

IT'S A *Generational* THING



Creating an Understanding of MS between Parents and Their Children

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MS Disease Overview



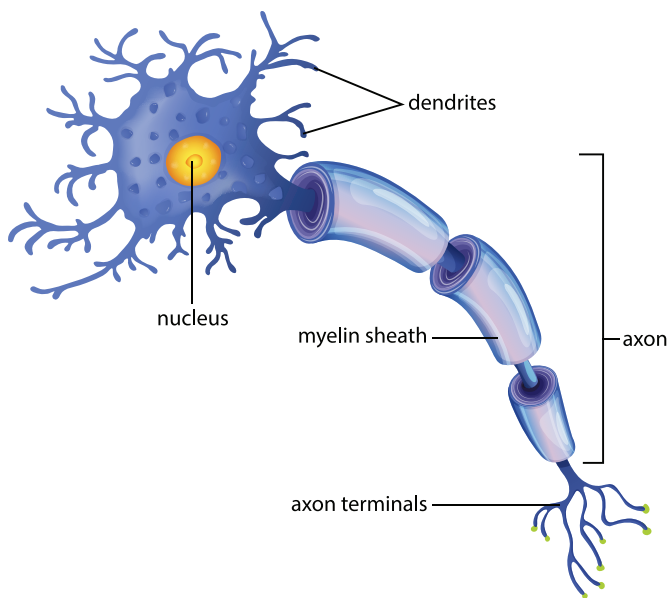
The Role of the Brain and Nervous System

Multiple sclerosis (MS) is a disease of the central nervous system (CNS), which consists of the brain, optic nerves, and spinal cord. With MS, areas of the CNS become inflamed, damaging the protective covering (known as “myelin”) that surrounds and insulates the nerves (known as “axons”).¹

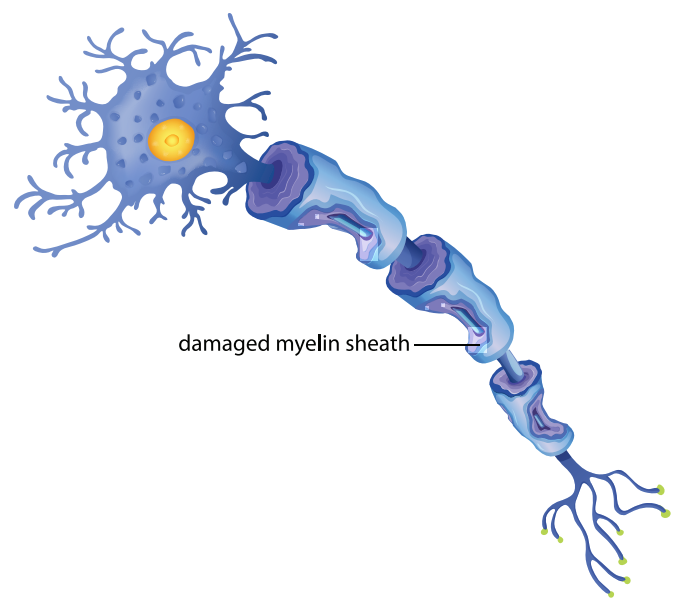
In addition to the myelin, over time, the axons and nerve cells (neurons) within the CNS may also become damaged.¹

The damage to the protective covering and the nerves disrupts the smooth flow of nerve impulses. As a result, messages from the brain and spinal cord going to other parts of the body may be delayed and have trouble reaching their destination – causing the symptoms of MS.¹

NORMAL HEALTHY NERVE CELL



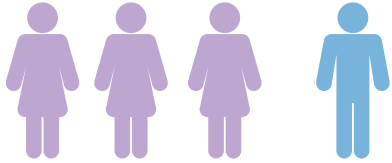
MULTIPLE SCLEROSIS NERVE CELL



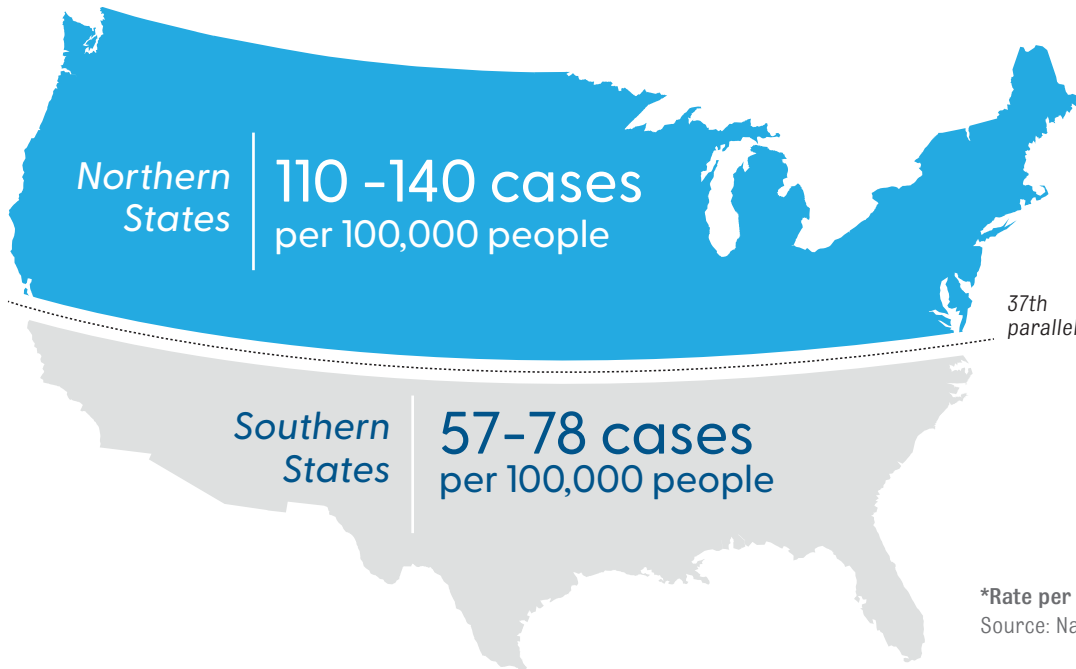
Myelin is the insulation that covers the nerve. A healthy nerve is able to transmit signals at a very fast speed. Damage to the myelin as a result of MS causes the nerve signals to slow down.¹

