

My Cystic Fibrosis Care Checklist: 13 to 14 Years

What to know and expect as you grow with cystic fibrosis

This tool has some very important things for you to know about caring for yourself with CF, now that you are age 13 or 14. Use this guide as a reference to talk with your parents or CF care provider.

General knowledge

I know these things about my CF:

- I can describe what it means to have CF to my friends, teachers, coaches, and other adults
- I know the basic genetics of CF and my own mutation
- I know the role of each member of my CF Team (respiratory therapist, nutritionist, social worker, nurse and doctor)
- I know the power of germs! I understand basic infection control practices, including why it is particularly important when I am around someone else with CF
- I know all my medicines' names, doses and reason for taking them
- I can describe how sports and/or regular exercise help my lungs
- I know the life-lasting health consequences of poor choices made in teenage years, such as being in denial, smoking, stopping treatments, not eating enough, etc.
- I learned about the changes CF causes to my reproductive system and how it may affect my chances of having a baby
- I know the common signs of cystic fibrosis-related diabetes
- I know what my GI baseline is and signs of malabsorption (when I am not getting nutrients absorbed into my body)

I take an active part in my medical visits:

- I ask a lot of questions at my clinic visits and answer questions about my medical condition on my own
- I answer all the questions I can on my own when I am in the hospital
- I know what PFTs are and what my provider is looking for with PFT results
- I know the reasons for yearly checkups and tests, and what they mean
- I have been told about CF research opportunities, and why it's important to participate when possible
- Each time I come to CF Clinic, I ask the nutritionist to help me understand:
 - My growth and weight charts
 - What foods are a good choice in my diet
 - What are the symptoms of malabsorption (when my body is not getting enough nutrients)

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To Learn More

- Cystic Fibrosis Clinic
206-987-2024
- Ask your child's healthcare provider
- seattlechildrens.org/clinics-programs/cystic-fibrosis/

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

Nutrition

Skills I can do on my own:

- I take enzymes on my own without parent reminders
- I take vitamins (and antacids, if prescribed) without parent reminders
- I know to take in more salt and liquids when I exercise or during hot weather
- I know how and when to choose high-calorie foods
- I made a plan that reminds me to always have enzymes with me, and I use it
- I can prepare a few meals or snacks that meet CF diet guidelines on my own
- I know that my parents' job is to make sure I am eating enough and help teach me about high-calorie and healthy choices

Respiratory

Things I know

- Why respiratory therapy and airway clearance is important for someone with CF
- How lungs work
- The names of normal bacteria as well as unfriendly bacteria that are growing in my lungs
- To develop an understanding of my own respiratory baseline and help identify when exacerbations occur
- Understand that my parents' role is to encourage me to be increasingly independent in my care but still watch me to assure its getting done. They also help make sure the equipment is properly cleaned

Skills I can do on my own:

- Use inhaled/nebulizer therapy in the correct order in airway clearance therapy
- Create a schedule for the best time each day to fit in all my treatments
- Wash my own nebulizers at home
- Check my compressor filter

Family and social support

Things for me to know

- The signs and symptoms of depression
- How CF can impact my mental health
- How to discuss body image and how having CF makes me feel
- The best ways to find other teens who have CF
- How to practice good self-care and stress management
- Communication skills like problem solving, expressing feelings appropriately and solving conflicts, etc.

Things for me to do

- Talk with my parents, mentors and CF team about issues like sexuality, dating and reproduction
- Talk with my parents, mentors, and CF team about healthy choices and possible challenges with friends who might be drinking alcohol, using drugs or smoking
- Continue to explore future career options

Family and social support continued

Things for parents to know

- Helpful communication skills to use with your teen:
 - Empathy and reflective listening
 - Techniques including using realistic choices
 - Collaborative problem solving
 - Motivational interviewing
 - Setting limits
 - Logical and natural consequences
 - Encouragement
- The signs of depression, grief and PTSD in yourself, your partner and your teen
- The role of support and what is effective and ineffective support for you
- How the diagnosis affects couples, well siblings and other family members
- That it is typical to feel overprotective of your teen and that it is not helpful to be overprotective, especially as they gain independence

