How to Talk to Patients About Home Dialysis

Dori Schatell, MS
Executive Director, Medical Education Institute
MEI Mission: Help people with chronic disease learn to manage and improve their health.
What We’ll Cover

- Emotions come first
- Comparing in-center to home
- Listen for and use “teachable moments”
- Options education resources
Emotions Come First
Kidney failure is a personal tsunami

*iStock*
Strong emotions are normal
Fear, anger, depression are common

*Pixaby-fear, anger Wikimedia-depression
“3 times a week, I go to bed dreading the AM and get up dreading the treatment. I feel like I glue myself together to get through it. I cannot believe this is my life now.”
WE May View Options Like This...

PD!!!

*Pixabay

Home HD!!!
Patients May See Them More Like This

Drown? Or Burn?*

*Pixabay
They Want the Lives They Had

*Bigstock*
A lot of the fear is about a life not worth living

*Wikimedia*
Dialysis Affects EVERY Aspect of Lifestyle

Choice of a treatment needs to reflect this

*Pixabay-luggage, vegetables, painter, iStock-couple hugging, man sleeping, bigstock-runner
We CANNOT learn when we are afraid

*Pixabay
AVOID a Modality-first approach!

“Have you thought about PD?”

“You would do great at home!”
Offer **HOPE** Linked to Values

*Pixabay*
N=103 UK adults on dialysis¹
Higher levels of hope:
< Anxiety
< Depression
< Disease burden
> Mental functioning

“Hopefulness could serve to lessen the emotional impact of ESRF and treatment by empowering the individual to reframe threats as challenges”

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

HOPE is as important as OXYGEN
Without HOPE, patients CANNOT hear us

*Bigstock
Help Patients Find Their Best Fit

*Source- Dori Schatell, MS*
As Patients’ Needs Change, Their Modality Can—and Should—Too
Comparing In-center to Home Dialysis
Treatments that Keep Balance can Improve Lives
*iStock
Recovery Time After Standard In-center HD

Lindsay RM et al. *CJASN* 2006 Sep;1(5):952-9
*Pixabay
What happens in the body with standard in-center hemodialysis

BIG Ups & Downs in Water and Wastes


*MEI owned image
Standard In-center HD: the 2-day “Killer Gap” (by Day)

P=0.0005

Standard In-Center HD: the 2-day “Killer Gap” (by Hour)

Types of Home Dialysis

- CAPD, CCPD
- Standard home HD
- Short daily home HD
- Nocturnal home HD
- Nocturnal In-center HD
What Happens in the Body with Short Daily Hemodialysis

Small Ups & Downs in Water and Wastes
Recovery Time After Short Daily HD

Lindsay RM et al. CJASN 2006 Sep;1(5):952-9
*Pixabay
What Happens in the Body with Nocturnal Hemodialysis

VERY Small Ups & Downs in Water and Wastes
More Dialysis FEELS More Like Having Healthy Kidneys Did

- LEAST
  - Standard HD
- Daily HD
- Nocturnal Home HD
- In-center Nocturnal HD
- PD
- Transplant
- MOST
  - Healthy

*MEI owned image*
# More dialysis = Longer Survival

<table>
<thead>
<tr>
<th>Modality</th>
<th>Days/week</th>
<th>Hours/day</th>
<th>TOTAL hours</th>
<th>5-year Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard in-center hemodialysis (HD)*</td>
<td>3</td>
<td>3.5-4</td>
<td>10.5-12</td>
<td>42%</td>
</tr>
<tr>
<td>Peritoneal dialysis*</td>
<td>7</td>
<td>8-24</td>
<td>14-70</td>
<td>52%</td>
</tr>
<tr>
<td>Short daily home HD¹</td>
<td>4-6</td>
<td>2.5-4</td>
<td>10-24</td>
<td>64-72%</td>
</tr>
<tr>
<td>In-center nocturnal HD²</td>
<td>3</td>
<td>8</td>
<td>24</td>
<td>72%</td>
</tr>
<tr>
<td>Nocturnal home HD³</td>
<td>4-6</td>
<td>8</td>
<td>32-48</td>
<td>85%</td>
</tr>
</tbody>
</table>

*USRDS ADR 2016, Tables I.17 and I.23


*MEI owned image
Home Treatments Offer More FREEDOM
*iStock
Nocturnal HD:

- Significantly lower phosphate levels
- Fewer/no fluid limits

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Home Patients Can Eat & Drink More Normally

*Thinkstock-pizza, Pixabay-lemonade, Wikimedia-Almond Joy, pngmart-bananas
Home Dialysis Can Improve Sleep

*Source: Dori Schatell, MS

Home Treatments Can Make Travel Easier

Home treatments are flexible—and can come along for the ride

*MEI owned images
Home is Work-friendly (& Work Reduces Depression)¹

¹Kutner NG et al. *CJASN*. 2010 Sept 30
Anecdotally, patients who get more HD report better sex lives.

