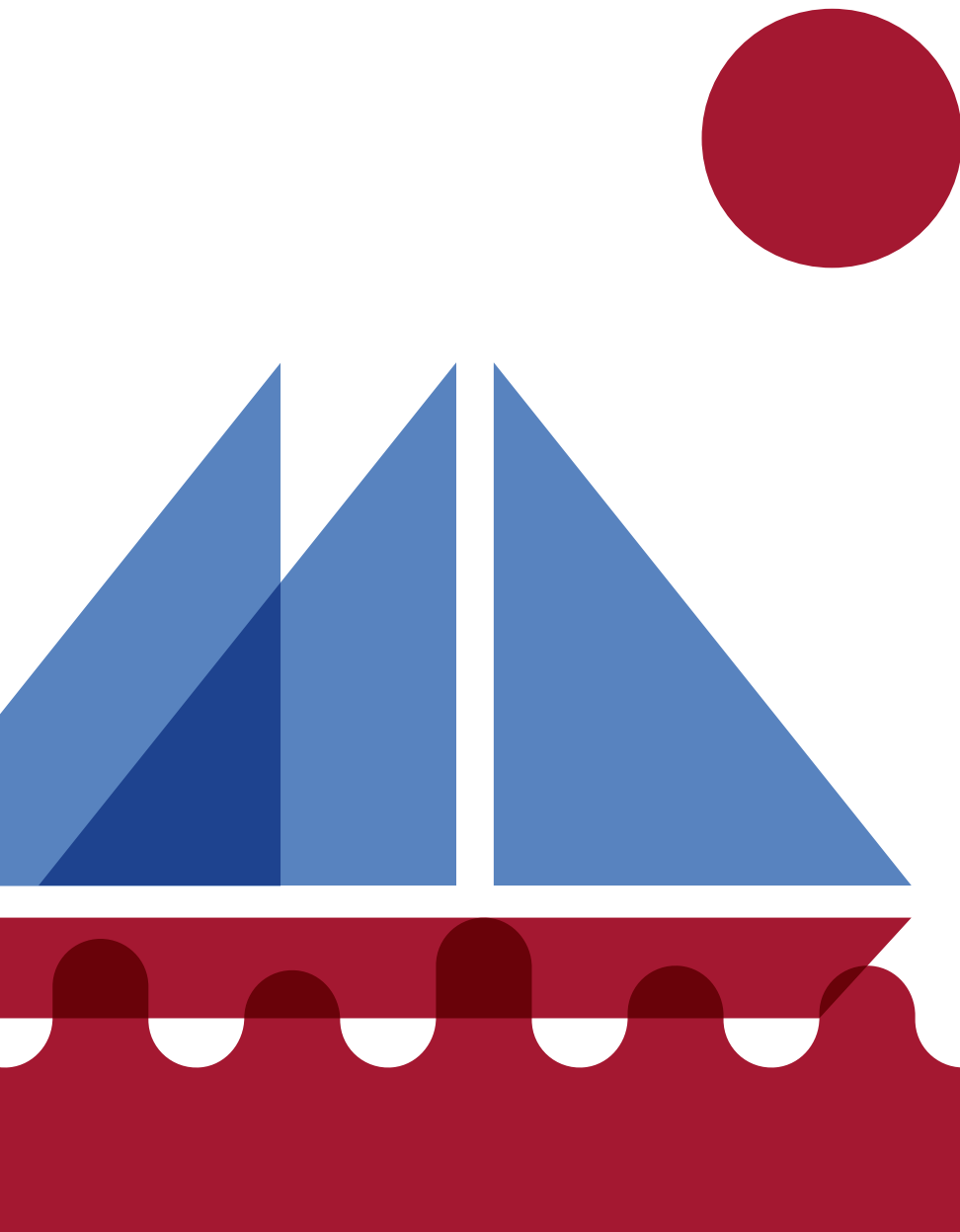


# Treatment Decision Making and Relapsing Remitting Multiple Sclerosis



**The CRIMSON Project  
Decision Aid Booklet**

# The Disease Modifying Treatments Decision Aid Booklet

This booklet aims to help people with Relapsing Remitting Multiple Sclerosis (RRMS) make decisions about starting, switching and/or stopping Disease Modifying Treatments (DMTs).

This booklet has information to help people with RRMS, and their friends and family, talk with health professionals about why some treatments fit into their life better than others. It was made by the Considering Risks and Benefits in Multiple Sclerosis Treatment Selection (CRIMSON) project team. More details about the project are given at the end of the booklet and at our website [crimson.leeds.ac.uk](http://crimson.leeds.ac.uk)

**Use the space below to write your name.**

Knowing who the booklet belongs to means it can be returned if it gets left behind in clinic.

**Name:**



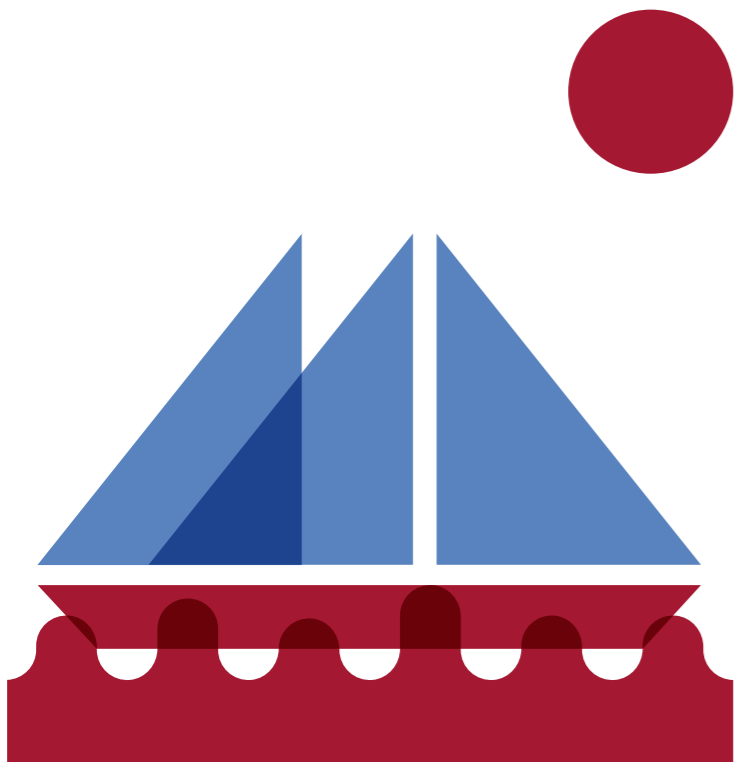
**MS Clinic:**

Details of your MS professional team can be added here:

**Clinic Team:**



**Contact Details:**



# Content

People use this Decision Aid Booklet in different ways. Some people read it on their own from the beginning to end, or dip in and out of sections. Some people like to talk through the booklet with friends, family and/or health professionals.

The Booklet is split into sections to help people think about what is important to them about their experience of illness and treatment decisions:

- Section A** - Understanding Relapsing Remitting Multiple Sclerosis
- Section B** - Living with Relapsing Remitting Multiple Sclerosis
- Section C** - Disease Modifying Treatments for Relapsing Remitting Multiple Sclerosis
- Section D** - Making My Disease Modifying Treatment Decisions
- Section E** - Planned-Unplanned Pregnancy and Disease Modifying Treatments
- Next Steps** - Navigating the Ups and Downs of Relapsing Remitting Multiple Sclerosis
- Reference** - Glossary, Resources, Project Details

### Each section has information, a decision map and prompts:

- Information** and tables provide facts useful to people making treatment decisions for RRMS. Some sections have numbers in brackets linking facts with their medical sources. For example, [19, 25, 26] links the facts with the number of the source, listed on pages 32-34.
- Decision maps** sign-post the focus of each section and how it links with other information in The Booklet. For example, Decision Map 1 has a red box around RRMS, which is the content of section A.
- Prompts** help people note down their thoughts and questions about what is important to them about their lives when making these treatment decisions.

