Additional File 1 – Episodic Disability Questionnaire (EDQ) Items

Physical Domain	
Item #	Item
1	I feel fatigued (or tired) when doing my usual activities.
2	I have headaches.
3	I have aches or pains.
4	I have numbness or tingling in my hands or feet.
5	I have shortness of breath.
6	I feel nauseous.*
7	I have fever, chills, or sweats.
8	I have muscle cramps.
9	I have trouble sleeping.
10	I feel dizzy.
Physical Total Number	10 items
of Items	

Cognitive Domain	
Item #	Item
11	I have trouble remembering things like appointments and when to take my medication.
12	I have trouble thinking clearly.
13	I have trouble concentrating.
Cognitive Total	3 items
Number of Items	

Mental-Emotional Domain	
Item #	Item
14	I feel anxious.
15	I feel sad, down, or depressed.
16	I am afraid for my future.
17	I lack confidence around others.
18	I feel lonely.
Mental-Emotional	5 items
Total Number of Items	

Uncertainty or Worry about the Future Domain	
Item #	Item
19	I worry about my future health.
20	I worry about my lab (blood) or other test results (or investigations).
21	I worry about the side effects of treatments (including medications).
22	I worry about my income or financial security.
23	I worry what might happen to my family and friends if I get sick.
Uncertainty Total Number of Items	5 items

Day-to-Day Activities Domain	
Item #	Item
24	I am unsteady on my feet.
25	I have trouble walking or climbing stairs.
26	I have trouble doing household chores such as cleaning, doing dishes, laundry, and cooking.
27	I have trouble taking part in leisure or recreational activities, such as exercise or dancing.
28	I have trouble getting out to do errands, such as grocery shopping, banking, or doctor's
	appointments
Day Total Number of	5 items
Items	

Date Last Revised: December 14, 2023

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Social Inclusion Domain	
Item #	Item
29	I find hard to meet the needs of those I care for (such as children, parents, grandparents, partners, or pets). (0=not at all or not applicable)
30	I feel that my work or volunteer performance is limited because of my illness (0=not at all or not applicable).
31	I struggle to maintain safe and stable housing.*
32	I find it hard to ask others for help when go through an episode of illness.
33	I find it hard to start new, intimate, sexual relationships. (0=not at all or not applicable)*
34	I tend to isolate myself from others.
35	Because of my financial situation, I find it hard to take part in leisure or recreational activities such as going to the movies, out to dinner or on vacation.
Social Inclusion Total Number of Items	7 items

Good Day or Bad Day Question	
Item #	Item
36	People living with long-term health conditions sometimes talk about having 'good days' and 'bad
	days'. This refers to the 'ups and downs' or periods of wellness and illness.
	In terms of your overall health, are you having a good day or a bad day today?

LEGEND: *Presence and Severity Scales: Response options are 0-4 for all items with the exception of Item #6 (response options 0-3) and Item #31 and #33 (response options 0=2).

Episodic Scale: For each item, respondents are asked, 'Has this challenge fluctuated (or changed) over the past week? Response options: Yes or No.

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