

How to Talk to Patients About Home Dialysis: Four Steps for Professionals

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You have a patient who will soon need dialysis. Or, an in-center hemodialysis (HD) patient seems like a good candidate for home. **What is the best way to discuss treatment options, and what should you say?** This guide will help make that challenging conversation easier—even if you don't have any experience with home treatments.

Times are Changing

In 1972 when President Nixon signed Public Law 92-603 to create the Medicare ESRD Program, about **40%** of patients dialyzed at home.¹ By 2009, just **8.9%** did.² Our 2010 nephrologist survey found that even though **92%** of U.S. patients were on standard in-center hemodialysis (HD)—just **6%** would choose it for themselves if their own kidneys failed.³ This was quite a disconnect!

After the Executive Order on [Advancing American Kidney Health](#) took effect in 2019, Medicare developed payment models to promote home dialysis, like the **ESRD Treatment Choices (ETC) Model**, now mandatory for 30% of U.S. dialysis clinics. Those that meet targets to increase use of home treatments will get payment incentives. **The goal for home dialysis is at least 19% of eligible patients by the end of 2027.**⁴ This is why it will help you and your clinic to know how best to approach patients—and how not to. Here are the steps we recommend.

Step 1: Address the Storm of Emotions

MEI did some of the first research talking with dialysis patients about how they felt. What came through loud and clear were their **emotions**:

- **Anger:** with themselves, doctors who missed a diagnosis, God.
- **Depression:** their new lives were not what they expected.
- **Fear and Anxiety:** they *all* feared dying—or a life not worth living.

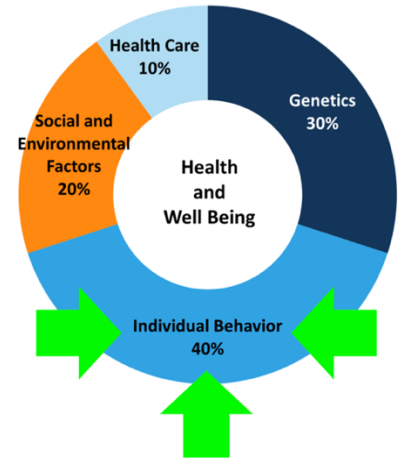


Importantly, **almost no one told their care teams of their worries.** Some made poor choices in the grip of fear—like the college student who broke off her engagement and got her tubes tied, believing she could not marry or become a mother. Or, the man who never bought a home, since he would not live long enough to pay off a mortgage. (Do any of us know that we will?)

Since then, we have answered the **“How long can you live?”** and **“How well can you live?”** questions **proactively** in our materials—even if patients never ask out loud. What we share with you here is informed by more than **20,000** kidney patients over 30+ years.

Education is key to modality choice. But, **we humans cannot learn when we are afraid.**⁵ When stress hormones (cortisol, adrenaline) course through our veins, we can fight. We can flee. We can freeze. But, we can't form new memories.

Education at this point is wasted: your patients cannot hear you and will not recall what you say. Yet, **40% of key health outcomes are driven by patient behavior.**⁶ We *must* engage patients in their own care and healthcare decisions. To succeed, we have to help them get past fear.



What You Can Do: *Normalize Patients' Feelings*

Help them see that they are not alone and that how they feel is expected. Sit down. Put a hand on their arm or shoulder. Say something like:

- ***"I know this must be scary for you."***
- ***"What questions can I answer?"***

Find out what they know—or believe—so myths can be addressed. Acknowledge patients' fears or find someone who can, like the social worker. A patient mentor can help, as patients often want to know what their fellows think.

Step 2: Offer Hope for a Good Life

What gets people past fear? **Hope.** Hope and fear are *"two sides of the same coin,"* found authors of a meta-analysis.⁷ Studies have found that hopeful kidney patients:

- **Slowed CKD progression and reduced the risk of fast kidney decline.**⁸
- **Were less depressed, anxious, and stressed.**⁹
- **Had better mental functioning.**¹⁰ This predicts fewer hospital stays and deaths.¹¹
- **Had higher quality of life**¹²**—and so did care partners.**^{13,14}
- **Felt less burdened by diet and fluid limits and had lower blood pressure.**¹⁵
- **Gained less fluid weight, missed fewer sessions, and followed potassium limits.**¹⁶



Hope looks like life before kidney disease. We may know that people are lucky to have options to live past kidney failure. Yet, each option can affect **every aspect of life**—work, travel, intimacy, pets, energy level, sleep... A poor fit can threaten everything that matters to someone. Like chemo or radiation for cancer, **all of the choices look bad: patients don't want to need any of them.**

For this reason, **we do not recommend saying things like, “You would do great on PD!” or “Have you thought about home dialysis?”** A **modality-first** approach like this assumes that patients are as enthusiastic about home treatments as we may be. But, to paraphrase Joan Lunden, *“People have to want something more than they are afraid of it.”* And, our patients are **very afraid**.

