



Family Matters

For Families and Friends of People Living with MS

3. Caring for a Person with MS



A U S T R A L I A

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MS Australia 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

3. Caring for a Person with MS

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 resource 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 place to start.

Caring for a Person with MS is booklet three in this series. It is designed to provide families with information and strategies in relation to the symptoms and issues that their family member with MS may experience.

As a family member or carer, knowing how to access support, services and advice can help you to manage the changes that the symptoms of MS may bring. This knowledge also enables you to better assist the person with MS.

Health professionals who can help

Due to the way that MS progresses, there may be long periods of time during which a person with MS will not need to see a health professional. There are times, however, when consultation is necessary.

The following is a list of health professionals you may have contact with, as well as their roles and responsibilities.

Clinical psychologists can help a person with MS and their family to cope with a diagnosis of MS. They can help with depression, anxiety, behaviour changes and relationships. A clinical psychologist can help to distinguish between problems caused by actual damage to the brain and those that occur as an emotional reaction to the damage.

Doctors/general practitioners (GPs) are usually the first point of contact. A GP manages people's day-to-day health problems, including supporting those in a caring role. GPs may provide medical assessment and treatment options, review and prescribe medications, order clinical tests and write referrals to medical specialists.

Gastroenterologists specialise in gastrointestinal diseases and investigate the causes and contributing factors to severe bowel dysfunction.

Neurologists specialise in conditions that affect the brain and the nervous system. Neurologists are involved in diagnosing conditions affecting the nervous system and establishing treatment. They monitor the person with MS over the years and are also likely to refer the person to other health professionals or specialists for further management.

Neuropsychologists are concerned with understanding how the brain works in the areas of thinking, memory, behaviour and personality. There is also a focus on how changes in the brain function affect these areas. Neuropsychologists can help identify which functions have changed and which remain intact. They can also advise on ways to manage such changes.

Neurosurgeons are surgeons who operate on the brain and spinal cord.

Ophthalmologists are eye doctors.

Psychiatrists specialise in helping people with conditions that affect the mind — including depression. Treatment may involve both medication and counselling. Some psychiatrists have expertise in personality and behaviour changes that result from a neurological condition such as MS.

Radiologists specialise in using and interpreting x-rays, including CT scans to diagnose disease.

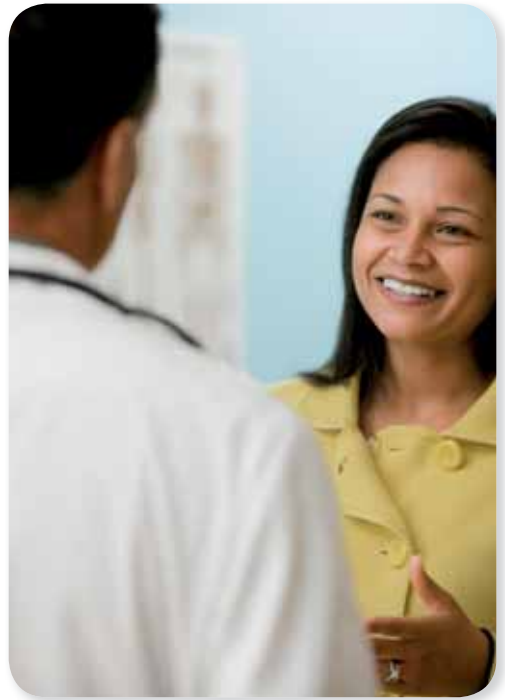
Urologists treat people with kidney, bladder and urinary problems. Urologists also care for men's sexual and reproductive health.

Urogynaecologists are gynaecologists who have undertaken advanced, specialist training to deal with complex bladder issues, including urinary incontinence.

Other health professionals and services

Community support workers (CSW) are MS health professionals who provide information, education and individualised support. They help to minimise the impact of MS on the individual, their family and carers. The CSW liaises with local health and community services to provide a better understanding of MS symptoms and management strategies.

Continence nurse advisers (CNA) are extensively trained in continence care. A continence nurse adviser can assess a person's condition, advising



on its management, and in some cases, treatment. A person with MS can see a continence nurse adviser at a continence clinic or at home.

Dietitians often work with people with MS who have difficulty eating or swallowing. They particularly help with finding food that people will enjoy and that will supply the best nutritional value. They can also give advice on diet.

District or community nurses provide a range of services to people in their own homes. A health professional such as a GP can write a referral for a person with MS or their family members so that they can use this service.

MS nurses are often the first point of contact for people with MS and can discuss all MS concerns. They

- liaise and refer people to the most appropriate health professionals to ensure their concerns are addressed appropriately.

Occupational therapists (OT) help people to cope with everyday tasks such as dressing, going to the toilet, shopping and preparing meals. They also help with work related and leisure activities. OTs assist people so they can be as independent as possible, often visiting people at home to advise on equipment or home alterations.

Pharmacists are health professionals who have many areas of expertise and a wide range of medical knowledge. As well as filling medical prescriptions, they may be able to assist in providing advice on general health matters.



Image: Jupiterimages/Corbis/Thinkstock

Physiotherapists help with movement, coordination and balance, including walking, fine hand movements or moving in bed. Physiotherapists can help people with MS to make the most of the muscle strength they have; and to relieve or prevent stiffness caused by wasting, spasticity and cramps. They can instruct carers on exercises for the person with MS, as well as inform them how to lift and move the person safely.

Rehabilitation physicians treat injuries or illnesses that affect how people move. They are nerve, muscle and bone experts who work on putting together treatment plans for people to carry out on their own or with the help of other healthcare professionals.

