

## Attachment 2: Chronic Fatigue Syndrome: Symptoms from the Patient Perspective Interview

### INTRODUCTION

#### **Voluntary Consent to Participate in an Individual Interview Discussing Chronic Fatigue Syndrome**

Hello/Good morning/Good afternoon.... May I speak with \_\_\_\_\_? (If not available, leave a message).

My name is Dana Brimmer. I am calling from the Aspen Group. You are scheduled to conduct an interview regarding chronic fatigue syndrome or CFS (which is also known as Myalgic Encephalomyelitis (ME). Is this still a good time to do the interview?

If No – May I reschedule the interview at a time that is convenient for you?

If Yes – Before we begin the interview, I need to review a few details about the study with you.

### PURPOSE

This interview is part of a series of focus groups and interviews called *Chronic Fatigue Syndrome: Symptoms from the Patient Perspective*. Educators want to learn how CFS patients think about their symptoms and learn how doctors could ask CFS patients about the symptoms they are experiencing. The information will help assess current CFS educational materials and assist in revising and developing new materials. The new educational materials will help educate healthcare professionals and guide them in communicating with CFS patients.

The Centers for Disease Control and Prevention (CDC) is sponsoring this interview; Aspen Government Information Solutions, a company headquartered in Torrance, California is the CDC's contractor to conduct this interview.

You have been asked to participate in a one-on-one interview because you are a patient with chronic fatigue syndrome. We will be conducting up to 12 telephone interviews with other CFS patients.

Our interview today will take about one hour.

Public reporting burden of this collection of information is estimated to average 75 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D74, Atlanta, Georgia 30333; ATTN: PRA (0920-1026)

## CONFIDENTIALITY

CDC will treat data in a secure manner and will not disclose, unless otherwise compelled by law. The interview will be audiotaped so that we have accurate documentation of your responses. The audiotape of your interview will be labeled with a study code, not your name. The audiotape will be transcribed and your name will not be linked to the responses you provide in the interview. The information you provide during the interview will be used in reports to the government in summary form only; your name will not be included in the report. The Aspen Group will continue to keep the audiotape of your interview in locked storage until five years from this interview (Month Year). At that time, the tape will be destroyed.

## VOLUNTARY PARTICIPATION

Please understand that your participation in this interview is voluntary. You may stop at any time. You do not need to give a reason. If you decide not to participate, you may still take part in other CDC programs and research, now or in the future, without forfeiting benefits. You may also withdraw from this study without penalty after starting your interview. Even if you agree to participate, you are not required to answer all the questions you are asked.

## COMPENSATION

You will not receive any compensation for participating in the interview.

## QUESTIONS

Do you have any questions?

You may phone Study Co-Director Dana Brimmer, Ph.D., a contractor with the Aspen Group, at (310) 294-9601 to have your questions answered. If you have any questions about your rights as a focus group participant you may call the CDC Human Research Protection Office at (800) 584-8814. You may also call the CDC Principal Investigator, Sally Lin, Ph.D., at (404) 639-1646. Calls to Dr. Brimmer or Dr. Lin may be toll calls.

Given the information that I have just reviewed with you, do you still wish to participate in this study/interview?

If Yes, \_\_\_\_\_ [Interviewer's initials]. Great. Let me begin with the first question.

If No, \_\_\_\_\_ [Interviewer's initials]. That is fine. We appreciate your time. Thank you.

Great, and I want to let you know that there are no right or wrong answers for this interview. We'd like you to be honest in your responses.

We invited you for this telephone interview today because you received a CFS diagnosis from a physician and are limited in your ability to do things outside your house. I'd like to ask you about your CFS symptoms. While we would like to have time to hear about your personal history with CFS, today we want to talk specifically about your symptoms.

