

# ESRD NCC NPFE-LAN Patient Summit

## *Going for the Gold: Overcoming Obstacles*

### Day 1

September 24, 2024




ESRD = End Stage Renal Disease  
NCC = National Coordinating Center  
NPFE = National patient and Family Engagement  
LAN = Learning and Action Network


# Meeting Logistics

- This event is being recorded and will be made available after summit concludes.
- Everyone is encouraged to use the chat feature (located in the bottom right corner of your screen) for submitting questions or comments
- Let's practice! Please type your first name and where you are from in the chat box.

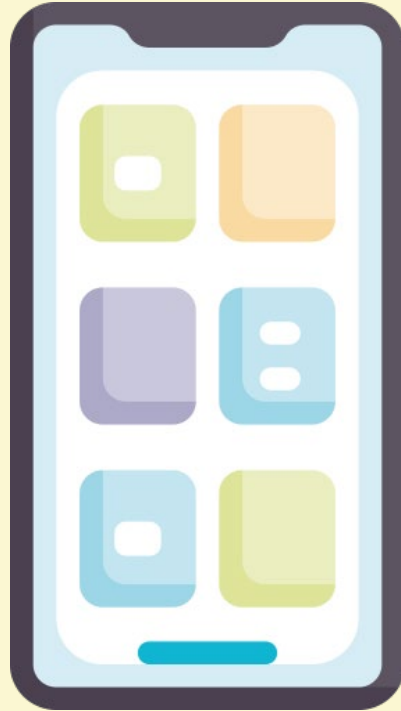


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*Share your Patient Summit experience on social media!*

- Use event hashtags on Instagram, X, and Facebook.
  - #ESRDChamp
  - #TopOfThePodium
- Tag the NCC's account so we can repost your content.

# Agenda

Time	Topic	Presenter
12:00 p.m. ET	Welcome and Introduction	Centers for Medicare & Medicaid Services (CMS)
12:15 p.m.–1:15 p.m. ET	Insurance: Everything You Need to Know	Kelli Collins Damron, MSW Marissa Argentina, MSW
1:15 p.m.–2:15 p.m. ET	Mental Health	Lori Hartwell Anthony Peters
2:15 p.m.–2:45 p.m. ET	Break	
2:45 p.m.–3:45 p.m. ET	Caregiver Self Care Tips	Vernon Silva, LCSW
3:45 p.m.–4:45 p.m. ET	Health Equity: Patient Activation	Chiao Wen Lan, PhD Ken Teasley Sarah Ruiz
4:45 p.m.–4:50 p.m. ET	Closing Remarks	ESRD NCC



# CMS Welcome



CDR Daniel Thompson, MSN, COR, PFE-SME  
Health Insurance Specialist | Division of Kidney Health  
Center for Clinical Standards and Quality (CCSQ)  
CMS

# NPFE-LAN Patient Summit

*Going for the Gold:  
Overcoming Obstacles*

## Insurance: Everything You Need to Know

Kelli Collis Damron, MSW

Marissa Argentina, MSW



# Insurance: Everything You Need to Know

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## 2024: Updates & More

September 24, 2024

Kelli Collins Damron, MSW  
Marissa Argentina, MSW



## AGENDA

# Overview

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- Types of Insurance/Financial Assistance
- Common terms defined
- What you need to know about Medicare
- Original Medicare with a Medicare Supplement or Medicare Advantage Plans
- Immunosuppressant Medicare Coverage
- Questions?



# What are the main types of health insurance?



## Medicaid:

State insurance programs for persons with low income and/ or uninsured children.



## Employer Group Health Plan (EGHP):

Insurance plan offered by your employer.



## Individual Plan

insurance plan you buy in the marketplace through the Affordable Care Act (ACA), or through an insurance broker.



## Medicare

Federal insurance program for people over 65, disabled or with ESRD.

# Medicare Insurance Terms

## ➤ Medicare Supplement (Medigap):

Supplemental insurance policies that people often buy to supplement their Medicare coverage.

## ➤ Medicare Advantage:

A Medicare Advantage Plan is a type of Medicare health plan offered by private insurance companies as an alternative to Original Medicare.

# Common Insurance Terms



## Coinsurance:

Amount you may still need to pay after meeting your deductible. Coinsurance is most often a percent (for example 20%).



