the day. If they know that this is because of fatigue, rather than a problem with your legs, they will be in a better position to offer assistance – perhaps by helping out with a tiring task.

### What causes fatigue?

There may be many different causes of fatigue in MS. If you experience fatigue, it could be due to one of these factors, or a combination of several.

### The effects of MS on the central nervous system (Primary Fatigue)

Some fatigue may be caused by the effects of MS on the central nervous system (the brain and spinal cord). There's more information on this over the page.

#### Other MS symptoms

Other MS symptoms – like muscle weakness, stiffness, pain, tremor and depression – may lead to feelings of fatigue.<sup>7</sup> It's important to treat and manage these symptoms, which could be the root cause of your fatigue.

#### Living with the condition

There may be other causes of fatigue that do not directly result from MS symptoms. Living with MS can have knock-on effects.<sup>7</sup> Lack of sleep, or disturbed sleep, for example, might cause fatigue and could be due to bladder problems or muscle spasms. If you are less mobile and, as a result, less fit than you once were, you might have lower energy levels. Some people find that living with MS causes anxiety or low mood and that this adds to feelings of fatigue.

### What might be happening in the central nervous system to cause fatigue?

The effects of MS on the central nervous system are complex and not yet fully understood. This makes it difficult to be sure of the exact cause, or causes, of fatigue.

#### MS damage

In MS, the immune system attacks the protective layer of myelin that surrounds the nerve fibres in the central nervous system. This damages the myelin and strips it off the nerve fibres, either partially or completely. Damage to the myelin, and to the nerve fibre itself, disrupts the messages passing from the brain and spinal cord to the rest of the body. Depending on the job of the nerve affected, different symptoms can appear. For example, if the nerves responsible for vision are affected, a person may have problems with their eyesight.

However, research has not identified any single area of the central nervous system that is affected in people with fatigue. Fatigue may be due to damage in one or more areas of the brain or spinal cord.<sup>6</sup>

#### How the brain adapts

Some researchers suggest that fatigue might be caused by the way that the brain adapts to the impact of MS. Brain scans of people who have fatigue show that they use larger areas of the brain to carry out activities than people without fatigue. This might be because the brain is finding new routes for messages when the usual nerve paths have been affected. Having to do this might mean it takes more 'brain power' to carry out an action, which may cause fatigue<sup>.8</sup>

However, there are other processes happening in the brain and spinal cord that may also have an effect, and an exact link between nerve damage and fatigue is not yet clear.

Research continues, to improve understanding of the processes involved and how they might be managed.

MS Ireland's 'Getting the Balance Right' research programme is one such programme that has looked at the benefits of exercise on fatigue. Some 1,500 people took part in both the research and activity elements of the programme, which was completed by the University of Limerick.

People participated in group and one-to-one physiotherapy, yoga, instructor- led gym classes, tai-chi and hydrotherapy. The results, which were released in September 2009, found that physiotherapy and exercise can have a positive effect on fatigue. Some 22% of the total number of people who at most use a stick improved their level of fatigue to the extent that they moved them from a clinical measurement of 'fatigued' to 'non-fatigued'. This was reported in 27% of those on physiotherapy programmes; 18% of those on yoga programmes and 23% of those on instructor-led programmes.

MS Ireland runs a number of fatigue management programmes as part of its menus of service programmes. Contact your local MS Regional Office for further details.

### Analyse your fatigue

How you manage your fatigue will depend partly on whether other MS symptoms and lifestyle factors are having an effect. Analysing these can be a valuable first step in identifying how to minimise the problem.

#### Fill in a fatigue diary

One way of doing this is to work with a health care professional to fill in a fatigue diary, like the example over the page. By rating your fatigue levels at different times of the day, and in relation to different activities, you might start to see patterns. Perhaps you notice your fatigue is worse after large meals or in the afternoon, but better after an hour's rest. Do certain activities make you more tired than others?

#### How do you sleep?

You might also monitor how you are sleeping at night and keep a diary of this. If you share a bed, your partner might notice disturbances in your sleep that you have been unaware of. Muscle spasms, for instance, may not wake you but can affect the quality of your sleep. You should note this down too.

#### How to use the diary

Over the page there is an example of a fatigue diary, completed for one day. Activities have been listed throughout the day and rated on a scale of one to 10, one being very low levels of fatigue and 10 being very high. It might seem strange at first to rate your fatigue like this, as so many things can influence how you feel on any particular day. But your diary will also include information to put these numbers in context. Under the section for 'Comments', all MS symptoms that appear or change through the day are noted down. And when describing activities, it helps to put down details of how they are done. For example, shopping could be a short trip to a small local shop for a few items, or it could involve a good deal of walking around a large supermarket, carrying a basket or pushing a trolley. The more detail you give, the more useful the diary will be.

It is important to complete the diary on 'good' days as well as 'bad' days. Over time, this can highlight particular factors that may be causing fatigue, making it better or making it worse. Once identified, you can discuss ways to treat or manage these factors.

#### Fatigue diary: One day example

#### Date 15 July 2009

Describe last night's sleep: Worse than normal. The weather was quite hot last night which made it hard to get to sleep and I woke up a few times in the night. Felt more tired than usual when I woke up.

#### Time **Description of activity** Fatigue rating 1-10 3 07.15 Wake up and shower (standing up) and brush teeth. Comments: Slight balance difficulty and numbress in my left arm makes washing harder. 07.30 Get dressed while partner gets children (aged seven and nine) up and dressed. 4 *Comments:* I get dressed slowly so it is not such an effort. Make breakfast for children. 08.00 5 Comments: I tend to rely on my right hand - my 'better' hand – so things take a bit longer than before. 08.30 Drive children to school (four-mile round trip). 5 3 09.00 Make breakfast for myself and have a sit down for half an hour. 10.00 Sort out the post and pay the phone bill. Make phone calls. 2 11.00 Drive to supermarket for weekly shop (about three miles). 2 11.15-12.45 Walk round the supermarket, pushing trolley. Queue for six or seven minutes, standing up. Pack bags and load them into the car. 8 *Comments:* My balance gets worse about half way round the shop, which slows minutes, me down even more 12.45-13.00 Have a sit down in supermarket café before driving home. 6 13.00 Drive home. 6 13.15 Take out frozen shopping and put in freezer. Leave rest of 7 bags in car until later. *Comments:* My right arm – my 'good' one – is starting to feel tired now, in car until later. because of all the lifting and carrying.

#### 13.30 Prepare a light lunch (standing in kitchen, making sandwich). 13.40-14.30 Sit down in front of TV with lunch. 14.30-15.00 Hoover downstairs (living room and hallway). Comments: The hoover helps with balancing, but it is a really heavy one to push. Wash breakfast and lunch dishes (standing up at sink). 15.00 15.30 Bring in rest of shopping from car and put it away. 16.15 Chop vegetables and prepare fish for evening meal (sitting down while chopping, getting up to go to fridge, cupboards and cooker.Reaching for ingredients on high shelves occasionally). Comments: Again, my right arm gets tired quickly, but both arms feel quite heavy now. 17.00 Cook meal (put fish in oven and boil pans of vegetables). 17.15 Partner arrives home with children from child-minder. Partner serves food while I get children washed and ready to eat.

Fatigue rating 1-10

7

5

6

7

8

7

8

8

17.30-

Time

**Description of activity** 

17.45	Sit down to eat with family.	8
	<i>Comments:</i> Feel a bit 'fuzzy-headed' – difficult to concentrate fully.	
17.45	Play with younger son while partner takes the nine-year-old	
	to judo class.	7
	Comments: I am glad to sit down for most of the time while	
	he plays on the computer because by now I am a bit unsteady	
	on my feet. We also did some reading, but my eyes start	
	'swimming', which always makes it hard to continue.	
19.45	Sit down while partner gets kids ready for bed. Go upstairs to	
	say goodnight to them.	8
20.00	Chance to sit and talk with partner.	8
	Comments: Still a bit 'fuzzy-headed'. My arms and legs feel heavy	

### Deal with factors that contribute to fatigue (Secondary fatigue)

Looking at the diary, your general health and any medications you take could reveal factors that contribute to your fatigue.

You may be referred to specialists to help with specific problems – for example, a urology team to help with continence, or physiotherapist for managing muscle spasms. Or, there may be lifestyle changes that you can make to cut your levels of fatigue.

By completing another diary after you have made changes or had underlying symptoms treated, you can compare the two and see if the changes you have made have had the desired effect.

#### Sleep

Lack of sleep might be the main cause of your fatigue, or one of several. As mentioned earlier, sleep problems might be caused by MS symptoms that can be better controlled. Alternatively, other issues, such as noise or drinking too much caffeine could be involved. Try to make any adjustments you can to ensure you have the best chance of an undisturbed night's rest.

#### Infection

Everyone can be exposed to infections like colds, flu or bladder infections. These can lead to unexpected tiredness. If you have been particularly fatigued recently, have you checked you are not coming down with an infection that could be treated?

#### Medication

Many common drugs used to manage MS and related symptoms have side effects that include fatigue. If you are taking any medications, you may want to discuss this with your doctor, particularly if your fatigue got worse after a new medication was prescribed. They can assess possible side effects and may suggest alternative drug options.

#### Anxiety, low mood and depression

Anxiety, low mood and depression are not uncommon in MS, and they can cause feelings of fatigue.<sup>9</sup> But because fatigue may also have an effect on your mood, it can be difficult to untangle the two issues – they might be affecting each other. However, if you feel your mood is low, your doctor or MS nurse can help you tackle the problem. There are many options for treating depression and other emotional symptoms, and successful treatment may also lessen fatigue. Equally, finding ways to minimise your fatigue can help beat stress and anxiety. For more information see the MS Ireland information booklets Mood, Depression and Emotions.

#### Other conditions

MS can cause a wide variety of symptoms, but remember that not every health issue you experience will necessarily be related to your MS. Other possible causes should be considered. Shortness of breath, for example, could be caused by asthma or heart problems, which should be looked into further by your doctor.

## Manage the fatigue that remains

Having identified and tackled fatigue caused by other MS symptoms, living with the condition, or by factors unrelated to MS, what remains may be fatigue linked directly to the activity of MS in the central nervous system.<sup>10</sup>

Managing this kind of fatigue can involve further lifestyle analysis: looking at how you, and those around you, approach work, rest and leisure time might reveal ways to make tasks easier and make best use of the energy you have.

#### **Consider realistic changes**

Think realistically about how fatigue affects you and consider what adjustments you and others feel able to make. Try to find a balance of activity and relaxation, exercise and rest, work and social life. Remember that some of the changes you make could involve family, friends or work colleagues.

#### At work

At work, you may need to ask your employer to make some changes – perhaps more flexible hours would help, or arranging a parking space closer to the entrance. Under the Disability Act, most employers are legally obliged to make 'reasonable adjustments' to allow you to carry on working. MS Ireland regional staff and Citizens Information Board (CIB) staff can explain your rights and responsibilities and help you get the adjustments you need.

#### **Professional support**

At home and in the workplace, an occupational therapist may look at the following areas with you to see where you might be able to save energy in the everyday tasks you do. Other health and social care professionals might also be helpful when you are looking at how you approach daily activities.

#### Rest

For some people, rest helps relieve fatigue and is an important part of fatigue management. Resting can prevent you getting to a point of complete exhaustion and coming to a sudden halt, mid task. Planned rest can give you more control over when you choose to be active and when you take a break.

A few short rests, or 'power naps', through the day are best for some people; or you might feel better after just one longer rest, at a particular time. For example, you might take a break after coming home from work so that you can enjoy a fuller evening with family or friends. By not launching straight into the cooking, cleaning or catching up with people's news, you might also avoid the kind of 'burn out' some people experience after struggling on until they can do no more.

When you rest, try to make your rest as complete as possible. Doing smaller jobs around the house, talking to the family or watching TV might be more relaxing than work or chores, but it is not really resting. It can be tricky, but the aim should be to switch off both the mind and the body. You might want to have a short sleep, or use relaxing music to help you clear your mind. Some people find yoga or meditation useful. If worries disturb time set aside for rest, try writing down these concerns and 'shelving' them while you are resting. You might find it easier to tackle them once your energy levels are back up again. If resting helps you manage your fatigue, it is important that other people realise how valuable this quiet, undisturbed time is.

#### **Prioritise**

Everyone's priorities are different, and most people find they vary from time to time. If fatigue means you cannot get everything done in a day that you would like, concentrating on the most important tasks can help. Making changes to your routine can be hard, but prioritising activities can mean you save energy for the things you really want or need to do.

One way to do this is to list all the activities you do in a typical day or week. As well as marking down the priorities, make a list of those jobs you would rather not do. Perhaps some can be done less often, or don't need doing at all. Consider the activities you have prioritised. Can they be done in a more energy-efficient way, or at different times of the day, to make them easier? Can you get help with any of these tasks?

 In Ireland, people with MS can avail of home help, but it is limited and available to medical card holders. Disability Allowance is a weekly allowance paid to people with a disability. To avail of it you must have had a disease, injury or physical disability that has continued or may be expected to continue for at least one year. Disability Allowance is a means tested payment, Disability Benefit is based on PRSI contributions but only lasts one year before the allowance kicks in. Meanwhile, the Invalidity Pension is based on PRSI contributions but not means tested.

Whatever your priorities are, try to be realistic about how much you can get done – don't try to take on too much.

#### Asking for help

People might say to you 'If there's anything you need...' or 'If there's anything I can do...', but it is not always easy to ask for help, even when it is offered. It can be useful to prepare a list of tasks that you'd like help with. Then, when someone does ask if there is anything they can do, you can explain exactly what would be most helpful. Here are some tips to help you define what you need:

- All jobs are made up of individual tasks. Try and break down the help you need into manageable sized tasks.
- Work out how long you think a task will take and when it needs to be done by.
- It may help to categorise tasks into: personal; household; or health care.
   You may not feel comfortable asking some people to do certain kinds of tasks.

• Understand that asking for help is a sign of strength, organisation and desire to get on with things. It is not a sign of weakness.

#### Plan

Knowing your priorities can help you plan your time more effectively. The idea of making a timetable for your day or week may seem a little strange or regimented at first, but planning ahead can help you be more confident of getting things done.

Be realistic about what can be done each day and try to balance activity and rest. If your fatigue makes you tired at a similar time each day, build in your 'down time' to recuperate. Equally, if you have a particularly tiring task ahead, a plan lets you make space for rest before or afterwards.

Some simple tips can make planning easier:

- Set yourself targets, but keep them realistic.
- Try to balance your day between heavy tasks and lighter ones. A heavy task for one person might be going to the supermarket or doing the laundry; for someone else, it could be getting dressed or washing. You will know your own situation. Aim for a balance between those you find easier and those that are more difficult.
- Split a heavy task into manageable stages, to be done a bit at a time. For example, if you are cooking a large meal, perhaps find recipes where you can pre-prepare parts of the dish, allowing for breaks in between.
- Try to avoid activities that can't be stopped or interrupted. For example, if you are walking the dog, make sure you have somewhere to stop and sit down if you need to. Perhaps walk along bus routes so that you can catch the bus home if you get more tired than expected.

#### Organise living and work spaces

You might find there are practical changes that can be made to the places you work and live. This could involve re-organising desks or cupboards, or adjusting the temperature or lighting to suit you better.

Sometimes, the simplest of changes can make the workplace or home more 'energy efficient':

• Keep items that you use regularly within easy reach to avoid frequently getting up and down, or having to stretch and bend unnecessarily.

- Items that are used together can be stored together in the kitchen, for example, you might want to keep the kettle, tea and mugs together in one place.
- Store lightweight items that are rarely used in higher spaces.
- Store heavy items that you use less often at a lower level.
- Keep work areas as uncluttered as possible.
- Make sure the lighting is good, to avoid eyestrain.
- Consider the items you use, like pens or cutlery would they be easier to use if they were lighter, had larger handles, or were adapted in any way?

An occupational therapist can help you assess the spaces you use – at work and at home – and may suggest adaptations or equipment that could help. The website www.assistireland.ie contains information on assistive technology and a directory of products available from Irish suppliers for people with MS, other disabilities and older people. Remember, useful changes to your environment such as those mentioned here don't always have to involve specialist equipment or major alterations.

#### Posture

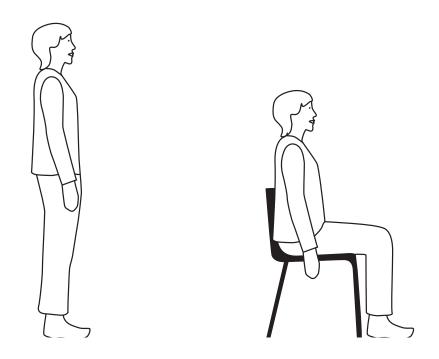
Many tasks can be carried out more efficiently if you have a good, relaxed posture, like those shown in the diagrams next page. Try to keep an upright and symmetrical posture and avoid excessive twisting and bending. Keeping a good posture takes practice, but with time it can become easier, as your body re-aligns itself, and it can help you save energy. A physiotherapist can help you identify any problems you might have with posture and suggest suitable exercises to help.

