

# National Patient and Family Engagement- Learning and Action Network (NPFE-LAN) Care Partner Peer Connection Call

August 22, 2024



# Before We Get Started

- Please be respectful and remember:
- Please mute your line when not speaking.
- Use the chat box.
- This call is being recorded and will be made public.
- Do not disclose any personally identifiable information.
- Do not ask for medical advice.
- Each person's situation and experience is unique.
- Before making changes to your health practices, speak with a member of your healthcare team.



# Disclaimer

The views and opinions expressed during this call are those of the panelists and do not necessarily reflect the official policy or position of the End Stage Renal Disease (ESRD) National Coordinating Center (NCC) or the Centers for Medicare & Medicaid Services (CMS). Any content provided by the panelists is of their opinions and is not intended to substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.



# Today's Moderators

**Emma Okamoto**



**Stephanie Hull**



# Midwest Kidney Network 11

## Guide for Care Partners

Jeff Nelson  
Consumer Committee  
Chairperson



# 2023 Consumer Committee Project

- In January 2023, CMS asked the ESRD networks to work on a project that supported key CMS goals and initiatives such as:
  - Home dialysis.
  - Transplant.
  - Depression screening.
  - Reducing hospitalizations, readmissions and ER visits.
  - Others.

# 2023 Consumer Committee Project

- The Midwest Kidney Network 11 Consumer Committee met to come up with some ideas that we could work on:
  - An outdoor billboard or indoor poster.
  - Transplant kidney care.
  - Awareness and care for high blood pressure.
  - Identifying depression in patients.

# Brochure Content Planning

- A subcommittee was formed from volunteers and planning meetings were held along with ideas and feedback from the larger consumer committee.
- Project team met twice in February to come up with some ideas:
  - Facebook Live presentation.
  - Supporting home dialysis patients.
  - The committee settled on an informational tri-fold brochure.



# What is the difference in terms Caregiver vs. Care Partner?

- We began planning the tri-fold using the term 'caregiver', but it was suggested that we consider the term 'care partner' instead.
- A caregiver gives care, where a care partner partners in care.
- Just changing the term changes the perspective from a hierarchical relationship to an equal footing partnership.

# Who is a Care Partner?

- Home and family members
- Friends
- Home care support staff
- Can be a team effort – too often it's a single individual
- Not all heroes wear a cape!

# Care Partner Stress and Burnout

- Being a partner in someone's care often starts out slow and small.
- Those with acute health care needs recover over time and the care partner role decreases.
- Those with chronic health care needs like ESRD patients, may need help over a longer time which may lead to stress and burnout.

# Key Signs of Stress and Burnout

- Feeling overburdened.
- Making mistakes or stressing over making a mistake.
- Fatigue.
- Mental exhaustion.
- Mentally feeling tired.
- Relationship challenges.
- Feeling like the caregiving will never end.
- Crying.

# Tools for Managing Care Partner Burnout

- The first step is to admit that you need help.
- Stop and take care of yourself!
- Reach out for help and share the work.
- Switch days and duties.
- Join a care partner support group.

# Care Partners with ESRD Focus

- Home Dialysis
  - Must have a care partner present during treatment.
  - Home dialysis machine requires cleaning and maintenance.
  - May need help purifying water for dialysate.
  - Help receiving and organizing supplies.

# Care Partners and Clinical Dialysis

- Should someone drive you to and from dialysis treatments?
- Help with understanding lab reports.
- Assisting with meals and dietary restrictions.

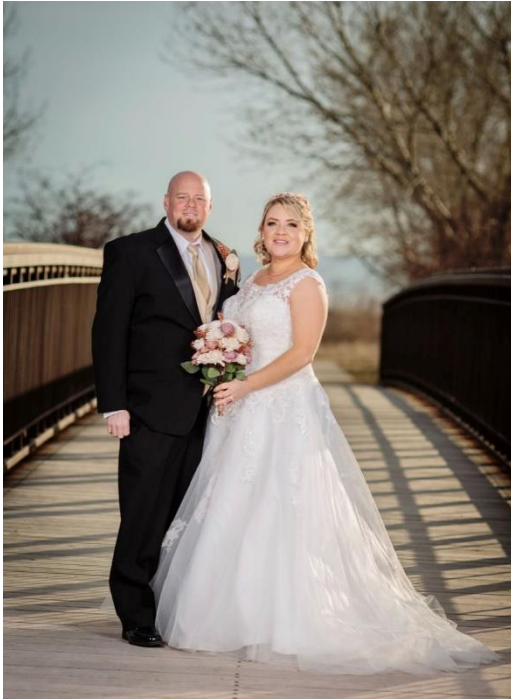
# Post-Transplant Care

- Having care partners at every post-transplant follow-up visit.
- Care partners may assist with filling pill boxes and medication management.
- Care partners helping to remind you to take your medications.



