

How to S.E.A.R.C.H.TM for the Right MS Therapy for You!

S.E.A.R.C.H.TM Workbook



MSAA

**MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA**

*Improving Lives Today!*TM

About this Workbook:

The MSAA S.E.A.R.C.H.™ Patient Workbook serves as an effective tool to help you research, collect, organize, and store information about your decision to start an MS disease-modifying therapy or re-evaluate your current treatment options. This workbook includes:

1. MS Disease-Modifying Therapy Chart

- an easy-to-follow chart that organizes currently approved, MS-treatment options

2. MS Resource Guide

- a comprehensive listing of MS resources to aid your research efforts

3. SEARCH Questions and Notes

- suggested questions for each aspect of SEARCH with ample space for notes

4. Office Visit Questionnaire

- a guide to help prioritize your SEARCH questions and maximize your office visit

Maximizing Your Visit:

Unfortunately, doctors today are increasingly busy and are not able to spend as much time with their patients as they were able to do in the past. In order to make the most of the limited time with the doctor, patients need to come as prepared as possible and prioritize their issues for discussion. The MSAA SEARCH model helps you learn about treatment decisions, prioritize key issues, and ask informative questions to help maximize your office visit.

Using the SEARCH Questions:

MSAA developed the SEARCH questions to serve as a sample, or guide, for you to consider when evaluating your own healthcare needs. These SEARCH questions merely reflect a starting point to help you think about your own medical situation, issues to prioritize, and ways to develop questions that address your specific healthcare needs.

How to S.E.A.R.C.H.™ for the Right MS Therapy For You!

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MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

Those affiliated with this booklet and MSAA cannot be held responsible for any unintentional errors in the writing of this booklet, or changes in information that may occur, possibly affecting certain details of an explanation, assumption, or treatment.

The MSAA S.E.A.R.C.H.™ initiative is made possible with support from EMD Serono and Sanofi Genzyme. MSAA is solely responsible for the development of S.E.A.R.C.H.™ and its content.

What is S.E.A.R.C.H.™ ?

The first treatment for relapsing-remitting multiple sclerosis (RRMS) was approved by the United States Food and Drug Administration (FDA) in 1993. This forever changed the landscape of how MS could be managed. Since then, more than a dozen disease-modifying therapies (DMTs) for MS have become available, giving neurologists and patients a variety of treatment options — including self-injected, infused, and oral medications.

Healthcare providers continue to encourage their patients to take an active, decision-making role in selecting a treatment. In doing so, many factors need to be considered when choosing an appropriate MS therapy or switching from one DMT to another. Among the numerous questions to consider include: What are the therapies? Am I a candidate? What should I know about each one? How will my body react to taking one of these medications? How are the different medications administered? What about the costs or insurance? Once I have begun taking a DMT, how do I know if the one I am prescribed is working?

These and other important considerations require ongoing conversations with your doctor and other healthcare professionals. The treatment decision for each individual is unique and must be addressed individually between the person and his or her healthcare team. Additionally, patients must recognize the need to prioritize their issues, questions, and concerns in order to maximize the time with their healthcare team. With so much information to remember, organize, and prioritize, MSAA recognized the need to help frame these important discussions and created SEARCH.

Designed as a memory aid, the SEARCH acronym represents the key areas that should be considered when “searching” for the most appropriate MS treatment. Each letter represents an important topic that must be considered by patients, physicians, and other healthcare professionals. SEARCH stands for:

Safety
Effectiveness
Access
Risks
Convenience
Health Outcomes
(overall wellness and quality of life)

Important Note: *The 14 disease-modifying therapies (DMTs) for MS shown in the chart in the next section are limited to those approved by the FDA as of the printing of this workbook. At any time, more long-term treatments may become available as new medications are submitted to the FDA for approval. To learn more about these approved treatments as well as new medications as they become approved, please visit MSAA’s website at mymsaa.org and select “Treatments” under “MS Information.”*

Section 1: MS Disease-Modifying Therapy Chart

Self-Injected Medications

MEDICATION	SIDE EFFECTS	HOW ADMINISTERED	ADDITIONAL NOTES
Avonex® (interferon beta-1a) immune system modulator with antiviral properties	Flu-like symptoms and headache, blood count and liver test abnormalities	30 micrograms taken via weekly intramuscular injection	Side effects may be prevented and/or managed effectively through various treatment strategies; side effect problems are usually temporary. Blood tests may be given periodically to monitor liver enzymes, blood-cell counts, and neutralizing antibodies.
Betaseron® (interferon beta-1b) immune system modulator with antiviral properties	Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	250 micrograms taken via subcutaneous injection every other day	Side effects may be prevented and/or managed effectively through various treatment strategies; side effect problems are usually temporary. Blood tests may be given periodically to monitor liver enzymes, blood-cell counts, and neutralizing antibodies.
Copaxone® (glatiramer acetate) Synthetic chain of four amino acids found in myelin (immune system modulator that blocks attacks on myelin)	Injection-site skin reaction as well as an occasional systemic reaction – occurring at least once in approximately 10 percent of those tested	20 (daily) or 40 (three-times weekly) milligrams taken via subcutaneous injection	Systemic reactions occur about five to 15 minutes following an injection and may include anxiety, flushing, chest tightness, dizziness, palpitations, and/or shortness of breath. Usually lasting for only a few minutes, these symptoms do not require specific treatment and have no long-term negative effects. Copaxone was originally approved at a dose of 20 milligrams daily, but in January 2014, a new dose of 40 milligrams three-times weekly was approved by the FDA. The original 20-milligram daily dose remains available, so patients and their doctors may now choose their preferred dosing regimen.
Extavia® (interferon beta-1b) immune system modulator with antiviral properties	Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	250 micrograms taken via subcutaneous injection every other day	Side effects may be prevented and/or managed effectively through various treatment strategies; side effect problems are usually temporary. Blood tests may be given periodically to monitor liver enzymes, blood-cell counts, and neutralizing antibodies.

Self-Injected Medications

MEDICATION	SIDE EFFECTS	HOW ADMINISTERED	ADDITIONAL NOTES
<p>Glatopa™ (glatiramer acetate) As a generic version of Copaxone, Glatopa is a synthetic chain of four amino acids found in myelin (immune system modulator that blocks attacks on myelin)</p>	Using study results from trials with Copaxone, side effects include injection-site skin reaction as well as an occasional systemic reaction – occurring at least once in approximately 10 percent of those tested with Copaxone	20 milligrams taken daily via subcutaneous injection	Using study results from trials with Copaxone, systemic reactions occur about five to 15 minutes following an injection and may include anxiety, flushing, chest tightness, dizziness, palpitations, and/or shortness of breath. Usually lasting for only a few minutes, these symptoms do not require specific treatment and have no long-term negative effects.
<p>Plegridy® (interferon beta-1a) immune system modulator with antiviral properties</p>	Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	125 micrograms taken via subcutaneous injection once every two weeks	Side effects may be prevented and/or managed effectively through various treatment strategies; side effect problems are usually temporary. Blood tests may be given periodically to monitor liver enzymes, blood-cell counts, and neutralizing antibodies.
<p>Rebif® (interferon beta-1a) immune system modulator with antiviral properties</p>	Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	44 micrograms taken via subcutaneous injection three-times weekly	Side effects may be prevented and/or managed effectively through various treatment strategies; side effect problems are usually temporary. Blood tests may be given periodically to monitor liver enzymes, blood-cell counts, and neutralizing antibodies.
<p>Zinbrya™ (daclizumab) Genetically engineered monoclonal antibody that binds to CD25, a receptor on T cells that is thought to become activated in response to MS.</p>	Side effects include cold symptoms, upper-respiratory tract infection, rash, influenza, throat pain, eczema, enlargement of lymph nodes, depression, and increased liver enzymes	150 milligrams taken via subcutaneous injection once per month	Zinbrya has a boxed warning stating that the drug can cause severe liver injury and monthly blood tests to monitor the patient's liver function are required. Other risks include: immune conditions, hypersensitivity reactions (anaphylaxis or angioedema), increased risk of infections, and depression and/or suicidal ideation. Zinbrya should be used only in patients who have had an inadequate response to two or more MS drugs.

