

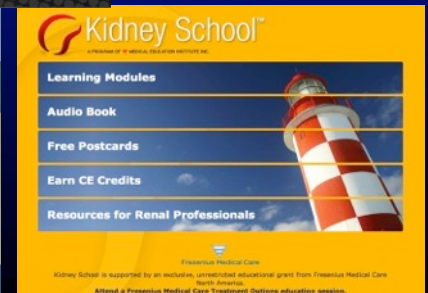
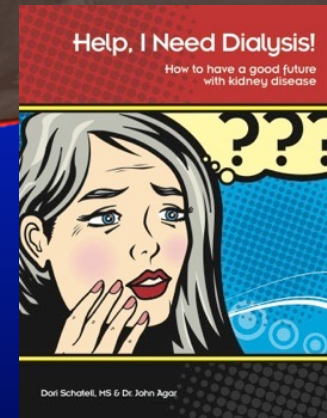
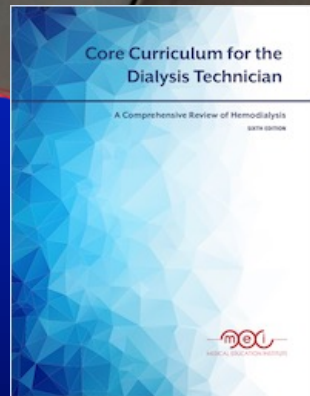


MEDICAL EDUCATION INSTITUTE

Patients' Kidney Life Plan: Values-based Treatment Matcher

Dori Schatell, MS

MEI Mission: *Help people with chronic disease learn to manage and improve their health.*



What We'll Cover:

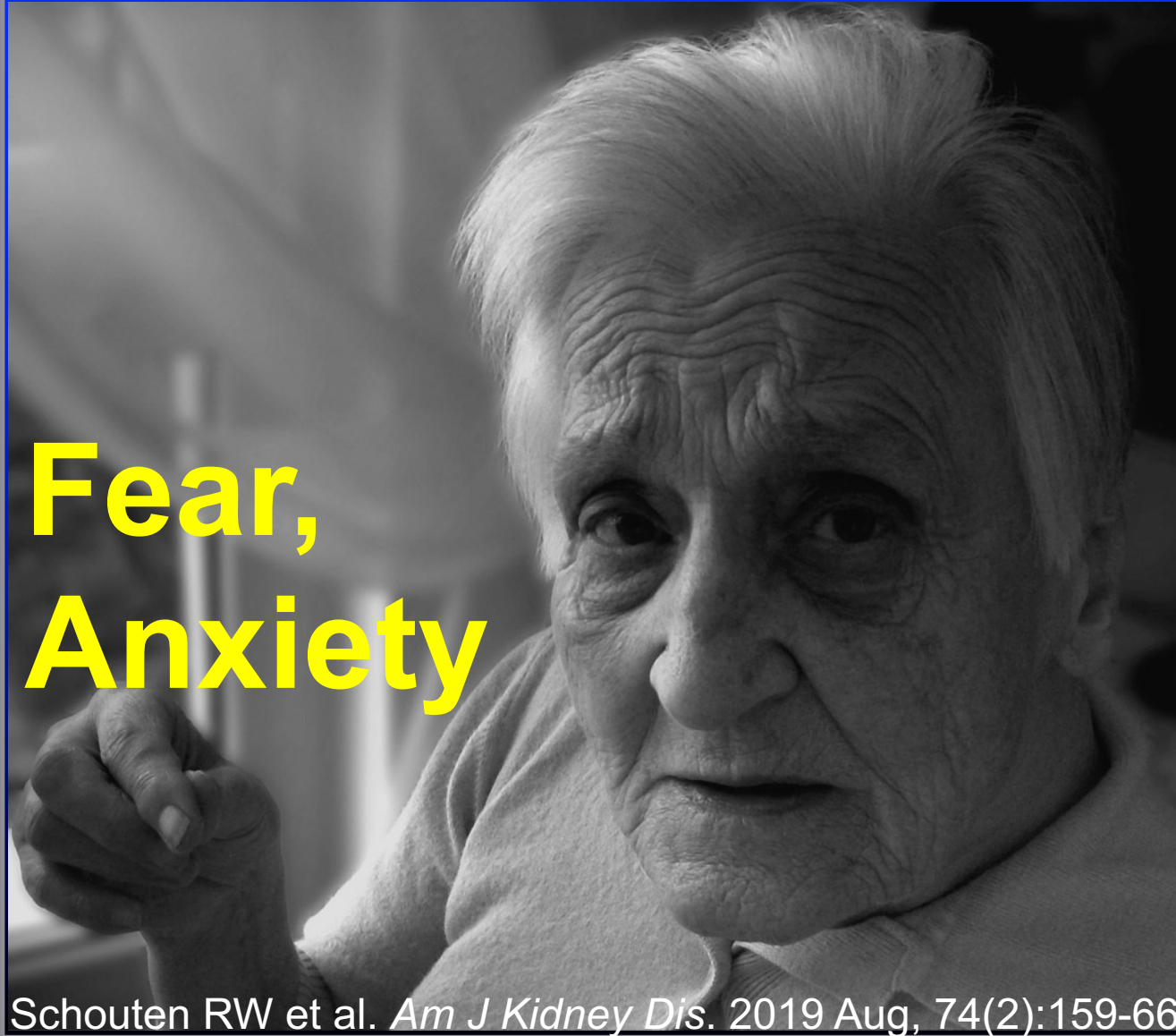
- ✳ Fear as a barrier to ESKD treatment choice
- ✳ Benefits of an evidence-based decision aid
- ✳ How to use My Kidney Life Plan