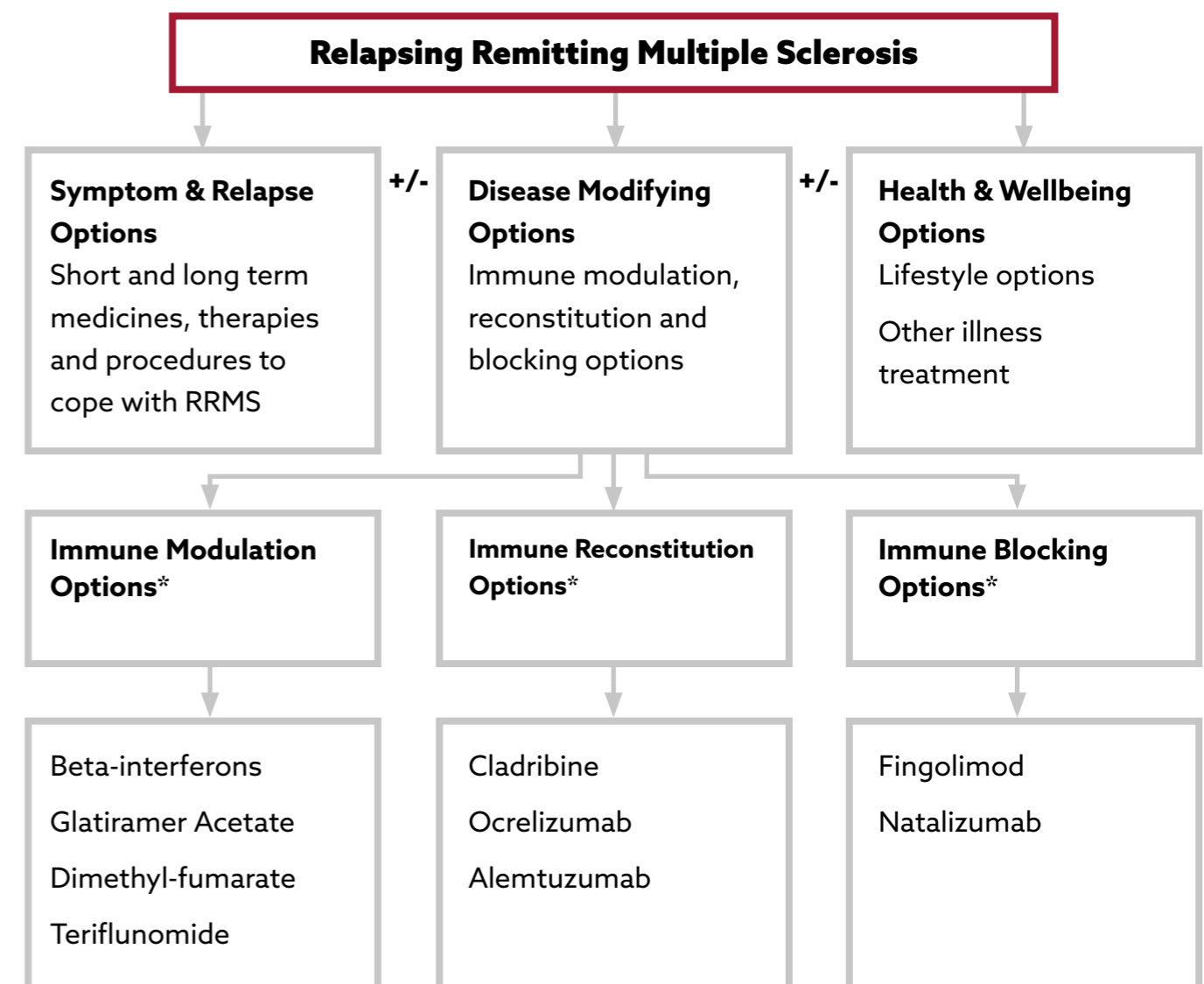
**Disclaimer:** Every effort was made to provide accurate information at the date of publication (August 2019). However, facts about treating RRMS in the UK change over time. To check facts about RRMS and which treatment works best for you, talk about your decision making and choices with your MS professionals.

# SECTION A: Understanding Relapsing Remitting Multiple Sclerosis

This section has information about:

- Relapsing Remitting Multiple Sclerosis (RRMS)
- Immune system attacks and relapses
- Specialist health teams and managing RRMS

## Decision Map 1: Relapsing Remitting Multiple Sclerosis



\*The decision maps use the chemical name of treatments; treatment brand names are used in section C.

## The Health Problem RRMS

RRMS is the main type of Multiple Sclerosis (MS). MS is a life-long condition caused by a person's immune system attacking their central nervous system, including the nerve cells and myelin sheaths protecting nerve fibres. When attacked the sheaths and nerves can become swollen and damaged. This damage can slow down or stop the signals travelling along the nerves in the brain and spinal cord. Changes to these signals means different parts of the body can stop working.

People get symptoms when these signals do not work as usual, such as blurred vision, numbness, pain, fuzzy thinking, extreme tiredness, weakness and poor balance.

People with RRMS get immune system attacks called relapses or episodes. The symptoms people get with RRMS depend on which nerves are damaged and which signals are changed. The symptoms can last days, weeks, months, or never go away. Some symptoms can come back, or new symptoms appear. Relapsing and remitting means the symptoms people get from the immune system attacks come and go, and fluctuate over time. About 85% (85 out of 100) of people with MS have RRMS [13, 18-21].

### RRMS symptoms affect people's health in two ways:

- Symptoms that happen often like pins and needles, numbness or bladder problems. Some people may take over-the-counter treatments to cope with these symptoms. These symptoms are not relapses.
- A part of the body suddenly stops working as well as it did. For example, a person may experience worse vision in an eye, less grip in their hand or unsteadiness when walking, over a few days or weeks. MS professionals call these symptoms a relapse. Some relapses may be treated with a course of steroid medications; some people may be left with a long-term disability.

## Worsening RRMS

It is not known what causes Multiple Sclerosis, or why some people's disease worsens, and others do not. Around 110,000 people in the UK have MS, about 2 in every 1000 people. People cannot tell when a relapse will happen, how long it will last, and how many relapses will happen in a year.

For many people, their RRMS will get worse over time and may change to Secondary Progressive Multiple Sclerosis (SPMS). SPMS means symptoms are less likely to go away and people are more likely to be left with a disability. Medications known as Disease Modifying Treatments (DMTs) slow down MS activity, and make it more likely people with RRMS have fewer relapses and live longer without disability [16-26].

## Specialist health teams and RRMS management

People manage their RRMS, relapses and other symptoms with support from health professionals, who know about illnesses caused by damage to the nervous system such as the brain and spinal cord. A neurologist is the name given to doctors who treat people with nerve damage.

Specialist MS teams include neurologists, nurses, pharmacists, physiotherapists, occupational therapists, psychologists and others who deliver care, and help people get on with their lives. Community health professionals such as general practitioners (GPs), community nurses and pharmacists give advice about treatments to manage people's daily symptoms.

## Everyone's experience of RRMS is different

The prompts in this booklet help people note down what is important to them when managing their RRMS. Health professionals want people to tell them about their own experiences of RRMS, symptoms and treatment.

People find writing these notes can help them to talk with health professionals when making decisions together about their RRMS management [28-33]. See the REFERENCE section for links to health service and patient-based websites and resources about living with MS [pages 34-36].

