

Cystic Fibrosis: Barriers to Care



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Cystic fibrosis is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time.

Cystic Fibrosis: Barriers to Care is a recently published series of articles that spotlights two organizations dedicated to helping people with CF get the care and support they need.



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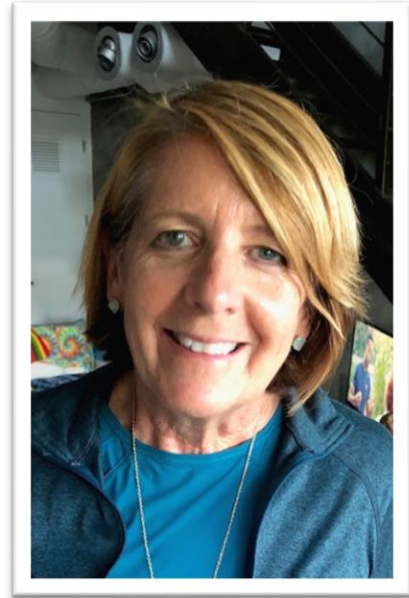
Cystic Fibrosis Research Institute

Cystic Fibrosis Patients Struggle to Afford Medication Delivery Devices

For patients with cystic fibrosis (CF), the struggle to breathe is real. The progressive, genetic disease causes persistent lung infections and limits the ability to breathe over time. Thick, sticky mucus clogs the airways and traps germs, like bacteria, leading to infections, inflammation, respiratory failure and other complications. Mucus buildup in the pancreas prevents the release of digestive enzymes that help the body absorb food and key nutrients, resulting in malnutrition and poor growth.

While there is no cure for CF, there are treatments that can help add years and quality of life to those with the disease. Treatments involve much more than popping a daily pill; they require a daily combination of therapies including:

- Airway clearance to help loosen and get rid of the thick mucus that can build up in the lungs.
- Inhaled medicines to open the airways or thin the mucus. These are liquid medicines that are made into a mist or aerosol and then inhaled through a nebulizer and include antibiotics to fight lung infections and therapies to help keep the airway clear.
- Pancreatic enzyme supplement capsules to improve the absorption of vital nutrients. These supplements are taken with every meal and most snacks. People with CF also usually take multivitamins.
- An individualized fitness plan to help improve energy, lung function and overall health.
- CFTR (cystic fibrosis transmembrane conductance regulator) modulators to target the underlying defect in the CFTR protein, which are effective only in people with specific mutations.



Mary Lester

"Patients with CF do a tremendous amount of at-home therapy," explained Mary Lester, a respiratory therapist in the [Anton Yelchin Center for Cystic Fibrosis](#) at the Keck Medical Center of the University of Southern California. "Most patients must administer at-home nebulizer treatments two or three times daily, and some patients are doing up to 200 nebulizer treatments every month for their entire lives."

Insurance Restrictions Create Barrier to Care

According to Lester, inhaled medications for CF can be expensive – up to \$75 a dose in some cases – and they must be deposited precisely in the lungs, at just the right particle size, to be effective. Unfortunately, she said, not all drug delivery devices fit the bill.

"CF centers are very specific about the equipment needed to deliver therapies based on research and testing," she said. "A cheap, subpar nebulizer kit like those included in many HMO plans is not going to be therapeutically beneficial."

Lester said she and her colleagues spend significant time helping patients work through the maze of medical insurance variables that can keep them from access to the right devices. This counseling is especially important for new patients to her clinic, which treats adults with CF after they transition from a pediatric CF clinic.

"After years of having their insurance coordinated and paid for by their parents, these adult patients need to get savvy fairly quickly and learn how to deal with the complicated restrictions and requirements placed by some plans," she said.

Cystic Fibrosis Foundation's *Compass* Program Provides Navigation Assistance

Often, Lester will point patients to the Cystic Fibrosis Foundation *Compass* program, a personalized service that helps with insurance, financial, legal and other issues faced by anyone with CF, their family, and their care teams.

Compass case managers are available by phone at 844-266-7277, by email at compass@cff.org and online at <https://www.cff.org/Assistance-Services/Compass-Service-Request/> to provide free and expert guidance such as:

- Troubleshooting access-to-care issues and researching options to help with challenges related to living with CF.
- Navigating resources offered by community organizations, local and state governments, foundations or other groups.
- Conducting a benefits assessment and providing a side-by-side comparison of insurance plan options during open enrollment or special enrollment periods.
- Connecting to other resources within the Foundation such as a clinical trial finder, virtual events, and peer mentoring.

