



Family Matters

For Families and Friends of People Living with MS

2. *Living Well with MS*





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MS Limited – ACT/NSW/TAS/VIC
The Nerve Centre
54 Railway Road, Blackburn, Victoria 3130

P: (03) 9845 2700
W: www.ms.org.au

MS Connect™: 1800 042 138

MS Limited – ACT/NSW/TAS/VIC strives for a world without multiple sclerosis (MS) through quality research and for service excellence to people with MS, their families and carers.

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Family Matters

For Families and Friends of People Living with MS

2. Living Well with MS

Multiple sclerosis (MS) can have a significant impact on the lives of family members and friends of a person living with MS. *Family Matters* is an information series that offers useful guidelines so that family and friends can understand the challenges they may face and the strategies that they can adopt to manage better.

As each family and person with MS is unique, not all the suggestions or information will be relevant to everyone, but the *Family Matters* series is a good starting point for finding out more.

Living Well with MS is booklet two in this series and is designed to help you on your journey alongside the person with MS.

MS can be demanding so you need to maintain your own health and wellbeing. Knowing how to manage MS, as well as making improvements to your own lifestyle, can make it easier for you to support the person with MS.

Eating well

Eating is often considered one of the great pleasures in life. By preparing and eating healthy meals together, your family can benefit both emotionally and physically.

Maintaining a healthy and balanced diet is important for everyone, especially for the person in your family with MS. Very often, family life centres around meal times. This time is a good opportunity for families to connect and talk about their day or any concerns they may have.

A balanced diet

Eating nutritionally balanced meals helps the body work to its full potential. A good diet can help the body to fight infection, minimise fatigue, and promote a better sense of wellbeing.

The Australian Government has developed guidelines for healthy eating. This information is available in the Department of Health and Ageing booklet, *Food for Health — Dietary Guidelines for Australians*.

There have been suggestions that special MS diets or supplements may help people with MS. However, these can not only be expensive and difficult to follow, but they can sometimes be harmful if the person with MS cuts out important nutrients from their diet. A great deal of research is being conducted about the benefits of certain diets in relation to MS. The person with MS should always consult their doctor before they change their diet or undertake any treatments.

To maintain a healthy diet, it is recommended that you and your whole family develop some simple 'good habits', such as those listed below:

- Follow a healthy, balanced eating plan, with a variety from each of the food groups, including vegetables, legumes, fruit, and low fat foods.
- Eat small, regular meals and snacks, including breakfast every morning.
- Choose mainly slowly-digested (low-GI) carbohydrate foods.
- Drink plenty of water.
- Limit alcohol.
- Avoid excess caffeine.
- Avoid too many sugary snacks.
- Choose foods low in salt.
- Limit saturated fat and try to cut down your overall fat intake.
- Avoid skipping meals.



Where to go for support:

Turn to page 22 to learn more about the information and support services that are available.

- Department of Health and Ageing
- Dietitians Association of Australia
- Nutrition Australia

Keeping active

There are a number of reasons why staying active is so important to our general health and wellbeing. It can help to reduce weight gain, the risk of heart disease and diabetes, as well as a number of other diseases.

For people with MS, a lack of physical activity can aggravate the impact of symptoms such as weakness and fatigue, so staying active can be very beneficial. Physical activity can also help to improve psychological health and protect against such things as stress, anxiety and depression.

Because it is an essential part of life for everybody — young or old — your whole family can get involved in staying active and enjoy the benefits. It is a great way to nurture your relationships and have some fun.

It is motivating and enjoyable to do things together such as walking the dog, playing a game of backyard cricket, or even having a family relay at the local pool. The important thing to remember is that everyone in your family is an individual. They will have different capabilities and preferences when it comes to keeping active, so it's a good idea to keep things flexible and ensure that everyone is comfortable. It may be that your family does certain activities together and then gives each other the time and opportunity to do other activities alone.

If you or members of your family have not been active for a while, check with your doctor before starting something new. Consulting a physiotherapist or exercise physiologist on the most effective exercises for the person with MS is also essential.

Strength, stamina and stretching

Finding activities that fit into your family's daily or weekly routine is the best approach. Including strength, stamina and stretching into your routine can help to ensure that you are getting an overall workout.

Strength training may include hand weights or ankle cuffs, resistance bands or even body weight. The great thing about strengthening exercises is that you can start to feel the benefits within two weeks if you're doing them once to twice a week.

Stamina and fitness can improve via cardiovascular exercises (e.g. walking, swimming and gardening). Stamina exercises are often the easiest for you to do as a family. Be mindful that a person with MS might find it hard to do these



- ▶ exercises at the same rate as the rest of the family. They may need to sit out a lap or do a shorter circuit.

Stretching exercises should be part of your daily routine. It's much easier to maintain flexibility than it is to try to regain lost movement. Try coupling a stretch with a routine activity, for example, if you have young children, do some stretches just before bedtime.

Tips for getting started

- Choose an activity that your family enjoys. You can modify the activity when necessary if the person with MS is experiencing any effects such as fatigue, or a potential increase in symptoms.
- Don't try to do too much right away. Start slowly and build up your activity gradually, several times a week. This is better than undertaking intense activity once a week.
- Activities should be carefully timed so that hotter periods of the day and excessive fatigue do not pose a problem for the family member with MS.
- It's beneficial for the family to appreciate the changes that occur due to an increase in activity, for example, an improvement in symptoms or ability for a person with MS. It's also important to assess what works for the family or what doesn't. This will help you plan future activities.