**Use this space to note down your views about:**



**Experience of symptoms**

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**Ways of coping with symptoms**

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**Experiences to talk about with doctors, friends and family**

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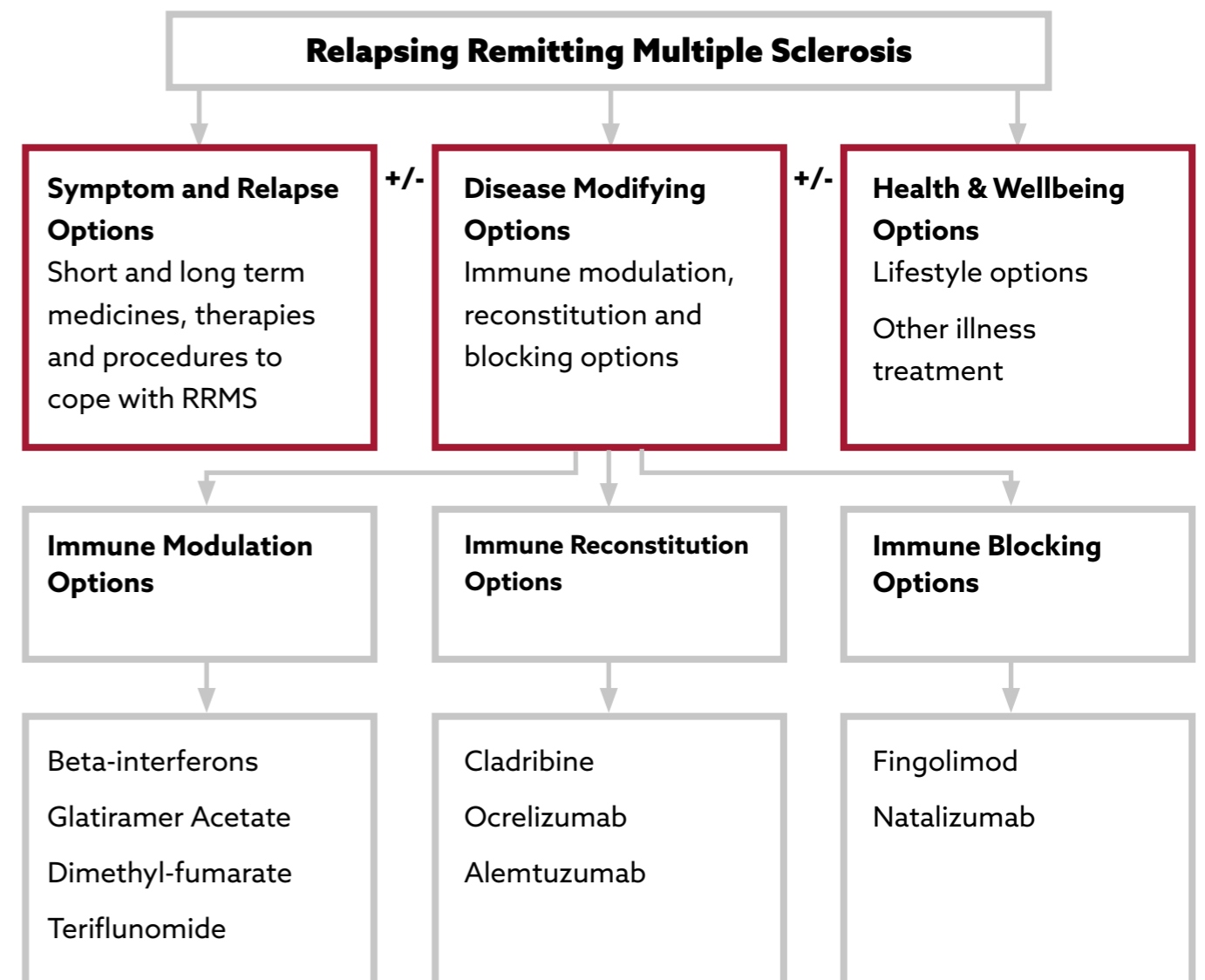
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# SECTION B: Living with Relapsing Remitting Multiple Sclerosis

**This section has information about:**

- Stages of Relapsing Remitting Multiple Sclerosis
- Treatment options for living with Relapsing Remitting Multiple Sclerosis
- Making treatment decisions

**Decision Map 2: Living with Relapsing Remitting Multiple Sclerosis**



# Stages of Relapsing Remitting Multiple Sclerosis (RRMS)

People have regular check-ups with MS services to see if their RRMS is stable, or getting worse. There are tests to check eyesight, arm and leg strength, balance, bladder and bowel function. Some people have brain scans using magnetic resonance imaging (MRI) to look for the effects of MS, such as a brain lesion or scar. These check-ups give health professionals and people with RRMS information about their disease activity to use when making treatment decisions together [17, 19-21, 23, 24]. Over time, many people with RRMS shift to having another type of MS known as Secondary Progressive Multiple Sclerosis (SPMS).

## RRMS stages can be known as:

- **Stable** - no new relapses in the last 12 months
- **Active** - at least two relapses in the last 24 months
- **Highly active** - new or ongoing relapses in the last 12 months, when taking a disease modifying treatment like Beta-interferon.
- **Rapidly evolving severe** - at least two disabling relapses and new brain scars in the last 12 months.

Treatment decisions can be difficult to make because of the way RRMS and symptoms change, the different types of RRMS medications, and changes in what people think is important to them [15, 27]. People may go through phases in their lives when their RRMS is controlled, then they have relapses, then the RRMS is controlled again, and so on.

This pattern means people go through times when they can get on with their lives as planned, and times when they adjust to coping with relapses and their symptoms. This booklet aims to help people with RRMS make the best treatment decision for them at this time, and sign-post what options may suit them better in the future.

# Treatment options for people living with RRMS

People make many decisions to start, switch and/or stop treatments when managing their RRMS. There is no single best treatment option. People experience their RRMS and its treatment in different ways. As people get older, or have different experiences, their views about what treatments fit best into their life can change.

## The three broad types of treatment plans people think about to manage their symptoms and live well with RRMS are as follows:

**Symptom & Relapse Treatment** options help people manage the symptoms and relapses from their RRMS. MS services provide medications and therapies to help people cope with their symptoms. There are different options for different symptoms and relapses, at different times in people's lives. Examples include physiotherapy, psychological therapy, and occupational therapy to help with everyday function, fatigue, memory and strength problems, and medications for sensory or bladder problems.

Sometimes relapses can be treated with steroids. Some people use exercise, diet and alternative therapies to cope with symptoms. People talk together with pharmacists, general practice professionals, MS professionals and support groups about which wellbeing and MS service options work well for them.

**Health and Wellbeing** options are lifestyle and treatment options people choose to keep themselves well. People with RRMS can make lifestyle changes to help keep themselves as healthy as possible. Finding ways to manage stress, eat well, and keep the body and mind fit means people are less likely to get diseases like diabetes, heart disease, and cancer. Some people take treatments for other health and illness problems, for example in managing their depression, heart disease, or diabetes. People make decisions about treatment for these other conditions, as well as RRMS. People with RRMS talk with their pharmacists, general practice professionals, MS professionals and support groups to find ways of keeping as well as possible.

**Disease Modifying Treatment (DMT)** options are medications to reduce relapses, and to try to delay or stop people's RRMS from getting worse. People with RRMS take DMTs to stop their immune system or cells from attacking their nerves. People taking these medications have fewer relapses, and the relapses may not be as bad, compared to people who are not taking DMTs. These medications cannot cure RRMS or fix the damage to people's nervous systems caused by their condition.

These treatments may have side-effects or make it more likely a person will get another health problem. If people taking DMTs experience other symptoms and/or a relapse, they may take symptom and relapse treatments at the same time. When people are diagnosed with RRMS, they will talk with their MS professionals about the decision to start taking DMTs.

