



**MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA**

S.E.A.R.C.H.™ Patient Workbook

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

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, numerous effective disease modifying therapies (DMTs) for MS have become available, giving neurologists and patients a variety of treatment options for slowing disease activity. With the recent introduction of oral medications, and with new investigational drugs nearing completion of their trials, changes in the MS landscape continue to evolve at a rapid pace.

Healthcare providers continue to encourage their patients to become more health literate and to take an active, decision-making role in selecting a treatment. In doing so, an extraordinary number of 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 patient 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. By doing so, MSAA is able to support patients and their physicians in their S.E.A.R.C.H.™ for the most appropriate therapy for each individual.

Designed as a memory aid, the S.E.A.R.C.H.™ 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 and social service professionals. S.E.A.R.C.H.™ stands for:

S. = Safety

E. = Effectiveness

A. = Affordability

R. = Risks

C. = Convenience

H. = Health Outcomes (overall wellness and quality of life)

Much like the design of a Global Positioning System (GPS), MS patients and their physicians can employ the S.E.A.R.C.H.™ model to navigate through this dynamic, ever-changing landscape and reach their desired destination. Also, patients can use the S.E.A.R.C.H.™ tool to “recalculate” their decisions and adjust treatments if necessary in order to maximize optimum health outcomes.

About this Workbook:

The MSAA S.E.A.R.C.H.TM 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. With so much information to manage, this Workbook offers you a convenient way to journal and maintain accurate notes on research information, key questions and answers from your healthcare providers, and additional resources.

The MSAA S.E.A.R.C.H.TM Patient Workbook includes the following sections:

1. MS Disease Modifying Therapy Chart

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

2. MS Resource Guide

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

3. S.E.A.R.C.H.SM Questions and Notes

- suggested questions for each aspect of S.E.A.R.C.H.TM with ample space for notes

4. Office Visit Questionnaire

- a guide to help prioritize your S.E.A.R.C.H.TM questions and maximize your office visit

Maximizing Your Visit:

Unfortunately, doctors today face an increasing workload of patients, restrictive managed-care regulations, and other factors that prevent many physicians from spending as much time with their patients as they were able to do in the past. The reality of these brief and often rushed doctor visits can leave both the patient and physician feeling dissatisfied with the outcome and “searching” for a better way to manage their time.

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 S.E.A.R.C.H.TM model helps you learn about and prioritize the keys issues which are most important to your healthcare needs. By concentrating on a few of these key areas, you can present your questions and concerns in a clear cut, easy, and efficient way which will allow the most important topics to be discussed upfront and help maximize your office visit.

Using the S.E.A.R.C.H.TM Questions:

MSAA developed the S.E.A.R.C.H.TM questions to serve as a sample, or guide, for you to consider when evaluating your own healthcare needs. These S.E.A.R.C.H.TM questions merely reflect a starting point to help you think about your own medical situation, issues to prioritize, and ways to develop questions which address your specific healthcare needs.

When using the S.E.A.R.C.H.TM model, it is also important to recognize that reviewing key topics and questions will likely require more than one office visit with members of your healthcare team. The S.E.A.R.C.H.TM framework can also be helpful when conducting your own research before or after visiting your healthcare provider.

Section 1. MS Disease Modifying Therapy Chart

The Currently Approved Long-Term Treatments for MS

SELF-INJECTED MEDICATIONS

Avonex	Type Interferon beta-1a* (immune system modulator with antiviral properties)	Side Effects Flu-like symptoms and headache	How Administered 30 micrograms taken via weekly intermuscular injections
Betaseron	Type Interferon beta-1b* (immune system modulator with antiviral properties)	Side Effects Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	How Administered 250 micrograms taken via subcutaneous injections every other day
Copaxone	Type Synthetic chain of four amino acids found in myelin (immune system modulator that blocks attacks on myelin)	Side Effects Injection-site skin reaction as well as an occasional systemic reaction - occurring at least once in approximately 10 percent of those tested	How Administered 20 milligrams taken via daily subcutaneous injections
Extavia	Type Interferon beta-1b* (immune system modulator with antiviral properties)	Side Effects Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	How Administered 250 micrograms taken via subcutaneous injections every other day
Rebif	Type Interferon beta-1a* (immune system modulator with antiviral properties)	Side Effects Flu-like symptoms, injection-site skin reaction, blood count and liver test abnormalities	How Administered 44 micrograms taken via subcutaneous injections three times weekly
-Continued-			