## Copayment (copay):

Amount you may have to pay for healthcare or medications. A copay is often a fixed amount (for example \$25).



## Deductible:

Amount you must pay for healthcare or medications before your insurance will pay.



## Out-of-Pocket Maximum:

The most you'll have to pay during a period (usually a year). Once you reach the out-of-pocket maximum your plan pay 100% of covered services.

# Medicaid

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- State run insurance program.
- Must meet income and asset requirements.
- Coverage and eligibility varies by state.
- Programs have different names in each state:  
[www.medicaid.gov](http://www.medicaid.gov)
- You can apply on [healthcare.gov](http://healthcare.gov) for Medicaid and to determine if you are eligible for any subsidies.

# Private Insurance

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- Employer group health plan (EGHP)

# Private Insurance

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- Affordable Care Act (ACA) plans - [healthcare.gov](https://www.healthcare.gov)
- Private plans through an insurance broker

# Medicare

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- Federal entitlement program.
- What does “entitlement” mean?
- When people turn 65 they automatically become eligible if they or their spouse have paid taxes into the system and worked enough hours over the years (work credits).
- Also, persons under 65 who are disabled may qualify.
- People with ESRD are eligible for Medicare due to a special entitlement program.

# What are the Four Parts of Medicare?



**Part A  
Hospital  
Insurance**



**Part B  
Medical  
Insurance**



**Part C Medicare  
Advantage  
Plans, like  
HMOs & PPOs.  
Includes Part A  
& B, usually  
Part D coverage**



**Part D  
Prescription  
Drug  
Coverage**



# Medicare Premium Costs

- **Part A – FREE**
- **Part B – \$174.70/month (2024)** Note: Price may be higher if you have higher income
- **Part D – Patients have a choice of plans with different costs**

**\*\*Medicare Part B covers 80% of the cost of dialysis treatments and transplant immunosuppressant medications\*\***

# When does Medicare coverage start?



## Dialysis:

- In-center hemodialysis
  - 4th month
- Home Dialysis (Home Hemodialysis or Peritoneal)
  - 1st month



## Transplant:

- The month you're admitted to the hospital for a kidney transplant or for healthcare needed prior to a transplant if the transplant takes place within the following two months.

## What if I have private insurance through an employer (EGHP) when I become eligible for Medicare?

- You can apply at any time in the first 30 months without penalty.
- However, if you apply for only Part A and not Part B:
  - you may face a penalty, and
  - can only enroll during general open enrollment period (Jan 1- Mar 31)
  - Part B will be effective in July of the year you apply

Coordination of Benefits (COB) period		
	First 30 months	After 30 months
EGHP	Pays 1 <sup>st</sup>	Pays 2 <sup>nd</sup>
Medicare	Pays 2 <sup>nd</sup>	Pays 1 <sup>st</sup>

# What if I have private insurance through the ACA when I start dialysis?

- You can choose to apply for Medicare **OR** keep your individual plan. **You cannot have Medicare and your ACA plan.**
- There are costs associated with both. NKF's has a worksheet that can help evaluate your costs and coverage with the ACA plan vs Medicare.
- Important to note:
  - If you apply for Medicare you will lose any subsidies you receive from your ACA Marketplace coverage.
  - If you chose not to enroll in Medicare when your kidneys fail, you will have penalties with higher premiums if you chose to enroll later.

# When does Medicare Coverage End?

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**\*\*\*If you're over 65 or you receive Social Security Disability your Medicare coverage will not end.\*\*\***

**If you are eligible for Medicare ONLY because of kidney failure (ESRD), full Medicare coverage ends 36 months after a successful transplant. However, if you have no other insurance, Medicare will continue to pay for your immunosuppressant medication for as long as you have your transplant.**

# Immunosuppressant Medicare Coverage



Immunosuppressants are medications you'll take after transplant.



They are covered under Medicare **Part B** if you had Part A at the time.



Part B only covers 80% of the cost of these medications, so you may need additional insurance to avoid high out of pocket costs.