1. What are your CFS symptoms?

**Probe:**

- Sore throat
- Chronic pain: in joints, in muscles
- Severe headaches
- Forgetfulness/memory problems or problems with thinking or concentrating
- Unrefreshing sleep, insomnia
- Crash/collapse - fatigue or exhaustion following exertion
- Sensitivity to light, sound
- Severe fatigue, exhaustion, weakness, lack of energy
- Dizziness, losing balance, fainting, light-headedness
- Color changes on skin, hands or feet
- Intolerance of low-impact exercise

2. How do your CFS symptoms affect you?

3. When in your illness did your symptoms affect you the most?

**Probe:**

- Early in your illness (2 years or less)
- Later on in your illness (more than two years)
- Which symptoms

4. Have your CFS symptoms changed over time? If so, how?

**Probe:**

- Improved
- Worsened
- Developed new symptoms
- Some symptoms gone away

5. How would you describe your symptoms to a doctor?

**Probe:**

- Worst symptoms
- Why

6. How would you describe your symptoms to a friend or family member?

**Patients' Experience with Cognitive Symptoms (15 minutes)**

**INTERVIEWER TRANSITION:** OK, now let's talk about your experience of how CFS affects your cognition. By "cognition," I mean how symptoms of CFS affect how you concentrate or think about things.

7. What are some of the cognitive symptoms you feel from CFS?

**Probe:**

- Confusion

- Disorientation
- Can't focus
- Can't find right words
- Problems with decision making

8. How would you describe your cognitive symptoms to your doctor?

9. How would you describe your cognitive symptoms to your friends and family?

10. Have you become more forgetful or feel like you are in a fog? If yes, please describe.

11. How do the cognitive symptoms of CFS affect you?

**Probe:**

- Work/Occupation
- Housework (complete tasks under time constraints, etc.)
- Family
- Friends
- Social Life (following or participating in the conversation)
- Bathing
- Preparing food
- Getting dressed
- Housework
- Walking or driving ability

12. Have your cognitive symptoms changed over time? If so, how?

**Probe:**

- Improved
- Worsened
- Gone away
- New symptoms
- Duration
- "Come and go"

13. What are some of the things that make your cognitive symptoms feel better? Worse?

**Probe:**

- Medications
- Activity/exercise
- Sleep
- Alternative medicines
- Self-management

14. Have you seen a physician or other health care provider for your cognitive symptoms? If yes, what kind of health care provider?

**Probe:**

- Internist, family practice doctor
- Psychologist
- Specialist (what kind)
- Alternative medicine provider - chiropractor, acupuncturist
- Physical therapist
- Other

## **Patient's Experience with Physical Symptoms (15 minutes)**

**INTERVIEWER TRANSITION:** OK, now let's get more specific and focus on how CFS affects you physically. By physical, I mean how symptoms of CFS affect your physical functioning. You may have mentioned some of these already but it is OK to list them again.

15. What are some of the physical symptoms you feel from CFS?

16. How would you describe your physical symptoms to your doctor?

17. How would you describe your physical symptoms to your friends and family?

18. Have you had to cut down on your physical activity? If so, how?

19. How do the physical symptoms of CFS affect you?

**Probe:**

- Work/Occupation
- Housework
- Family
- Friends
- Social life
- Bathing, showering, getting dressed
- Preparing food, meals
- Getting dressed
- Walking or driving ability

20. Have any of your physical symptoms changed over time? If so, how?

**Probe:**

- Improved
- Worsened
- Gone away
- New symptoms
- "Come and go"
- Duration

21. What are some of the things that make your physical symptoms feel better? Worse?

**Probe:**

- Medications
- Activity/exercise
- Sleep
- Alternative medicine
- Self-management

22. Have you seen a physician or other health care provider for your physical symptoms? If yes, what kind of health care provider?

**Probe:**

- Internist, family practice doctor
- Specialist (what kind)
- Alternative medicine provider - chiropractor, acupuncturist
- Physical therapist
- Personal trainer
- Other

### **Patients' Experience with Post-Exertional Malaise (10 minutes)**

**INTERVIEWER TRANSITION:** I'd now like to ask you about your experience with how you feel after doing either physical or mental activities.

#### **Scenario 1**

Now I am going to read a scenario and ask you to comment on it.

You have gone to the grocery store to shop for groceries and household goods. After you pay for everything you roll the cart to your car and start to unload the bags. As you climb into the driver's seat, you suddenly "crash" and can barely lift up your arm to insert the keys in the ignition.

