



My MS Workbook



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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



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.



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.

Date:

Background information

Current diagnosis if known

Relapsing-Remitting MS
Secondary Progressive MS

Primary 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

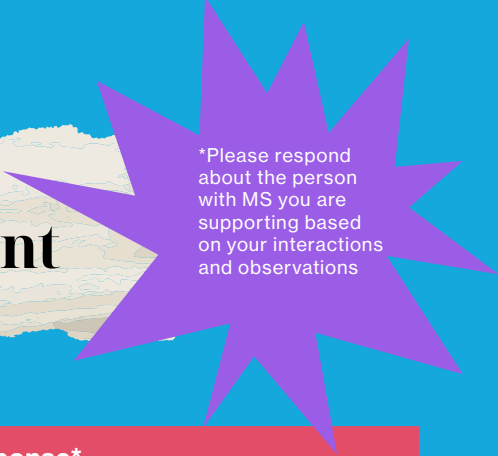
Improved

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:

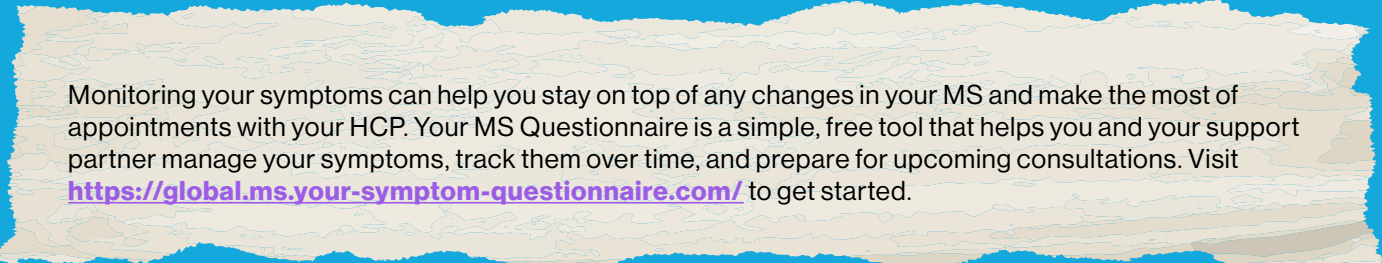
Yes No

Comment:

Yes No

Comment:

I am most interested in treatment that can help with the symptoms in the following ways:



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://global.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	Acupuncture
Occupational therapy	Chiropractor
Mental health therapy	Treatment for pain
Speech therapy	Treatment for fatigue
Cognitive rehab	Treatment for sphincteric disfunction
Other	

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

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- Self-care practices
- Mindfulness practices
- Journalling
- Meditation
- Breathwork exercises

Other:

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

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.