Fear as a Barrier to ESKD Treatment Choice

Kidney Failure: a Personal Tsunami



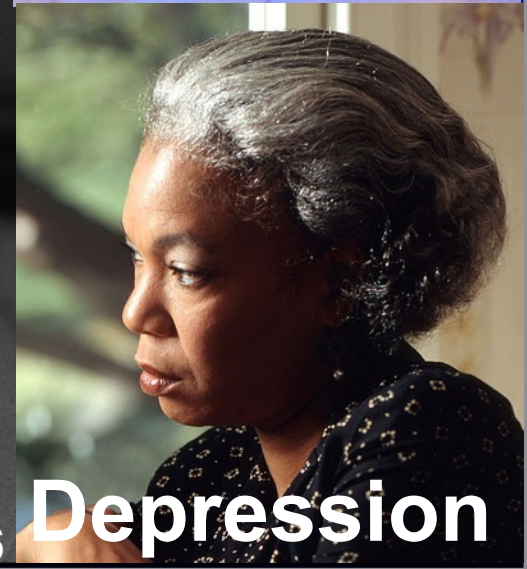
Strong Emotions Are Normal



**Fear,
Anxiety**



Anger



Depression



Fear of a Life that is Not Worth Living

ESKD Treatment Affects *Every* Part of Life

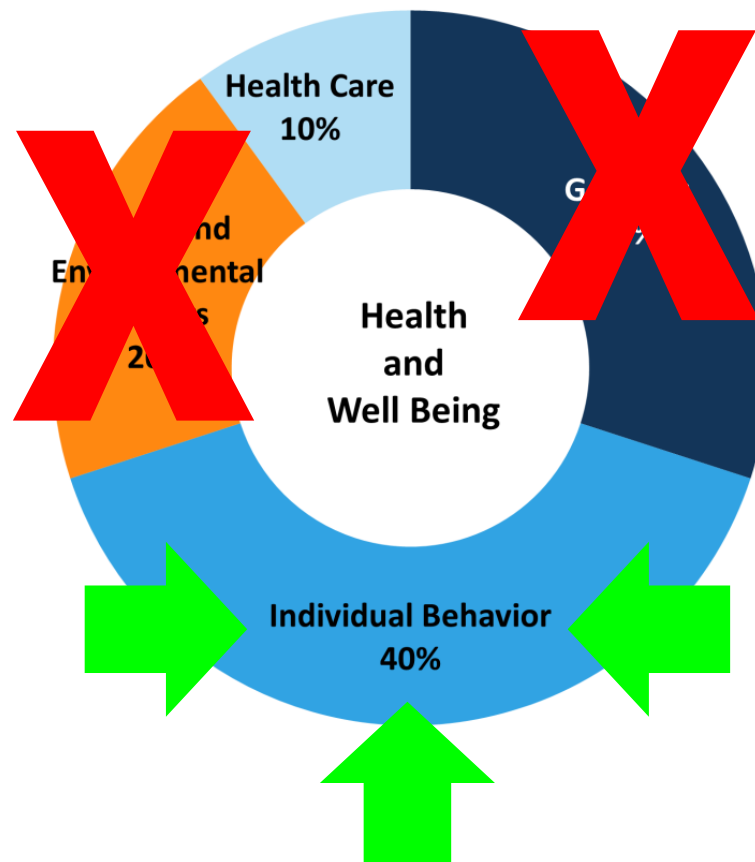
A wrong choice
has a HIGH COST



40% of Key Health Outcomes are *Patient Driven*

Figure 1

Impact of Different Factors on Risk of Premature Death



SOURCE: Schroeder, SA. (2007). We Can Do Better — Improving the Health of the American People. *NEJM*. 357:1221-8.