# Medicare Part D

Prescription Drug coverage

- **You can newly enroll or change plans October 15th - December 7th each year.**
- **Coverage of medications varies by plan, check to make sure your medications are covered before enrolling.**

# Apply for Extra Help

- If you have Medicare and are having trouble paying for your prescriptions, you should apply for "Extra Help" with Medicare Prescription Drug Plan Costs through the Social Security Administration.
- Apply online or call Social Security at 1 (800) 772-1213 or visit your local social security office.
- Extra Help Income and Asset Limits (2024)  
Single \$1,903 and \$17,220  
Couple \$2,575 and \$34,360



# Medicare Supplement (Medigap)

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- Supplemental insurance policies that people often buy to supplement their Medicare coverage.
- *Remember:* Medicare Part B pays 80% of dialysis and immunosuppressant costs.
- Medigap plans cover other 20%.
- Aimed at people over 65 although some states offer policies to those on Medicare who are under 65 as well.
- Contact your State Health Insurance Program (SHIP) to see what is available in your area: [www.shiptacenter.org](http://www.shiptacenter.org)

# Medicare Advantage (MA) Plans

➤ A type of Medicare health plan offered by private insurance companies as an alternative to Original Medicare.

➤ Monthly premiums for MA plans are usually less than Medigap plans

➤ Provides all Part A and Part B benefits can also often offer additional coverage benefits:

- Prescription drug coverage
- Transportation (10 trips/year)
- Dental

# Medicare Advantage (MA) Plans

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- Consider “hidden costs.”  
out of pocket costs including deductibles, co-pays, co-insurance, and lifetime limits.
- In-network vs out-of-network:  
Make sure your preferred healthcare providers (dialysis and transplant centers) are in-network  
May limit your ability to travel.
- If you want to switch back to Original Medicare in the future, you will likely be unable to get a Medigap plan, which could leave you without secondary insurance to pay for the 20% not covered by Original Medicare.

# Medicare Savings Programs (MSP)

MSP	Income Limits *	Asset Limits	Benefit
<b><u>Qualified Medicare Beneficiary (QMB) Program</u></b>	Single \$1,275 Couple \$1,724	Single \$9,430 Couple \$14,130	QMB helps pay Medicare Part A premiums, Medicare Part B premiums, deductibles, coinsurance, and co-payments
<b><u>Specified Low-Income Medicare Beneficiary (SLMB) Program</u></b>	Single \$1,526 Couple \$2,064	Single \$9,430 Couple \$14,130	SLMB helps pay Medicare Part B premiums
<b><u>Qualifying Individual (QI) Program</u></b>	Single \$1,715 Couple \$2,320	Single \$9,430 Couple \$14,130	QI helps pay Medicare Part B premiums
<b><u>Qualified Disabled and Working Individuals (QDWI) Program</u></b>	Single \$5,105 Couple \$6,899	Single \$4,000 Couple \$6,000	QDWI helps pay Medicare Part A premiums

# Insurance and Transplant

- Insurance is required to be eligible for a transplant.
- Transplant centers may want to make sure that your insurance is stable and you will be able to afford your medications, etc. after you receive a transplant.
- If receiving insurance premium coverage through AKF's HIPP program, you are eligible for coverage through AKF after your transplant through the remainder of the coverage plan year. You must have been receiving AKF coverage for at least 3 consecutive months prior to your transplant to be eligible for this continuation of premium coverage.

# Insurance and Living Donation

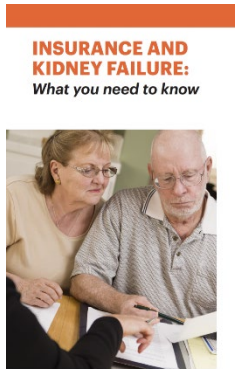
- If you are being worked up to become a living donor, all costs should be covered by the recipient's insurance.
- If you are becoming a non-directed living donor, the up-front costs will be covered by the transplant center.
- However, transplant centers may still require you to have your own insurance even if your insurance is not being used for the evaluation.