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Staying motivated

Setting goals and recording personal progress will help your family to stay motivated. Small realistic goals and personal incentives can ensure successful goal setting. Goals provide encouragement and allow you to see the progress you have made. It is up to you and your family to decide if you would like to set individual goals or a common family goal.

There will be times when your family will lose interest, but trying a new activity or a new venue can help to revive the motivation. This can also be a good time to set new goals and build on your positive experiences.

Where to go for support:

If you're concerned about how MS symptoms may affect your ability to stay active as a family, contact MS Connect. You can also find out more about 'Heartmoves for people with MS', an exercise program developed by the Heart Foundation with MS Limited – ACT/NSW/TAS/VIC.

Complementary therapies and MS

There are many complementary therapies available and many people find these helpful. These therapies include a broad group of health-related practices that are not considered part of mainstream medicine.

Complementary therapies are becoming more popular. In fact, 50 to 70 percent of people with MS and their families say that they have tried some form of complementary therapy.

Complementary therapies are not considered part of mainstream medicine. However, you may have heard about some of the most common forms, which include acupuncture, aromatherapy, homeopathy, massage, Pilates, reflexology, reiki, relaxation and meditation, tai chi and yoga.

If your family member with MS is interested in exploring complementary therapies, it is important that you support their decision. It may also be worthwhile considering some of these complementary therapies for yourself. For example, mindfulness meditation can help you to maintain or reduce your stress levels and achieve a calmer frame of mind.

The important thing to remember is that a doctor should be consulted. This will ensure that any new treatment you or the person with MS choose to undertake will not affect any medications you take or symptoms already present.

For the family member with MS, it is important that they continue to manage their MS through their healthcare team. Most mainstream doctors and healthcare teams are more than happy to include complementary therapies into a person's healthcare portfolio.

If you and your family would like to try any of these therapies, it's important that you research the practitioner's qualifications thoroughly.

MS Limited offers Wellness Days for the whole family. You and your family can come along and try out some of the complementary therapy activities on offer, as well as gain advice on healthy diets. Information on Wellness Days can be obtained by calling MS Connect.



Coping with stress

At times, families living with MS can feel stressed. It's important to understand that there are ways that you and your family can manage your stress.



Often people talk about how specific life events cause their stresses; however, it is important to keep in mind that your perception of an event is more likely to cause the stress than the actual event itself. For example, some people report that organising a wedding is a stressful experience; however, other people enjoy the process and don't find it stressful at all. The important thing to remember is that just because an event 'could' be stressful it does not mean that it actually will be.

You might hear some people say that they are not very good at 'dealing with stress' or that they're stressed more often than their friends or colleagues. If you feel this way, it is important to remember that stress is a very common experience and everyone experiences stress at some time or another. You're not alone.

Stress is described as the body's physical response to a perceived threat. There are two things to keep in mind about this description:

■ **Stress is a physical response.**

The 'symptoms of stress' include muscle tension, increased heart rate, increased breathing rate, sweating, feeling light-headed, butterflies in the stomach. This is what your body does when you are experiencing stress.

■ **Stress is a response to a perceived threat.** This includes anything that you personally feel might be physically or psychologically threatening, dangerous or worrying.

Supporting a family member with stress

If a family member is stressed, try to remain calm and find out if you can do anything to help and support them. You might also like to suggest the three-step approach.

Otherwise, suggest they visit their doctor or speak to someone about it. A counsellor or psychologist can help them manage their stress.

A three-step approach

If you're trying to manage your stress, it's important to address all the aspects that are causing you to feel the way you do. You can do this by following this three-step approach to stress management:

1. Slow breathing

Stress is a physical response. When you're stressed, your breathing increases, your heart rate increases and you experience other unpleasant physical sensations.

Taking a few slow, deep breaths can help you reverse the physical effects of stress. Slow breathing is not complicated. Try breathing in for four seconds and breathing out for four seconds. Do this for a few minutes.

2. Take action

Stress is a response to threat. When a person feels threatened, the common response is to avoid the threat. This avoidance strategy has no impact on the cause of the stress (the stressor). In many cases, avoiding the stressor can make things even harder when the time finally comes to confront it.

Take 'action' on the thing that is causing your stress. For example, if a son's messy room is making you feel stressed, visiting your doctor will not make you feel better; making your son tidy his room will. Alternatively, if you're stressed about the results of a recent medical test, nagging your son to clean his room won't make you feel better, but finding out the results of the test will.

3. Challenging unhelpful thinking

Often when a person is experiencing a stressful event, it seems more serious or distressing at the time. It is common for a person to get panicky and overly worried about a situation if they are thinking about the worst possible outcome rather than the most likely outcome.

Challenge your own thinking and ask, "How likely is it that this will happen?" or "Is there another way I could look at this situation?".

If the above strategy doesn't help, visit your doctor and obtain a referral to see a psychologist. A psychologist can assist you to find the best stress management technique for you.



