

What to Expect from Rehabilitation Care: A Guide for People with MS



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Introduction to rehabilitation care

Multiple sclerosis can have a significant impact on everyday activities. It can affect many aspects of your daily life, including mobility, personal care, driving, thinking skills and mood. Rehabilitation is key to successfully managing your multiple sclerosis.

Taking charge of your health by seeking help from rehab professionals at all stages of your MS journey is important, particularly soon after your diagnosis. Gathering your team and understanding what each specialist can provide will help you function better in all parts of your life.

This guide is for you, no matter your age or where you are in the course of the disease. You may be newly diagnosed or have had MS for years. Perhaps you are undergoing recent changes. You may be new to rehab or looking to re-engage with your rehab professionals. In all situations, rehab will be helpful.

The goal of rehabilitation is to improve and maintain your function — an important piece of comprehensive care for people living with MS throughout their lives. Rehab should be individualized and tailored to your needs. From the time of diagnosis onward, rehab is a team effort involving you, the necessary healthcare providers and your support partners. Early attention is critical, as is developing a long-term relationship with your medical team. How and when you connect with your rehab professionals will vary based on your needs over time but should ideally be an occasional and ongoing process.

The following guide provides basic information about rehabilitation, wellness and health maintenance, explains the roles of the rehab team and outlines what to expect from a rehab evaluation. It also discusses some of the barriers you may encounter and offers suggestions for overcoming them. Finally, it reviews a few sample MS journeys so you can see how rehabilitation might address real-life symptoms.

Key terms in the world of rehabilitation

Before we begin to talk about rehabilitation, let's define three of the terms that will appear repeatedly in this guide: rehabilitation, wellness and health maintenance.

Rehabilitation

Rehabilitation is an active process in which you and your team work together to identify and execute a plan to strengthen and maintain your ability to perform in areas that are important to you: at home, at work, at school or in the community. Rehabilitation providers recommend customized treatments addressing common symptoms of MS such as fatigue, pain, weakness, swallowing difficulties, speech, mood changes, cognitive challenges, lack of concentration, as well as bowel and bladder problems and difficulties with sexual function.

The goal of rehabilitation is to help you do the activities you want and need to do despite having MS. You might need rehabilitation throughout your life, and it may look different depending on the type of MS you have and the symptoms you are experiencing. Rehabilitation is frequently delivered by a team, which may include physical therapists, occupational therapists, speech language pathologists, psychologists, physicians, nurses, social workers and recreational therapists. The team will get to know you and the difficulties you are facing before coming up with a custom plan. For the best results and experience, actively participate. Think about what is most important to you and use those priorities to set your goals. Rehabilitation includes asking questions, learning and letting your providers know what treatment plan makes the most sense to you. It works best when it is a two-way street with you and your providers sharing ideas and understanding.

Wellness

Wellness includes making choices to be in the best possible health, and is a process that involves the physical, emotional, social, intellectual, spiritual, vocational, financial and environmental aspects of our lives. Examples include making lifestyle choices like deciding to adopt an exercise program or learning strategies to reduce stress.

Health maintenance

Health maintenance focuses on healthy lifestyle choices. It is important to identify known possible health risks, like diabetes or high blood pressure. Health maintenance includes all activities that can promote health, like getting your yearly physical or dental exam and making sure you take your medications. A healthy life focused on wellness may be different for each person, depending on their individual goals and priorities.

MS is with you for life, so wellness and health maintenance are critical to living your life to its fullest. You can be healthy and well, even in light of a diagnosis of MS. You may address wellness goals and questions about health maintenance to your healthcare providers and rehabilitation specialists.



JOYCE (CENTER)
DIAGNOSED IN 2011

Who is part of the rehab team?

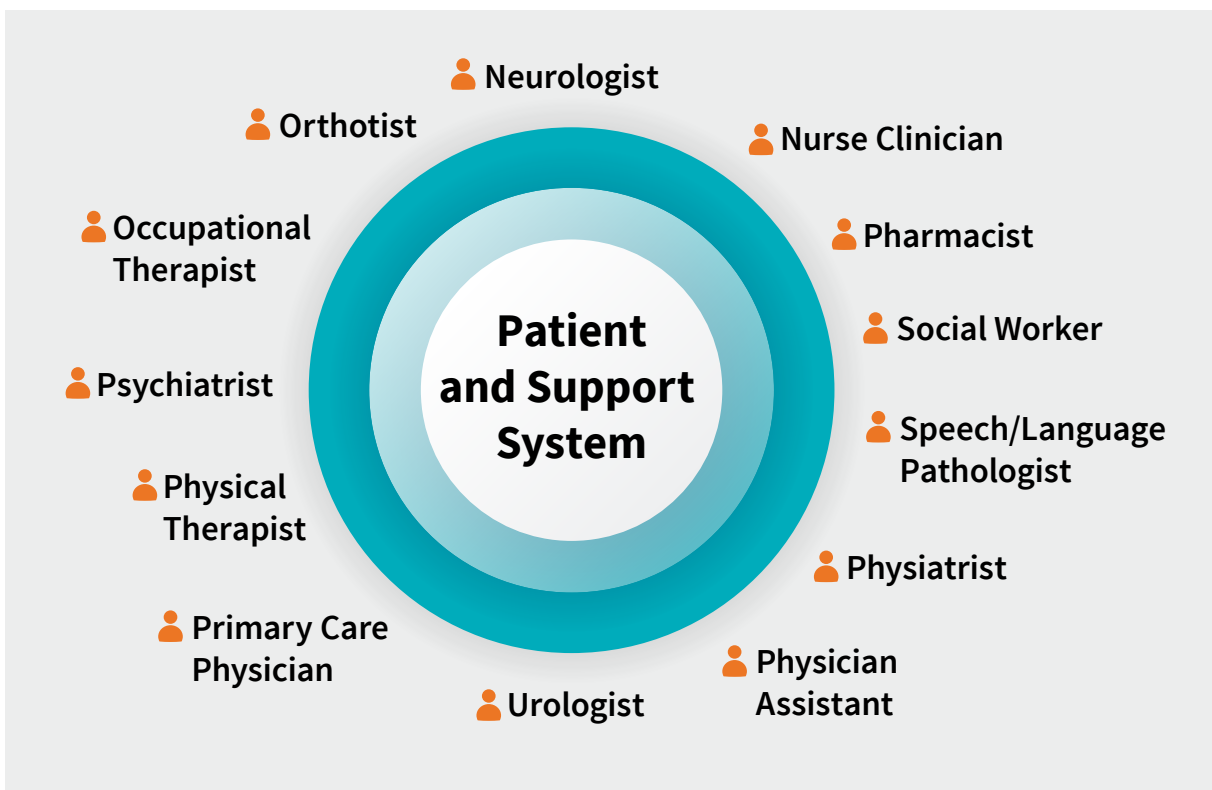
MS rehab takes a multidisciplinary team approach to care and interventions. This means that many different professionals will work together to help you navigate your MS symptoms. A rehabilitation physician, physiatrist or neurologist often directs the team, but YOU are its most important member.

You will need different team members at different times, and you may see those professionals intermittently throughout the course of your care. Which team members take part in your care will depend on your current needs, available resources and, sometimes, insurance coverage.

For more information on team members and their roles, click on the following links:

- [The National MS Society's Rehabilitation webpage](#)
- [AAPM&R's What Is a Physiatrist?](#)
- [What to Expect From Mental Healthcare: A Guide for People With MS](#)

Multi-disciplinary team approach



What to expect from a rehab evaluation

Most facilities require a referral or prescription from your doctor to see a rehab therapist. To get a referral, be open with your healthcare provider about your symptoms and any physical or emotional challenges you are experiencing. Because your physician may be addressing many issues in an appointment, it may be up to you to ask for the referral to rehab. Being an active participant in your overall plan of care is essential. Your time with each therapist will start with an evaluation.

Physical therapy



Your physical therapist will ask you for information about your past activities, job, current living situation, hobbies, interests and exercise routine. They will identify your ability to move, walk and balance safely, among others.

They will also ask you about other possible symptoms that may not be related to physical movement such as:

- Do you cough or choke while eating or drinking?
- Do you have difficulties falling asleep or sleeping through the night?
- Do you have difficulties dressing yourself?

This conversation enables them to refer you to the appropriate specialist. During the evaluation, they will assess posture, coordination, swelling, your ability to feel different sensations and changes in muscle tension and strength. They may look at how you get up and down from a chair or the floor, move around in bed, and walk on flat surfaces or climb stairs, as well as how stable you are when you do these activities. At the end of the evaluation, you and your therapist will discuss goals and recommendations for continued therapy.

Occupational therapy



Your occupational therapist will ask about your daily routines and what you need to be able to do to perform them. They will ask about how you take care of yourself (dressing, showering, toileting), how you care for your home and family (cleaning, bill paying, grocery shopping, childcare), how you do your job and how you relax. They will identify areas that are difficult and develop ways to make them less so. In addition, they may look at wellness behaviors (sleep, exercise, eating, sex, eliminating waste), evaluate your need to make changes and recommend equipment to keep you independent. Like all of your rehab professionals, your occupational therapist may make referrals to other professionals if needed. A complete screening may take multiple visits. At the end of the evaluation, you and your therapist will work together to develop a plan for future visits.

Speech therapy



Your speech-language pathologist (SLP) will gather information about your past abilities, your current or previous job, your living arrangements and your hobbies and interests. They will also ask how your current MS symptoms are affecting you. Your speech-language pathologist will screen for swallowing difficulties, speech and voice changes and thinking skills. They will consider whether or not adaptive equipment might help you. They may recommend additional tests to take a closer look at your ability to swallow. If various areas need evaluation, testing might occur over a few sessions. Once your therapist completes the evaluation, they will work with you to develop a treatment plan for future visits.

Rehab physician



The primary goal of the doctor is to diagnose and treat medical problems.

MS can cause many common problems, such as pain, weakness, fatigue, memory challenges, swallowing difficulty, vision problems and bowel and bladder issues. The doctor's job is to figure out what is causing these symptoms and help you make a plan to treat them. During your visit, your doctor will ask you when your symptoms started, what you have done about them and how they are changing. The cause of your symptoms may be MS or something else. You can expect your doctor to ask questions and order tests and treatments. Some treatments may be medications and some may be therapies or equipment. You should expect your doctor to listen to you and your family members, talk to you in language you comprehend and include you in making decisions. At the end, your doctor should make sure you understand everything.

Mental health



Rehabilitation psychologists are specially trained to study and work with individuals with disabilities and chronic health conditions. They can help their patients learn how to adapt and make lifestyle choices that promote good health. Other mental health professionals who work with MS include neuropsychologists (who assess thinking, reasoning and concentration symptoms), health psychologists, social workers, counselors, and therapists. It is recommended that you seek help from someone that, at a minimum, has experience working with individuals living with chronic illnesses.

Top 10 barriers to accessing rehabilitation services and how to overcome them

Many barriers may prevent you from accessing therapy services. Here are some common problems and suggestions for overcoming them.

1 Transportation to clinic

Getting to the clinic is difficult if you are unable to drive or don't have someone to assist you. Speak with your provider or therapy clinic to investigate other transportation options. Some insurance plans cover transportation to medical and therapy appointments. You may need to work with your therapy team to come up with a schedule that works with your transportation options.

2 Family/care support

Having **a strong support system is important**. In addition to friends and family, look for opportunities to connect locally with people affected by MS to find support. If your support system is overburdened, your rehab providers may offer carepartner support resources as well.

3 Fatigue

Fatigue plays a major role in our motivation and ability to participate in therapy. Fatigue management will be part of your rehab therapies. Your therapy team will help you develop strategies to better manage day-to-day tasks, work and family responsibilities. These strategies will be flexible and may change over time if your needs change.

4 Bowel/bladder issues

Fear of having an accident is common and can make you feel uncomfortable about leaving your home. Speak with your rehab doctor (physiatrist), urologist, primary care provider or occupational therapist to develop a plan for bowel and bladder management to allow you to participate in activities in and out of the home. It can be helpful to identify restroom locations in your plan. For many people, it is reassuring to wear absorbent products, such as pads or briefs, or to carry an extra set of clothing.

5 Weather

Extreme conditions, such as very hot or cold weather, can make your symptoms worse. You may find that, if you get too hot, your walking or balance isn't as good or your vision changes. These changes are temporary but need to be managed. Using cooling devices and/or wearing several layers of clothing can help prevent these symptom fluctuations due to the temperature changes.

6 Access to telehealth visits

Although telehealth visits have increased access for many people, they still have some limitations. Perhaps you don't have a computer or internet connection. Some insurance plans might not cover virtual visits, so it is important to check with your provider. And some issues must be assessed during a face-to-face visit, so a video appointment is not an option.

7 Insurance limitations

Insurance frequently pays for therapy visits. However, some insurance policies do not provide coverage for therapy or may only approve a certain number of visits per year. Make sure your therapist is aware of any limitations so you can work together to develop the best therapy plan for you. If you don't have insurance coverage, ask if there are non-coverage payment options, grant opportunities or a local university that provides free therapy. Speak with your insurance carrier to see if another setting such as a private clinic is covered as opposed to a clinic associated with a hospital.

