

# MS Relapse Toolkit

Helpful tools for understanding MS relapses, learning about treatments, and preparing for these unexpected flare-ups in disease activity



*MSAA*

MULTIPLE SCLEROSIS  
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# Introduction

From carpenters to artists and writers to gardeners, the essential tools found in a toolkit are designed to help build or achieve an important goal. Tools include not only helpful equipment, but information and/or instructions as well. For example, a carpenter needs tools, materials, and a blueprint, for building a structure... and for a gardener, common tools include a spade, rake, and a watering can for growing flowers.

In this case, the goal is to better recognize MS relapses, their treatments, and their impact on daily life. The tools in this *MS Relapse Toolkit* include useful information, treatment descriptions, and forms to complete. With these tools, you'll be able to build a more thorough understanding of MS relapses, which will help you to know what to expect, reduce anxiety, and prepare for the possibility of a relapse in the future.





**The *MS Relapse Toolkit* includes:**

- Informative details on relapses and symptoms
- Important checklists to share with your doctor and family
- What to discuss with your healthcare team
- Planning ahead for a possible relapse
- FDA-approved and experimental treatment options
- Crossword puzzle with relapse-related terminology

The authors of this toolkit hope that you find the information to be useful in helping you to manage your MS relapses. Knowing what to expect, how to plan ahead, and having information ready for your neurologist will avoid the confusion and last-minute scrambling to accommodate the temporary – but often very significant – changes in symptoms during a flare-up of one’s MS.

For additional information about MS relapses, treatments, and helpful resources, please visit MSAA’s online **MS Relapse Resource Center** at **[relapses.mymxaa.org](http://relapses.mymxaa.org)**. For general information about MS – including important details on disease-modifying therapies, symptom management, wellness strategies, research news, and more – please visit **[mymxaa.org](http://mymxaa.org)**.



# What is an MS relapse?



## ***Relapse Facts***

- ✓ Inflammation along nerves and myelin
- ✓ New or worsening symptoms
- ✓ Symptoms must be present for at least 24 to 48 hours, without a fever
- ✓ **Duration of a few days to a few months**

Relapses, also referred to as exacerbations, attacks, flare-ups, episodes, or bouts, are experienced by most people diagnosed with multiple sclerosis (MS). When someone experiences a relapse, he or she may be having new symptoms or an increase in existing symptoms. Relapses occur with relapsing-remitting, progressive-relapsing, and sometimes secondary-progressive forms of MS. Relapses do not occur with primary-progressive MS, although individuals may experience day-to-day fluctuations in how they feel.

During a relapse, inflammation is occurring along the nerves and the myelin, causing people with MS to have a temporary worsening or recurrence of existing symptoms and/or the appearance of new symptoms. This can range from a few days in duration to a few months, followed by a complete or partial recovery (remission). Acute physical symptoms and neurological signs must be present for at least 24 to 48 hours, without any signs of infection or fever, before the treating physician may consider this type of flare-up to be a true relapse.

# What is a “pseudoexacerbation”?



## ***Pseudoexacerbation Facts***

- ✓ Not caused by new damage
- ✓ Brought on by other influences
- ✓ Urinary tract infection is most common cause
- ✓ **Usually subsides within 24 hours**

It is important to know that occasionally symptoms are not caused by new damage and these flare-ups are called pseudoexacerbations. A pseudoexacerbation is a temporary worsening of symptoms without actual myelin inflammation or damage, brought on by other influences. These can include other illnesses or infection, exercise, a warm environment, depression, exhaustion, and stress. When symptoms flare, checking for a fever is important, since even a minor infection and slight increase in temperature can cause symptoms to appear.

Urinary tract infection (UTI) is the most common type of infection to cause a pseudoexacerbation. Additionally, people with “heat-sensitive” MS will experience a temporary increase in symptoms when their body temperature rises, often after exercise. Many heat-sensitive individuals may opt to avoid hot tubs, saunas, or other situations that can raise the body’s temperature. Cooling vests and other types of cooling apparel or devices may be used, and these are often helpful for people with heat-sensitive MS to keep their body temperature down while in a warm environment.

While a pseudoexacerbation is a flare-up of symptoms, similar to a relapse, it is not caused by an increase in disease activity. Instead, it’s usually caused by various types of physical stress that impact your overall health. Once the cause of the stress is resolved, this type of symptom flare-up will usually subside within 24 hours.