#### Standing

When standing up, try to keep your chin tucked in, your shoulders relaxed and your bottom tucked in. All of this helps to keep the spine in its natural shape. Try not to 'lock' your knees – keep them straight but loose – and stand with your feet slightly apart, toes pointing forward.

#### Sitting

When sitting down, try to keep your chin tucked in, your head level, and your shoulders relaxed, to avoid straining your neck. Your weight should be spread evenly across both buttocks. Your thighs should be supported on the chair and both feet supported by the floor. With some seats, you may want to use a foot rest to support your feet at the right level – a telephone directory or large book often works well. If you use a wheelchair, make sure the foot-plates are adjusted correctly for you.



By resting when you need to, you can reduce the strain on your posture. Some tasks, like preparing vegetables or ironing, can be done sitting down instead of standing. An adjustable stool with a sloping seat (sometimes known as a 'perching stool') can make getting up and down less of an effort. Sticks with seats attached can also be helpful when outside away from home – they can help with balance when walking and can fold out into a seat when you want to sit. The website www.assistireland.ie has more information about specialist equipment. As you might expect, there are also online suppliers of equipment. It is worth getting the advice of an occupational therapist or physiotherapist before buying.

#### Exercise

The symptoms of MS can make it harder to exercise and it almost goes against common sense to exert yourself if you experience fatigue. But exercise helps keep your body working at its best and can improve strength, fitness and mood.<sup>11</sup> These benefits can help with managing fatigue.

But it is possible to do too much exercise. It is important to balance the exercise with rest, and to keep cool while you exercise, especially if heat makes your fatigue worse. You might want to plan your exercise and avoid long sessions to prevent overheating. Some people find water-based exercise helpful for maintaining a steady temperature. Cooling vests may also help.

A physiotherapist can help you devise a suitable exercise programme. See MS Ireland's 'Getting the Balance Right' programme for more information.

#### Healthy eating

Combining sensible exercise with a balanced diet can also help you maintain a healthy weight and get the energy you need. Weight loss and weight gain can both be issues for people with MS and can make coping with fatigue more difficult.<sup>12</sup> A dietician can work with you to plan a suitable diet to maintain a healthy weight.

What you eat can also make a difference. For example, large, hot meals can make fatigue worse and caffeine or sugary snacks might have an initial 'pick-me-up' effect, but leave you feeling more tired later.

### Self-management programmes

In some parts of the country, MS Ireland Regional offices, hospitals, HSE community teams and rehabilitation centres run fatigue management programmes. These are often based on the kind of strategies outlined above. They are sometimes done in group settings, sometimes individually, and might involve family members, friends and carers as well. These courses help people living with a long-term health condition maintain their health and improve their quality of life. They include techniques for managing fatigue. Courses take place over six weeks (two-and- a-half hours a week) or over weekends and are led by people with expertise in managing fatigue in MS. To find out about courses in your area, go to www.ms-society.ie or ask your GP or MS nurse for information about local courses.

### Drugs for MS fatigue

Some people find that drug treatments help them manage their fatigue. Although there are currently no drugs licensed in Ireland specifically for MS fatigue, certain drugs licensed for other conditions are sometimes prescribed.

#### Amantadine (Symmetrel)

This drug is licensed to treat Parkinson's disease, as well as some viral infections. Unfortunately, research regarding its use in treating fatigue in MS is not conclusive.<sup>14</sup> However, the UK's National Institute of Clinical Excellence guideline for MS states that a small benefit might be gained from taking a dose of 200mg daily.<sup>13</sup> Side effects can include insomnia and vivid dreams.

#### Modafinil (Provigil)

This drug is used to treat narcolepsy, a sleep disorder which causes people to sleep excessively during the day. There have been several small studies looking at Modafinil to treat fatigue in MS, but they have had conflicting results and have not proved the benefits of taking it.<sup>15, 16, 17</sup> However, it is sometimes prescribed for people with MS fatigue and some people who take it say it helps. Side effects can include insomnia, headaches, lymphoedema (swollen legs) and liviad reticularis (a red network over lower legs).

