Patient Facility Representative (PFR) Alliance Meeting

09/07/2023
Patient and Family Engagement Facilitators

Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Julia Gesick
Emergency Management Speaker

Yvonne Heavner
Quality Improvement Speaker
Today’s Agenda
Topics for Review/Discussion

Meeting Reminders
PFR Check-In
Quality Improvement Topic

Patient Services Topic
Closing Remarks
Meeting Reminders

• All phone lines are muted upon entry to eliminate background noise/distractions

• We will be monitoring Chat throughout the meeting for questions or comments

• All slides will be shared within a week of completion of the meeting
IPRO ESRD Network Program

• The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:
  ○ Network 1: ESRD Network of New England
  ○ Network 2: ESRD Network of New York
  ○ Network 6: ESRD Network of the South Atlantic
  ○ Network 9: ESRD Network of the Ohio River Valley

• The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, efficient, patient-centered, timely, and equitable.
Network Check-In
Polling Question

Which Network are you from?

- Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
- Network 2 (New York)
- Network 6 (North Carolina, South Carolina, Georgia)
- Network 9 (Indiana, Kentucky, Ohio)
August
Follow Up

Kidney Transplant Compare
Kidney Transplant Compare

August Action Item Follow Up

Last month the PFRs were asked to:

1. Work with your facility staff to PRINT and POST the patient flyer for Kidney Transplant Compare
2. Gather feedback from a patient on their use of the application - be ready to share!
Action Item

Polling Question

Did you print and post the Kidney Transplant Compare flyer in your facility?

1. Yes
2. No
**Action Item**

**Polling Question**

Please share any patient feedback you gathered from sharing the application last month:

1. free type in the text box
Network Check-In
Polling Question

Do you feel prepared for an emergency situation?

- Yes
- No
- Unsure
What Do Dialysis Patients Need to Know About Emergency Preparedness?

Julia Gesick BSW
Emergency Management Specialist
Objectives

• Emergency preparedness is essential for patients to ensure continuity of care. It is important for people on dialysis to plan ahead for emergencies and disasters in order to stay safe. This webinar provides information that will help understand:
  • Types of emergencies
  • How travel can impact your care
  • What to ask your team
  • What supplies may be needed
What is the Network’s Role in an Emergency?
Preparedness, Mitigation & Response

• Networks monitor conditions that impact a facility’s ability to provide service to dialysis patients
• Establish relationships with state emergency management officials and healthcare coalitions
• Work to identify challenges and barriers impacting patients and their facilities
• Communicate barriers, needs and outcomes to CMS
What is an Emergency?
Emergencies can be Local, State Level, Regional or National

- Weather Event
- Facility Closed/Altered (Water, Power, Structural)
- Public Health Issues (COVID-19)
- Man Made Event (Terrorism, Supply Shortage)
- Transportation Event (Weather, Bridge Collapse)
- Communications Event (Phone/Internet Outage)
Basic Requirements for Dialysis

- **Space** to do the treatment
- **Electrical Power** to run the equipment
- **Dialysis Machines**
- **Portable Water** for use in the treatment (each treatment requires a minimum of about 100 gallons of treated, pressurized water)
- **Supplies** such as dialyzers, blood lines, saline, medications, etc.
- **Personnel** qualified to perform dialysis
- A **physician's prescription** for dialysis and medical records to support the treatment
- A **hospital** or other similarly equipped system and means to transport a patient if complications occur during treatment
- **Transportation** to and from dialysis
What to Ask Your Team

• What is my facility’s emergency plan?
• How will my facility contact me if there is an emergency?
• How will I receive dialysis if my facility is unable to open?
• How can I best prepare my home for an emergency?
• What should I do if an emergency happens during treatment?
• Where is my closest medical needs shelter?
Resources and Supplies Needed

Have a “to-go” bag ready with essentials such as:
• Water and food
• Health Documents
• Emergency Tools
• Clothes and Toiletries
December 2022, a large snow storm impacted Buffalo, NY
Patients and staff were forced to spend the night at their clinic due to lack of transportation/rapid rate of snowfall

What are TWO items you would feel are a need for staying overnight in an emergency at your dialysis facility?
Depression - How can we better approach this topic with patients?
Why is it important to address depression with patients?

• Studies show that patients on dialysis with a diagnosis of depression have a decreased quality of life.
• Depression may lead to missed treatments/medications which can lead to decreased physical health as well.
How can depression be better addressed in facilities?
Common Barriers

• Stigma
• Appointment fatigue
• Patients aren’t interested
• Mental health professional shortages
• Lack of support
Increasing Patient Engagement at the Facility Level

How can a facility patient representatives help?

• Studies show that peer support can have a positive impact on patient outcomes.
• The success in peer support comes from building relationships and sharing real life experiences.
• Additional benefits can be gained by the peer mentor. They feel a sense of worth and accomplishment through helping others.
Ideas on how facility staff or patient facility representatives can help?