# What are the common symptoms of an MS relapse?

MS is known for causing a wide variety of symptoms, but those listed below are some of the more common symptoms that may arise (or worsen) during a relapse.

- Changes in vision
- Numbness
- Issues with muscle functioning or spasms
- Tremor
- Difficulties in walking or balance
- Extreme fatigue or weakness
- Difficulty speaking
- Problems with memory or attention
- Reduced sensation, or increased, painful sensation





# Is this a relapse or a pseudoexacerbation?

You should call your neurologist or healthcare team about the possibility of a relapse when the following criteria are met:

- The new or recurring symptom(s) has been present for at least 24 to 48 hours
- If it's been less than 24 hours but your symptoms are severe and could affect your health or safety
- You do not have a fever or any other signs of infection, e.g., a urinary tract infection
- Your body is not overheated, which may result from the temperature around you, exercise, etc.
- You didn't overexert yourself today and do too much
- You aren't having an unusually stressful day

It's important to note that you should not dismiss symptoms simply because you feel that you may have been under significant stress as of late.



# Questions to ask when developing a plan with your healthcare team

Developing a plan with your neurologist about what you should do and whom you should contact when you are experiencing a relapse is important. This plan should be developed in consultation with your medical team before you have a relapse, so that both you and your healthcare team know what to expect when a relapse occurs. To follow are questions to ask your doctor:

- Whom should I contact in your office when I am experiencing a relapse?  
Name of healthcare practitioner: \_\_\_\_\_  
Phone: \_\_\_\_\_
  - If I am experiencing a relapse, when should I contact your office? For example, should I call the office at the first sign of a relapse or within 24 hours of experiencing the symptoms of a relapse? \_\_\_\_\_
  - What information will you need from me when I call to report a relapse? \_\_\_\_\_  
\_\_\_\_\_
  - What are your treatment protocols for relapses? \_\_\_\_\_  
\_\_\_\_\_
  - How will I know if the treatment is working for me? \_\_\_\_\_  
\_\_\_\_\_
  - When was my last relapse and how was it treated? \_\_\_\_\_  
\_\_\_\_\_
- Did any problems or issues come up during the course of treatment that should be discussed? \_\_\_\_\_
- Would I be willing to take the same treatment again? \_\_\_\_\_
- How do I follow-up after the treatment? \_\_\_\_\_
- How else can I plan in advance for a relapse? \_\_\_\_\_

# Medical Team Information

**Neurologist:** \_\_\_\_\_

Phone: \_\_\_\_\_

Affiliated Hospital: \_\_\_\_\_

**Primary Doctor:** \_\_\_\_\_

Phone: \_\_\_\_\_

Affiliated Hospital: \_\_\_\_\_

**Nurse/Nurse Practitioner/Physician Assistant:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Psychologist/Mental-Health Specialist:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Social Worker:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Home Care Attendant:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Physical Therapist:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Occupational Therapist:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Speech Therapist:** \_\_\_\_\_

Phone: \_\_\_\_\_

**Other:** \_\_\_\_\_

Phone: \_\_\_\_\_

# Contact information for your support team of family and friends

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

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Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

# Medication List

Keep your medication list up to date, so in case of a relapse, you can accurately report this information to your healthcare provider(s). Some medications could be causing new or worsened symptoms as a side effect, or they may possibly interfere with other treatments.

Pharmacy Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
Phone Number: \_\_\_\_\_  
Insurance: \_\_\_\_\_  
Policy Number: \_\_\_\_\_  
Group Number: \_\_\_\_\_  
Insurance Contact Info: \_\_\_\_\_

## Medication #1

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_

## Medication #4

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_

## Medication #2

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_

## Medication #5

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_

## Medication #3

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_

## Medication #6

Name: \_\_\_\_\_  
Dose: \_\_\_\_\_  
Frequency: \_\_\_\_\_  
Notes: \_\_\_\_\_



# What should you tell your doctor when you call?

While speaking with your doctor, you need to be as specific as possible while describing the symptoms that you have been experiencing. To follow are some basic questions your doctor may ask:

- When did your symptoms begin, how did they make you feel, and how are they limiting or changing your daily activities and overall function?
- Have any changes been made to your MS-treatment plan?
- Has a new medication been added to your regimen for a condition not related to MS?
- Have you recently given birth?
- Have you had any vaccinations within the past three months?
- Have you experienced any significant changes in your life or stressful situations since you last met with your physician?
- Has another healthcare provider, other than your neurologist, been involved in your care and treatment recently?
- How would you describe your fatigue level, and how would you describe your mood?