Education: Necessary, *But Not Sufficient*

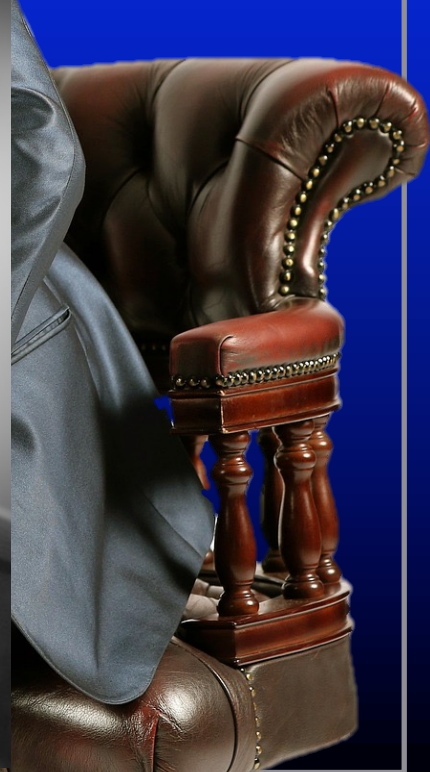
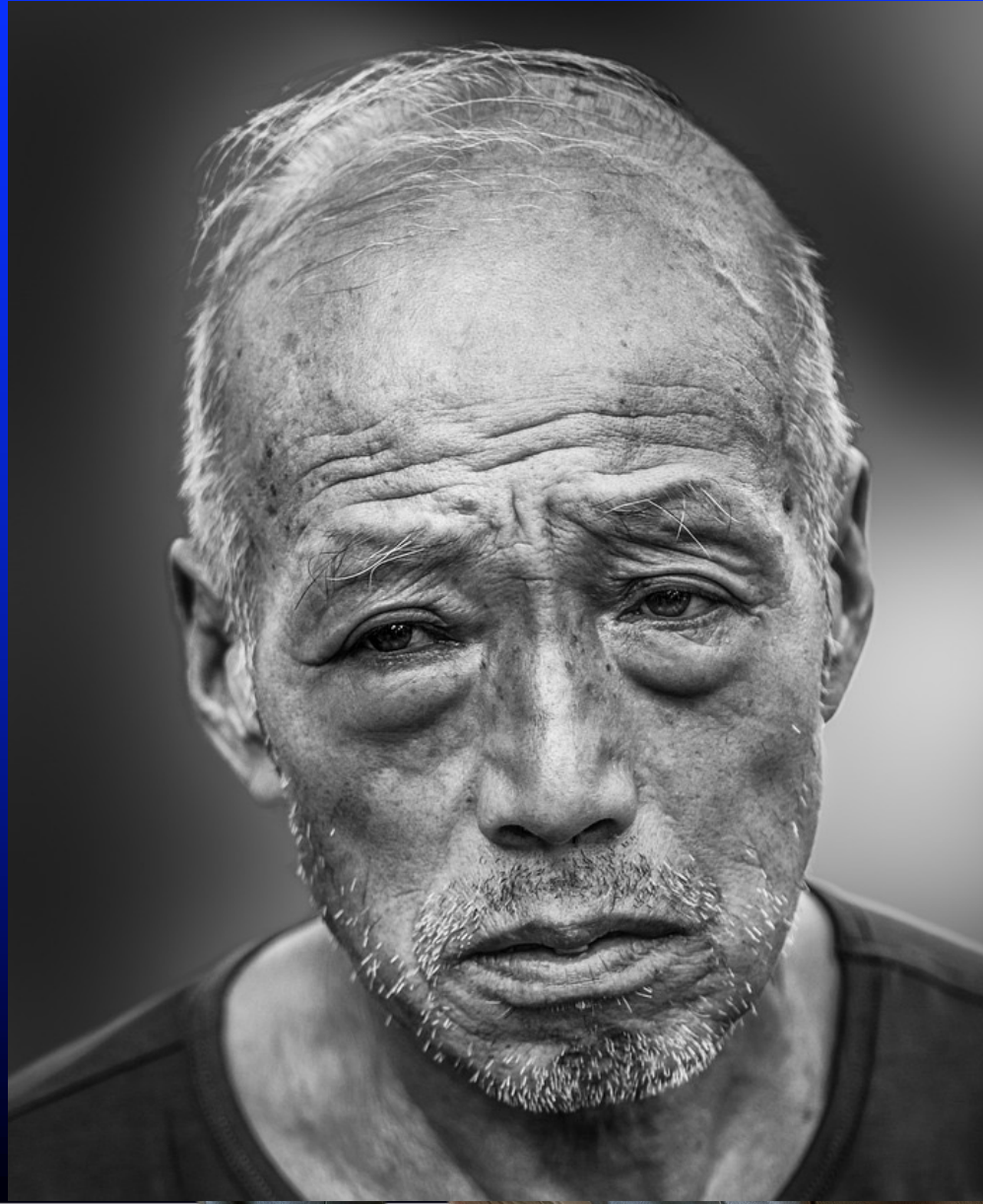