# Questions and Discussion

# Care Partner—Subject Matter Expert



**Michael and Christina Gilchrist**

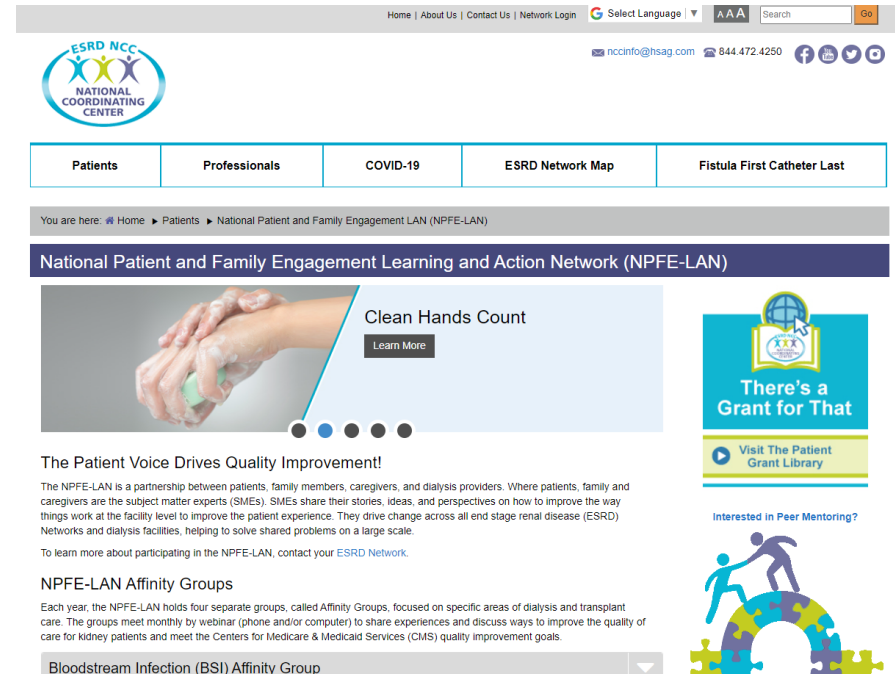


**Ramieka and Keith McDonald**

# Patient and Care Partner Resources

For tools and resources to help you in your kidney disease journey, visit : [esrdncc.org/en/patients/national-patient-and-family-engagement-lan-npfe-lan/](https://esrdncc.org/en/patients/national-patient-and-family-engagement-lan-npfe-lan/)

- Caregiver/Care partner
- Depression
- Home dialysis
- Kidney transplant



The screenshot shows the website for the ESRD NCC National Coordinating Center. The navigation bar includes links for Home, About Us, Contact Us, Network Login, Select Language, and a search bar. The main navigation menu has tabs for Patients, Professionals, COVID-19, ESRD Network Map, and Fistula First Catheter Last. The breadcrumb trail indicates the current location: Home > Patients > National Patient and Family Engagement LAN (NPFE-LAN). The main heading is "National Patient and Family Engagement Learning and Action Network (NPFE-LAN)".

Key features visible on the page include:

- Clean Hands Count:** A section with an image of hands being washed and a "Learn More" button.
- The Patient Voice Drives Quality Improvement!** A section describing the NPFE-LAN partnership between patients, family members, caregivers, and dialysis providers. It mentions that SIMEs (Subject Matter Experts) share their stories and ideas to improve patient experience and drive change across all end stage renal disease (ESRD) Networks and dialysis facilities.
- NPFE-LAN Affinity Groups:** A section explaining that the NPFE-LAN holds four separate groups, called Affinity Groups, focused on specific areas of dialysis and transplant care. These groups meet monthly via webinar to share experiences and discuss ways to improve the quality of care for kidney patients and meet the Centers for Medicare & Medicaid Services (CMS) quality improvement goals.
- There's a Grant for That:** A section with a "Visit The Patient Grant Library" button.
- Interested in Peer Mentoring?** A section with an illustration of two people climbing a rainbow made of puzzle pieces.

