

Health Education and Health Promotion in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Knowledge, Attitudes and Beliefs in the U.S. General Public

Thank you for agreeing to participate in a short survey that should take 8 to 10 minutes of your time (average 8 minutes).

SECTION A - ME/CFS KNOWLEDGE ASSESSMENT

SECTION A ASKED TO EVERYONE

A1. How knowledgeable do you feel about ME/CFS?

1. Extremely knowledgeable
2. Moderately knowledgeable
3. Somewhat knowledgeable
4. Slightly knowledgeable
5. Not at all knowledgeable

A2. To the best of your knowledge, please indicate whether each of the following statements about ME/CFS is true or false.

RANDOMIZE	True	False
a. There is no laboratory test or procedure to confirm someone has ME/CFS	x	
b. About 90% of people with ME/CFS have not been diagnosed by a doctor	x	
c. Among adults, women are affected by ME/CFS more than men	x	
d. Children (both adolescents and younger children) cannot get ME/CFS		x
e. There are currently no FDA-approved treatments for ME/CFS	x	
f. ME/CFS can get worse with mild physical or mental activity	x	
g. Whites/Caucasians are affected by ME/CFS more than other races or ethnicities		x

A3. To the best of your knowledge, which of the following may be symptoms of ME/CFS? Please select all that apply.

RANDOMIZE

1. Unrefreshing sleep
2. Rash on the trunk or extremities
3. Unexplained fatigue not improved by bedrest
4. Impaired memory or concentration
5. Post-exertional malaise (i.e., feeling worse after minimal physical or mental exertion)
6. Vomiting
7. Other (specify): **DO NOT FORCE ENTRY, ANCHOR**
8. None of the above **EXCLUSIVE, ANCHOR**

Public reporting burden of this collection of information is estimated to average 8 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 D-74, Atlanta, Georgia 30333; ATTN: PRA 0920-1154

A4. To the best of your knowledge, which of the following do you think might be possible causes of ME/CFS? Please select all that apply.

RANDOMIZE

1. Viral infections
2. Changes in the immune system
3. Physical or emotional stress
4. Changes in how cells produce energy
5. Genetics
6. Other (specify): **DO NOT FORCE ENTRY, ANCHOR**
7. None of the above **EXCLUSIVE, ANCHOR**

SECTION B - ME/CFS ATTITUDES & PERCEPTIONS

SECTION B ASKED TO EVERYONE

B1. How much do you agree or disagree with each of the following statements about ME/CFS?

RANDOMIZE	Strongly Disagree	Somewhat Disagree	Neither Agree Nor Disagree	Somewhat Agree	Strongly Agree
a. ME/CFS is a real illness					
b. ME/CFS should be taken as seriously as diseases like heart failure and multiple sclerosis					
c. ME/CFS is about being tired all of the time					
d. ME/CFS primarily affects white, middle-aged, affluent women					
e. People like me are at low risk for developing ME/CFS					
f. People with ME/CFS are just depressed					
g. If people with ME/CFS rest, then they will get better					

DO NOT ASK IF S5=1, 2, OR 3

B2. In your opinion, how much of an impact do you think ME/CFS can have on someone's overall quality of life?

1. Significantly impactful
2. Moderately impactful
3. Somewhat impactful
4. Slightly impactful
5. Not at all impactful

DO NOT ASK IF S5=1, 2, OR 3

B3. Which resources do you typically use when looking for information about your health? Please select all that apply.

RANDOMIZE

1. Health information websites
2. Social media networks (e.g., Facebook, Twitter)
3. Online blogs or message boards
4. Magazines or newspapers
5. Family or friends
6. Government websites (e.g., CDC.gov, NIH.gov)
7. Doctors
8. Nurses, nurse practitioners or physician assistants
9. Brochures, posters, or pamphlets from my doctor's office
10. Radio programs or podcasts
11. Medical journals (online or print)
12. Books
13. Other, please specify: **DO NOT FORCE ANSWER; ANCHOR**
14. None of the above **EXCLUSIVE, ANCHOR**

SECTION C - ME/CFS SYMPTOMATIC EXPERIENCES AND BEHAVIOR

SECTION C ASKED IF S5=2 "SYMPTOMATIC"

C1. How long have you been experiencing symptoms related to ME/CFS?

