

Appendix A

DePaul Symptom Questionnaire

Please answer the following questions.

1. What is your height? _____

2. What is your weight? _____

4. What is your gender? _____

5. To which of the following race(s) do you belong?

Black, African-American

White

American Indian or Alaska Native

Asian or Pacific Islander

Other race (*Please specify*) _____

6. Are you of Latino or Hispanic origin?

Yes No

7. What is your current marital status?

Married or living with partner

Separated

Widowed

Divorced

Never married

8. Do you have any children?

Yes No (*Skip to Question 9*)

8a. How many children do you have? _____

8b. How many of your children are under 18 years old? _____

9. How many people live in your home? _____

10. What grade or degree have you completed in school?

- Less than high school
- Some high school
- High school degree or GED
- Partial college (at least one year) or specialized training
- Standard college degree
- Graduate professional degree including masters and doctorate

11. What is your current work status? (Check all that apply)

- On disability
- Student
- Homemaker
- Retired
- Unemployed
- Working part-time
- Working full-time

11a. If you are on disability, for what condition do you receive disability compensation?

Please Specify _____

12. What is your current occupation?

Current _____

12a. If you are currently not working, what was your most recent occupation?

Most Recent _____

For the following questions (13-66), we would like to know **how often you have had each symptom** and **how much each symptom has bothered you over the last 6 months**. For each symptom please circle one number for frequency and one number for severity. Please fill the chart out from left to right.

Symptoms	<i>Frequency:</i>					<i>Severity:</i>				
	Throughout the <u>past 6 months</u> , how <u>often</u> have you had this symptom?					Throughout the <u>past 6 months</u> , how <u>much</u> has this symptom bothered you?				
	For each symptom listed below, circle a number from:					For each symptom listed below, circle a number from:				
	0 = none of the time					0 = symptom not present				
	1 = a little of the time					1 = mild				
	2 = about half the time					2 = moderate				
	3 = most of the time					3 = severe				
	4 = all of the time					4 = very severe				
13) Fatigue/extreme tiredness	0	1	2	3	4	0	1	2	3	4
14) Dead, heavy feeling after starting to exercise	0	1	2	3	4	0	1	2	3	4
15) Next day soreness or fatigue after non-strenuous, everyday activities	0	1	2	3	4	0	1	2	3	4
16) Mentally tired after the slightest effort	0	1	2	3	4	0	1	2	3	4
17) Minimum exercise makes you physically tired	0	1	2	3	4	0	1	2	3	4
18) Physically drained or sick after mild activity	0	1	2	3	4	0	1	2	3	4
19) Feeling unrefreshed after you wake up in the morning	0	1	2	3	4	0	1	2	3	4
20) Need to nap daily	0	1	2	3	4	0	1	2	3	4
21) Problems falling asleep	0	1	2	3	4	0	1	2	3	4
22) Problems staying asleep	0	1	2	3	4	0	1	2	3	4
23) Waking up early in the morning (e.g. 3am)	0	1	2	3	4	0	1	2	3	4
24) Sleep all day and stay awake all night	0	1	2	3	4	0	1	2	3	4
25) Pain or aching in your muscles	0	1	2	3	4	0	1	2	3	4
26) Pain/stiffness/tenderness in more than one joint without swelling or redness	0	1	2	3	4	0	1	2	3	4
27) Eye pain	0	1	2	3	4	0	1	2	3	4

Symptoms	<i>Frequency:</i>					<i>Severity:</i>				
	Throughout the past 6 months , how often have you had this symptom?					Throughout the past 6 months , how much has this symptom bothered you?				
	For each symptom listed below, circle a number from:					For each symptom listed below, circle a number from:				
	0 = none of the time					0 = symptom not present				
	1 = a little of the time					1 = mild				
	2 = about half the time					2 = moderate				
	3 = most of the time					3 = severe				
	4 = all of the time					4 = very severe				
28) Chest pain	0	1	2	3	4	0	1	2	3	4
29) Bloating	0	1	2	3	4	0	1	2	3	4
30) Abdomen/stomach pain	0	1	2	3	4	0	1	2	3	4
31) Headaches	0	1	2	3	4	0	1	2	3	4
32) Muscle twitches	0	1	2	3	4	0	1	2	3	4
33) Muscle weakness	0	1	2	3	4	0	1	2	3	4
34) Sensitivity to noise	0	1	2	3	4	0	1	2	3	4
35) Sensitivity to bright lights	0	1	2	3	4	0	1	2	3	4
36) Problems remembering things	0	1	2	3	4	0	1	2	3	4
37) Difficulty paying attention for a long period of time	0	1	2	3	4	0	1	2	3	4
38) Difficulty finding the right word to say or expressing thoughts	0	1	2	3	4	0	1	2	3	4
39) Difficulty understanding things	0	1	2	3	4	0	1	2	3	4
40) Only able to focus on one thing at a time	0	1	2	3	4	0	1	2	3	4
41) Unable to focus vision and/or attention	0	1	2	3	4	0	1	2	3	4
42) Loss of depth perception	0	1	2	3	4	0	1	2	3	4
43) Slowness of thought	0	1	2	3	4	0	1	2	3	4
44) Absent-mindedness or forgetfulness	0	1	2	3	4	0	1	2	3	4
45) Bladder problems	0	1	2	3	4	0	1	2	3	4
46) Irritable bowel problems	0	1	2	3	4	0	1	2	3	4

Symptoms	<i>Frequency:</i> Throughout the past 6 months , how often have you had this symptom? For each symptom listed below, circle a number from: 0 = none of the time 1 = a little of the time 2 = about half the time 3 = most of the time 4 = all of the time					<i>Severity:</i> Throughout the past 6 months , how much has this symptom bothered you? For each symptom listed below, circle a number from: 0 = symptom not present 1 = mild 2 = moderate 3 = severe 4 = very severe				
	0	1	2	3	4	0	1	2	3	4
47) Nausea	0	1	2	3	4	0	1	2	3	4
48) Feeling unsteady on your feet, like you might fall	0	1	2	3	4	0	1	2	3	4
49) Shortness of breath or trouble catching your breath	0	1	2	3	4	0	1	2	3	4
50) Dizziness or fainting	0	1	2	3	4	0	1	2	3	4
51) Irregular heart beats	0	1	2	3	4	0	1	2	3	4
52) Losing or gaining weight without trying	0	1	2	3	4	0	1	2	3	4
53) No appetite	0	1	2	3	4	0	1	2	3	4
54) Sweating hands	0	1	2	3	4	0	1	2	3	4
55) Night sweats	0	1	2	3	4	0	1	2	3	4
56) Cold limbs (e.g. arms, legs, hands)	0	1	2	3	4	0	1	2	3	4
57) Feeling chills or shivers	0	1	2	3	4	0	1	2	3	4
58) Feeling hot or cold for no reason	0	1	2	3	4	0	1	2	3	4
59) Feeling like you have a high temperature	0	1	2	3	4	0	1	2	3	4
60) Feeling like you have a low temperature	0	1	2	3	4	0	1	2	3	4
61) Alcohol intolerance	0	1	2	3	4	0	1	2	3	4
62) Sore throat	0	1	2	3	4	0	1	2	3	4
63) Tender/sore lymph nodes	0	1	2	3	4	0	1	2	3	4
64) Fever	0	1	2	3	4	0	1	2	3	4
65) Flu-like symptoms	0	1	2	3	4	0	1	2	3	4
66) Some smells, foods, medications,	0	1	2	3	4	0	1	2	3	4

or chemicals make you feel sick		
---------------------------------	--	--

67. Have you **always** had persistent or recurring **fatigue/energy problems**, even back to your earliest memories as a child? (By persistent or recurring, we mean that the fatigue/energy problems are usually ongoing and constant, but sometimes there are good periods and bad periods.)

- Yes No Not having a problem with fatigue/energy

68. Since your **fatigue/energy related illness** began, do your headaches either happen more often, feel worse or more severe, or are they in a different place or spot?