Fear Makes Learning IMPOSSIBLE



Lindström BR, Bohlin G. *Emotion*. 2012 Apr;12(2):384-93

How to Recognize Fear



Hope is the flip side of fear



HOPE Improves Health-related QOL

- ✱ More hopeful: better mental functioning (n=103; SF36)¹
- ✱ Hope scores predicted QOL in HD patients and care partners (n=123 dyads; WHO QOL BREF tool)²
- ✱ Higher hope scores: better QOL in HD patients (n=202; WHO QOL BREF tool)³



¹Billington E et al. *Br J Health Psychol.* 2008 13:683-99

²Al-Rawashdeh S et al. *Qual Life Res.* 2020 Jan;29(1):81-89

³Alshraifeen A et al. *Br J Nurs.* 2020 Nov 26;29(21):1260-1265

HOPE Eases Fear

- ✱ 8-week RCT hope-teaching intervention (n=50)¹
- ✱ Significantly reduced depression, anxiety, stress



¹ Rahimipour M et al. Iran J Nurse Midwif Res. 2015 Nov-Dec; 20(6):694-699

HOPE Boosts Autonomy/Control

“Maintaining control through staying informed, self-determination, and independence has elicited a strong sense of hope in participants of many studies.”



Benefits of Evidence-based Decision Aids

Decision Aids Increase Patient Knowledge

✳️ Cochrane review, 105 studies, 31,043 patients

✳️ High quality evidence

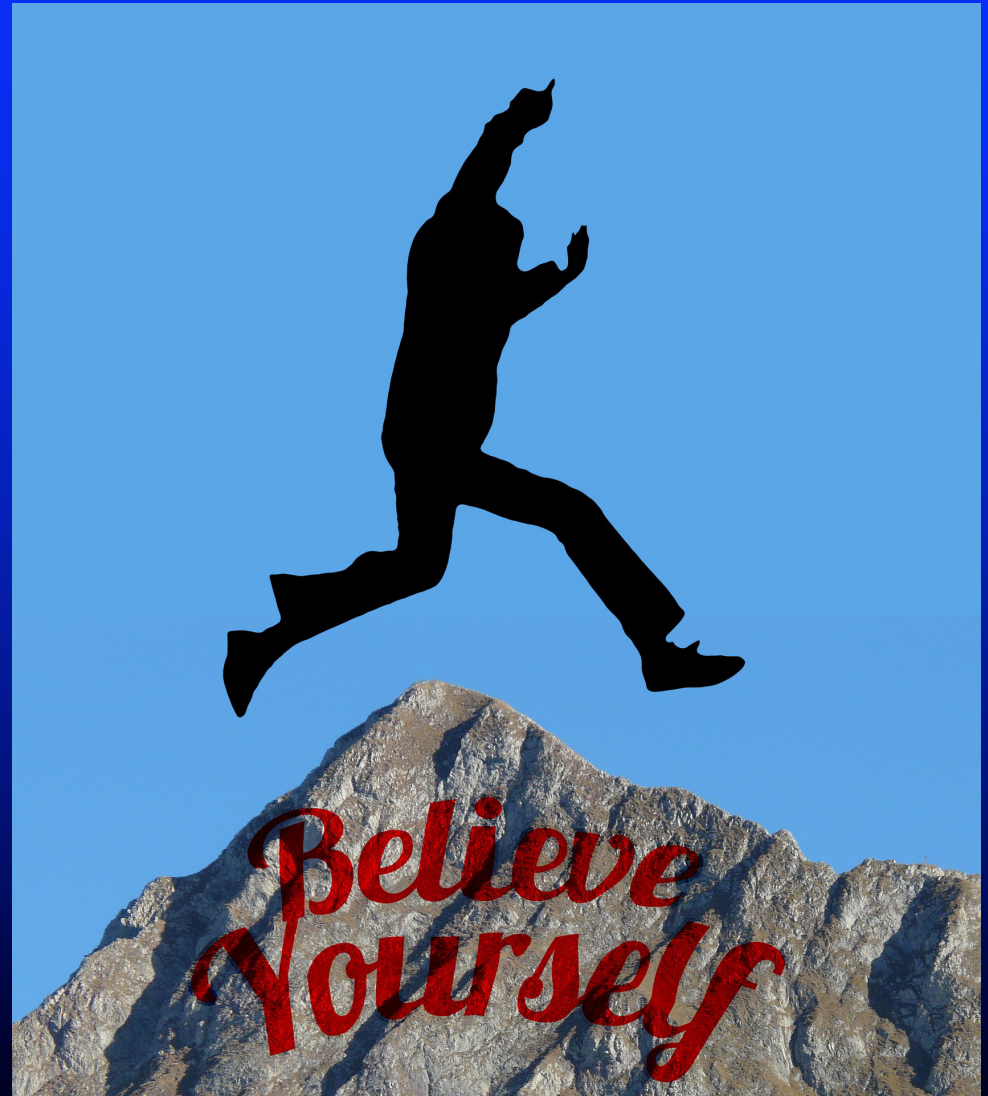
Stacey D et al. *Cochran Database Syst Rev.* 2017 Apr 12;4(4):CD001431



Decision Aids Reduce Decisional Conflict

✳ High quality evidence

Stacey D et al. *Cochran Database Syst Rev.* 2017 Apr
12;4(4):CD001431



Decision Aids Clarify Personal Values

✳ High quality evidence



Decision Aids Engaged Patients Actively in Decision-making

✱ Moderate quality evidence



My Kidney Life Plan and How to Use It

HOPE Looks Like Life *Before* ESKD



2015: My Life, My Dialysis Choice

My life, My Dialysis Choice

a program of the non-profit —mei—

If your kidneys fail, dialysis
can save your life.

But, dialysis is not just a
medical treatment.

It can also affect every
aspect of your lifestyle.

This tool will help you choose the right treatment
for *you*, so you can feel your best *and* live the way
you want to.

Get Started ▼

2022: Transplant & Comfort Care

Español

My Kidney Life Plan

a program of the non-profit—mexi—




