

Family Matters

For Families and Friends of People Living with MS

1 . Learning to Live with MS: An Introduction





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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 strives for a world without multiple sclerosis (MS) through quality research and for service excellence to people with MS, their family and carers.

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Family Matters

For Families and Friends of People Living with MS

1. *Learning to Live with MS: An Introduction*

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 members 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.

Learning to Live with MS: An Introduction is booklet one in a three-part series. It focusses on some of the immediate issues that a person may experience when someone close to them is diagnosed with MS.

At times, it can be hard for families to cope with the complexity of MS, especially when dealing with the complexity of family life itself. People often liken MS to the 'uninvited guest' who arrives complete with baggage — and never goes home. Nevertheless, if people can find a place for MS in their lives, they can learn to live well with MS, without allowing it to take over.

Supporting a person with MS



When a person receives the news that someone close to them has MS, they want to help and support the person through their diagnosis. Although it can be difficult to know what to do, a number of strategies can help you through this uncertain time.

You do not have to become an MS expert, but understanding MS is an important first step. By learning the basics, you will have the confidence to find the answers you need and ensure that the person with MS feels well supported.

MS Australia – ACT/NSW/VIC provides a broad range of up-to-date resources. If you prefer to talk to someone in person, you can contact our specialised telephone and support service MS Connect™ on **1800 042 138**. This service is available free of charge to all people with MS, family members, friends and health professionals. MS Connect will also respond to email queries sent to msconnect@msaustralia.org.au

MS Connect telephone lines are open Monday to Friday during the hours of 9 am to 4 pm and all calls go to experienced MS staff. If your first language is not English, MS Connect offers a call-back interpreter service, and you can request an interpreter for any of the other direct services we provide. A number of MS Australia publications have also been translated into other languages.

MS Connect is a great first 'port of call' for any problem related to MS. Staff can assist with general or medical issues. They can provide advice and details about local services such as occupational therapists and physiotherapists, community bus services, support groups or local recreational facilities. You can also access our health professionals and enquire about services via MS Connect.

Find out where to seek reliable and useful information about MS on page 17.





Get organised

Too often, families wait until there is a crisis before asking for help. By using the resources available to you and by being prepared, you and your family will feel more balanced and in control of your lives. You'll also feel that you are better able to support the person with MS.

It's comforting to know that there is help available in your area. When you are aware of where and how to access support, it allows you and your family to tackle problems quickly and with less stress.

The 'Day-to-day with MS' chapter on page 12 provides information on how you can better prepare and manage the issues that may arise due to MS.



Stay well

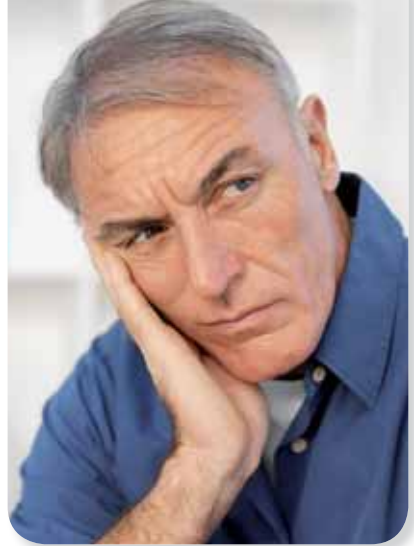
Supporting a person with MS requires you to give emotional and physical support, so it is important to remember to take care of yourself. The following tips can help you to maintain your own health and wellbeing:

- It is important to recognise that stress and anxiety are normal reactions.
- Where possible, maintain and enjoy social, community or charitable activities. The latest research shows that individuals who belong to social groups are better able to cope with challenging life issues.
- Your health is a priority, too, especially if you are providing support to another person. Have regular check-ups with your doctor and seek advice about any health concerns.
- It is essential that you understand the value of rest and relaxation. Aromatherapy, massage, meditation or simply having some time out on a regular basis can make a world of difference.
- Diet and exercise are an important factor in staying well.
- Sometimes it's hard to tell the difference between depression and sadness. If you suspect you are depressed, it is important that you seek advice and treatment. The treatment of depression is likely to have a positive effect on your ability to cope.

