

My Cystic Fibrosis Care Checklist: 15 to 17 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 15 to 17. There is some information for your parents as well, so feel free to share this with them.

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, and how it is treated
- I know the basic genetics of CF and my own mutation
- I know the names of all my medicines, their purposes, and the dosages
- I know the names and purpose of the treatments, medical equipment and how to care for and wash the equipment
- I am aware of the consequences of making poor choices that can affect my health for life, such as being in denial of my CF, stopping treatments, smoking, not eating enough, etc.
- I know the power of germs! I know about infection control practices, and why it is particularly important when I am around someone else with CF
- I have a regular exercise plan or play sports and understand the benefits of exercise
- I have a set daily routine with medicines and treatments
- I know the changes CF causes in my reproductive system and how it may affect my chances of having a baby
- I know how to prevent sexually transmitted infections and unintended pregnancy
- I am beginning to plan for higher education or jobs

I take an active role in my medical visits:

- I know the purpose of the annual tests and screening, including blood tests, sputum, X-rays, PFTs and diabetes screening (OGTT)
- I know all my healthcare providers both within the CF clinic and out in my community, their roles and how to contact them
- I talk with my health providers about my concerns, ask questions, and report health changes
- I see healthcare providers in clinic on my own, without my parents
- I have created a health information list with my parents and keep it in a set place. I asked my social worker and CF team members for help in creating this list. It contains:
 - All my doctors with their phone numbers, emails, addresses
 - All my pharmacies' phone numbers and addresses
 - Name of my health insurance, phone number for customer service, and card number
- I am starting to learn about health insurance and coverage

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.

General knowledge (continued)

- I am aware of how much medicine I have at all times and work with my parents to keep the prescriptions filled
- I know where and how to access programs for financial and medical assistance with help from my social worker and parents
- With a little bit of help (advice) from parents, I use some kind of health tracking system like a notebook or phone/tablet apps that can help track calories, medicines, treatments, etc.
- I am aware of ongoing research and possible drug trials

Nutrition

Things I know

- The basics of CF nutrition and its importance for lung health and growth
- The need to eat a high level of calories and why I take calorie supplements (if prescribed) and vitamins
- Which foods are high in calories and which are not
- Why it's important to take enzymes before meals and snacks
- How to count calories and use apps, electronic programs, or written methods of tracking calorie intake
- What my GI baseline is and how to contact my provider if I see any changes in my body that may indicate malabsorption (when my body is not getting enough nutrients)
- Be aware of DIOS (Distal Intestinal Obstruction Syndrome)
- Why salt and liquids are important in my diet and especially when exercising and when it is hot outside
- Awareness of CFRD (Cystic Fibrosis Related Diabetes), the common symptoms and how it develops

Things I can do

- Eat healthy foods and use "MyPlate" guidelines to eat a balanced diet
- Take enzymes and vitamins before meals and snacks on my own, without needing my parents to remind me
- Always carry enzymes with me. I have a reminder system that works for me
- Ask my nutritionist about these things each time I come to CF clinic:
 - My weight and where I am on the growth charts
 - What food that will be a good choice in my diet
 - Signs and symptoms of malabsorption
- Prepare a few meals on my own that meet my diet plan
- Take some cooking classes, perhaps with my parents or friends
- Have a weight scale at home and a habit of checking my weight to help track my GI baseline
- Find foods that are rich in fat and protein and/or salty snacks that are easy to prepare so I can have them handy when "on the go"

Respiratory

Things I know

- How lung health impacts my overall health and how it is key to a long life
- That lung health is:
 - Reducing or preventing clogged airways
 - Treating and preventing lung infection
 - Treating and preventing infection inflammation
- Airway clearance techniques that I can do on my own (Flutter, Acapella, etc.)
- My own respiratory baseline and how to spot when my symptoms worsen:
 - I know how to recognize pulmonary exacerbations
 - I know to promptly call my doctor to decide on next steps that need to be taken

Things I can do

- I have a sputum test done regularly and know the growth of bacteria in my lungs
- I use inhaled/nebulized therapies on my own, in the order in which they should be done
- I do airway clearance therapy on my own
- I have a schedule for my best times to do the treatments during the day and am consistent in doing them
- I clean my own nebulizers and medical equipment
- I check the compressor filter regularly
- I stay on top of my appointments, schedule them ahead, and reschedule the visit if I have to cancel one

Family and social support

Things for me to know

- Signs of depression
- When living with a chronic illness is affecting my mental health, and identifying signs of anxiety and depression
- How to discuss how having CF makes me feel and affects my body image
- The best ways to meet and network with other teens with CF
- How to talk to friends and other people about CF
- How to manage dating and romantic relationships with a CF diagnosis
- Good self-care and stress management
- Healthy communication skills including conflict resolution, problem solving, expressing feelings appropriately, etc.
- The negative effects of smoking, doing drugs and drinking alcohol

Things for my 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 and your teen
- 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 your teen gains growing independence

Things for me to do

- Talk with my parents, mentors, and CF team about:
- Sexuality, dating and reproductive issues
- Self image. How do I see myself? What kind of feelings do I have about CF? How do I deal with them?
- Healthy choices and possible challenges with friends who might be drinking alcohol, using drugs or smoking
- Explore career options with parents, mentors, guidance counselors, CF team, etc.
- Talk to CF clinic staff about my educational goals and plans for the future
- Consider finding a grownup with CF to be my guide as I move on to an adult CF center (possibly someone from a CF center that I am going to join)
- Ask a staff person working at the CF clinic if they can help me find such a person to be able to share experiences, successes, mistakes, etc.

Things for my parents to do

- Enjoy your teen and celebrate their developmental changes
- Expect your teen to grow and develop normally
- 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
- Help your teen with using a planner/calendar, to-do lists, medicine planners, phone/tablet apps, and other organizational tools

Family and social support continued

- If and/or when you or your teen want to connect to 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 to support your 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: “Raising Successful Teens,” etc. www.cysticlife.org/cystic-fibrosis-reading-materials.php
- An online community for people with CF: www.cfvoice.com
- Free apps that can be downloaded via cell phone or tablet:
 - For help with organization: Planner Plus, Awesome Calendar Life, RemindMe Prescription app, MediSafe Meds & Pill Reminder, Med Coach medication reminder, Balanced-Goals & Habits Motivation.
 - For tracking calories: www.myfitnesspal.com
- 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

Parenting

- Raising Emotionally Intelligent Teenagers, M. Elias et al
- The Seven-Year Stretch: How Families Work Together Through Adolescence, I. Kastner, et al.
- Cruising On. Next Stop... Adulthood: Successful Strategies for Adolescents and Young Adults with Cystic Fibrosis, Mary Jo McCracken, RN, MS, CPNP

Transition

- Care Notebook pages for teens: cshcn.org/planning-record-keeping/teen-care-organizer/
- Transitioning into adult healthcare: www.gottransition.org/
- Resources on stress management: www.pamf.org/teen/life/stress/managestress
www.jhsph.edu/adolescenthealth