# Using “Ask-Tell-Ask” in Person-Centered Care

Promoting goals of care conversations with
dialysis patients and their families during COVID-19

PATHWAYS Project

nursing.gwu.edu/pathways-project

Coalition for Supportive Care of Kidney Patients

kidneysupportivecare.org

# How to implement the "Ask-Tell-Ask" approach to goals of care talks during COVID-19

## Simple ways to help patients with kidney disease say what they would want if they got sicker

## Three topics:

| | | |
|---|---|---|
| Why "Don't Ask, Don't Tell" isn't working | The "Ask-Tell-Ask" framework | Documenting patient wishes to make them actionable |

# **Pre–pandemic:** Few Conversations; High Intensity Care

Kurella Tamura M, et al. Advance Directives and End-of-Life Care among Nursing Home Residents Receiving Maintenance Dialysis. *Clin J Am Soc Nephrol*. 2017.

## Patients waited for clinician to initiate

- Patients expected physician to bring it up
- Did not want to disappoint by not being “hopeful”
- May have completed forms with lawyer, but not brought them to clinic

## But, clinicians didn’t initiate

- No time
- Afraid of upsetting patients
- Didn’t know skillful approaches

# “Don’t Ask, Don’t Tell” not effective because:

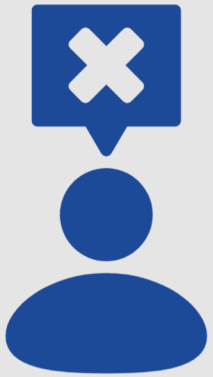
Patients have diverse goals and values

Clinicians think they know what patients want, but they are wrong most of the time!

# Patients with CKD & ESKD vary in their values

Baddour NA, et al. Serious Illness Treatment Preferences for Older Adults with Advanced CKD. *JASN.* 2019.

# But, clinicians did not know what patients with ESKD wanted

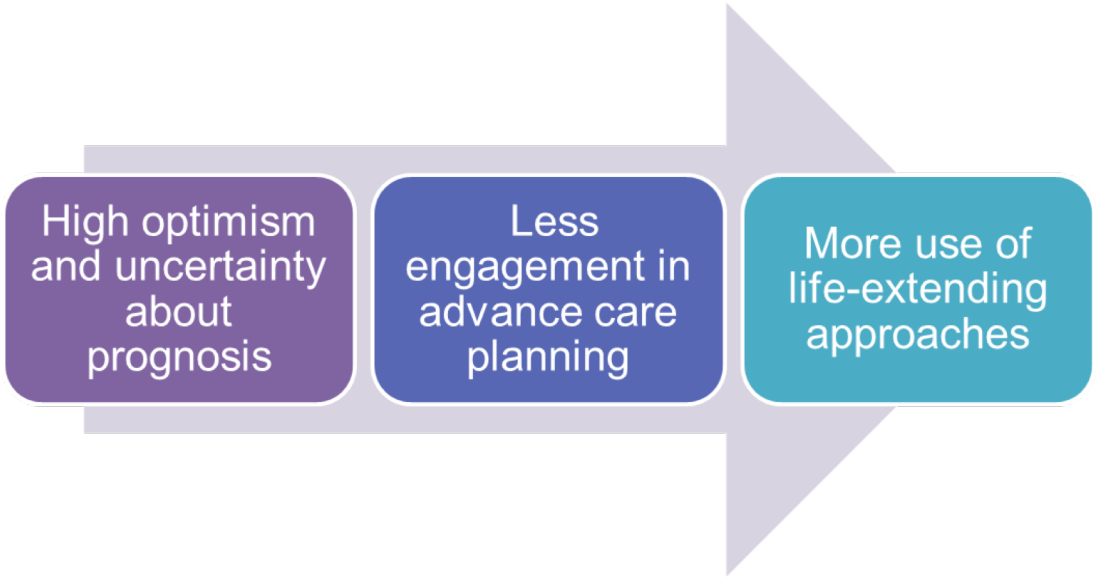


- Clinician's perceptions of their patients' priorities were **wrong 65% of the time**.
- 271 older patients with stage 4 or 5 chronic kidney disease rated **top health priority:**
  - Maintain independence (49%)
  - Stay alive (35%)
  - Reduce pain (9%)
  - Reduce other symptoms (6%)

