Cystic Fibrosis Research News

Title:
Enteral tube feeding for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed guidelines

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What was your research question?
Nutrition is an important part of care in cystic fibrosis (CF). Current nutrition recommendations from the Cystic Fibrosis Foundation (CFF) do not include detailed guidelines for tube feedings. Our aim was to develop recommendations for tube feeding based on the available research and expert opinion.

Why is this important?
Better nutrition has been linked to better lung function. Some people with CF benefit from a feeding tube to help gain and maintain weight. The guidelines about tube feedings, including when to consider a tube, steps to take before and after placement and education for patients and families, will help guide the CF care team, individuals with CF and their families, through the tube feeding process.

What did you do?
We decided which questions we wanted to answer about tube feedings and divided the information into 3 sections: shared decision making, management before tube placement and management after tube placement. The group reviewed the existing medical research to answer the questions. Recommendations, or answers to the questions, were made based on the research and expert opinion. All recommendations were voted on by the group.
What did you find?
We found that there is not a lot of research about tube feeding in CF. We used the research that was available, and expert opinion, to develop 33 recommendations. The committee voted on each recommendation. These recommendations cover the entire tube feeding process, starting with when to think about a tube and ending with when to consider removing the tube. We included education for individuals with CF and their families, who should be included in the process and important issues to consider.

What does this mean and reasons for caution?
Although tube feedings are used frequently in CF, there is not a lot of research to say that there is one best way to handle certain parts of the process, like how to give enzymes or what kind of formula to use. Our committee made recommendations based on the available research and expert opinion. We could not make a recommendation for some aspects of tube feeding because there is not enough information.

What’s next?
The committee hopes that these guidelines will help individuals with CF, their families and care teams navigate the tube feeding process. More studies looking at how to give enzymes with tube feedings, what kind of formula to use, and who benefits from tube feedings would be useful in the future.

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