



Living Well With My Multiple Sclerosis



A Self Management Journal

By

Jolie Suidy

Tessa Price

Cindy Stumme

Index

Page 1.....	General Information
Page 2.....	Health History
Pages 3 to 6.....	Doctor's Appointments
Pages 7 to 8.....	Diagnostic Testing
Pages 9 to 14.....	My Symptoms
Pages 15 to 16.....	Pain
Pages 17 to 21.....	Medications
Page 22.....	Lifestyle
Page 23.....	My Emotions
Page 24.....	Social/Recreational Activities
Page 25.....	Financial Information
Page 26 to 28.....	MS Society Publications
Page 29 to 30.....	Personal Notes

General Information

Name _____

Age _____

Address _____

Type of Multiple Sclerosis:

- Clinically Isolated Syndrome (CIS)
- Relapsing Remitting MS (RRMS)
- Primary Progressive MS
- Secondary Progressive MS
- Progressive Relapsing MS

Date of Diagnosis _____

MS Society Contact _____

General Practitioner _____

Contact Info _____

Neurologist _____

Contact Info _____

Other referrals/physicians _____

~You are the same person as you were before MS~

Health History

Previous Diagnoses

Allergies

Family History

Procedures/Surgeries:

Type

Reason

Date

Type

Reason

Date

Type

Reason

Date

Doctors and Appointments

(This is an area for you to keep track of all the appointments you have with different physicians...)

Doctor _____ Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____ Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____ Date _____

Reason for visit _____

My concerns/Questions _____

Doctor _____ Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

Doctor _____

Date _____

Reason for visit _____

My concerns/Questions _____

Outcome/Plan _____

~Keep pressing for answers until you get the answers you need.~

Diagnostics/Testing

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

Hospital _____ Doctor _____

Test _____ Date _____

Results _____

My Symptoms

- Problems with Balance and Dizziness
- Bladder dysfunction
- Bowel Constipation, Diarrhea and Incontinence
- Cognitive Impairment
- Depression
- Pseudobulbar affect (uncontrollable laughing and/or crying)
- Dry Mouth
- Dysarthria (difficulty speaking)
- Dysphagia (difficulty swallowing)
- Fatigue and Fatigability
- Gait (difficulty in walking)
- Hormonal Influences for women with MS
- Inappropriate Affect (also known as pseudo bulbar affect, emotional incontinence, involuntary emotional expression disorder-IEED)

My other symptoms: _____

~Listen to your body.~

Symptoms (Continued)

Bladder Dysfunction

Do you get bladder infections? - Yes No

If yes how many per year _____

Do you use catheterization? Yes No

Are you incontinent of urine? Yes No

TIPS:

Don't try to self-treat your bladder problems by drinking less fluid! This can lead to constipation or urinary tract infections.

Urinary tract infections, which are common in people with bladder dysfunction, can cause MS relapses. Prevent them by drinking plenty of fluids and include a daily glass of cranberry juice. (Sugar free is best)

Cognitive Impairment

Do you have memory problems? Yes No

- Example: Remembering recent events or misplacing items.

Do you find it difficult to concentrate for long periods of time? Yes No

Do you have difficulties in word finding? Yes No

Do you have difficulty planning or problem solving? Yes No

Emotions:

Depression

Do you have a support system? Yes No

Who is in your support system?

-Name _____ Phone Number _____

Name _____ Phone Number _____

Name _____ Phone Number _____

Are you seeing a physician, psychiatrist or psychologist? Yes No

Do you attend any community support groups? Yes No

If yes, which

groups? _____

Tips for managing your stress and emotions:

1. Be an active partner in your own health care

-Seek out good information about MS and its management - the more you know, the more prepared you'll feel to make the treatment and lifestyle choices that work for you.

2. Appraise your MS with realism and flexibility

- Allow yourself to grieve over whatever changes or losses the MS brings yours way. A realistic approach means letting go of some activities (or learning how to do them differently) and/or taking on new ones that are more feasible – and thus more enjoyable and rewarding.

3. Maintain strong bonds with family and friends

-Strong connections with others are an important ingredient in a fulfilling life whether one has MS or not. Although MS may alter some of the things you're able to do with and for other people, it's important to maintain meaningful relationships in which you're on both the giving and receiving end.