You may wish to track your symptoms so you can provide accurate details about your MS to your doctor. MSAA's mobile app, **My MS Manager™**, can be used to track this information, or you can journal in a notebook. Please visit [mymsaa.org/mobile](http://mymsaa.org/mobile) for more information.



# What should you expect when you see your neurologist?

Your neurologist or healthcare provider will test for an MS relapse by performing a neurological exam to see what changes may have occurred since you were last seen. Your physician will also test for any signs of illness or infection, to rule out that possibility. If you have an illness or infection, this will need to be addressed before your symptoms subside. If your neurologist determines that you are having a true relapse, he or she will then discuss possible treatment plans.

Although most relapses remit or resolve on their own over time, neurologists usually recommend treatment when the symptoms are severe enough to affect a person's ability to function normally. Early treatment may shorten the time to recovery. However, if you have less intrusive symptoms (as with a mild attack), such as numbness or spasticity, you and your neurologist may elect to use symptom-management strategies, reserving stronger treatments for a more severe relapse.



# Treatment Options

To follow is a list of some of the medications and therapies that may be used in the treatment of an MS relapse. Not all of these treatments are approved by the United States Food and Drug Administration (FDA) specifically for the treatment of MS.

## Corticosteroid Overview

The corticosteroids listed below are approved by the FDA for the treatment of MS relapses. They may be given via intravenous (IV) infusion, intramuscular injection (IM), or orally (by mouth). However, each one typically has a preferred route of administration, which is noted where relevant.

- Solu-Medrol® (IV methylprednisolone)
- Prednisone
- Decadron® (dexamethasone)

## Details on Corticosteroids

Corticosteroids work by reducing inflammation in the central nervous system (CNS). While they usually lessen the severity and duration of a relapse, they may not affect the long-term progression of the disease.

When treatment is required, relapses are usually treated with a high-dose course of powerful corticosteroids (a type of steroid) over a period of three-to-five days. These are given by intravenous (IV) infusion, introducing the drug directly into the bloodstream for a quicker response. Administration may be performed in a hospital, infusion center, or sometimes at home.

The corticosteroid Solu-Medrol (methylprednisolone) is frequently used to treat an MS relapse via IV infusion. In practice, doctors may sometimes prescribe the corticosteroid Decadron (dexamethasone) in place of methylprednisolone. Occasionally, but not often, an “oral taper” may be prescribed after a high-dose IV treatment to ease the patient off the treatment. Tapered over one-to-two weeks, oral forms of prednisone or Decadron are commonly used for this purpose.

As noted, Solu-Medrol or Decadron is usually given in large doses via IV infusion to initially treat an MS relapse. However, either of these corticosteroids may be given orally when IV infusions are not practical or appropriate for an individual. This enables patients to receive the high-dose treatment for a relapse without leaving their home or requiring a medical professional to administer an IV. However, many pills are required to equal the same dose as that given via IV. While still controversial, this method of administration has been gaining support among some MS experts.

### Additional Treatment Options Overview

Of the following three additional treatment options, only the first one – ACTH – is approved by the FDA specifically for the treatment of MS relapses. The latter two have not been FDA-approved specifically for MS relapses. Clinical trials have yielded mixed results.

- Acthar<sup>®</sup> Gel (ACTH) – injected either into the muscle (intramuscularly) or under the skin (subcutaneously)
- Plasmapheresis (plasma exchange or PE)
- Intravenous immunoglobulin (IVIG) therapy

### Details on Additional Treatment Options

#### **FDA-Approved ACTH**

ACTH (brand name, Acthar<sup>®</sup> Gel) is also approved by the FDA to treat MS relapses and has been used as an alternative to corticosteroids for more than 30 years. This may be helpful for individuals who are not able to tolerate the side effects of steroids, who have found that previous treatments were not effective, or who may have difficulty getting timely medical support for IV infusions. Studies suggest that the effectiveness of ACTH is similar to corticosteroids.

ACTH contains a highly purified form of the hormone adrenocorticotropin in gelatin. It is given once daily for two-to-three weeks and is injected either into the muscle or under the skin. The ACTH is then absorbed slowly into the bloodstream. ACTH works differently than corticosteroids by helping the body to produce its own natural steroid hormones that reduce inflammation and aid in recovery.

#### **Experimental Therapies**

Experimental therapies include plasmapheresis (also known as plasma exchange or “PE”) and intravenous immunoglobulin (IVIG). Neither of these is approved by the FDA specifically for MS relapses, but either therapy may occasionally be used for individuals who are experiencing a severe relapse and are not responding to other treatments. With PE, blood is taken from the patient, cleansed of potentially toxic elements, and returned to the patient. IVIG therapy uses human immunoglobulin, an antibody derived from the blood of healthy donors. With both of these therapies, more studies are needed to determine their effectiveness in the treatment of MS relapses.



# In what other ways can I plan in advance for a relapse?

Relapses occur without warning, and depending on your individual symptoms, can greatly impact your ability to perform everyday tasks. Developing a plan for coping with these types of changes can be very helpful. Individuals need to consult with their care partner and family members to ensure they are prepared. Counselors and MSAA's Helpline specialists can also provide assistance in adequately planning for these unpredictable events.

**Families:** If an individual with MS also plays a role in the care of his or her family at home, many responsibilities must be planned for in advance. Talking to your family members and care partners about relapses will help to prepare them for what your needs might be and how they may be able to assist. Things to consider include:

- Child care
- Transportation to your medical appointments
- Meal preparation
- Pet sitting/walking
- Other household duties





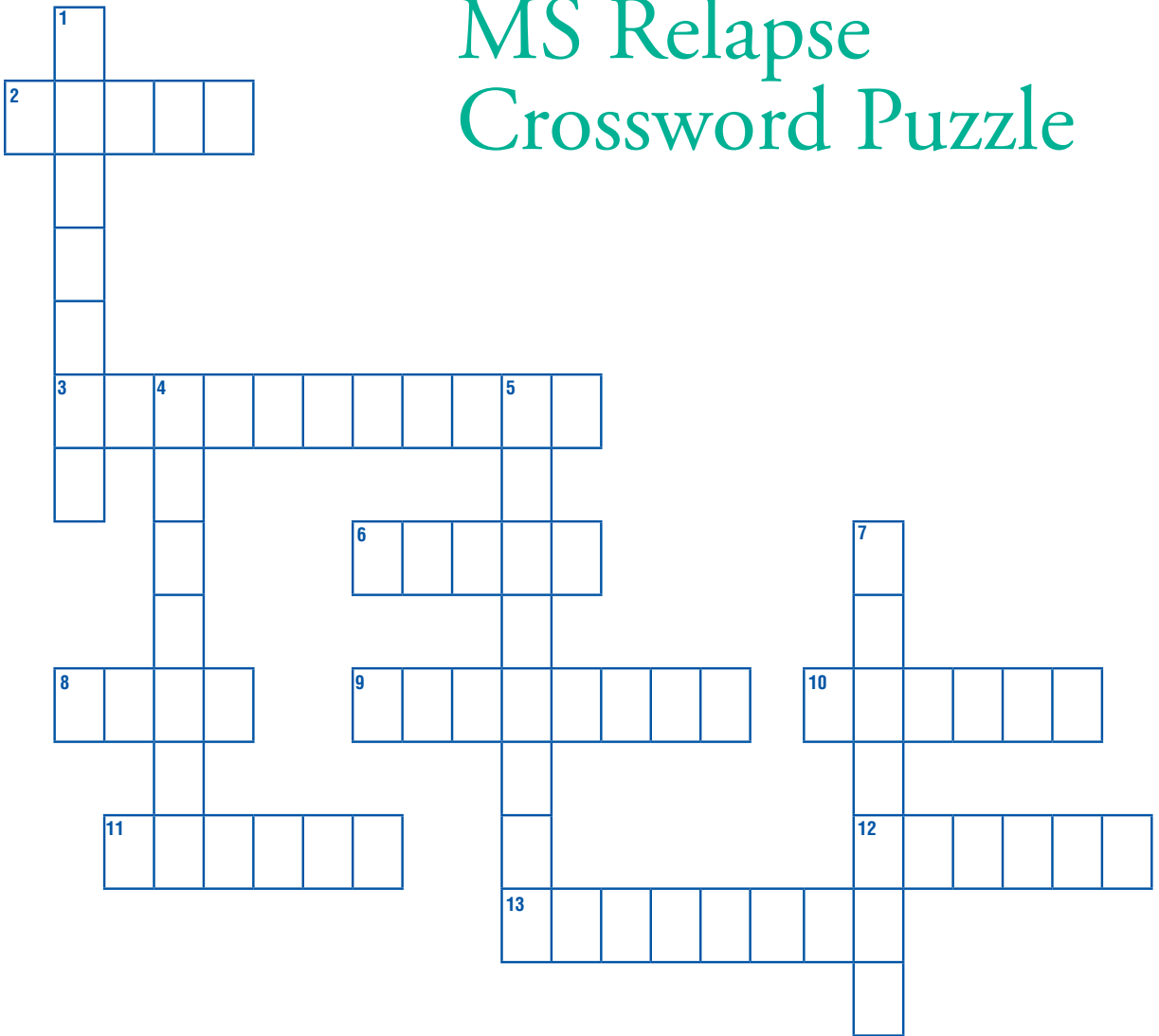
**New mothers:** Asking for help is a difficult task, but doing so in advance and having a plan in place will help to make things go more smoothly. New moms with MS may be particularly at risk for a relapse. New mothers need to make a plan as to whom they can call if they begin to experience symptoms without warning while caring for an infant.