### Research into fatigue

There has been some research into the use of drugs for MS fatigue. However, the trials have generally involved only small numbers of people, have lasted only a short time, or have used varying ways to measure fatigue. This makes it difficult to compare the studies and to draw definite conclusions from their results.<sup>18</sup>

### **Further information**

#### **MS** Ireland publications

MS Ireland has a number of publications relating to many aspects of living with MS. To view and download all our publications for free, log onto our website <u>www.ms-society.ie</u>.

#### MS Ireland website and magazine

Keep up to date with news relating to MS by logging onto our website <u>www.ms-society.ie</u> and signing up to receive regular email updates. Members also receive our magazine, MSNews.

#### MS Information Line, 1850 233 233

The MS Information Line is an information and listening service for anyone needing immediate information or support on any aspect of MS. It is a confidential service

#### **Regional Services**

10 Regional offices around the country provide individuals and their families a home visit service where our trained staff can answer queries, offer advice and provide referrals, if necessary. Regional offices also provide a programme of activities for groups of people; newly diagnosed days, carers support groups, personal development sessions and a range of physiotherapy and exercise interventions.

#### Local Branch Network

MS Ireland has 41 voluntary Branches that provide information and support to the local MS community. Run by people affected by MS, the Branches offer many social opportunities to people with MS and their families to come together and share experiences.

#### **MS Care Centre**

The centre provides short-term respite care, therapy services, neurological assessments and social activities for residents. While staying at the Centre residents can speak to our many trained professionals including the MS nurse and the Physiotherapist.

Your neurologist, MS nurse, GP, physiotherapy and other health-care professionals are also a key source of information.

### Further reading

### Coping with Multiple Sclerosis. A practical guide to understanding and living with MS

by Cynthia Benz and Richard Reynolds. Published by Vermilion (Revised edition 2005), ISBN: 0091902460. This book includes information on coping with the symptoms and uncertainties of MS, where to find help and a summary of MS research.

#### Fatigue management for people with Multiple Sclerosis

by Sarah Harrison. Published by the College of Occupational Therapists (Second edition 2007), ISBN: 978-1-905944-03-3. This book includes detailed information about fatigue, some of which is aimed primarily at occupational therapists. It also contains an example of a fatigue management workbook.

#### Are you sitting comfortably..? A self-help guide to good posture in sitting by Wendy Hendrie. Published by the Multiple Sclerosis Trust (2009) ISBN: 1-904156-18-5. This pocket-sized publication illustrates and describes ways to improve your posture when sitting down.

### Useful organisations

#### Citizens Information Board (with 250 locations nationwide) Locall 1890 777 121 www.citizensinformation.ie

Irish Wheelchair Association

Tel: 01 8186 400 www.iwa.ie

#### Disabled Drivers Association of Ireland

Ballindine Claremorris Co. Mayo Ireland Tel: 094 936 4054 www.ddai.ie

#### Health Service Executive (HSE)

HSE Information Line: 1850 24 150 www.hse.ie

#### Cheshire Ireland

Central Office Block 4 Bracken Business Park Bracken Road Sandyford Industrial Estate Dublin 18 Tel: 01 297 4100 www.cheshire.ie

#### Association of Occupational Therapists of Ireland:

Ground Floor Office Bowbridge House Montgomery Lane Dublin 8 Tel: 01 633 7222 www.aoti.ie

#### Irish Society of Chartered Physiotherapists

Royal College of Surgeons 123 St Stephen's Green Dublin 2 Tel: 01 402 2148 Fax: 01 402 2160 Email: info@iscp.ie www.iscp.ie or www.physicaltherapy.ie

#### Assist Ireland.ie

Tel: 1890 277 478 www.assistireland.ie

#### North West MS Therapy Centre, Sligo

Ballytivnan Sligo Tel: 071 914 4748 Helpline: 071 914 6067 www.mstherapycentre.ie