Where to go for support:

Turn to page 22 to learn more about the information and support services that are available.

- Lifeline

Dealing with depression

Depression is not just a feeling of sadness, having a bad day or a passing phase that comes and goes. Depression can impact on people's lives, so seeking help is important.

Depression is a mood disorder that causes a person to experience a significant disruption to their mood (feeling sad, low or down) or a disruption to their ability to enjoy themselves and experience pleasure. People with depression find it hard to function every day and may be reluctant to participate in activities they once enjoyed.

What can I do if I feel depressed?

If you're feeling depressed, the first step is to see your doctor. They can discuss the situation with you and may provide a referral to a psychologist or other healthcare professional.

Your doctor can also provide general advice about some of the things you can do to improve your mood such as taking on new activities, doing exercise or spending time with friends. Most people report that they end up feeling a little better after these activities.

What if someone in my family is depressed?

The first thing to remember is that it is nobody's fault if a person is depressed. They haven't chosen to be depressed and there is nothing that you or anyone else could have done to stop their depression occurring.

It's very common for people to blame themselves or those close to them when depression occurs; however, this blame really just makes everyone feel worse.

Showing support and interest in the way a person is feeling is a positive approach. Doing some research, reading about depression on the internet and learning more about how it can affect people can also help.

If you're concerned that a family member is depressed, talk to them and ask if you can do anything to help. If you have tried this approach and it hasn't worked, the next step is to encourage them to seek professional help. Suggest that they book a long appointment with their doctor to discuss their feelings.

When someone is depressed there's a problem with their mood, not their physical abilities or their brain. Try not to take over their usual jobs and tasks.

It's okay to offer your help if they're finding certain activities more difficult than usual, but encouraging them to keep up with their daily duties keeps them active despite their depression.

At times, you may feel the need to speak for the family member who is depressed, trying to shelter them from dealing with their everyday hassles. Again, while this is well meaning, it takes something away from them (such as expressing their own opinions), leading them to become less active.

Living with a family member who is depressed can be difficult and draining. It's important that you, and other members of your family, remember how to look after your own wellbeing.

Plan some time out and schedule enjoyable activities for the whole family. Spending quality time together in a pleasant environment can be helpful. Encourage family members to do things outside the family unit, such as spending time with friends. This can help everyone feel better and help them to maintain their usual activity levels.

Depression in MS

Depression is more common in people with MS than in the general population. In the general population, approximately one in five people will experience an episode of major depression in their lives. Among people with MS, it's approximately one person in every two that will experience an episode of depression.

The reason for the high rate of depression in people with MS is still unknown. Experts think that there are several factors that lead to depression in MS including the MS itself, changes in lifestyle and thinking because of MS, and MS progression.



Where to go for support:

Turn to page 22 to learn more about the information and support services that are available.

- Lifeline
- Beyondblue

If a person experiences at least five of the following symptoms (including one of the first two) for at least two weeks, their doctor may decide that they are depressed:

- feeling sad, 'down' or crying most of the day — every day
- much less interest or pleasure in things and people
- significant weight/appetite gain or loss
- sleep disturbance — insomnia or sleeping too much; agitation and anxiety or sluggishness
- fatigue and loss of energy
- feelings of worthlessness or guilt
- finding it hard to concentrate and difficult to make decisions — even small things
- irritability and anger
- recurrent thoughts of death or suicide.

Managing MS-fatigue

MS-fatigue is characterised by a sudden loss of energy and the inability to continue an activity. The effect of fatigue on the overall experience of life is profound for a person with MS and their family.

You may have experienced fatigue after an excessively busy day or a lack of sleep, but this is very different to the fatigue experienced by a person with MS. With nervous system disorders such as MS, the affected person often notices that they tire more easily. Generally, the fatigue that a person with MS experiences is not in proportion to the activity they have undertaken.

Unlike other types of tiredness due to excessive activity or lack of sleep, MS-fatigue cannot be worked through. It can be persistent and recovery time tends to be much longer. Up to 75 percent of people with MS-fatigue say that it prevents them from meeting their social, family and professional responsibilities.

Some common challenges for people with MS-fatigue include:

- problems concentrating or making decisions
- absence of energy or strength
- loss of sex drive
- difficulty sleeping
- being easily upset.

As well as disrupting daily life, MS-fatigue may cause anxiety, as other MS symptoms can occur during periods of MS-fatigue. This is particularly the case when exertion or high air temperature causes a rise in body temperature. However, symptoms generally subside after rest.

MS-fatigue is often referred to as a 'hidden' symptom of MS as it is a symptom that others can't see. It can be difficult for the person with MS to explain, and in some cases, even convince others that they are experiencing this hidden symptom.

