Instructions for the DePaul Pediatric Health Questionnaire

The DePaul Pediatric Health Questionnaire (DPHQ) is used among children who are under the age of 18 years old. It can be administered to 12 -17 year olds as a self-report or for children younger than 12 years old, an adult guardian should fill out the questionnaire along with the child. The adult guardian should record the answers given by the child, unless the child is unable to recall information.

Only one questionnaire should be completed so that there is only one set of data for each participant. It is important to emphasize mutuality and agreement of reporting between child and adult guardian when completing the questionnaire. Guardian parents may remember and recall the child's experiences and symptoms better than the child can. At the same time, they may also remember inaccurate or incomplete information that disagrees with the child's experiences and symptoms. If an adult is assisting a child in filling out the questionnaire, it is important that the pair comes to a consensus so that duplicate data is not provided.

If the child is at a location away from adult guardians, such as a school or a tertiary care center, an adult such as a nurse or a teacher may simply record the child's responses to the questionnaire. Mutuality and agreement of reporting cannot exist in such cases, but a child report is adequate, as long as it is based on an adult's assistance in administering the questionnaire to the child.

All children under age 18 who have a chronic illness such as CFS or cancer should have the assistance of an adult, in order to reduce respondent burden and increase accuracy of reporting.

Scoring Sheet: **To meet criteria, a symptom must have a rating for Frequency and Severity of 4 or more, and be of 3 months or longer duration**

Categories	Question	Frequency	Severity	Duration	
I. Fatigue: **Question 8**	**8**				Meets Fatigue Criterion Yes_____
II. Post-Exertional Malaise: **Question 9**	**9**				Meets Post-Exertional Malaise Criterion Yes____
III. Sleep: At least one symptom from **Questions 10** to **14**	**10**				Meets Sleep Criterion Yes_____
	11				
	12				
	13				
	14				
IV. Pain: At least one symptom from **Questions 15** to **25**	**15**				Meets Pain Criterion Yes_____
	16				
	17				
	18				
	19				
	20				
	21				
	22				
	23				
	24				
	25				
V. Neurocognition: At least two symptoms from **Questions 26** to **34**	**26**				Meets Neurocognition Criterion Yes_____
	27				
	28				
	29				
	30				
	31				
	32				
	33				
	34				
VI. Other Category: Autonomic manifestations: **Questions 35** to **38**	**35**				Meets Other Category Criteria (At least one symptom from two of the following categories: Automonic, Neuroendocrine, Immune) Yes_____
	36				
	37				
	38				
Neuroendocrine manifestations: **Questions 39** to **46**	**39**				
	40				
	41				
	42				
	43				
	44				
	45				
	46				
Immune manifestations: **Questions 47** to **50**	**47**				
	48				
	49				
	50				

Diagnosis

_______**Severe ME/CFS**
Meets Criteria for categories I, II, III, IV V and VI

______**Moderate ME/CFS**
Meets Criteria for 5 of the 6 categories. Also, for Category VI, only one criterion symptom is needed.

_______**Atypical ME/CFS**
(Reporting 4 or fewer criteria categories).

_______ **ME/CFS-Like**
(Exhibiting all criteria symptoms but not for a duration of three or more months, or lacking medical evaluation).

_______**Remission**
(Met full symptom criteria at one time but not currently experiencing severe or moderate symptomology).

Definition of Severe ME/CFS for Children

I. Clinically evaluated, unexplained, persistent or relapsing chronic fatigue over the past 3 months that:

A. Is not the result of ongoing exertion
B. Is not substantially alleviated by rest
C. Results in substantial reduction in previous levels of educational, social and personal activities
D. Must persist or reoccur for at least three months

II. The concurrent occurrence of the following classic ME/CFS symptoms, which must have persisted or recurred during the past three months of illness (symptoms may predate the reported onset of fatigue).

A. Post-exertional malaise and/ or post-exertional fatigue.

With activity (it need not be strenuous and may include walking up a flight of stairs, using a computer, or reading a book), there must be a loss of physical or mental stamina, rapid/sudden muscle or cognitive fatigability, post-exertional malaise and/or fatigue and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. The recovery is slow, often taking 24 hours or longer.

