



Event Resources

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EDUCATIONAL RESOURCES

| | Description & Link |
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| Lung Transplant Phases Guide CF Foundation | This handout provides a brief overview of the lung transplant journey and is intended to help you discuss transplant as a future treatment option. https://www.cff.org/sites/default/files/2021-10/Lung-Transplant-Phases-Guide.pdf |
| Lung Transplantation CF Foundation | Visit this page for every resource offered by the CF Foundation related to lung transplantation. Topics include; What is a Lung Transplant?, What to Consider Regarding a Lung Transplant, Being Referred and Evaluated, Waiting for the Transplant, and Surgery, Recovery, and Life Post-Transplant. https://www.cff.org/managing-cf/lung-transplantation |
| Planning to Pay for a Transplant CF Foundation | It is important to understand that having a lung transplant can be expensive before, during, and after the transplant. Your health insurance may cover many of the costs, but not all of them. https://www.cff.org/Life-With-CF/Treatments-and-Therapies/Lung-Transplantation/What-to-Consider-Regarding-a-Lung-Transplant/Planning-to-Pay-for-a-Transplant/ |
| A Guide to Your Health Care - After Lung Transplantation International Transplant Nurses Society | This handbook provides general information for care after lung transplantation. It also will give you an idea of what to expect during the transplant process. Transplant centers often have different care routines, monitoring guidelines, and immunosuppressive routines following lung transplant. It is important to check with your transplant coordinator when you have a question or concern about any aspect of your care. Review this handbook with your nurse, transplant coordinator, or clinical nurse specialist and know your center's specific guidelines. https://app.etapestry.com/onlineforms/LungTransplantFoundation_1/lthandbook.html Courtesy of the Lung Transplant Foundation - https://lungtransplantfoundation.org/ |
| CF Roundtable | The purpose of CF Roundtable is to provide a source of information for CF adults regarding the basis, nature, and progression of the disease, as well as the latest treatments and research to fight it. It also offers a forum for CF adults to communicate with each other. https://www.cfroundtable.com/ |
| Lung Transplant Referral Guidelines CF Foundation | These guidelines provide recommendations for making timely lung transplant referrals for people with cystic fibrosis with advanced lung disease. https://www.cff.org/Care/Clinical-Care-Guidelines/Respiratory-Clinical-Care-Guidelines/Lung-Transplant-Referral-Guidelines/ |
| Advanced Cystic Fibrosis Lung | These guidelines provide guidance for management of advanced CF lung disease (ACFLD). Recognizing that care must be customized to each individual, these recommendations aim to |

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| Disease Guidelines Journal of Cystic Fibrosis | reduce practice variability, improve the quality of life and survival of those with ACFLD, and identify gaps in clinical knowledge where future research is needed. https://www.cysticfibrosisjournal.com/article/S1569-1993(20)30064-3/pdf |
| Models of Palliative Care Guidelines | Palliative care focuses on reducing physical and emotional symptoms and improving quality of life for people with CF throughout their lives. Palliative care occurs alongside usual treatments and is individualized according to the unique goals, hopes, and values of each person with CF. As such, these guidelines aim to assist clinicians involved in the care of individuals with CF to recognize and adopt tangible practices to address sources of distress among individuals with CF and their caregivers. https://www.liebertpub.com/doi/full/10.1089/jpm.2020.0311 |
| Managing Procedural Anxiety CF Foundation | Fear, worry, stress, and anxiety about medical procedures is common. The body is supposed to “signal” to us when something is new, unexpected, potentially harmful, or uncomfortable to help keep us safe and healthy. Sometimes the signal is too strong, which can lead to anxiety growing and getting out of control. These feelings can begin even days before the procedure and last after it. The good news is that there is a lot we can do to prevent or manage procedural anxiety. https://www.cff.org/sites/default/files/2022-03/CF-and-Mental-Health-Procedural%20Anxiety-A-Guide-for-People-Living-with-CF.pdf |
| Post-Lung Transplant Nutrition for People with Cystic Fibrosis Cystic Fibrosis Trust | People with cystic fibrosis may find that their nutritional needs change following a lung transplant procedure. This leaflet gives you information about what aspects of your nutritional treatment may change in the short and long term after a lung transplant, and how you can expect these to be managed by your transplant and CF teams. https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/Postlung%20transplant%20nutrition%20for%20people%20with%20CF%20July%202019.pdf |
| Improving Life with CF, A Primary Palliative Care Project | This project will create and test a new approach for primary palliative care. Our goals are to increase the ability of the CF care teams to manage problems identified through routine palliative care needs assessments, and to improve clinical skills through educational programming and quality improvement. https://improvinglifewithcf.org/ |
| Caring for Your New Lungs CF Foundation | Taking care of your new lungs is a big responsibility. Your transplant team will help you learn how to reduce the risk of infection and rejection and keep your lungs healthy. https://www.cff.org/managing-cf/caring-your-new-lungs#managing-rejection:~:text=people%20with%20CF.-,Managing%20Rejection,-Your%20body%20may |
| Surgery and Recovery CF Foundation | Surgery and recovery involves more than replacing your lungs. The process also includes making the physical and emotional adjustment to life with your new lungs. https://www.cff.org/managing-cf/surgery-and-recovery |
| CF Community Blog - Stories About Lung Transplantation CF Foundation | The CF Community Blog features stories from the CF community. Check out over 30 stories from community members on topics like knowing when to list, deciding not to list, lessons learned, second transplants, and more! https://www.cff.org/search?s=Blog&f%5B0%5D=topic%3A256 |