Managing MS-fatigue

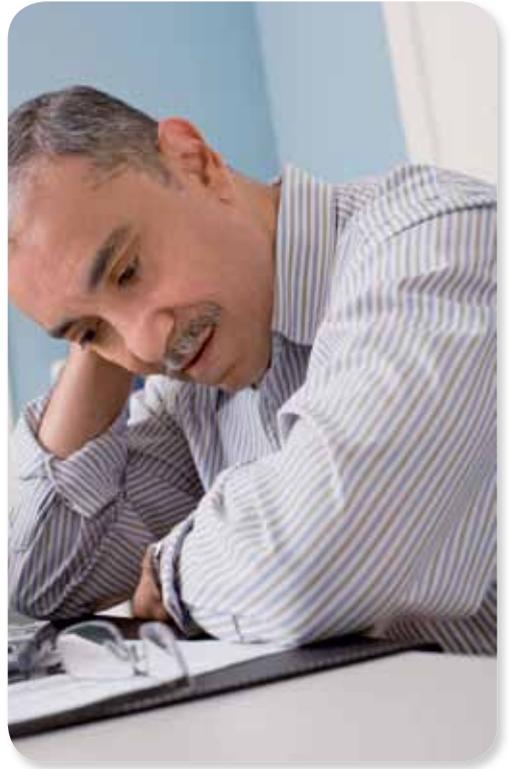
By understanding and accommodating MS-fatigue, you can help your family member with MS to manage it. Unfortunately, people don't often report this symptom to their family or healthcare team, and fail to seek treatment or advice about managing it.

More than any other MS symptom, a team including medical staff is needed to manage MS-fatigue. This team should consist of a physical and occupational

therapist, a clinical psychologist, social worker, nutritionist, the person with MS, you and other family members.

Because of the complexity of MS-fatigue, the first step in effective treatment is to identify the causes of the fatigue (causes may include things such as coexisting medical illnesses, medication side effects, depression or disrupted sleep).

While coping with ongoing MS-fatigue can be very draining, there are strategies that can help to reduce its impact on your family's everyday life. Maintaining a healthy lifestyle can help with coping better. Managing time, energy and stress is also important. Overall, a proactive approach to coping can provide you and your family with more control and confidence.



Assisting your family member to cope

As it is a hidden symptom of MS, family, friends or colleagues can sometimes misinterpret MS-fatigue. They may assume that the person with MS is depressed or just not trying hard enough. It may be the case that your family member with MS is finding it too hard or too tiring to explain how it feels and is making other excuses for their difficulties instead.

It's important to work on relationships and communication with those close to you, especially young children, to try and find an effective way to talk about MS-fatigue and the effects it may have on the family unit.

Since MS-fatigue affects a person's physical functions, it may be necessary for them to change their role or reassess their day-to-day routines. Sit down as a family and talk about which activities are important to everyone. Create a plan so that the person with MS will have the energy to participate as much as possible in those activities.

Learning about the impact of this symptom on your family member with MS can help you prepare for the challenges that may arise. If you and your other



- ▶ family members have a clear understanding of how MS-fatigue can affect the person with MS, you will all be keen to help out. Reconsidering family activities, reorganising the house and your habits so that the person with MS can function as best they can, makes a difference.

By managing stress, people with MS may be better able to manage their MS-fatigue. The information on 'Coping with stress' and 'Complementary therapies and MS' in this booklet may be useful.



About MS-fatigue

MS-fatigue is a common and frustrating symptom of MS. It affects many areas of daily life. It's one of the most difficult symptoms to treat and understand because it's 'invisible'.

The exact nature of MS-fatigue is not completely understood, but clinicians know that it's definitely a problem caused by MS. The level of MS-fatigue does not reflect the severity of someone's MS. Some people can experience MS-fatigue that interrupts their daily life or prevents them from working, but have no other symptoms.

Like all symptoms, MS-fatigue affects people differently and to varying degrees. It can be very hard to define, but people have described it as a sense of tiredness, a lack of energy, a total body 'give-out' that strongly impacts on their ability to do things. Rest does not easily overcome it and it is not weakness. It is often described as a low-energy feeling.

Almost all people find that their MS-fatigue is much worse on a hot and humid day and some people say that MS-fatigue makes their other MS symptoms worse.



Where to go for support:

Contact MS Connect on **1800 042 138** for information and education resources about MS-fatigue.

MS Limited – ACT/NSW/TAS/VIC runs education sessions on MS-fatigue and bookings can be arranged by contacting MS Connect. The sessions discuss why MS-fatigue occurs in people with MS and how it can be managed.

Your family member with MS should see their doctor when fatigue becomes a major problem or if they experience the sudden onset of severe, disabling fatigue.

A thorough medical evaluation will help to eliminate any other causes of fatigue. Their doctor can also discuss treatment options and offer referrals to other health professionals.

Managing a relapse

Some people with MS have symptoms that come and go on a daily basis. This is why families often find it difficult to tell if the person with MS is experiencing a relapse.

Generally, a relapse is defined as new symptoms or the worsening of old symptoms that last longer than 24 hours.

Relapses can be minor or major. Minor relapses include symptoms such as tingling in the hands or legs, pain or increased fatigue. Major relapses include visual disturbances, or muscle disturbances affecting the arms or legs, and therefore coordination and gait.

Symptoms from a relapse usually resolve after four to six weeks, but some can take longer to disappear or remain indefinitely. There are treatments that can reduce the time that it takes for these symptoms to resolve; but all treatments can also have side effects. Because of this, they are not used every time a new symptom or group of symptoms appear. Treatments are most effective in the first week or so after new symptoms appear.