4. Keep a sense of purpose by setting goals

-Personal goals help point you in the direction you want to go and provide a feeling of accomplishment and pride when you get there. An unpredictable disease that saps your energy and alters your ability to get things done can make progress towards your goals more difficult. It may even make it necessary for you to re-think previous goals and develop new goals over time. Whatever course your MS takes, it's important to set your sights on things that are important to you. And working toward your personal goals – whatever they may be – will help you maintain your self-confidence and self-esteem, and feel more in control.

5. Talk about your concerns and feelings

-It's important for people with MS to have at least one trusted individual to talk with about how MS is affecting their life. While this may be a relative or friend, many people find it helpful to have someone to talk to. Most people find that talking with someone from time-to-time lets off steam and helps them develop perspective.

Dry Mouth

Tips:

- Sip water or other sugar-free/caffeine free juices or drinks frequently

- Stimulate the flow of your saliva

By eating foods which require chewing

By chewing sugarless gum

By using, *if possible*, sugarless candies.

By "sucking" a cherry or olive pit; or the rind of a lemon or lime.

Fatigue

What times of the day are you most tired? _____

What times of the day do you have the most energy? _____

Tips:

1. Discover what triggers your fatigue

Find out what's causing you to feel tired, what makes it worse, and what reduces your fatigue. A good way to find patterns in your fatigue is to keep a daily activity diary for a brief time period.

2. Adjusting medications that can cause fatigue

Discuss your medications with your prescriber. It may be possible to dose sedating-medications in the evening, when they will actually help you sleep, making you feel more refreshed the next morning. Some sedating medications, such as antihistamines, have non-drowsy alternatives. It may also be possible to reduce the dose of certain medications. Always discuss medication adjustments with your prescriber first.

3. Follow a healthy nutrition plan

Developing a solid nutrition program can maintain your health, increase your energy reserves, help you sleep better, and reduce your level of tiredness. If you're unfamiliar with the elements of good nutrition, ask your health care provider to refer you to a nutritionist.

4. Use energy-effectiveness strategies

These are a few steps that can be taken to conserve energy and to accomplish tasks of daily living in the most efficient way possible. An occupational therapist can help you to devise more efficient ways to work, perform household chores, and accomplish important tasks. Some tips include:

- Take advantage of times when fatigue is mild. Use these times to accomplish important tasks that require sustained energy, such as shopping, cooking, or yard work.
- Take frequent breaks and pace yourself. Short, 15-minute rests throughout the day can help you conserve energy. However, avoid frequent napping, which can interfere with nighttime sleep.
- Maintain a regular sleep schedule. Go to bed and wake up at the same times every day (even on the weekends). This will help you regulate your internal clock and stabilize your energy levels.
- Postpone nonessential activities when you are feeling fatigued. Always keep in mind that you are battling a very real and very disabling symptom of MS. You should never feel guilty for not accomplishing everything on your list.
- Engage in restorative activities. Activities such as yoga, meditation, sitting in the park, and walking on the beach can help restore your internal sense of balance and energy, and also reduce stress.
- Rearrange your work and home environments to conserve energy. For example, if you have bathrooms on both the first and second floors, keep cleaning products both upstairs and downstairs to avoid unnecessary trips when you are cleaning.
- Ask for help. Devise a plan for the whole family to accomplish chores and other activities.

5. Exercise therapy

Exercise has many important benefits for the fatigued person. It increases lung capacity and your body's ability to use oxygen efficiently. It preserves or increases muscle flexibility, and can reduce pain. It increases strength and energy reserves. It can help strengthen the respiratory muscles (the muscles that help you breathe), which become use from disuse when your mobility is limited. It can also help to relieve feelings of depressed mood, anxiety, and stress, all of which have been linked to fatigue.

