

# EVENT RESOURCES



NEXTBREATH



CYSTIC FIBROSIS  
FOUNDATION

## GENERAL RESOURCES

<b>Lung Transplant Phases Guide   CF Foundation</b>	<a href="#">This handout</a> provides a brief overview of the lung transplant journey and is intended to help you discuss transplant as a future treatment option.
<b>Lung Transplantation   CF Foundation</b>	Visit <a href="#">this page</a> 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.
<b>Planning to Pay for a Transplant   CF Foundation</b>	It is important to understand that <a href="#">having a lung transplant can be expensive</a> before, during, and after the transplant. Your health insurance may cover many of the costs, but not all of them.
<b>Consensus statements for lung transplant patients</b>	Cystic Fibrosis Foundation <a href="#">consensus statements</a> for the care of cystic fibrosis lung transplant recipients.
<b>A Guide to Your Health Care - After Lung Transplantation   International Transplant Nurses Society</b>	<a href="#">This handbook</a> 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.  Courtesy of the <a href="#">Lung Transplant Foundation</a>
<b>CF Roundtable</b>	The purpose of <a href="#">CF Roundtable</a> 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.  <b>Winter 2024 Topic: Organ Transplant</b> , share your stories and <a href="#">submit an article</a> by 12/15/23
<b>Lung Transplant Referral Guidelines   CF Foundation</b>	<a href="#">These guidelines</a> provide recommendations for making timely lung transplant referrals for people with cystic fibrosis with advanced lung disease.  <a href="#">Lung Transplant Referral Form</a>
<b>Advanced Cystic Fibrosis Lung Disease Guidelines   Journal of Cystic Fibrosis</b>	<a href="#">These guidelines</a> provide guidance for management of advanced CF lung disease (ACFLD). Recognizing that care must be customized to each individual, these recommendations aim to 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. <a href="#">Additional talking points</a> for conversations with your care provider.

<b>Models of Palliative Care Guidelines   Journal of Palliative Medicine</b>	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, <a href="#">these guidelines</a> 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.
<b>Managing Procedural Anxiety   CF Foundation</b>	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 <a href="#">prevent or manage procedural anxiety</a> .
<b>Post-Lung Transplant Nutrition for People with Cystic Fibrosis   Cystic Fibrosis Trust</b>	People with cystic fibrosis may find that their nutritional needs change following a lung transplant procedure. <a href="#">This leaflet</a> 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.
<b>Improving Life with CF, A Primary Palliative Care Project</b>	<a href="#">This project</a> 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.
<b>Caring for Your New Lungs   CF Foundation</b>	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 <a href="#">keep your lungs healthy</a> .
<b>Surgery and Recovery   CF Foundation</b>	Surgery and recovery involve more than replacing your lungs. The process also includes <a href="#">making the physical and emotional adjustment</a> to life with your new lungs.
<b>CF Community Blog - Stories About Lung Transplantation   CF Foundation</b>	The CF Community Blog features stories from the CF community. Check out <a href="#">over 30 stories</a> from community members on topics like knowing when to list, deciding not to list, lessons learned, second transplants, and more!  Blog post emphasizing the <a href="#">importance of screening for cancer post-transplant</a> .
<b>Cystic Fibrosis Patient Fund   Children's Organ Transplant Association (COTA)</b>	<a href="#">COTA helps CF patients of all ages</a> . 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.
<b>Lung Transplant Foundation Mentorship Program</b>	<a href="#">The Lung Transplant Foundation Joseph J. Carter Mentorship Program</a> 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. The 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.
<b>Now You Tell Me: Navigating care throughout the lung transplant journey   2023 ResearchCon</b>	<ul style="list-style-type: none"> <li>• <a href="#">Now You Tell Me: Navigating care throughout the lung transplant journey recording</a></li> <li>• <a href="#">ResearchCon 2023 “Now You Tell Me” PowerPoint Slides</a></li> <li>• <a href="#">Models of post-transplant care for individuals with CF</a></li> <li>• <a href="#">Find a lung transplant center</a></li> </ul>

	<ul style="list-style-type: none"> <li>• <a href="#">OPTN Policy Notice Lung Continuous Distribution Jan 2023 PC (hrsa.gov)</a></li> <li>• <a href="#">Learn about lung CAS - OPTN (hrsa.gov)</a></li> <li>• <a href="#">CF Foundation Launches Lung Transplant Biorepository and Patient Registry   Cystic Fibrosis Foundation</a></li> <li>• <a href="#">Patient Registry   Cystic Fibrosis Foundation (cff.org)</a></li> </ul>
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## CF FOUNDATION SUPPORT SERVICES AND PROGRAMS

<a href="#">Community Conferences</a>	There is something for everyone at a Community Conference. Whether you'd like to meet others going through similar experiences or learn more about CF-related topics, there is an event for you to virtually connect, share, and learn together.
<a href="#">Compass</a>	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. <a href="#">También disponible en español.</a>
<a href="#">CF Peer Connect</a>	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.
<a href="#">Impact Grant Program</a>	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 <a href="#">2022 Community Grant Directory</a> for a list of presently funded projects that are available to the community.
<a href="#">Community Voice</a>	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.
<a href="#">Mutation Analysis Program</a>	The Mutation Analysis Program provides free genetic testing to people with cystic fibrosis to help identify their CF gene mutations.