Instead, our job is to help them *reframe* the options in terms of what they *do* want: full, vibrant lives. How? Use our evidence-based decision aid that does the work for you (see the blue box). Say something like:

- ***“I have a tool that can help you figure out how to have the life you want.”***
- ***“Let me help you get started.”***

What You Can Do: Use My Life, My Dialysis Choice

This free [MEI](#) tool in English and Spanish is written at a 5th grade level, *designed* to offer hope, and starts with patients’ values. It **maps values onto dialysis options—so you don’t have to—**and has been extensively tested and adopted by a large dialysis organization. **Start options education here.** Use a large tablet. Ask patients to choose their top 3 values.

For each value, the tool will display a page that explains the value and has seven dialysis options in four boxes. **Each box contains pros and cons for that value.** The patient rates each box with 0-4 stars. Each value will take about 5 minutes. Some patients will need help to use the tablet.

The first screenshot shows the landing page with the title "My Life, My Dialysis Choice" and a "Get Started" button. The second screenshot shows the "Hospital Stays" section with a red header and four boxes for rating treatment options. The third screenshot shows the "Summary" page with a yellow header and a table of results for four dialysis modalities.

My Values	A PD	Standard HD	Short Daily HD	Extended HD
Wish of Success	★★★★	★★	★★★★	★★★★
Leisure/Working	★★★	★★★★	★★★	★★★★
Feeling Well	★★★	★★★★	★★★	★★★★
Freedom	★★★★	★★★★	★★★★	★★★★
Totals	0	31	0	0

Once done, the tool creates a **1-page summary** of a patient’s values and star ratings. This can be printed as part of the medical record, and serves as a Plan of Care for modality choice.

Try it yourself! Your choice of treatment option might surprise you. **NOTE:** Watch for an update, coming soon, with a new name and a new look. It will include transplant and comfort care. Once it is live, you will see it when you go to *My Life, My Dialysis Choice*.

Step 3: See if Patients *Can* Do the Treatment(s) They Prefer

***My Life, My Dialysis Choice* can help patients and clinicians communicate for shared decision-making.** It *cannot* assess whether patient choices will suit their anatomy, mental health, or living situation. For example, about **87%** of people may be physically suited for PD;¹⁷ the rest are not.

What You Can Do: Use our free Method to Assess Treatment Choices for Home Dialysis ([MATCH-D](#)) for PD and home HD.

The MATCH-D levels the playing field to help remove implicit and explicit bias and ensure that all patients are treated fairly. It will help you determine who may be excellent candidates for PD or home HD, who may have challenges that can be overcome, and who would need help to dialyze at home.

Method to Assess Treatment Choices for Home Dialysis (MATCH-D)
HomeDialysis.org/match-d

Suitability Criteria for Self Peritoneal Dialysis: CAPD or CCPD

Strongly Encourage PD	Encourage PD After Assessing and Eliminating Barriers	May Not Be Able to Do PD (or will require a Helper)
<ul style="list-style-type: none"> ○ Any patient who wants to do PD or has no barriers to it ○ Employed full- or part-time ○ Student – grade school to grad school ○ Caregiver for child, elder, or person with disability ○ New to dialysis or has had transplant rejection ○ Lives far from clinic and/or has unreliable transportation ○ Needs/wants to travel for work or enjoyment ○ Has needles fear or no remaining HD access sites ○ BP not controlled with drugs ○ Can't or won't limit fluids or follow in-center HD diet ○ No (required) partner for home HD ○ Wants control; unhappy in-center 	<ul style="list-style-type: none"> ○ Minority – not a barrier to PD ○ Unemployed, low income, no High School diploma – not barriers to PD ○ Simple abdominal surgeries (e.g. appendectomy, hernia repair, kidney transplant) – not barriers to PD ○ Has pet(s)/houseplants (carry bacteria) – bar from room at least during PD connections ○ Hernia risk or recurrence after mesh repair – use low daytime volume or dry days on cyclist ○ Blind, has no use of one hand, or neuropathy in both hands – train with assist device(s) as needed ○ Frail or can't walk/stand – assess lifting, offer PT, offer CAPD, use 3L instead of larger bags for cyclist ○ Illiterate – use pictures to train, return demonstrations to verify learning, tape recorders for patient reports ○ Hearing impaired – use light/vibration for alarms ○ Depressed, angry, or disruptive – increased personal control with PD may be helpful ○ Unkempt – provide hygiene education; assess results ○ Anuric with BSA >2 arm – assess PD adequacy†‡ ○ Swimmer – ostomy dressings, chlorinated pool, ocean ○ Limited supply space – visit home, 2x/1mo, delivery ○ Large polycystic kidneys or back pain – use low daytime volume or dry days on cyclist†‡ ○ Obese – consider preterminal PD catheter ○ Has colostomy – consider preterminal PD catheter ○ Rx drugs impair function – consider drug change 	<ul style="list-style-type: none"> ○ Homeless and no supply storage available ○ Can't maintain personal hygiene even after education ○ Home is unclear health hazard; patient/family won't consent ○ No/unreliable electricity for CCPD; unable to do CAPD ○ Multiple or complex abdominal surgeries; negative physician evaluation.†‡ ○ Brain damage, dementia, or poor short-term memory* ○ Reduced awareness/ability to report body symptoms ○ Malnutrition after PD trial leads to peritonitis†‡ ○ *Uncontrolled anxiety/psychosis*

