



**Supporting
someone with a
new MS diagnosis**

A resource for family & friends

About this resource

This resource was developed in collaboration with people who have a diagnosis of multiple sclerosis (MS) and their family and friends - people just like you.

It has been created for ordinary, everyday people, who are going through the challenging and often-emotional time that happens when a person they know is diagnosed with a long-term health condition.

The quotes used throughout this resource come from people who shared their lived experiences and stories.

MS is often diagnosed when people are in their 20s to 40s, a time of life that is focused on the busyness of careers, families and social lives. Having a diagnosis of MS can be life-changing for both the person and for those who care about them.

This resource is designed to empower you with the knowledge and strategies to help support someone with MS. By educating yourself and seeking help, you can play a crucial role in enhancing the wellbeing and quality of life for you and the person you care about.

Take a moment

We have provided opportunities for reflection throughout this guide, sign-posted with a thought bubble. This is a chance to pause and think about what you have read and how it might apply in your own life.



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About MS

MS is one of the most prevalent conditions affecting the central nervous system, and everyone experiences MS differently.



What is MS

MS is a chronic neurological condition that affects the central nervous system, including the brain and spinal cord.

It arises when the immune system damages the protective covering of nerve fibers, known as myelin.

This damage disrupts the transmission of signals between the brain and the rest of the body, leading to a wide range of symptoms.

The journey to receiving an MS diagnosis is unique to each person, but it typically involves:

- a thorough medical history detailing all symptoms,
- a clinical neurological examination, and
- a magnetic resonance imaging (MRI) scan of the brain and spinal cord.

This phase often means navigating unfamiliar medical terminology and procedures, while also worrying about the wellbeing of the person you are supporting.

The process of confirming an MS diagnosis can extend over several days or even weeks, creating a sense of turbulence. During this time, it's common to encounter varying medical opinions.

Such uncertainties can be particularly challenging when both you and your family member or friend are feeling emotionally vulnerable.

While the desire for immediate answers is natural, it is important to have trust in the medical team.

Types of MS

MS has traditionally been divided into different types, depending on the disease activity and progression. As knowledge and understanding of the disease improves, these definitions and types are changing.

Relapsing-Remitting MS (RRMS)	Primary Progressive MS (PPMS)	Secondary Progressive MS (SPMS)
<p>RRMS is the most common form of MS. It is characterised by periods of relapse or exacerbation, during which new symptoms or existing symptoms worsen, followed by periods where symptoms may partially or completely improve.</p>	<p>PPMS is less common and involves a steady worsening of symptoms from the outset, without distinct relapses. In rare cases, relapses can occasionally occur, and this is sometimes called progressive relapsing MS.</p>	<p>SPMS is the transitioning phase from a relapsing disease into a more progressive form, where there is a gradual worsening of the disease without distinct relapses. However, there may still be periods of minor improvement or temporary stability.</p>

Additional descriptions have been added to the diagnosis of MS that can help describe the way MS affects people. These terms are becoming more widely used by healthcare professionals:

Active or not active is used for all types of MS to describe the presence of relapses and/or new lesions on an MRI scan, which is one indicator of disease activity.

For instance, if a person has RRMS and they're experiencing relapses, their MS would be considered active.

Alternatively, if there are no new lesions or any indicators of new activity the disease could be considered not active.

Worsening or stable is used in people with MS to describe whether the disability is increasing or staying at the same level.

With progression or without progression is used in people with MS to describe whether their level of disability is increasing or staying the same over a period.

Progression independent of relapse activity (PIRA), also known as silent progression, is a term used to describe disability progression outside of relapse.



Helpful tip

The type of MS a person has, may not be known at the time of diagnosis and is not an indicator of how a person's MS will develop and impact them over time.



Common tests for MS

There are a range of tests that help diagnose MS. The medical team will determine the most appropriate tests based on symptoms and medical history.

MRI scan: this detailed imaging test looks for signs of MS related damage in the brain and spinal cord.

Lumbar puncture (spinal tap): a small amount of spinal fluid is analysed to check for abnormalities linked to MS.

Evoked potentials: these tests measure electrical signals in the brain in response to stimuli, helping to identify nerve signal delays.

Blood tests: these tests rule out other conditions and might indicate markers associated with MS.

Neurological exam: a doctor assesses your reflexes, coordination, balance, and other neurological functions.



Causes of MS

There seems to be no single cause of MS. It's thought that several genetic and environmental factors play a role in a person's susceptibility to MS.