As a family member, it is important to know what the person with MS is experiencing on a day-to-day basis and how they are functioning. This way you're aware of what symptoms are new and those that are old. Secondly, it's important to ask how these symptoms are affecting the person with MS. Are they struggling? Is it affecting their quality of life or is it just a nuisance? When vision, mobility or coordination are affected, it can be problematic, whereas numbness in the leg or minor pain may not be as serious. Most of the time the person with MS is in the best position to know how serious it is. Sometimes they will need your help, both in recognising the changes that are occurring to their body and the significance of the problem.



If symptoms are not severe and don't interrupt daily living or routines, your doctor may advise a 'wait and see' approach. The neurologist should be consulted if new or worsening symptom(s) persist for more than 24 to 48 hours.

How to tell

A family member with MS may try to protect you by not being up-front about the changes in their symptoms or they may be trying to ignore it. They may also not want to appear to be complaining about the MS.

In particular, you need to be aware of the 'hidden' symptoms of MS, such as changes in memory and thinking, that might accompany a relapse. In these situations, your family member with MS may not be aware of the significance of what is happening to them.

Another 'hidden' symptom you need to be aware of is increased fatigue. Make sure you acknowledge that the person with MS is having difficulties, as it could be quite distressing for them if you don't.

Page 10 of this booklet provides more information on MS-fatigue.



What else could be happening?

When a person is first diagnosed, they may mistake any symptoms they experience as a relapse. It's important to remind yourself and the person with MS that they are just as prone to everyday illnesses as everyone else.

It's not uncommon for the person with MS to experience a worsening of their MS symptoms, due to such things as a rise in core body temperature. A person's temperature may rise for many reasons including over-exertion and high air temperature. If this is the case, the symptoms will settle down as the body cools.

A rise in core body temperature can also be caused by infections, such as a urinary tract infection, a cold or flu. If it's obvious that the rise in temperature is due to infection, encourage the person with MS to consult their doctor or relevant health professional, and to drink plenty of fluids.

Stress can also be a trigger to physical, neurological and psychological symptoms. Normal day-to-day stressors such as a job change, divorce, bereavement, raising teenagers, moving home, going away on holidays or even a doctor's appointment can affect a person's wellbeing.

Immunotherapy treatments can also cause flu-like reactions and a rise in temperature, causing symptoms to increase for a short period. You may have to remind your family member with MS to keep their MS immunotherapy nurse informed if they are experiencing symptoms so that side effects can be minimised as much as possible. A temporary increase in symptoms due to overheating or stress does not cause the MS to get worse.

Planning for a relapse

One of the most important things a family can do is to learn about MS and plan ahead. Planning can help you manage a relapse and may help lessen the stress that often accompanies it.

Your family member with MS should have a management plan in place, which helps them cope with the day-to-day management of the MS. Everyone in your family should be aware of this management plan, as well as where the relevant documentation is kept. Our staff can help you to develop such a plan.

In addition to this, an emergency care plan for the whole family should also be prepared, outlining the whole family's weekly activities and details on how they can be contacted. It should also contain the details of local health services in your area, and what they can do for both your family and the person with MS.

If you need assistance during a relapse, either around the home or for the person with MS, you should contact a Commonwealth Respite and Carelink Centre.

Managing employment issues

Relapses are unpredictable they can occur at the most inconvenient times. Additional responsibilities at home may make going to work a little harder and lead to worries about financial security. Similarly, the person with MS may have difficulty negotiating time off work to recover from a relapse.

Impact on the family

The impact of a relapse can be significant on your family, especially if it leads to hospitalisation. Your children may be very upset if someone they are close to has to go to hospital, even if it is just for a few days. Children over six may be very vulnerable as they are more aware of mortality and may think the person with MS is at risk of dying.



Where to go for support:

MS Connect on **1800 042 138** can help you plan for a relapse by providing further information or by linking you in with our specialised staff. **Turn to page 22** to learn more about the other information and support services that are available.

- Commonwealth Respite and Carelink Centres



Read the chapter in this booklet titled 'Balancing work and home' for further information.



Information on 'Communicating with children' is available in the first booklet in the *Family Matters* series. Information on MS for children can be obtained by calling MS Connect on 1800 042 138.

Balancing work and home

You and your family members are entitled to work if you choose to. You have a right to feel supported by your employer so that you can maintain a balance between your working life and caring responsibilities.

Having to care for someone with MS can be overwhelming at times. As well as having to support a person with MS for a few hours a week or every day of the week, you may also have the added pressure of full-time or part-time employment. You may begin to feel as though maintaining a positive and productive working relationship with your employer is becoming a challenge.

You and your family members are entitled to work if you choose to. You have a right to feel supported by your employer so that you can maintain a balance between your working life and caring responsibilities.

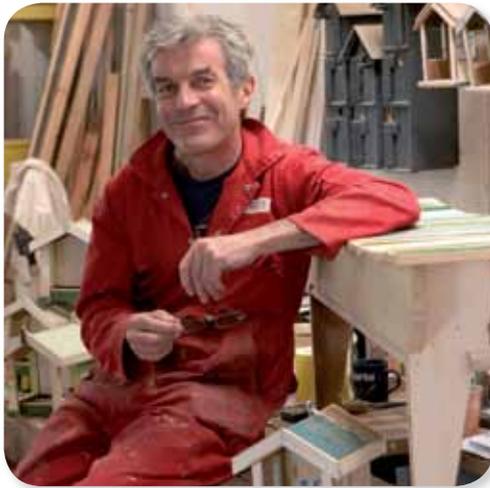
If you're covered by an award or an Enterprise Bargaining Agreement (EBA), family-friendly work arrangements should be available to you and can be discussed directly with your employer.

When entering into negotiations with your employer, it is important to remain positive and adopt a sense of pride when you are talking about your caring responsibilities. In most cases, an employer will be flexible if they fully understand your issues as a carer. They may even help you to identify the support options that best suit your situation.

Communicating with the person with MS

Before talking with your employer, it's a good idea to have a discussion with the person with MS. This discussion will help you to clarify what responsibilities are priorities so that you can support the person with MS as best you can. This will help you to negotiate a lot better with your employer, too.

Before approaching your employer, also ensure that you speak with the person with MS to establish clear boundaries and guidelines in relation to what they are happy for you to discuss with your colleagues. When communicating with your employer, try to be mindful of respecting the privacy and confidentiality of the person with MS.



Communicating with an employer

Discussing caring responsibilities is very different to discussing work duties; but many employers are committed to ensuring employees maintain a healthy work-life balance. It's important to ensure that your employer understands the level of commitment you have to your carer duties and the impact this has on your work and personal life.

An informed employer will be able to put plans in place that will allow them to be more flexible and supportive. It's useful to keep timeframes in mind in relation to your caring responsibilities. By doing so, your employer can set review dates with you and come up with some employment options that suit everyone's needs.

It may also be useful for you to schedule regular review meetings with your line supervisor so that he or she is always up to date on your carer

commitments, and informed about your future work priorities.

Try to keep in mind that you are more likely to succeed in negotiating a win-win position if your direct work colleagues and/or subordinates are prepared to work with you to accommodate your carer responsibilities. Including them in discussions can alleviate conflict, especially if they're required to take on additional responsibilities. Maintaining positive and constructive working relationships with your colleagues is just as important as seeking approval from your employer.

What to disclose

Don't assume that because you're talking about your caring role with your employer, you must provide intimate details about your personal life.

An employer will be interested to know how your caring role will impact on work, but this doesn't mean they need to know everything about your at-home routine or the duties you perform.

Rights of an employee

It is important that you make yourself familiar with what your rights are at work. There is a chance that your employer will not agree to support carer-related requests. This may be because they are unwilling to change current work practices or unsettle working arrangements with other staff. If this occurs, you need to continue to talk to, and influence, the decision makers at work.



- ▶ Always give your employer the opportunity to follow the appropriate workplace policies and protocols. Sometimes all it takes is a friendly conversation with your boss to remind them that you have certain rights as an employee. This can open up communication channels and lead to positive outcomes.

If necessary, you might have to put things in writing and follow the company grievance procedure as a next step. If you choose to pursue this path, make sure you understand your rights.

Although at times this experience can be stressful and intimidating, it's important to keep in mind that you will have more legal protection if you maintain your contract of employment. Resigning because of frustration or conflict will mean that you can't negotiate with your employer.



If an employer or work colleague asks a question that you feel is 'off limits', you should always respond professionally and politely, while maintaining your own personal boundaries.

Changes to your working arrangements

If you decide to work part-time or cease employment altogether to become a full-time carer, it's important that you seek advice before reducing your hours or handing in your notice. You should look into things such as the benefits you may be entitled to, as well as your superannuation policy. A financial planner or lawyer can provide you with superannuation and insurance advice.

 **Where to go for support:**

You can obtain information about employment issues, industrial awards and legislation that applies to you from MS Connect on **1800 042 138**. **Turn to page 22** to learn more about the information and support services that are available.

- HelpDomain
- Maurice Blackburn Lawyers
- Public advocates and guardians

If you feel unfairly treated by your employer, find out more information about commonwealth and state legislative protection, particularly the Disability Discrimination Act. Another option is the Human Rights and Equal Opportunity Commission (HREOC).



Relationships, sexuality and intimacy

A diagnosis of MS often brings with it concerns about physical ability and how this will affect a person's, and in turn, their family's future. Because MS is unpredictable it can make your family feel as though you have lost all control over future plans and expectations. In some cases, more than anything else, it is the fear of not knowing that causes a family the most stress.

All the time and energy you and your family spend thinking about these things, as well as the changes brought about by MS, can affect relationships — especially those that are close and intimate. Although you, your family and friends are not experiencing the symptoms of MS first hand, you may still be experiencing the impact. As you are all busy dealing with the demands of treatment regimes and symptoms, you might end up neglecting the emotional and psychological aspects of your relationships — the 'quality' time.

As a partner, you may find that you're taking on new and varied roles. It can be increasingly difficult to change from physical carer to intimate partner. You need to ensure that you maximise your own quality of life by maintaining social and leisure activities. Make sure you seek advice, support and counselling, if necessary.

A family living with MS must remember to nurture and value their relationships. This takes time, respect, and the ability to express feelings and listen to the feelings of others.

When managing and coping with changes in sexual and intimate relationships, it's essential that you and your family communicate openly and honestly.

A chapter on 'Understanding emotions' is available in the first book in the *Family Matters* series, which can be obtained by contacting MS Connect.





The impact of MS on sexuality and intimacy

MS can have an impact on sexual and intimate functions. This may be a result of the MS, its symptoms, or psychological factors. These issues are likely to affect, not just the person with MS, but you and your family, too.

Understanding the sexual changes that MS can bring, and knowing how to deal with such issues, can help you to manage challenges that may arise in this area of your life.

There are three different ways that sexual changes can occur in MS. These changes can occur in the person with MS because of impairment in the central nervous system (CNS), which consists of the brain and the spinal cord. This can alter or stop the nerve messages that the body sends, leading to changes in libido (sexual desire), changes to sensations in the genital area, reduction in vaginal lubrication, decreased erectile ability and reduced orgasmic response.

MS symptoms can also indirectly alter sexual responses and desire. For example, fatigue, bladder and bowel problems, weakness, spasticity and memory and thinking changes can all affect sexual function. These symptoms may have an impact on sexuality in a physical sense, by altering the person's sexual activity, involvement and response; or emotionally, by causing them to withdraw or avoid such activity.

By managing these symptoms, a person with MS can experience enjoyment, improve their confidence, relationships and overall quality of life. MS-fatigue, in particular, is a symptom that can influence sexuality. Feeling 'too tired' is a real problem. A partner may misinterpret this as a lack of interest, which can

Questions about sexuality may be overlooked as part of routine visits and check-ups. You and the person with MS might need to introduce the topic to your doctor or MS specialist if you have concerns. Discussing intimate changes can be hard, but its important if you wish to manage the issue effectively.



lead to feelings of resentment. It is important to understand that it can be a result of MS.

By planning time to nurture relationships, and ensuring that sexuality and intimacy are a priority for you and your partner, you can enhance and maintain sexuality as one of life's pleasures. It may mean that you need to make a little more effort by organising your time and getting a little creative. For example, you might replace late night candle-lit dinners with an outdoor picnic lunch.

Self-esteem and MS

Psychological issues associated with MS, such as changes in self-esteem, self-image, mood, confidence and social functioning can also be an issue. The challenges of MS can leave you or the person with MS feeling overwhelmed and less sexual or sexually attractive.

People define themselves based on their role within the family, friendship groups, occupation and leisure activities. Changes to these roles because of MS can leave a person feeling less confident, leading to low self-esteem and insecurity.

In the media, sexuality is portrayed by images of beauty, fitness and health. For a person with MS or a person who is dedicated to caring for a person with MS, it can be hard to relate to these images.

Intimacy and intimate relationships are a part of our overall sexuality. Sexuality involves both physical and social relationships and has an important part to play in the ongoing development of our personal identity, wellbeing, self-esteem and quality of life. This is a significant part of your life and it deserves as much attention as any of the other MS-related issues that affect your family.

It is important to remember that there are others in similar situations that still have satisfying relationships. Your doctor will be able to assess your needs and issues, provide education and treatment, as well as referral to other professionals as required.



Images: iStockphoto/Thinkstock; iStockphoto/Thinkstock



Where to go for support:

You can contact MS Connect on **1800 042 138** for more advice. They can direct you to health professionals who can help you and your family to manage your personal challenges and relationships. **Turn to page 22** for other information and support services.

- Relationships Australia

Where to go for support

For general help and advice

You can contact the MS Limited – ACT/NSW/TAS/VIC information and support line MS Connect™ on **1800 042 138**, Monday to Friday from 9 am to 4 pm. You can also email **msconnect@ms.org.au**. This free service is available to people with MS, family members, friends, carers and health professionals.

A directory of websites and other useful resources can be found in the 'Family and Carers' section of the website **www.ms.org.au**

In addition, several agencies can provide you with information on services and support in your local area. You can also obtain legal advice from a local community legal centre, legal aid or solicitor, law society or law institute. Obtain a local community directory from your local council or library for contact details.

Banks, building societies, credit unions or an accredited financial adviser can assist you with financial advice.

Useful contacts

Listed below are the contact details of some of the agencies that may be of use to you and your family member with MS:

Carers Australia exists for relatives and friends who care for people. They are the only state-based organisations with carers as a primary focus.

Carer Resource Centres and the Carer Line is a free service for carers seeking information. They provide referrals; information about programs and services, such as financial assistance and carer support groups; and other issues that affect carers. Their *Carers Pack* and information for children and teenagers through their Young Carers program is useful.

Carers have access to counselling and assistance through the National Carers Counselling Program.

p: 1800 242 636

w: www.carersaustralia.com.au

Centrelink offers a range of services and provides advice on Carers Allowance and Mobility Allowance.

p: 13 2717

w: www.centrelink.gov.au

Commonwealth Respite and Carelink Centres provide free information on the range of services that support independent living.

The National Respite for Carers Program gives carers the opportunity to take time out from their caring role.