The "Bloodstream Infection (BSI) Affinity Group" is highlighted in the bottom navigation bar.

# Patient and Care Partner Resources (cont)

## Tips for Kidney Caregivers

From kidney patients who appreciate their support and the caregivers who understand the experience. Read through the tips and check the boxes you want to accomplish.

### Tip 1—Talk About It

The person diagnosed with kidney disease may not act like the person you knew prior to starting treatment. Get to know them as they adjust to treatments. If you have a hard time talking with your loved one, ask to speak with the social worker or another member of the care team.

#### To keep the lines of communication open:

- Be honest with your feelings and talk about concerns together.
- Do something together, such as taking a walk while you talk.
- Listen openly, stay positive, but don't feel you have to have all the answers.



### Tip 2—Be Prepared

Kidney disease comes with many changes and decisions to be made. Learn more about it and the different treatment options.

#### To learn about kidney disease:

- Visit [www.esrdncc.org](http://www.esrdncc.org) for resources.
- Create a list of your loved one's medications and medical history. Keep it with you.
- Talk to a healthcare professional about kidney resources.



### Tip 3—Set a Schedule

A daily plan keeps things on track and lets you see how your time is spent.\* It can also highlight if there is a need to ask others for help.

#### To start your schedule:

- Write down and prioritize your daily and weekly tasks.
- Ask for help when you need it.
- Plan for breaks.



### Tip 4—Take Time for You

It's okay, and necessary, to take time for yourself. Make time for activities that help you relax. When you feel recharged, you're better able to help others.

#### To use a moment for you:

- Take 30 minutes and go to your favorite place.
- Try a relaxation method, such as yoga or meditation.
- Find local and online support groups or talk to a healthcare professional. (Contact your End Stage Renal Disease Network for a listing of local support groups.)



\*Bova Collis R, MSW, LCSW. A Caregiver's Wish List: Tips on How Dialysis Patients Can Help Their Caregivers. *At Home with AAMP* (online). Nov 2011. Available at: <https://aha.org/caregivers-wish-list-tips-on-how-dialysis-patients-can-help-their-caregivers>. Accessed on June 6, 2015.

## Important Medical Information

Name	Phone/email	Additional Info



Care Team

Medication	Reaction



Medication Allergies

Name	Phone/email	Additional Info



Other Important Numbers

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## Understanding How Dialysis Makes Me Feel, and How You Can Help

Dialysis is a medical treatment that does some of the things that healthy kidneys usually perform. The treatment can be performed at a dialysis center, or it can be performed at home. During the treatment, the patient is connected to a dialysis machine. The machine removes blood from the body, cleans it, and returns the clean blood back to the body. This process can take 3 to 5 hours. And it's done at least 3 times a week.

The treatment can leave the patient very tired. The patient may need to rest or may need help doing things that he/she normally would not have trouble doing. If you are a caregiver, family member, or friend to someone who receives dialysis treatment, here are some ways you can support the dialysis patient.

How I Feel After Dialysis Treatment	How You Can Help
I feel tired after treatment.	Let me sleep. It may be for an hour. It may be for 3 hours. My body needs time to recover.
I have an upset stomach, or I want to vomit.	Allow me to lay down. Offer me crackers or sip of Ginger Ale.
My skin itches.	Remind me to keep my skin moisturized. I may also need help finding foods with less phosphorus.
I'm hungry.	Help me make food to eat.
I don't feel like eating.	Make sure I eat something. Offer me a small snack instead of a big meal.
My mouth is dry.	Offer me a hard candy, frozen grapes, a lemon to suck on, or mouth wash to soothe my mouth. Don't give me water.
I feel dizzy or have blurred vision.	Let me sit down for 15–30 minutes.
My muscles are cramping.	Help me talk to my dialysis team about my treatment plan.
I feel overwhelmed.	Suggest listening to music, writing down my feelings, taking a hot bath, or going for a walk.
My blood pressure dropped.	Help me talk to my dialysis team about my treatment plan.
My body shakes.	Let me lay down when I get home and cover up with a blanket.
I feel moody.	Give me some time to be by myself. Don't keep asking if something is wrong.



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# Engage With Us on Social Media!

- Educate and inspire others in the ESRD Community.
- Highlight and celebrate our NPFE-LAN members.
- Submit a few sentences about your journey and a picture.



@esrd\_ncc



ESRD National Coordinating Center



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# Thank You!

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