FOR CARE TEAMS

Living With Cystic Fibrosis

How people with cystic fibrosis (CF) may manage their disease as they transition through life.

There are challenges to living with cystic fibrosis (CF), but a CF care team can help patients stay well by making healthy choices every day.[1]

People living with CF face 4 main issues[1]

Staying fit and healthy

Sticking to daily treatments

Managing respiratory problems

Managing nutrition and digestive problems

CF challenges change through life[1]

Raising a child with CF can present social, emotional, and psychological challenges. Here is some information about age-related CF concerns and recommendations that may be helpful for your understanding of the disease.

Raising a child with CF[1]

Children with CF grow up, go to school, have friends, have hobbies, and can exercise and play sports. The Cystic Fibrosis Foundation encourages parents of children with CF to:

- Treat their child as a normal child who happens to have CF
- Not be overprotective or neglectful
- Foster their child's independence as he or she grows up

Talking to children about CF[1]

Children should be taught about CF as soon as they are able to understand. What to say to a child depends on his or her age, personality, and ability to comprehend. A CF care team can help with any questions.

In speaking with a child about CF, the goals are to help them understand:

- What CF is and that they will have it for the rest of their lives
- Why eating right, taking enzymes and other medicines, and doing airway clearance is important
- How to be ready to handle their own CF care as they grow

Children also need to learn how to talk about CF in a matter-of-fact way. CF care teams can help teach children about CF and how to answer questions.

Keep life as normal as possible

Adolescence and CF[1]

The CF care team can help teens assume many CF-related responsibilities from their parents. Sticking to CF treatment plans will help teens enjoy the milestones of dating, learning to drive, having a first job, and planning their future education.

Most people with CF have normal experiences with school, sports, and hobbies. The more exercise and activity they do, the better for their health.

Adolescents with CF may be self-conscious about their cough. They may be smaller than their friends and may tire more easily. They may have to take medicines or treatments at school.

It may help if adolescents explain to friends that:

- The cough is not contagious and helps them clear their lungs
- Medicines help digest food, fight respiratory infection, or provide vitamins
- CF is what they have, not who they are

Steps toward independence for adolescents and young adults with CF[1]

- Learn about their treatments, including the names of their medications, dosages, and when and how to take them
- Learn how to take care of their airway clearance equipment, including cleaning it correctly
- Call the CF clinic themselves to ask questions
- Write down questions for their CF care team before their clinic appointments

While entering high school, adolescents should look forward to higher education or job training. There are scholarships available specifically for people with CF. There are also programs to help people with CF cope with the stress of high school and college or to find job training. A CF social worker can help adolescents find these programs.

Adult life with CF[1]

For people with CF, adulthood brings new issues concerning independent living, marriage, family planning, career, and finances.

Did you know[1]

- **Most adults with CF live on their own and do their own CF care**
- **Family planning can be difficult as women with CF may be less fertile than women without CF, and 98% percent of men with CF are infertile**
- **Adults must manage the effects of CF on their careers. Treatment schedules and medicine routines must fit into work schedules**

Good nutrition is essential for people of all ages with CF[1]

Blocked pancreatic ducts are the cause of most CF-related gastrointestinal problems. The blockage keeps enzymes from reaching the small intestine. This causes digestive problems and malabsorption. Effective treatment is available, including:

- Pancreatic enzyme replacements—capsules/beads taken with food and drinks (such as milk or formula)
- Nutrition—with foods high in calories, fat, protein, and salt
- Extra vitamins—specially formulated water-soluble vitamins
- Fluid intake

Your patients can find much more information and many useful tips about living with CF at Everyday-CF.com*

*Everyday-CF.com is an educational website developed by Vertex Pharmaceuticals Incorporated.

Reference: 1. Cystic Fibrosis Foundation. An introduction to cystic fibrosis for patients and their families. https://www.cff.org/PDF-Archive/An-Introduction-to-Cystic-Fibrosis-for-Patients-and-Their-Families/. Accessed December 4, 2020.

VERTEX

CCMC®
Commission for Case Manager Certification