1. 6 months or less
2. 7 to 12 months
3. 1 to 2 years
4. 3 to 5 years
5. 6 to 9 years
6. 10 years or more

C2. How much of an impact are your symptoms related to ME/CFS having on your overall quality of life?

1. Significantly impactful
2. Moderately impactful
3. Somewhat impactful
4. Slightly impactful
5. Not at all impactful

C3. Have you spoken to a healthcare professional about your symptoms related to ME/CFS?

1. Yes
2. No

ASK IF C3=YES

C4. Which type of doctor(s) have you spoken to about your symptoms related to ME/CFS? Please select all that apply.

RANDOMIZE

1. Endocrinologist
2. Infectious disease specialist
3. Neurologist
4. Nurse practitioner or physician assistant
5. OB/GYN or other Women's Health doctor

6. Primary care physician, internist, family medicine, or general practitioner
7. Psychologist
8. Rheumatologist
9. Sleep medicine specialist
10. Other, please specify: **DO NOT FORCE ANSWER, ANCHOR**

ASK IF C3=YES

C5. Did you experience any of the following when you talked to a healthcare professional about your symptoms related to ME/CFS?

RANDOMIZE	Yes	No
a. I was told it might be ME/CFS, but I am still being evaluated or undergoing testing		
b. I was referred to a specialist (e.g., neurologist, rheumatologist)		
c. I was told my symptoms were due to a mental issue (e.g., depression, anxiety)		
d. I was told my symptoms were due to chronic pain		
e. My healthcare professional did not take me seriously		
f. My healthcare professional told me to get some rest		

ASK IF C3=NO

C6. What are the primary reasons you have not talked to a healthcare professional about your symptoms related to ME/CFS? Please select all that apply.

RANDOMIZE

1. I don't think my symptoms are that serious
2. I think my symptoms will resolve on their own
3. I don't think ME/CFS is a real disease
4. I don't think my healthcare professional will take me seriously
5. I prefer to manage my symptoms on my own before seeing a healthcare professional
6. I think my symptoms are unrelated to ME/CFS
7. Other, specify: **DO NOT FORCE; ANCHOR**
8. None of the above **EXCLUSIVE, ANCHOR**

SECTION D - ME/CFS DIAGNOSED EXPERIENCES AND BEHAVIOR

SECTION D ASKED IF S5=1 "DIAGNOSED" OR S5=3 "CAREGIVER"

PROGRAMMING: USE PHRASE ON LEFT IF DIAGNOSED/PHRASE ON RIGHT IF CAREGIVER

D1. How long have you/has the person in your care been diagnosed with ME/CFS?

1. 6 months or less
2. 7 to 12 months
3. 1 to 2 years
4. 3 to 5 years
5. 6 to 9 years
6. 10 years or more

D2. Which type of doctor(s) are you/is the person in your care seeing to treat your/their ME/CFS? Please select all that apply.

RANDOMIZE

1. Endocrinologist
2. Infectious disease specialist
3. Neurologist
4. Nurse practitioner or physician assistant

5. OB/GYN or other Women's Health doctor
6. Primary care physician, internist, family medicine, or general practitioner
7. Psychologist
8. Rheumatologist
9. Sleep medicine specialist
10. Other, please specify: **DO NOT FORCE ANSWER, ANCHOR**

D3. How much of an impact does ME/CFS have on **your overall quality of life/the quality of life of the person in your care?**

1. Significantly impactful
2. Moderately impactful
3. Somewhat impactful
4. Slightly impactful
5. Not at all impactful

D4. Which resources have you ever used to get more information about ME/CFS for **yourself/the person in your care? Please select all that apply.**