Infused Medications

MEDICATION	SIDE EFFECTS	HOW ADMINISTERED	ADDITIONAL NOTES
<p>Lemtrada® (alemtuzumab) Humanized monoclonal antibody that rapidly depletes or suppresses immune system cells (T and B cells), which can damage the myelin and nerves of the central nervous system (CNS).</p>	<p>Common side effects include rash, itching, headache, pyrexia (increase in temperature), nasopharyngitis (inflammation of the nose and throat), nausea, diarrhea and vomiting, insomnia, numbness/tingling, dizziness, pain, flushing, and infection</p>	<p>Lemtrada is given for a course of five days via intravenous (IV) infusion and followed one year later by a second three-day course.</p>	<p>Adverse events from Lemtrada can include infusion reactions to the medication, an increased risk of infection, emergent autoimmune diseases, a potentially severe bleeding disorder called immune thrombocytopenic purpura (ITP), and an increased risk of malignancies including thyroid cancer, melanoma, and lymphoproliferative disorders. For early detection and management of these risks, Lemtrada is only available through a restricted distribution program, the Lemtrada REMS (Risk Evaluation and Mitigation Strategy).</p>
<p>Novantrone® (mitoxantrone) Antineoplastic agent (immune system modulator and suppressor)</p>	<p>Side effects include nausea, thinning hair, loss of menstrual periods, bladder infections, and mouth sores; additionally, urine and whites of the eyes may turn a bluish color temporarily</p>	<p>IV infusion once every three months (for two to three years maximum)</p>	<p>Novantrone carries the risk of cardiotoxicity (heart damage) and leukemia; it may not be given beyond two or three years. People undergoing treatment must have regular testing for cardiotoxicity, white blood cell counts, and liver function. Because of the potential risks, Novantrone is seldom prescribed for individuals with MS. Anyone taking Novantrone now or given Novantrone previously needs to have annual evaluations of his or her heart function, even if no longer receiving this medication.</p>
<p>Tysabri® (natalizumab) Humanized monoclonal antibody (inhibits adhesion molecules; thought to prevent damaging immune cells from crossing the blood-brain barrier)</p>	<p>Headache, fatigue, depression, joint pain, abdominal discomfort, and infection</p>	<p>IV infusion every four weeks</p>	<p>Risk of infection (including pneumonia) was the most common serious adverse event during the studies (occurring in a small percentage of patients). The TOUCH Prescribing Program monitors patients for signs of PML, a potentially fatal viral infection of the brain. Risk factors for PML include: the presence of JC virus antibodies, previous treatment with immunosuppressive drugs, and taking Tysabri for more than two years.</p>

Oral Medications

MEDICATION	SIDE EFFECTS	HOW ADMINISTERED	ADDITIONAL NOTES
<p>Aubagio® (teriflunomide) Immunomodulator (affecting the production of T and B cells; may also inhibit nerve degeneration)</p>	<p>Headache, elevations in liver enzymes, hair thinning, diarrhea, nausea, neutropenia (a condition that reduces the number of certain white blood cells), and paresthesia (tingling, burning, or numbing sensation)</p>	<p>7- or 14-milligram tablet taken orally, once per day</p>	<p>More severe adverse events include the risk of severe liver injury and the risk of birth defects if used during pregnancy. A TB test and blood tests for liver function must be performed within six months prior to starting Aubagio, and liver function must be checked regularly. If liver damage is detected, or if someone becomes pregnant while taking this drug, accelerated elimination of the drug is prescribed.</p>
<p>Gilenya® (fingolimod, FTY720) S1P-receptor modulator (blocks potentially damaging T cells from leaving lymph nodes)</p>	<p>Headache, flu, diarrhea, back pain, abnormal liver tests and cough</p>	<p>0.5-milligram capsule taken orally once per day</p>	<p>Adverse events include: a reduction in heart rate (dose-related and transient); infrequent transient AV conduction block of the heart; a mild increase in blood pressure; macular edema (a condition that can affect vision, caused by swelling behind the eye); reversible elevation of liver enzymes; and a slight increase in lung infections (primarily bronchitis). Infections, including herpes infection, are also of concern. A six-hour observation period is required immediately after the first dose, to monitor for cardiovascular changes.*</p>
<p>Tecfidera® (dimethyl fumarate) Immunomodulator with anti-inflammatory properties; may have neuroprotective effects, potentially protecting the nerves and myelin covering from damage</p>	<p>Flushing and gastrointestinal events; reduced white blood cell (lymphocyte) counts; elevated liver enzymes in small percentage of patients</p>	<p>240-milligram tablet taken twice daily</p>	<p>Other adverse events include mild or moderate upper respiratory infection, pruritus (chronic itching), and erythema (skin redness or rash). In studies, the only serious adverse events to occur in two or more patients taking Tecfidera was gastroenteritis (an inflammation of the lining of the intestines) and gastritis (an inflammation of the stomach lining). Reduced white blood cell (lymphocyte) counts were seen during the first year of treatment. Liver enzymes were elevated in 6 percent of individuals taking Tecfidera, compared to 3 percent on placebo.*</p>

* PML, a potentially fatal, viral infection of the brain, has also occurred in a few patients taking either Gilenya or Tecfidera. The Tecfidera cases have been associated with low counts of lymphocytes, a type of white blood cell.