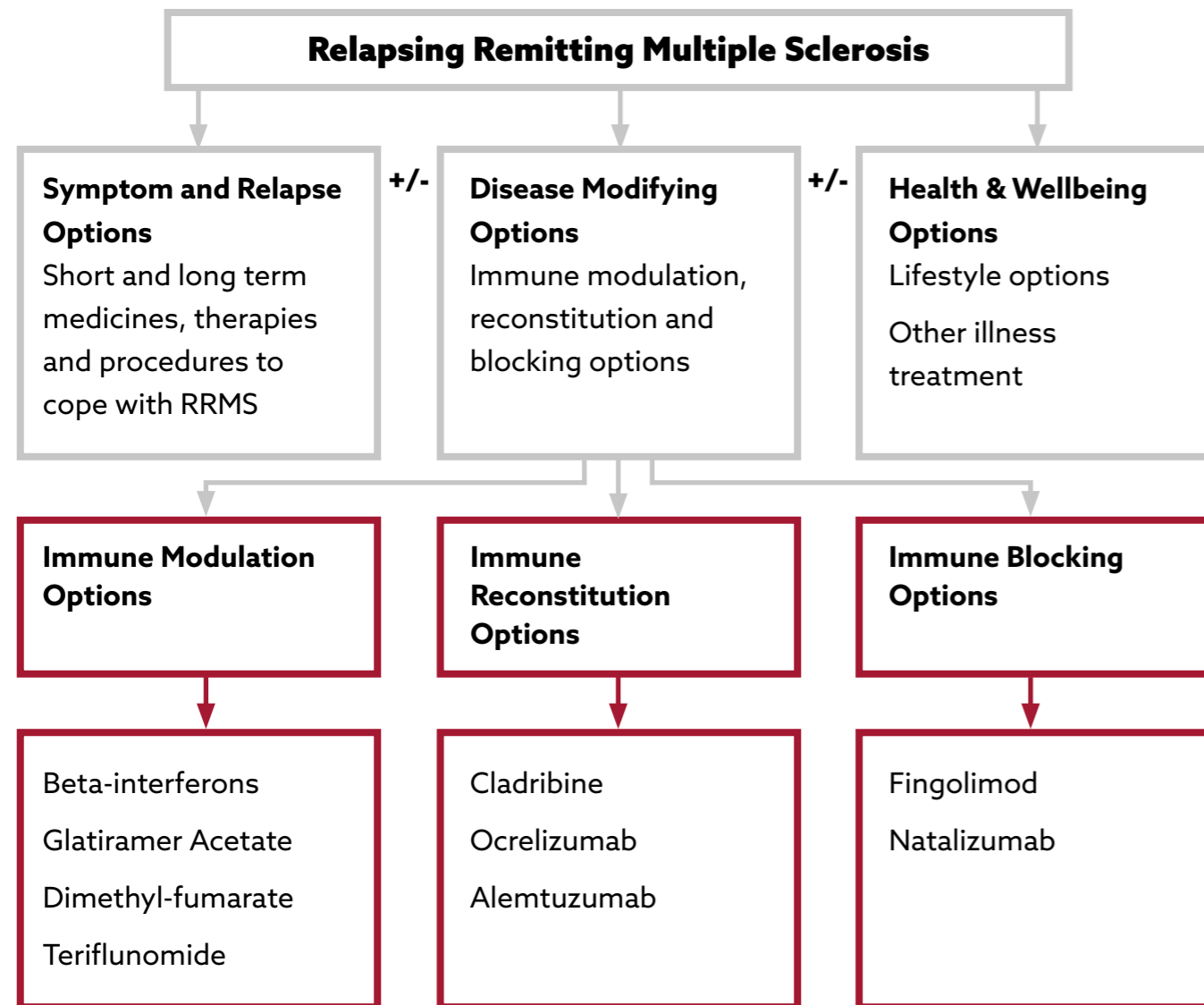


# SECTION C: Disease Modifying Treatments for Relapsing Remitting Multiple Sclerosis

This section has information about:

- Disease Modifying Treatments (DMTs) for RRMS
- Planning when to make DMT decisions
- A table summarising the consequences of taking DMTs
- A table describing briefly each DMT option

**Decision Map 3: Disease Modifying Treatment options**



# Types of Disease Modifying Treatments

Disease Modifying Treatments (DMTs) for RRMS change how people's immune system cells work. Studies show people taking DMTs have fewer relapses, and more time free from disability, than people who do not take DMTs [12, 19-27]. MS professionals plan with people how best to start, switch or stop treatment.

The best chance of living without a long-term disability is for people with RRMS to talk with their MS professionals about taking a DMT option. Talking about symptoms, relapses and test results helps people with RRMS and MS professionals plan the best treatment options for them at this time. When the RRMS moves into an active stage, people can start having a DMT option.

The three types of DMTs work in different ways to delay people's RRMS from getting worse:

- **Immune Modulation** options change the strength of white cells in the immune system (lymphocytes). The immune system is then less able to damage the nerves. In the UK, these medicines include: Beta-interferons, Glatiramer Acetate, Dimethyl-fumarate, Teriflunomide. [1-5]
- **Immune Reconstitution** options change the types and strength of white cells in the immune system (lymphocytes). The immune system is then made up of a different number of cells which are less likely to damage the immune system. In the UK, these medicines include: Cladribine, Ocrelizumab and Alemtuzumab. [6-9]
- **Immune Blocking** options can stop immune cells from getting out of the lymph nodes (Fingolimod) or from getting into the brain (Natalizumab). This means there are fewer cells that can damage the nerves. In the UK, these medicines include: Fingolimod and Natalizumab. [10,11]



# Planning when to make decisions about DMTs

MS professionals work with people with RRMS to find the DMT option that works best for their symptoms and disease experience, and can fit into a person's everyday life. Some people may have medical reasons why one type of DMT works better for them than another.

In time, some people switch to a different DMT option because it is not working, or they are having new side-effects. Some people may stop taking DMTs when deciding to have a baby, or if they have another health problem [14, 21-23].

Each person with RRMS has a different experience of their disease, the symptoms they get, the number of relapses they have, and how quickly their RRMS changes. For many people with RRMS, taking a DMT means they have fewer, or no, relapses. For some people taking a DMT, their RRMS may still worsen. All DMTs have a chance of side-effects and long-term health problems.

People taking DMTs will fit an extra medication routine into their lives, even if they do not have RRMS symptoms. Until people start taking a DMT, they cannot know if it will work for them, if they will get a side-effect, which one they may get, or how severe it may be.

MS services are guided by advice from national health organisations about which treatments to offer, and when, for people at different stages of their RRMS [19-23].

Not all MS services offer all types of DMT options to people with all RRMS stages, and can signpost people to get other treatments from another MS centre.

This booklet used medical studies for facts about MS and DMTs [25,26]. Different studies tested treatments in different ways and collected different facts. People taking part in these studies were chosen for different reasons based on their characteristics such as age, sex, length of having RRMS, treatments, and other health problems.

These types of studies mean facts are not known for how well a DMT works in people with other characteristics. These fact-gaps mean figures cannot be calculated for all treatments about how well they work or the chance of side effects and health problems. Ask your MS team if there are new facts about how a treatment may work for you.

Table 1 Overview of DISEASE MODIFYING TREATMENT options

	Immune Modulation Options	Immune Reconstitution Options	Immune Blocking Options
<b>Chemical Names of Treatments</b>	Beta-interferons, Glatiramer Acetate, Dimethyl-fumarate, Teriflunomide.	Cladribine, Ocrelizumab and Alemtuzumab.	Fingolimod and Natalizumab.
<b>How DMTs Work</b>	Change how cells work. Cells are less able to damage nerves.	Change the number of cells. Fewer cells can damage nerves; Other cells less able to damage nerves.	Change how cells move in body. Nerve-damaging cells stopped from getting into the blood or moving into brain.
<b>Where Taken</b>	All types at home or place of choice.	Cladribine at home or place of choice. Ocrelizumab / Alemtuzumab at a day clinic.	Fingolimod at home or place of choice. Natalizumab at a day clinic.
<b>Monitoring</b>	Usual MS care.	Regular blood tests in some and usual MS care.	Regular blood tests and usual MS care.
<b>Health Impact</b>	Chance less likely to get relapses and disability; Chance of more side-effects and long-term health problems.	Chance less likely to get relapses and disability; Chance of more side-effects and long-term health problems.	Chance less likely to get relapses and disability; Chance of more side-effects and long-term health problems.
<b>Pregnancy</b>	Glatiramer Acetate for pregnant or breast-feeding women.	Talk with the MS team.	Talk with the MS team.

