1.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| How much do your health problems interfere with the following activities of daily  living? | On average, on good days, and on bad days? *Circle a number for each.* | Not at all | A little | Some | A lot | Completely |
| Sleeping | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Eating | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Working | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Doing household tasks   * making beds * vacuuming | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Shopping | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Exercising | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Socializing | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |
| Bathing | On average | 1 | 2 | 3 | 4 | 5 |
| On good days | 1 | 2 | 3 | 4 | 5 |
| On bad days | 1 | 2 | 3 | 4 | 5 |

2. Which of the following statements best describes the severity of your fatigue ON AN AVERAGE DAY over the past months (check ONLY ONE)?:

I am bedridden and can do virtually nothing.

I am shut-in: I can walk around the house but cannot even do light housework or its equivalent.

I can work only part-time at my work or on family responsibilities.

I can do all the things I usually do at home or work, but I feel much more easily fatigued from them and don’t do things as well as I should.

I can do all the things I want to do, even though I am fatigued.

1. Have you been so fatigued that you have had to reduce your average activity level below half of what was your normal level before you became ill?

Yes, all the time

Yes, some of the time

Yes, but rarely

No

1. Have your activities (personal, at home, social, educational, and/or occupational) been affected by this tiredness, weariness or fatigue?

Not at all

A little, but I can usually still do everything or most things normally

I have needed to substantially reduce at least some activities

I can no longer do at least some of the activities I used to do

I can no longer do most of the activities I used to do

1. How would you describe the course of your illness?

Constantly getting worse

Constantly improving

No change

Relapsing and remitting (good periods with no or few symptoms, and bad periods)

Fluctuating (symptoms vary a lot but never disappear)

No symptoms, I am not ill or have recovered completely.

.

1. Do you live with someone who can take care of you?  Yes  No
2. How long have you been tired? \_\_\_\_\_ years \_\_\_\_\_ months
3. In a typical month, how often do you go out of the house for any reason::

Less than once a month

Once or twice a month

Three to 10 times a month

10 to 20 times a month

Almost daily

Daily

1. **Daily Activity level:** Estimate how much time you spent in each of the activities listed on a good day and a bad day over the past month.

Total for each column should be 24 Hrs.

|  |  |  |
| --- | --- | --- |
|  | **Good Day** | **Bad Day** |
| Sleep | Hrs | Hrs |
| Activities in bed or chair (ex. TV, audiobooks) | Hrs | Hrs |
| light activity (example, use computer at desk,  microwave a meal, pay bills) | Hrs | Hrs |
| moderate activity (example, shopping) | Hrs | Hrs |
| exercise | Hrs | Hrs |
| **TOTAL =** | **24 Hrs** | **24 Hrs** |

1. Questionnaire for Candidates for Inactive Control **Participants**

**Physical Activity History Questionnaire**

Do you have pain/injury that would prohibit exercise on a stationary cycle? yes / no

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Select the activity code that best describes your level of daily physical activity for the past 6 months (circle one):**

**1** - You have a sit-down job and do no regular physical activity

***OR***

3-4 hours of walking or standing per day are usual. You do no regular organized physical activity during leisure time (e.g., fitness walking or exercise class).

**2** - Your occupation is physically demanding (e.g., farmer, mail deliverer, stockroom worker,

professional athlete, firefighter) but you do no regular, organized physical activity during leisure time.

**3** - You are physically active during leisure time 2 or more times per week, for a total of 30 minutes or more per day.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If your activity code is *1*, please complete the following section:**

How long (yrs) have you maintained your current level of physical activity? \_\_\_\_\_\_\_\_\_\_

Place list any physical activities/sports you did in the past, the age(s) during which you did the activity, and the approximate number of days per week that you participated at that time.

ACTIVITY AGE(s) Days/Week

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_

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1. Questionnaire for **ME/CFS Participants**

**Survey of Activity Level Before and After Two-Day Cardiopulmonary Exercise Tests** Actual date recording started \_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
|  | **Day 7 before** | **Day 6 before** |
| How many hours did you spend in bed? |  |  |
| Of hours in bed, how many were sleeping? |  |  |
| How many hours did you spend in upright activities (in chair or standing)? |  |  |
| How many hours that you were awake did you  engage in activities that required mental clarity? |  |  |
|  | **Day 5 before** | **Day 4 before** |
| How many hours did you spend in bed? |  |  |
| Of hours in bed, how many were sleeping? |  |  |
| How many hours did you spend in upright activities (in chair or standing)? |  |  |
| How many hours that you were awake did you  engage in activities that required mental clarity? |  |  |
|  | **Day 3 before** | **Day 2 before** |
| How many hours did you spend in bed? |  |  |
| Of hours in bed, how many were sleeping? |  |  |
| How many hours did you spend in upright activities (in chair or standing)? |  |  |
| How many hours that you were awake did you  engage in activities that required mental clarity? |  |  |

**Circle the number of hours per day that you spend in vertical/horizontal activity.**

Hours vertical/24 hours 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15, 16, 17, 18, 19, 20, 21, 22, 23, 24

**(average time with feet on the floor---sitting, standing or walking)**

Hours horizontal/24 hours 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15, 16, 17, 18, 19, 20, 21, 22, 23, 24

**(average time with feet up--- resting in recliner, feet up, napping, sleeping in bed )**

1. Questionnaire for **ME/CFS & CONTROL Participants**

EXERCISE HISTORY

1. Do you currently engage in any exercise? **Yes** **No**
   * 1. If yes, what type?: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
     2. How intense?  light (e.g., light weights, yoga, regular walking) moderate (e.g., vigorous walking or light jogging, moderate cycling)  hard (e.g., running, fast-paced sports, heavy weight lifting)
     3. How often? (days/week on average) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. How many minutes of exercise do you get on average (on days that you exercise)? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
3. If not presently exercising, why not exercising? **(Check all boxes that you agree with)**

Not interested

No time

Would like to but causes problems with fatigue/energy

Cannot because exercise makes symptoms worse

1. Before becoming ill with CFS/ME
2. Did you engage in exercise?
3. If yes, what type? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. How intense? light (e.g., light weights, yoga, regular walking) moderate (eg, vigorous walking or light jogging, moderate cycling) hard (e.g., running, fast-paced sports, heavy weight lifting)
5. How often? (days/week on average) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
6. How many minutes of exercise did you get on average (on days that you exercise)? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
7. Do you have discomfort, shortness of breath or pain with exercise? **Yes** **No**
   * 1. If yes, what type of physical activity causes these symptoms? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_