

My MS Workbook

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Multiple Sclerosis Association of America

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My MS Workbook

As a person living with multiple sclerosis (PLwMS) you can have an active role to play in decisions about how your MS is treated through ongoing discussions with your healthcare provider (HCP). You can advocate for yourself about your care in collaborative discussions with your HCP. Sharing your lived experience, symptoms, and side effects as well as your expectations and concerns will help you stay in control with your MS.

The purpose of this workbook is to help you and your care partner to prepare for MS management discussions with your HCP in advance of your next appointment. Alternatively, you can also complete this workbook on your own and use it for self-reflection to organize your thoughts in advance of your next HCP appointment.

Co-developed by Novartis, the Multiple Sclerosis Association of America (MSAA), and an expert steering committee comprised of Prof Alice Laroni, Amanda Montague, Dr Amy Sullivan, Anita Williams, Colleen Harris, George Pepper, Guillaume Molinier, Karen Foster, Pieter Van Galen and Dr Sharon Stoll.



A quick guide for using My MS Workbook

Tip

Reflect on and complete this workbook on your own at home or with your care partner.

You may find that not all topics in the workbook apply to you at this time. Complete only the sections that are relevant to you and your experience.

Tip

Summarize key points and questions to raise with your HCP at your next appointment.

Use the summary page at the end of the workbook entries as a guide to discuss your expectations. This information can assist you and your HCP in designing your care plan together. It can also help you feel comfortable to share any concerns you would like to discuss with your HCP to help you make the best decisions for yourself.

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Date:

Background information

Current diagnosis if known

- ☐ Relapsing-Remitting MS
- ☐ Primary Progressive MS
- ☐ Secondary Progressive MS
- ☐ Unknown/Not Sure

Diagnosis date *(month/year)*

I am considering...

- ☐ Starting treatment for my MS
- ☐ Discussing current treatment for my MS

Regarding my MS and/or treatment considerations, I am feeling...

Since my last consultation with my HCP...

My MS symptoms have:

- ☐ Stayed the same
- ☐ Improved
- ☐ Gotten worse

My health has:

- ☐ Stayed the same
- ☐ Improved
- ☐ Gotten worse

Please provide further details

Symptom Management

*Please respond about the person with MS you are supporting based on your interactions and observations

PLwMS Response	Care Partner's Response*
I have noticed changes in these symptoms recently:	
☐ Physical ☐ Cognitive (*thinking, remembering)* ☐ Mood *(emotions, anxiety, depression, agitation)* ☐ Behavioral *(interactions)* ☐ Fatigue *(physical and/or mental exhaustion)* ☐ Difficulty identifying words ☐ Other ☐ None Comment:	☐ Physical ☐ Cognitive (*thinking, remembering)* ☐ Mood *(emotions, anxiety, depression, agitation)* ☐ Behavioral *(interactions)* ☐ Fatigue *(physical and/or mental exhaustion)* ☐ Difficulty identifying words ☐ Other ☐ None Comment:
The most significant ways my symptoms impact me right now are:	
I have identified what causes the symptoms:	
☐ Yes ☐ No Comment:	☐ Yes ☐ No Comment:

Monitoring your symptoms can help you stay on top of any changes in your MS and make the most of appointments with your HCP. Your MS Questionnaire is a simple, free tool that helps you and your support partner manage your symptoms, track them over time, and prepare for upcoming consultations. Visit https://us.ms.your-symptom-questionnaire.com/ to get started.

Lifestyle and Pursuits

PLwMS Response

Beyond my MS treatment, I am additionally receiving, or plan to receive in the near future:

- ☐ Physical therapy
- ☐ Occupational therapy
- ☐ Mental health therapy
- ☐ Speech therapy
- ☐ Cognitive rehab
- ☐ Other
- ☐ Acupuncture
- ☐ Chiropractor
- ☐ Treatment for pain
- ☐ Treatment for fatigue
- ☐ Treatment for sphincteric disfunction

When thinking about my usual routine, the following apply to me:

I eat meals on a regular schedule each day

☐ Yes ☐ No

If yes, breakfast is around

my lunch is around

and dinner is around

I am well rested upon awakening:

☐ Yes ☐ No

I usually have uninterrupted sleep:

☐ Yes ☐ No

I often have fatigue despite uninterrupted sleep:

☐ Yes ☐ No

I usually wake up to use the bathroom in the middle of the night:

☐ Yes ☐ No

My work schedule is flexible:

☐ Yes ☐ No ☐ Does not apply

I am someone's primary or sole caregiver *(e.g., caring for a parent, child, spouse, or other loved one)*:

☐ Yes ☐ No

PLwMS Response

I travel away from home often:

☐ Yes ☐ No

If yes, I am usually away for hours/days (*choose one*).

I can come to the hospital/doctor's office: :

☐ Daily ☐ Weekly ☐ Monthly

Other:

What are important aspects of my lifestyle that are meaningful to preserve?
(This might include physical activity, time with friends or family, hobbies, etc.)