- Yes No Not having a problem with fatigue/energy

69. How long ago did your problem with **fatigue/energy** begin?

- Less than 6 months
 6-12 months
 1-2 years
 Longer than 2 years
 Had problem with fatigue/energy since childhood or adolescence
 Not having a problem with fatigue/energy

70. Have you been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?

- Yes No

70a. If yes, what year were you diagnosed? _____

70b. Do you currently have a diagnosis of Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?

- Yes No

70c. Who diagnosed you with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?

- Medical Doctor Alternative Practitioner Self-Diagnosed

70d. Have any of your family members been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?

Yes No

If yes, please list their relation to you and current age _____

71. Did you experience any of the following symptoms regularly and repeatedly in the months and years before your fatigue/energy problems began?

- Sore throat
- Tender/sore lymph nodes
- Unrefreshing sleep
- Impaired memory and concentration
- Prolonged fatigue following physical or mental exertion
- Muscle pain
- Headaches
- Joint Pain
- Not having a problem with fatigue/energy

72. If you rest, does your problem with **fatigue/energy** go away? (Check one)

- Entirely
- Partially
- My fatigue/energy problem is not improved by rest (*Skip to Question 73*)
- I am not having a problem with fatigue/energy (*Skip to Question 73*)

72a. How long do you have to rest for your problem with **fatigue/energy** to entirely or partially go away?

- Less than 30 minutes 30 to 59 minutes 1-2 hours more than 2 hours

73. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?

- Yes No

74. Do you reduce your activity level to avoid experiencing problems with **fatigue/energy**?

- Yes No Not having a problem with fatigue/energy

75. Do you experience a worsening of your **fatigue/energy related illness** after engaging in minimal physical effort?

- Yes No Not having a problem with fatigue/energy

75a. Do you experience a worsening of your **fatigue/energy related illness** after engaging in mental effort?

- Yes No

75b. If you feel worse after activities, how long does this last? (**Check one**)

- 1 hour or less 2-3 Hrs 4-10 Hrs 11-13 Hrs
 14-23 Hrs More than 24 Hrs (Please specify _____)

76. Are you currently engaging in any form of exercise?

- Yes (*Skip to Question 77*) No

76a. If you do not exercise, why aren't you exercising? (**Check all boxes that you agree with**)

- Not interested
 No time
 Would like to but cannot because of problems with fatigue/energy
 Cannot because exercise makes symptoms worse

77. Over what period of time did your **fatigue/energy related illness**, develop? **(Check one)**

- Within 24 hours
- Over 1 week
- Over 1 month
- Over 2-6 months
- Over 7-12 months
- Over 1-2 years
- Longer than 2 years
- Had problem with fatigue/energy since childhood or adolescence
- I am not ill

78. How would you describe the course of your **fatigue/energy related illness**? **(Check one)**

- Constantly getting worse
- Constantly improving
- Persisting (no change)
- Relapsing & remitting (having "good" periods with no symptoms & "bad" periods)
- Fluctuating (symptoms periodically get better and get worse, but never disappear completely)
- No Symptoms/I am not ill

79. Which statement best describes your **fatigue/energy related illness** during the **last 6 months**? **(Check one)**

- I am not able to work or do anything, and I am bedridden.?
- I can walk around the house, but I cannot do light housework.
- I can do light housework, but I cannot work part-time.
- I can only work part-time at work or on some family responsibilities.
- I can work full time, but I have no energy left for anything else.
- I can work full time and finish some family responsibilities but I have no energy left for anything else.
- I can do all work or family responsibilities without any problems with my energy.

80. Did your **fatigue/energy related illness** start after you experienced any of the following?
(Check one or more and please specify)

- An infectious illness _____
- An accident _____
- A trip or vacation _____
- An immunization (shot at doctor's office) _____
- Surgery _____
- Severe stress (bad or unhappy event(s)) _____
- Other _____
- I am not ill

81. Have you ever consulted a medical doctor or health professional about your **fatigue/energy** problem?

- Yes No (*Skip to Question 83*)

82. Do you currently have a medical doctor overseeing your **fatigue/energy** problem?

- Yes No

83. Do you have any medical illness (es) that might be causing your symptoms?

- Yes No (*Skip to Question 84*)

83a. What medical illnesses do you have?