Social workers help people to cope with the effects of illness. They can help a person with MS or their family members to: obtain practical support from community/government services; find accommodation and support groups; by providing advice on the services, accommodation and benefits available to them, as well as financial, legal, employment and superannuation advice.

Speech therapists help with problems in communication or swallowing. Speech therapists can also give advice on communication aids.

This glossary has been adapted from the arbias, BrainLink and Headway Victoria fact sheet *Getting the best from your Health Care Team*.

Safety in the home

Your family member with MS may experience problems with their mobility and balance throughout the course of their MS. If they're often at home on their own, you may become concerned for their safety.

Before you rush out and make expensive alterations or move house, you should consider a few things:

- Does the house satisfy your family's current needs, and are these needs likely to change in the near future. For example, will children need a room of their own or will they be moving out shortly?
- Will the house present serious barriers to movement if the person with MS has less mobility and stamina?
- What changes must occur so that the needs of each of your family members are met?

In order to answer these questions, it may be useful for you and your family to do an 'audit' of the activities that take place in the house. You may also wish to talk with specialists who can help you to identify some of the options available to ensure safety at home.

Occupational therapists (OTs) and physiotherapists can provide advice on the different techniques a person with MS can use to complete difficult tasks.

Although it is always best to speak to a professional, you can put some basic precautions in place for some peace of mind:

- Make your home as uncluttered as possible.
- Look at how the furniture is arranged — is more space needed between pieces to allow easier access?
- Install a smoke detector, especially if people smoke in the house.
- Install handrails and grips in the toilets, around steps or stairs in the house (in some cases these must meet Australian standards and may need development approval).
- Minimise the use of rugs and make sure there are no loose carpet edges.
- Ensure the floors are clear of electrical cables.
- Install a thermostatically controlled hot water system.

Independent Living Centres display a comprehensive range of products to assist with day-to-day living. You may like to visit one in your area to see what is available.



Planning ahead

Planning in certain areas can also ensure that your family is equipped to cope in urgent situations.

Emergency care plan. Having an emergency care plan is an important aspect to feeling safe. This plan should cover all members of the family.

Tips on how to implement an emergency care plan can be found in the first booklet in the *Family Matters* series, specifically the chapter titled 'Day-to-day with MS'. You can obtain a copy of this booklet by contacting MS Connect on 1800 042 138.



Fire safety. This is a very important area to address, particularly if you're caring for someone with limited mobility. Ensure the proper smoke alarms are in place, as well as a fire extinguisher and fire blanket. Having an evacuation plan that details how to exit from various points in the house in case of a fire can also be very useful. Local fire authorities can also help with advice on fire safety requirements.

Personal safety. If the family member with MS is home by themselves, it's important to consider personal safety. For example, it's best to ensure that only known and trusted people can gain access into your home. Entrance video cameras, intercoms and electronic locks are also good forms of security. More simple measures include not leaving keys under mats or doors unlocked.

The person with MS can wear a personal alarm for times when they may need assistance. Certain alarms can be set up to alert you or other family members directly, while others go through to trained operators or emergency services.

Accessibility

Too often, when a family member with MS has problems with accessibility, families look at short-term solutions rather than looking to the long term. If your home does need to be more accessible, you need to think of it in the same way as any other life change. For example, when a toddler starts walking, adjustments are made to ensure a home is safe for them to roam around. The same applies when adapting the home for a family member with MS.



Where to go for support:

MS Connect can put you in contact with specialists who will be able to identify some of the options available to ensure safety at home. Occupational therapists and physiotherapists can provide advice, especially around equipment use and modifications.

Turn to page 27 to learn more about the information and support services that are available.

- Home and Community Care
- Independence Australia
- Independent Living Centres

Physical assistance and MS

There may be times when you will need to physically assist your family member with MS. The level or type of assistance you will need to provide will vary depending on a person's level of ability.

In some cases it may be as simple as helping a person with MS to get out of a chair or with their initial balance as they are trying to stand. In other instances, the person may be unable to stand at all.

If your family member with MS needs physical assistance, it's important that a healthcare professional such as an OT, community nurse or physiotherapist is consulted. These professionals can:

- educate you and your family on how to move the person with MS safely
- inform you about the use of aids such as a walking stick or frame
- enable you to assist the person with MS by using larger pieces of equipment such as a hoist, which is particularly important if physical assistance is needed on a regular basis
- help you and your family to find alternative ways to do tasks to minimise the amount of physical assistance.

Assisting someone to move

Remember, each person has a different level of ability. It's essential to seek professional advice when you're providing physical assistance, to ensure it's as easy and as safe as possible.

If you have a back injury, you should not attempt to move the person with MS. To reduce the possibility of back strain, you need to be aware of some general things:

- It's important to brief the person with MS about how the move is going to happen; reassure them that you know what you're doing.
- If more than one person is assisting the person with MS, one person should lead so that there is a single set of clear instructions.

- Before commencing a move, tighten your stomach muscles and tuck your chin in to your chest to stabilise your spine.
- Your back should remain straight, knees slightly bent, feet width apart. Use the large muscles in your legs not your back.
- Lift by straightening your knees and hips; use whatever movement the person with MS has.
- Stand close to the person in case they need to use your body for support.
- Use your palms rather than your fingers so that you don't dig into the person's flesh. If you're using one hand, keep the other on a firm surface for support.
- Keep your actions coordinated with the person you are moving. Counting may help, for example, "One, two, three, go!"
- When assisting the person with MS to stand or walk, provide gentle support under an elbow or around the waist. This allows the person to lean on you.
- Only use a mobility aid or equipment if you and the person with MS know how to use it correctly.
- Never pull on a person's weak or paralysed arm, or under their shoulder. It can cause damage, possibly tear a ligament, and can be very slow to heal.