# Resources



## National Kidney Foundation

- <https://www.kidney.org/kidney-topics/insurance-options>
- <https://www.kidney.org/kidney-topics/insurance-resources>



## Others

- State Health Insurance Assistance Programs: [shiptacenter.org](http://shiptacenter.org)
- ACA: [healthcare.gov](http://healthcare.gov)
- Medicaid: [medicaid.gov](http://medicaid.gov)
- Medicare: [medicare.gov](http://medicare.gov)
- Medicare and You Handbook
- Medicare and ESRD Handbook
- For new beneficiaries Get started with Medicare: <https://rb.gy/iz3nrm>
- SSA Extra Help: <https://www.ssa.gov/pubs/EN-05-10508.pdf>

T H A N K   Y O U



Image Source: National Kidney Foundation



# Let Us Hear From You

Questions and Answers



# NPFE-LAN Patient Summit

*Going for the Gold:  
Overcoming Obstacles*

## Mental Health

Lori Hartwell

Anthony Peters



NPFE-LAN=National Patient and Family Engagement (NPFE) Learning and Action Network (LAN)



Anthony Peters  
Subject Matter Expert

Lori Hartwell  
Renal Support Network, Founder  
[rsnhope.org](http://rsnhope.org)



# Let Us Hear From You

Pt2

Questions and Answers



# NPFE-LAN Summit

## *Going for the Gold: Overcoming Obstacles*

**Break time.**

**The program will resume at 2:45 p.m. ET**



# NPFE-LAN Patient Summit

*Going for the Gold:  
Overcoming Obstacles*

## Caregiver Self Care Tips

Vernon Silva, LCSW





# Caregiver Self Care Tips

**Vernon Silva, LCSW**

Nephrology Social Worker

Toiyabe Indian Health Project

Bishop, CA



# Acknowledgment

Thank you

ESRD National Coordinating  
Center





# Caregiver Self Care Tips

**Vernon Silva, LCSW**

**Psychotherapist**

**Nephrology  
Social Worker**





# Caregiver Self Care Tips

**Clinical Tips**

**Concrete Tips**





# Disclaimer

**None of the options, recommendations, suggestions should be taken as personal medical advice.**

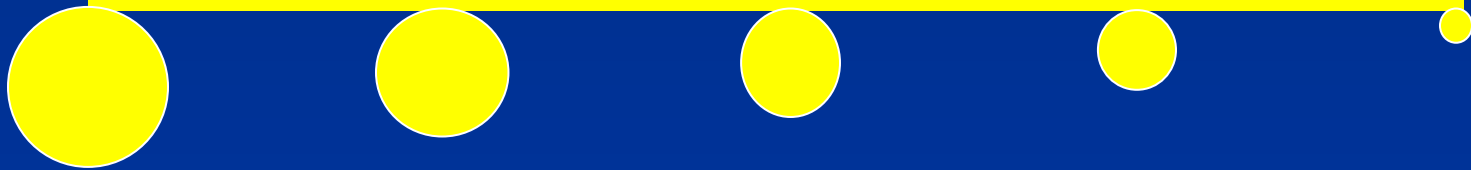
The information provided in this presentation is for educational or informational purposes only and should not be considered a substitute for professional medical advice or consultation with healthcare professionals.



# Caregiver Self Care Tips

Total Embrace

Total Discard



# What's It like to Be a Caregiver?



# What Is a Caregiver?

Care Partner

Caregiver

Caretaker

Helper



# What's It like to Be a Patient?





# What Is a Patient?

Care Partner

Care Receiver



# Caregiver

# Patient

Approximately 1 in 5 Americans is a caregiver, according to the U.S. Department of Health and Human Services.



# Caregiver

# Patient

Most caregivers also have paid jobs in addition to the time they spend helping a friend or loved one.

For some, caregiving is a full-time role.

Caregivers dedicate so much time caring for other people that it can be easy for them to forget to take time for themselves.



# Ways to Care for the Caregiver

## Set aside “me” time

Everyone deserves time for themselves and there's no need to feel guilty about it.

It's important to establish boundaries and to designate this time for yourself.

Whether it is spent reading, at the gym, or listening to music, having “me” time is important.

It allows you to decompress and focus on your own needs, in addition to those of your loved one.