## Comparing facts about DMT options

These tables summarise facts about each treatment to help you compare what is similar and different. The prompts at the end of this section are for you to note down your views about each option [20]. People find it useful to ask MS professionals questions about if and how these treatments may change something about their everyday life [15, 27], for example:

- **Daily routines** such as getting dressed, diet, exercise, chores, relaxation, gardening
- **Work and study** such as flexible work hours, travel, and support in the workplace
- **Leisure and hobbies** such as trips away with friends, and playing music
- **Friends, family and pets** such as going out, having people round, and caring for others
- **Health and RRMS routines** such as going for tests and time for extra treatments

**Table 2 Comparing IMMUNE MODULATION options [1-5, 26]**

	<b>BETA-INTERFERONS</b>	<b>DIMETHYL FUMARATE</b>	<b>GLATIRAMER ACETATE</b>	<b>TERIFLUNOMIDE</b>
<b>BRAND NAMES</b>	Avonex, Extavia, Plegridy, Rebif	Tecfidera	Copaxone, Brabio	Aubagio
<b>In a group of 100 people taking this DMT, each year there are about...</b>	35 relapses	24 relapses	35 relapses	36 relapses
<b>Side-effects, often going away; about 10% (100 in 1000) of people get...</b>	For a few days after each dose: flu, skin reaction from injection, stomach upset	For a few weeks or months: flushes, stomach upset, itchy skin	Immediately, then goes away: flushes, chest tightness, palpitations Later: stomach upset, back pain, low blood pressure, skin reaction from injection	For a few months: flu, headache, stomach upset, urine and chest infections
<b>Long-term problem, often needs treatment</b>	Less blood cells to fight infection - up to 10% (100 in 1000) of people Liver, kidney problems - up to 10% (100 in 1000) of people	Less blood cells to fight infection - up to 10% (100 in 1000) of people Kidney and liver problems - up to 10% (100 in 1000) of people	Skin damage in injection areas - more than 2% (20 in 1000) of people Liver problems - up to 10% (100 in 1000) of people	Anaemia - up to 10% (100 in 1000) of people Liver problems - up to 10% (100 in 1000) of people Less blood cells to fight infection - up to 10% (100 in 1000) of people
<b>Life-threatening problem, needs treatment; can be fatal</b>	None that can be worked out from the data	Brain infection progressive multifocal leukoencephalopathy (PML) - rare, not enough people to work out figures	None that can be worked out from the data	None that can be worked out from the data
<b>DMT routine</b>	Self-injection: one a day/ every other day/weekly/ fortnightly	Pill: twice a day	Self-injection: one a day/every other day	Pill: one a day

**Table 3 Comparing IMMUNE RECONSTITUTION options [6-9, 26]**

	<b>CLADRIBINE</b>	<b>OCRELIZUMAB</b>	<b>ALEMTUZUMAB</b>
<b>BRAND NAMES</b>	Mavenclad	Ocrevus	Lemtrada
<b>In a group of 100 people taking this DMT, each year there are about ...</b>	22 relapses	19 relapses	16 relapses
<b>Side-effects, often going away; about 10% (100 in 1000) of people get...</b>	Rash, infections like shingles, cold sores	Immediately, then goes away: headache, rash, palpitations, feeling sick Later: infections like flu, stomach flu, cold sores	Immediately, then goes away: headache, rash, palpitations Later: infections like colds, flu, urine
<b>Long-term problem, often needs treatment</b>	Less blood cells to fight infections - more than 10% (100 in 1000) of people	Less blood cells to fight infections - more than 10% (100 in 1000) of people	Less blood cells to fight infections - more than 10% (100 in 1000) of people Thyroid problems - about 37% (370 in 1000) of people Kidney problems - up to 0.1 % (1 in 1000) of people
<b>Life-threatening problem, needs treatment and can be fatal</b>	Tuberculosis - rare, not enough people to work out figures	None that can be worked out	Listeriosis - rare, not enough people to work out figures Blood clotting problems - up to 2% (20 in 1000) of people
<b>DMT routine</b>	Pill during ten days in years 1 and 2, then no treatment unless new relapses	Drip at hospital every six months	Drip at hospital. Two treatments, one over five days, and another one a year later over three days

**Table 4 Comparing IMMUNE BLOCKING options [10,11, 26]**

	<b>FINGOLIMOD</b>	<b>NATALIZUMAB</b>
<b>BRAND NAMES</b>	Gilenya	Tysabri
<b>In a group of 100 people taking this DMT, each year there are about...</b>	24 relapses	16 relapses
<b>Side-effects, often going away; about 10% (100 in 1000) of people get ...</b>	Infections like shingles, cold sores, and flu, palpitations, benign skin cancer, headache, stomach upset	Infections like throat, urine infections, stomach upset, headache
<b>Long-term problem, often needs treatment.</b>	Lower blood cells to fight infections - up to 1% (10 in 1000) of people Vision problems, blood clotting problems - up to 1% (10 in 1000) of people	None that can be worked out
<b>Life-threatening problem, needs treatment and can be fatal</b>	Skin cancer - up to 1% (10 in 1000) of people or cancer in the lymph system - up to 0.1% (1 in 1000) of people Brain infection called progressive multifocal leukoencephalopathy (PML) - rare, not enough people to work out figures	Brain infection called progressive multifocal leukoencephalopathy (PML) - up to 1% (10 in 1000) of people at 2 years
<b>DMT routine</b>	Pill: one a day	Drip at hospital: one half day, every four weeks

# My views about



## My views about Immune Modulation options

My views about	My Reasons For	My Reasons Against	Rank 1 <sup>st</sup> - 4 <sup>th</sup>
Beta-Interferons			
Glatiramer Acetate			
Dimethyl-Fumarate			
Teriflunomide			

## My views about Immune Reconstitution options

My views about	My Reasons For	My Reasons Against	Rank 1 <sup>st</sup> - 3 <sup>rd</sup>
Cladribine			
Ocrelizumab			
Alemtuzumab			

## My views about Immune Blocking options

My views about	My Reasons For	My Reasons Against	Rank 1 <sup>st</sup> - 2 <sup>nd</sup>
Fingolimod			
Natalizumab			

# SECTION D: Making my Disease Modifying Treatment decisions

This section has information and prompts to help you make your Disease Modifying Treatment (DMT) decisions.

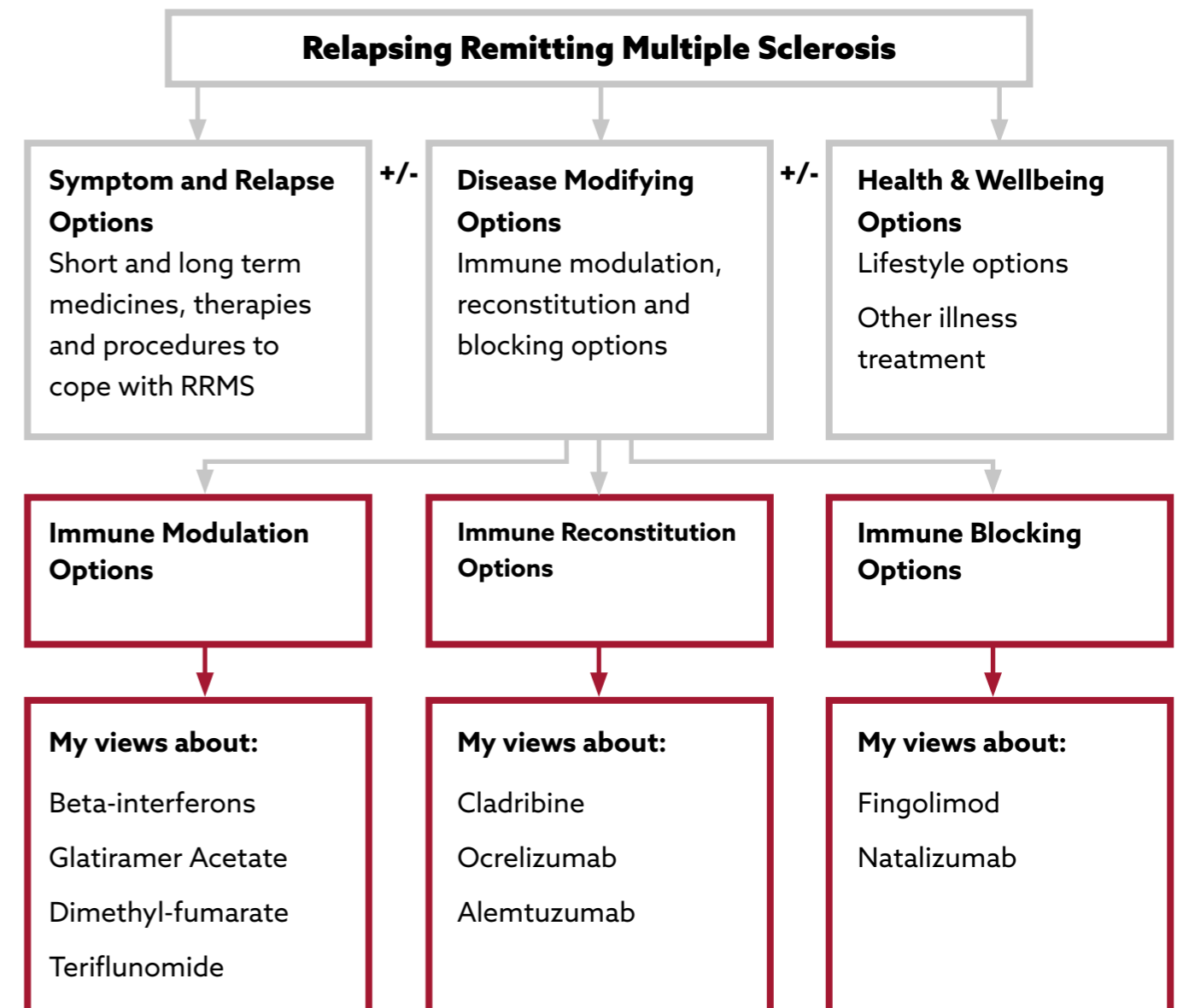
There are three types of decision to make:

Decision Problem 1 - To Start Taking a DMT or Not To Start.

Decision Problem 2 - Deciding between DMT Options.

Decision Problem 3 - Switching between DMT Options.

## Decision Map 4: Disease Modifying Treatment options and decisions



# DMTs decisions

People with RRMS start, switch and stop their DMT options when their RRMS is active, their health is worsening, and/or their lifestyle is changing. These decisions are difficult to make because it means making judgments about your own health, the chance of a treatment working, and your work, family and lifestyle plans. Talking with family about what is important can help people make these decisions [15, 27-33].

## Decision Problem 1 - To start taking a DMT or not to start

When deciding whether or not to start taking a DMT, people think about how their RRMS is impacting on their life, what they feel is important to them now, and their views about future plans for work, study, family and hobbies. Some people find it useful to trade-off their reasons for or against one option compared with another. In the box below is an example of a trade-off you might make between the chances of managing your RRMS with the side-effects of new treatments.

Options	Reasons For	Reasons Against
<b>Symptom &amp; Relapse</b> Take treatment when have symptoms.	Manage symptoms and relapse. No extra chance of getting a life-limiting illness.	No extra chance of having fewer relapses or less serious relapses, or living longer without disability.
<b>Disease Modifying</b> Take medication long-term, even when no symptoms.	Chance of living longer without disability. Chance of fewer or less serious relapses.	Chance of getting another health problem. Chance of getting a life-threatening illness.

Given what you know about Symptom and Relapse Treatments and DMTs, on balance which of these statements best matches your view about managing your RRMS:

- 1. Keep using Symptom & Relapse Treatments only to manage my RRMS
- 2. Take Symptom & Relapse Treatments until my next RRMS relapse
- 3. Plan to start taking a Disease Modifying Treatment

## Decision Problem 2 - Deciding between DMT options

When people are deciding which DMT type and option suits them best, they think about their experiences of taking treatments, which medication routines fit best into their lifestyle now, and their views about future plans for work, study, family and hobbies. People's views will be different, and change over time.

In section C (page 18-20) there were facts about each type of DMT and prompts to help you think about why one DMT might suit you better than another. You may find it useful to make trade-offs about the reasons for and against each DMT option when thinking about this decision.

For example, which medication has:

- The best chance of slowing down my RRMS with the lowest chance of getting another health problem.
- The best chance of fitting into my life with the lowest effort needed to cope with any side-effects I may get.

Given what you know about DMTs now, circle **one** option from each DMT group you want to talk about taking first with your MS health professionals.

Immune Modulation Options	Immune Reconstitution Options	Immune Blocking Options
Beta-interferons [brand names: Avonex, Extavia, Plegridy, Rebif]	Cladribine [brand name: Mavenclad]	Fingolimod [brand name: Gilenya]
Glatiramer Acetate [brand name: Copaxone, Brabio]	Ocrelizumab [brand name: Ocrevus]	Natalizumab [brand name: Tysabri]
Dimethyl-Fumerate [brand name: Tecfidera]	Alemtuzumab [brand name: Lemtrada]	
Teriflunomide [brand name: Aubagio]		

Use this space to note down points you want more facts about:

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### Decision Problem 3 – Switching between DMT options

The lives and health of people with RRMS change in the same ways as those of people without RRMS. People in their 20s have different experiences, goals and needs than when they are in their 40s or 60s. Some people want to stop taking DMTs for a short time to get pregnant or have treatment for another health condition. Some people need to stop taking DMTs because their MS has worsened and/or the DMT is not working for them [14, 19-26].

MS professionals talk with people about if they need to change or stop their medications as their lives change. Some DMTs need to be stopped slowly for the medication to leave a person's body a little bit at a time. For some DMTs, stopping the medication too quickly can mean people have a relapse. The time taken from when a person stops taking a treatment to when the body is free of its chemicals is known as a washout period. Each DMT has a different wash out period.

Most people with RRMS taking a DMT will switch to another option over time. It can take up to six months before people know if a DMT option is working at its full strength. When people are deciding whether to keep or stop taking a DMT option, they are thinking about how their RRMS is changing, the effect of relapses on their health, the effect of the DMT on their longer-term health, their life plans, and the future plans of those people close to them.

