How caregivers can help

ASK FOR HELP
Your teen’s current care team may be able to let you know at what age your teen should start transitioning. Not only can the pediatric care team answer any questions and provide details on the transition process, they can also suggest adult care centers, if needed.

RESEARCH INSURANCE DETAILS
Some insurance plans may have an age limit for pediatric care. Check the terms of coverage to determine if there is a limit on your plan. You may also want to find out how your insurance company handles referrals to an adult care team.

GET TO KNOW YOUR ADULT CENTER
Not all CF centers offer exactly the same services. Here are a few questions to ask your adult center:

- What specialists and services are available at this center?
- How does this center support and educate your teen as he or she navigates becoming an adult?
- What plan does this center have in place for receiving new patients—specifically patients transitioning from a pediatric center?
How teens can help,
if they feel ready and comfortable

- **Take the lead.** You may have already started encouraging your teen to take a bigger role in communicating with their care team and asking any questions they may have. Moving to adult care can be an opportunity for them to be more involved in discussions about their care.

- **Start to move to self-management.** When transitioning to adult care, encourage your teen to start actively participating in the management of their CF treatments. CF centers may have social workers, psychologists, or child life specialists who can help, but you can start small with having your teen take on more responsibility for their daily care. One way to start is by having your teen help you coordinate his or her refills, or clean their own nebulizer.

- **Know the ins and outs of CF.** Some centers have checklists that patients complete that demonstrate they are knowledgeable enough for self-management. Ask your CF center if they have a checklist your teen can complete.

- **Understand their treatment.** If your teen is starting to take the lead in their treatment, it may help them to understand what each treatment does and how it contributes to his or her overall CF treatment. You can even have them look each treatment up so they can learn what each one does.

- **Keep an updated personal health list.** This list should include all medications and doctors, and any other information about their CF treatment routine and schedule.

- **Speak with a peer who’s been through it.** Talking to someone who recently transitioned to an adult care team may help your teen know what to expect. Your CF center may be able to advise your teen how best to safely connect with someone.

- **Jot down questions to ask the new care team on the next page.** Here are a few to start:
  - What’s the best way to get in touch with my healthcare providers at the CF center?
  - Will I be able to contact an on-call healthcare provider when the CF center is closed?
  - Will I be able to see a healthcare provider if I’m sick, but do not require a hospital visit?
  - What resources are available to help me manage my care?
  - How often will I need to visit the CF center?
  - Does this CF center arrange for transportation?
  - Will I need to take any new tests?
  - Will I see the same care team every visit?
Questions for my new CF care team

This information was downloaded from Navigating Life With CF. To read more about managing CF at different life stages, visit www.VertexGPS.com/navigating-life-with-cf.