



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, & 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:

- | | | |
|---|-----------------------|---|
|  A Dietitian or Nutritionist | <input type="radio"/> | Gives you emotional and social support |
|  B Respiratory or Physical Therapist | <input type="radio"/> | Helps you keep a healthy weight and create an eating plan |
|  C Nurse | <input type="radio"/> | Gives you pulmonary function tests (PFTs). Also teaches you the right way to use airway clearance and nebulizer equipment |
|  D 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 |
|  E Social Worker or Psychologist | <input type="radio"/> | Creates your medical plan and prescribes your medicines |
|  F 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