If someone has a fall

If the person with MS is having trouble with their balance, be prepared to help in the case of a fall. If they have a fall and you find you can't safely assist them, make sure they're comfortable. Place a pillow under their head, cover them with a blanket and contact someone for help.

Seeking professional advice for your individual situation is essential; however, it's helpful to know the basics of helping someone who has had a fall.

Firstly, ensure that the person is unhurt and can be moved. Allow some time for them and yourself to calm down and then follow these steps:

- turn them onto their side
- help them onto their hands and knees
- assist them to crawl to a heavy piece of furniture
- place their stronger hand or both their hands on the table/bench
- bring their better knee up, helping them to place their foot firmly on the floor
- tell them to push up through their hands and straighten their knees so that they're in a standing position.



Where to go for support:

Turn to page 27 to learn more about the information and support services that are available.

- Carers Australia
- Department of Health and Ageing

Vision and communication in MS

It can be difficult when a person with MS experiences vision and communication problems. It's important that you and your family are aware of the strategies that can help them to manage with these symptoms of MS.

Vision and MS

Changes in vision are particularly common in MS. They often clear up without medication, however, a small number of people do develop a persistent problem. It's important for your family member with MS to see a GP, ophthalmologist or neurologist if they have any changes in their vision.

It can be difficult to know if a family member with MS is having problems with vision. You may notice that they

are having difficulty with tasks at certain times in the day or in different lighting environments.

Our ability to see and understand what we see involves many parts of the brain and eye. Damage to the brain or to the optic nerves that connect the eyes and brain may affect vision in different ways.

The most common visual problems in MS are:

- **Optic neuritis** — inflammation of the optic nerve, usually resulting in blurred vision, pain, flashing lights, and colour problems
- **Blurred vision** in one or both eyes
- **Double vision (diplopia)** — seeing a single object as two images
- **Movement/instability of vision (nystagmus)** — involuntary rapid movement of the eyeball
- **Uhthoff's symptom** — temporary blurred vision occurring during exercise and in hot environments.



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You can employ the following strategies to help a person with vision problems:

- label things well; black ink on white background
- provide a telephone with large numbers and programmable memory
- place a lamp (preferably halogen) near the phone, computer and by the bed (particularly for getting up at night)
- group clothing by outfits or colour
- supply a torch or small lamp if the person is staying away from home
- keep food and cleaning material in separate areas
- buy kitchen equipment in contrasting, solid colours not clear glass
- buy shampoo and conditioner in different shaped containers for easy differentiation
- provide clear margins on a page for when a person is reading or writing
- ensure that glare, low-level lighting and fluorescent lights are not problematic; incandescent and halogen lighting is best
- ensure lights do not reflect off mirrors and shiny objects.

Vision problems can result from a number of factors, not just MS. Regular check-ups are advised.



Speech and communication in MS

Communication may be affected in many different ways in a family member with MS:

- **Dysarthria**, as a result of weak or uncoordinated speech muscles, which produces slurred speech as well as other voice changes.
- **Dysphasia or aphasia**, caused by changes in the language centres of the brain, affecting the ability to use words and sentences and to understand others.
- **Body language, facial expression and tone of voice** can make communication difficult if affected by MS.
- **Changes in thinking and memory** can also affect communication.

If your family member with MS is affected by dysarthria, you may like to use the following strategies:

- Give the person with MS some time; talking may be frustrating.
- If you do not understand what the person with MS is saying, let them know, and ask them to repeat it. Ensure that you repeat back to them the words that you do understand to make it easier for them.
- Ask the person to speak more slowly, and echo their phrases.
- Ask the person to use shorter phrases or single words.

- Try a 'questioning' approach to find the subject of the conversation.
- Indicate to the person that you understand by nodding your head or saying, "I see".
- Let the person finish — guessing what they're about to say won't help.
- Be honest when repeated attempts fail and say something like "I'm sorry I don't understand, but let's try again later".
- Ask the person to write down the message, and if they can't use a pen, alphabet cards or a communication chart may help.
- Call an occupational therapist, speech pathologist, or the Independent Living Centre. They can help. There are also new technologies that can assist with communication.

You may like to use these strategies for communicating with a family member with dysphasia:

- Talk in short, clear sentences and only talk about one thing at a time.
- Check if the person understands, then repeat or simplify the message or gesture if necessary,
- Give the person time to speak.
- Listen for the message, not just how the words sound.
- If the person with MS needs to talk to someone outside the family, you can always help them. Also encourage them to communicate



Refer to the second book in the *Family Matters* series or contact MS Connect for information on how to manage a relapse.



on their own as this helps to develop their confidence.

- When their frustration begins to show, let the person with MS know that you understand how difficult it is.
- Use the same method to communicate with the person with MS that they use to communicate with you so that they can 'mirror' you.
- Always include the person in conversations, even if they can't reply in words.

Where to go for support:

Turn to page 27 to learn more about the information and support services that are available.

- Commonwealth Respite and Carelink Centres
- Speech Pathology Australia
- Vision Australia

Cognitive changes

You may notice that the person you're caring for is experiencing difficulties with remembering things, getting organised or concentrating. The process our brain uses to do these things is known as cognition.