Illness name(s) and year it began: _____

83b. For which of these conditions are you currently receiving treatment? _____

84. Are you currently taking any medications (over the counter or prescription)?

Yes No (*Skip to Question 86*)

84a. What medications are you taking? _____

85. Do you think any medication(s) is (are) causing your problem with **fatigue/energy**?

Yes No (*Skip to Question 86*)

I do not have a problem with fatigue/energy (*Skip to Question 86*)

85a. Please specify which medications: _____

86. Have you ever been diagnosed and/or treated for any of the following: **(Check all that apply and write year (s) experienced, years treated, and medication (if applicable) in the blank)**

- Major depression _____
- Major depression with melancholic or psychotic features _____
- Bipolar disorder (Manic-depression) _____
- Anxiety _____
- Schizophrenia _____
- Eating disorder _____
- Substance abuse _____
- Multiple chemical sensitivities _____
- Fibromyalgia _____
- Allergies _____
- Other (*Please specify*) _____
- No diagnosis/treatment

87. What do you think is the cause of your problem with **fatigue/energy**? **(Check one)**

- Definitely physical
- Mainly physical
- Equally physical and psychological
- Mainly psychological
- Definitely psychological
- No problem with fatigue/energy

88. Do you think anything specific in your personal life or environment accounts for your problem with **fatigue/energy**?

- Yes No (*Skip to Question 89*)
- I do not have a problem with fatigue/energy (*Skip to Question 89*)

88a. Please specify: _____

89. In the **past 4 weeks**, approximately how many hours per week have you spent doing:

Household related activities? _____ hours per week

Social/Recreational related activities? _____ hours per week

Family related activities? _____ hours per week

Work related activities? _____ hours per week

90. In the **past 4 weeks**, have you had to reduce the number of hours you previously spent (prior to your illness) on occupational, social or family activities because of your health or problems with **fatigue/energy**?

Yes No (*Skip to Question 91*) Not having a problem with fatigue/energy

90a. **Before your fatigue/energy related illness**, approximately how many hours did you used to spend on:

Household related activities? _____ hours per week

Social/Recreational related activities? _____ hours per week

Family related activities? _____ hours per week

Work related activities? _____ hours per week

NOTE: For those people who are **not** having a problem with fatigue/energy, please answer questions 91-96 assuming that a score of 100 = having abundant energy such that you could work full time and complete your family responsibilities.

91. Please rate the amount of **energy** you had available **yesterday**, using a scale from 1 to 100 where 1 = no energy and 100 = your pre-illness energy level _____

92. Please rate the amount of **energy** you expended (used) **yesterday**, using a scale from 1 to 100 where 1 = no energy and 100 = your pre-illness energy expended _____

93. Please rate the amount of **fatigue** you had **yesterday**, using a scale from 1 to 100 where 1 = no fatigue and 100 = severe fatigue _____
94. For the **past week**, please rate the amount of **energy** you had available using a scale from 1 to 100 where 1=no energy and 100=your pre-illness energy level _____
95. For the **past week**, please rate the amount of **energy** you have expended (used) using a scale from 1 to 100 where 1 = no energy and 100 = your pre-illness energy expended _____
96. For the **past week**, please rate the amount of **fatigue** you have had using a scale from 1 to 100 where 1 = no fatigue and 100 = severe fatigue _____

The Medical Outcomes Study SF-36 Health Survey (Short Form)

Instructions: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, neighbors, or groups? (**Please check one**)

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

2. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? **(Please check one)**

- All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

During the past 4 weeks , have you had any of the following problems with your work or other regular daily activities as a result of your physical health ?	Yes	No
3a. Cut down on the amount of time you spent on work or other activities	1	2
3b. Accomplished less than you would like	1	2
3c. Were limited in the kind of work or other activities	1	2
3d. Had difficulty performing the work or other activities (For example, it took extra effort)	1	2

These questions are about how you feel and how things have been with you during the past 4 weeks . For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
4a. Did you feel full of pep?	1	2	3	4	5	6
4b. Did you have a lot of energy?	1	2	3	4	5	6
4c. Did you feel worn out?	1	2	3	4	5	6
4d. Did you feel tired?	1	2	3	4	5	6