Where to go for support:

Turn to page 20 to learn more about the information and support services that are available.

Understanding emotions



The period following diagnosis is often a time of adjustment for all family members. Each member of your family will experience a mixture of emotions, and work through these emotions in different ways and at different times.

Shock and disbelief are the most common initial reactions to a diagnosis of MS. You and your family may also experience a sense of relief from finally having an answer after months or years of uncertainty.

It is expected that you may all feel a wide and confusing range of emotions at this time. They may include one or some of the following:

Grief. A person commonly experiences grief when they lose something that is important to them — a particular way of doing things, a valued activity, or even their sense of security and general wellbeing.

Anger/resentment. It's common to feel angry or resentful toward MS itself because it has taken something away or made life harder. You may feel angry about not being able to make a family member feel better or the extra demands on your time and energy. A person with MS may be angry about the diagnosis, resentful

about the family's reaction to the diagnosis or the family's lack of understanding about their MS symptoms.

Fear/anxiety. It is natural to have fears about the future — how your family will manage financially, emotionally and as a unit. Due to the unpredictability of MS, your family and the person with MS may occasionally feel anxious.

Blame/guilt. A diagnosis of MS can lead to guilt and can often drive you to seek a reason for what has happened. You may attempt to blame someone or something for the diagnosis of MS. It is important to acknowledge that no-one is to blame for MS and that MS is not caused by factors that you or anyone else has control over.

Isolation. Your family may feel alone at times, particularly if MS creates distance between you and your relatives or friends. It's common for a person with MS to feel isolated from

the family or feel that living with MS is a journey they must take on their own.

Sadness/depression. Sadness is a feeling that may be brought about by a sense of loss after diagnosis, the changes that might take place due to MS, or by the unpredictability of MS itself. Depression can be a serious condition that can cause a person to lose interest in life, feel like a burden and worry about the worth of life itself. Clinical depression does not come and go, it can last for weeks. If you feel depressed, you need to see your doctor for assessment and

treatment. This also applies to other family members.

Denial. Denial is quite common, particularly at the time of diagnosis, when you or your family members are trying to hold on to your existing lifestyle or pretend that it is not happening.

Frustration. Time is a valuable commodity for today's busy families and finding the time and energy levels to deal with a new challenge can be frustrating. Postponed activities, rearranged schedules and a slower pace can all add to the stress.

Information about coping with depression is provided in the second booklet in the *Family Matters* series, which can be obtained by contacting MS Connect on 1800 042 138.



Respecting the feelings of others

Life has its ups and downs; these emotions do not occur in an orderly fashion. There may be times when you will want to deny that it is all really happening, feel that you want to run away, become very angry or experience feelings of depression. On the other hand, there may be times when you are more willing to accept that MS is a part of your life. Trying to cope with these changing emotions can sometimes place a strain on even the most secure and stable family.

The way different family members feel about life with MS may not necessarily be the same or you might not all experience similar feelings at a similar time. Each of you will react in your own way depending on your personal experiences, personality, coping skills and individual relationships within the family. The fact that each of you might be at a different stage in the coping process might even lead to conflict.

It's natural to experience a mixture of strong emotions. Talking about powerful and personal emotions may be hard, but it is healthy for all of you to try to find a way to share them. At the same time, a family needs to acknowledge that there may be occasions when one of you is simply unable to express your thoughts and feelings. It's not unusual for you or others in your family to feel as though you need some time alone. You may prefer to talk to close friends or people who are not directly involved with the person with MS, such as your doctor or our health professionals. ▶

- ▶ It might be the case that you or another person in your family are finding it hard to express your feelings of grief and loss, instead focussing all your energy into caring for the person with MS. You may also be trying to protect the feelings of other family members. If you are finding it hard to talk about your feelings, consider keeping a journal. Writing things down can help you identify emotions and work through them. The journal can be private or you can share it with other members of your family, if appropriate.