INFUSED MEDICATIONS	Novantrone	Type Antineoplastic agent (immune system modulator and suppressor)	Side Effects Usually well tolerated; 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.	How Administered IV infusion once every 3 months (for two to three years maximum)
	Tysabri	Type Humanized monoclonal antibody (inhibits adhesion molecules; thought to prevent damaging immune cells from crossing the blood-brain barrier)	Side Effects Headache, fatigue, depression, joint pain, abdominal discomfort, and infection	How Administered IV infusion every four weeks
ORAL MEDICATIONS	Aubagio	Type Immunomodulator (affecting the production of T and B cells; may also inhibit nerve degeneration)	Side Effects 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)	How Administered 7- or 14-milligram tablet taken orally, once per day
	Gilenya	Type S1P-receptor modulator (blocks potentially damaging T cells from leaving lymph nodes)	Side Effects Headache, flu, diarrhea, back pain, abnormal liver tests and cough	How Administered 0.5-milligram capsule taken orally once per day
	Tecfidera	Type Immunomodulator with anti-inflammatory properties; may have neuroprotective effects, potentially protecting the nerves and myelin covering from damage	Side Effects Flushing and gastrointestinal events; reduced white-blood cell (lymphocyte) counts; elevated liver enzymes in small percentage of patients	How Administered 240 mg tablet taken twice daily

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 this website or contact MSAA at (800) 532-7667 or MSQuestions@mymsa.org.

MS Coalition: The MS Coalition is a collaborative network of independent MS organizations. The MS Coalition's mission is to increase opportunities for cooperation and provide greater opportunity to leverage the effective use of resources for the benefit of the MS community. Please visit: www.multiplesclerosiscoalition.org.

In addition to MSAA, the MS Coalition members (listed alphabetically) include:

Accelerated Cure Project for Multiple Sclerosis
Phone: (781) 487-0008; Website: www.acceleratedcure.org

Consortium of Multiple Sclerosis Centers (CMSC)
Phone: (201) 837-0727; Website: www.ms-care.org or www.narcoms.org

Can Do Multiple Sclerosis
Phone: (800) 367-3101; Website: www.msando.org

International Organization of Multiple Sclerosis Nurses
Phone: (201) 487-1050; Website: www.iomsn.org

Multiple Sclerosis Foundation
Phone: (800) 225-6495; Website: www.msfocus.org

National Multiple Sclerosis Society
Phone: (800) 344-4867; Website: www.nmss.org

United Spinal Association
Phone: (718) 803-3782; Website: www.unitedspinal.org

Assistance Programs of Approved MS Therapies:

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

Aubagio

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

The "MS One to One" program provides access to nurses experienced with MS patients on Genzyme treatments. Financial assistance will be available to individuals who qualify.

Avonex

Program name: MS ActiveSource

Phone: **(800) 456-2255**

Website: www.avonex.com

MS ActiveSource will assist patients in the following ways:

1. If the person has insurance (including Medicare), they will give co-pay assistance. The patient's co-pay will be \$10 monthly, and this program is ongoing and will not end.
2. If the person has no insurance, they will help through the Access Program. The drug will be free for two years. There is an undisclosed financial eligibility criterion. After a year and a half, the person will need to reapply. If he or she is not eligible at this time, then the individual will be referred to the National MS Society.

Betaseron

Program name: BetaPlus

Phone: **(800) 788-1467**

Website: www.betaseron.com

BetaPlus will assist patients in the following ways:

1. For people with no insurance, or if they have Medicare, they can apply for the Patient Assistance Program. If they are approved, they can receive a three-month supply for a participation fee ranging from \$30 to \$150. There is an undisclosed financial eligibility criterion. This will continue for one year, at which time they can reapply. If they are not eligible at this time, they will be referred to a list of agencies for assistance.
2. If they have insurance, they can receive co-pay assistance up to \$9,500 yearly. Patients will have no co-pay expense until they reach the maximum assistance limit of \$9,500 yearly.

Copaxone

Program name: Shared Solutions

Phone: **(800) 887-8100**

Website: www.copaxone.com

Shared Solutions will assist patients in the following ways:

1. Individuals with no insurance are referred to Assist RX. The Shared Solutions case manager will conference-call with the patient and the Assist RX organization. The information about eligibility is not public. An individual's cost would be zero for one year. He or she will then need to reapply. If not eligible at this time, there is no further assistance.
2. If a person is on Medicare, the Medicare Team, working with a specialty pharmacy (ACS) will pay through the coverage gap. This program is ongoing.
3. For people with private insurance, the Co-Pay Solutions program will assist. Individuals pay \$35 monthly. This program is ongoing.

Extavia

Patient Services Program

Phone: **(866) 925-2333**

Website: www.extavia.com

Extavia's Patient Services Program will assist patients in the following ways:

1. For individuals with no insurance and who meet the financial criteria, they can receive free medication up to one year, at which time they may reapply. The financial criteria are not public.
2. For individuals who have insurance with a high co-pay, they can receive assistance if they are financially eligible. This is also true if they have Medicare and need help with the coverage gap.

Both of these programs require that the patient reapply after one year. If the patient is no longer eligible at this time, referrals are made to other agencies such as NORD.