SUPPORT SERVICES AND PROGRAMS

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| Cystic Fibrosis Patient Fund Children's Organ | 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 |

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| Transplant Association (COTA) | members have raised millions of dollars to help these patients and their families meet transplant-related expenses. https://cota.org/give/cystic-fibrosis-patient-fund/ |
| Mutation Analysis Program CF Foundation | The Mutation Analysis Program provides free genetic testing to people with cystic fibrosis to help identify their CF gene mutations. https://www.cff.org/Care/Clinician-Resources/Mutation-Analysis-Program/ |
| Compass CF Foundation | 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. Compass provides people in the CF community a resource to navigate complex issues, becoming a trusted partner in their care. https://www.cff.org/Assistance-Services/About-Compass/What-Is-Compass/ |
| CF Peer Connect CF Foundation | 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. https://www.cff.org/PeerConnect |
| CFRI Psychosocial Support Programs and Classes | 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. https://www.cfri.org/education-support/psychosocial-support-programs/ |
| Community Voice CF Foundation | 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. https://my.cff.org/CommunityVoiceSignup |
| Attain Health - Peer Engagement Virtual Groups | We know all too well the isolation and overwhelm that is associated with having CF. Attain Health offers video-based peer engagement groups to offer a place of support, encouragement, and friendship in a variety of categories including the LGBTQAI+ community, Black people with CF, post-transplant, adults with CF in recovery, moms with CF, and more. http://attainhealth.org/peer-engagement-groups |
| The Intersectional CF Coalition | The Intersectional CF Coalition is a collective of people with CF who also live at the intersections of other marginalized identities. We dream of a CF community that is actively seeking to uncover and undo its own ways of marginalizing others within the CF community (racism, xenophobia, homophobia, genderphobia, etc.), consistently asking itself who isn't at the table, and following the lead of those whose voices have been neglected. We see ourselves as a resource for various CF organizations on evolving their culture to one of inclusivity and justice. For more information, contact April Biggs at abiggs1@gmail.com |
| Lung Transplant Foundation Mentorship Program | The Lung Transplant Foundation Joseph J. Carter Mentorship Program was founded to provide support to patients and caregivers throughout the lung transplant process. Whether you are a patient or a caregiver, having someone to talk to who has walked this path before you can help to ease uncertainties and provide hope for the future. Our trained Mentors are passionate about encouraging those going through a lung transplant to be better able to handle the demands of this journey. Well-supported patients and caregivers lead to greater success for everyone. https://lungtransplantfoundation.org/wp-content/uploads/2021/02/LTF-MENTOR-electronic_brochure.pdf |

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| CF Community Blog CF Foundation | 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! |
| Impact Grants Program CF Foundation | The Impact Grant program provides grants of up to \$10,000 per year to individuals or organizations for programs that provide meaningful engagement opportunities to 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. https://www.cff.org/get-involved/impact-grants |
| | Meet the 2022 Impact Grant Awardees |
| Beam | 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 and ACFLD |
| The Nourished Breath | The Nourished Breath strives to create a safe space for the cystic fibrosis community to come together and support their mental wellness through journaling and connection with one another. We aim to do this by hosting monthly virtual journaling sessions where prompts and guidance are provided and where sharing with one another is encouraged but never required. https://www.thenourishedbreath.com/ |