Section 2:

MS Resource Guide

MSAA: For more information on FDA-approved therapies, symptom-management treatments, and MSAA programs and services, please access additional sections of MSAA's website, mymsaa.org, or contact MSAA at **(800) 532-7667** or email MSquestions@mymsaa.org.

Assistance Programs for Approved MS Therapies:

The following pharmaceutical companies (listed alphabetically) offer patient programs to provide information, instruction, and resources for advocacy and financial assistance.

Aubagio

Program name: MS One to One
Phone: **(855) 676-6326**
Website: www.aubagio.com

Avonex

Program name: Above MS
Phone: **(800) 456-2255**
Website: www.avonex.com

Betaseron

Program name: BetaPlus
Phone: **(800) 788-1467**
Website: www.betaseron.com

Copaxone

Program name: Shared Solutions
Phone: **(800) 887-8100**
Website: www.copaxone.com

Extavia

Program name: Extavia Go Program
Phone: **(866) 398-2842**
Website: www.extavia.com

Gilenya

Program name: Gilenya Go Program
Phone: **(800) 445-3692**
Website: www.gilenya.com

Glatopa

Program name: GlatopaCare
Phone: **(855) GLATOPA / (855) 452-8672**
Website: www.glatopa.com

Lemtrada

Program name: MS One to One
Phone: **(855) 676-6326**
Website: www.lemtrada.com

Plegridy

Program name: Above MS
Phone: **(800) 456-2255**
Website: www.plegridy.com

Rebif

Program name: MS Lifelines
Phone: **(877) 447-3243**
Website: www.rebif.com

Tecfidera

Program name: Above MS
Phone: **(800) 456-2255**
Website: www.tecfidera.com

Tysabri

Program name: Above MS
Phone: **(800) 456-2255**
Website: www.tysabri.com

Zinbryta

Program name: Above MS
Phone: **(800) 456-2255**
Website: www.zinbryta.com

Section 3: SEARCH Questions and Notes

SAFETY

Suggested Questions:

- What are the long-term safety profiles of these FDA-approved MS disease-modifying therapies (DMTs)?
- What tests are required prior to taking a certain DMT? What tests are required while receiving a certain DMT?
- How will DMTs interact with my current medical treatments, other medical conditions, and any complementary and alternative medicines?

Your Questions:

Notes:

EFFECTIVENESS

Suggested Questions:

- How effective are these DMTs in reducing MS relapses, disability, and disease activity?
- What are my realistic expectations regarding the effectiveness of these DMTs?
- How can I tell if my DMT is working?

Your Questions:

Notes:

ACCESS

Important Note: Access to DMT medications and the ability to switch from one to another can vary greatly based on your insurance provider, coverage levels, and step-therapy requirements. To help the MS community better understand and utilize health insurance, MSAA developed an online resource center titled: My Health Insurance Guide.

Accessed at mymsaa.org/healthinsurance, this easy-to-use website section features a useful glossary of common insurance terms, downloadable brochures on the ACA and Medicare, a video, two archived webinars, helpful questions to ask when looking at insurance coverage or appealing a denial, and many other resources.

Suggested Questions:

- Which MS DMT medications are covered by my insurance carrier?
- What are their Tier Levels and how does that affect the cost?
- If I needed to change my MS medication, what alternative DMTs are available to me?
- Are assistance programs available through the pharmaceutical companies, government, or charities?

Your Questions:

Notes:

RISKS

Suggested Questions:

- What are the risks and side effects associated with these DMTs?
- How frequent and severe are the side effects? How soon do they subside?
- Can these side effects be managed, and if so, how?

Your Questions:

Notes:

CONVENIENCE

Suggested Questions:

- How are the DMTs administered?
- How often do I take these DMTs?
- Must I have regular tests or visits to other healthcare providers to monitor the effects of my treatment?

Your Questions:

Notes:

HEALTH OUTCOMES

Suggested Questions:

- How will my general health and quality of life be affected by these DMTs?
- Will taking a DMT lower my immune system and cause other problems?
- Can these DMTs assist with my mobility, cognition, and other health factors?

Your Questions:

Notes:

Section 4: Office Visit Questionnaire

Based on your review of the six elements of SEARCH and your notes from this workbook, please develop and list very specific questions that stand out as the most important issues to discuss with your doctor or healthcare provider. These questions can relate to any of the six aspects of SEARCH.

My top priority SEARCH questions are:

My secondary SEARCH questions are:

Notes:



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