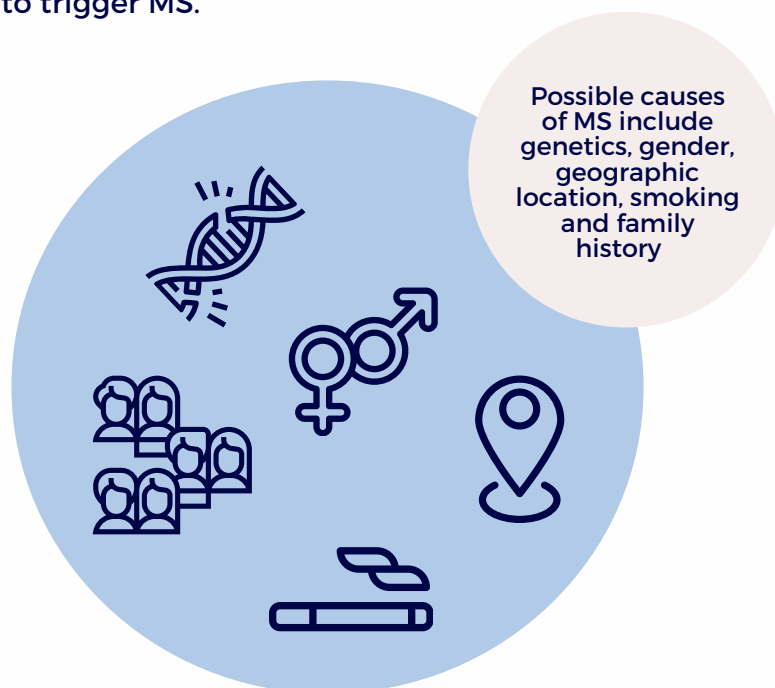
MS results when an abnormal immune response causes inflammation and myelin damage.

Possible causes of the abnormal immune response include viral infection, smoking or low vitamin D. It's likely that different factors need to come together to trigger MS.

MS is not considered an inherited condition (passed down from parent to child) because it's not passed on in a predictable way.

There are identified genes that make it more likely that someone will develop MS, however these genes alone are not enough to trigger the condition.

This means that the chance of other members of the family getting MS is small.



“It took me a while to stop feeling guilty about my daughter’s MS, as if I had caused it somehow. I soon realised it wasn’t healthy or helpful for me to feel this way. MS is no one’s fault.”

- Malinda, parent of a teen with MS

Treatments for MS

Various MS treatments are available to manage symptoms, slow disease progression and improve quality of life. The goal of MS treatment is to delay progression and reduce inflammatory activity.

Here are a range of treatments, medications and symptom management strategies:



Disease-Modifying Therapies (DMTs)

There are several different DMTs available for the treatment of MS. Most DMTs work by manipulating different parts of a person's immune system to reduce the inflammatory activity that occurs in MS. They do this by targeting specific immune cells or pathways that are involved in the damaging process.



Symptom management

MS can cause a wide range of symptoms like muscle weakness, problems with balance, nerve pain or bladder dysfunction. Treatments can help manage these symptoms to improve a person's quality of life. For example, medications might be used for common symptoms to reduce muscle spasms, improve bladder function or alleviate pain.



Managing other medical conditions

Managing other medical conditions alongside MS can be challenging, but it's crucial for maintaining overall brain health and wellbeing. Regular checkups are important to help identify and address issues early.



Lifestyle changes

Maintaining a healthy lifestyle through regular exercise, eating a balanced and nutritious diet, not smoking, reducing stress and adequate rest can contribute to better symptom management.



Rehabilitation therapies

Alongside medications, there are rehabilitation therapies such as physical therapy, speech therapy and occupational therapy.

These can be important in helping individuals with MS regain or maintain their mobility, independence and overall wellbeing.



Experimental therapies

Ongoing research is exploring new treatments and approaches to managing MS.



Supportive care

MS can affect emotional wellbeing, so counselling or peer support can be valuable.

Finding information

Deciding how much you want to know about MS and its treatment, is important for you and the person you want to support.

Healthcare information

Some people may prefer to get a lot of information quickly, and others may prefer a very gradual 'need to know' approach.

Gaining knowledge holds significant value for some people, but it doesn't always equate to empowerment for everyone.

It's important to pause and take time to talk to your person with MS and ask them if they are interested in receiving information before sharing what you've learned.

By doing this, you ensure you respect their wishes and provide the right support for their needs.

Accessing reliable information from trusted sources can help you feel more prepared, confident and self-assured.

