

Clearing the Road to Home: Overcoming Barriers and Misconceptions to Home Dialysis





Introduction

In Course 1, you learned about home hemodialysis and peritoneal dialysis. You now know the benefits of home dialysis and that home dialysis is a possibility for everyone with end stage kidney disease or ESRD. You also gained insight into how to educate patients on the home dialysis choice.

In this course, you will read about how individuals can transition to home dialysis, referrals, failure rates, and common barriers and misconceptions. You will become knowledgeable about these topics and your role in educating patients about home dialysis.

Overview of the Path to Home Dialysis

Let's start with some of the most common ways people start on dialysis. These are shown in the diagram on the next page, along with the reasons why individuals start on either home or in-center dialysis. The diagram also describes reasons why people switch from in-center dialysis to home or vice versa.

<p>New ESRD patients choose home dialysis</p>	<ul style="list-style-type: none"> • These individuals are called “direct start” patients. • In-center hemodialysis facility staff may never meet these patients unless there is a reason for them to treat in-center later. 	
<p>New ESRD patients start in-center dialysis</p>	<ul style="list-style-type: none"> • Individuals could choose in-center after understanding their treatment choices. • Or, individuals may not have been involved in their chronic kidney disease care, suddenly got worse, didn’t understand all of their options, were encouraged to do in-center because of a perceived barrier to home dialysis (like age, weight, lack of formal education, or home life) or were emotionally overwhelmed or too afraid to be able to advocate for their choices. 	
<p>New ESRD patients “crash” into dialysis</p>	<ul style="list-style-type: none"> • These individuals didn’t know they had end stage renal disease (ESRD) and never saw a kidney doctor. • Most of these patients will be directed to in-center hemodialysis while being educated on all dialysis treatment types. 	
<p>A transplanted kidney is no longer working and now dialysis is needed</p>	<ul style="list-style-type: none"> • These individuals may return to whatever dialysis treatment they had before transplant, if they were on dialysis. • Having experience with the healthcare system and enjoying freedom with a transplanted kidney, these people might find home dialysis attractive. 	
<p>Individuals decide to change from home to in-center dialysis</p>	<ul style="list-style-type: none"> • People say that treating at home, even if returning to in-center, made them more involved, better educated patients. • Individuals may move from home to in-center due to a medical or home concern or other personal decision. • If individuals move from home to in-center, at least they were given a chance to try home dialysis. 	
<p>Individuals decide to change from in-center to home dialysis</p>	<ul style="list-style-type: none"> • Individuals may move from in-center to home dialysis due to a medical or facility concern or other personal decision. • Or, individuals may have crashed into dialysis or had to start suddenly, but prefer home dialysis. • Or, individuals have been on dialysis for some time and find in-center treatment is not meeting their needs. 	



Moving from in-center dialysis to home dialysis is a difficult way for people to start on home dialysis, yet it is one of the most common paths. When people start in-center first, they:

- Usually lose residual kidney function in the first few months, which makes controlling fluid balance more difficult.
- May become accustomed to the friendly faces and support they receive in-center, making them worry about feeling alone if dialyzing at home.
- May quit their job because of the in-center treatment schedule or emotional response to dialysis, which contributes to feelings of hopelessness and not having a purpose in life.
- See professional staff handle every aspect of dialysis treatment, making them think home dialysis would be too complicated or scary to do themselves. (This may also make individuals feel helpless to help themselves.)
- May feel so “wiped out” or tired after treatments and other medical appointments, they don’t have the energy to think or follow through with more appointments.
- May have less hope for their future or feel depressed or anxious, which makes advocating for themselves or trying something new harder to do.