More Home HD Seems to Improve Sex Lives

*iStock-both images

Anecdotally, patients who get more HD report better sex lives.
Nocturnal HD: Survival Comparable to Transplant\textsuperscript{1-3}

\textsuperscript{1}Stock-Asian couple with bike, grandmother granddaughter gardening, Gettyimages-grandpa

\textsuperscript{1}Nishio-Lucar AG et al. KI Reports, 2020. \textsuperscript{2}Pauly RP et al. NDT. 2009 Sept;24(9):2915-9. \textsuperscript{3}Johansen et al. KI. 2009 Nov;76(9):984-90
Medicare Starts on Day 1 for Home Patients (vs. After 3 Months for Standard In-center HD)
Listen for and Use Teachable Moments
CONCERNS or COMPLAINTS are Teachable Moments
*Pixabay
"I’m so thirsty all the time!"

*Source: Dori Schatell, MS*
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>You could chew some gum</td>
<td>More dialysis removes more water—so you can drink more</td>
</tr>
<tr>
<td>Do you want some ice chips?</td>
<td>I can have you talk to the home training nurse</td>
</tr>
<tr>
<td>You need to eat less salt</td>
<td></td>
</tr>
<tr>
<td>Talk to the dietitian for tips</td>
<td></td>
</tr>
</tbody>
</table>

**How to Use the Moment**
“I may as well forget about food & just eat DIRT!”

*Wikimedia*
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s all about portion size</td>
<td>More dialysis removes more wastes—so you can eat more</td>
</tr>
<tr>
<td>Substitute other foods you like</td>
<td></td>
</tr>
<tr>
<td>After a while, you won’t even notice there’s no salt…</td>
<td></td>
</tr>
<tr>
<td>Talk to the dietitian for tips</td>
<td></td>
</tr>
</tbody>
</table>

**How to Use the Moment**
“I can’t take (& pay for) all of these meds!”

*Pixabay*
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>Put them by your toothbrush</td>
<td>More dialysis removes more wastes—so you don't need as many meds</td>
</tr>
<tr>
<td>Make up a reminder chart</td>
<td></td>
</tr>
<tr>
<td>The social worker can help you</td>
<td></td>
</tr>
<tr>
<td>find low income programs</td>
<td></td>
</tr>
<tr>
<td>Maybe the doctor has samples</td>
<td></td>
</tr>
</tbody>
</table>

How to Use the Moment
“If I can’t work, I’ll lose my house!”

*iStock*
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>You may be able to get Social Security disability</td>
<td>Some kinds of dialysis are more work-friendly so you can keep your job</td>
</tr>
<tr>
<td>Could you take in a boarder?</td>
<td></td>
</tr>
<tr>
<td>Maybe you could work part-time</td>
<td></td>
</tr>
<tr>
<td>Talk to the social worker about your options</td>
<td></td>
</tr>
</tbody>
</table>
"I don’t want to live like this. I’m better off dead."

*iStock*
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your doctor can prescribe antidepressants for you</td>
<td>If you do a different treatment, your life can look more like you want it to</td>
</tr>
<tr>
<td>Make a list of things you used to like to do</td>
<td></td>
</tr>
<tr>
<td>Talk to the social worker</td>
<td></td>
</tr>
</tbody>
</table>
“I want to have a baby!”
<table>
<thead>
<tr>
<th>Old</th>
<th>New</th>
</tr>
</thead>
<tbody>
<tr>
<td>You may be able to adopt</td>
<td>The chance of getting pregnant and having a healthy baby are much higher with more hemo.</td>
</tr>
<tr>
<td>Two years after a transplant, you may be able to try…</td>
<td>With 36+ hours of HD per week, the chance of a healthy baby is 85%. With 35 or fewer hours, it’s 50/50.</td>
</tr>
<tr>
<td>Talk to the social worker</td>
<td>Hladunewich MA et al. JASN 2014 May;25(5):1103-9</td>
</tr>
</tbody>
</table>
Modality Education Resources
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.

Free Decision Aid:  www.mydialysischoice.org

*MEI owned image
Help, I Need Dialysis!

How to have a good future with kidney disease

Dori Schatell, MS & Dr. John Agar

www.lifeoptions.org/help_book

*MEI owned image
I want to stay out of the hospital

With longer or more frequent dialysis, you have a better chance of staying out of the hospital. The type of access you have also plays a role. An access infection can land you in the hospital. Heart problems and fluid overload also cause lots of hospital stays.