RANDOMIZE

1. Health information websites
2. Social media networks (e.g., Facebook, Twitter)
3. Online blogs or message boards
4. Magazines or newspapers
5. Family or friends
6. Government websites (e.g., CDC.gov, NIH.gov)
7. Doctors
8. Nurses, nurse practitioners or physician assistants
9. Brochures, posters, or pamphlets from my doctor's office
10. Radio programs or podcasts
11. Medical journals (online or print)
12. Books
13. Other, please specify: **DO NOT FORCE ANSWER; ANCHOR**
14. None of the above **EXCLUSIVE, ANCHOR**

D5. Have you/Has the person in your care experienced any of the following during the time **you/they have been living with ME/CFS?**

RANDOMIZE	Yes	No
a. Healthcare professionals who did not take my/their condition seriously		
b. Lack of local access to healthcare or treatment options that could make me/them feel better		
c. Getting information from healthcare professionals that was confusing or difficult to understand		
d. Friends, coworkers, or family who were not sympathetic to my/their condition		
e. Lack of emotional support from family and loved ones		
f. I/They had to cut down or give up work activities due to my/their condition		
g. I/They had to give up social or recreational activities due to my/their condition		

DEMOGRAPHICS

Z1. Are you of Hispanic/Latino/a, or of Spanish origin?

1. Yes
2. No

Z2. What is your race? (Select one or more)

RANDOMIZE

1. White
2. Black or African American
3. Asian
4. American Indian or Alaska Native
5. Native Hawaiian or Other Pacific Islander

Z3. Including yourself, how many total people currently live in your household?

1. 1
2. 2
3. 3
4. 4
5. 5 or more

Z4. What is your marital status?

1. Never married or single
2. Married
3. Domestic partner or living together
4. Divorced, separated, or widowed

Z5. Which of the following best describes the highest level of education you have completed?

1. Some high school or less
2. High school graduate/GED
3. Technical/vocational school
4. Some college (no degree)
5. Associate's degree
6. Bachelor's degree
7. Some post-graduate (no degree)
8. Post-graduate degree

Z6. Which of the following describes your current employment status?

1. Employed full-time (40 or more hours per week)
2. Employed part-time (up to 39 hours per week)
3. Unemployed and currently looking for work
4. Unemployed and not currently looking for work
5. Student
6. Retired
7. Homemaker
8. Self-employed
9. Unable to work

Z7. What is your approximate household income before taxes?

1. Under \$20,000
2. \$20,000 - \$29,999
3. \$30,000 - \$39,999
4. \$40,000 - \$49,999
5. \$50,000 - \$74,999
6. \$75,000 - \$99,999
7. \$100,000 - \$149,999
8. \$150,000 - \$199,999

9. Over \$200,000
10. Rather not say

Z8. In which state or U.S. territory do you live?

INCLUDE DROP DOWN OF 50 STATES PLUS "DISTRICT OF COLUMBIA" AND "OTHER--U.S. TERRITORY OR PROCTECTORATE" AND CODE INTO THE CATEGORIES BELOW

1. Northeast (ME, NH, VT, MA, CT, RI)
2. Mid Atlantic (WV, VA, DE, MD, DC, NC, PA, NY, NJ)
3. Great Lakes (OH, MI, IN, IL, WI, MN)
4. Southeast (SC, GA, FL, AL, MS, LA, TN, KY)
5. South Central (TX, OK, AR)
6. Southwest (AZ, UT, CO, NM, NV)
7. North Central (IA, MO, KS, NE, SD, ND)
8. Northwest (MT, WY, ID, OR, WA)
9. West (CA, AK, HI)
10. Other—U.S. territory or protectorate

Z9. How would you describe your location of residence?

1. Urban
2. Suburban
3. Exurban (farther outside of city than suburban, but more populated than rural)
4. Rural