Gilenya

Patient Services Program

Phone: **(800) 445-3692**

Website: www.gilenya.com

Gilenya's Patient Services Program will conduct a benefits investigation and determine on an individual basis what assistance a person may be eligible to receive. They can provide a free starter packet while this is proceeding. The program will assist patients in the following ways:

1. For individuals with no insurance, they can receive free medication if their income is less than five times the Federal Poverty Level, under the Patient Assistance Foundation. People with Medicare can also receive assistance in this program. The benefit continues for one year, at which time the patient may reapply. If there is an alternative program, the patient will be referred.
2. For individuals with commercial insurance, they can receive help up to \$800 monthly under the Medical Co-Pay Support Program. This program is based on the present calendar year. There is currently no information available on this program beyond December 31, 2011.

Please note that certain states are not covered under these programs. Individuals living in those states need to ask the Patient Services representative about other assistance.

Rebif

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

MS Lifelines will assist patients in the following ways:

1. If a person has no insurance, he or she will be provided with free medication for up to one year, under the Access Made Simple program. At that time, the patient may reapply and is often still eligible.
2. If a person has Medicare, he or she may apply for assistance once reaching the coverage gap. This assistance is also available for one year, and a person may reapply after that time. Both 1 and 2 require financial eligibility, the terms of which are not disclosed. If the person is not eligible when reapplying, there is no further assistance available.
3. If a person is insured but has a high co-pay, there is a program to assist. For the first three months, there is no cost. After three months, it is \$50 monthly. This is ongoing, with no need to reapply.

Tecfidera

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

MS ActiveSource will assist patients in the following ways:

1. Individuals with private insurance will be eligible for a \$10 co-pay assistance program. There are no income limits as to who may be eligible. Individuals on Medicare who need assistance can call in to speak with a representative about other ways to receive help.
2. Individuals will need to re-enroll in the patient assistance program every year.
3. Uninsured individuals may be eligible to receive Tecfidera for free; there is an undisclosed financial criteria.

**Individuals on any insurance through a Federal program such as Medicare, Medicaid, and VA/DoD are not eligible to qualify for assistance.*

Tysabri

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

MS ActiveSource will assist patients in the following ways (the guidelines are similar to Avonex):

1. If a person has insurance (including Medicare), he or she will receive co-pay assistance. The patient's co-pay will be \$10 monthly, and this program is ongoing and does not end.
2. If the person has no insurance, he or she will be helped though the Access Program. The drug will be free for two years. There is an undisclosed financial eligibility criterion. After a year and a half, the person will need to reapply.

MS Active Source does not pay for any costs charged by the infusion center.

Section 3. S.E.A.R.C.H.™ Questions and Notes

S = 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 DMTs? What tests are required while receiving DMTs?
 - How will DMTs interact with my current medical treatments, other medical conditions, and any complementary and alternative medicines?

Additional Questions:

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Notes: _____

E = Effectiveness:

Suggested Questions:

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

Additional Questions:

- -
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Notes: _____

A = Affordability: (These questions could be directed to other healthcare team members including your social worker, insurance representative, MS organization, etc.)

Suggested Questions:

- What are the costs and insurance coverage for these DMTs?
 - Does the insurance coverage have caps, gaps or limitations?
 - Are there assistance programs through the pharmaceutical companies, government, or charities?

Additional Questions:

- -
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Notes: _____

R = Risks:

Suggested Questions:

- What are the risks of 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?

Additional Questions:

- -
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Notes: _____

C = 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?

Additional Questions:

- -
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Notes: _____

H = 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?

Additional Questions:

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Notes: _____

Section 4. Office Visit Questionnaire

As mentioned in this Workbook, the goal of S.E.A.R.C.H.TM is to help you achieve optimum healthcare by improving your own health literacy and inspiring you to actively manage your MS. By using the S.E.A.R.C.H.TM framework, you should be able to learn more about your specific needs and prioritize questions and concerns in order to maximize your time with your doctor or healthcare provider.

Please review all of your Workbook notes, complete the following section, and bring with you during your office visits with your doctor or healthcare provider.

Based on your review of the six elements of S.E.A.R.C.H.TM and a careful evaluation of the notes from this Workbook, please develop and list very specific questions which 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 S.E.A.R.C.H.TM

My top priority S.E.A.R.C.H.TM questions are:

1. _____
2. _____
3. _____

Given the comprehensiveness of S.E.A.R.C.H.TM, MSAA recognizes you may also have supplemental questions which factor into this important decision-making process. Please develop and list very specific supplemental questions to discuss with your doctor or healthcare provider. Again, these questions can relate to all aspects of S.E.A.R.C.H.TM

My supplemental S.E.A.R.C.H.TM questions are:

4. _____
5. _____
6. _____

Please know your questions may also be addressed by support staff within your doctor's office or among the many resources listed in this Workbook. It is important to realize you may need to schedule follow-up appointments with your doctor and healthcare team to fully review all aspects of S.E.A.R.C.H.TM before choosing a therapy that is right for you.

Notes:

Notes continued:

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