When the myelin becomes damaged, signals can no longer travel across the nerve fibers efficiently. Lost or slowing signals cause the symptoms of MS, and based on their location, these signals can influence what kinds of symptoms a person might experience.¹

MS Disease Overview



More than **two to three times** as many women as men develop **MS**, and this gender difference has been increasing over the past 50 years.²



MS cases in the US

Nearly one million individuals are living with **MS** in the United States.²

*Rate per 100,000 individuals
Source: National Multiple Sclerosis Society



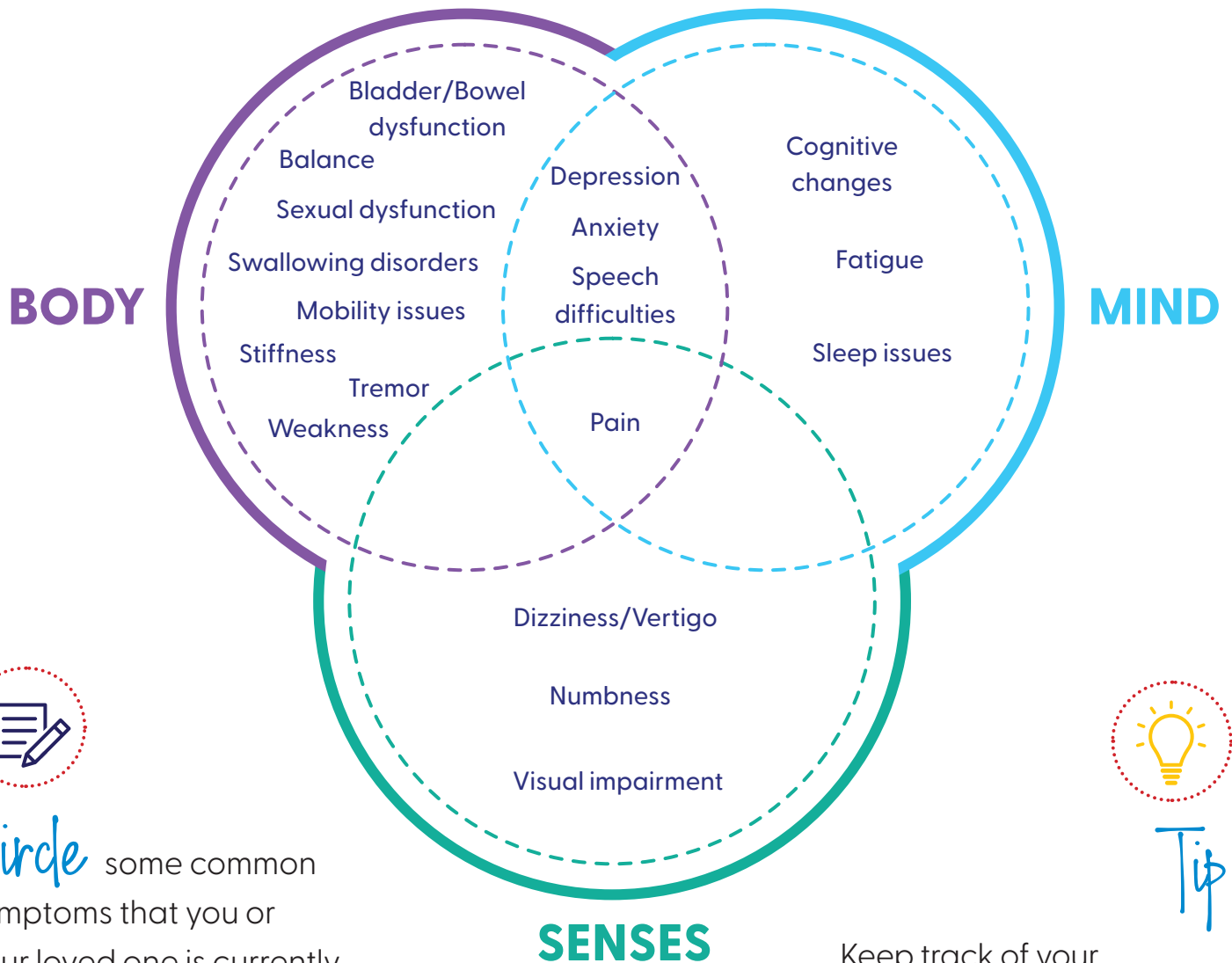
In my own words, I would describe **MS** to a friend as....

MS Disease Overview



MS Symptoms Overview

Symptoms are different for each person, and they can impact the body, mind, and senses. Some of the symptoms might fall under a number of the categories below.¹



Circle some common symptoms that you or your loved one is currently experiencing.

You could use this as a tool to track disease progression or bring it to your next doctor's appointment to help describe what you are experiencing.



Tip:

Keep track of your symptoms in a journal. What makes each symptom better or worse? Consider sharing this information with your doctor.

MS Disease Overview



Multiple sclerosis (**MS**) affects each person differently. There is no way to predict how **MS** will progress in each individual. The most common types of **MS** are:³

Clinically Isolated Syndrome (CIS)

Clinically Isolated Syndrome is caused by an inflammation and demyelination (damage to the protective covering surrounding the nerve fibers) in the central nervous system and lasts at least 24 hours. Not everyone who has a clinically isolated episode will go on to develop MS. Those with CIS who are considered high risk for developing MS may be treated with a therapy shown to delay the onset of multiple sclerosis.³

Relapsing-Relmitting MS (RRMS)

In the beginning, most people with MS experience symptom flare-ups, which are also known as relapses, exacerbations, or attacks. When someone experiences a relapse, they may be having new symptoms or an increase in existing symptoms. These usually persist for a short time (from a few days to a few months). Afterward, they may remain symptom-free for periods of months or years. This is known as relapsing-relmitting MS.

