

Appendix A. The DePaul Post-Exertional Malaise Questionnaire (DPEMQ)

Section 1: Demographic and Illness Information

1. What is your age? _____
(must be over 18 years old)
2. What is your gender?
 - Male
 - Female
 - Other
 - Prefer not to answer
3. To which of the following race(s) do you belong?
 - Black, African-American
 - White
 - American Indian or Alaska Native
 - Asian or Pacific Islander
4. Other race (*Please specify*) _____
5. Are you of Latino or Hispanic origin?
 - Yes
 - No
6. Do you currently live in the United States?
 - Yes
 - No
 - 6a. If you do not live in the United States, what country do you currently live in?

7. What is your current marital status?
 - Married or living with partner
 - Separated
 - Widowed
 - Divorced
 - Never married
 - Prefer not to answer
8. What is the highest degree or level of education you have completed?
 - Less than high school
 - Some high school
 - High school degree or GED
 - Partial college/university (at least one year) or specialized training
 - Standard college/university degree
 - Graduate professional degree including masters and doctorate

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

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

9a. If you are on disability, for what condition do you receive disability compensation?
Please Specify _____

10. If you are currently working, what work do you do and what is your job title?

Current _____

11. If you are currently not working, what was the type of work you did and what was your job title?

Most Recent _____

12. Prior to leaving the workforce, did you cut back either in number of hours worked or in work responsibilities?

- Yes
- No

13. What is your current annual income in US dollars?

- Less than \$24,999
- \$25,000 to \$49,999
- \$50,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 to \$249,999
- \$250,000 or more
- Prefer Not to Respond

14. What was your annual income *prior to becoming ill* in US dollars?

- Less than \$24,999
- \$25,000 to \$49,999
- \$50,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 to \$249,999
- \$250,000 or more
- Prefer Not to Respond

15. What have you been diagnosed with?

- Chronic Fatigue Syndrome (CFS)

- Myalgic Encephalomyelitis (ME)

16. Other (please specify) _____

17. If you have a diagnosis, what year were you diagnosed? _____

18. What age were you when you were diagnosed? _____

19. Who diagnosed you?

- Medical Doctor
- Alternative Practitioner
- Self-Diagnosed

19a. If you were diagnosed by a medical doctor, was he/she an expert/knowledgeable of ME or CFS?

- Yes
- No

20. How long ago did your problem with ME or CFS begin?

- Less than 6 months
- 6-11 months
- 1-2 years
- 3-5 years
- 6-10 years
- Over 10 years
- Had problem with ME or CFS since childhood or adolescence
- Not having a problem with ME or CFS

21. Has your ME or CFS illness been present for more than 50% of the time since you became ill?

- Yes
- No

22. How would you describe the course of your ME or CFS 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.

23. Which statement best describes your ME or CFS illness during the last 6 months? (Check one)

- I am not able to work or do anything, and I am bedridden/completely incapacitated.
- 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.

Section 2: Onset and Triggers

24. Is the onset of your symptom exacerbation ever *immediately* after exertion?

- Yes
- No

24a. If you answered yes, do you experience immediate symptom exacerbation after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

24b. If your onset is *immediate*, please indicate after *what activities*:

24c. If your onset is *immediate*, please indicate for *which symptoms*:

25. Is the onset of your symptom exacerbation ever *delayed* after exertion?

- Yes
- No

25a. If you answered yes, do you experience immediate symptom exacerbation after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

25b. If your onset is delayed, indicate how long after the exertion does your symptom exacerbation occur (you may check more than one box):

- 1 hour or less
- 2-6 hrs
- 7-12 hrs
- 13-24 hrs
- 1-2 days
- 3-4 days
- 5-6 days
- More than 1 week

25c. If your onset is *delayed*, please indicate after *what activities*:

25d. If your onset is *delayed*, please indicate for *which symptoms*:

26. Do basic activities of daily living like going to the toilet, bathing, dressing, communicating, and/or reading trigger your symptom exacerbation?

- Yes
- No

26a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

27. Do positional changes (e.g., your body *position* is shifted from the lying down to standing) lead to symptom exacerbation?