Email is also a good way to tell family members how you feel without talking face-to-face. A chat room specifically for families of people with MS may also help you to manage emotions. MS Connect can provide information about the chat rooms that are available, or you can read more in the 'Finding information about MS' chapter on page 17.

The main benefits of communicating fears and concerns with your family include:

- overcoming fears and putting them into perspective
- feeling less alone
- resolving problems together
- understanding the feelings of others.



Where to go for support:

Turn to page 20 to learn more about the information and support services that are available.

- Lifeline
- Relationships Australia

Communication tips for you and your family

You and your family members might benefit from the following strategies:

- Talking about your feelings together can help you to recognise what is bothering you and to provide each other with support so that you can come to terms with it.
- People may not be ready to talk when you are. Give them some time and keep looking for clues that indicate they might be ready.
- When you listen quietly without offering advice, you give a person the chance to say what is on their mind.
- Everyone will react in a different way to the person with MS putting on a happy face, denying the diagnosis, playing down anxieties or being overly protective are just some of the examples. If someone is behaving in a way that is upsetting you, point it out.
- Talking about powerful emotions can be hard, but clear, open and honest communication can be worthwhile.
- It's important that your family can talk about other things, not just MS. You all still have a favourite TV show or football team.

Communicating with your children



The time after diagnosis can be particularly stressful for your family. As a parent, you may be feeling emotionally vulnerable as you try to make sense of what is going on around you. Talking and explaining MS to your children can be difficult, but open communication in the home can help everyone, young or old, feel a lot better.

Children can usually sense when their parents are upset. They may begin to worry about the future or feel they cannot ask questions for fear of upsetting you.

The news that someone in the family has MS should come from you, the parent, or someone they love and trust. It helps if you let them know what is happening and give them the opportunity to ask questions.

It is not easy to explain concepts such as the unpredictable nature of MS, uncertainty about the future and the potential effect of MS on the family, to your child. Talking to them in words that they can understand is the best approach. It is possible to tell your children about MS without overwhelming them. Each child's age, maturity and personality will help you to determine how much and what information to tell them.

Telling a young child about MS

Children under the age of six do not generally need a lengthy explanation; they will struggle to completely understand MS and its potential consequences. In most cases, as long as they feel you are still attending to their daily needs, younger children will be able to cope.

A young child will benefit from a brief, simple explanation and examples, such as "Mummy has a problem called MS and this means she is a bit wobbly when she walks" or "Uncle Joe's MS makes him feel tired sometimes".

Younger children may also want to know if they can 'catch' MS or if people die from it. It is also important to remember that at this age children have a vivid imagination. Try to reassure them that they are not to blame and that their actions do not affect MS.

Speaking with older children and teenagers

Although they can appear outwardly calm, and possibly even indifferent, your older children are most likely experiencing a great deal of concern. You need to provide them with as much information on MS as they need. Encourage them to speak with you, or someone else they trust, when issues come up.

Generally, teenagers like to be treated as adults. If your child feels as though they do not have a responsible part to play in solving family problems, they may feel both hurt and resentment. If you try to shelter them from problems, it will not spare them any anxiety. However, it is important that they do not take on too much responsibility as this is a time in their life when they are seeking their own identity and independence.

At this age, children tend to worry about getting MS or passing it on to their own children.

How might they react?

When children receive bad news, they don't behave in the same way as adults. If you notice a change in your child's behaviour, it may be a sign that they are struggling to cope. Some of the things to look out for include:

- increased concern with their own body and wellness
- difficulty maintaining close friendships
- starting fights with close friends for no apparent reason
- higher anxiety and stress
- acting younger or older
- behaving badly in public/temper tantrums
- lying to friends about MS
- asking for things (such as help with homework) at the end of the day when everyone is tired
- poor performance in school
- nightmares, bed-wetting and trouble falling asleep.