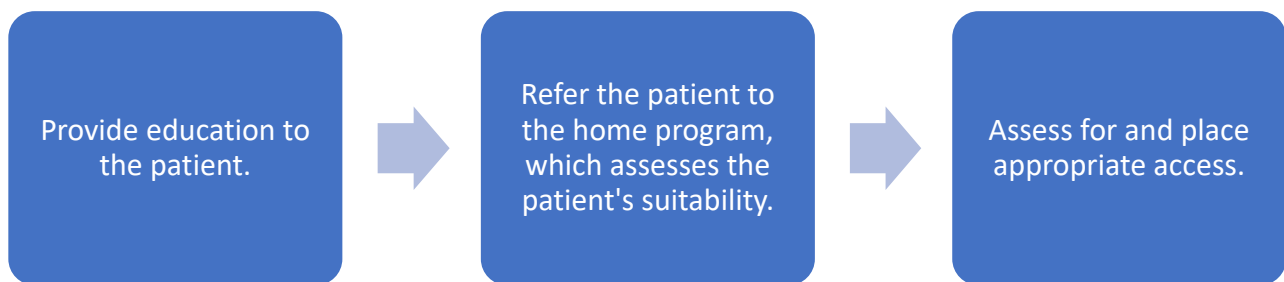
Those are some pretty big reasons why it may be challenging for patients to move to home dialysis after starting in-center. Is it any wonder that more people already on in-center hemodialysis don’t get referred or start on home dialysis?

In your role, how might you help with these issues?

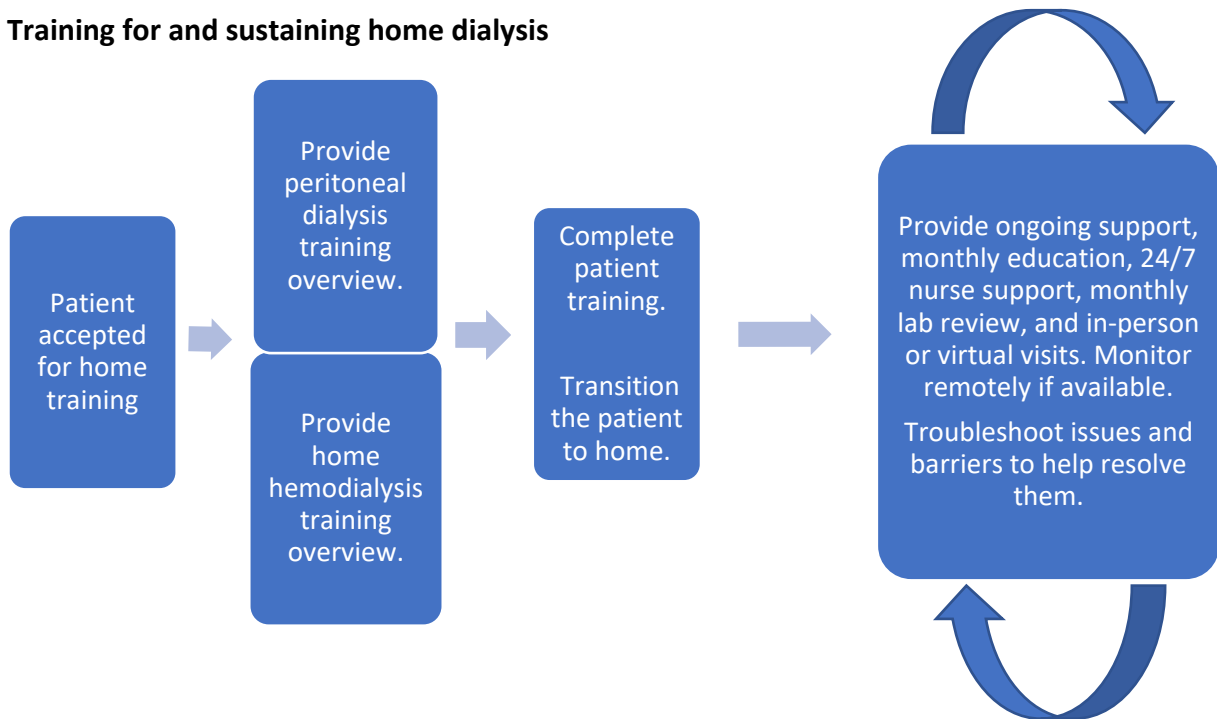
Transitioning to Home Dialysis

Steps to transition a patient from in-center to home dialysis may vary from company to company and sometimes even facility to facility. The length of training time for patients and/or care partners is individualized to what each patient needs. The diagrams below show an overview of the steps to refer patients to home dialysis and to train patients for and sustain home dialysis.