# **Solution-Focused Discussion #1**

**What do I give up as a caregiver?**

**What do I sacrifice as a caregiver?**

Health – gym/exercise, social life,  
emotional eating, sleep



# **Solution-Focused Discussion #1**

**What do I gain as a caregiver?**

**What do I acquire as a caregiver?**

Relationship – affection, sense of family,  
appreciation for partner role

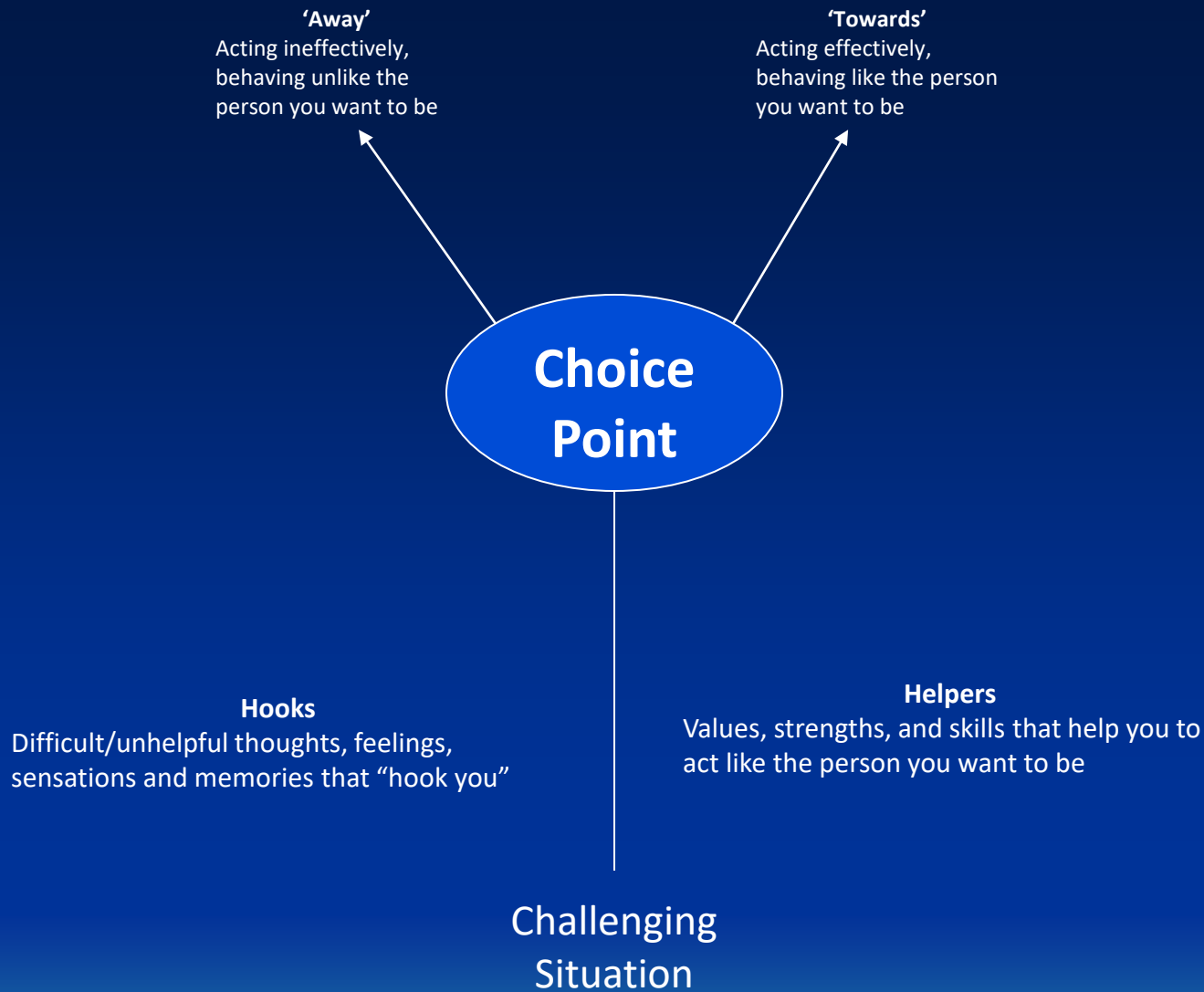


# Acceptance & Commitment Theory



Choice Point





**At the choice point, STOP:**

**S**-Slow down. Slowly breath, press your feet down, or stretch

**T**-Take note-Notice what you are feeling & thinking. Notice the work around you & what you are doing.

**O**-Open up. Make space for your thoughts & feelings. Allow them to freely flow through you

**P**-Pursue values. Remember your values, and find a way to act on them (no matter how small)



# Ways to Care for the Caregiver

## Do something to relieve stress

Take a walk.

Write in a journal.

