

APPENDIX D-4

Document the Impact of Your Multiple Sclerosis with Diary and Worksheets

DIARY TIPS

A diary with rating scales (such as the attached samples), although subjective, does allow you to quantify your experiences. Using a rating scale saves time when recording and assessing data and it takes little effort compared to a narrative description. Adapt the following evaluation system to document and quantify your daily experiences.

The important thing is to **START NOW!** It is not necessary to write diary entries. Keep a calendar by your bed and write good, bad, or okay on the date before you nod off to sleep. Even smiley faces will do. Get your spouse to write something for you if you are unable to lift the pencil, but put down something on paper every day. At the end of the week, you'll have some useful information and you'll have even better data at the end of the month.

Tip: At your first opportunity, take a moment to jot down what constitutes a good day for you, and list at least three characteristics. Repeat the process for "okay" and "bad" days. Combine this information with the following scale to create a daily log that's meaningful to you. In the long run, this will ensure consistency in your evaluations.

Example:

Minimum attributes of a GOOD day:

1. No severe pain
2. Adequate energy
3. Ability to focus attention

Next, describe a typical good day. Tell what you are able to do, for how long, and with how much or how little assistance. You'll soon be able to review any given day at a glance.

RATING SCALES

Activity Level:

- 1 = slug-like (in bed most of day)
- 2 = coping (seated activity only)
- 3 = typical (limited walking, standing)
- 4 = zippy (able to walk up stairs)
- 5 = vigorous (vacuuming, gardening, etc.)

Pace:

Spurt = 5 to 30 minutes of activity before resting

Sustained = 30 or more minutes of activity before resting

Energy Level:

- 1 = necessities only
- 2 = low
- 3 = moderate
- 4 = high
- 5 = normal (how you used to feel before MS)

Pains/Symptoms: Severity:

- 1 = buzzing; fidgets

- 2 = pins and needles; bug bites
- 3 = electric shocks; voodoo pins; bee stings
- 4 = thunderbolts; knifepoint
- 5 = stun gun; psycho knives

Tip: Creating daily schedules for “good” and “bad” days will work too.

Pain/Symptoms: Frequency:

- 1 = single occurrence
- 2 = a few episodes with several hours between occurrences
- 3 = several episodes occurring in streaks; clusters
- 4 = many episodes occurring frequently
- 5 = symptom is present constantly

S M T W Th F S
Date: _____

Activities/Energy

Activity #1

Description: _____

Time: Morning Afternoon Evening

Level: 1 2 3 4 5

Pace: Spurt Sustained

Time Spent: _____

Activity #2

Description: _____

Time: Morning Afternoon Evening

Level: 1 2 3 4 5

Pace: Spurt Sustained

Time Spent: _____

Activity #3

Description: _____

Pains/Symptoms

Symptom 1:

Location: _____

Time: Morning Afternoon Evening Night

Severity: 1 2 3 4 5

Frequency: 1 2 3 4 5

Symptom 2:

Location: _____

Time: Morning Afternoon Evening Night

Severity: 1 2 3 4 5

Frequency: 1 2 3 4 5

Symptom 3:

Location: _____

Time: Morning Afternoon Evening Night

Severity: 1 2 3 4 5

Time: Morning Afternoon Evening

Frequency: 1 2 3 4 5

Level: 1 2 3 4 5

Symptom 4:

Pace: Spurt Sustained

Location: _____

Time Spent: _____

Time: Morning Afternoon Evening Night

Energy

Severity: 1 2 3 4 5

Morning: 1 2 3 4 5

Frequency: 1 2 3 4 5

Afternoon: 1 2 3 4 5

Medications and Dosage

Evening: 1 2 3 4 5

1.@ ____ A.M./P.M.

Sleep/Rest

2.@ ____ A.M./P.M.

Nap/Rest

3.@ ____ A.M./P.M.

Length: _____

4.@ ____ A.M./P.M.

Time: Morning Afternoon Evening

5.@ ____ A.M./P.M.

Sleep

6.@ ____ A.M./P.M.

