

Understanding the impact of your illness and treatments on your everyday life can help your healthcare team keep track of your health and adjust your treatments. For this reason, this questionnaire was specifically developed for people who have cystic fibrosis. Thank you for your willingness to complete this form.

**Instructions:** The following questions are about the current state of your health, as you perceive it. This information will allow us to better understand how you feel in your everyday life.

Please answer all the questions. There are **no** right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation.

## Section I. Demographics

*Please fill-in the information or tick the box indicating your answer.*

- A. What is your date of birth?
- Date
- Day                      Month                      Year
- B. What is your gender?
- Male       Female
- C. During the **past two weeks**, have you been on holiday or out of school or work for reasons **NOT** related to your health?
- Yes       No
- D. What is your current marital status?
- Single/never married
- Married
- Widowed
- Divorced
- Separated
- Remarried
- With a partner
- E. Which of the following best describes your racial background?
- White - UK
- White - other
- Indian/ Pakistani
- Chinese/ Asian
- African
- Caribbean
- Other [not represented above or people whose predominant origin cannot be determined/ mixed race]
- Prefer not to answer this question
- F. What is the highest level of education you have completed?
- Some secondary school or less
- GCSEs/ O-levels
- A/AS-levels
- Other higher education
- University degree
- Professional qualification or post-graduate study
- G. Which of the following best describes your current work or school status?
- Attending school outside the home
- Taking educational courses at home
- Seeking work
- Working full or part time (either outside the home or at a home-based business)
- Full time homemaker
- Not attending school or working due to my health
- Not working for other reasons

**Section II. Quality of Life**

*Please tick the box indicating your answer.*

<i>During the past <b>two weeks</b>, to what extent have you had difficulty:</i>	<b>A lot of difficulty</b>	<b>Some difficulty</b>	<b>A little difficulty</b>	<b>No difficulty</b>
1. Performing vigorous activities such as running or playing sports.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Walking as fast as others .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Carrying or lifting heavy things such as books, shopping, or school bags.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Climbing one flight of stairs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Climbing stairs as fast as others.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<i>During the past <b>two weeks</b>, indicate how often:</i>	<b>Always</b>	<b>Often</b>	<b>Sometimes</b>	<b>Never</b>
6. You felt well .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. You felt worried.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. You felt useless .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. You felt tired.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. You felt full of energy.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. You felt exhausted .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. You felt sad.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please circle the number indicating your answer. Please choose only one answer for each question.*

*Thinking about the state of your health over the last **two weeks**:*

13. To what extent do you have difficulty walking?
  1. You can walk a long time without getting tired
  2. You can walk a long time but you get tired
  3. You cannot walk a long time because you get tired quickly
  4. You avoid walking whenever possible because it's too tiring for you
  
14. How do you feel about eating?
  1. Just thinking about food makes you feel sick
  2. You never enjoy eating
  3. You are sometimes able to enjoy eating
  4. You are always able to enjoy eating
  
15. To what extent do your treatments make your daily life more difficult?
  1. Not at all
  2. A little
  3. Moderately
  4. A lot

16. How much time do you currently spend each day on your treatments?  
 1. A lot  
 2. Some  
 3. A little  
 4. Not very much
17. How difficult is it for you to do your treatments (including medications) each day?  
 1. Not at all  
 2. A little  
 3. Moderately  
 4. Very
18. How do you think your health is now?  
 1. Excellent  
 2. Good  
 3. Fair  
 4. Poor

**Please select a box indicating your answer.**

*Thinking about your health during the past **two weeks**, indicate the extent to which each sentence is true or false for you.*

	Very true	Somewhat true	Somewhat false	Very false
19. I have trouble recovering after physical effort.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I have to limit vigorous activities such as running or playing sports.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I have to force myself to eat.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I have to stay at home more than I want to .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I feel comfortable discussing my illness with others .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I think I am too thin .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I think I look different from others my age.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I feel bad about my physical appearance .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. People are afraid that I may be contagious .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I get together with my friends a lot.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I think my coughing bothers others .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I feel comfortable going out at night.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I often feel lonely .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I feel healthy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. It is difficult to make plans for the future (for example, going to college, getting married, getting promoted at work, etc.) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I lead a normal life .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Section III. School, Work, or Daily Activities**

*Questions 35 to 38 are about school, work, or other daily tasks.*

35. To what extent did you have trouble keeping up with your schoolwork, professional work, or other daily activities during the past **two weeks**?
1. You have had no trouble keeping up
  2. You have managed to keep up but it's been difficult
  3. You have been behind
  4. You have not been able to do these activities at all
36. How often were you absent from school, work, or unable to complete daily activities during the last two weeks because of your illness or treatments?
- Always                       Often                       Sometimes                       Never
37. How often does CF get in the way of meeting your school, work, or personal goals?
- Always                       Often                       Sometimes                       Never
38. How often does CF interfere with getting out of the house to run errands such as shopping or going to the bank?
- Always                       Often                       Sometimes                       Never

**Section IV. Symptom Difficulties**

*Please select a box indicating your answer.*

- Indicate how you have been feeling during the past two weeks.*
- |  | A great deal                   | Somewhat                                 | A little                                 | Not at all  |
|--|--------------------------------|--|--|---|
| 39. Have you had trouble gaining weight? .....   | <input type="checkbox"/>       | <input type="checkbox"/>                 | <input type="checkbox"/>                 | <input type="checkbox"/>                            |
| 40. Have you been congested? .....               | <input type="checkbox"/>       | <input type="checkbox"/>                 | <input type="checkbox"/>                 | <input type="checkbox"/>                            |
| 41. Have you been coughing during the day? ..... | <input type="checkbox"/>       | <input type="checkbox"/>                 | <input type="checkbox"/>                 | <input type="checkbox"/>                            |
| 42. Have you had to cough up mucus? .....        | <input type="checkbox"/>       | <input type="checkbox"/>                 | <input type="checkbox"/>                 | <input type="checkbox"/>                            |
| Go to<br>Question 44                             |                                |  |  |   |
| 43. Has your mucus been mostly:                  |                                |  |  |   |
|  | <input type="checkbox"/> Clear | <input type="checkbox"/> Clear to yellow | <input type="checkbox"/> Yellowish-green | <input type="checkbox"/> Green with traces of blood |
|  |                                |  |  | <input type="checkbox"/> Don't know                 |

- How often during the past two weeks:*
- |   | Always                   | Often                    | Sometimes                | Never                    |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 44. Have you been wheezing? .....                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 45. Have you had trouble breathing? .....                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 46. Have you woken up during the night because you were coughing? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 47. Have you had problems with wind? .....                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 48. Have you had diarrhoea? .....                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 49. Have you had abdominal pain? .....                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 50. Have you had eating problems? .....                                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

*Please make sure you have answered all the questions.*

**THANK YOU FOR YOUR COOPERATION!**