Approximately 80 to 85 percent of people with MS are initially diagnosed with this form of the disease.³

Types of MS

Secondary-Progressive MS (SPMS)

Over time, relapsing-relmitting MS may advance to secondary-progressive MS (SPMS). This form of MS has a slow, steady progression – with or without relapses. If relapses do occur, they usually do not entirely suspend. However, with the introduction of long-term disease-modifying therapies (DMTs), fewer individuals advance to this latter form of the disease.

Without treatment, approximately half of individuals with RRMS convert to SPMS within ten years.³

Primary-Progressive MS (PPMS)

Primary-progressive MS (PPMS) is where individuals experience a steady worsening of symptoms from the start and do not have periodic relapses and remissions. Individuals who are not initially diagnosed with RRMS may experience a steadier disease progression from the onset.

Approximately 10 to 15 percent of the MS population is diagnosed with PPMS.³

Accepting the Diagnosis as a Family Unit



Emotional Health

It is entirely normal for someone who is newly diagnosed to feel many different emotions after a new diagnosis. Family and friends may also feel emotional.



Common Emotions:

Worry and stress:

Members of the MS community are more likely to experience depression and anxiety than individuals without MS.¹

Grief:

Grief is a common reaction. The stages of grief include denial, bargaining, anger, and sadness. Acceptance is also one of the stages of grief. People may experience *all* the stages or just *some* of them. The stages are not necessarily linear. You may feel like you are on a roller coaster of emotions. One day you feel fine; the next day you feel angry – this is normal and will ease with time.²

There are treatments and strategies to help you, your care partner, and others in your life. Facing your diagnosis may be the best way to cope.

What Can Help

Be Informed

Information about MS can help you to feel more in control and empowered to manage your new diagnosis. Write down all the questions you have for your doctor. It is encouraged for family and care partners to ask questions as well. Here are a few questions to get you started – be sure to add your own below.³

Questions that may be helpful when seeing members of your healthcare team include:³

- What happens if I have new symptoms or if problems arise between visits?
- Do I need to make any changes with my exercise routine and diet?
- What types of rehabilitation services do you provide or recommend should the need arise?
- Where can I go for help with personal relationships and business, such as support groups, family counseling, employment, insurance, and finance?
- Where can I find accurate information to review on my own if I have questions?
- What can you tell me about medications and treatments?
- As a care partner, what do I need to know to support my family member/friend living with MS?





Are there questions you'd like to ask your healthcare team at your next appointment? Jot them down below. Make a list of your questions for your doctor and care team:

Accepting the Diagnosis as a Family Unit



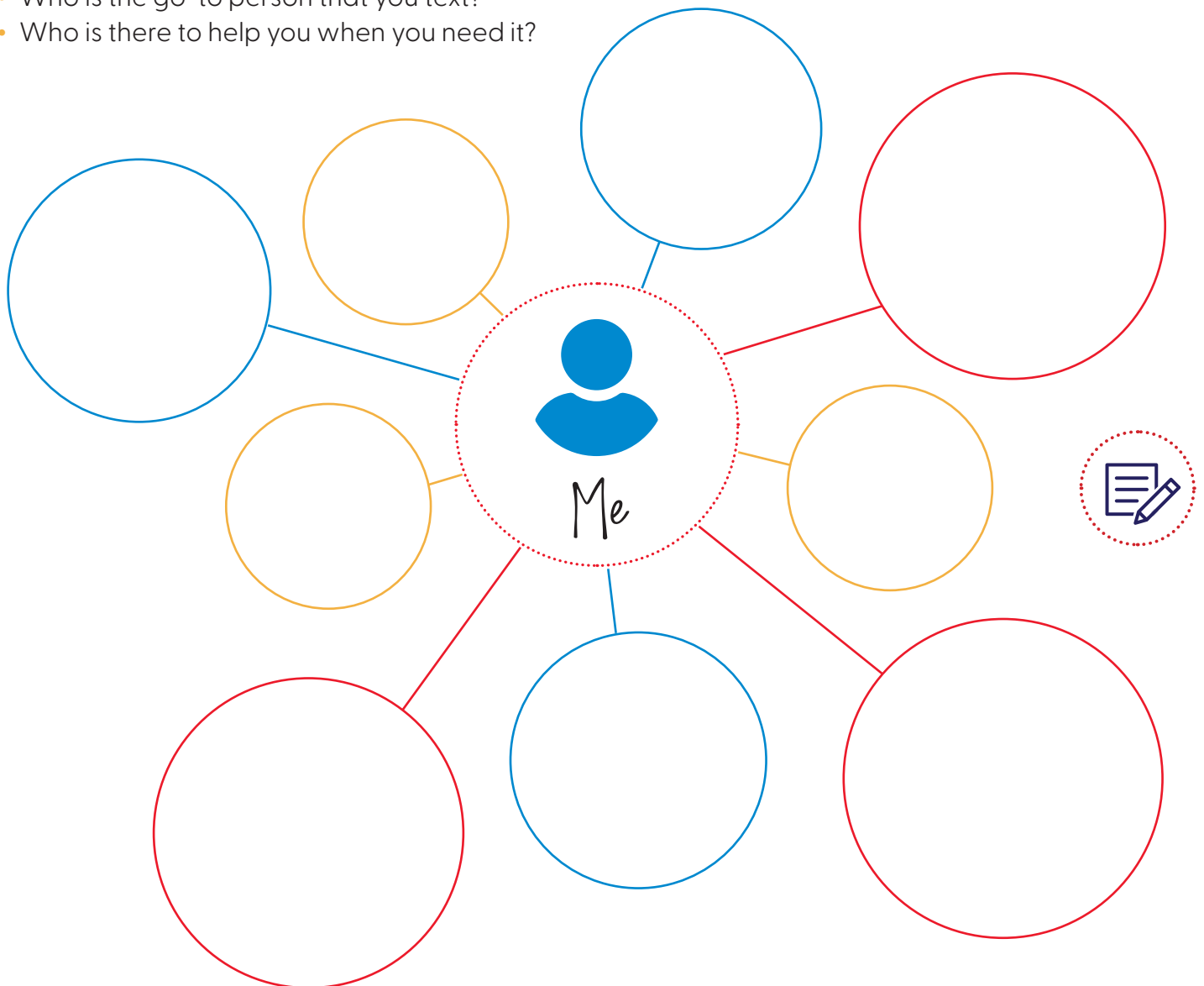
Support



Tip: Building a network of friends and family you can rely on will help you cope. This tip is for those newly diagnosed and their family and care partners.²

You may already know who is part of your support network, but here are some questions you may want to ask yourself as you build your network:

- Who is part of your network?
- Who is the go-to person that you text?
- Who is there to help you when you need it?



Accepting the Diagnosis as a Family Unit



An MS diagnosis can be challenging for everyone in the family. Having open discussions with family members and friends – when you are ready – can significantly help with their understanding of MS and your feelings. Explain to your family that you are still the same person that you were before the diagnosis. Share with them that you may have good days and bad days – and that you welcome their support through this process.

Communicate with your friends and family members about how they can be helpful and when. This is true for both care partners and the person living with MS. Make sure you take care of yourself and plan for self-care. Don't be afraid to ask for help. Most people will be willing and relieved to help, and the worst they can say is no. ⁴

Support Groups

A support group can provide you with a place to connect and discuss your questions with people who understand from personal experience. To find a group, start by asking your doctor's office if they have any recommendations, reach out to a local nonprofit organization, or join MSAA's online peer-to-peer forum, My MSAA Community, at healthunlocked.com/msaa.

Support groups are beneficial in many ways. Participation can help you to feel less lonely and isolated. ⁵

Online support groups have certain benefits, such as more regular participation and opportunities for those who don't have a local group. Still, it is essential to be aware of the risks involved.

Communication can include disrespectful comments and inaccurate information. People may try to promote a product they are selling. ⁵

Support groups are not the same as therapy or group therapy with a licensed mental health professional. Medical advice should come from your doctor.

Always look for and ask about confidentiality. Here are a few other things to consider if you join a support group: ⁵

In-person

When and where does the group meet?
Does a trained facilitator lead the group?
Are there ground rules for group participation?
What does a typical meeting agenda include?
Is there a confidentiality agreement?
Are there fees?

Online

Is there a moderator?
Are there guidelines for group members?



Watch out for high membership fees and/or pressure to purchase products. There shouldn't be pressure or high costs involved in support groups.

Accepting the Diagnosis as a Family Unit



Conversation Starters:

“Nurse, I’m interested in joining a support group – do you have any recommendations?”

“Friend, would you mind driving me to my doctor’s appointment next week?”

“Since my daughter was diagnosed with MS, I’m having such a hard time. Could you meet for (virtual) coffee next week? I would love to connect with a friend.”

“I have an appointment with a new doctor next week. Let’s discuss and make a list of questions we have.”

Accepting the Diagnosis as a Family Unit



Establishing Expectations



Tip:

Creating meaningful, achievable goals takes work, but the process can be rewarding. Consider the following when setting and working towards meeting your goals.

- Start with one easy goal. Work your way up to more challenging goals.
- Do not give up. Revisit your goals and adjust if necessary.
- Have a day of the week or month that you assess your goal(s). Set a reminder in your phone or calendar.
- Take notes and reflect on how meeting goals made you feel. Is there anything you could do differently?
- Set family goals but start small.

Creating daily, weekly, or monthly goals, will give you and your care partners the opportunity for growth and reflection.⁶



The worksheet is for the person living with MS and their care partners.

Name(s) _____

Your Goal	When would you like to achieve your goal by?	What do you need to achieve your goal? What steps do you need to take in order to reach your goal?	How will you know you achieved your goal? What will have happened?

Examples: Write in my journal twice a week about symptoms I'm experiencing / Prepare for my next doctor's appointment with notes and questions / Put my phone down at 8:00 pm each night / Exercise for 30 minutes 3 times a week / Have a game night once a week with family / Ask for help with picking up groceries.

Mind Health: Depression, Anxiety, and Stress



Depression

Depression is a common medical illness that negatively affects how you feel, how you think, and how you act. Depression causes feelings of sadness and a loss of interest in activities once enjoyed. It can lead to various emotional and physical problems and may decrease a person's ability to function at work and home.¹

It is not uncommon for those newly diagnosed with MS and their families to experience a period of depression. It can take time to come to terms with the new diagnosis. People do adjust and adapt, but it can take time.²

Depression is treatable, and you should talk to your doctor if you experience any of the following symptoms for two weeks or more:¹

- Feeling sad most days
- No or little interest in activities you used to enjoy
- Weight loss or gain
- Trouble sleeping or sleeping too much
- Loss of energy or increased fatigue
- Feeling worthless or guilty
- Difficulty thinking, concentrating or making decisions
- Thoughts of death or suicide

If you become withdrawn, family members may withdraw too, as they may not fully understand what is needed. Depression is not overcome by the power of positive thinking. Family members should avoid giving advice. Instead, a referral to a skilled mental health professional who can work with both the individual and/or family is needed to determine what course of treatment and support would be most helpful.³

Anxiety

Anxiety is perhaps the most challenging and under-treated psychological effect of living with MS. It does not appear to result from the physical disease process of MS, but from the realities of living with MS. The unpredictability in planning and preparing for the effects of MS on your life drives anxiety.⁴