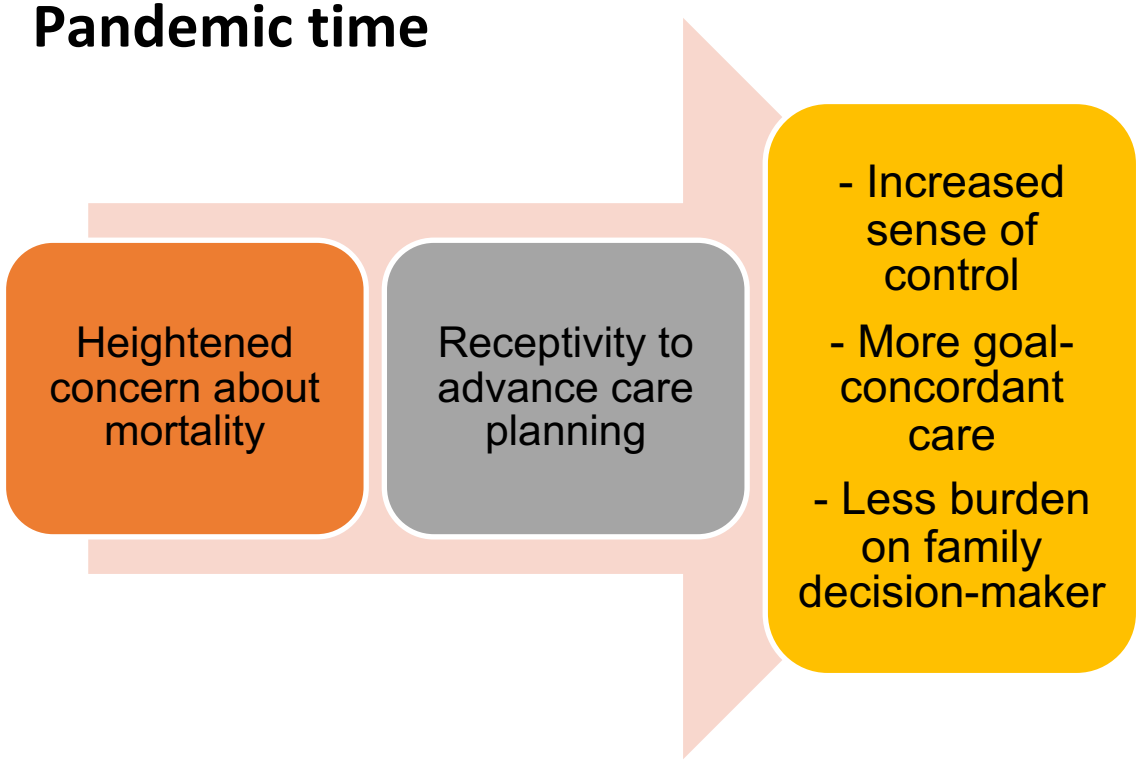
Ramer SJ, et al. Health Outcome Priorities of Older Adults with Advanced CKD and Concordance with Their Nephrology Providers' Perceptions. *JASN*. 2018.