Total Hours: _____

Weather

Times Awakened: _____

Temperature: _____

Reasons Awakened: _____

Conditions: _____

Notes:

USING THE WORKSHEETS

The following worksheets can be helpful in documenting the impact of fatigue on your daily activities, work functioning, and other nonfatigue symptoms as they also impact your daily activities, and your job functioning. Simply copy as many other symptom worksheets as you need.

MS FATIGUE WORKSHEET

Information about your fatigue and how it affects daily activity

<p>Describe your MS-related fatigue:</p> <ul style="list-style-type: none"> ■ Tell how it differs from “normal” tired or sleep feelings. ■ Give a graphic example of how it feels.
<p>Do you take any medication for your fatigue?</p>
<p>Does your fatigue follow any discernable pattern?</p>
<p>What level of activity produces your fatigue?</p>
<p>Do you ever become fatigued to the point of incapacity?</p> <ul style="list-style-type: none"> ■ How often? ■ How long does that extreme condition typically last?
<p>How many hours of sleep do you need each night?</p>
<p>How often and how long do you need to nap or rest?</p>
<p>Is your fatigue affected by heat or any other conditions?</p>
<p>Do your other symptoms become aggravated when you are fatigued?</p> <ul style="list-style-type: none"> ■ Which ones?
<p>To what degree does fatigue restrict your normal daily activities? (Use specific numbers/amounts when possible.)</p>
<p>List anything your doctor has told you to do (such as rehabilitation or physical therapy) or not to do (restrictions in environments or reduced hours).</p> <p>Note: Give the doctor's name and the date you were told to cut back or otherwise alter your activities.</p>

MS FATIGUE WORKSHEET (CONTINUED)

Information about how fatigue deeps you from working

Which of these basic physical activities did this symptom limit (check all that apply):				
<input type="checkbox"/> Sitting	<input type="checkbox"/> Standing	<input type="checkbox"/> Walking	<input type="checkbox"/> Lifting	<input type="checkbox"/> Carrying
<input type="checkbox"/> Handling	<input type="checkbox"/> Pushing	<input type="checkbox"/> Pulling	<input type="checkbox"/> Reaching	<input type="checkbox"/> Climbing
<input type="checkbox"/> Stooping	<input type="checkbox"/> Crouching	<input type="checkbox"/> Seeing	<input type="checkbox"/> Hearing	<input type="checkbox"/> Speaking
How often were you absent from your job during the last six months you worked because of fatigue?				
How did fatigue get in your way?				
What did fatigue keep you from doing?				
What were you unable to do as much as before?				
What were you unable to do as well as before?				
What did you have to do differently?				
How many times a day/week/month did fatigue interfere with your work?				

MS SYMPTOM WORKSHEET

Information about this symptom

Is this symptom present most of the time or does it come and go?
How often does this symptom occur (frequency)?
How long does this symptom last (duration)?
What happens to your body?
Where does this symptom affect you (body location)?
How does this symptom feel? (Give a graphic example.)
Does a particular activity or environment make this symptom occur?
In what way does this symptom limit your normal activities?
To what degree does this symptom restrict your normal daily activities? (Use specific numbers/amounts when possible.)
List anything your doctor has told you to do (such as rehabilitation or physical therapy) or not to do (restrictions in environments or reduced hours). Note: Give the doctor's name and the date you were told to cut back or otherwise alter your activities.

MS SYMPTOM WORKSHEET (CONTINUED)

Information about how this symptom keeps you from working:

Which of these basic physical activities did this symptom limit (check all that apply):				
<input type="checkbox"/> Sitting	<input type="checkbox"/> Standing	<input type="checkbox"/> Walking	<input type="checkbox"/> Lifting	<input type="checkbox"/> Carrying
<input type="checkbox"/> Handling	<input type="checkbox"/> Pushing	<input type="checkbox"/> Pulling	<input type="checkbox"/> Reaching	<input type="checkbox"/> Climbing
<input type="checkbox"/> Stooping	<input type="checkbox"/> Crouching	<input type="checkbox"/> Seeing	<input type="checkbox"/> Hearing	<input type="checkbox"/> Speaking
How did this symptom get in your way?				
What did it keep you from doing?				
What were you not able to do as much as before?				
What were you unable to do as well as before?				
What did you have to do differently?				
How many times a day/week/month did this symptom interfere with your work?				