In Australia, most people can access up to date information, MS specialist neurologists and medical teams. Sometimes these professionals may not be local, however telehealth appointments can help access the quality healthcare you need.

Helpful tip

If you think the person you are supporting isn't feeling confident or comfortable with their team, you might talk to them about:

- writing down concerns and talking to their healthcare provider.
- providing patient feedback to the healthcare service.
- seeking a second opinion.

These options are the responsibility of the person with MS; however, you can be there to support them in their decisions.

“When you're newly diagnosed everyone is quick to give you advice or tell you something they saw on social media or read online. They soon realised this wasn't helpful and started letting me initiate the conversation.”

- Clara, partner of someone with MS



Searching for information online

Searching for health information online can be useful to help educate yourself about MS and to identify local support and services. Yet the abundance of information can also be overwhelming, time-consuming and confusing.

When searching for reliable medical information, keep these tips in mind:

Check the source: look for information from reputable sources, like government health agencies, medical associations and respected hospitals or universities.

Expert authors: make sure the content is written or reviewed by qualified medical professionals or experts in the field.

Up to date: check for publication and website dates to ensure the information is current and relevant.

References: reliable articles provide sources and references for their information. This shows they're based on solid research.


Avoid bias: be cautious of websites promoting miracle cures or overly sensationalised content. Stick to balanced and evidence-based information.

Multiple sources: cross-reference the information you find across a few reputable sources to verify accuracy.

Transparency: trustworthy sources are transparent about their affiliations, authors and funding sources.

Domain: websites with domains ending in ".gov" or ".edu" are generally trustworthy sources.

Ask your doctor: if in doubt, bring the information you've found to your healthcare provider for their expert opinion.



Educating yourself can help you navigate the complexities of MS and empower you to provide better support to your person with MS.

Offering support

Finding out that a family member or friend has been diagnosed with MS will take some time to process, for both the person with MS and for you.



Early days

The support you offer will be unique to you and who you are. This will change over time. There is no one-size-fits-all approach.

Here are some things you can do to support your person through the early days of receiving a diagnosis:

- avoid making judgments or giving advice, especially medical.
- resist the urge to solve the problem.
- be prepared to listen without interrupting.
- let them know you are there for the long haul.
- offer to be there for any medical visits or go out for a coffee afterwards.
- organise something to look forward to.



Healthcare appointments

Navigating the complexities of the healthcare system can sometimes be confusing and challenging.

The person you are supporting may find it helpful to have you with them at appointments to advocate for them, or they may wish to go it alone.

If the person you are supporting asks you to attend appointments with them, here are some helpful tips:

Managing time: aim to arrive at appointments early to allow enough time for parking, check-in or any unexpected delays.

Know what to expect:

Talk through appointment goals with the person you are supporting and help them prepare a short list of questions, concerns or specific topics to discuss.

The value of admin

support: prior to the appointment, ensure the person you are supporting has all the relevant documents, medical history and health information readily accessible. Being your person's "assistant" can be the best role you play.

Be the note taker: you can write notes during the appointment as this can be a valuable reference for the person you are supporting.

“If you need to take time out to process what’s going on, let your person with MS know and take the time you need.”

- Ryan, partner of someone with MS



Ongoing support for your person

Providing ongoing support to someone with MS will vary depending on your unique situation and you will probably find yourself learning and adapting along the way.

Asking someone how they'd like you to support them, rather than assuming what they might need, may be an option. Also, they might suggest ways of helping that you hadn't considered.

Keep in mind that the type of support someone needs can vary over time due to the nature of MS. Symptoms can fluctuate and change, so it's important to provide the right assistance at the right time.

If you are able to, you could offer to help with:

- regular tasks such as preparing meals, vacuuming or gardening.
- going to appointments to avoid them having to find parking.
- being an assistant, taking notes or sourcing specific information.
- just being there for emotional support.



Take a moment

Have a think about what support you can provide and for how long. If you are unable to at some point, who would provide support to your person with MS?

Talking about MS

Hearing the news that your family member or friend has been diagnosed with MS can bring on a range of emotions and concerns, especially in the weeks and months following a diagnosis.

Common feelings

This period is often a time of adjustment, and you might go back and forth between different emotions. It's ok to hold many emotions at once. Recognising your feelings can help you look after your own emotional wellbeing.

There may be times when you find it difficult to talk about how you are feeling. Talking about personal emotions can be hard but finding a way to express your thoughts and emotions is important.