Kidney disease can affect every part of your life.

Use this free tool to see how **dialysis, transplant, or comfort care** may impact your life.

Your treatment is your choice, we can help you choose the right treatment for YOU.

What brings you here today?

Here's how to get started:

- Check  3 values that matter to you. Then click the "Next" button.
- Click  to open the treatment options and read how your value works for each.
- Select  0-5 stars to rate how each treatment works for you. (More stars = works better.)
- Share your chart at the end with your care team.

NEW: Turn Options Categories On & Off

Español

My Kidney Life Plan

a program of the non-profit 

Work/School

Progress: 1 of 5



I need to be able to work or go to school

Dialysis

You CAN work or go to school on **dialysis** — If you choose a **workfriendly** option. **Workfriendly** treatments fit YOUR schedule. They give you more energy and mental focus. And, they help you stay out of the hospital, so you miss less work.

☆☆☆☆ Rate how well each treatment fits this value



Peritoneal Dialysis & Burden

rate this: ☆☆☆☆

- Do **PD** at home with a **cycler** at night while you sleep
 - You may be able to do **PD** at work
 - Take **PD** with you on work trips
- But...**
- You need to keep your **PD catheter** clean as your nurse will teach you
 - Your doctor may give you limits on how much weight you can lift
 - Average of 11.3 hospital days per year (NOTE: Includes those who switched options during the year)



Standard Hemodialysis & Burden

rate this: ☆☆☆☆

- Ask for an in-center shift before or after work or school
 - You can do **standard home HD** on your own schedule
- But...**
- Do home **HD** on your own schedule
 - **Standard in-center HD** may take time out of your work or school day
 - It may take 2-12+ hours to feel well after each treatment
 - Average of 11 hospital days per year for standard in-center HD. (NOTE: includes those who switched options during a year)
 - One small study found 1/3 fewer hospital stays for **standard home HD**
 - You may not have much energy
 - You may not think as clearly



