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DOCTOR DISCUSSION GUIDE

Managing Cystic Fibrosis

Cystic fibrosis (CF) is a genetic disorder that affects the cells in the body that produce mucous, digestive enzymes, and sweat. Asking the right questions during your conversation with your doctor will help you know what to expect and how to better navigate this condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

Airway Clearance Techniques (ACT's)	Treatments used by people with CF to help loosen and thin mucous in the lungs. This may include inhaled medications such as bronchodilators or wearing vests that provide vibration or percussion. Most treatments involve some sort of coughing or huffing.
CFTR Gene	The CFTR gene causes cystic fibrosis only if you inherit two copies that contain mutations. An individual who inherits only one copy of this gene with mutations is called a CF carrier.
CFTR Modulators	Medications which specifically target the CFTR gene. Only some mutations are able to be helped with the three medications currently approved for use, which are: ivacaftor, lumacaftor, and tezacaftor.
Pancreas	A large gland located behind the stomach which secretes digestive enzymes and produces insulin. Pancreas function is frequently impaired in people with CF.
Pancreatic Enzymes	Cystic fibrosis can impair the ability of the pancreas to function and release pancreatic enzymes which function to break down important nutrients so they can be utilized by the body. Most people with cystic fibrosis take pills which contain pancreatic enzymes with each meal.

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Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage cystic fibrosis.

About Symptoms

- ❑ I understand that CF can cause a variety of symptoms. Which symptoms would warrant medical attention should I experience them?
- ❑ Is it typical to experience new symptoms or a worsening of symptoms over time?
- ❑ What are some of the complications of CF that I should be aware of at this time?

About Causes & Risk Factors

- ❑ I understand that CF is an inherited (genetic) disorder. Are my children at risk of inheriting CF? Should I undergo further testing to determine this?
- ❑ Do other members of my family need to be tested for CF?
- ❑ What lifestyle changes can I make at this time which might help me to avoid complications of CF in the future?

About Diagnosis

- ❑ I have read about many different tests which are used to diagnose CF. Are the tests that I have had definitive? Is further testing at this point necessary to confirm my diagnosis?

About Treatment

- ❑ What other specialists besides yourself can help me to manage my CF?
- ❑ Am I a candidate for a CFTR modulator?
- ❑ What other medications can help me with my symptoms at this time?
- ❑ I understand that people with CF usually need to make changes to their diet. Can we discuss that now or can you refer me to another expert who can go over that with me?