8 Limited English

If you do not speak English or are not confident in speaking it well, try to find a therapist or clinic with bilingual staff. When you call to make an appointment, ask about availability of interpreting services.

9 Education or attitude toward therapy

A lack of understanding about the benefits of therapy can be a barrier to participating in rehabilitation services. This may be because you, your support system or your medical provider aren't aware of how therapy can help. If you aren't sure therapy is right for you, ask for more information on what areas of your life rehab can improve.

10 Time

If you have a lot of doctor appointments, a busy work schedule or childcare responsibilities, the idea of more appointments for rehabilitation therapy can be daunting. It may be helpful for you to find therapists who offer evening or weekend appointments to fit your needs and schedule. Also, ask your rehab team to help you prioritize your appointments when you don't have time to do it all.

THINGS YOU CAN DO RIGHT NOW



Work with your healthcare providers to add **exercise** into your daily routine.

Work with a professional mental health counselor or psychologist to learn ways to better manage **stress, anxiety and/or depression.**



Attend cognitive behavioral therapy (CBT) sessions if recommended by your neurologist or care provider.

Work with your healthcare provider and/or nutritionist to incorporate healthy eating habits.



Work with your speech-language pathologist or occupational therapist to learn strategies to improve organization, thinking, communication and memory.

Engage in cognitive challenges such as word games and puzzles, including apps, that are supported by research.



Remain socially active by engaging with friends, family, local support groups, etc.

Finding a rehab professional

Choosing the right rehabilitation professionals is a crucial step in your journey. This process may feel overwhelming for you and your family. When choosing a facility or provider, these questions may help ensure you receive care that meets your needs:

1 What are my needs at this time? What rehabilitation options are there for me?

- Depending on the level of care you require, treatment may include outpatient therapy, a stay in a facility, or at-home therapy.

2 What rehab professionals will I have access to? (PT/OT/SLP/mental health professionals, etc.)

3 Does the facility or rehab professional meet my rehab needs?

- How experienced is the staff in working with people who have MS?
- How many patients have they treated with MS?
- What programs and services do they offer for people with MS?
Are education programs, training and support groups available?

8 resources to help

The organizations, services and tools below will help you locate rehab professionals in your area.

- 1 Contact one of the Society's **MS Navigators** for more information or for a recommendation to a rehabilitation specialist in your area.
- 2 The Society's **Find Doctors & Resources tool** can help you locate a rehab specialist with expertise in treating people with MS.
- 3 The **American Academy of Clinical Neuropsychology** features an online search tool to locate board-certified clinical neuropsychologists. Learn about **adult neuropsychology**.
- 4 The **American Academy of Pediatric Neuropsychology** offers an online search tool with which you can find board-certified pediatric neuropsychologists. Learn about **pediatric neuropsychology**.
- 5 The **American Academy of Physical Medicine and Rehabilitation** provides an online search tool to locate physiatrists.
- 6 The **American Physical Therapy Association (APTA)** houses information and an **online search tool** to locate APTA member physical therapists. View tips for **choosing a physical therapist** and **preparing for the visit**.
- 7 The **American Speech-Language-Hearing Association** can help you find certified speech-language-hearing pathologists (SLPs) and audiologists using their online search tool. SLPs address **speech, language or swallowing concerns** while audiologists address **hearing issues**.
- 8 **The Consortium of MS Centers (CMSC)** has compiled a list of MS member centers.



MARQUES
DIAGNOSED IN 2010



SHEEL (R)
DIAGNOSED IN 2014

MS journeys: examples of rehab experiences


The rehabilitation journey is unique to every individual living with MS. Below are three stories, each describing the experience of a person who has MS, how their symptoms affect their activities and how rehab specialists can help that person live their best life with MS.

MARY'S JOURNEY

Mary is a 25-year-old nurse in a local hospital. She was diagnosed with multiple sclerosis two months ago. After a long workday, she struggles to walk to her car; her legs feel weak and her foot drags. Her vision gets blurry, so sometimes she must sit in the car with the air conditioning on for a few minutes. Mary often feels self-conscious because she must quickly find a bathroom when she has to urinate. She has stopped going to the gym and dating due to this. She feels overly tired and foggy sometimes. She is concerned about making a mistake at work and is fearful someone is going to find out that she is “sick.”

How can rehab professionals help Mary?

A physical therapist can:

- Assist her in developing a home exercise program (stretching, strengthening, aerobic conditioning and balance) and assist with a transition to a community-based exercise program 
- Explore options to address walking issues and recommend exercises and/or external supports such as a brace
- Offer education on energy-management techniques as well as exercises to prevent deconditioning
- Offer education on heat sensitivity and assist with obtaining cooling products
- A pelvic health specialist, which is a specialized physical therapist, can assist with bladder management and retraining, sexual health and wellness.

An occupational therapist can:

- Assess vision and develop appropriate exercises or strategies to minimize impact on day-to-day activities, including work 

- Offer education on energy-management techniques as well as assist in developing strategies for work/home/life balance
- Assess and develop strategies to manage thinking skills issues
- Make recommendations for modifications to home and work environments to optimize posture and vision, and minimize fatigue

A Speech-Language Pathologist can:

- Assess and develop strategies for managing cognitive issues, especially memory, attention, and executive function, to remain successful at work and home
- Make recommendations for work modifications for fatigue management (extra breaks during the workday, prioritizing workload, etc.)



A mental health professional can:

- Offer education on strategies for managing uncertainty about the future
- Identify strategies for managing fear of bladder accidents or visible symptoms to maintain activities and relationships
- Discuss the benefits and potential consequences of workplace disclosure



If Mary needs or wants accommodations at work, a psychologist can also write a letter to support her accommodation requests.

A physiatrist can:

- Assess bladder function and help determine why her bladder isn't working
- Check for a bladder infection, examine retention and prescribe medications to help, as needed
- Rule out other reasons for fatigue like thyroid problems or anemia
- Discuss medications to improve her ability to walk
- Coordinate referrals to other providers, including memory testing, vocational rehab and bracing



All of Mary's rehab team members can:

- Help Mary achieve success at work and home
- Promote her mobility
- Help her engage in all of her desired activities



KEY POINTS

- Build your rehab team early! Getting early assistance can prevent some future issues and improve your quality of life.
- Tell your rehab team what is important to you. They are there to meet your needs and priorities.

KAREN'S JOURNEY

Karen is a stay-at-home mom who lives with her husband and two teenage sons. She was diagnosed with MS 10 years ago but has noticed lately some numbness and burning in her feet and hands, which keeps her up at night. When getting up from a chair, she feels stiff, and if she sits too long, it is hard for her to get moving. When she gets tired, her words slur, and she is afraid that people will think that she is drunk. Also, when she speaks to friends on the phone or is out in the community with her family, they have a hard time hearing her. Karen is turning down social invitations because she is self-conscious about her symptoms. She is worried she is missing out on being a part of her family and that she is not the type of mom she wants to be.

How can rehab professionals help Karen?

A physical therapist can:

- Assess Karen for abnormal stiffness (spasticity) and design an exercise program to manage this symptom
- Work with medical team to explore medication and other treatments to minimize stiffness
- Assess balance and develop balance interventions
- Offer education on preventing falls
- Work on getting up and down from the floor safely
- Assess for assistive device for long-distance walking or when fatigued
- Offer education on strategies for managing abnormal sensations
- Update previous home exercise program; continue to support community-based exercise programs



An occupational therapist can:

- Offer education and exercise for fatigue management
- Offer education on strategies for abnormal sensations and safety for any sensory loss
- Update previous home exercise program
- Discuss and educate on improving quality of sleep
- Perform a home evaluation for safety and optimal energy conservation and suggest modifications/recommendations, either in person or with photos brought to the therapist



A Speech-Language Pathologist can:



- Develop exercise program and strategies for improving speech
- Offer script training for improved intelligibility of functional phrases or questions that are meaningful to her
- Teach breath support exercises for improved coordination of breath while speaking for improved intelligibility, rate of speech and volume of speech
- Make recommendations regarding augmentative or alternative communication, as needed, such as text to speech application on phone or a voice amplification system to conserve energy while communicating in louder environments (restaurant, family sporting event, etc.)
- Offer training in positioning and strategy for clear speech (facing communication partner; over-articulation, pacing/rate adjustments)
- Teach exercises for muscles in mouth that are used for communication for precision of movements

A mental health professional can:



- Work on strategies to prevent or reduce insomnia using cognitive behavioral therapy (CBT)
- Offer education about the interaction between cognition and emotion to encourage continued use of language and conversation despite slurring
- Use cognitive behavioral therapy strategies to address unhelpful thoughts around what people think of her and her symptoms
- Implement acceptance and commitment therapy (ACT) techniques to identify values and valued activities, as well as ways to engage in those activities despite uncomfortable emotions