Suitability Criteria for Self Home Hemodialysis: Conventional, Daily, or Extended

Strongly Encourage Home HD	Encourage Home HD After Assessing and Eliminating Barriers	May Not Be Able to Do Home HD (or Helper Must Do More)
<ul style="list-style-type: none"> ○ Any patient who wants to do home HD or has no barriers to it ○ Employed full- or part-time ○ Drives a car – skill set is very similar to learning home HD ○ Caregiver for a child, elder, or person with disability ○ Lives far from clinic and/or has unreliable transportation ○ Student: grade school to grad school ○ Needs/wants to travel for work or enjoyment ○ Wants a flexible schedule for any reason ○ Has rejected a transplant ○ Has neuropathy, amyloidosis, LVH, uncontrollable BP†‡ ○ Obese/large; conventional HD or PD are not adequate †‡ ○ Can't/won't follow in-center HD diet & fluid limits†‡ ○ Is pregnant or wants to be †‡ ○ Frail/elderly with involved, caring help-er who wants home HD* ○ Wants control; unhappy in-center ○ No longer able to do PD 	<ul style="list-style-type: none"> ○ No employer insurance – not a barrier to nocturnal 3x/wk home HD, which Medicare & Medicaid cover ○ Unkempt – provide hygiene education; assess results ○ Has pet(s)/houseplants (carry bacteria) – bar from room at least while canulating/connecting access ○ Frail or can't walk/stand – assess lifting ability, offer PT* ○ Illiterate – use pictures to train, return demonstrations to verify learning, tape recorders for patient reports ○ Hearing impaired – use light/vibration for alarms ○ Depressed, angry, or disruptive – increased control with home HD may help ○ No helper & clinic requires one – reconsider policy, monitor remotely, use LifeLine device to call for help ○ Plants – check with landlord if home changes needed ○ Can't/won't self-cannulate – use patient mentor, practice arm, local anesthetic cream, desensitization* ○ No running water, poor water quality, low water pressure – assess machine & water treatment options ○ Limited space for supplies – visit home, 2x/1mo, delivery, consider machine with fewer supply needs ○ Drug or alcohol abuse – consider after rehab ○ Bedridden and/or has tracheostomy/ventilator – assess self-care and helper ability* ○ Rx drugs impair function – consider drug change 	<ul style="list-style-type: none"> ○ Homeless; consider PD if storage is available ○ Can't maintain personal hygiene ○ Home is health hazard, will not correct ○ Unreliable or no electricity ○ Brain damage, dementia, or poor short-term memory* ○ No use of either hand* ○ Uncontrolled psychosis or anxiety* ○ Blind or severely visually impaired – consider PD* ○ Uncontrolled seizure disorder* – consider PD ○ No remaining HD access sites – consider PD ○ Reduced awareness/ability to report bodily symptoms ○ Has living donor, transplant is imminent – consider PD

Method to Assess Treatment Choices for Home Dialysis (MATCH-D)
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 Developed by Dorl Schattell, MS, and Beth Witkin, MSW, ACSW, LCSW, for Home Dialysis Central (HomeDialysis.org).

Step 4: Refer the Patient for Options Education

Once people have their goal in place—a desire to keep what matters most in their lives—they will be more hopeful and open to education. Now, you can ask them to attend a class or a one-on-one education session to learn more of the details of the option(s) they are willing to consider.

What You Can Do: Send Patients to a Local Class—Or Offer Your Own

Live classes are terrific, especially when members of the care team, including the home training nurse if your clinic has one, and patients using different options can be included. In these COVID days, classes may have to be held online, which can still work well for those with a smartphone or computer access.

No class in your area? Use our [free *How to Have a Good Future with Kidney Disease* slide toolkit or videos](#). After education, talk to them, see what their choice is, and help them get started.

Conclusion

The steps to help patients understand their treatment options are:

1. Address—and *normalize*—the storm of emotions.
2. Offer patients **hope** for a good life.
3. See if patients *can* do the treatments they are interested in.
4. Refer patients for options education.

Selected Resources & Tools

- **Home Dialysis Central** - www.homedialysis.org
- **Home Dialysis Central Facebook Discussion Group** (Private group,) - www.facebook.com/groups/HomeDialysisCentral
- **Kidney School** (18 modules English/Spanish, print, audio) – www.kidneyschool.org
- **Life Options** – www.lifeoptions.org
- **Partner Agreement on Tasks for Home Dialysis (PATH-D)** – PD and home HD. www.homedialysis.org/professional-tools/path-d
- **Teaching Resources** – www.lifeoptions.org/resources-for-professionals/#teaching-resources

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