In a recent blog post, *Compass* case manager Karen Carey explains the increased impact different insurance issues – such as copay accumulators – can have on medication delivery devices. She noted that the manufacturers of many CF medications have copay assistance programs in place to offset the amount patients

owe. In the past, some health insurance plans allowed members to count the total assistance received from these programs toward their annual deductible and out-of-pocket maximum. With copay accumulator programs, that is no longer the case.

"You can still use the copay assistance you receive," she wrote. "But without the dollar value of that assistance 'accumulating,' you may not hit your deductible or reach your out-of-pocket maximum for the year as quickly, if at all."

HealthWell Foundation's Cystic Fibrosis Funds Help Pay the Bills

The HealthWell Foundation offers a Cystic Fibrosis Treatment Fund to assist eligible patients by providing up to \$15,000 a year to help cover cost-shares associated with CF-specific treatments. In addition, HealthWell is also able to consider assisting with the full cost of hypertonic saline solution, nebulizers paired with treatments, and certain handsets. Device coverage is especially important, because devices like handsets need to be replaced every couple of weeks so they don't become reservoirs for germs that can lead to infections.

Good nutrition is crucial for people with CF, who require a high-calorie, high-fat diet, along with vitamin and mineral supplements. To help meet patients' nutritional needs, HealthWell offers a Cystic Fibrosis Vitamins and Supplements Fund, which provides up to \$1,500 a year in copay assistance.



Fred Larbi

"We are committed to holistic support for the CF community and addressing the areas of greatest need for the majority of people living with CF," said Fred Larbi, director of operations, HealthWell Foundation. "We understand there are additional areas to be addressed and, over time, it is our hope to be able to expand our coverage even further."

To date, the Cystic Fibrosis Treatment Fund has provided nearly 32,000 grants totaling over \$53 million. The Cystic Fibrosis Vitamin and Supplements Fund has provided more than 29,000 grants totaling nearly \$14 million.

HealthWell also helped to support the CF patient community during the COVID-19 pandemic, through a COVID-19 Ancillary Costs fund, which provided up to \$250 to cover the cost of delivered food, medication, diagnostics, transportation and telehealth as a result of COVID-19 risk or incidence. HealthWell also offered a COVID-19 Insurance Premium Payment Assistance Fund, which provided up to

\$8,000 in limited-time assistance with employees' portion of insurance premium costs related to COVID-19 furloughs and COBRA premium costs related to COVID-19 layoffs and unemployment.

"These COVID-19 funds were available to people with other chronic health conditions as well," Larbi concluded. "But they were especially useful for people with CF, whose ability to work and shop during the pandemic were impacted due to their compromised immune systems and difficulty fighting infection."

To help change the life of CF patients, HealthWell invites individuals and corporations to donate to one of the Foundation's CF-related funds.

Psychosocial Support and Wellness Programs for the Cystic Fibrosis Community

Today, Siri Vaeth, MSW, works as executive director of the Cystic Fibrosis Research Institute (CFRI), a charitable organization that serves as a global resource for the cystic fibrosis (CF) community. But back in 1995, Vaeth had never even heard of CFRI. She had a daughter who was newly diagnosed with the disease, and she found a flyer for CFRI's annual conference at her daughter's CF clinic – a serendipitous event that would change everything.

Real World Health Care recently spoke with Vaeth about how CFRI supports the CF community through multi-faceted programs focusing on the psychosocial and wellness needs of CF patients and their caregivers.

Connections and Community

Real World Health Care: What drew you to get involved with CFRI?

Siri Vaeth: I was in shock when first learning about my daughter's CF diagnosis – she's now 26 years old. I saw a flyer for CFRI's annual conference in my daughter's clinic and decided to go. It was like walking through a magic door – I found my tribe!



Siri Vaeth and her daughter Tess

The event was a perfect blend of incredible information from experts around the globe and a strong focus on community. It was a wonderful opportunity to connect with other parents who had children with CF as well as adults with CF. Most importantly, it gave me hope.

I came to learn that CFRI was founded in 1975 by a group of parents whose children weren't expected to survive to adulthood. CFRI was formed specifically to fund research, but it quickly evolved and grew beyond research to include

advocacy, educational programs and very strong psychosocial support and wellness programs. I am incredibly honored to serve as the executive director for an organization that has not only changed the lives of my daughter and me, but so many individuals and families impacted by CF.

