DPC EDUCATION CENTER

MY WAY: Make Your Wishes About You
How to speak up to get the healthcare you want - now and in the future

This webinar will start shortly

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Today’s Presenters

- Dale Lupu, MPH PHD
- George Washington University

- Elizabeth Anderson, DSW, LCSW
- Western Carolina University

On behalf of

Coalition for Supportive Care of Kidney Patients

https://www.kidneysupportivecare.org/

Key points

- What is advance care planning and what are its benefits?
    - (Hint: control over your health care in the future, if you can't speak for yourself.)
- What is shared-decision making and why is it important?
    - (Hint: Helps you get the health care that best fits YOU.)
- What are common barriers to advance care planning?
- What are common barriers to shared decision making?
- How to leap over, tunnel under, or go around those barriers

How we arrived here

- COVID-19
- Concerns about future healthcare
  - What if I am alone at the hospital?
  - What if I can’t speak for myself?
- Avoiding surprises

Which response best describes you?

a. I have **no idea** what advance care planning is

b. I’ve **heard of** advance care planning

c. I **know** what advance care planning is

d. I am an advance care planning **nerd.**

Which response best describes you?

A. I HAVE **NO IDEA** WHAT SHARED-DECISION MAKING MEANS

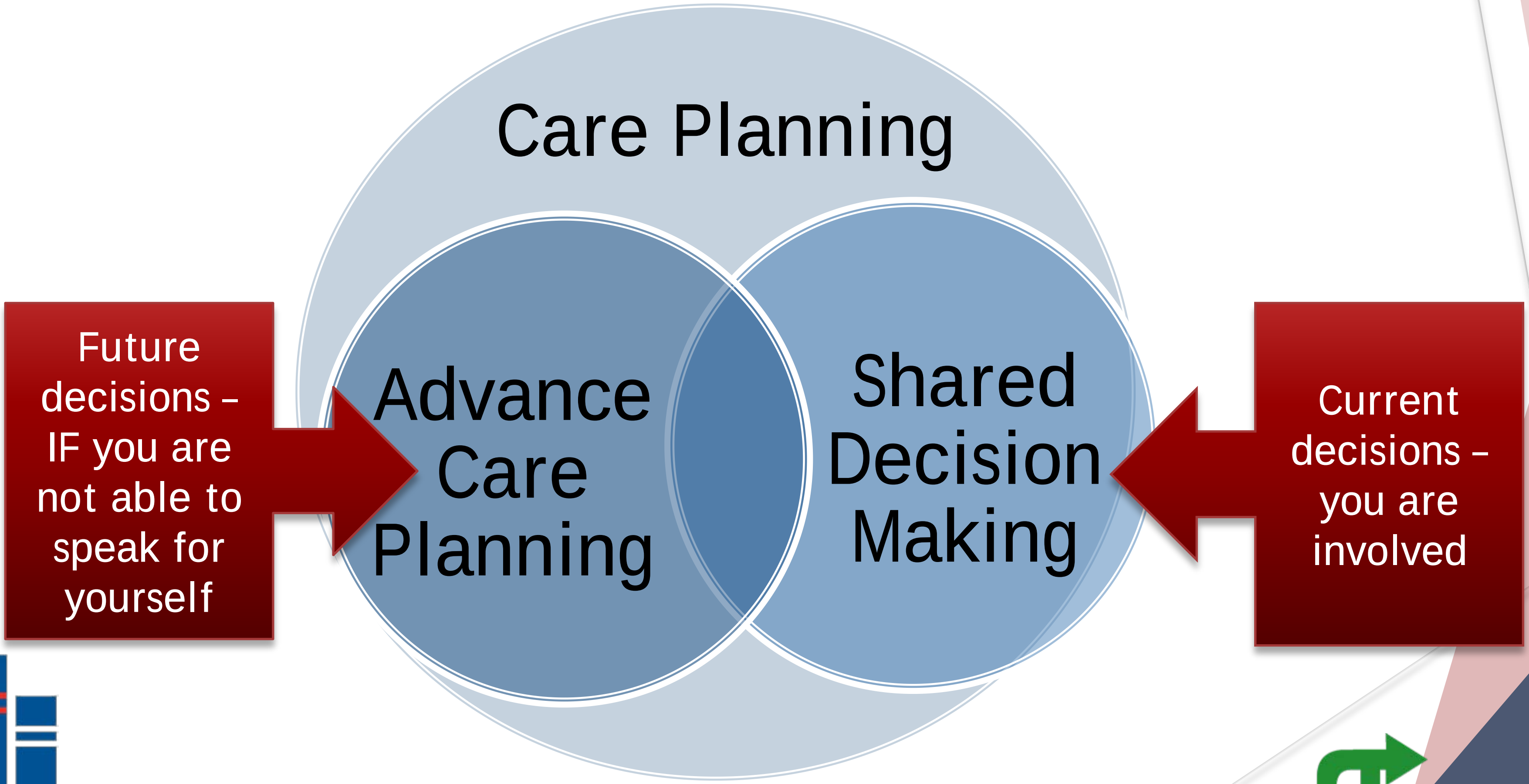
B. I HAVE **HEARD OF** SHARED-DECISION MAKING

C. I **KNOW** WHAT SHARED-DECISION MAKING IS

D. I ENGAGE IN SHARED-DECISION MAKING **ALL THE TIME**!

What's the difference?

Advance Care Planning vs. Shared-Decision Making



Care Planning

Advance Care Planning

Shared Decision Making

Future decisions – IF you are not able to speak for yourself

Current decisions – you are involved

Which of the following best describes you?

- I want control of my healthcare even when I can’t speak for myself.
- I want to have a say in my healthcare decisions.
- I don’t want to have to wonder about my future healthcare.
- I want to show love to my family by speaking up about what I want in my healthcare.
    - Massachusetts Coalition for Serious Illness Care

MY WAY

Make Your Wishes About You

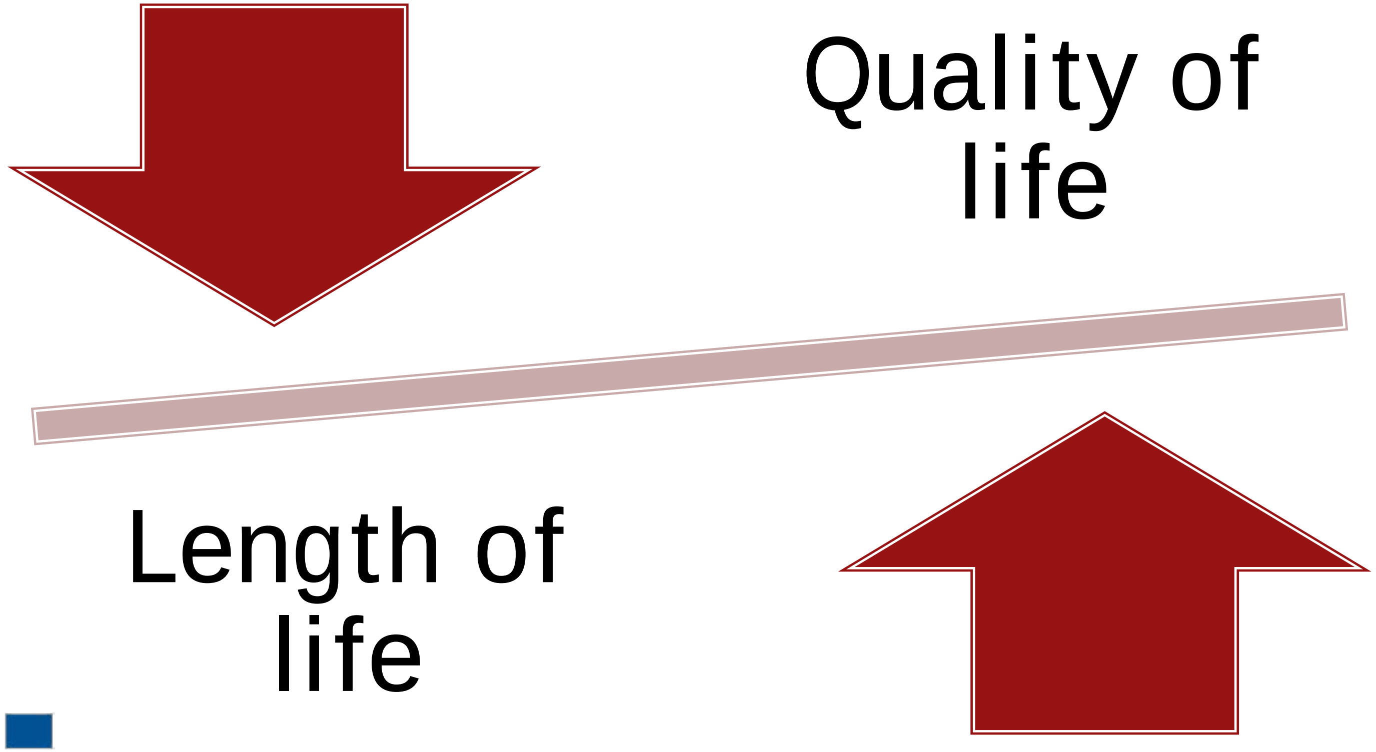
- Normalize ACP – everyone should have a plan!
- 5-step approach
- Your values & preferences, not a list of do/don't of specific interventions
- NOT the same as decision-making about dialysis or no, or preferred form of dialysis