Commonwealth Respite and Carelink Centres act as a single point of contact for the public; service providers; general practitioners.

p: 1800 052 222

w: www.commcarelink.health.gov.au

p: 1800 059 059 (for emergency respite support outside standard hours)

Dietitians Association of Australia

p: 1800 812 942

w: www.daa.asn.au

The Financial Planning Association of Australia Limited (FPA) exist to ensure the financial wellbeing of Australians.

p: 1300 626 393

w: www.fpa.asn.au

HelpDomain provides general advice on financial and legal planning.

w: www.helpdomain.com.au

Home and Community Care Services (HACC) provides services to assist in maintaining independent living.

ACT Contact regional community service organisations in the area.

NSW p: 1800 350 792

VIC Councils can be contacted for more information.

Home Help Service ACT provides quality in-home support to people with disabilities and their carers.

p: (02) 6287 3777

w: www.homehelp.org.au

Home Modification and Maintenance Service NSW can assist in the areas of access, safety and independence.

p: (02) 6622 8386

w: www.nswhmms.org

Home Renovation Service VIC helps people to remain living in their own home environment with support from family and community networks.

p: 1300 136 513

w: www.housing.vic.gov.au/home-owners-assistance

Independence Australia supplies specifically tailored services and products that empower people to retain their independence.

p: 1300 704 456

w: www.independenceaustralia.com

Independent Living Centres Australia display a comprehensive range of products to assist with day-to-day living.

p: 1300 885 886

ACT p: (02) 6205 1900

w: www.ilcaustralia.org

Lifeline provides a 24-hour, crisis telephone counselling service.

p: 13 11 14

w: www.lifeline.org.au

Local councils can also provide the details of a number of relevant agencies.

Maurice Blackburn Lawyers offer a free legal service, including super and insurance advice to people with MS and their families.

p: 1800 810 812

w: www.mauriceblackburn.com.au

National Continence Foundation of Australia/National Continence Helpline

p: National Continence

Helpline: 1800 330 066

w: www.continence.org.au

National Public Toilet Map shows the location of more than 14,000 public and private toilet facilities, and details about accessibility for people with disabilities.

p: 1800 990 646

w: www.toiletmap.gov.au

National Welfare Rights Network

provides free information, advice and representation about Social Security law and its administration.

w: www.welfarerights.org.au

ACT p: (02) 6247 2177

NSW p: (02) 9211 5300 or 1800 226 028
(outside Sydney metro area)

VIC p: (03) 9416 1111 or 1800 094 164
(outside Melbourne and Geelong metro area)

Nutrition Australia promotes and encourages healthy living for all Australians.

w: www.nutritionaustralia.org

ACT p: 0420 379 560

NSW p: (02) 4257 9011

VIC p: (03) 9650 5165

Public advocates and guardians

recognise that people need additional support and assistance to ensure their quality of life is maintained.



- ▶ **ACT** p: (02) 6207 0707
 w: www.publicadvocate.act.gov.au
- NSW** p: (02) 8688 6070 or
 1800 451 510 (outside Sydney
 metro area)
 w: www.lawlink.nsw.gov.au/opg
- VIC** p: 1300 309 337
 w: www.publicadvocate.vic.gov.au

Relationships Australia (RA) is Australia's leading provider of professional services to support relationships.

p: 1300 364 277
 w: www.relationships.com.au

Salvation Army

p: 1300 36 36 22
 w: www.salvationarmy.org.au

Speech Pathology Australia

p: (03) 9642 4899
 w: www.speechpathologyaustralia.org.au

St Vincent de Paul Society

w: www.vinnies.org.au

ACT p: (02) 6282 2722

NSW p: (02) 9560 8666

VIC p: (03) 9895 5800

Technical Aid to the Disabled make, modify or repair equipment to improve quality of life.

p: 1300 663 243
 w: www.tadaustralia.org.au

Vision Australia works to ensure that people who are blind or have low vision can fully participate in every part of life they choose.

p: 1300 847 466
 w: www.visionaustralia.org.au

Useful publications

The Benevolent Society works for a caring and just society. Their information resource provides information for families planning ahead.

p: (02) 9339 0000
 w: www.bensoc.org.au

Department of Health and Ageing

resources include information that outlines Australian dietary guidelines.

p: 1800 020 103
 w: www.nhmrc.gov.au/publications/synopses/dietsyn.htm

The Department of Ageing, Disability and Home Care (ADHC) resource *Planning Ahead Kit* is a useful resource available in the 'Publications and Policies' section of the ADHC website under 'Ageing' or by contacting the number below.

p: (02) 8270 2000
 w: www.dadhc.nsw.gov.au

Transport contacts

Community transport information

ACT Contact your local community service centre.

NSW p: 1300 138 794

VIC Contact your local council.

Taxi subsidy scheme

ACT p: (02) 6207 1108

w: www.dhcs.act.gov.au

NSW p: 1800 623 724

w: www.transport.nsw.gov.au/ttss

VIC p: 1800 638 802

w: www.transport.vic.gov.au

Phone numbers that start with **1800** are free of charge. Those beginning with **13** are charged at local call rates. Mobile rates apply to mobile calls.

Family Matters is a three-part series for families, friends and carers of people with MS.

Please contact MS Connect™ on **1800 042 138** to receive other booklets in the *Family Matters* series:

- 1** **Learning to Live with MS: An Introduction**
- 2** **Living Well with MS** 
- 3** **Caring for a Person with MS**