#### The types of decisions people are making are to:

- Change to a medication in the same DMT group
- Change to a medication from a different DMT group
- Stop taking a DMT for a health-related reason

#### Given what you know about taking a DMT, which of these statements best matches your view about your DMT decision

- 1. Keep taking the same Disease Modifying Treatment option
- 2. Plan to change my Disease Modifying Treatment option
- 3. Plan to stop taking my Disease Modifying Treatment option

## Questions to help you talk about your DMT decisions with others



**Is there something about my symptoms to suggest my RRMS is active?**

**Is there something in my lifestyle to suggest I need to plan for starting a DMT?**

**Is there something from my check-ups to suggest my RRMS is active?**

**Is there something in my lifestyle to suggest I might need to put off planning for a DMT?**

**Does my MS service offer all DMTs?**

**Is there something in my medical history to say one DMT type is better for me?**

**Is there something in my medical history to say one DMT type is worse for me?**

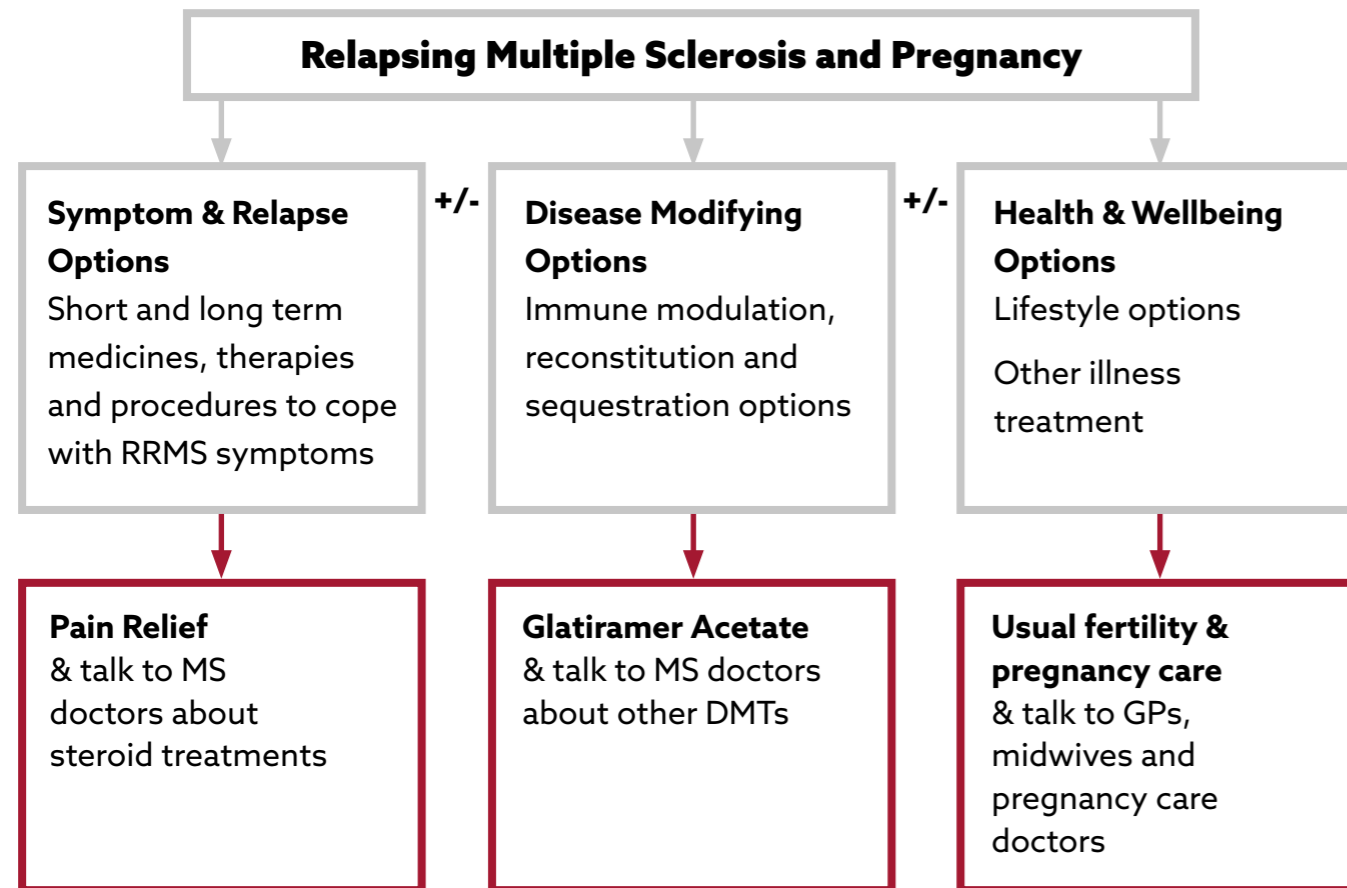
**Is there something in my lifestyle to suggest one DMT type is better for me?**

# SECTION E: Planned-unplanned pregnancy and Disease Modifying Treatments

This section has information for men and women with RRMS taking disease modifying treatments when they, or their partner, has an unplanned pregnancy and/or plans to get pregnant:

- Fertility and Relapsing Remitting Multiple Sclerosis
- Conception and Pregnancy, and Disease Modifying Treatments

**Decision Map 5: Disease Modifying options during conception & pregnancy**



## RRMS and fertility

Both men and women with RRMS must use birth control methods if they do not want an unplanned pregnancy. Women with RRMS and female sexual partners of men with RRMS are as likely to get pregnant as people without RRMS. RRMS does not affect women or men's fertility.

In women, some side-effects of RRMS medications can make the oral contraceptive pill less likely to work. For example, a stomach upset or sickness can mean the hormones from the contraceptive pill needed to stop a pregnancy are not taken into the blood stream in time.

Men and women with RRMS face the same problems and decisions about fertility, pregnancy and parenthood as people without RRMS. They can follow the usual advice for having a healthy conception and pregnancy, such as taking supplements, and not smoking or drinking alcohol.

Women and men can take steroids to treat relapses without affecting their chances of conception, miscarriage and/or the baby's health. MS professionals talk with men and women about how to manage their RRMS treatment and make fertility and pregnancy decisions.

## DMTs and conception

Studies describing the chance of people taking DMTs conceiving and miscarrying show DMTs do not affect women's fertility. For men, the immune modulation treatment Teriflunomide can lower sperm count and make it more difficult for a couple to get pregnant.

MS professionals talk with couples about decisions to carry on or stop taking DMTs when planning to get pregnant. People who stop taking DMTs are more likely to get a severe relapse, sometimes known as a rebound [14].

Some studies tested how much, and how long, DMT chemicals stay in a body. DMT chemicals can stay in the body from 2 months to 2 years after people stop taking them. The time taken from when a person stops taking a treatment to when the body is free of its chemicals is known as a washout period.

MS professionals talk about the different washout period for each DMT. It is not known how harmful these chemicals are to a baby's health. MS professionals talk with people planning to get pregnant, or already pregnant, about their views on keeping or ending a pregnancy when there are worries about how DMTs can affect a baby's health.

# DMTs and pregnancy

If you or your partner have an unplanned pregnancy, or are planning to get pregnant, talk with your MS doctor about the best treatment to have for you or your partner's RRMS, the pregnancy, and the baby.

For women, studies show taking the immune modulator treatment, Glatiramer Acetate, does not increase the chance of miscarriage or affect the baby's health during pregnancy.

Each pregnancy is different and some women relapse in one pregnancy but not another. Some women with RRMS are less likely to have a relapse during their pregnancy. After a baby is born, women with RRMS are more likely to have a relapse.

Glatiramer Acetate can be taken by women who decide to breast feed their baby. Women who decide to stop taking their DMT during pregnancy are advised to start taking their DMT soon after giving birth. It can take up to six months before the DMTs work at full strength again.