Everyone releases stress differently, but do what works for you.

People with kidney disease can also get fit and relieve stress through exercise.



# **Solution-Focused Discussion #2**

**How am I coping as a caregiver?**

**How am I holding up as a caregiver?**

Mental Health – sense of purpose, anxiety,  
grief / low spirits



# PHQ-9

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
<b>Depression Screening</b>				
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
<b>PHQ-2 Depression Assessment</b>				
3. Feeling nervous, anxious, or on edge	0	1	2	3
4. Not being able to stop or control worrying	0	1	2	3
5. Worrying too much about different things	0	1	2	3
6. Trouble relaxing	0	1	2	3
7. Being so restless that it is hard to sit still	0	1	2	3
8. Becoming easily annoyed or irritable	0	1	2	3
9. Feeling afraid, as if something awful might happen	0	1	2	3
10. If you check any of these problems how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	0	1	2	3
0-Not difficult difficult	1-Somewhat difficult			
2-Very difficult difficult	3-Extremely difficult			

# PHQ-9 Scoring

Total Score	Depression Severity
1-4	Minimal depression
5-9	Mild depression
10-14	Moderate depression
15-19	Moderately severe depression
19-27	Severe depression

# GAD-7

Over the last two weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid, as if something awful might happen	0	1	2	3

Column totals \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_ =

Total score \_\_\_\_\_

GAD = General Anxiety Disorder

# GAD-7 Scoring

**0-5: Mild anxiety**

**6-10: Moderate anxiety**

**11-15: Moderately severe anxiety**

**15-21: Severe anxiety**

# Ways to Care for the Caregiver

## Do something to relieve stress

Caregivers aren't invincible. They can also get sick and it's important to keep healthy or it will be difficult to care for someone else. Be careful to not take care of another's health needs to the detriment of your own emotional and physical health.

Listen to your body for cues. Eat meals sitting down rather than on the go, and aim to get 6-8 hours of sleep each night. Schedule regular check-ups and be sure to see your own doctors.



# Solution-Focused Discussion #3

What is my attitude as a caregiver?

What is my mindset as a caregiver?

Self-Regulation – thinking negatively, being reactive vs proactive





# Cognitive Behavioral Theory

- ★ CBT Algorithm
- ★ “Action Precedes Motivation”
- ★ Behavioral Activation

Get outside into the air / sunlight / light

Move forward in space



# Ways to Care for the Caregiver

## Accept others' offers to help and ask for help when you need it

Remember that you don't have to do it all, all of the time. Perhaps other people are willing to help but may not know how to help or even how to offer. Speak up when you're in need and give people specific tasks to assist you, even if this just means letting someone else drive your loved one to a dialysis treatment or a medical appointment.

Additionally, there may be organizations that help with transportation, personal care, respite and meals. You can speak with your dialysis clinic social worker for more information about the resources in your area.



# Refueling

- ★ Get a massage, manicure / pedicure, facial
- ★ Sleep
- ★ Rest, lounge
- ★ Treats
- ★ Bath, soak feet
- ★ Hair done / haircut



# Ways to Care for the Caregiver

## Connect with others who understand what you are experiencing

You're not alone. There are support groups that exist to connect caregivers with other caregivers. Some of these meet in person while others take place online or over the phone to form a community of individuals who understand one another's situations.

You can also speak with a friend, clergy member, or therapist for more one-on-one support.



# Resource

## Caregiver's Path Compassionate Decision Making by Viki Kind, MD

Guides caregivers in making care and living decisions for others who can no longer express their wishes.



# Questions





# Thank you!

**Vernon Silva, LCSW**

vernonsilva2@yahoo.com

(415) 320-4517



# Let Us Hear From You

Pt.3

Questions and Answers





# NPFE-LAN Patient Summit

*Going for the Gold:  
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## Advancing Health Equity— Supporting Patient Activation for Better Health

Chiao Wen Lan, PhD

Ken Teasley

Sarah Ruiz



# NPFE-LAN Health Equity Committee Work

The ESRD NCC, in collaboration with the CMS Office of Minority Health (OMH):

- Has developed a patient and family health equity committee.
  - We identify and discuss social determinants of health that affect the ESRD community.
  - Create health equity educational resources for patients and dialysis staff.
  - Support dialysis facilities and transplant centers with programs that advance health equity and that have reduced disparities.