B. Unrefreshing sleep or disturbance of sleep quantity or rhythm disturbance.

May include prolonged sleep (including frequent naps), disturbed sleep (e.g., inability to fall asleep or early awakening), and/or day/night reversal.

C. Pain (or discomfort) that is often widespread and migratory in nature. At least one symptom from any of the following:

Myofascial and/or joint pain (Myofascial pain can include deep pain, muscle twitches, or achy and sore muscles. Pain, stiffness, or tenderness may occur in any joint but must be present in more than one joint and lacking edema or other signs of inflammation.)
Abdominal and/or head pain (May experience eye pain/sensitivity to bright light, stomach pain, nausea, vomiting, or chest pain. Headaches often described as localized behind the eyes or in the back of the head. May include headaches localized elsewhere, including migraines.)

D. Two or more neurocognitive manifestations:

Impaired memory (self-reported or observable disturbance in ability to recall information or events on a short-term basis)
Difficulty focusing (disturbed concentration may impair ability to remain on task, to screen out extraneous/excessive stimuli in a classroom, or to focus on reading, computer/work activity, or television programs)
Difficulty finding the right word
Frequently forget what wanted to say
Absent mindedness
Slowness of thought
Difficulty recalling information
Need to focus on one thing at a time
Trouble expressing thought
Difficulty comprehending information
Frequently lose train of thought
New trouble with math or other educational subjects

E. At least one symptom from two of the following three categories:

1. Autonomic manifestations: Neurally mediated hypotension, postural orthostatic tachycardia, delayed postural hypotension, palpitations with or without cardiac arrhythmias, dizziness, feeling unsteady on the feet--disturbed balance, shortness of breath.

2. Neuroendocrine manifestations Recurrent feelings of feverishness and cold extremities, subnormal body temperature and marked diurnal fluctuations, sweating episodes, intolerance of extremes of heat and cold, marked weight change-loss of appetite or abnormal appetite, worsening of symptoms with stress.

3. Immune manifestations: Recurrent flu-like symptoms, non-exudative sore or scratchy throat, repeated fevers and sweats, lymph nodes tender to palpitation--generally minimal swelling noted, new sensitivities to food, odors, or chemicals.

III. Exclusionary conditions:

A. Any active medical condition that may explain the presence of chronic fatigue, such as:

1. Untreated hypothyroidism
2. Sleep apnea
3. Narcolepsy
4. Malignancies
5. Leukemia
6. Unresolved hepatitis
7. Multiple Sclerosis
8. Juvenile rheumatoid arthritis
9. Lupus erythematosus
10. HIV/AIDS
11. Severe obesity (BMI greater than 40)
12. Celiac disease
13. Lyme disease

B. Some active psychiatric conditions that may explain the presence of chronic fatigue, such as:

1. Childhood schizophrenia or psychotic disorders
2. Bipolar disorder
3. Active alcohol or substance abuse – except as below:
    a) Alcohol or substance abuse that has been successfully treated and resolved should not be considered exclusionary.
4. Active anorexia nervosa or bulimia nervosa – except as below:
    a) Eating disorders that have been treated and resolved should not be considered exclusionary.
5. Depressive disorders

IV. May have presence of concomitant disorders that do not adequately explain fatigue, and are, therefore, not necessarily exclusionary.

1. Psychiatric diagnoses such as:
    a) School phobia
    b) Separation anxiety
    c) Anxiety disorders
    d) Somatoform disorders
    e) Depressive disorders
2. Other conditions defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, such as:
    a) Multiple food and/or chemical sensitivity
    b) Fibromyalgia
3. Any condition under specific treatment sufficient to alleviate all symptoms related to that condition and for which the adequacy of treatment has been documented.
4. Any condition, that was treated with definitive therapy before development of chronic symptomatic sequelae.
5. Any isolated and unexplained physical examination, laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition.

Child Name____________________ Date____________________

DePaul Pediatric Health Questionnaire (Child Version)

For all of the following questions, please provide or circle only one answer unless otherwise asked.