In moderation, all these behaviours are normal. In some cases, however, it may be necessary to seek professional help for your child, particularly if you notice any of the following signs:

- feeling low, sad, flat and down most of the time
- severe or chronic behaviour problems
- consistent sleep disturbances and/or nightmares
- loss of appetite or sudden increase in appetite
- loss of interest in schoolwork and extracurricular activities
- persistent mood swings and changes in personality.

These behaviours can be indicators of other upsets in your child's life. It is important to understand that a child's reaction is not a personal attack on you or the person with MS.

Open communication

Keeping communication lines open can help a family deal with the emotional pressures of living with MS. It is natural for your children to worry about the person with MS. Encourage them to talk openly and express their feelings as this helps to relieve their anxiety. Your child may misinterpret silence as an indication that the situation is too bad to talk about. Some children even hold on to illogical notions, for example, that they are somehow to blame for the MS.

You need to encourage but not pressure your children to talk about their concerns. A child will feel better if they can discuss anything at any time, whether it is MS or something that is unrelated to MS that is troubling them. When a child trusts that they can express certain emotions to you, it will be easier to talk openly with them and put them at ease.

Your family may even become closer as your children begin to understand that you won't dismiss how they feel, and that you can help them manage their emotions.

The 'Finding information about MS' chapter on page 17 lists specific internet sites and chat rooms for young people.



Practical ways to describe MS

When you decide that you are ready to discuss some of the symptoms of MS with your children, try to describe and demonstrate them in a practical way. Children have the greatest difficulty understanding symptoms that they cannot see. These suggestions may help you:

- Ask your child to do up buttons on a blouse, turn pages in a

book, or pick up paper clips while they are wearing oven or rubber gloves.

- To experience what vision problems are like, give your child some wire mesh or bubble wrap to look through.
- Running a comb up your child's arm will help them to understand the prickling sensation/pins and needles that people with MS experience.



Where to go for support:

Most children will want to know more about MS. They may want to do this alone, or with you. Contact MS Connect on 1800 042 138 if you would like information on MS for young children.

You and your child may also look things up on the internet together, watch a video or DVD, visit your doctor or speak with a professional from MS Limited.

Telling family and friends



Deciding whether to tell others that someone in your family has MS is a very personal decision. It is important that you discuss this decision with the person with MS so that you can both decide when and who you would like to tell. The person with MS may feel comfortable about disclosing their diagnosis to certain family and friends, but not to everyone.

Trying to hide a diagnosis of MS can be hard. Other family and friends may notice the symptoms of MS or sense a troubling issue. If you choose not to tell them, it may leave them feeling confused, hurt or left out. Often, it is a relief when you are able to talk, share your fears or anxieties and develop strong bonds with others who know. It can also help you to get through those difficult times, particularly when you need support.

It's impossible to determine how another person will respond to the information that a family member or friend has MS. You may find you need to comfort them, reassure them that most people with MS do not become seriously disabled and emphasise that helpful treatments are available.

After learning that someone has MS, people may offer you help and support. If you don't need help at the time, it is okay to say so; you can mention that their support and help might be needed in the future. Also, let them know that their support does not have to be time consuming or even ongoing. This will put them at ease and shows them that you genuinely appreciate their offer.

Family life and MS

As well as the possible financial strain associated with MS, you may find that there is a drain on time, energy and emotions. This can sometimes feel like a daily challenge for families living with MS.

Family members are often protective of one another. They may be afraid to express their feelings for fear of hurting someone or resist asking for help because they worry about being a burden. Remember, feelings that are bottled up do not usually stay that way forever.



Your family members will be able to sense when you're not being honest and open about your feelings. It's easier and less stressful to bring feelings into the open where everyone in your family can begin to deal with them together. If your family finds this difficult, it may help to seek family counselling.

There is no correct way to deal with a family member's diagnosis of MS — people adopt different coping strategies at different times. The key to coping is having the ability to be flexible and creative. Often, other family members misinterpret a person's coping style as selfish, uncaring or misguided. It's important that you and your family try to recognise that each one of you has different needs and is possibly experiencing different things.