# NPFE-LAN Health Equity Committee Resource

## What Is Person-First Language?

Person-first language emphasizes the **person** and views the condition a person has as **only one part of the whole person**.

For example, **a person with diabetes** not a diabetic.



## Contact Us

Email: [npfelan@hsag.com](mailto:npfelan@hsag.com)

Website: [www.esrdncc.org](http://www.esrdncc.org)



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FL-ESRD NCC-NC3PFE-01242024-01



The words we use can make a big difference in how someone feels. Being mindful of the words we use is the first step in changing the culture. Use this list to start a conversation around destigmatizing language with your friends, family, and care team.



## Examples

Instead of failed treatment...

Use **the treatment was not effective in the patient** or **the patient did not respond to treatment**.

Instead of homeless people...

Use **persons who are unhoused**, or **persons without an address**.

Instead of addicts/drug abusers...

Use **persons with substance use disorder**, **persons who use drugs**, or **persons who returned to use**.

## Examples

Instead of caretaker...

Use **caregiver** or **care partner**.

Instead of crazy, insane, mental defect...

Use **persons with a mental illness**, or **persons with a diagnosis of mental health disorder**.

Instead of rural people...

Use **residents of rural areas** or **persons who live in sparsely populated areas**.



Tri-fold brochure available on our website in English, Spanish, and large print.  
<https://esrdncc.org/en/patients/national-patient-and-family-engagement-lan-npfe-lan/>

# Patient Activation and Empowerment

## Patient Activation

Patients' **knowledge, skill, and confidence** to manage their health and healthcare

## Patient Empowerment

Patients' self-efficacy and capacity to make **informed decisions** about their healthcare



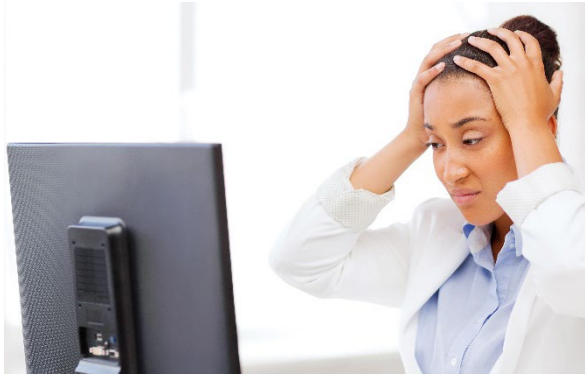
## Focus on Patient Engagement

CMS. Gains in Patient Activation Measure (PAM) Scores at 12 Months. Accessed on Aug 8, 2024. Available at [https://qpp.cms.gov/docs/QPP\\_quality\\_measure\\_specifications/CQM-Measures/2024\\_Measure\\_503\\_MIPSCQM.pdf](https://qpp.cms.gov/docs/QPP_quality_measure_specifications/CQM-Measures/2024_Measure_503_MIPSCQM.pdf). Parker J, Regan J, Petroski J. Beneficiary activation in the Medicare population. *MMRR*. 2014; 4:E1–E14.