- Yes
- No

27a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

28. Does emotional stress (good or bad) lead to symptom exacerbation?

- Yes
- No

28a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

29. Are there some instances in which the specific precipitants of your symptom exacerbation cannot be identified?

- Yes
- No

30. On a day you are recovering from symptom exacerbation, does it take less exposure that usual to a trigger to exacerbate your symptoms?

- Yes
- No

31. If you have mild overexertion over several days, can this also produce an abnormal physical or cognitive response?

- Yes

- No

32. Do you have other triggers that provoke symptom exacerbation such as (check box if yes):

- Chemicals
- Foods
- Light
- Heat
- Cold
- Noise
- Visual overload
- Watching movement (such as a video)
- Sensory overload

Section 3: Consequences and Symptoms

33. If you go beyond your energy limits by engaging in pre-illness tolerated exercise or activities of daily living, do you experience any of the following (check box if yes):

- An abnormal response to minimal amounts of physical and/or cognitive exertion
- An onset that is immediate or delayed by hours or days
- A severity and duration of symptoms that are out of proportion to the initial trigger
- A loss of functional capacity and/or stamina
- Post-exertional exhaustion
- Symptom exacerbation

Section 4: In the next set of questions, indicate whether or not the following symptoms **made worse due to physical or cognitive exertion** (which we will refer to as “**symptom exacerbation**”):

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
34. Reduced stamina and/or functional capacity	0 1 2 3 4	0 1 2 3 4
35. Physically fatigued while mentally wired	0 1 2 3 4	0 1 2 3 4
36. Cognitive exhaustion	0 1 2 3 4	0 1 2 3 4
37. Problems thinking	0 1 2 3 4	0 1 2 3 4

38. Unrefreshing sleep	0	1	2	3	4	0	1	2	3	4
39. Insomnia	0	1	2	3	4	0	1	2	3	4
40. Muscle pain	0	1	2	3	4	0	1	2	3	4
41. Muscle weakness/instability	0	1	2	3	4	0	1	2	3	4
42. Aches all over your body	0	1	2	3	4	0	1	2	3	4
43. Dizziness	0	1	2	3	4	0	1	2	3	4
44. Flu-like symptoms	0	1	2	3	4	0	1	2	3	4
45. Temperature dysregulation	0	1	2	3	4	0	1	2	3	4

46. Please list any other PEM symptoms you experience:

Section 5: Duration, Recovery, and Pacing

47. Does your prolonged, unpredictable recovery period from symptom exacerbation last days, weeks, or even months?

- Yes
- No

47a. If yes, how long does your prolonged, unpredictable recovery period typically last (you may check more than one box):

- Within 24 hours
- Between 24 hours and 1 week
- Between 1 week and 1 month
- Between 1 month and 6 months
- Between 6 months and 12 months
- Between 12 months and 2 years
- Over 2 years

48. Is the severity and duration of your symptom exacerbation out-of-proportion to the *type* of the exertion?

- Yes
- No

48a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

49. Is the severity and duration of your symptom exacerbation symptoms out-of-proportion to the *intensity* of the exertion?

- Yes
- No

49a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

50. Is the severity and duration of your symptom exacerbation out-of-proportion to the *frequency* of the exertion?

- Yes
- No

50a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

51. Is the severity and duration of your symptom exacerbation out-of-proportion to the *duration* of the exertion?

- Yes
- No

51a. If you answered yes, do you experience the worsening of symptoms after exertion:

- All of the time
- Most of the time
- About half the time
- A little of the time

52. Does pacing allow you to completely avoid your symptom exacerbation?

- Yes
- No

53. Does pacing allow you to avoid only to a certain degree your symptom exacerbation?

- Yes
- No

53a. If yes, how frequently do you find pacing to be effective in avoiding symptom exacerbation?

- All of the time
- Most of the time
- About half the time
- A little of the time

53b. If yes, how effectively do you find pacing to be in reducing the level of severity of your symptoms?

- ❑ Very effective
- ❑ Moderately effective
- ❑ Mildly effective
- ❑ Barely effective