Friends and MS

Many families living with MS comment on the changing relationships they have with their friends. Some of your friends may not call because they feel uncomfortable or unsure about what to say. Others may find it difficult to cope with the change or may feel that they have lost your friendship, as it was.

On a positive note, many friends become a lifeline for you and your family in the months and years ahead. It's possible you will become closer to them as they support you with responding to the needs of the person with MS.

Deciding who to tell

Be clear about why you choose to tell a friend or colleague that your family member has MS. There may be consequences to disclosing, and things can get awkward if you regret disclosing to a friend or business associate.

Think carefully about when and how you share the information, and who you want to share it with. It is also very important to consider how the disclosure affects the person with MS.

Tips for telling your family and friends

You'll probably experience mixed emotions when you disclose that your family member has MS. The following tips might make things a little easier for you:

- Your family and friends should hear the news when the time is right for the person with MS.
- Another family member or friend may be prepared to do the disclosing if you feel overwhelmed by it all.
- Many people will want to know more about MS so try to be prepared for questions. This booklet is also available to your family and friends through MS Connect on **1800 042 138** or **www.ms.org.au**
- Boundaries should be set —you don't have to share every detail of the condition if you're not comfortable doing so.
- When disclosing a diagnosis of MS, it's important to remember that each person will react and behave differently to such news.

Day-to-day with MS

The unpredictability of MS is one of the challenges that you and your family will face. MS affects everybody differently. It can be hard for you and your family to plan for the week, let alone the years ahead. It's important that you feel prepared for whatever comes your way so that life continues to run as smoothly as possible for you and your family.

People sometimes think that planning for the worst will make the worst happen, but not planning can make things harder than they have to be. You have nothing to lose by having a plan — instead, you and your family members are likely to experience a sense of security from knowing that you're as prepared as you can be.

Also, try to remain open to change from time-to-time and be flexible. By doing so, you and your family can overcome the obstacles when MS symptoms change unexpectedly.

The impact of 'hidden' symptoms

Being prepared and flexible is particularly important when you and your family are dealing with symptoms that you can't see or understand. MS-related fatigue, sensory symptoms (like pain or pins and needles) and cognitive (memory and thinking) changes can be easily misunderstood. You and your family need to be aware of these 'hidden' symptoms of MS.

It is especially important that you acknowledge these symptoms when they occur as they are difficult for the person with MS to explain.

MS Limited – ACT/NSW/TAS/VIC provides a number of information sessions, resources and other programs that can assist you and your family member with MS to better understand the impact of hidden symptoms. By understanding the affect of these symptoms on your family member with MS, you can determine how to support them and how to plan around these symptoms if they occur.

There are ways to manage hidden symptoms. More information is provided in the second booklet in the *Family Matters* series, which is available from MS Connect.



What to expect with hidden symptoms

Changes in memory and thinking.

It is estimated that 50 percent of people with MS experience cognitive (memory and thinking) changes. You and your family may begin to think that the person with MS doesn't care, doesn't listen, or is unwilling to cooperate. However, these behaviours are a result of the changes they're experiencing.

Fatigue and MS. A person with MS may appear to be lazy or unmotivated — in fact, they're experiencing MS-fatigue. If you have a clear understanding of MS-fatigue and its impact on the person with MS, you might reorganise the house and family routines so that the person with MS can conserve their energy.

Strategies for conserving energy are essential as they allow a person with MS to feel better, giving them more energy to participate with the family.

Sensory and visual symptoms.

Although hidden, these symptoms can have a big impact on the daily functions of the person with MS. Sensory symptoms can include numbness, tingling, pins and needles or vibrations in various parts of the body. Visual symptoms can include double vision, eye pain and seeing flashing lights. As with MS-fatigue, you need to ensure that the person with MS explains the effects of these symptoms to you and other family members so that you can help them to manage it.

Adjusting to change

As with any change, it may take your family a little time to work out what works best for you. The following suggestions can make a significant difference and start you thinking about other strategies.