Mind Health: Depression, Anxiety, and Stress



Stress

Stress can trigger MS symptoms. It is important to learn coping mechanisms and how to identify what triggers you. Stress management is also essential for care partners. Remember, you are not alone.⁵

There are many reasons you may feel stressed:

- Uncertainty about new symptoms and the future
- Change and loss
- Unpredictability of MS
- Invisible symptoms
- Physical challenges
- Loss of control
- Family impact
- Parenting with MS
- Financial concerns

Mind Health: Depression, Anxiety, and Stress



Coping Mechanisms

Self-awareness

Building self-awareness around the causes of your stress and anxiety can help you to address it. Knowing what causes your anxiety or stress can help you manage it more effectively in the future. There are times it may be a challenge to tell the difference between stress and MS symptoms. When possible, try to avoid your stressors or develop a plan if you know a situation might cause you stress. Keeping a journal can help you to identify the differences.⁶



Keep a journal to help you to tell the difference.



Tip:

Share your feelings

Talking about your feelings with others can help. Talk to family, friends, or health professionals about the stress you are experiencing. They can help you to cope and see things in a different light.²



10 Journal Prompts^{7,8}

- 1 What energizes you?
- 2 What is not working, and why?
- 3 What daily activities cause the most stress?
- 4 What gives you hope?
- 5 List 5 things you are grateful for and why.
- 6 What have you overcome regarding MS? What have these experiences taught you?
- 7 What does it look like when you are kind to yourself?
- 8 What do I do during periods of remission to take care of myself?
- 9 Are my basic needs met? How can I improve my situation?
- 10 Are there any ways to bridge the gap between feeling good and not feeling good?

Mind Health: Depression, Anxiety, and Stress



Finding “Me” Time

Carving out time for yourself can take a bit of effort and practice. Find ways to protect your time and possibly turn down commitments you have made in the past. It’s okay to say ‘no’ to protect your energy. Learn how to protect your time by saying no, setting boundaries, and practicing self-compassion. Start with small changes.

“That sounds fun, but I won’t be able to make it this time.”

“I have several other priorities I’m focused on right now.”

“We have that time set aside for family, but I hope you have a nice time.”

“Thank you for thinking of me, but I can’t commit right now.”



“You can’t pour from an empty cup.”

Mind Health: Depression, Anxiety, and Stress



Questions to ask yourself. Use the space immediately below for reflection.

Could you cut back on or eliminate a commitment you have?



How do you currently take care of yourself?

What does self-care mean to you?

When can you carve out time in your schedule each week for yourself?

Mind Health: Depression, Anxiety, and Stress



What you do during your downtime (or personal time) is up to you. ^{5,6}

Use the checklist below to help identify positive activities you'd like to do during your personal time.

- ☐ Deep breathing
- ☐ Meditation
- ☐ Read – consider joining your local library
- ☐ Journal
- ☐ Art – paint, draw, photography
- ☐ Yoga or Tai Chi
- ☐ Nap
- ☐ Zoom or Facetime with a friend/family member
- ☐ Make a special meal
- ☐ Movie or Netflix binge
- ☐ Hobbies – what makes YOU happy
- ☐ Listen to or play music
- ☐ Puzzles
- ☐ Bath
- ☐ Listen to a podcast



Start by listing
10 things you
are grateful for. ⁸



Mind Health: Depression, Anxiety, and Stress



Counseling

It is important to find a mental health professional with whom you connect. Meeting with more than one person to find the right fit is reasonable.

There are different types of mental health professionals. Psychiatrists can prescribe you medications, and they are trained medical doctors. Licensed Clinical Social Workers, counselors, and psychologists are also good options depending on what you are looking for – talk to your doctor to see what type of professional they recommend.²

Often families feel helpless as they watch a loved one suffer from depression. Many will ask, “What can I do?” Family members may be pleased to learn that they can help in several ways. One of the first things to do is to encourage the patient to seek treatment. As a family member or close friend, you may want to specifically describe the changes that you have seen take place in the person’s life and explain the effect that this has on you. Doing research ahead of time and having the names and numbers of therapists to call can make that next step easier.³

Questions to consider asking:³

- Does my insurance cover your services?
Will I have a copay?
- Do you have experience working with people who have MS?
- How do you feel about using medications to treat anxiety and depression?
- What is your approach to treatment?
- Can you tell me about a typical visit?
- Do you work closely with any physicians or doctors?
- Do you work with care partners and family members?
- What are your office hours?
- Is teletherapy an option?



List the questions you would like to ask when looking for a counselor. Any other questions you would like to ask? List them here.

Pathway to Positive Communication and Meaningful Experiences



Since MS impacts families, not just individuals, communication is key.

For family members and care partners of those diagnosed with MS, there is an immediate impact on everyone. Positive communication to keep relationships healthy is essential.



“When I was diagnosed, it was a lot to process. I was having a hard time even making sense of what to say to myself, let alone my family. I especially found it difficult to remain positive for my children—I want to always be there for them, but I was unsure how my MS diagnosis was going to impact my ability to support them.”

Communication^{1,2}

Examples of Positive Communication	Examples of Negative Communication
<ul style="list-style-type: none">• Giving your full attention• Using “I” messages• Being honest and candid• Being aware of the time and place• Listening	<ul style="list-style-type: none">• Turning away from the person• Interrupting or using “you” statements• Judging the person or the situation• Name-calling or placing blame• Using silence to express feelings

What Positive Communication SOUNDS Like:²



“I feel sad when you don’t ask me about my day.”

What Negative Communication SOUNDS Like:



“You never ask me how my day was!”