**Given what you know about taking DMTs and pregnancy, which of these statements best matches your view about your DMT routine**

- 1. Keep taking my Disease Modifying Treatment
- 2. Plan to take a break from my Disease Modifying Treatment
- 3. Plan to switch to Glatiramer Acetate from my current DMT

**Note questions you have about fertility, conception, pregnancy and parenting to talk over with your general practitioner, midwife, health visitor and MS professionals:**

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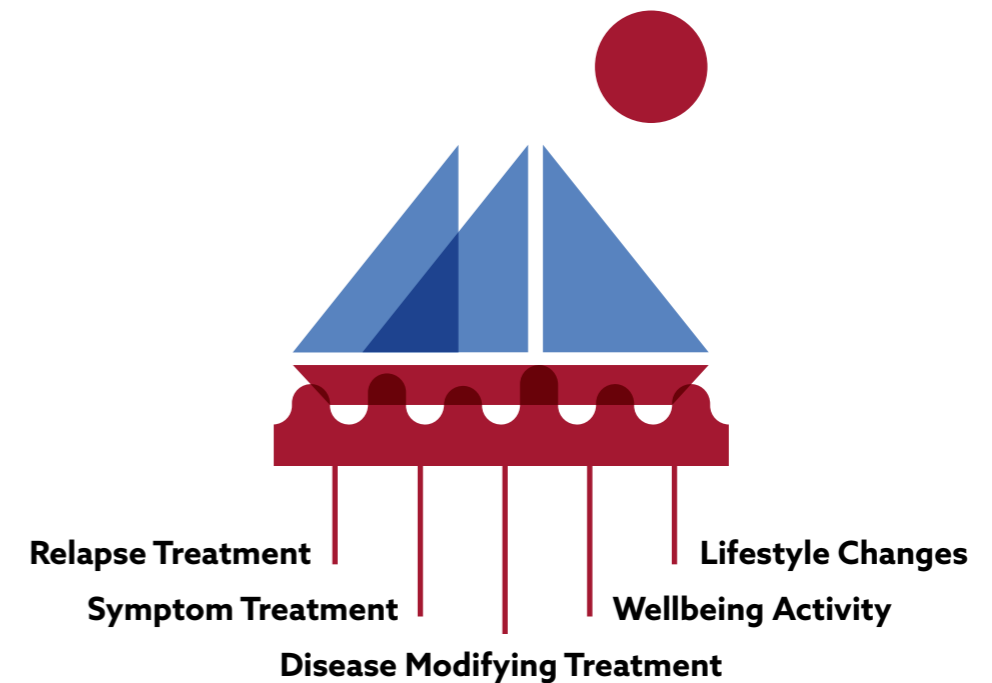
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# NEXT STEPS: Navigating the ups and downs of Relapsing Remitting Multiple Sclerosis

Living with RRMS means making many decisions about different treatments as your life changes. The facts and guidance in this booklet help people think about what is important to them, when planning treatments [27-33].



**Given what you know now:**

**Do you feel sure about the best choices for you?** Yes / No

**Do you know the advantages and disadvantages of each option?** Yes / No

**Are you clear about the advantages and disadvantages matter most to you?** Yes / No

**Do you have enough support and advice to make a choice?** Yes / No

**Talking with others to plan for my RRMS treatments:**

- MS Services ...
- Local Health Service...
- Friends & Family ....
- RRMS Support Group...

# REFERENCE:

## Glossary of terms

This table summarises common words people with Multiple Sclerosis and health professionals use when making treatment decisions.

Term	Description of term
<b>Active Multiple Sclerosis (MS)</b>	The MS stage where people had at least one relapse and/or brain scar in the last 12-24 months.
<b>Attack</b>	See relapse
<b>Brain Lesions Or Scar</b>	Area of damage or scarring (sclerosis) in the brain and central nervous system caused by MS.
<b>Brain Scan</b>	Pictures of the brain using magnetic fields. See MRI.
<b>Cell</b>	The smallest part of the body that works on its own. There are millions of different types of cells in everyone's body.
<b>Disease Modifying Treatment (DMT)</b>	Medications that change how the cells work in the body to slow down MS activity. People with RRMS taking DMTs have fewer relapses than those not taking DMTs.
<b>Flare</b>	Temporary worsening of symptoms that means a person gets new symptoms or a worsening of old symptoms.
<b>Highly Active Multiple Sclerosis (MS)</b>	The MS stage where people have new relapses and/or brain scars in the last 12 months.
<b>Health and Wellbeing Options</b>	Lifestyle and treatment options people with MS choose to keep themselves well. For example to manage stress, eat well, exercise, etc.
<b>Immune Modulation Options</b>	Treatments changing the white cell strength in the immune system (lymphocytes); they are less able to damage nerves.
<b>Immune Reconstruction Options</b>	Treatments changing the types and strength of white cells (lymphocytes); there are fewer cells and they are less likely to damage the immune system.
<b>Immune Blocking Options</b>	Treatments stopping immune cells getting into the blood stream or brain; fewer cells to damage the nerves
<b>Immune System</b>	A complex system of cells, substances and tissues protecting people's bodies from infections.
<b>Immune System Cells</b>	The different types of cells and proteins in the body that recognize and/or react against infections.
<b>Infusion</b>	Treatment injected into a vein through drip equipment.

<b>Lymph Nodes</b>	Small, round structures used by the body to filter fluids, waste, and germs in the body. They contain immune cells to fight infections.
<b>Lymphocytes</b>	White blood cells found in the system of lymph nodes (lymphatic) which defend the body against bacteria and viruses
<b>Magnetic Resonance Imaging (MRI)</b>	Pictures of the brain using magnetic fields and radio waves, a brain scan.
<b>Myelin Sheath</b>	A protective sheath around people's nerves and cells.
<b>Multiple Sclerosis (MS)</b>	Life-long condition caused by a person's immune system attacking their central nervous system and brain, nerve cells and myelin sheaths.
<b>Multiple Sclerosis Team</b>	Health professionals including neurologists, nurses, physiotherapists, occupational therapists and others who deliver care to people with MS.
<b>Nerves</b>	A group of fibres carrying signals between the brain and other parts of the body.
<b>Neurologist</b>	A type of doctor who treat people with nerve damage.
<b>Primary Progressive Multiple Sclerosis (PPMS)</b>	A type of MS where the first symptoms get worse over time without going away (primary and progressive).
<b>Rapid Evolving Multiple Sclerosis (MS)</b>	A type of MS where people have at least two severe relapses and new brain scars in the last 12 months.
<b>Relapse</b>	People with RRMS who get an immune system attack of worsening symptoms or symptom episode, known as a relapse.
<b>Relapsing Remitting Multiple Sclerosis (RRMS)</b>	A type of MS. Relapsing and remitting means the symptoms people get come and go over time.
<b>Secondary Progressive Multiple Sclerosis (SPMS)</b>	A type of MS. Progressive means symptoms are less likely to go away and people are more likely to get a long-term disability.
<b>Spinal Cord</b>	A column of nerve tissue going from the brain down the spine carrying signals to and from the brain to all parts of the body. The spinal cord controls some body functions independently of the brain.
<b>Stable Multiple Sclerosis (MS)</b>	The MS stage where the person has no new relapses in the last 12 months.
<b>Steroid Medication or Corticosteroids</b>	Medication used to treat MS relapse. They speed up recovery but do not stop a relapse from happening or the MS getting worse over time.
<b>Symptom And Relapse Treatments</b>	Treatments to cope with MS symptoms, episodes and relapses.
<b>Wash Out Period</b>	The time taken from when a person stops taking a treatment to when the body is free of its chemicals.



# REFERENCE: Resources and sources of evidence

## Other Information for people with RRMS, their friends and family

- MS Trust (charity) <https://www.mstrust.org.uk/>
- MS Society (charity) <https://www.mssociety.org.uk/>
- MS social network group (charity) <https://shift.ms/>
- NHS-UK <https://www.nhs.uk/conditions/multiple-sclerosis/>
- NICE-UK <https://www.nice.org.uk/guidance/cg186/ifp/chapter/Multiple-sclerosis>
- BartsMS (research) <https://multiple-sclerosis-research.org/>
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### Organisations of The CRIMSON Project Team



## REFERENCE: CRIMSON project team and outputs

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For more details see [crimson.leeds.ac.uk/](http://crimson.leeds.ac.uk/)

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