I am willing/able to make lifestyle changes to support my MS Management *(tick all that apply)*

- ☐ Diet
- ☐ Physical exercise
- ☐ Quit smoking
- ☐ Mental health support

Other:

I have a reliable transportation that could take me to/from where I receive care for my MS:

☐ Yes ☐ No

Am I receiving treatment for another medical condition that needs to be taken into consideration?

☐ Yes ☐ No

If yes, you can list the condition and the other treatments here:

If a treatment affects my ability to respond properly to a vaccination or to receive specific vaccines *(i.e. live/attenuated vaccines)*, would it impact my treatment decision?

☐ Yes ☐ No

Treatment administration and lifestyle

PLwMS Response	Care Partner's Response*
Considering my lifestyle, what MS treatment would be most convenient?	
Rank in order of preference, with 1 as your most preferred schedule: Daily Weekly Monthly Yearly This is because:	Rank in order of preference, with 1 as your most preferred schedule: Daily Weekly Monthly Yearly This is because:
I would prefer an MS treatment that is administered *(select all that apply)*:	
☐ At home ☐ Hospital/doctor's office/treatment center or similar ☐ Within a specific distance from home ☐ No preference Other: This is because:	☐ At home ☐ Hospital/doctor's office/treatment center or similar ☐ Within a specific distance from home ☐ No preference Other: This is because:
My main concerns about MS treatment administration are:	

Treatment Benefit and Concerns

PLwMS Response	Care Partner's Response*
I am satisfied with my current MS treatment.	
☐ Yes ☐ No ☐ Somewhat ☐ Not currently on treatment/Does not apply Comment:	☐ Yes ☐ No ☐ Somewhat ☐ Not currently on treatment/Does not apply Comment:
My questions about potential side effects and how to manage them are:	
For me, success with an MS treatment would look like:	
My concerns *(if any)* about MS treatment are:	

Mental Health

PLwMS Response	Care Partner's Response*
Resources and practices I have to help me care for my mental health include: *(Tick all that apply)*	
☐ Mental health professional support If yes, how often do you see this professional?	☐ Mental health professional support If yes, how often do you see this professional?
☐ Peer/support group ☐ Online tools ☐ Self-care practices ☐ Mindfulness practices ☐ Journalling ☐ Meditation ☐ Breathwork exercises Other:	☐ Peer/support group ☐ Online tools ☐ Self-care practices ☐ Mindfulness practices ☐ Journalling ☐ Meditation ☐ Breathwork exercises Other:
In what ways does living with MS currently impact my mental health?	

Family Planning

PLwMS Response	Care Partner's Response*
I am considering starting or expanding my family in the next 1-2 years:	
☐ Yes ☐ No ☐ Does not apply If yes, when?	
I am currently trying to conceive or plan to begin trying soon:	
☐ Yes ☐ No ☐ Does not apply If yes, I am planning to use assisted reproduction techniques. ☐ Yes ☐ No ☐ Does not apply	
I am currently involved in the adoption or foster process or plan to initiate soon:	
☐ Yes ☐ No ☐ Does not apply	
I am currently pregnant:	
☐ Yes ☐ No ☐ Does not apply	
I am currently breastfeeding:	
☐ Yes ☐ No ☐ Does not apply	
I am currently undergoing menopause:	
☐ Yes ☐ No ☐ Does not apply	
I am currently taking hormone replacement therapy *(HRT)*:	
☐ Yes ☐ No ☐ Does not apply	

Treatment Access and Coverage

This section is intended for people living in or receiving care in countries where the Healthcare System does not provide free MS treatment – however, please reflect on these questions if they are relevant to your health coverage.

PLwMS Response

The MS treatment options available to me will depend on my heath insurance coverage:

☐ Yes ☐ No ☐ Does not apply

The MS treatment options available to me will depend on availability at my treatment center:

☐ Yes ☐ No ☐ Does not apply

The cost of an MS treatment is an important part of my decision:

☐ Yes ☐ No ☐ Does not apply

Patient advocacy groups can often help you navigate questions or information about accessing treatment. We recommend contacting your local patient advocacy group for further support.

Reflections summary

Now that you have thought about all of these aspects of your MS management, you may be more comfortable making decisions and having discussions with your HCP about your preferences.

Use the space below to summarize the most important factors to you when it comes to your MS management and reflect on the key things you want to discuss with your HCP at your next appointment.

My biggest expectation for my MS management is...

My biggest concern around my MS management is...

Key questions I want to discuss with my HCP are... *(e.g. How do I know if an MS treatment is working for me? What potential lifestyle changes could I expect from this treatment?)*

Now that you have completed this workbook and reflected on your priorities, we hope that you feel prepared to have more collaborative discussions with your HCP. The notes you made in the "Reflections Summary" section can be helpful talking points for you to start the conversation with your HCP about managing your MS.

We recommend that you revisit the workbook ahead of each consultation to organize your thoughts and questions and that you want to raise with your HCP. This can help you keep track of how your priorities change with time.

Complete this short survey to let us know how your experience using the workbook was by scanning the QR code below or visiting https://survey.alchemer.eu/s3/90588263/My-MS-Workbook-survey.

Please note that your feedback is anonymous and will only be used for the purpose of understanding to what extent this resource has helped you.



Additional thoughts/notes

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