# Activated Patients Are Confident to Manage Their Health

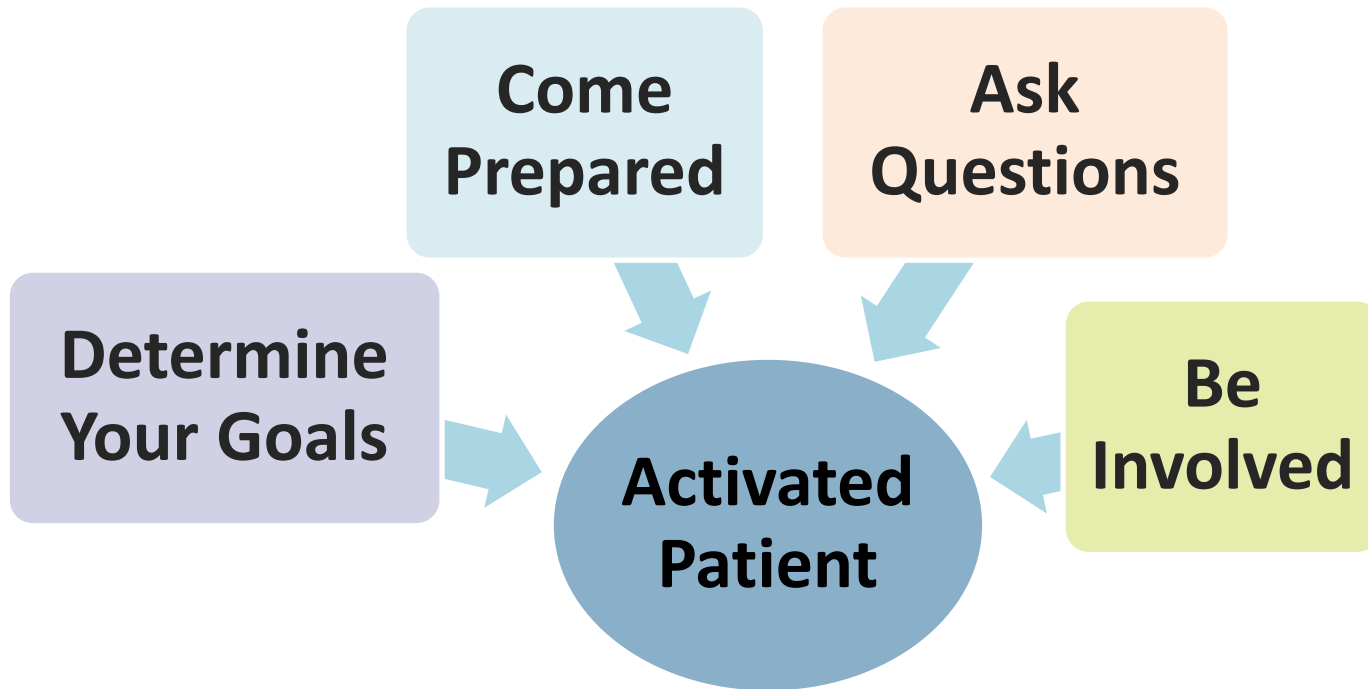


# Common Patient Activation and Engagement Challenges



# Ways to Become an Activated Patient

## Action Steps



# What Providers Can Do to Support Patient Activation

## Action Steps

**Provide Education Based on How Activated the Patient Is**

**Use Motivational Interviewing and Coaching**

**Encourage Self-Management Training, Goal Setting, and Peer Mentoring**

**Be Supportive, Offer Options, and Take Time to Build Trust**

Hussein W, Bennett P, Abra G, et al. Integrating Patient Activation Into Dialysis Care. *American Journal of Kidney Diseases*. 2022; 79(1): 105–112. Accessed on July 23, 2024.



# Panel Discussion



# Speakers



Ken Teasley



Sarah Ruiz

# How Do You Become an Activated Patient?



# How Do You Stay Actively Engaged in Your Care?



# Questions & Answers




# Let Us Hear From You


Pt.4

Questions and Answers

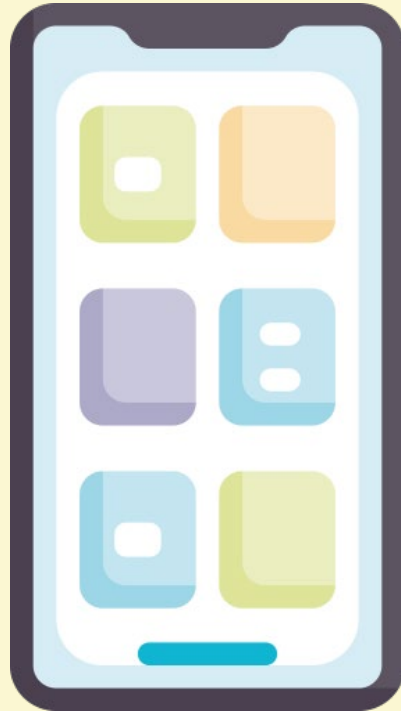


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- Use event hashtags on Instagram, X, and Facebook.
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# Thank You



## Complete the Post-Event Evaluation:

- 1) Open the camera on your cell phone
- 2) Point and scan QR code
- 3) Access link and complete post-event evaluation

All attendees will receive an email with the evaluation link and CEU information immediately following this call.

Contact [NCCInfo@hsag.com](mailto:NCCInfo@hsag.com) if you need assistance