You might find using this clock to help you plan your day can be helpful. Mark on the clock the time of day you usually take naps and mark what times of the day you have the most energy



Gait (difficulty walking)

Do you use a walk aide? Yes No

If yes what kind of aide? _____

Do you use a wheel chair? Yes No

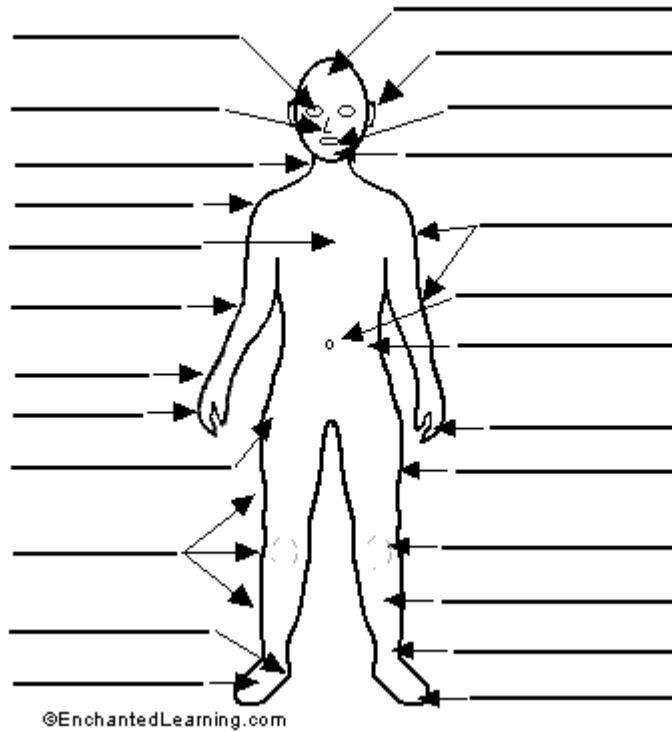
How does your walking difficulty affect your daily life?

~You have an illness – the illness doesn't have you.~

Pain

Where is your pain? _____

(Here is a diagram for you to illustrate where you're feeling pain, shade in the areas if you like!)



What does your pain feel like? _____

<input type="checkbox"/> Aching	<input type="checkbox"/> Tearing
<input type="checkbox"/> Sharp	<input type="checkbox"/> Radiating
<input type="checkbox"/> Throbbing	<input type="checkbox"/> Cramping
<input type="checkbox"/> Tingling	<input type="checkbox"/> Burning
<input type="checkbox"/> Tender	<input type="checkbox"/> Stabbing
<input type="checkbox"/> Dull	<input type="checkbox"/> Crushing

What kind of things relieve your pain? _____

What kind of things increases your pain?

Tips:

Exercise: Can help maintain function and lessen pain. People with MS should always discuss exercise plans with their doctor.

Hydrotherapy / Water Therapy: Can decrease pain and stiffness. Exercising in a pool or spa may be easier because water takes some weight off. Some also find relief from the movement provided by water exercise.

Rest: Pain can also be an indicator of the need for rest. It is important to pay attention to the signal and allow the body the required time to recharge. However too much stillness can lead to muscle weakness. It is essential to strike a balance between rest and exercise.

Massage: Massage Therapy can hasten pain relief and soothe stiff sore muscles. As muscle tension is relaxed and circulation is increased, pain is decreased.

Meditation / Relaxation: Meditation and relaxation can ease muscle tension and help fight fatigue. Relaxation techniques may reduce anxiety, stress and depression.

Deep breathing: Deep breathing involves clearing the mind by breathing in and out, slowly, deeply, and rhythmically. You inhale through the nose and exhale through the mouth, releasing tension.

Progressive Relaxation / Creative Imagery: Progressive relaxation involves lying on your back to systematically tense and relax each part of your body. The relaxation works toward controlling pain. Following progressive relaxation, the mind can be engaged into imagining a pleasant and happy scene. As the mind is occupied with the scene, stress levels diminish, as do pain levels.

Occupational Therapy: is rooted in physical medicine, psychiatry, and behavioural psychology. The objectives of occupational therapy are:

- to help the pain sufferer determine which activities or behaviours intensify pain
- teach methods for decreasing the amount of time in pain
- use techniques to decrease pain intensity
- help patients become more functional in daily activities and in the workplace
- introduce a lifestyle based on good health habits

Pain management techniques used can include:

- body mechanics (learning to move the body in ways that do not increase pain)
- conserving energy (often by adapting daily activities)
- exercise (can reduce pain by increasing strength)
- developing a focus on abilities rather than limitations
- using adaptive equipment and assistive devices
- relaxation techniques

Most pain in MS can be treated. But not all pain a person with MS has is due to MS. Whatever the source, pain is a complex problem that should not be ignored. Many factors may contribute, including fear and worry. **A multidisciplinary pain clinic** may be able to treat chronic disabling pain with medication in combination with such alternative therapies as biofeedback, hypnosis, yoga, meditation or acupuncture. Self-help may also play an important role in pain control. People who stay active and maintain positive attitudes are often able to reduce the impact of pain on their quality of life.