In the home. You may like to consider some changes that will make household and personal tasks easier. For example, a lighter iron or a front loading washing machine may be more practical for the person with MS. Speaking to an occupational therapist can help. Also, if you're thinking about moving, consider choosing a single storey house or ground floor apartment. It is also wise to check that you can make modifications at a later date, if you need to.

Transport. If you're looking for a new family car, you may want to think about whether an automatic would be better than a manual or how easy it is for the person with MS to get in and out of the car. Also, look into other transport options in your area. Other issues to consider include legal requirements regarding driving and insurance.

Local resources. Many families living with MS have difficulty coping because they are not familiar with the support and services they can access. It's important that you know what entitlements are available to you and how to apply for them. This knowledge can help you to cope better when things change and can also minimise the impact these changes have on your family life. The information on page 20 in this booklet and the community directory available from local council or libraries are a good starting point.

Talking to each other. Hold family meetings where you and your family members can openly discuss issues or new symptoms. Talk about the things that have occurred during the week or month, issues that need to be resolved, or even some of the positive outcomes. This can be a positive exercise and may be as easy as organising a weekly 'family dinner'.

Emergency care plan. It's possible for anyone to have an accident. Having an emergency care plan is a useful strategy for looking after everyone — the person with MS and other members of the family.

One of the simplest ways to organise an emergency care plan is to keep a family calendar on the wall that lists all your family activities, everyone's movements for the week or month, as well as contact numbers. This is especially important if you have children. It is also useful to nominate someone who can pick up your children in an emergency.

You can take this a step further and create a folder with information such as contact details, emergency numbers and maps to services. If someone has to take on some of your responsibilities, you can just hand them the folder containing all the relevant details.

Discuss the emergency care plan with your family, friends and service providers who may need to be involved. If plans are in place and anything happens unexpectedly, you can make a few quick phone calls to the relevant people.



Where to go for support:

Turn to page 20 to learn more about the information and support services that are available.

- Carers Australia
- Commonwealth Respite and Carelink Centres

Looking ahead

Looking ahead can minimise some of the stress associated with living with MS. While it is normal for you and your family to put MS at the back of your mind when the person with MS is doing well, it is beneficial to think ahead. Families that discuss future needs and issues usually cope best.

It can be daunting for your family to plan for the future, especially when life is already very busy. However, having strategies in place and talking through the possibilities that may arise can provide a sense of security and peace of mind. Anticipating situations can help you to avoid having to make difficult decisions in times of crisis.

Although your family's direction may change, it's important to remember that despite these changes, the future can remain positive.

Legal and financial planning

Legal and financial planning is applicable to everyone; however, it's particularly important to your family because of the unpredictable nature of MS. It's hard to predict the future; how much time may be required to care for someone with MS as well as the costs involved are things you won't be able to determine.

Looking ahead may include sitting down to talk with your family members, or it may also involve a professional. Although information is widely available, it is best for you and your family to seek professional advice from a reliable source.

Things to consider when planning for the future

When you are looking ahead, it's helpful to investigate your options. By doing so, you will have enough information to allow you and your family to make informed decisions that provide peace of mind and security.

The following points outline the financial and legal areas you may want to think about when you're planning:

- It is essential to assess your family's immediate needs and how you will manage them in the long term.
- Does your family have a workable budget? Does it need to be reviewed to ensure that assets are protected and income is generated? It may also be a time to look into the credit arrangements you have.