# Pandemic heightens patient concerns about what will happen to them if they get sicker

**Usual times***




**Pandemic time**



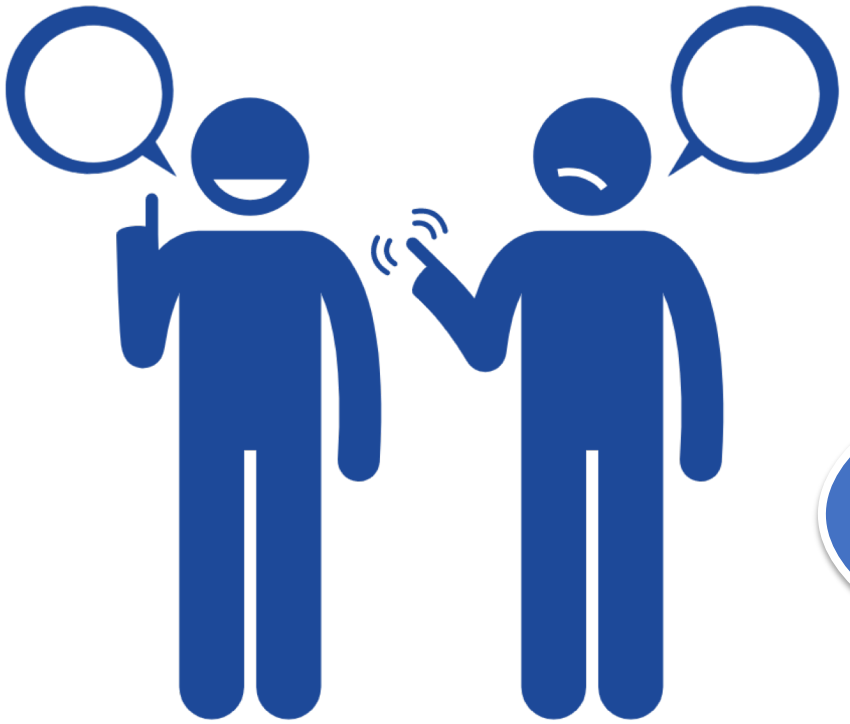

* O'Hare AM. Prognostic Expectations of Survey Participants & Actuarial Survival Among Prevalent US In-center HD Patients *JAMA Intern Med*. 2019;179(10):1325-1333.

# Clinicians need to take the lead

Use “Ask-Tell-Ask” approach to open a conversation about what a patient values, is concerned about

Even if you *think* you know, COVID-19 situation may have changed patients’ concerns and priorities

# Match the value statement to the person



"I know I can't be maintained by dialysis forever, but I never imagined an infection like COVID-19 could end my life so quickly. I'm not ready to call it quits. I want to do everything to fight to have a few more years with my family."

"I'm so tired. I've already been to the hospital four times this year. I don't want to go back – especially with COVID-19. If it's my time, then it's my time. I would rather be with my family when the time comes."

# ASK-TELL-ASK

## ASK

- ✓ Understanding of situation
- ✓ Concerns
- ✓ Values – what is most important
- ✓ Who patient chooses to speak for them in future if needed

## TELL

- ✓ Likely future complications
- ✓ Prognosis
- ✓ Information about possible future interventions such as ventilator and CPR
- ✓ **Explore** again to elicit concerns, understanding of effectiveness of treatments, values for what is important in future circumstances

## ASK

- ✓ “What questions do you have?”
- ✓ Understanding of conversation
- ✓ What plan to discuss with family

# ASK – about understanding, values, concerns

- Start by assessing patient's understanding and concerns about the **current** situation.
- This strengthens relationship.

"What is most important to you in receiving treatment if you get sicker?"
PAUSE
"What do you hope for?"
PAUSE
"What would you most want to avoid?"
PAUSE

"What is your understanding of your health now? How serious is it?"
PAUSE
"How are you doing compared to a year ago?"

# Ask – about decision-maker

- Establish preferred healthcare decision-maker

"Who would you want to make medical decisions for you if you couldn't speak for yourself?"

- To the decision-maker

"What are you thinking about your role as healthcare decision-maker?"

# TELL

- Give information related to worries patient raised earlier.
- Give information in small chunks.

"You said you were worried that if you got COVID-19 you would die."
PAUSE.
"What we are learning is that COVID-19 is indeed serious for people with kidney disease. Yet MOST dialysis patients who go to the hospital with COVID-19 have survived."*
PAUSE.

"However, the recovery after leaving the hospital may be long. What questions do you have about what might happen?"
PAUSE.

*adjust statement to experience in your practice, individual patient condition, and as evidence evolves

# Another TELL – for different patient, other concerns

"You said you really don't want to go back to the hospital, even if it gets hard for you to breathe."
PAUSE.
"There are medicines we can use while you are at home to make you feel more comfortable if it becomes hard to breathe from an infection."
PAUSE.