Daily Hemodialysis & Burden

rate this: ☆☆☆☆

- Do your treatments before or after work or school
 - More treatments for more energy
 - Take a small (75lbs.) **HD** machine with you for work trips
- But...**
- Along with work, set-up and clean-up can mean your day is full
 - Average of 9.6 hospital days per year



Nocturnal Hemodialysis & Burden

rate this: ☆☆☆☆

- Done at night while you sleep at home, or in a clinic—no time out of your day
 - Most treatment for most energy
 - Take a small (75 lbs.) **HD** machine with you for work trips
- But...**
- Work travel can be a challenge if you use a large **HD** machine
 - Average of 1-6 hospital days per year for **nocturnal home HD**
 - Average of 9.6 hospital days per year for in-center **nocturnal HD**

Transplant

You CAN work or go to school with a transplant as long as you feel healthy enough to do so.



Transplant

rate this: ☆☆☆☆

- Bullet points here
- Lorem Ipsum

Comfort Care

Click to learn how Comfort Care affects this value



Meets All IPDAS Criteria



Year of last update or review	2022
Format	Web
How to obtain	Click here to view the decision aid on the developer website
Developer	Dori Schatell, MS
Where was it developed?	https://meiresearch.org/contacts/new Medical Education Institute, Inc. USA
Health condition	Chronic Kidney Disease
Type of decision aid	Treatment
Language	English, Spanish

Based on IPDAS criteria (International Patient Decision Aid Standards) this decision aid (and/or supporting materials) meets:

- 7 out of 7 criteria to be defined as a patient decision aid
- 8 out of 8 criteria to lower the risk of making a biased decision
- Not applicable:** other criteria for decision aids about screening or testing

Choose 3 Values

What matters most to you?

Check the values that matter *most* to you. For each value you select, you'll be able to rate how each treatment option fits your life. We'll show you a summary when you're done.

My Health Values: I Want To...

- ☒ Feel well from day to day
- ☐ Sleep well
- ☐ Protect my heart
- ☒ Protect my brain
- ☐ Protect my nerves and bones
- ☐ Avoid needles
- ☐ Take as few medicines as I can
- ☐ Get a **transplant**
- ☐ Stay out of the hospital

My Lifestyle Values: I Want To...

- ☐ Work or go to school
- ☐ Travel
- ☐ Eat and drink what I like
- ☐ Swim and/ or take tub baths
- ☐ Have my pets
- ☐ Afford my care
- ☒ Feel in control of my time and life
- ☐ Not turn my home into a clinic

My Relationship Values:

Rate Each Value with 0-5 Stars



Daily HD & Feel well



- People tend to have much more energy.
- They feel well about **1 hour** after each treatment.
- There is much less pain vs. standard in-center HD.

But...

- It takes energy to do daily HD and deal with supplies.



Nocturnal HD & Feel well



- People tend to have much more energy.
- It takes **6-20 minutes** to feel well after each treatment.
- There is much less pain vs. standard in-center HD.

But...

- It takes energy to do nocturnal home HD and deal with supplies.

Transplant

Surgery to get a new kidney from a donor.

—

Most people who got a transplant had more energy—and less pain.



Transplant & Feel well



- Of 1,200+ people, **50-60%** had much more energy.

Share Summary with Care Team

Español









My Kidney Life Plan
a program of the non-profit 

Summary

Progress: Summary ▾

Totals

My Values	 PD	 Standard HD	 Daily HD	 Nocturnal HD	 Transplant	 Comfort Care
<u>Feel well</u>	★★★★	★	★★★★★	★★★★★★	★★★★★★	
<u>Brain/Nerves</u>	★★		★★★	★★★★	★★★★★	
<u>Feel in control</u>	★★★★★	★	★★★	★★★★★★	★★★★★	
Totals	9	2	10	14	14	0

+ Add More Values

Discuss Preferred Options w/MD



Learn More About Options that Could Work



Take Aways

- ✱ ***We cannot* learn when we are afraid.**
- ✱ **Decision aids clarify values and increase knowledge, confidence, and engagement.**
- ✱ ***My Kidney Life Plan* is a free, evidence-based tool to enhance shared decision-making.**