



Name: \_\_\_\_\_

Date: \_\_\_\_\_

This tool is to help your care team see how they can help you learn more about your Cystic Fibrosis (CF).

Please read each answer carefully before choosing the **one** answer you think is **best**. If you don't know an answer, no big deal. Just leave it blank and move on to the next question.



## GENERAL CF HEALTH

### 1 Cystic Fibrosis:

- Can be caught from another person
- Only affects boys
- Causes a buildup of thick, sticky mucus in your body
- Is something you will grow out of over time

### 2 Match the treatment listed below with what it helps to do in the body:

- |  |                       |   |
|--|-----------------------|---|
| a. Pancreatic enzymes (ie, _____)          | <input type="radio"/> | May help improve how the salt channel works                   |
| b. Airway clearance (ie, _____)            | <input type="radio"/> | Help fight infections by killing bacteria                     |
| c. Antibiotics (ie, _____)                 | <input type="radio"/> | Loosen thick, sticky mucus in your lungs                      |
| d. CFTR modulators (ie, _____)             | <input type="radio"/> | Support the normal growth, function, and health of our bodies |
| e. Vitamins (ie, <u>A, D, E, &amp; K</u> ) | <input type="radio"/> | Break down food for your body to use                          |

### 3 What do mucolytics (such as dornase alfa) help to do?

- Digest food
- Thin mucus to make it easier to cough out
- Fight infections
- None of the above

### 4 Bronchodilators help by:

- Fighting infections
- Making mucus thicker
- Opening the airways
- None of the above

### 5 Match the care team member with how they help you manage your CF:

- |   |                       |   |
|---|-----------------------|---|
|  <b>A</b> Dietitian or Nutritionist         | <input type="radio"/> | Gives you emotional and social support  |
|  <b>B</b> Respiratory or Physical Therapist | <input type="radio"/> | Helps you keep a healthy weight and create an eating plan   |
|  <b>C</b> Nurse                             | <input type="radio"/> | Gives you pulmonary function tests (PFTs). Also teaches you the right way to use airway clearance and nebulizer equipment     |
|  <b>D</b> Doctor                            | <input type="radio"/> | Provides details and answers your questions on clinical research trials and can help you know if a new trial is right for you |
|  <b>E</b> Social Worker or Psychologist     | <input type="radio"/> | Creates your medical plan and prescribes your medicines   |
|  <b>F</b> Research Coordinator              | <input type="radio"/> | Coordinates your CF care and tells other members of the care team when your care plan changes                                 |



# GENERAL CF HEALTH

Please read each answer carefully before choosing the **one** answer you think is **best**.  
If you don't know an answer, no big deal. Just leave it blank and move on to the next question.

- 6 People get CF by:**
- Touching someone who has CF
  - Getting a bad fever as a baby
  - Getting a CF gene from both parents
  - None of the above
- 7 What part(s) of the body can CF affect?**
- Pancreas
  - Intestines
  - Lungs
  - All of the above
- 8 Most people with CF have mucus that is:**
- Thin and dry
  - Thin and sticky
  - Thick and sticky
  - Hard and cold
- 9 Which is not a symptom of CF?**
- Coughing and wheezing
  - Frequent lung infections
  - Trouble with learning
  - Poor weight gain
- 10 Which of these are signs or symptoms of a flare-up or exacerbation (a lung infection that needs tougher treatment)?**
- Coughing up more mucus than usual
  - Shortness of breath or wheezing
  - Feeling bad or run down
  - All of the above
- 11 How long should you wait before telling your parents or CF care team that you are feeling sicker or worse than usual?**
- A week later
  - After a few days
  - Right away
  - None of the above

- 12 When a flare-up or exacerbation (a lung infection that needs tougher treatment) occurs, it means you may need:**
- To take more enzymes
  - To do extra treatments and take more medicines
  - To eat less
  - None of the above
- 13 Some people with CF may also get:**
- CF-Related Diabetes (CFRD)
  - Depression
  - Liver disease
  - All of the above

The following questions are for people with CF ages 13-15 only:

- 14 True or False? A CF carrier is someone who has only one copy of the CF gene mutation.**
- True
  - False

Use the image below to help you answer the next question:

- 15 If a person with CF has a baby with someone who doesn't have CF, but who is a carrier, the baby:**
- Will always have CF
  - Will have a 50% chance of having CF
  - Will never have CF
  - None of the above