Anderson, E., Aldous, A., & Lupu, D. (2018). Make Your Wishes About You (MY WAY): Using motivational interviewing to foster advance care planning for patients with chronic kidney disease. Nephrology Nursing Journal, 45(5), 411-421.

STEPS IN ADVANCE CARE PLANNING

Choose	Choose who you want to make your healthcare decisions if you cannot speak for yourself.
Think about	Think about what kind of healthcare you would want if you were unlikely to get better. Discuss your wishes with your family and friends.
Write	Write your wishes down in a legal form, known as an advance directive (sometimes called a “living will”).
Give	Give a copy of your advance directive to your healthcare agent and your kidney care team.
Discuss	Discuss with your kidney care team when a medical order form (usually called POLST or MOLST) might be right for you.

The BIG picture



Quality of life

Length of life

If you got so sick you couldn’t do most of what you like to do

What would you want if you were very sick and not likely to get better?

- “I want treatments to try to stay alive as long as possible, even if there is little hope of getting better and no matter how much pain or discomfort the care involves.”
- “I want to try out treatments for a period of time, but not stay on them if there is little hope of getting better or living a life I value.”
- “I want to be as comfortable as possible, even if it might mean not living as long.”
- “I’m not sure.”

Write your wishes down

- Advance care planning forms for your state: YOU complete this (with help)
  - PREPARE. https://prepareforyourcare.org/welcome
- POLST or MOLST form for your state: Your provider completes this with you
  - https://polst.org/starting-polst/

SHARED DECISION-MAKING

People want a patient-centered experience.

- 8 in 10 people want their clinician to listen to them.
- 8 in 10 people want to hear the full truth about their diagnosis.
- 7 in 10 people want to understand the risks of treatments.

But there is a gap between what people want and what the experience in their care.

- 8 in 10 people want their health care provider to listen to them, but just 6 in 10 say it actually happens.
- Fewer than half of people say their clinician asks about their goals and concerns for their health and health care.

Source: Alston, C. et al. 2012. Communicating with Patients on Health Care Evidence. *NAM Perspectives.* Discussion Paper, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/201209d cited in
Alston, C., et al. 2014. Shared Decision-Making Strategies for Best Care: Patient Decision Aids. *NAM Perspectives.* Discussion Paper, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/201409f