Pathway to Positive Communication and Meaningful Experiences



Helpful tips for relationships: ^{1,3}

- Take turns sharing, so both partners have the opportunity to feel heard.
- Ask follow-up questions – do not assume you understand.
- Do your best not to take things personally – it can make you defensive.
- Take deep breaths if you feel frustrated or uneasy.
- Ask questions to clarify what happened or your understanding of the situation.
- See a professional to help mediate your conversations. There is no shame in seeking professional support.



Pathway to Positive Communication and Meaningful Experiences



The Power of Family Meetings: Not Just During Stressful Times

Families often discuss stressful situations at the moment. By planning family meetings when everyone is relaxed, you can have more productive and meaningful conversations. You can establish a time for fun family activities, discuss stressors or concerns, and take a moment to express gratitude.⁴

It is beneficial to allow each family member an equal amount of time to share.



Discussion Topics

This activity can work for a pair or a family. Eliminate distractions by turning the TV off and putting phones away.

Select one of the below three topics to discuss with your partner or family. There may be other topics that you'd like to discuss, but below are suggestions along with conversation-starters. Depending on the topics, it could be 2-3 minutes or up to 5 minutes.⁴

Topic: Gratitude

Conversation Starter: "Let's start by stating 2-3 things we are grateful for."

Conversation Starter: "What is one thing that you felt grateful for today? It can be something 'big' or something 'small' - it's important to feel grateful for the 'small' things in life."

Topic: Stressors and Concerns

Conversation Starter: "Is there anything that currently concerns you?"

Conversation Starter: "What is causing us stress. Let's work this out together."

Topic: Solutions

Conversation Starter: "How can we support one another?"

Conversation Starter: "What are the solutions to your concerns?"

Are there other topics and/or conversation starters that you'd like to use as part of your next Family Meeting?

Topic: _____

Conversation Starter: _____

Conversation Starter: _____

Topic: _____

Conversation Starter: _____

Conversation Starter: _____

Pathway to Positive Communication and Meaningful Experiences



Conversation Starters for When Your Family Member Needs Your Support ⁵

Are you worried that a family member might need your support?

Here are a few conversation starters for support. Think about who you are in relation to the person living with MS.

Do you consider yourself a care partner to someone living with MS? If so, here are some conversation starters to help you show that you care and are there for support. ⁵

“Let me help. If you make an appointment with your doctor, I can give you a ride.”

“Can I help remind you to take your medicine?”

“You can call me at any time if you need support.”

“You’re not alone.”

Are you someone living with MS and trying to find the words to ask your care partner for help? If so, here are some ways that may help you start the conversation. ⁵

“I appreciate all you do to help me with my MS. You need to take care of yourself too.”

“How are you feeling? I’m here to listen.”

“Maybe there is someone else who can take me to that appointment. Let’s reach out to _____.”

“You’re not alone.”

Being a parent is a tough job.

If you are living with MS, parenting may be challenging and may leave you wondering how to best support your child as you navigate your journey with MS.



“ It was difficult for us when we found out that mum had MS. She just said I may have MS. Then a thousand questions came up, and she answered I don’t know, I don’t know. I don’t know because she didn’t know either. It was all new to her. I would have preferred someone on the staff to explain what MS means.”

Pathway to Positive Communication and Meaningful Experiences



Telling Your Kids about Your MS Diagnosis

What can you do to help support your child? ⁶

- Do your best to keep your kids informed about your diagnosis. They adapt well.
- Talk to your doctor about your diagnosis and ask questions to feel more informed. Share this information with your family.
- Let your kids know about symptoms and encourage them to ask questions. Open communication will provide them with a sense of control, build trust, and help them feel they can voice their concerns and fears.
- Let them know that they are not the cause of the problem. MS is not contagious. And although there is no cure, there are treatments.

Positive comments for your kids:



“Do you have any questions about what I told you?”

“I’m proud of you.”

“How could I do better next time?”

“I appreciate that you came to me when you didn’t understand...”

“Thank you for asking me. I’m glad we can learn together.”

“Would you like to go to an appointment with me to meet my doctor?”

Pathway to Positive Communication and Meaningful Experiences



If Your Child Has MS



Tip:

Try not to wait to talk to your child about their MS diagnosis. If you are worried about age-appropriate conversations, talk to your doctor or ask them to help you explain what is going on. Children know when something is wrong – you would not want their imaginations to run wild.⁷

What Can We Do?⁷

- ☐ Encourage open and honest communication.
- ☐ Explain that it is important to let you know when they are not feeling well.
- ☐ As much as possible, include them in decisions about their care – this will help them take more control of their diagnosis as they age and with their current treatment plans.
- ☐ Do your best to stay calm when you talk to your kids about MS. The more comfortable you feel the less anxious your kids will be.
- ☐ Especially as they age, encourage your kids to take more control of their medical appointments. Have them talk to the doctor directly, write down questions they have before appointments, and let the healthcare team know if something is confusing.

Pathway to Positive Communication and Meaningful Experiences



Sibling Support: Communication is Key

Having a sibling that is facing the challenge of living with MS can feel isolating. Feelings of jealousy, guilt (that they don't have MS), resentment, and curiosity are common. Keeping them informed and involved will help to address these feelings and make them feel included.⁸

6 Tips to Help “Sibs”⁸

1. Have a particular time each week or month when they get to choose a short activity alone with a parent or guardian.
2. If they feel upset and don't want to talk, have them write their feelings down or draw a picture.
3. Encourage them to ask questions if they are confused.
4. Sometimes siblings are asked to do more chores around the house because their sibling cannot help – acknowledge that and have a small reward.
5. Make a list of fun activities your kids can do safely together.
6. Invite them to come to a doctor's appointment with their sibling to see and understand what happens and encourage them to ask questions.



Pathway to Positive Communication and Meaningful Experiences



Family Activities for All Ages

Setting aside time for your family can be a great way to address stress and improve communication. Create an activity calendar or pick one day a week to have a movie night, family dinner, or go for a walk. It might be a challenge to stick to a routine with busy schedules but do your best to carve out the time and prioritize. It will be fun to have something to look forward to regularly.