23. Have you ever had a similar experience in which your body just "crashes" after doing something physical? If so, can you please describe?

**Probe:**

- Body
- Mind
- Emotions

24. What are some words you would use to describe this feeling of "crashing?"

**Probe:**

- Intolerance
- collapse

25. How do your symptoms from "crashing" affect you for the rest of the day?

**Probe:**

- Length of time – hours, days

26. What strategies do you use to help yourself feel better?

#### **Scenario 2**

Now I am going to read a second scenario and ask you to comment on it.

Your friend has come over to help plan another's friends birthday lunch. As you sit and talk about the guest list and menu, your head starts to hurt and you suddenly feel wiped out. You have trouble following the conversation and feel like you are in a fog.

27. Have you ever had a similar experience in which you “crash” after doing something that takes mental concentration? If so, can you please describe?

**Probe:**

- Body
- Mind
- Emotions

28. What are some words you would use to describe this feeling of “being in a fog?”

29. How do your symptoms from “being in a fog” affect you for the rest of the day?

30. What strategies do you use to help yourself feel better?

**Patients’ Expectations (10 minutes)**

**INTERVIEWER TRANSITION:** We have just a few more questions. I’d like you to now tell me what you expect in terms of your CFS treatment and management.

1. When a healthcare provider evaluates you for your CFS, what would you like him or her to ask you? Why?

- If I were to give you a questionnaire today that asks about CFS, what would be most important to ask you?

**Probe:**

- Physical
- Cognitive – thinking, concentrating
- PEM – crashing
- Medications

- If I were to give you a questionnaire 6 months from today that asks about CFS, what would be most important to ask you?

**Probe:**

- Physical
- Cognitive – thinking, concentrating
- PEM – crashing
- Medications

Do you have any questions for me?

Thank you for your time.



NOTE: THE FOLLOWING IS THE DEMOGRAPHIC FORM THAT WILL BE SENT TO PARTICIPANTS ONCE THEY AGREE TO PARTICIPATE IN THE INTERVIEW. A PRE-PAID, ADDRESSED RETURN ENVELOPE WILL BE INCLUDED WITH THE TWO-AGE FORM.

Month of Birth: \_\_\_\_\_ Year of Birth \_\_\_\_\_

Please indicate your sex.

- Male
- Female

Please indicate your ethnicity.

- Hispanic or Latino
- Non Hispanic or Latino

Please indicate your race.

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

What best describes your marital status?

- Single
- Not Married
- Married
- Living with partner
- Separated
- Divorced
- Widowed

What best describes your employment status?

- Employed full-time
- Employed part-time
- Not employed, but looking for work
- Not employed and not looking for work
- Retired
- Student
- Homemaker

What best describes your level of education?

- Some high school
- High school graduate or equivalent
- Some college
- Bachelor's degree
- Graduate or professional degree

Which one of the following ranges includes your total yearly household income before taxes?

- Under \$20,000
- \$20,000 - \$29,999

- \$30,000 - \$39,999
- \$40,000 - \$49,999
- \$50,000 - \$69,999
- \$70,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 or more

Do you currently receiving unemployment benefits

- Yes
- No

Do you currently have health insurance?

- Yes
- No

When were you diagnosed with CFS?

Month\_\_\_\_\_ Year\_\_\_\_\_

When did this illness that you are currently experiencing first begin? (If you cannot remember specific dates, please estimate to the best of your ability)

Month\_\_\_\_\_ Year\_\_\_\_\_

When this illness began, would you say that it came on all of a sudden or slowly over time?

- All of sudden
- Slowly over time
- Not applicable
- Don't know

Did your illness start after you experienced any of the following?  
(Check one or more and please specify)

- An infection illness
- An accident
- A trip or vacation
- An immunization
- Surgery
- Severe stress
- Other

In terms of your health today, would you describe today as a good day (reasonable physical functioning) or a bad day (worsening functioning)?

- Good day
- Bad day

How quickly would you say your health status changes from good to bad? Please circle.  
1-2 days    3-5 days    one week    two weeks    one month    more than a month