**Employment:** If you are employed and have not yet disclosed the diagnosis, you may want to review your employee benefits in terms of allowances for leave or sick time, before deciding whether or not to tell your employer. Knowing the company's policies on all of these issues is helpful, and discussing the policies with your Human Resources manager (without disclosing your MS until you choose to do so) may be helpful too, if appropriate. Employees who are new to a position sometimes have a more difficult time than others who have been employed in the same position for a longer period of time.

**Work accommodations:** If you choose to disclose your diagnosis, remember that companies are interested in how your duties will be accomplished. Designing a plan as to how the duties of the position can be accomplished with accommodation(s) can help. MSAA's Helpline specialists can offer suggestions and referrals for legal advice. They can also direct you to the Office of Vocational Rehabilitation (OVR) in your state, along with the Job Accommodation Network (JAN), at [askjan.org](http://askjan.org). Both of these resources can help you to effectively evaluate these issues. To contact MSAA's Helpline specialists, please email [MSquestions@mymsaa.org](mailto:MSquestions@mymsaa.org) or call (800) 532-7667, extension 154.



# MS Relapse Crossword Puzzle



## DOWN

1. Clue: \_\_\_\_ equipment, such as vests, may help individuals with heat sensitivity
4. Clue: \_\_\_\_ tract infection is the most common type of infection to cause a pseudoexacerbation
5. Clue: When treatment is required, relapses are often treated with a high-dose course of powerful cortico \_\_\_\_ over a period of three to five days, usually by IV infusion
7. Clue: Also referred to as an exacerbation, attack, flare-up, episode, or bout

## ACROSS

2. Clue: Acute physical symptoms and neurological signs must be present for at least 24 to 48 \_\_\_\_ to be considered a true relapse
3. Clue: Whom to call if your symptoms are severe or if they've continued more than a day or two
6. Clue: When symptoms flare, checking for a \_\_\_\_ is important, since even a minor infection and slight increase in temperature can cause symptoms to appear
8. Clue: Some people with MS have \_\_\_\_ sensitivity and will experience a temporary increase in symptoms when their body temperature rises
9. Clue: MSAA's Relapse \_\_\_\_ Center at [relapses.mymsaa.org](http://relapses.mymsaa.org) offers a wide variety of relapse information
10. Clue: Although not approved by the FDA specifically for MS relapses, \_\_\_\_ pheresis (also known as \_\_\_\_ exchange) and intravenous immunoglobulin (IVIG) are two other treatment options that are sometimes used for individuals who are experiencing a severe relapse and are not responding to other treatments
11. Clue: The protective covering that insulates the nerves of the central nervous system
12. Clue: A \_\_\_\_ exacerbation is a temporary worsening of symptoms without actual myelin inflammation or damage, brought on by other influences, i.e., infection or stress
13. Clue: During a relapse, inflammation occurs along the myelin, causing patients to have a temporary worsening or recurrence of existing \_\_\_\_ and/or the appearance of new ones

Answers:  
**DOWN:** 1. Cooling, 4. Urinary, 5. Steroids, 7. Relapse, **ACROSS:** 2. Hours, 3. Neurologist, 6. Fever, 8. Heat, 9. Resource, 10. Plasma, 11. Myelin, 12. Pseudo, 13. Symptoms









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