Things for parents to do

- Enjoy your teen and celebrate their developmental changes
- Expect your teen to grow and develop normally
- Discuss body image and mental health with your child
- Begin to discuss teen issues surrounding sexuality, dating and reproduction
- Start to let go and turn over the responsibility for medical management to your teen. However:
 - It is very important that you monitor your teen
 - Set firm limits around what is expected and ensure that your teen is adhering to these expectations
 - Use appropriate parenting and communication skills to address challenges around non-adherence
- Fit CF into your everyday life. Support your teen in managing treatment routines that fit within school schedules and extracurricular activities
- Continue to teach and support your teen with using a planner/calendar, to-do lists, medicine planners, phone/tablet apps, and other organizational tools
- Practice and model good self-care and stress management
- Continue to support your teen's school experience including 504 plans and medicine management
- Help your child learn social skills like how to handle teasing; and how to be successful with friendships, peers, and managing social networking
- If and/or when you or your teen want to connect with another CF family, ask your CF clinic social worker for a referral
- Have a discussion with your teen about how to evaluate/share medical information (and how much to share) with family and others
- Set healthy boundaries around CF denial, smoking and secondhand smoke, infection control, hot tub use and privacy
- Be an advocate for your teen and teach your teen effective advocacy skills
- Envision a future for your teen. Focus on hopes and dreams and set high expectations with a "can-do" attitude
- Identify your teen's strengths and passions while starting to think about possible career paths together

Ways for parents to support their family

- Seek ways to reduce family risk stressors like conflict, criticism, blame, and lack of support from others. If you identify a risk or need, talk with the CF social worker, a clergy member or therapist.
- Seek ways to increase family protective factors:
 - Set fun weekly family outings or activities
 - Take personal time and caregiver breaks
 - Create family job lists or a chore chart
 - Talk openly and honestly about CF and how it affects your whole family
 - Build a bond with your medical team

Resources

CF care

- Cystic Fibrosis Parent Handbook, Seattle Children's Hospital
www.seattlechildrens.org/pdf/PE387.pdf
- Cystic Fibrosis website at Seattle Children's Hospital
www.seattlechildrens.org/clinics-programs/cystic-fibrosis/
- The Cystic Fibrosis Foundation
www.CFF.org
- Cystic Fibrosis: A Guide for Patient and Family, 4th ed., D. Orenstein
- An Introduction to Cystic Fibrosis for Patients and Families, 5th Edition, Cystic Fibrosis Foundation. A book for families newly diagnosed with CF. Download for free at www.cff.org (226 pages). To order a hard copy, send an e-mail to info@cff.org
- Living with CF Series: "The Elementary School Years," "Raising Successful Teens," etc.
www.cysticlife.org/cystic-fibrosis-reading-materials.php
- Nebulizers: Every Medication Should Have Its Own Nebulizer, Resources section at www.seattlechildrens.org/clinics-programs/cystic-fibrosis/resources/
- High-calorie foods list, from dietician in CF Clinic
- Psychosocial resource list, from social worker in CF Clinic
- Free apps for help with organization to download on cell phone or tablet: Planner Plus, Awesome Calendar Life, RemindMe Prescription app, MediSafe Meds & Pill Reminder, Med Coach Medication reminder, Balanced-Goals & Habits Motivation
- Resources on stress management
www.pamf.org/teen/life/stress/managestress.html & www.jhsph.edu/adolescenthealth

Parenting

- Raising Emotionally Intelligent Teenagers, M. Elias et al.
- The Seven-Year Stretch: How Families Work Together Through Adolescence, I. Kastner, et al.

Transition

- Transitioning into adult healthcare
www.gottransition.org/youthfamilies/
- Teen Care Organizer
cshcn.org/planning-record-keeping/teen-care-organizer/