~Don't suffer in silence.~

Medications

List all of the medications that you are currently taking.

<u>Medication</u>	<u>Dose</u>
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10 _____	_____
11 _____	_____
12 _____	_____
13 _____	_____
14 _____	_____
15 _____	_____
16 _____	_____
17 _____	_____
18 _____	_____
19 _____	_____

Medications (Continued)

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Name _____

Why it was
prescribed _____

Start Date _____

Side effects

Positive (*How does the medication benefit
you?*) _____

Negative _____

Lifestyle

(Write down a few things that you do to take some control over your multiple sclerosis or methods you use to help manage your symptoms.)

Diet _____

Exercise _____

Alternative therapy (ie...Massage, Acupuncture, other
therapy??) _____

What benefits do you receive from each of your alternative therapies? How do they help you in
managing your multiple sclerosis? _____

~Having MS does not mean you have to abandon your dreams and goals.~

Social / Recreational Activities

(Don't forget to make time for activities you enjoy...socializing is important and helps reduce stress!)

What are some activities you enjoy doing with your family? _____

What about things you do with friends? _____

How has your multiple sclerosis affected your social life? _____

Financial Information

Are you working? Yes No

Full Time Part Time

Do you have health care benefits? Yes No

Who is your coverage through? _____

Are you receiving CPP? Yes No

Do you receive any other financial assistance? Yes No

If yes

explain _____

Do you Life Insurance? Yes No

Who is your insurance through? _____

What kind of Insurance do you have? _____

Do you have a Will? Yes No

Do you have a Health care Directive? Yes No

Do you have a Power of attorney? Yes No

Are you entitled to Tax Credits? Yes No

MS Society Publications

About multiple sclerosis – general information

- MS Canada
- Multiple Sclerosis and how we can help
- The Treatment Question: Should I start and MS Medication?

- Key facts for those affected with MS
- MS: Its effects on you and those you love
- Living with Progressive Multiple Sclerosis
- Red Flags, Green Flags

Managing MS Symptoms

- MS Attacks: What they are and what you can do about them
- Living well with MS: Managing Fatigue
- Living well with MS: Mind Matters
- Intimacy and Sexuality in MS
- Urinary Dysfunction and MS: A guide for people with Multiple Sclerosis
- Understanding bowel problems
- Living for Today: Managing MS pain
- Pain and MS: Options exist to manage this difficult symptom
- Mind Matters: MS can bring changes to mood and memory
- Cognitive change and MS

Health and Wellness

- Women's Health and MS
- 10 Tips for people living with MS
- Healthy Eating
- Multiple Sclerosis and Your Emotions
- Everybody Stretch
- Multiple Sclerosis and Fitness
- Taming Stress

Multiple Sclerosis and Family

- Parenting with Multiple Sclerosis: How parent with MS- and their kids- adapt and get stronger
- Parenthood and MS: Arriving at a decision that works for you
- How to talk about MS with your children
- Keep S'myelin
- Keep your balance!
- My mommy has MS
- Benjamin: My mum is special

Managing Practical Issues

- A guide to employment and income support
- Adapting: Financial planning for life with Multiple Sclerosis
- MS in the Workplace: An employer's guide
- Talking with your MS Patients about Difficult Topics
- Insuring Your Future: Your guide to life insurance and Multiple Sclerosis
- MS, Work and Income Support: Finding Your Way Through the Maze
- Adapting: Financial Planning for a Life with Multiple Sclerosis

MS and Caregivers

- A guide for Caregivers
- Caregiver & Poverty Stakeholder Forum Summary Report

Young persons with MS

- Mighty special kids
- Kids get MS Too: A guide for Parents Whose Child or Teen has MS
- Kids Get MS Too: Questions and Answers

Personal Notes