• Do you feel comfortable as a PFR talking about depression?

• Any ideas for additional resources?

• What do you feel would be good information for patients to learn about depression/mental health treatments

• Working on a new handout “What to expect during your first therapy appointment”?

• Any input on this topic?
Recently Released Handout

You have a chronic illness...
You have a lot of questions about how your life will change...

- How will people view me now that I am on dialysis?
- Will I still be able to work?
- Will I still have a good quality of life?
- Can I still enjoy my hobbies?

Often when people are diagnosed with a chronic illness they feel a sense of loss and sadness. They don’t know the answers to many questions. But help is available to address these feelings.

Working Through Feelings
For many people, change is not easy. When newly diagnosed with a chronic illness, people often are forced to deal with necessary changes in lifestyle, lower energy levels, increased responsibility, threats to financial security and other concerns. These changes often cause feelings of sadness, grief, loss, or anger that can negatively affect the way people think and act and may lead to depression for some.

After speaking with kidney patients, we have learned that many do not seek treatment for these difficult and painful feelings due to fear of being seen in a negative light (stigma) and shame. It is important to know that while kidney disease affects everyone differently, many people have feelings of loss and sadness as they face the realities of a chronic illness such as kidney disease.

If you are experiencing overwhelming feelings, it’s important to know you’re not alone. Many react the same way to changes in their lives. It’s important to remember that talking to professionals and getting support can help you move through these feelings and remind you that your feelings are normal and you are not alone!

A Process
In 1969, a Swiss psychiatrist, Elisabeth Kubler-Ross, introduced a five-stage model that describes what people often experience (in part or in total) as they deal with grief or loss. The five stages of grief/loss are:

- Denial – withdrawing, avoidance, forgetfulness, anxiety, difficulty focusing, missing treatments
- Anger – irritability, easily frustrated, anger outbursts, short temper
- Bargaining – feeling guilty, overthinking, feelings of “What if”
- Depression – feeling sad, withdrawing from family and friends, lack of motivation, decreased energy, hopelessness, sleep disturbances, anxiety
- Acceptance – hopeful, coping, and learning to adapt

continued on next page
Network Check-In
Polling Question

Do you feel this idea for a new handout will be helpful to patients hesitant to go to therapy for depression?

• Yes
• No
• Unsure
Next Steps

Aisha Edmondson
Patient Family Engagement
Next Steps

• **Follow** us on social media!
• **Join** the PFR Alliance Facebook Group [https://www.facebook.com/groups/ipropfralliance](https://www.facebook.com/groups/ipropfralliance)
• **Create** your IPRO Learn Account [https://esrd.iprolearn.org/login/index.php/](https://esrd.iprolearn.org/login/index.php/)
• **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
• **Become** a Peer Mentor:
  ○ Understand the steps [https://esrd.ipro.org/patients-family/pfe/peer-mentoring/](https://esrd.ipro.org/patients-family/pfe/peer-mentoring/)
  ○ Register online: [https://redcap.ipro.org/surveys/?s=CJMXNF9DNR](https://redcap.ipro.org/surveys/?s=CJMXNF9DNR)
  ○ Have questions?
• **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042
Next PRF Meeting - Mark Your Calendar!
Thursday, October 5th 2023 at 5:30pm ET

• Upcoming Topics: Reducing Hospitalizations, providing patients on knowledge on where to go.

• Things to Think About: Should you always go straight to the ER if you need care?
Community Awareness Campaigns
Sepsis Awareness Month ***Get Ready Day–9/19/2023

4 WAYS TO GET AHEAD OF SEPSIS

1. PREVENT INFECTIONS
   Talk to your doctor or nurse about steps you can take to prevent infections.

2. PRACTICE GOOD HYGIENE
   Remember to wash your hands and keep your hands and feet clean and covered until healed.

3. KNOW THE SYMPTOMS
   Symptoms of sepsis can include any one or a combination of these:
   - Fever or feverish
   - Fasting or sweating
   - Chills
   - Confusion or drowsiness
   - High blood pressure

4. ACT FAST
   Get medical care IMMEDIATELY if you suspect sepsis or have a situation where it’s not getting better or is getting worse.
   
Sepsis is a medical emergency. Time matters.

To learn more about sepsis and how to prevent infections, visit www.cdc.gov/sepsis.

Don’t leave it to luck! Be prepared. Make a plan for emergencies.

www.APHAGetReady.org
Social Media
Follow Us!

- IPRO ESRD Network Program’s Facebook Page
- IPRO ESRD Patient Facility Representative (PFR) Alliance Group
- IPRO ESRD Network Program’s Twitter Page
- IPRO ESRD Network Program’s Linkedin Page
- IPRO ESRD Network Program’s Instagram
Questions?
Comments?
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication #