

EVENT RESOURCES



BREATHECON



CYSTIC FIBROSIS
FOUNDATION

EDUCATIONAL RESOURCES

| | |
|---|---|
| Diagnosed with CF as an Adult – CF Foundation | Diagnosed as an adult? You may have a lot of questions and may not know where to start. While there is a wealth of information available, we pulled together a few of the key things you should know, and sources of help and support, right here on this page. |
| Models of Palliative Care Delivery for Individuals with Cystic Fibrosis | Palliative care guidelines provide recommendations to help reduce physical and emotional symptoms and improve quality of life for people with cystic fibrosis throughout their lives. |
| Mental Health Resources | Living with a chronic disease can be emotionally challenging. Although moments of sadness and anxiety due to the uncertainty of your health may come and go, depression and persistent anxiety should be treated as part of your overall health and emotional wellness. |
| Prioritizing Research in Mental Health Working Group | Because of the wide variety of mental health concerns and needs of the CF population, the Cystic Fibrosis Foundation has formed the Prioritizing Research in Mental Health (PRIME) Working Group, which is dedicated to mental health research. |
| Nutritional Basics | Individuals with CF require more energy to breathe normally, fight lung infections and compensate for poor digestion. For these reasons, they need more calories than people without CF. |
| Our Commitment to Equity, Racial Justice, Diversity, and Inclusion | At the CF Foundation, we commit to equity, racial justice, diversity, and inclusion as core principles guiding our efforts to provide all people with CF the opportunity to live long, fulfilling lives. |
| Fundación de Fibrosis Quística (CFF) En español | Esta lista incluye todos los videos y grabaciones de la Fundación de Fibrosis Quística disponibles en español. |
| Research Into Cystic Fibrosis-Related Diabetes | Cystic fibrosis-related diabetes (CFRD) is a unique type of diabetes that is common in people with CF. Learn about research underway to improve CFRD diagnosis and treatment. |

| | |
|---|--|
| Managing Cystic Fibrosis-Related Diabetes | An instruction guide for patients and families. |
| ResearchCon 2023 Recordings | YouTube recordings of ResearchCon 2023, including information sessions on: CFRD, Mental Health, Nutrition, and more. |
| ResearchCon 2023 en español | Grabaciones de ResearchCon 2023, incluidas sesiones sobre: CFRD, Salud Mental, Nutrición y más. |
| Research Into Genetic Therapies | To treat cystic fibrosis, scientists are exploring ways to use gene editing, which would correct mutations in the CFTR gene, or gene therapy, which would provide a correct copy of the CFTR gene to cells. First, they must find a way to deliver the treatment to the right cells. |
| CF Foundation News & Press Releases | Read the latest in cystic fibrosis news from the CF Foundation. |

SESSION & ACTIVITY RESOURCES

| | |
|--|--|
| Unleash your Potential – Managing CF Daily Care | <ul style="list-style-type: none"> • Session Presentation • Service Dog Resources • Managing cystic fibrosis can feel overwhelming at times – but we’re here to help. Learn how to navigate life with CF. • The CF Foundation made a strategic commitment to develop a multi-pronged approach to help people with cystic fibrosis stick with their treatment plans called Partnerships for Sustaining Daily Care. Learn more about this initiative and how you can get involved. • Managing Your Treatment Plan |
| Balancing Act: Parenting with CF | <ul style="list-style-type: none"> • Parenting as an Adult with CF • Researchers from the University of Pittsburgh wanted to better understand the realities of parenting as a person with cystic fibrosis, so they collected firsthand accounts from members of the CF community. Learn more. |
| Thriving in the Workplace: Navigating Working Full-Time with Cystic Fibrosis | <p>Resources for navigating insurance:</p> <ul style="list-style-type: none"> • Navigating CF is a series of short videos from CF Foundation Compass that can help you understand health insurance. Whether you want to better understand the costs of coverage, have recently been denied coverage for the care you need, are changing jobs, or are starting off on your own and need to figure out your insurance options, Navigating CF is an easy place to start. Remember, you are not alone. Compass case managers are here whenever you need help! |
| Finding our Authentic Stories | <ul style="list-style-type: none"> • Seeds Information • Activity Presentation |

| | |
|----------------------|--|
| Mindfulness Workshop | <ul style="list-style-type: none"> • Activity Presentation • CF Wellbeing Collective Resources |
| Cooking with Caleigh | <ul style="list-style-type: none"> • Cooking Class Recipe |

CF FOUNDATION SUPPORT SERVICES AND PROGRAMS

| | |
|---|--|
| Compass Servicio de Compass | <p>Cystic Fibrosis Foundation Compass is a personalized, one-on-one service that provides people living with cystic fibrosis, their families, and their care teams with a partner in dealing with challenges related to life with CF.</p> <p>Compass One-Pager</p> |
| CF Peer Connect CF Peer Connect en español | <p>CF Peer Connect offers one-to-one peer support for adults with CF and their family members to connect about shared experiences including living with advanced lung disease, considering a lung transplant, or living post-transplant. No matter what you're going through, there is someone who has been through a similar experience and can offer support.</p> |
| CF Community Blog | <p>The CF Community Blog is all about sharing the experiences, reflections, and perspectives of the cystic fibrosis community: the good days, the bad days, and all the tough and wonderful things in between. If you are interested in sharing your story, fill out the CF Community Blog interest form today!</p> |
| Impact Grant Program | <p>The Impact Grant program provides grants of up to \$10,000 per year to individuals or organizations for projects that provide meaningful engagement opportunities for the CF community. The best ideas come from personal experience, and no one knows the ins and outs of life with CF like the CF community. This program is a chance to make your vision a reality. Please see our 2023 Community Grant Directory for a list of presently funded projects that are available to the community.</p> |
| Community Voice Community Voice en español | <p>Community Voice is a chance to be heard. People living with cystic fibrosis and their families know CF better than anyone, and Community Voice is an empowering volunteer opportunity for you to share your experiences, perspectives, and knowledge. Members make an impact by bringing their insights and priorities to the forefront of CF research, care, and programs. Join Community Voice Today.</p> <ul style="list-style-type: none"> • English Flyer • Folleto en español |
| Mutation Analysis Program | <p>The Mutation Analysis Program provides free genetic testing to people with cystic fibrosis to help identify their CF gene mutations.</p> |

COMMUNITY SUPPORT SERVICES AND PROGRAMS

| | |
|--|---|
| COTA | <p>COTA helps CF patients of all ages. Since its founding in 1986, the Children’s Organ Transplant Association has assisted hundreds of cystic fibrosis patients, many of whom have received a life-saving lung or liver transplant. During that time, teams of COTA volunteers and COTA staff members have raised millions of dollars to help these patients and their families meet transplant-related expenses.</p> |
| CFRI Psychosocial Support Programs and Classes | <p>In light of the high rates of depression and anxiety that are common among those impacted by cystic fibrosis, CFRI offers financial support for counseling sessions as well as monthly caregiver support groups. CFRI also offers “Mindfulness 2.0,” an online class which draws upon Mindfulness-Based Stress Reduction techniques. These programs address the impact of chronic illness on emotional health. Participation in these programs helps improve health and quality of life. Counseling assistance and support groups are open to the CF community nationwide.</p> |
| BEAM | <p>With Beam, you can access fun exercise that's tailored for you and your health needs, online, any time, any place. You can exercise along with on demand classes at a time that suits you or join a live class that allows you to interact with the instructor and other Beam members. There are also groups where you can connect with physiotherapists, instructors, and other people living with similar challenges to you. Beam Youth Flyer</p> |
| CF Senior Saturdays* | <p>CF Senior Saturday Meet & Greet is a virtual space for people aging with cystic fibrosis to connect, build relationships, find support, and share experiences. Whether you were diagnosed with cystic fibrosis early or later in life, attendees are committed to an atmosphere of trust and compassion. Meetings are every second Saturday of the month.</p> |
| <p>Spit it Out (A CF Storytellers Training)*</p> | <p>Spit it Out is a virtual public speaking program that uses trauma-informed training to help people with CF share their stories. Speakers will learn how to familiarize themselves with their own story, structure their story to connect with others, and deliver their story with power. To apply, complete this interest form.</p> |
| <p>CF Wellbeing Collective*</p> | <p>A monthly mindfulness program by Aliyah Novelli — an adult with cystic fibrosis and licensed social worker — that provides young adults with CF the support and strategies they need to address the unique challenges of life with their disease. Complete this interest form to join upcoming mindfulness and well-being monthly program.</p> |

*Supported by an Impact Grant from the CF Foundation