- It may be useful for your family to put money aside each month as a safety net, should any unexpected costs arise.
- It is essential that your family members have an up-to-date will, taking into consideration that they may need a power of attorney, enduring power of attorney or a Centrelink nominee. Looking into the legalities of putting a guardianship in place is also important.
- You may like to discuss living wills or advanced care directives to ensure that you and your family's health is in the hands of people you can trust, should there come a time when you're unable to make a decision. Talking about decisions regarding healthcare treatments with your doctor can also be useful.
- Personal files and accounts should be well organised. You need to consider any joint legal standing and signatures required for financial documents such as bank, building society and credit union accounts; safety deposit boxes, trust funds, mortgages and shares.
- Someone outside the family and/or a solicitor needs to know where your family's important legal documents are stored, including wills, house and land titles, superannuation documents and so forth.
- Your family needs to be aware of their entitlements, including those provided by Medicare and any provisions that are available from private medical insurance.
- Does anyone in your family have superannuation? It is important to understand the superannuation policy and the provisions available should the person with MS have to leave work or if a member of your family becomes a fulltime carer. You may need to seek professional advice in this area.
- You and your family should look into the benefits and entitlements available if someone has to take on more of a caring role, including Carer Payment, Carer Allowance, Rent Assistance, Disability Support Pension, Pharmaceutical Allowance, Telephone Allowance, Mobility Allowance and concession cards. You can obtain information from Centrelink.
- The law does not recognise all relationships. You may need to determine if your relationship with the person with MS is legally recognised, otherwise a number of areas, including ownership of joint property, joint bank accounts, medical decision making and superannuation benefits can become an issue. You may need to contact a solicitor or lawyer to formalise your relationship.

Disclaimer: Information in this booklet is intended as a guide. Legal and financial decisions require the assistance of a qualified person such as a solicitor or accountant.



Where to go for support:

Turn to page 20 to learn more about the information and support services that are available.

- Centrelink
- The Financial Planning Association of Australia
- Maurice Blackburn Lawyers

Finding information about MS

MS Australia – ACT/NSW/VIC

Phone or email. MS Connect™ **1800 042 138** is our specialised telephone and support service that offers information on any issues related to MS, including information on relevant local services.

You can access this service Monday to Friday from 9 am to 4 pm or email your enquiry to **mconnect@ms.org.au**



Offices in ACT, NSW, Tasmania and Victoria. To make an appointment with our health professional staff, you or the person with MS can contact MS Connect on **1800 042 138**.

Our ACT office is located in Deakin. Our NSW office is located at Lidcombe, with regional offices in Chatswood, Kogarah, Narellan, Wollongong, Erina, Raymond Terrace, Coffs Harbour, Wagga Wagga, Orange, Penrith, Tamworth, Alstonville and Batemans Bay.

The head office of MS Limited – ACT/NSW/TAS/VIC is located in Blackburn, Victoria; with regional offices located in Ballarat, Bendigo, East Keilor, Footscray, Geelong, Traralgon, Wangaratta, Warrnambool, Watsonia and Williamstown.

MS Australia on the web. Every state MS Society has a website, which you can access through the MS Australia website **www.ms.org.au** Each state's site may contain different information so it's worthwhile browsing through them.

The MS Limited – ACT/NSW/TAS/VIC website is **www.ms.org.au** There's a 'Families and Carers' section on this site with relevant information. Fill out the registration form in this section of the site to receive information about new publications or events.

Your children can also access further information via the internet. A useful site▶ for young people is **www.youngms.org.uk**

- ▶ MS Connect can also provide information for young children.

Your family may also like to seek support by speaking with others who are living with MS, or have a family member with MS. MS Australia – ACT/NSW/VIC has its own online community, the Peer Support Carers Group at <http://mc2.vicnet.net.au/home/mscarers>

MS Australia resources. MS Limited – ACT/NSW/TAS/VIC produces information resources to support people with MS, their family members, carers and health professionals. Our resources include information and brochures on symptom management, treatment options, lifestyle issues and much more. Details can be found on our website www.ms.org.au or by contacting MS Connect.

Peer support. Many families benefit from talking to others in a similar situation to themselves, and we offer this support through our Peer Support Program. Through the MS Limited – ACT/NSW/TAS/VIC Peer Support Program we can put you and the person with MS in touch with others who are living with MS. It is a free and confidential service and includes telephone, online or face-to-face support. Information is available from MS Connect on **1800 042 138**.