If you are struggling to cope or having a tough time, you can speak with MS Plus on 1800 042 138. For 24-hour crisis support call Lifeline on 13 11 14.


Common emotions and responses experienced may include:

- anger and frustration
- confusion
- depression and sadness
- fear and anxiety
- guilt
- loss and grief
- shock
- stress
- acceptance
- relief.



Helpful tip

Try writing down your thoughts or feelings, talking to a close friend, or making an appointment with your GP to discuss your emotional wellbeing.



Find a good friend that you can talk to regularly and candidly, someone who can listen with empathy rather than judgement.



I decided to tell people on a needs-to-know basis and asked my family to also do this. This made me feel more in control and that I was still me.



Hearing about the diagnosis

Your reaction to learning about the MS diagnosis might depend on your relationship with the person. Some people think they 'need to stay strong' and avoid showing how they are really feeling.

Being strong doesn't mean not talking about how you feel. Instead, it can be immensely helpful to find someone who can listen to you about how you feel.

This may be:

- a counsellor
- psychologist
- family member or friend
- peer support program.

Feeling a sense of guilt can happen, particularly in parents of people diagnosed with MS. This can interfere with being the supporter you want to be.

It can be hard to focus on the person's needs when you are coming to terms with strong feelings yourself. Sharing this pain and grief with an independent person can be helpful.



Take a moment

Think about what you want to share with the person you are supporting in the first few weeks after diagnosis. You can try writing some notes down or talking it through with a friend.



Talking to your person with MS

Many people worry they may say the wrong thing when talking to someone who has been diagnosed with MS. However, letting your person know you care and asking them how they would like to talk about things is a good start.

Things to consider:

- if you're feeling awkward and not sure how to respond, be honest and say so.
- be patient if your partner, family member or friend isn't ready to talk just yet.
- don't avoid them or the topic because you feel uncomfortable.
- if you feel you need ideas about ways to communicate, you can consider counselling services.

It can be helpful to think about what role you normally play in that person's life and how you can best talk to them and meet them on that level.

For example, you may be the friend who is there to have a good cry with, you may be the person's party go-to, or you may be the practical helper.

Listening and offering your presence can mean a lot during challenging times. Everyone's emotions and needs are different, so just let the person know that you're there to support them in whatever way they feel comfortable.

What can you say?

- 'I just want you to know that I'm here for you. I'm truly sorry to hear about your diagnosis.'
- 'Please know that I'm here to listen, and to support you in any way you need.'
- 'We're in this together, you're not alone. If you ever want to talk, share your feelings, or even just take a break from it all, I'm here.'
- 'I've been thinking about you and I care about you. I'd like to understand more and I'm here to help.'

**“Ask the question:
‘what do you need right now?’
A person in the early stages of diagnosis
may feel a bit lost or overwhelmed and
not know what support they need or how
to ask for it.”**

– Erin, person with MS





Talking to others

It's helpful to talk to your own support network when you are feeling worried or upset about something. However, it can be tricky when you're talking about another person's medical condition.

Before revealing any information, have a conversation with the person you're supporting about whether information can be shared.

People may react in different ways when learning about the diagnosis, potentially raising various questions or offering support.

It's okay to not have all the answers or provide extensive explanations.

You don't need to reveal any confidential information.

If you have talked with the person you are supporting about the language you will use and the amount of information you can share, this will be your guide.

When considering what to say to others, you can start with:

"My (partner, family member, friend) has recently been diagnosed with MS..."

From there, you can communicate your specific needs:

"Right now, I just need someone to talk with and listen to me. I value your support during this time."

or

"We're doing fine. However, I would appreciate it if we could focus on other topics for now. Your understanding means a lot."

If you'd prefer not to discuss the topic any further, you can respond by saying:

"I'd rather not talk about that right now."

Take a moment

It can be helpful to recognise that being open to other people in your life can create opportunities for more support for you and for your person with MS.





Social media

Think carefully if you share news and experiences through social media.

This can be a way to let your wider circle know what's happening, however it can put pressure on the person you are supporting to talk about it before they are ready.

If you are considering posting online, take a moment to pause and think about the information you are sharing and what that will mean for you and the person with MS.

Social media can offer immediate gratification, but it can also have long-term consequences.

It may also have implications for future disclosure in the workplace and other areas in life where people searching may find details about the person you are supporting.

Helpful tip



Talk with the person you are supporting about what information (if any) they want to share on social media.



In the workplace

Supporting a person with MS while balancing paid work can present challenges. You don't have to tell your employer about your support role; however, it may help.