Making medical decisions

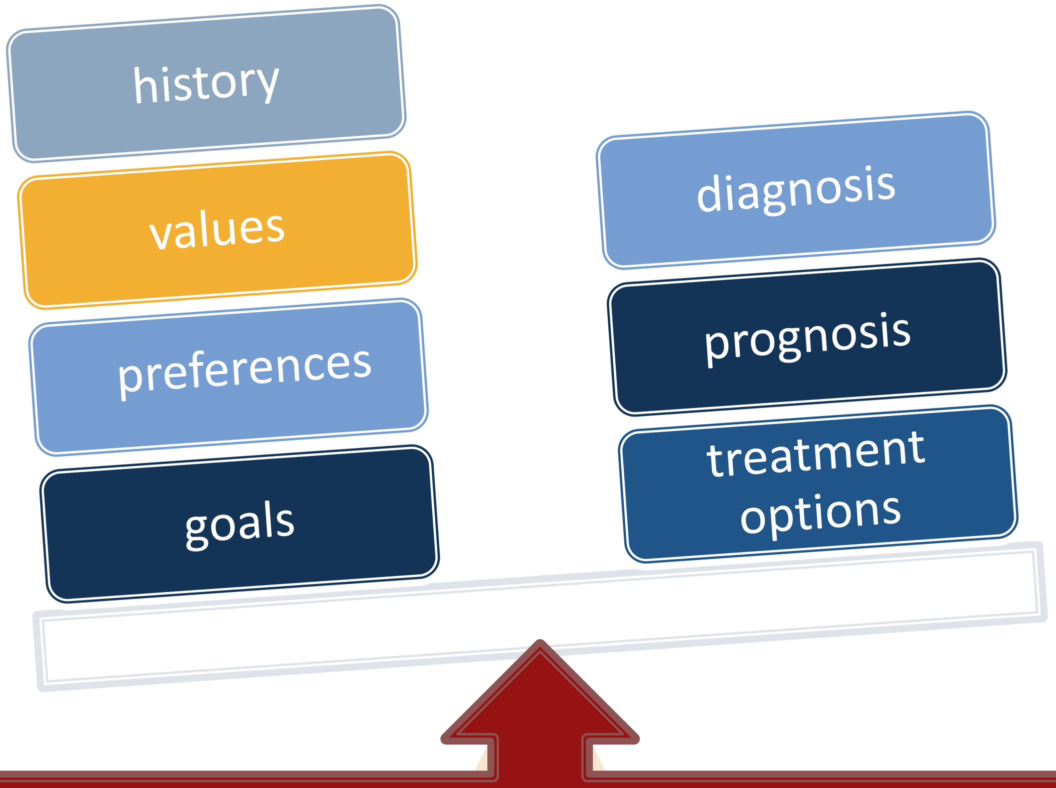
Old model:

- Doctor decides what is best

New model:

- Doctor and patient decide together

Shared decision making



Patient describes:

- history
- values
- preferences
- goals

Physician gives information about:

- diagnosis
- prognosis
- treatment options

Attention is paid to be sure patient understands information

and

physician understands patient's values, preferences, and goals

What are barriers to advance care planning & shared decision making?

Which barriers do you find the most challenging?

- I feel like the healthcare providers don’t share everything I need to know
- I’ve had negative conversations about this topic with other family members and I don’t feel comfortable bringing it up.
- I am afraid that if I bring this up, the healthcare providers will feel like I am stepping on their toes or being offensive.
- I am worried that I will get emotional or that my family members will be emotional.

Assertively asking for help when on dialysis

- You are your best advocate! It is important to be confident in asserting your needs to staff. Assertive communication is HARD, but important.
  - **H**onest
  - **A**ppropriate
  - **R**espectful
  - **D**irect

I feel X	When you do Y	In situation Z	And I would like *
I feel anxious	when the staff don't wear masks	when they are cannulating me and sneezing.	I would like it if staff would wear masks all the time.
I feel upset	when I see other patients	That are coming into dialysis sick.	I would like it if there was a rule about dialyzing when sick.

Hunter, C. L., Goodie, J. L., Oordt, M. S., & Dobmeyer, A. C. (2009). *Integrated behavioral health in primary care: Step-by-step guidance for assessment and intervention*. American Psychological Association.

Recommended resources

Coalition for Supportive Care of Kidney Patients

- https://www.kidneysupportivecare.org/

MY WAY: Make Your Wishes About You

- https://www.kidneysupportivecare.org/advanced-care-planning/

PREPARE for your care

https://prepareforyourcare.org/welcome

POLST patient site

https://polst.org/starting-polst/

Questions?

Please use the Chat Box

Thank You for Attending Today!

Please complete the Feedback Form

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