A GUIDE TO EDUCATING CAREGIVERS ABOUT CYSTIC FIBROSIS (CF)

Vertex has created this guide to help you discuss the contents of the accompanying Patient/Caregiver Disease Education brochure and CFSource.com with patients and caregivers of patients with CF. Each section listed below aligns with the brochure and offers potential questions to ask caregivers to facilitate a conversation. While a disease discussion is not always easy to have, our aim is to help you educate your caregivers, and patients if appropriate, and empower them with knowledge of CF progression.

Section 1: “Underlying Impact”

- What questions do you have for me about disease progression in CF? Were you aware of the impact of CF on these different body systems?
- Is your child experiencing any of these symptoms of lung damage?
- Are you familiar with the relationship between pulmonary exacerbations and loss of lung function?

You may also inform caregivers that depending on which genotype their child has, the child may experience varying severity of symptoms. Even so, all CF patients face disease progression, so caregivers should stay vigilant even if their child doesn’t yet show symptoms.

Section 2: “Uncovering CF Progression”

- Are you familiar with some of these long-term effects of CF? Is there anything I can explain to you in more detail?
- How, if at all, do you discuss these topics with your loved ones?

It is also important for caregivers to know that even if their child looks “healthy,” CF can progress.
Section 3: “Advances in CF Management”

- Are you familiar with some of these tests? Is there anything I can explain to you in more detail?
- What has your experience been with these tests, if any?
- Are you aware of the progress that has been made in the management of CF? Is there anything I can clarify for you?

*Remind caregivers of ways to effectively manage their child’s CF, including testing, monitoring, and keeping up with the latest disease management information.*

*Suggest that caregivers write their questions in the “Start a Conversation” section for future discussions.*

**More resources are available for your patients and their caregivers at CFSource.com**

- CFSource.com offers even more information you can share with your caregivers and your patients about all of the above, including videos and downloadable resources
- Caregivers can test their knowledge of their child’s condition in the “CF Fact or Fiction” section
- Caregivers can also sign up to receive the latest updates from CFSource.com

**NOTE:** This quick guide and associated Patient/Caregiver Disease Education brochure are both available in print from your Vertex Therapeutic Specialist. They are also available online at CFSource.com.