It's important to recognise that you have the right to receive support from your workplace, and talking with your employer can help you to maintain a healthy work-life balance.

Before talking with your employer make sure you have discussed it with the person you are supporting to understand their support needs.

You may not need to make any changes right now, and things may change in the future.

Take a moment



Try writing down or have a think about what you might say to different groups of people such as:

- close friends and family,
- work colleagues, or
- other social groups.

Your support team

Connecting with the right people and having your own support network is an important part of maintaining your own wellbeing and providing ongoing support to your person with MS.



Building your support team

Your support team might consist of one or two people or several people, depending on your needs.

When gathering your own support team, it can be useful to reflect on past challenging situations and consider what was helpful then.

You can also seek insights from others by asking questions like:

- 'How did you go about finding support?'
- 'What resources were particularly valuable?'

We've put together a list of support ideas for you to consider:

Information and guidance support

Imagine having that person or people who are always there to share advice, tips and information to help you make informed decisions and solve problems. You can find this kind of support from healthcare professionals, MS Nurses, or other people who know someone or are themselves living with MS.

Check-in and feedback support

When life gets uncertain, or things change, think of that one person you can lean on.

They're the friend who appraises the situation and helps you sort out your feelings, thoughts and situations.

Safety and validation support

You know that friend who lets you be yourself, no matter what? They don't judge; they just listen and understand. That's the kind of support that helps you feel safe, even during tough times.

Optimism and self-esteem support

Friends who boost our confidence, remind us of our worth, and bring hope when we're feeling low, just like a personal cheerleader.



Take a moment

Have a think about your current support networks. You could write down the details of people you can call on when needed, and the type of support they might provide.

Emotional and mental health support

Everyone needs someone to talk to, especially when things get tough. This friend or mental health professional can provide comfort, empathy and a listening ear.

Practical and instrumental support

Your practical friend or person is the one who's always ready to lend a hand cooking meals, helping with tasks or even offering a little financial support.

Community connections support

This type of support helps you expand your circle of people by connecting you with a broader network and community, enhancing the quality of your relationships.

Now that you have a better understanding of the types of support you might need, consider the following:

- identify your specific needs.
- recognise your existing networks.
- reflect on how your team is working for you.
- think about how your support needs might change overtime.

Next, do a self-scan on the types of support mentioned:

- do I need this type of support right now?
- is there someone who already provides that support?
- is there someone who can assist with a type of support that I haven't considered yet?



Helpful tip

Let people know that you value the specific type of support they provide and validate them for their role.


Sometimes people don't offer their support because they assume you have everything under control or they are unsure how to help.

By asking for and accepting small offers of support now, it will be easier to accept more support in the future if needed.

“Build your supports from the beginning - you absolutely cannot do it on your own. The better support you have the better and longer you can care.”

- Betty, sister of someone with MS





While hard to speak up, I found having the difficult conversation up front about how my family and friends could support me was helpful.



Roles & relationships

A diagnosis of MS often impacts the roles and relationships people have with their partners, family members or friends. It is normal to experience challenges and bumps along the way, but it's also possible for relationships to grow stronger and deeper.



Partners

Open and honest communication, shared decision making and maintaining intimacy can be key focus areas. If you are struggling, it may be helpful to seek counselling on your own or with your partner.



Families

MS often affects the whole family, including children and extended relatives. Involving family members in discussions about the diagnosis, educating them about MS and encouraging open dialogue is helpful.

If you have children, they will likely have unique needs. Be prepared when you tell children about the diagnosis. Get some helpful tips from the Resource hub on the MS Plus website or call MS Plus for advice and support.



Friends

Friends play a significant role in providing support to someone with MS. Keeping lines of communication open, being empathetic, and offering practical support can strengthen friendships during challenging times.



Here are some tips on talking to children about supporting someone with MS:

- explain the diagnosis to your child in age-appropriate language. If the MS is within the immediate family, reassure them that MS is not anyone's fault.
- depending on their age and maturity, involve your children in discussions about the diagnosis and how they can be supportive.
- let them know it's okay to have a range of emotions and they can always come to you with their worries.
- try to maintain a stable routine for your children. Consistency can provide a sense of security during uncertain times.
- reassure them that they are loved and that everything is going to be okay.
- let teachers or caregivers know about any changes in your family situation so they can provide additional support if needed.
- if you notice significant behavioural changes in your children that are causing distress or affecting their wellbeing, consider seeking professional help.



Supporting someone from a distance

When a family member or friend with MS lives far away you may be unsure about what support you can offer. However, distance doesn't mean you can't be there for them in some way, even small gestures can be meaningful.

Here are some ways you can make a difference:

Stay in touch: regular phone calls, video chats, or even sending a short message to say "I'm thinking of you" can mean so much.

Be there: validate their feelings and offer words of hope and encouragement. Expressing your love and support regularly can remind them they are not alone.

Educate yourself: take the initiative to learn more about MS. Understanding the condition and its impact can help you empathise and have more meaningful conversations.

Be mindful: each person with MS has unique challenges and preferences. Ask your family member or friend about their specific needs, limitations and priorities. By being aware of their situation, you can offer support that is tailored to them.



Take a moment

Think about your role and how you can best support your person with MS.



Looking after yourself

Paying attention to your own health and wellbeing is a vital part of taking the best care of your person with MS.



5 ways to wellbeing

During challenging times, it's easy to ignore your own wellbeing. It can feel like it's all too hard to even consider where you could start to make some improvements.

Sometimes, it's good to keep it simple and there are actions and activities you can incorporate into each day to help improve your mental and emotional health.

The 5 ways to wellbeing offers a free, uncomplicated and adaptable approach that can be done anytime, in ways that work for you.

“This was one of the hardest times I've ever faced, and I just had to be kind to myself.”

- Sue, partner of someone with MS

The five principles revolve around small everyday actions that can make a big difference. Plus, you might be doing some of these actions already, so it's important to recognise this and acknowledge the efforts you already put in.

You don't need to start big projects or major endeavours, it can be as simple as saying hello to a new person, going for a walk or texting a friend some words of encouragement.

By practicing these small actions, you are actively contributing to your own health and wellbeing, as well as others.

Let's take a look at the 5 ways to wellbeing →



1 Connect

Building and nurturing positive relationships and broadening your social networks creates a sense of belonging and community and can reduce loneliness.

Here are some ways to connect:

- organise a regular catchup with a family member or friend.
- phone or email someone you don't see often.
- join a carers group, 1:1 peer support or MS event.
- invite a friend for a 'walk and talk' in a park.

4 Keep learning

Learning new things can be fun, boost your self-esteem and help to find meaning and purpose in life.

Here are some ways to keep learning:

- explore "How To" videos online or listen to a podcast.
- try a crossword or puzzle.
- visit a museum, art gallery or local library.
- try a new recipe.

2 Be aware

Be aware of your surroundings and take time to enjoy the moment you are in.

Here are some ways to be aware:

- take time to identify how you're feeling, why you're feeling that way, and what you can do to address those feelings in a healthy way. Journaling can be a useful tool for this.
- write down or think about three things you are grateful for that happened in your day.
- declutter and organise your work or study space.
- take a moment and look at the world around you.

5 Be active

Regular exercise is proven to boost mood, reduce stress and improve physical health. It doesn't have to be intense; even a brisk walk can make a difference.

Here are some ways to be active:

- go for a walk, run, swim or ride.
- if catching public transport, get off a stop earlier and walk the final part of your journey.

3 Help others

Supporting someone with MS means you are already engaged in helping others and providing a wide range of support. It's important to acknowledge this and give yourself credit for this.

Here are some ways to help others:

- share your valuable knowledge with a peer support group.
- write a thank you note or send an encouraging text message to someone.
- donate something you don't use anymore.
- smile and say hello to a neighbour.

- join a local sports club to be active and meet new people.
- household activities such as vacuuming, gardening and mowing the lawn count too!

MS Plus support

We hope you've found this resource helpful. At MS Plus, we offer a range of support for carers, family and friends of people living with MS and other neurological conditions including:



Plus Connect is the gateway to information, advice, support and services.



Plus Advisor provides personalised advice from an MS Nurse or Social Worker.



Plus Peer Support connects you with a community of other people living with MS, their family and carers.



Plus Education empowers you with support and information to build your skills and knowledge.



Plus so much more...find out about our comprehensive suite of emotional and practical support at **www.msplus.org.au**



Alternatively, you can give our Plus Connect team a call on **1800 042 138** for personalised support.

Contact us:

1800 042 138

connect@msplus.org.au

www.msplus.org.au

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Helping your loved ones break down barriers and achieve goals

with emotional and practical support for every neuro journey.



Our services

- Information and advice
- NDIS services
- Occupational therapy
- Physiotherapy
- Exercise physiology
- Accommodation
- Continence support
- Diet and nutrition
- Employment support service