Over 50 percent of people with MS experience some degree of cognitive impairment. Cognitive impairment in MS often impacts on the following:

- **Short-term memory** — difficulty learning, remembering new information that has just been heard, seen or read in the last few minutes or hours ('old memories' are usually not affected much).
- **Attention** — difficulty focussing, sustaining concentration over time or doing more than one thing at the same time.
- **Slowed speed of information processing** — difficulty taking-in and responding to events or conversations at a normal pace.
- **Executive functioning** — difficulty with complex thinking functions, such as planning, problem-solving, abstract reasoning, flexibility of thought, or insight.¹

Initially, your stress will revolve around trying to understand what's happening; why the person is acting so 'out of character'. What you're experiencing is very common.

The process of emotional adjustment can be challenging. You're likely to experience a range of emotional responses such as grief, sadness, anger and guilt. It's possible that you or those in your family will experience an episode of stress when cognitive impairment is revealed or each time there is an 'episode'. For example, the person with MS may forget a major event, which upsets the family.

Over time, your family will get better at working out when these episodes of stress are likely to occur, what triggers them, and how to get support in order to cope better with each episode.

If a family member with MS is experiencing moderate to severe cognitive difficulties, it's best managed via close collaborative teamwork between the person with MS; your family; and health professionals specialising in cognitive rehabilitation, such as a clinical neuropsychologist, occupational therapist and/or a rehabilitation physician.



Learning to manage cognitive impairment, as a family, can be an enriching and satisfying process. The initial stresses and challenges can bring you closer together and make the important things in life more meaningful.

It's natural for you or other members of your family to feel like you are struggling to manage your stress and other feelings. Regular use of various

services can be very helpful, allowing you and your family some time to breathe and stock up on energy levels. In addition to providing professional advice, MS Connect staff can help you find support and services that can help.

Reducing the risk

Scientific evidence shows that immunotherapy treatments can help reduce the rate at which damage to the brain tissue occurs and, therefore, the risk of significant cognitive impairment in people with MS. Immunotherapy medication is available to people with MS in Australia through the Pharmaceuticals Benefit Scheme (PBS).

Also, simple lifestyle changes can help reduce the risk of developing cognitive impairment. These include limiting alcohol intake, keeping the mind active by learning new skills or taking up a hobby and maintaining an active social life.

Detection and diagnosis

Cognitive impairment is difficult to detect in a person with MS. It tends to develop subtly and slowly over time. The damage doesn't really affect their language skills, simple attention skills or routine social skills, so you won't really notice it in a brief, social interaction.

The person with MS may recognise changes that bother them and try to seek assessment and advice. Otherwise, family members are likely to notice. If you're concerned about cognitive changes, raise the issue kindly and discretely with the person with MS and assist them to seek assessment and advice.

Managing the change

If a person with MS is experiencing cognitive changes, you may notice these everyday signs:

- ▶ ■ slow to solve problems
- forgets appointments
- misses the point of conversations
- laughs or cries easily
- talks excessively about personal interests.²

Depression, anxiety, fatigue and medication can all affect a person's cognitive function. If the person with MS says they're experiencing difficulty with cognition, these areas should also be explored.

Systems that can be useful for managing mild cognitive difficulties include:

- an appointment diary/wall calendar to record events and activities to remember
- a notebook including important tasks for each day, medication details and contact numbers
- keeping important items in special places (door keys next to the phone)
- keeping distractions to a minimum when the person with MS needs to concentrate (turning off the radio when cooking, avoiding conversations when driving)
- encouraging the person with MS to negotiate and share important decisions with a 'problem-solving buddy'.

An occupational therapist can help you to set up some of these systems.

About cognitive changes

Cognitive impairment and physical impairment in MS (such as problems with walking or mobility) are not related. While people with MS may have some difficulty with both, there are people with MS who have problems with their mobility but no cognitive difficulties.

Cognitive impairment and its development depends on how 'active' the MS is within the brain tissue. Once damage has built up in the brain and cognitive impairment has developed, it's permanent. Impairment does not fluctuate from day to day or from week to week, as do some of the other symptoms of MS.

References: 1. The National MS Society. Cognitive Function. National MS Society Information Sourcebook 2006; 2. Benedict RHB, Munschauer FE, Linn R, Miller C, Foley FW, Jacobs LD. Screening for multiple sclerosis cognitive impairment using a self-administered 15-item questionnaire. Mult Scler. 2003;9.

Information about understanding emotions and family communication is provided in the first booklet in the *Family Matters* series, which can be obtained by contacting MS Connect on 1800 042 138.



Bowel and bladder control

A person with MS may have trouble with their bowel and bladder control — a condition known as incontinence. It is common for a person with MS to feel isolated and embarrassed because of their incontinence and this may affect your whole family.

If your family member with MS is experiencing incontinence, there are products, aids, information and techniques to help.

You can find out more about the services and support available at the end of this booklet. It's important to remember that seeking help early is always best.



The emotional impact of incontinence

Loss of bowel and bladder control can have an emotional affect on your family. It's normal to feel angry and overwhelmed by having to deal with incontinence. If you're finding it difficult to cope, seeking help is essential. Trying to cope alone will not benefit you or the person with MS.

As a partner, you can also experience emotional difficulties when providing continence care, which can affect your sexual relationship with the person with MS. For some people, the aids and techniques used to manage incontinence can also affect sexuality for a number of reasons. This is an important concern and needs to be discussed with an appropriate health professional.