MS Therapy Centre Trim Tel: 046 943 6474

### References

- 1 MS Society (1997) Symptom management survey. London, MS Society.
- 2 Krupp, L. B. et al. (1996) Fatigue in multiple sclerosis. The International MS Journal, 3 (1), 9-17.
- 3 Benz, C. and Reynolds R. (2005) Coping with Multiple Sclerosis. London, Vermilion.
- 4 Whitaker, J. N. and Mitchell, G. W. (1997) Clinical features of multiple sclerosis. In: C. S. Raine et al. (eds.) Multiple sclerosis. Clinical and pathogenic basis. London, Chapman and Hall Medical. p.3-19.
- 5 MS Council for Clinical Practice Guidelines (1998) Fatigue and multiple sclerosis. Evidence-based management strategies for fatigue in multiple sclerosis. Washington, Paralysed Veterans of America.
- 6 Krupp, L. B. (2004) Fatigue in multiple sclerosis. A guide to diagnosis and management. New York, Demos Medical Publishing.
- Anon (2003) Fatigue in multiple sclerosis: common, disabling and measurable. Neura: Perspectives on CNS Disease Management, 3 (1), 5-7.
- Tartaglia, M. et al. (2004) The relationship between diffuse axonal damage and fatigue in multiple sclerosis. Archives of Neurology, 61, 201-7.
- 9 MS Society (2005) Mood, depression and emotions. London, MS Society
- 10 Bakshi, R. (2003) Fatigue associated with multiple sclerosis: diagnosis, impact and management. Multiple Sclerosis, 9, 219-27.
- Rietberg, M. B. et al. (2004) Exercise therapy for multiple sclerosis. The Cochrane Database of Systematic Reviews 2004, Issue 3, Art. No: CD003980.
- 12 Schwarz, S. and Leweling, H. (2005) Multiple sclerosis and nutrition. Multiple Sclerosis, 11, 24-32.
- National Institute for Clinical Excellence (2003) NICE Clinical Guideline
   8. Multiple Sclerosis: Management of multiple sclerosis in primary and secondary care. London, NICE.
- 14 Lapiere, Y. and Hum, S. (2007) Treating fatigue. The International MS Journal, 14(2), 64-71.
- Stankoff, B. et al. (2005) Modafinil for fatigue in MS? Neurology, 64, 1139-43.

- 16 Rammohan, K. W. et al. (2002) Efficacy and safety of modafinil (Provigil) for the treatment of fatigue in multiple sclerosis: a two centre phase 2 study. Journal of Neurology, Neurosurgery and Psychiatry, 72, 179-83.
- 17 Brioschi, A. et al. (2009) Effect of modafinil on subjective fatigue in multiple sclerosis and stroke patients. European Neurology, 62(4), 43-9.
- 18 Schwid, S. and Murray, T. J. (2005) Treating fatigue in patients with MS. One step forward, one step back. Neurology, 64, 1111-2.

### Authors and contributors

The original text for the publication was taken from the MS Society UK's MS Essentials publication.

MS Ireland wishes to thank the MS Society UK for its kind permission to adapt this publication for use in Ireland.

MS Essentials: Fatigue is written by James Bailey.

With thanks to: Adrienne Cox, Professor Scott Glickman, Nikki Ounsworth, Carole Shaw, Catherine Sykes, Professor Peter Thomas, Nicki Ward-Abel and the people affected by MS who contributed to this publication.

Adapted for Ireland by Aidan Larkin.

© Multiple Sclerosis Ireland, 2011 First edition, May 2011

Disclaimer: We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions, and policy and practice may change. Seek advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to info@ms-society.ie

### Multiple Sclerosis Ireland

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults, and we estimate that around 8,000 people in the Ireland have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body. For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

MS Ireland is the only national organisation providing information, support and advocacy services to those affected by MS, their families, employers, health professionals and others interested in MS.

- Individual and family support
- Living with MS programmes, activities and workshops
- Confidential Information Line, 1850 233 233
- Respite and therapy centre
- Advocacy and lobbying
- National Conferences

- Professional counselling
- 41 Voluntary Branches, nationwide
- MSnews magazine and e-newsletter
- Website www.ms-society.ie
- Information and research

You can help the work of MS Ireland by:

- becoming a member (open to anyone);
- making a donation or fundraising;
- offering your time as a volunteer.

#### **Contact information**

To learn more about our services or to make contact with local services, contact our national office:

#### **Multiple Sclerosis Ireland**

80 Northumberland Road, Dublin 4

 Tel:
 01 678 1600

 Fax:
 01 678 1601

 Email:
 info@ms-society.ie

 Information Line:
 1850 233 233

 Web:
 www.ms-society.ie