Rate how well each treatment fits this value

**Peritoneal Dialysis & Hospital Stays**

- Do each PD exchange just as you are taught to avoid hospital stays
- Average of 11.3 hospital days per year. NOTE: includes those who switch options in a year

**Standard Hemodialysis & Hospital Stays**

- If you follow your treatment plan, you may be able to avoid some hospital stays
- Average of 11 hospital days per year. NOTE: Includes those who switch options in a year
- One small study found 1/3 fewer hospital stays for standard home HD than for in-center.

**Daily Hemodialysis & Hospital Stays**

- Daily dialysis means you can avoid going 2 days with no treatment
- Average of 9.6 hospital days per year

**Nocturnal Hemodialysis & Hospital Stays**

- Nocturnal home HD is the most dialysis you can get
- Average of 1-6 hospital days/year for nocturnal home HD
- Average of 9.6 hospital days per year for in-center nocturnal HD
## Results

<table>
<thead>
<tr>
<th>My Values</th>
<th>PD</th>
<th>Standard HD</th>
<th>Short Daily HD</th>
<th>Extended HD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work / School</td>
<td>★★★★★</td>
<td>★★★</td>
<td>★★★</td>
<td>★★★★★★</td>
</tr>
<tr>
<td>Eating/Drinking</td>
<td>★★★</td>
<td>★★★</td>
<td>★★★</td>
<td>★★★★★★</td>
</tr>
<tr>
<td>Feeling Well</td>
<td>★★★</td>
<td>★★★</td>
<td>★★★</td>
<td>★★★★★★</td>
</tr>
<tr>
<td>Survival</td>
<td>★★★</td>
<td>0</td>
<td>★★★</td>
<td>★★★★★★</td>
</tr>
<tr>
<td>Totals</td>
<td>10</td>
<td>0</td>
<td>11</td>
<td>16</td>
</tr>
</tbody>
</table>

**Save or send your results**

Bookmark this page and come back later to see your chart again. Or, fill in your email address and we will send you the link.

We will only use your email address to send you your link. We will not keep it. Promise!

Your Email

Send Link

1 page summary of values & star ratings

*MEI owned image*
Life@Home

Patient Stories

Kamal's Story
Kamal's kidney failure was a two in a million chance.

Patient Videos

Angela's Story
Watch the stories of these patients who overcame their challenges to thrive on NxStage System One home hemodialysis therapy.

Dialysis Needles

Buttonhole Technique
Stuart Mott, LPN, is a pioneer in buttonhole cannulation, whose articles about Touch Cannulation, Cushion Cannulation, and Tandem Hand cannulation have changed practice.

Life@Home Articles

Ultrapure Dialysate: What, How, And Why
Dialysate is a blend of water and chemicals that washes wastes and fluid out of the blood. During a treatment, dialysate comes in contact...

Care Partners

Learn How You Can Help.
Is someone you know a dialysis patient?

Choosing Your Treatment

My Life, My Dialysis Choice
How do you choose a treatment when you don't want any of them? This is what some people with kidney failure ask themselves.

www.homedialysis.org/life-at-home

*MEI owned images
Professional Tools

Nephrology is an ever-evolving field, and we want to share some of its highlights. We have compiled some great resources for you! Check them out:

**My Dialysis Choice**
Choose your values & see which dialysis choice will fit your life best.
Try our tool »

**MATCH-D**
Use our tool to help dialysis staff identify and assess candidates for home dialysis therapies.
Learn more »

**Medicare Start Date Calculator**
When does Medicare start for home dialysis vs. in-center? Find out!
Calculate your Medicare start date »

**.buttonhole: A How-To Manual**
Patients who self-cannulate have better access outcomes; they take ownership of their care and control of their lives.

**Core Curriculum For The Dialysis Technician**
The Core Curriculum is the industry’s premier, comprehensive training tool to help dialysis technicians—and nurses—learn to provide safe

**Ultrafiltration Rate Calculator**
Help your patients SEE how their fluid gains and treatment time affect them. Clinician/expert dialyzor version coming soon!

**PATH-D PD**
What do your patients and partners expect their roles to be in PD? This new tool can help them communicate.

**PATH-D HHD**
What will your home HD patients do, vs. their partners? Use the PATH-D-HHD to get them on the same page.

www.homedialysis.org/professional-tools

*MEI owned image*
Conclusions:

- Terrified patients CANNOT learn: they need HOPE
- Learn the lifestyle impact of each option
- Use teachable moments to offer hope
- There are lots of free & low-cost resources to help

*Pixabay