Continence problems can be further aggravated when the person with MS does not admit to the problem and tries to cover up accidents by hiding soiled clothes, or when they appear to be oblivious to their incontinence. The person with MS is also very likely to be embarrassed and frustrated because they're unable to carry out the most basic of functions without relying on someone. It's important that the person with MS is allowed as much privacy and independence as possible. You should encourage them to talk about it and try to be understanding.

In some cases, incontinence may not bother the person with MS. They may not be aware of it or may even deny it. Overall, it can be more of a problem for you, the person who is managing it. It's important that you are all honest about how you feel if the issue is to be dealt with effectively.

Physical symptoms

While bladder symptoms vary from person to person, there are broadly three types of bladder dysfunction: failure to empty; failure to store; and a combination of the two, simply referred to as combined dysfunction.

To avoid more serious issues, bladder problems need to be managed effectively. There has been a dramatic decrease in bladder related illnesses, due to improved diagnostic and management measures. Distressing or disruptive bladder symptoms can be successfully managed and bladder complications and associated serious illness can be prevented.

Bowel issues are less common than bladder problems but they can also occur at any time. Severe constipation is one of the main causes of bowel problems, but not the only one. Like bladder problems, bowel issues can usually be managed.

Exercise and diet

Exercise and diet play an important part in managing incontinence. You can help the person with MS to manage this area of their life.

Drinking enough water. Often people with bladder problems try to drink less for fear of urinating too frequently. This can make matters worse and result in constipation. In addition, urine becomes concentrated and irritates the bladder, causing more frequent urinating. It's important for the person with MS to drink one and a half to two litres



Image: iStockphoto/Thinkstock

of fluid every day (preferably water), even if they have bladder problems. Fluids can include jellies, custard, soups or yoghurt.

Suggest or ensure that the person with MS has their recommended fluid intake in three or four intervals throughout the day, rather than sipping small amounts continuously. This allows them to maintain their level of fluid intake without increasing urinary frequency.

It's also recommended that common sense is exercised, for example, it's best that the person with MS doesn't take too much fluid up to two hours before going to bed or before a social outing.

You can find out more about diet and exercise in the second booklet in the *Family Matters* series, which can be obtained by contacting MS Connect.



Eating well. A healthy bowel pattern depends on a well-balanced diet. Everyone needs a healthy, high-fibre diet. High fibre food includes oats or fruits — fresh, stewed or dried; vegetables; wholegrain or wholemeal including oatmeal, rice, wheat and barley; cereals and breads; and nuts and lentils.

Good habits. You can help ensure that the person with MS is mindful of how they sit on the toilet, and knows the importance of not straining. It's useful to encourage them into a routine of going to the toilet prior to leaving home.

Quit smoking. Smoking usually increases how frequently a person coughs, in turn increasing the risk of incontinence. Smoking can also cause many other health problems.

Maintain an ideal body weight. Pelvic floor muscles support the bowel and bladder to function properly. Excess body weight applies pressure to this area.

Exercise regularly. Regular exercise is recommended. Arm, leg, and body exercises can help if walking is not possible. Exercise improves blood flow throughout the body, including the gut, helping to prevent constipation.

Managing incontinence

Often, a few changes can make a big difference to bladder and bowel control issues. One of the important things to remember is that it's easier for the family member with MS to be continent if the toilet is easy to find and access.

Below are some general questions that could lead to some practical changes around your home:

- Can the person with MS readily walk the distance to the toilet?
- Is the lighting good enough?
- Are there mats they could trip on?
- Is there a linen service that can help you with the problem of constantly washing sheets?

The following are examples of what a physiotherapist or occupational therapist may consider during an assessment of your home:

- Are there steps to the toilet?
- Is the doorway and the room big enough for a wheelchair or walking frame?
- Can the person balance on the toilet?
- Is the toilet seat too low? Can a device be used to raise the seat?
- Are toilet rails needed?
- Can the person reach the toilet paper? Does poor balance or restricted movement in the shoulder, elbow or hand make it difficult to reach the toilet paper?
- Is clothing easy to get on and off or could velcro be better than zips or buttons?

- Ensure that trips with the person with MS are easier by making a note of the handicapped toilets along the way and also make note of the toilets with space for two people and a wheelchair (if necessary).



Financial assistance

Some assistance is available through the Continence Aids Payment Scheme, an Australian Government payment that can assist families living with MS to meet some of the costs of continence products. A doctor or continence adviser must fill in the forms needed to apply.

The Department of Veterans' Affairs (DVA) provides a range of continence products to eligible members of the veteran community via the Rehabilitation Appliances Program (RAP). A doctor or DVA can provide further information. DVA details are available at the end of this booklet.

Other financial assistance is available in certain states and territories through government-funded schemes. This varies widely in each state.

Who can help with continence information?

Doctors. For most people, the starting point is their GP. Arrange a long consultation when making an appointment with a doctor to allow enough time to explain the problem. Note down what is happening and any questions or concerns before your appointment. This ensures that nothing is missed. If the person with MS is going with you, it's best that you have a chat beforehand and complete a list of questions.

National Continence Foundation of Australia. The National Continence Foundation of Australia has trained continence advisers in each state and territory. An appointment can be made with a continence adviser without a doctor's referral, but it is helpful if a doctor is aware of the visit. A continence adviser will need the medical diagnosis; medical or surgical history; and a list of current medications, including those bought over the counter. Alternatively, take all the medications that the person with MS is on to the appointment.



Where to go for support:

Turn to page 27 to learn more about the information and support services that are available.

