Introduction to the National Patient and Family Engagement Learning and Action Network (NPFE-LAN)
Home Dialysis Resources

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Patient Subject Matter Expert
Uncovering Myths About Home Dialysis

The Myths vs. Reality booklet:

• Uncovers myths about:
  ▪ Peritoneal dialysis (PD)
  ▪ Home hemodialysis (HHD)

• Provides tips from patients about choosing a home modality

• Helps prepare patients to start a conversation about home dialysis with the healthcare team
Myths vs. Reality: PD

The booklet reviews topics such as:

- Infections
- Vision and hearing problems
- Body mass index
- Residual kidney fiction
- Storage space
- Lifestyle changes
Myths vs. Reality: HHD

The booklet reviews topics such as:

- Access to health experts
- Risk of adverse events
- Level of burden on care partners
- Needed medical knowledge
- Required access type

### Home Hemodialysis (HHD)

<table>
<thead>
<tr>
<th>Myth</th>
<th>Reality</th>
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<tbody>
<tr>
<td>You won’t have any experts at home to help.</td>
<td>You will learn to be an expert. Plus, your dialysis facility serves as 24-hour phone backup. You will always be near help.</td>
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<tr>
<td>You could bleed to death very quickly.</td>
<td>No one has ever died on HHD. Machine alarms alert you to the detection of just one drop of blood out of place. You will have time to react and fix the problem.</td>
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<tr>
<td>HHD is a huge burden of extra work for a care partner.</td>
<td>It is best if you do as much of your treatment as you can. Some people do HHD without a care partner.</td>
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<td>An HHD care partner needs to have a medical background.</td>
<td>No, no medical background is needed. The clinic will train you and a partner (if they require one, a care partner is not always needed).</td>
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<tr>
<td>You can’t do HHD with a dialysis catheter.</td>
<td>Some programs allow HHD with a catheter. It is best to use your catheter for a vascular access due to higher infection chances.</td>
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<tr>
<td>Your house must be perfectly clean all the time.</td>
<td>Your home does not have to be perfectly clean to perform hemodialysis at home.</td>
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<tr>
<td>If you do HHD, you must follow the same scheduled days of the week.</td>
<td>Many different schedules are available and can be arranged at home. For instance, short daily dialysis or extended dialysis. You might also consider nocturnal dialysis if you’re interested in dialyzing while you sleep. The purpose of home dialysis is to set your own schedule.</td>
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<tr>
<td>You can’t get training to do your dialysis at home right from the beginning.</td>
<td>There must be time for evaluation and practice. Everyone is a little different, both you and staff must be comfortable with your skills.</td>
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<tr>
<td>There’s a long waiting list to learn how to do HHD.</td>
<td>This varies among facilities offering a home program. Ask your nurse to be certain.</td>
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Patient Tips for Choosing a Home Modality

1. Research your many options
2. Think about your long-term goals
3. Involve your care partner in the preplanning process
4. Consider how you can add home dialysis in your living space
5. Ask to speak with a patient who is dialyzing at home
6. Discuss any questions you may have with your healthcare team
7. Form a partnership with your care team
Starting the Conversation

The Myths vs. Reality booklet provides suggestions on how patients can start a conversation by asking questions of their healthcare team.

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<th>Conversation Starter</th>
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<td>Below are a few sample questions to start your discussion:</td>
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<tr>
<td>1. I’d like to talk to you about being considered for home dialysis. Where do I start?</td>
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<tr>
<td>2. What are the benefits with dialyzing more frequently at home and what are the choices that are best for me?</td>
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<tr>
<td>3. How long does the training take and what does it entail?</td>
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<tr>
<td>4. Do you have a video I can watch or a web link for more information?</td>
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<tr>
<td>5. Can I talk to a patient who is dialyzing at home?</td>
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Home Dialysis Announcement

This announcement:

• Celebrates a patient’s decision to dialyze at home
• Helps patients to think, “If this patient can do it maybe I can too”
• Encourages conversations about home dialysis
• Provides closure by informing patients and staff why they may not see the a patient at the clinic anymore
Health Status Release Form

A signed Health Status Release Form allows the clinic to:

- Inform others about a patient’s health status change, such as switching to a home modality
- Provide closure about why a patient is not coming to the center for dialysis
To access these resources visit: https://esrdncc.org/en/npfe-ian/