Use the below calendar to plot out what activities you'll do this week! Planning activities can be just as fun as doing them.

Monday	Tuesday	Wednesday	Thursday
○ Yoga		○ Volunteer	
Friday	Weekend		
	○ Go for a walk		

Here are some ideas:

- Cook a meal together
- Have a proper family dinner
- Play games
- Puzzles
- Science experiments
- Read
- Have a movie night each week
- Go for a walk, bike ride, hike, kayaking
- Chair Yoga
- Go on an adventure (Geocaching)
- Volunteer
- Art project
- Trivia night
- Lawn games
- Museum
- Scavenger hunt
- Make a Youtube or Tiktok video
- Look for affordable local events

Pathway to Positive Communication and Meaningful Experiences



Keeping Everything Straight

Sometimes communication comes down to keeping everything straight—for yourself and your family. It is typically the person living with MS who receives updates and information from their doctor. It is up to that individual to inform their family. It can be challenging to relay lots of information, and sometimes you might not know how much to share with members of your family.



Tip: Try to take a family member or friend to your doctor's appointments (virtual or in-person depending on what your healthcare providers' policies are). They can help you remember things you want to discuss, take notes, and provide information to your family after the appointment. Moral support goes a long way for the entire family!

Start with trying to keep everything straight for yourself. Here are several suggested ways to do this:

- Create a binder or find an app with information you often need at your finger tips. You can include your notes, lists and other important documents.
- Take notes: Keeping a notebook helps you keep track of what is discussed at appointments and how you're feeling.
- Keep lists:
 - Keep an updated list of your medications. Doctors often ask for your medication list at each appointment.
 - Important contact information.
 - To-dos: remember, setting reasonable goals is important. Sometimes just crossing one thing off of your to-do list can help you feel motivated and energized!
- Keep all of your important documents in one place (a safe space).

Support for Children, Adolescents, and Young Adults



Tip: As your child progresses through school – from the earliest grades to high school graduation, it is important to keep various things in mind. Below are lists of questions and considerations you may want to consider as you support your child through their school-aged years.

REMEMBER: everyone's situation is different, so consider what is right for you, your child, your family and what is in line with your comfort level.

Educating others about MS: ^{1,2}

School nurses, teachers, coaches, etc. might not know about or know anyone with multiple sclerosis. It is important to consider when and with whom you educate about MS and whether or not you disclose your child's diagnosis.

Some basics to cover when thinking about educating others on multiple sclerosis are:

- What is MS in basic terms?
- What types of MS are there?

If appropriate and you feel comfortable, some basic information that you may want to share with your child's school nurse and/or teacher(s) are: ^{1,2}

- What type of MS your child has
- Any medications your child is on and when the medication should be given
- What symptoms your child may experience
- Emergency contact information – who should the school call when something comes up?

Important reminder: information about students must remain confidential. Disclosure is at each student's discretion.

Support for Children, Adolescents, and Young Adults



Time for School: an overview of 504s and IEPs

What is a 504 Plan?

Your child is entitled to services through Section 504 of the US Rehabilitation Act of 1973. It is a civil rights law designed to help parents of students with physical or mental impairments in public schools, or publicly funded private schools, work with educators to develop customized educational plans.^{3,4}

How do students qualify for a 504 plan?

Students can qualify for 504 plans if they have physical or mental impairments that affect or limit any of their abilities (disability that substantially limits a major life activity). Examples of accommodations could include (these are common ones):^{2,3}

- preferential seating
- reduced homework or classwork
- verbal, visual, or technology aids
- adapted physical education
- adjusted class schedules or grading
- verbal testing
- excused lateness, absence, or missed classwork
- pre-approved nurse's office visits and accompaniment to visits
- occupational or physical therapy



Tip: Services between schools can vary - depending on where you live and whether the school is public or private.

Support for Children, Adolescents, and Young Adults



Checklist for a 504 Accommodation

Below is a checklist of things you may want to be aware of about 504 accommodations. Remember: every situation is different.²

- The 504 coordinator or principal at the school may be your first point of contact to request the necessary paperwork.
 - Sometimes paperwork needs to be filled out by you, or your child's doctor. This paperwork may ask you to describe your child's MS diagnosis, current challenges, and why accommodations are necessary at this time.
- Typically, you would contact the school 504 coordinator and the principal to submit the paperwork and request a meeting.
 - Request that key staff is available for the meeting. The school principal or academic advisor will usually set up a meeting consisting of the child's parent(s), the principal, classroom teachers, and other school personnel (such as the school nurse, guidance counselor, psychologist, or social worker). You might request an appointment before the school day begins.
- During meetings:
 - Try to be patient with the school administration and teachers. They may not have much information on MS.
 - Bring information for the staff and nurse to the meeting and let them know you are always available for questions.
 - Take notes.
- If services are approved, the school should provide a written plan.
- If the school denies services, they must notify you in writing on how to appeal the decision.
- Update the 504 plan as needed and as your child ages. Get your child involved and ask what feels comfortable and what they do not feel comfortable with.

Support for Children, Adolescents, and Young Adults



Individualized Education Program (IEP)

The individualized education program (IEP) is a plan that supports students in special education. To determine the need for an IEP, a team at the school will gather data regarding your child's progress or academic challenges. To determine IEP eligibility, a multidisciplinary team of professionals will observe and evaluate your child. The team can consist of teachers, school administrators, therapists, and parents. Things to be considered can include standardized test performance; and daily work such as tests, quizzes, classwork, and homework. The process is more involved than a 504 plan.⁵

Who Needs an IEP?

Students struggling in school may qualify for support services, allowing them to receive support for reasons such as:

- emotional disorders
- cognitive challenges
- visual impairment
- speech or language impairment
- developmental delay
- physical disabilities

The information gathered helps school personnel determine the next step. At this point, strategies specific to the student could help the child become more successful in school. You may request additional methods if the identified approaches are not successful.