"Having a hospice program bring those medicines to you at home would help you stay out of the hospital and keep comfortable."
PAUSE.
"Does that sound like what you would want if you were to get sicker?"

# TELL

- Discuss common future complications and choices

"In my experience, and in what the medical community is learning about the COVID-19 virus, it may be hard on people whose kidneys already don't work well. Some need to use breathing machines. Have you been on a breathing machine or known anyone who has used one?"
PAUSE.

"COVID-19 may be hard on the body. If a person's heart stops, some want an attempt to restart the heart, called CPR. Unfortunately, CPR is not as successful as most people think. What would you like to know about CPR for people who are seriously ill?"
PAUSE.

# Explore

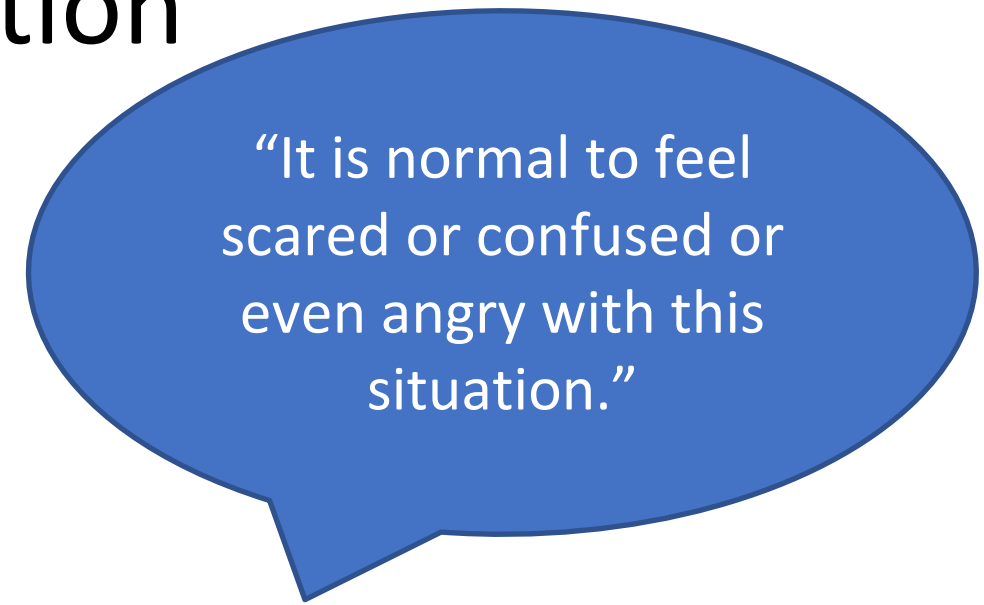
- What might make them want to stop dialysis?

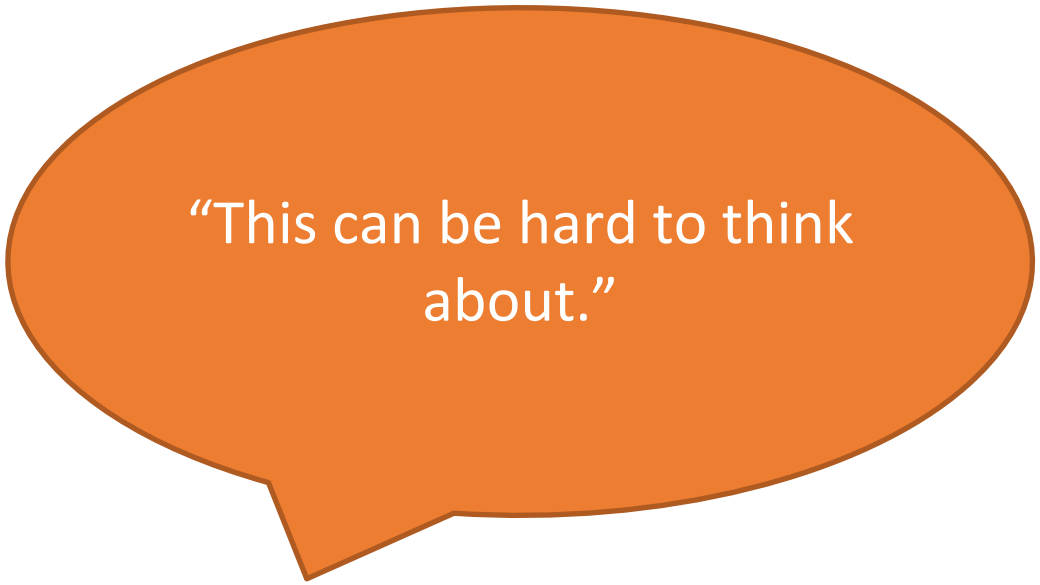
"Under what circumstances, if any, would you want to stop dialysis?"