- Independent Living Centres
- National Continence Foundation of Australia
- Department of Veterans' Affairs
- National Public Toilet Map

Respite care and accommodation

Taking time out from your caring role is commonly referred to as 'respite'. Respite provides a break for you and your family members. It allows you the time to focus on your self and maintain interests that support health and wellbeing — physically, emotionally, spiritually and socially.

Respite allows another person to step in and provide support, giving you a break for a few hours, a day, a week or more. This allows you to return to your caring role feeling refreshed.

Respite means different things to different people — what works for one may not work for another. When you're planning respite support, remember that there are several options and it's easy to combine these options to meet your individual needs. Everyone in your family can benefit and enjoy the break.

Why do you and your family need respite?

Providing emotional, financial and practical support can take its toll, even on those with the strongest disposition. When you accept the task to meet the ongoing needs of another, there's always the possibility that you will end up neglecting your own. This may even affect the care that you're able to provide. Establishing respite as part of a routine as early on as possible can prevent this from happening.

Respite will allow all parties to establish a partnership in care and an understanding of each others' needs. It will help you to redefine your role, value and purpose in life. It provides a change of conversation, an opportunity for alternative social experiences. It allows both you and your family members, including the person you're caring for, time to pursue personal interests. A temporary break gives everyone the chance to maintain their health and wellbeing.

You can find out more about healthy lifestyles in the second booklet in the *Family Matters* series. Contact MS Connect on 1800 042 138 for your free copy.



Respite provides benefits for your whole family. It can:

- reduce your family's stress
- enhance your family's coping abilities
- increase your feelings of wellbeing
- allow your family to stay involved in the community and help you to establish additional support systems so you don't feel isolated
- provide your family with peace of mind, helping you to relax and renew your humour and energy
- allow you all to enjoy your favourite pastimes and pursue new activities
- increase your opportunities for family interaction
- strengthen your family's capacity to care for your loved one at home
- allow your family to take a much-needed holiday, spend time together and time alone.

Creating a positive respite experience

The following tips may assist in making the transition to respite care easier for the family member with MS and yourself:

- Respite should start early — not when stress takes over.
- Planning respite is vital so that each of you can prepare for the experience. It should involve both parties having time off and this time should not only be used to do 'useful' or 'important' tasks.
- It's important to build a partnership of understanding so both of you know exactly what the expectations and boundaries are.
- The person providing the informal or formal respite should have comprehensive information about routines, preferences and specifics to ensure it all runs smoothly.
- Explore a range of possible respite options to find what best suits your family.
- In the event that facility respite is required, visit the service before arranging a stay. If this isn't possible, ask questions about what the service provides so that the equipment, facilities/environment and the staff are suited to your family's needs.
- If you choose to go with community respite, be sure to specify the hours, days, goals and expectations of the support.
- You should, if possible, discuss preferences regarding the profile of the carer, such as age-bracket, culture or gender.
- Both you and your family member should clearly understand the impact of respite and how you can support each other through it.

Respite options

Respite can be very flexible and tailored to suit your individual circumstances. It's a short-term, planned activity, which can be formal or informal. Formal arrangements generally involve you seeking a paid carer through an attendant care provider or a friend or relative who agrees to help you at set times, on a regular basis. Informal arrangements usually involve friends or relatives popping in, which gives you the time to do something else.



Short-term respite options

In-home respite. Many people prefer to remain in familiar surroundings. It's possible to have someone, be it a relative, friend or an in-home respite service provider, come to your home and support your family member with MS. This will allow you to go out or do tasks that you can't do while caring. Alternatively, the paid carer may support the person with MS to participate in the community. Both situations allow a break for a few hours at a time.

Centre-based respite. This form of respite may vary from several hours to five days a week. There are many different programs on offer, but they're all provided in a group setting, away from your home. This may help the person with MS to feel a sense of acceptance, satisfaction, wellbeing and enjoyment.

Short-term residential respite. A range of facility respite options are available. They vary in each state, as well as in rural and city areas. The options include community supported accommodation (non-aged care) and residential aged care facilities, both nursing homes and hostels. Specialist hospitals and local hospitals in small towns may be able to provide this service. There are regulations on the length of time a person can stay in respite accommodation. More advice is available through MS Connect.

Overnight or weekend respite. This form of respite is becoming more readily available in community respite houses that accommodate a small number of people at a time. It can provide a short break for your family.

Carer retreats. Providing a fun and supportive atmosphere, carer retreats allow you to spend time with other carers. Respite care is also provided for your family member with MS.

- **Holidays/time away.** You can go away alone, while respite is provided. Otherwise, both you and the family member with MS can go together. This may be an organised group, with other people in a similar situation; or individually planned.

Older parents respite. If you're an older parent caring for an adult child with MS, this service provides a broad range of high quality, flexible support responses tailored to meet your needs.

FlexiRest. FlexiRest is a new initiative that operates in NSW. FlexiRest can provide you with funding for short-term and time-limited breaks. The aim of this program is to support and maintain the primary carer relationship. Contact MS Connect for more information.

Emergency respite. This form of respite may not be available in your area, but you can obtain information from the Commonwealth Carers Respite Centre. In case emergency respite is not available, it's a good idea to have a relative, neighbour or a local service to call on. Details of some of these services are available at the end of this brochure.

Permanent accommodation

There may come a time when respite no longer meets a family's needs. The whole family, including the person with MS, may begin to feel as though they're struggling and no longer coping with the demands of everyday living. When respite no longer provides your family with the benefits it once did, alternative accommodation options may be necessary. It's important that your physical and mental health is a priority.