Support for Children, Adolescents, and Young Adults



Checklist for an IEP

Below is a check list of things you may want to be aware of about IEPs. Remember: every situation is different. ⁵

- ☐ To start the IEP process, a referral is made to the school counselor or psychologist, typically by a teacher, parent, or doctor.
- ☐ Ask about a timeline of the process.
- ☐ Request a copy of your parent or guardian rights from the school. The rights will inform you of how to proceed if you disagree with any part of the IEP.
- ☐ Gather information about your child's progress or academic and behavioral history.
- ☐ Review specific strategies that may help without additional tests. More testing for impairments may be necessary if this does not work.
- ☐ As a parent, you have a voice when it comes to testing your child. Professionals involved are psychologists, physical therapists, speech therapists, special education teachers, vision or hearing specialists. Ask them questions about the testing and why it is necessary.
- ☐ Team members will create a comprehensive evaluation report (CER), which provides an overview of their findings. If you disagree with the report, talk to the professionals working on your child's plan. Each state is different and may have different policies, procedures and terminology. Be sure to check your states policies regarding IEPs.
- ☐ Identify specific short-term and long-term goals for your child and determine which skills need the most attention.
- ☐ The process is complicated; don't hesitate to ask questions along the way.
- ☐ IEPs can and should change to address the needs of your child each year.

It's important to keep notes as you go. Use a notebook to date and record certain updates. You will be speaking with a lot of different school personnel, so it can be easy to lose track of the details without recording important information for yourself. Parents may consider putting all requests for services in writing.



Tip:

The presence of a disability doesn't automatically guarantee services. The problem must affect functioning at school.

Support for Children, Adolescents, and Young Adults



Transitioning to Adulthood

Independence

As your child becomes a young adult, it is important to help support your child in gaining the skills and confidence needed to ease into adulthood. Below are some additional responsibilities you may want to consider working on with your child – this will look different for every family. ^{6,7}

Tasks to consider:

General Household Chores

- ☐ Laundry
- ☐ Cooking
- ☐ Cleaning
- ☐ Other: _____
- _____

Managing Care

- ☐ Using tools such as MSAA's My MS Manager app, phone reminders, written calendars, etc. to track treatment adherence
- ☐ Engaging in wellness activities regularly
- ☐ Making and going to doctor's appointments
- ☐ Checking in with parents often to discuss progress

Disclosure

Is your teen ready to tell people about MS? It's not necessary, but this is something to discuss and prepare for in advance. A few things you and your teen may want to consider:



Tip: Discuss the pros and cons of telling people.

- It's up to your teen who to tell about their MS diagnosis.
- How much does the person need to know?
- How will your child handle too many questions being asked? Is your teen ready to answer?

Support for Children, Adolescents, and Young Adults



Life After High School

Questions for you and your teen:

- What's next for you? (college, job, vocational)
 - Each state may have their own vocational rehabilitation services that may provide school transition services.
- Will MS impact the decision?
- What concerns do you have?
- What are you excited about?



If your child decides to live close to home or far away, it is still important to discuss an emergency plan.

For example, if your teen is attending college, they may want to:

- Introduce themselves to the health center campus staff, know where the closest hospital is, and find a local neurologist.

Whether your child is moving to a new place, city or college campus, consider the living space layout or location and what day-to-day responsibilities may entail. A few things to consider:¹

- If your child lives in a new place, city or college, consider how easy or not easy it is to get around.
 - For example, if your teen chooses a school that is large and hilly, it could be a challenge to get around when the MS flares up. This may be something you consider when looking for a college.
 - Does the dorm or apartment building have elevators? Or is it a “walk up” with stairs? How easy will it be to get to classes and/or work?
- Think about a social and healthcare network – who can your child call for help?
- If living on a college campus, you may want to consider helping your child:⁸
 - Learn more about what the Center of Disability Rights may offer
 - How and in what ways to coordinate with the college Health Services department

Resources



Several helpful resources are available for those with MS and those supporting someone with MS. Below please find additional resources that you may find useful.

General Resources

[MyMSAA.org](https://mymsaa.org) - MSAA

[Toll-free Helpline and Chat](#) - MSAA

[My MS Manager mobile app](#) - MSAA

Insurance Resources

[My Health Insurance Guide](#) - MSAA

[Health Insurance and Medicare](#) - National MS Society

Mental Health Support Resources



National Suicide Prevention

Lifeline Phone: (800) 273-8255

Textline: Text HOME to 741741 to connect with a Crisis Counselor

Finding a Therapist

[Find a Therapist](#) - *Psychology Today*

Finding a Support Group or Online Community

[My MSAA Community online peer-to-peer forum](#) - MSAA

[Join a Local Support Group](#) - National MS Society

Resources

[Understanding and Treating Depression in Multiple Sclerosis](#) - MSAA

[Managing Depression and Anxiety in MS webcast](#) - MSAA

[Taming Stress with Multiple Sclerosis](#) - National MS Society

Resources for Kids and Teens

Books

[Mommy's Story: An Introduction for Younger Children to Learn about a Parent's MS](#) - MSAA

[Daddy's Story: An Introduction for Younger Children to Learn about a Parent's MS](#) - MSAA

Toolkits

[Kids Get MS Too](#) - National MS Society

[Students with MS & The Academic Setting: Handbook for School Personnel](#) - National MS Society

Resources



Write a letter

Now that you have read *It's a Generational Thing: Creating an Understanding of MS Between Parents and Their Children*, write a letter to your child sharing three things that you learned. These can be things you didn't know or information that resonated with you. Whether you or your child is living with MS, this will help you reflect on what you have learned and will be a special way to let them know you are here for them.



Dear _____,

1. _____

2. _____

3. _____

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