"Many people say they would not want to keep going with dialysis if they couldn't talk, for instance, if they had a major stroke or severe dementia. What do you think?"

# During TELL – expect emotion

- In the PAUSE – look for emotion and respond to emotion
  - name the emotion
  - normalize the emotion




- People cannot take in new information while they are in the grip of a strong emotion.
- Giving permission and space for the emotion helps people feel supported. This eventually allows them to process information better.

# Ask – questions about implementing plan

"What questions do you have now?"

"So that I can make sure I did a good job explaining, please tell me in your own words what you understand from our conversation."

"What will you tell your family about what we have discussed?"

# Document discussion to ensure respect for patient wishes

POLST/MOLST form

Notes in medical record

Completion of advance directive

# POLST/MOLST

POLST: medical orders to implement patient wishes across settings

POLST appropriate for many patients on dialysis

POLST resources during COVID-19:
https://polst.org/covid/

# Notes in medical record

Even very brief note helpful to clinicians and family to document patient preferences for future care

Establish consistent PLACE in your record to record these notes

Quote patient's own words on values, what's important

# Suggested template for goals of care note

- An advance care planning face-to-face discussion was held with PATIENT NAME and family/friends *** in which advance care planning was explained, the patient's values and goals of care were elicited, and the patient's choice for a decision-maker in the event of loss of decision-making capacity were discussed.
- The patient named *** to be medical power of attorney representative and *** to be medical power of attorney successor representative. A living will was described to the patient and the patient chose to complete/not complete one.
- Patient said *** (quote from patient) is most important consideration now.
- Because of the patient's advanced illness, a POLST form was offered which the patient chose to complete/not complete. The duration of the advance care planning discussion and completion of any forms does not include OR overlap with time spent on any other component of this encounter.
- Total time of face-to-face counseling for advance care planning:  *** minutes
- Can bill 99497 for first 16-30 minutes of advance care planning

# Some of the Barriers

No time!!!!!!!

PPE gets in the way of talking

No private space in dialysis center

# Possible work-arounds

Consider:

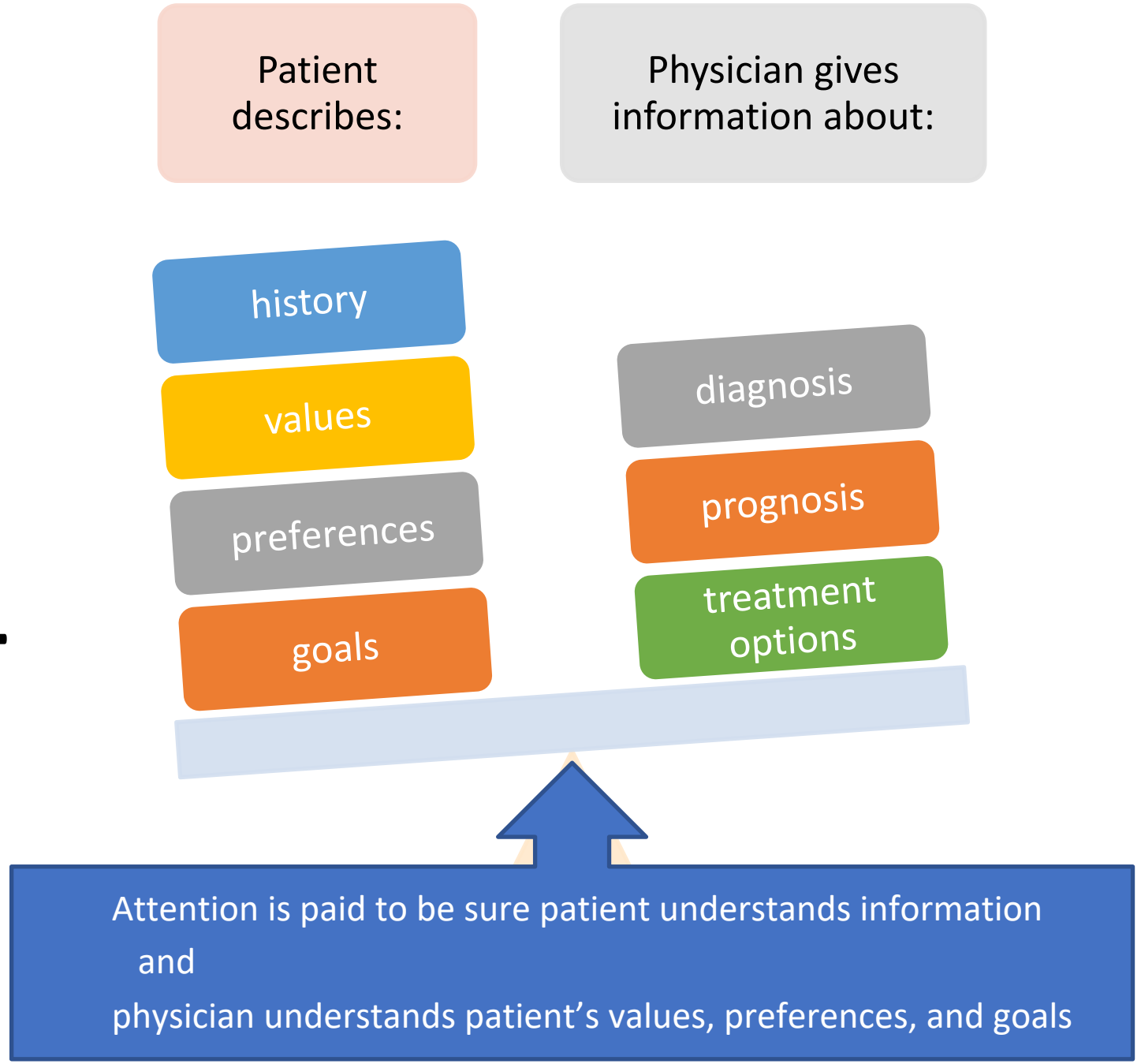
- Using telehealth
- Social workers in dialysis center take proactive role
- Use isolation room for private chairside conversation, if available

# Encourage patient to complete advance directive

"Everyone should have an advance directive, not just people who are sick.
It is a great gift to your family. It reassures them and relieves them of guilt if they need to make difficult decisions."

Patient-friendly documents for every state and many languages available from https://prepareforyourcare.org/welcome

# Summary:
# Ask – Tell – Ask fosters true shared decision-making



# More resources for goals of care conversations in the dialysis center during COVID-19

Ask-Tell-Ask pocket guide from Coalition for Supportive Care of Kidney Patients
https://go.gwu.edu/asktellask

National POLST COVID-19 resource page:
https://polst.org/covid/

Mandel EI, Bernacki RE, Block SD. Serious Illness Conversations in ESRD. *Clin J Am Soc Nephrol*. 2017;12(5):854–863. doi:10.2215/CJN.05760516

Back A, Tulsky JA, Arnold RM. Communication Skills in the Age of COVID-19. *Ann Intern Med*. April 2020. doi:10.7326/M20-1376

Vital Talk COVID-ready communication skills: **A playbook of VitalTalk Tips**

- This is excellent. Gives you the words to say in very difficult situations.
- https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0KmXIgaGKohl7SoeY2UXQ/edit

# Let us know what other communication and emotional dilemmas you are facing during COVID-19 Pandemic

Call 202.994.7969, Email kidneycoalition@gwu.edu, Tweet @kidneycoalition

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