Ageing, Disability and Home Care (ADHC), the Department of Human Services in New South Wales, the Department of Human Services in Victoria, and ACT Community Health can provide further information.

Some of the options include:

Community supported accommodation. This service provides a supportive environment for the person with MS who is unable to remain at home. Houses are based in the community and accommodate a small number of people. They're generally staffed with residential care workers who understand high care and support needs and who work toward a person-centred approach. They encourage wellness, purpose in life through meaningful activity, self-determination, community and family connectedness.

Residential aged care. Recent government reforms have introduced common classification and funding arrangements for hostels (low-level care facilities) and nursing homes (high-level care facilities). These arrangements allow aged

care homes to provide care for a range of people, provided they're equipped to do so. Facilities employ personal care workers trained to provide care and support to older and/or disabled people.

Choosing the right permanent accommodation

As MS can be progressive, it's important to anticipate future care and support needs when choosing a home for your family member with MS. This will reduce the necessity to change homes if their condition becomes more complex.

Choosing the right facility can be daunting. Sometimes initial impressions and feelings are a good starting point. There are also a few other things to consider:

Building/location

- Is it in a convenient location?
- Is everything well cared for?
- Does it have all the appropriate facilities/aids?

Staff

- What's the ratio of staff to residents?
- What qualifications do the staff have, for example, do they have specific MS training?
- Is there a qualified staff member on duty at all times?
- Do the staff members seem interested in your family member with MS and you?
- Will the person with MS be able to see their own regular doctor?
- Does the home offer other health services such as physiotherapy?

Daily living

- What's the room like? Is it single or shared?
- What facilities are in the room? For example, are there phone or computer sockets and individual heating controls?
- Is there a place where you can visit privately or stay overnight?
- Are you and your family still able to be involved in personal care (e.g. showering, feeding)?
- What personal items are allowed (e.g. furniture, pets, belongings)?
- What's the food like and is it of an adequate size and quality?

The emotional aspect

It can be a difficult time for you when the person you care for stays in a respite facility or needs to relocate into accommodation on a long-term basis. Guilt, grief, loss, anger, vulnerability, helplessness, loss of identity, fear, stress, relief, emptiness or failure are all common feelings. The person with MS may also feel these same emotions. Chatting together about these feelings can help you both.

You might be surprised by how up and down your feelings can be at this time. Again, these reactions are expected and many people feel the same way. Accessing support through a carer support group can assist you to understand how to accept the need for regular guilt-free time.



Image: Mediainages/Photodisc/Thinkstock

Families and carers that have used respite offer the following advice:

- It may take some time to begin enjoying the respite.
- The house may seem quiet and perhaps lonely so plan something for those 'quiet' moments such as dinner-time.
- Talk to someone who understands how you feel.
- Sleep as you need to — day or night — it can help you to feel refreshed.
- Plan an outing or go away for a complete break.
- Share a visit with another family member or friend — it can make things easier.
- Try to remember why you have decided to take this option — it will benefit both you and the person with MS.



Where to go for support:

Contact MS Connect and turn to page 27 to learn more about the information and support services that are available.

- Carers Australia
- Commonwealth Respite and Carelink Centres

If you find that you are having difficulty coping, information on stress and depression is provided in the second booklet in the *Family Matters* series. Contact MS Connect for your free copy.



Useful medical terms

Listed below are some of the words that you may read or hear when learning about MS or MS symptoms.

Acute. Is the rapid onset of a symptom or disease — often with recovery. Not chronic or long lasting.

Antigen. Any substance that triggers the immune system to produce an antibody — generally an infectious or toxic substance.

Ataxia. The unsteadiness and lack of coordination that results from the brain's failure to control the body's posture, strength and direction of limb movements. Ataxia is most often caused by disease activity in the cerebellum.

Autoimmune disease. A process in which the body's immune system causes illness by mistakenly attacking healthy cells, organs or tissues in the body. MS is believed to be an autoimmune disease.

Atrophy. A decrease in size and strength of a part of the body due to disease or inactivity.

Cerebellum. A part of the brain situated above the brainstem that controls balance and coordination of movement.

Cerebrum. The large, upper part of the brain, which acts as a master control system. It is responsible for initiating thought and motor activity.

Central Nervous System (CNS).

The part of the nervous system that includes the brain, optic nerves and spinal cord.

Chronic. Of long duration (the opposite of acute) — a term often used to describe a disease that becomes progressively worse.

Cognition. High-level functions carried out by the brain including: comprehension and use of speech; visual perception and construction; calculation ability; attention (information processing); memory and executive functions such as planning, problem solving and self-monitoring.

CAT scan. Computerised Axial Tomography (CAT) is a non-invasive diagnostic technique, which uses computer guided x-rays to examine soft tissues of the body.

Demyelination. A loss of myelin in the white matter (consisting mainly of nerve fibres) of the central nervous system.

Dysmetria. Disturbance in coordination, caused by lesions in the cerebellum. Dysmetria is usually characterised by a tendency to overestimate or underestimate the extent of motion needed to place an arm or a leg in a certain position.

Efficacy. The extent to which a specific intervention, procedure or regimen produces a beneficial result under ideal conditions.

Exacerbation. The appearance of new symptoms or the aggravation of old ones, lasting at least 24 hours (synonymous with attack, relapse, flare up or worsening).

Hemiparesis. Weakness of one side of the body, including one arm and one leg.

Hemiplegia. Paralysis of one side of the body, including one arm and one leg.

Immune system. A complex system of cells that protect the body against disease-producing organisms and other foreign invaders.

Incidence. The number of new cases of a disease, in a specified population, over a defined period of time.

Interferons. A group of immune system proteins produced and released by cells that are infected by a virus. They stop viral multiplication and modify the body's immune response.

Magnetic resonance imaging (MRI). A diagnostic procedure that produces visual images of different body parts without the use of x-rays. MRIs are an important diagnostic tool in MS, as they make it possible to visualise and count lesions in the white matter of the brain and spinal cord.

Myelin. A soft, white coating of nerve fibres in the central nervous system (CNS) composed of lipids (fats) and protein. Myelin insulates and aids efficient nerve fibre conduction (the sending of messages to the body). When myelin is damaged in MS, nerve fibre conduction is faulty or absent. Impaired bodily functions or changes in sensation that result from demyelinated nerve fibres, are known as symptoms of MS.

Neuro. To do with nerves or the nervous system (including the brain).

Paraparesis. Weakness of the lower extremities (legs).

Plaque. An area of inflamed or demyelinated central nervous system (CNS) tissue.

Relapsing remitting. A course of MS that is characterised by clearly defined acute attacks, with full or partial recovery and no disease progression between attacks.

Sclerosis. Hardening of tissue. In MS, sclerosis is scar tissue that acts as the body's replacement of lost myelin around central nervous system (CNS) nerve cells.

Spasticity. Abnormal increase in muscle tone resulting in spasms.

All definitions sourced from the *Glossary of medical terms for Multiple Sclerosis*, adapted from the *Berlex MS Resource* by Bayer HealthCare.

Where to go for support

For general help and advice

You can contact the MS Australia – ACT/NSW/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@msaustralia.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.mssociety.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.

A Carer Resource Centre is located in each state and territory and the Carer Line is a free service for carers seeking information. They provide referrals; information about programs and services, such as financial assistance, carer support groups; and other issues that affect carers.

Carers Australia also provide emotional support. Their *Carers Pack* is particularly useful, as is their information for

children and teenagers through their Young Carers program.

Carers also have access to short-term professional counselling and assistance through the National Carers Counselling Program, to help manage issues such as stress, loss and grief.

p: 1800 242 636

w: www.carersaustralia.com.au

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

p: 13 2717

w: www.centrelink.gov.au

Commonwealth Respite and Carelink Centres are for older people, people with disabilities and those who provide care.

Centres provide free and confidential information on the wide range of services available to support independent living in the community.

Information about respite services in a local area can be obtained from a Commonwealth Respite and Carelink Centre. The National Respite for Carers Program supports carers of older people and those with disabilities. It gives carers the opportunity to take time out from their caring role. The program provides families and carers with the comfort of knowing that dependents are being well looked after.

Commonwealth Respite and Carelink Centres also act as a single point of contact for the public; service providers; general practitioners and other health professionals who require information on community, aged and disability services, and carer support. The Centres can also assist with information about costs for services, assessment processes and eligibility criteria.

w: www.commcarelink.health.gov.au

p: 1800 052 222

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

Department of Veterans' Affairs

p: 133 254

w: www.dva.gov.au

HelpDomain provides general advice on financial and legal planning.

w: www.helpdomain.com.au

Home and Community Care Services

(HACC) provides services for the frail-aged, people with disabilities and carers to assist in maintaining independent living. Most HACC offices have leaflets that detail local services.

ACT Contact regional community service organisations in the ACT.

NSW p: 1800 350 792

VIC Councils must be contacted directly for more information.

Home Help Service ACT is an organisation that provides quality in-home support to the elderly, frail aged, people with disabilities and their carers in the ACT.

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 so aged people or those with a disability can live more independently in the community and remain living at home.

p: (02) 6622 8386

w: www.nswhmms.org

Home Renovation Service Victoria was established to help people to live independently in their own home, with support from family and community.

p: 1300 136 513

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

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

p: 1300 704 456

w: www.independenceaustralia.com

Independent Living Centres Australia

display a range of products to assist with day-to-day living.

p: 1300 885 886

ACT p: (02) 6205 1900

w: www.ilcaustralia.org

Lifeline is 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

Bookings to see a continence adviser in person can be made by calling the National Continence Helpline. The number is staffed by a team of continence nurse advisers who can provide information and advice to you or the person with MS.

**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, as well as details about their 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)

Public advocates and guardians recognise that people may need additional support and assistance to ensure their quality of life is maintained and that they are protected from the risk of neglect,

exploitation and abuse by organisations or other entities.

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 may also be able to help you with personal or practical issues.

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 may be able to help with personal or practical issues.

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 aims to help people of all ages with any kind of disability by designing, making, modifying or repairing equipment to improve the quality of their life.

p: 1300 663 243

w: www.tadaustralia.org.au

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

p: 1300 847 466

w: www.visionaustralia.org.au

Useful publications

The **Benevolent Society** works to create caring and inclusive communities and a just society. Their resource *Your Future Starts Now* provides information for families who are planning ahead. It can be located in the 'What we do' section on their site under 'Older people'.

p: (02) 9339 0000

w: www.bensoc.org.au

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



Notes

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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



AUSTRALIA

MS Australia – ACT/NSW/VIC

The Nerve Centre

54 Railway Road, Blackburn, Victoria 3130

P: (03) 9845 2700

W: www.mssociety.org.au

MS Connect™: 1800 042 138



A U S T R A L I A