



# Cystic Fibrosis Research News

## **Title:**

Advance Care Planning in Cystic Fibrosis: Current Practices, Challenges, and Opportunities

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## **What was your research question?**

Advance care planning (ACP) is a communication process intended to align medical treatments with goals and wishes of individuals. It is recommended that people with serious illness participate in ACP. We sought to understand how US programs that care for adults with CF address ACP.

## **Why is this important?**

Previous studies of ACP in CF suggest that important treatment decisions near the end of life are often made by family members because the individual with CF is too ill to express treatment preferences. CF care providers may be uncertain about when to address ACP given the variability in disease course and the option of lung transplant for advanced disease. The structure of CF care delivery, multidisciplinary health care teams and clinical practice guidelines, affords opportunities to establish a systematic process for ACP such that all people with CF have access to this important aspect of care.

## **What did you do?**

We invited all 113 US adult CF care programs to review the medical records of the last five patients who died between 2011 and 2013. Sixty-seven programs shared on 210 adults who died from CF lung disease. This information included age, cause and location of death, timing and setting of ACP, who participate in ACP, and whether patients had advance

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directives, or written statements of wishes for certain medical treatments and designation of alternative decision-makers, if they would not be capable of making decisions by themselves. We also looked at differences in ACP among adult CF care programs.

## **What did you find?**

We found that 61% of adults with CF participated in ACP, a larger percentage than reported in previous small studies. Most ACP took place more than one month before death, usually during hospitalization, and involved family members as well as members of the CF care team. ACP did not differ by patient age or severity of lung disease. People awaiting lung transplant were no more or less likely to participate in ACP than those were not. Those with ACP were more likely to have advance directives. Some CF care programs provided no ACP and some provided ACP to all patients.

## **What does this mean and reasons for caution?**

More adults with CF are participating in ACP now than in the past, which may reflect greater emphasis on palliative care, or care focused on patient comfort and quality of life, on a societal level. It appears that some CF care programs systematically offer ACP, and we could learn from the experiences of these programs. Note that we relied on reports from the medical records of people who died from CF, and these records may be missing some information. Additionally, we are not certain whether practices at programs opting to participate represent those of all US adult programs.

## **What's next?**

We intend to work with other key stakeholders – individuals with CF, family members, and CF care providers - to develop guidelines for ACP that can be incorporated into practice at all US adult CF care programs.

## **Original manuscript citation in Pubmed**

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