Psychosocial Support for a Demanding Disease

RWHC: Why is psychosocial support so important for people living with cystic fibrosis?

SV: CF is demanding. Many people associate it with lung disease, and respiratory failure is the main cause of death. But it's actually a systemic disease that involves every organ system in the body. The burden of care is quite high, and most people with CF put in hours of respiratory and medication therapies every day, which can be quite exhausting.

CF is an incredibly complex and capricious disease, and it can be incredibly depressing to live with – as a patient or a caregiver. Studies have shown that the rates of depression and anxiety among those living with CF are two to three times higher than that of the general population. And the highest rates are among mothers of kids with CF – a situation I know all too well.

Depression among CF patients has been correlated with poorer respiratory outcomes and other negative outcomes, including a low body mass index (BMI), which is particularly troublesome for CF patients who can't properly absorb enough nutrients to maintain a healthy weight.

RWHC: How does CFRI help to support the psychosocial health of those living with CF?

SV: CFRI understands the mind-body connection. We know we need to address every part of patients' and caregivers' physical and emotional well-being.

We offer a range of psychosocial support programs and classes that address the impact of chronic illness on emotional health. We have monthly support groups for adults with CF, parents of children with CF, and caregivers of adults with CF, all of which are available online. We also offer an online bereavement support group for those who have lost a loved one to CF. We will soon launch a new post-transplant support group as well.

Our semi-annual community retreats – which have moved from an in-person to a virtual platform – are another great resource that provides social support to people living with CF and helps them develop positive coping skills. These retreats are significant, meaningful weekends for everyone involved and they reach capacity

every year. When the COVID pandemic hit, we were initially concerned that our inability to host an in-person retreat would impact the ability of attendees to feel a sense of community, but I'm pleased to say that we had full capacity for our last two virtual retreats for mothers, with participants from across the country.

We also offer nationwide counseling support. Children and adults with CF, as well as their family members, are eligible to receive financial support for six individual therapy sessions per year with a licensed provider of their choice. CFRI covers the cost of insurance copays for six sessions, or pays up to \$120 per session for six sessions if you have no insurance, or your provider does not accept insurance or is outside your network. More information about this support program can be found on our website, or by [emailing Sabine Brants](#).

Work Out: CF Wellness Programs

RWHC: Why is physical movement and exercise so important for people living with CF?

SV: We know that exercise is good for everyone's physical and mental health. It provides a therapeutic benefit for people with CF by improving quality of life, muscular strength and cardiovascular endurance. But sticking to an exercise program can be challenging for people with CF who have respiratory issues including impaired lung function, shortness of breath, and incessant coughing, as well as GI issues, osteopenia, gastric reflux, and joint pain.

RWHC: How does CFRI help people with CF start and stick with an exercise program?

SV: Our [wellness programs](#) aren't generic exercise routines you may see at your local gym. They're specifically tailored to the needs of the CF community and in most cases are delivered by people who have CF, have a loved one with CF or work in a CF clinic. They are therefore attuned to offering modifications for every movement and tailoring routines to those with special needs. For example, one of our physical therapists offers exercises to strengthen the pelvic floor for women with stress urinary incontinence, which is common in CF. Another teaches a series of breathing exercises for post-transplant patients to help them relearn how to isolate parts of their lungs in order to take a full breath.

All of our exercise programs – from yoga to strength training to physical therapy – are offered virtually, and at no cost, so they can be accessed from anywhere.

Speaking the Language of CF

RWHC: In addition to many of your ongoing programs throughout the year, your annual conference switched to a virtual platform this year. How has that event changed since you went to your first CFRI conference all those years ago?

SV: Can I talk about one important way it hasn't changed instead? It continues to be a place where everyone speaks a common language, where even if you don't know someone else personally, you deeply understand each other based on your common life with cystic fibrosis.

This year, our virtual platform gave us the opportunity to extend those community connections beyond people who might typically attend in person. We had 650 registered attendees from every state in the U.S. and 20 countries around the globe. We had a rock-star list of presenters on a variety of topics, and Francis Collins, director of the National Institutes of Health, inspired us with his welcoming remarks.

For those who couldn't attend the live conference this past summer, we uploaded all the presentations to our [YouTube channel](#). I encourage everyone living with CF to avail themselves of these online presentations and to "find their tribe" here at CFRI by connecting with others who understand. Because for many, it can be a very lonely journey.