

PEP

QUARTERLY DIGEST

Resources to enhance PEP skills, stories of strengthening partnership and upcoming events to engage with the larger PEP community.

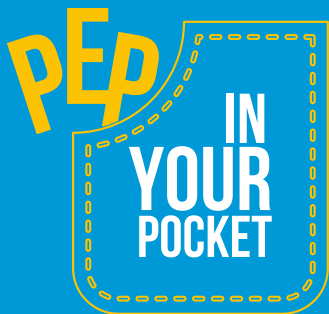
PEP IN ACTION

A young adult with CF at our care center is currently preparing for transition and simultaneously experiencing significant stressful situations leaving her overwhelmed and feeling lost in a "cloud of anxiety". She arrived at her appointment with a number of concerns, but feeling overwhelmed and stuck on where to start.

Our social worker, Alison, visited with the young adult and affirmed that she was not alone in accomplishing her to-do list and that her care team would be there to support her in creating a plan. Alison helped elicit the list of her concerns and worked to prioritize her to-do list to determine where to start.

By breaking down the items into smaller, digestible chunks, the young adult was able to isolate and articulate her top priorities and find a place to begin. The young adult left clinic that day feeling less stressed and armed with a plan that felt personalized, and supported by her care team. Alison partnered with the young adult rather than directing her to ensure she was empowered in her decision making and a reminder that she is equipped with many strengths. Alison will check-in with the young adult in the weeks to come to follow-up on the progress of her goals and discuss any modifications. Alison's approach of partnering and use of PEP skills supported this young adult to elicit the list of her concerns, determine where to begin and build confidence to take action towards her goals.

Kristi Gott PNP
University of Virginia Pediatric CF Team



Resources to boost PEP Skills:

Watch: [Power of Empathy - Helen Riess](#)

Utilize: [Discussion Aid - CF and COVID-19 Vaccination](#)

Read: [Developing Patient Teach-Back to Improve Patient Education](#)

FACILITATOR SPOTLIGHT

Our CF Clinic team room was busy with activity when I arrived. I had prepped the evening before, and was happy to see that a particular young adult was scheduled as my last appointment of the day. I had recently completed the first sessions of the PEP facilitator training, and was anxious to “try on” the skills. I was especially anxious to “try them on” with this particular young adult. I had followed her since infancy when she was diagnosed with CF, related to poor growth and weight gain along with recurrent pneumonia. We had spent many hours together through the years both on the wards and in clinic rooms, with visits to our hospital becoming ever more frequent. Now at age 18, as her life became more challenging, our visits had also become more challenging too. At her last visit, she rolled her eyes and asked me “Why do you always ask me the same questions?” She was clearly exasperated, and during recent visits, her answers had been curt and mostly mono-syllabic. I felt I was letting her down, and even with social work and nursing input, had not figured out how I could help her with her advancing and increasingly severe symptoms. (I had even asked the nurses to see if she wanted to switch to another CF physician - - “No, absolutely not!” they reported that she had replied. Perplexing me further...).

On that clinic morning, I was relieved she was the last patient of the day as I could take as much time as I wanted (and needed) with her. I knocked and smiled broadly as I entered the room, letting her know how happy I was to see her. She cocked her head. We talked about school and her beloved dogs. I caught a brief smile. Then I asked her, “What do you want to be sure we talk about today? Let’s start with a list.” Her eyes widened. She was silent for a minute, and I let the silence linger. Then she let me know that she was really happy that “the new therapies” (modulators) were available to others, and knew they would make a difference for them. She acknowledged that her CFTR mutations made her ineligible at this time – so what other options did she have? She really was trying to do all of her therapies as best she could, though knew she wasn’t perfect.

After some of our discussions, she had read a little bit about lung transplant. What more could I tell her about lung transplant? I was stunned – this was more conversation and information than she had shared with me for many months. I glanced at my PEP Skills Card, checking off PEARLS. I acknowledged how hard she was working to take her medications and do her treatments, and how difficult it must be for her to see others become eligible for new therapies while she was not. We talked about how others in her situation were feeling the same way. I let her know that I would continue to care for her and support her through next steps, and we would work on all this together. It was a very emotional moment.

Over the course of the next year, this young adult’s severe lung disease worsened. We do not have a lung transplant program at our Children’s Hospital, but work closely with our Adult CF Center at the University where there is a very active lung transplant program. The young adult and I made the decision together that this was the right time to transition from the pediatric to the adult CF Center, and she soon began lung transplant evaluation. As she transitioned, she wanted to know if she could keep in touch, and I assured her that we would. She would email me from time to time, giving me updates on her progress, her hospitalizations, and her lung transplant candidacy. She and her (adult) CF physician even brought me into a Zoom clinic visit.

Recently, the young adult sent me an email with her new phone number. She wanted me to call her and ended her email with the charming little emoji red heart. I called her that evening and could hear the lilt and smile in her voice – she had been accepted for lung transplant and was “on the list”. ❤️



Susan Marshall, MD
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ENGAGE WITH US

Coffee Chats

Review micro skills and discuss complex communication situations with PEP facilitators.

Webinars

Interactive sessions to enhance communication skills.

- April 14 (11-12pm EST) - Coffee Chat: [Register here](#)
- May 11 (3-4pm EST) - Coffee Chat: [Register here](#)
- May 24 (11-12pm EST) - Webinar: Understanding Barriers: Listening Efforts in BIPOC Communities: [Register here](#)
- June 21 (3-4pm EST) - Webinar: Understanding Barriers: Listening Efforts in BIPOC Communities: [Register here](#)

ON THE HORIZON

Virtual PEP Training - Open Sessions

Interested in attending a Virtual PEP Training this year? Sessions are open to any CF care team member that has yet to attend PEP, missed their care team's training, etc. We look forward to see you there!

July 13 & 20: 1:00-4:00pm EST: Virtual Open Session 1: [Register here](#)

September 19 & 26: 11:00-2:00pm EST: Virtual Open Session 2: [Register here](#)

Stay Tuned: Special PEP Course at NACFC, November 2022



**Questions?
Feedback?
Contact us at
PEP@cff.org**