Library service. Our library includes an extensive collection of books, journal articles, DVDs, CD ROMs and videos, all of which are available for loan to residents of Australia. You can find out more about library services on the MS Limited – ACT/NSW/TAS/VIC website www.ms.org.au or by contacting MS Connect.

Intouch magazine. *Intouch* is the official magazine of MS Limited – ACT/NSW/TAS/VIC. *Intouch* covers the latest in MS research, news and events, and informs readers of the services provided by MS Limited – ACT/NSW/TAS/VIC.

Intouch also provides health and lifestyle solutions to help families live well with MS.

The magazine is distributed quarterly to our registered clients (people with MS), as well as their family members and carers. You can obtain a copy of *Intouch* by contacting MS Connect or read it online at www.ms.org.au

Information on all aspects of MS is available on the internet. It's important to note that there may be information on the internet from unreliable sources, or information that isn't approved by reputable medical and scientific authorities.



Other sources of information

Books and publications. There are many useful publications on MS. Most of them are widely available from booksellers or local libraries.

International websites. Information about MS is accessible via the MS International Federation (MSIF) website www.msif.org The MSIF site provides information in several languages.

You can also search the websites of international MS societies:

- National MS Society, USA www.nationalmsociety.org
- MS Society, Great Britain www.mssociety.org.uk
- MS Society, Canada www.mssociety.ca/en
- MS Society, New Zealand www.msnz.org.nz

Online communities. In recent years, many families have welcomed the support they receive from online communities and email discussion groups. Although it is important to keep in mind that people in chat rooms may give opinions that aren't based on evidence or scientific fact, these sites offer you the chance to chat with others in a similar situation, both within Australia and overseas.

The following is not a comprehensive list, but a good starting point if you wish to use online communities for information or support:

OzMS — Multiple Sclerosis Peer Support

w: www.ozms.org

MS World

w: www.msworld.org

Jooly's Joint

w: www.mswebpals.org

Multiple Sclerosis Society Discussion Forum

w: www.mssociety.org.uk/applications/discussion

The Multiple Sclerosis Resource Centre

w: www.msrmc.co.uk

Australians with MS

w: <http://health.groups.yahoo.com/group/AustralianswithMS-online>

Where to go for support

For general help and advice

A directory of useful websites and links can be found on the MS Limited – ACT/NSW/TAS/VIC website www.ms.org.au

The links lead to a variety of organisations that provide information on government services, disability organisations, carers associations, respite, employment and more.

Several agencies can provide you with information on services and supports 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 also provide 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 exist to support relatives and friends who care for people with a disability, mental illness, chronic condition or who are frail-aged. 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 can provide referrals and information about programs and services.

Carers Australia provides emotional support and information for carers, including children and teenagers through their Young Carers program.

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

Commonwealth Respite and Carelink Centres 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.

p: 1800 052 222

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

w: www.commcarelink.health.gov.au

Dietitians Association of Australia is the largest professional nutrition organisation in Australia.

p: 1800 812 942

w: www.daa.asn.au

The Financial Planning Association of Australia Limited (FPA) exists 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 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 To access HACC services in the ACT, contact regional community service organisations in the area.

NSW p: 1800 350 792

VIC HACC services in Victoria are provided by local councils. Councils must be contacted directly for more information.

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 comprehensive range of products to assist with day-to-day living.

p: 1300 885 886 or

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

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 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 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 may need additional support 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)

p: 1300 364 277

w: www.relationships.com.au

Salvation Army may help with personal or practical issues.

p: 1300 36 36 22

w: www.salvationarmy.org.au

St Vincent de Paul Society may 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

Useful publications

The Benevolent Society resource *Your Future Starts Now* provides information on planning ahead. It is located in the 'What we do' section on the site under 'Older people'.

p: (02) 9339 0000

w: www.bensoc.org.au

Department of Health and Ageing

produces a resource titled *Food for Health*, which 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 useful. It is 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 the local community service centre.

NSW p: 1300 138 794

VIC Contact 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



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