1. How old are you? .... _______________

2. Are you male or female?

   Male.. 1

   Female 2

3. Are you of Latino or Hispanic origin?

   Yes 1

   No... 2

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

   Black, African-American 1

   White 2

   American Indian or Alaska Native 3

   Asian or Pacific Islander..................................... 4

   Some other race (***Please write-in below***) 5

   ____

5. What grade are you in or what was the last grade that you completed? _____

6. Do you attend school or do you have home-schooling/homebound instruction?

   Attend School 1

   Attend School Part-time 2

   Home-school/Homebound Instruction (***Please write-in below***) 3

   When did you start home-schooling/Homebound Instruction? __________

7. How many days of school do you usually miss in one month? ____________

Please fill out this chart (go from left to right)

Symptoms	Please write the number of months you have experienced this symptom below	*Frequency:* How often do you have this symptom? Please circle a number from 1-7 using this scale Hardly Ever 1 2 3 Half of the time 4 5 6 Always 7	*Severity:* How much does this symptom bother you? Please circle a number from 1-7 using this scale No Problem 1 2 3 Moderate Problem 4 5 6 Big Problem 7
8) Fatigue/ Extreme tiredness		1 2 3 4 5 6 7	1 2 3 4 5 6 7
9) Feeling worse after doing activities that require physical or mental effort		1 2 3 4 5 6 7	1 2 3 4 5 6 7
10) Feeling tired after you wake up in the morning		1 2 3 4 5 6 7	1 2 3 4 5 6 7
11) Need to nap daily		1 2 3 4 5 6 7	1 2 3 4 5 6 7
12) Problems falling asleep		1 2 3 4 5 6 7	1 2 3 4 5 6 7
13) Problems staying asleep		1 2 3 4 5 6 7	1 2 3 4 5 6 7
14) Waking up early in the morning (like 3am)		1 2 3 4 5 6 7	1 2 3 4 5 6 7
15) Pain or aching in your muscles		1 2 3 4 5 6 7	1 2 3 4 5 6 7
16) Muscle twitches		1 2 3 4 5 6 7	1 2 3 4 5 6 7
17) Pain/stiffness/tenderness in more than one joint without swelling or redness		1 2 3 4 5 6 7	1 2 3 4 5 6 7
18) Eye pain		1 2 3 4 5 6 7	1 2 3 4 5 6 7
19) Vomiting		1 2 3 4 5 6 7	1 2 3 4 5 6 7
20) Nausea		1 2 3 4 5 6 7	1 2 3 4 5 6 7
21) Chest pain or heartburn		1 2 3 4 5 6 7	1 2 3 4 5 6 7
22) Upset stomach		1 2 3 4 5 6 7	1 2 3 4 5 6 7
23) Abdomen/stomach pain		1 2 3 4 5 6 7	1 2 3 4 5 6 7
24) Ringing in ears		1 2 3 4 5 6 7	1 2 3 4 5 6 7
25) Headaches		1 2 3 4 5 6 7	1 2 3 4 5 6 7
26) Problems remembering things		1 2 3 4 5 6 7	1 2 3 4 5 6 7
27) Difficulty paying attention for a long period of time		1 2 3 4 5 6 7	1 2 3 4 5 6 7
28) Difficulty finding the right word to say		1 2 3 4 5 6 7	1 2 3 4 5 6 7