A physiatrist can:



- Screen for other reasons for Karen's numbness and tingling, like diabetes
- Discuss medications for stiffness management
- Look at other factors that may be contributing to fatigue, such as thyroid issues, anemia and sleep apnea
- Consider medication
- Make referral to rehab psychologist for coping strategies
- Review medications and make sure they are not contributing to fatigue

All of Karen's rehab team members can:



- Teach her to be safe
- Help her maintain her role in the family

KEY POINTS

- Managing your MS symptoms is a key component of what your rehab professionals will assist you with.
- Meeting with your rehab team on a regular basis is important to address issues early and make changes to your plan as needed to prevent bigger issues in the future. You should be having regular checkups with your rehab team, just as you do with your medical team.
- Rehab should be intermittent and ongoing. You may need to see your rehab professionals more often if you develop new symptoms, experience an exacerbation or are falling. MS is a changing disease. It is normal to have times when adjusting to the disease is discouraging. Reaching out to others with MS and to your rehab team can provide meaningful support.

JERRY'S JOURNEY

Jerry is a 68-year-old Veteran who has been living with MS for many years. He lives in a long-term care facility, where he has a circle of friends with whom he enjoys playing cards and eating meals. Jerry began using a power wheelchair because walking was fatiguing and he fell almost daily. He enjoys video chatting with his grandchildren and being outdoors. Lately, he has had difficulty holding his playing cards and accessing his phone or tablet. Sometimes he even has trouble pushing the button to turn on his power wheelchair. The last time he had lunch with his friends, he found himself dropping food on his lap and having a coughing spell. Jerry seems to be spending more time in bed and is more fatigued despite thinking that he sleeps a lot.

How can rehab professionals help Jerry?

A physical therapist can:

- Assist Jerry with appropriate exercises to limit deconditioning, maintain/improve strength and decrease fatigue
- Update home exercise program
- Assist with activities such as supported standing to decrease risk of skin breakdown, maintain bone density and assist with physiological functions such as breathing, digestion, bowel and waste elimination
- Explore alternate options for operating power mobility device and access to the environment
- Work on maintaining function, such as moving in bed and transferring into and out of his wheelchair
- Explore equipment that might assist with these activities
- Offer education on preventing falls during his mobility



An occupational therapist can:

- Assist with appropriate exercises to limit deconditioning, maintain or improve strength and manage fatigue
- Update home exercise program
- Work on fine motor coordination to help Jerry access his phone and play cards
- Evaluate and make recommendations for adaptive equipment to make daily tasks easier
- Work on maintaining function in activities of daily living, such as dressing, eating, driving and leisure activities



A Speech-Language Pathologist can:



- Collaborate with the seating specialist (physical or occupational therapist) regarding alternate access to phone and tablet, such as voice-recognition software, as well as alternate access to environment
- Assess swallowing and make recommendations for changes to diet and exercises and strategies to make swallowing safer
- Evaluate Jerry, if appropriate, for respiratory muscle strength training to improve or maintain current cough function for airway protection and reduced risk of developing aspiration pneumonia (when food, liquid or saliva goes down the “wrong pipe,” entering the airway and causing bacteria to form in the lungs)

A mental health professional can:



- Assess Jerry for depression and hopelessness
- Identify and address symptoms of grief and loss
- Teach Jerry to move between feelings of grief, loss, frustration, acceptance and problem solving
- Encourage continued engagement with friends
- Help Jerry work with peers to identify their strategies and journeys through progressive symptoms

A psychiatrist can:



- Assess for medical problems that are not MS but may be contributing to fatigue, such as cardiac issues, pulmonary issues, anemia, thyroid disorders, sleep problems, diabetes, nutritional issues, infection, substance abuse and medication-related fatigue
- Assess for MS worsening and change disease-modifying therapy if needed
- Discuss potential medication treatments for fatigue
- Facilitate referrals to PT, OT, speech and mental health professionals

All of Jerry’s rehab team members can:



- Help him maintain the greatest level of independence in all of his desired activities
- Encourage Jerry to maintain good health

KEY POINTS

- It is never too late to access rehab. Much can be done, even if your function has declined.
- Many technologies can help you stay connected to people or assist you with daily tasks. Seeking professional advice to match the right product to your needs is important.
- Devices such as wheelchairs or walkers can help you remain independent and continue to engage in the activities you want to participate in.
- Not all symptoms are MS related. It is important to be thoroughly evaluated for other possible causes and treatments, instead of being told, “it’s just your MS.”