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29) Difficulty understanding things		1	2	3	4	5	6	7	1	2	3	4	5	6	7
30) Only able to focus on one thing at a time		1	2	3	4	5	6	7	1	2	3	4	5	6	7
31) Frequently losing your train of thought		1	2	3	4	5	6	7	1	2	3	4	5	6	7
32) Slowness of thought		1	2	3	4	5	6	7	1	2	3	4	5	6	7
33) Absent-mindedness or forgetfulness		1	2	3	4	5	6	7	1	2	3	4	5	6	7
34) Recent trouble with math or numbers		1	2	3	4	5	6	7	1	2	3	4	5	6	7
35) Feel unsteady on your feet, like you might fall		1	2	3	4	5	6	7	1	2	3	4	5	6	7
36) Shortness of breath or trouble catching your breath		1	2	3	4	5	6	7	1	2	3	4	5	6	7
37) Dizziness		1	2	3	4	5	6	7	1	2	3	4	5	6	7
38) Irregular heart beats		1	2	3	4	5	6	7	1	2	3	4	5	6	7
39) Losing or gaining weight		1	2	3	4	5	6	7	1	2	3	4	5	6	7
40) Not wanting to eat		1	2	3	4	5	6	7	1	2	3	4	5	6	7
41) Sweating hands		1	2	3	4	5	6	7	1	2	3	4	5	6	7
42) Night sweats		1	2	3	4	5	6	7	1	2	3	4	5	6	7
43) Feel chills or shivers		1	2	3	4	5	6	7	1	2	3	4	5	6	7
44) Feeling hot or cold		1	2	3	4	5	6	7	1	2	3	4	5	6	7
45) Feeling like you have a high temperature		1	2	3	4	5	6	7	1	2	3	4	5	6	7
46) Feeling like you have a low temperature		1	2	3	4	5	6	7	1	2	3	4	5	6	7
47) Sore throat		1	2	3	4	5	6	7	1	2	3	4	5	6	7
48) Tender/sore lymph nodes		1	2	3	4	5	6	7	1	2	3	4	5	6	7
49) Fever and sweats		1	2	3	4	5	6	7	1	2	3	4	5	6	7
50) Some smells, foods, or chemicals make you feel sick		1	2	3	4	5	6	7	1	2	3	4	5	6	7
51) Rash(es)		1	2	3	4	5	6	7	1	2	3	4	5	6	7
52) Allergies		1	2	3	4	5	6	7	1	2	3	4	5	6	7
53) Mood changes		1	2	3	4	5	6	7	1	2	3	4	5	6	7
54) Anxiety		1	2	3	4	5	6	7	1	2	3	4	5	6	7

55. If you have headaches now, do you get them more often, in a different place, or do the headaches feel worse than they did in the past? (You may circle more than one answer.)

Headaches happen more often 1
Headaches feel worse/more severe 2
Headaches are in a different place/spot 3

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

No 1
Yes (***What medical illnesses do you have?***) 2

Illness name(s):____

Date(s) of onset or diagnosis:________________________________

57. Do you seem to catch illnesses more easily than other people your age?

No.. 1
Yes 2

58. Does it seem to take you longer to get better after you are sick than other people your age?

No.. 1
Yes 2

59. How does being physically active (such as using stairs, walking, playing sports, doing chores, getting dressed) make you feel for the rest of the day?

Much more tired than usual 1
More tired than usual 2
Has no effect 3
More energetic than usual 4
Much more energetic than usual 5

60. Do you participate in any activities or hobbies outside of school?

No.. 1
Yes 2

61. Are you currently able to carry out your activities or hobbies?

No 1

Yes 2

IF NO, when and why did you quit your activities:

____

62. Have you been experiencing any problems with fatigue/extreme tiredness? for at least one month?

No 1

Yes 2

IF YES, for about how many months? _______

63. What do you think the cause of your fatigue or tiredness is? (Skip to question 63 if you are not feeling fatigue or tiredness)

____

64. Do you think that your fatigue is caused by ongoing activity?

Yes 1

No 2

I do not have fatigue 3

65. Did your fatigue illness start after you experienced______? (Circle one or more.)

An infectious illness 1

An accident 2

A trip or vacation 3

An immunization (shot at doctor's office)............ 4

Surgery... 5

Severe stress (bad or unhappy event(s)) 6

Other (***Please write in below***) 7

____

I do not have fatigue 8

66. How long did it take for your problem with fatigue or tiredness to get started?

Rapidly - within 24 hours 1
Over 1 week.. 2
Over 1 month 3
Over 2-3 months 4
Over 4-6 months 5
Over 7-11 months 6
Over 1-2 years 7
Longer than 2 years 8
I have always experienced fatigue 9
I do not have fatigue 10

67. When you first became sick what were your worst 3 symptoms? (Skip to question 68 if you are not feeling fatigue or tiredness)

a. ____________________________________
b. ____________________________________
c. ____________________________________

68. Right now, what are your worst 3 symptoms? (Skip to question 69 if you are not feeling fatigue or tiredness)

a. ____________________________________
b. ____________________________________
c. ____________________________________

69. Do your symptoms change over time?

No.. 1
Yes 2
I do not have fatigue 3

70. Do you limit or cut back your activity levels to avoid feeling even more tired?

No.. 1
Yes 2

71. If you rest, does all of your fatigue go away, some of it go away, or none

of it go away?

All of it goes away 1

Some of it goes away... 2

None of it goes away 3

I do not have fatigue 4

72. How long do you have to rest before your fatigue gets better? (Skip to question 73 if you do not have fatigue)

____

73. Will your fatigue come back if you stop resting and start doing something?

No... 1

Yes 2

I do not have fatigue 3

74. How would you describe the way your fatigue illness is changing over time?

My fatigue is getting worse................................. 1

I have good and bad periods.............................. 2

There is no change 3

My fatigue is getting better 4

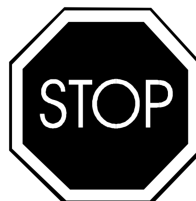
I do not have fatigue 5

75. Have you ever been diagnosed with ME/CFS by a physician?

No 1

Yes.. 2

If yes, when were you diagnosed?_________________________________



Thank you for filling out the DePaul Pediatric Health Questionnaire (Child Version).

Adult Name____________________ Date____________________

DePaul Pediatric Health Questionnaire (Adult Version)

For all of the following questions, please provide or circle only one answer unless otherwise asked.

1. What is your child's age (in years)? .... _______________

2. Is your child male or female?

   Male... 1
   Female 2

3. Is your child of Latino or Hispanic origin?

   Yes 1
   No... 2

4. To which of the following race(s) does your child belong?

   Black, African-American 1
   White 2
   American Indian or Alaska Native 3
   Asian or Pacific Islander..................................... 4
   Some other race (***Please write-in below***) 5

   ____

5. What grade is your child in or what was the last grade that he/she completed? ______

6. Does your child attend school or does he/she have home-schooling/homebound instruction?

   Attend School 1

   Attend School Part-time 2

   Home-school/Homebound Instruction (***Please write-in below***) 3

   When did he/she start home-schooling/Homebound Instruction?______________

7. How many days of school does your child usually miss in one month?____________

Please fill out this chart (go from left to right)

Symptoms	Please write the number of months your child has experienced this symptom below	*Frequency:* How often does your child have this symptom? Please circle a number from 1-7 using this scale Hardly Ever 1 2 3 Half of the time 4 5 6 Always 7	*Severity:* How much does this symptom bother your child? Please circle a number from 1-7 using this scale No Problem 1 2 3 Moderate Problem 4 5 6 Big Problem 7
8) Fatigue/ Extreme tiredness		1 2 3 4 5 6 7	1 2 3 4 5 6 7
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Symptoms	Please write the number of months your child has experienced this symptom below	*Frequency:* How often does your child have this symptom? Hardly Ever 1, 2, 3, Half of the time 4, 5, 6, Always 7	*Severity:* How much does this symptom bother your child? No Problem 1, 2, 3, Moderate Problem 4, 5, 6, Big Problem 7
29) Difficulty understanding things		1 2 3 4 5 6 7	1 2 3 4 5 6 7
30) Only able to focus on one thing at a time		1 2 3 4 5 6 7	1 2 3 4 5 6 7
31) Frequently losing his/her train of thought		1 2 3 4 5 6 7	1 2 3 4 5 6 7
32) Slowness of thought		1 2 3 4 5 6 7	1 2 3 4 5 6 7
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35) Feels unsteady on his/her feet, like he/she might fall		1 2 3 4 5 6 7	1 2 3 4 5 6 7
36) Shortness of breath or trouble catching his/her breath		1 2 3 4 5 6 7	1 2 3 4 5 6 7
37) Dizziness		1 2 3 4 5 6 7	1 2 3 4 5 6 7
38) Irregular heart beats		1 2 3 4 5 6 7	1 2 3 4 5 6 7
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50) Some smells, foods, or chemicals make your child feel sick		1 2 3 4 5 6 7	1 2 3 4 5 6 7
51) Rash(es)		1 2 3 4 5 6 7	1 2 3 4 5 6 7
52) Allergies		1 2 3 4 5 6 7	1 2 3 4 5 6 7
53) Mood changes		1 2 3 4 5 6 7	1 2 3 4 5 6 7
54) Anxiety		1 2 3 4 5 6 7	1 2 3 4 5 6 7

55. If your child has headaches now, does he/she get them more often, in a different place, or do the headaches feel worse than they did in the past? (You may circle more than one answer.)

Headaches happen more often 1
Headaches feel worse/more severe 2
Headaches are in a different place/spot 3

56. Does your child have any medical illness that might be causing his/her symptoms?

No 1
Yes (***What medical illnesses does he/she have?***) 2

Illness name(s):____

Date(s) of onset or diagnosis:__________________________________

57. Does your child seem to catch illnesses more easily than other people his/her age?

No... 1
Yes 2

58. Does it seem to take your child longer to get better after he/she is sick than other people his/her age?

No... 1
Yes 2

59. How does being physically active (such as using stairs, walking, playing sports, doing chores, getting dressed) make your child feel for the rest of the day?

Much more tired than usual 1
More tired than usual 2
Has no effect 3
More energetic than usual 4
Much more energetic than usual 5

60. Does your child participate in any activities or hobbies outside of school?

No... 1
Yes 2

61. Is he/she currently able to carry out his/her activities or hobbies?

No 1
Yes 2

IF NO, when and why did your child quit his/her activities:

____

62. Has your child been experiencing any problems with fatigue/extreme tiredness for at least one month?

No 1

Yes 2

IF YES, for about how many months? ________

63. What do you think is the cause of your child's fatigue or tiredness? (Skip to question 63 if he/she is not feeling fatigue or tiredness)

____

64. Do you think that your child's fatigue is caused by ongoing activity?

Yes 1
No 2

He/she does not have fatigue 3

65. Did your child's fatigue illness start after he/she experienced______? (Circle one or more.)

An infectious illness 1
An accident 2
A trip or vacation 3
An immunization (shot at doctor's office) 4
Surgery 5
Severe stress (bad or unhappy event(s)) 6
Other (***Please write in below***) 7

____

He/she does not have fatigue 8

66. How long did it take for your child's problem with fatigue or tiredness to get started?

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Over 1 week.. 2
Over 1 month 3
Over 2-3 months 4
Over 4-6 months 5
Over 7-11 months 6
Over 1-2 years 7
Longer than 2 years 8
He/she has always experienced fatigue 9
He/she does not have fatigue 10

67. When your child first became sick what were his/her worst 3 symptoms? (Skip to question 68 if he/she is not feeling fatigue or tiredness)

d. ____________________________________
e. ____________________________________
f. ____________________________________

68. Right now, what are your child's worst 3 symptoms? (Skip to question 69 if he/she is not feeling fatigue or tiredness)

d. ____________________________________
e. ____________________________________
f. ____________________________________

69. Do his/her symptoms change over time?

No.. 1
Yes 2
He/she does not have fatigue 3

70. Does your child limit or cut back his/her activity levels to avoid feeling even more tired?

No.. 1
Yes 2

71. If yours child rests, does all of his/her fatigue go away, some of it go away, or none of it go away?

All of it goes away 1

Some of it goes away... 2

None of it goes away 3

He/she does not have fatigue 4

72. How long does your child have to rest before his/her fatigue gets better? (Skip to question 73 if you do not have fatigue)

____

73. Will your child's fatigue return if he/she stops resting and starts doing something?

No... 1

Yes 2

He/she does not have fatigue 3

74. How would you describe the way your child's fatigue illness is changing over time?

His/her fatigue is getting worse.. 1

He/she has good and bad periods... 2

There is no change... 3

His/her fatigue is getting better 4

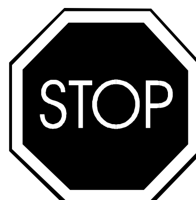
He/she does not have fatigue 5

75. Has your child ever been diagnosed with ME/CFS by a physician?

No 1

Yes... 2

If yes, when was he/she diagnosed?______________________________



Thank you for filling out the DePaul Pediatric Health Questionnaire (Adult Version).