Referral and evaluation to home dialysis



Training for and sustaining home dialysis





Consider these ideas when talking with patients about home dialysis:

- Check the patient’s understanding of home dialysis treatments by asking open-ended questions.
 - Remember in Course 1, you learned some of the talking points you could use. Have you thought of any new talking points?
- Urge patients to look into their home dialysis treatment options. This should include speaking with someone on the home dialysis team, a home dialysis patient, a caregiver, or a family member in addition to their kidney doctor. Many people want to hear from “someone like me.” If they cannot meet with another patient, look online for resources that feature patients speaking about their experiences.
 - In Course 3, you will see some of the best places for patients to find information, including those that offer a clear patient voice.
- Advise patients to discuss home dialysis with their nephrologists and make the referral to home.
 - Did you know that nephrologists are not mandated to get training on home dialysis when they are in their fellowships? So not all doctors may be comfortable recommending home dialysis as they themselves are not comfortable with it. That’s another reason why it’s important that patients and families make their voices and their needs heard by the healthcare team.
- Inform patients of the different home dialysis options.
 - Ask individuals how they might like to learn about something new. Do they prefer written handouts, extra materials to take home to their families, watching a video, or talking to another patient one on one? Do they have concerns specific to their home situation, care partner engagement, age, or family obligations or some other unique concern? If so, try to find a resource or a peer that speaks to those unique needs.
- Involve care partners in the education and planning process.
 - An older person may need assistance or someone with children in the home may be concerned about how to handle dialysis and childcare. These are examples of individuals who may need help. However, not all home treatments require a care partner. Some programs offer remote monitoring, and some treatments can be done solo. Even if a care partner is not needed, it’s often a good idea to encourage patients to speak to their families about home dialysis for added support.

I would encourage other patients to educate themselves on the type of kidney disease they have. Learn about the different types of dialysis. They should make sure that their concerns are being heard by their nephrologists.
Home hemodialysis patient,
Michigan



To prepare yourself to speak with patients about home dialysis, learn details about home dialysis programs:

- Consider meeting with a home program nurse to better understand the training requirements to transition from in-center to home dialysis. A home dialysis nurse will provide the training on performing the treatments, completing logs, and ordering supplies.
 - Reassure patients that although training “usually” takes a certain amount of time, most home programs are very flexible and work with individuals and families until they feel safe and comfortable.
 - Remember, home programs provide training and support in creative ways to help any patient who wants to treat at home to be able to do that. Programs have been able to train and sustain individuals who cannot read or write English, are sight-impaired, have manual dexterity issues, and so much more.
 - Review Information on how to prepare a home for dialysis, including details like what to do with empty boxes and extra trash. Don’t let someone’s small worries keep that person from exploring home dialysis.
- Ask about the specific support that patients will receive from the home program while they are performing home dialysis.
 - All patients have access to a nurse via phone 24/7. Some programs or companies offer remote monitoring. Home patients have monthly visits and ongoing re-education on infection control, technique, and all other important topics.
- Learn details about why clinic visits, whether in person or via telemedicine, with the healthcare team are still required.
 - Clinic visits are an important time for patients and the home team to connect. The home team reviews lab results and often supplies the patients with medications, such as Epogen. Patients meet with the social worker, dietitian, nurse, and, of course, their kidney doctor.



Referrals

For home dialysis utilization to increase, more patients need to transition from in-center to home dialysis. Successful programs are supportive of patients who ask about home dialysis. These programs promote home treatment options by ensuring that facility staff understand home treatment options and are aware of when to promote the options and encourage a referral to home dialysis. They also rise to the challenge of accepting as many patients as possible and avoid dismissing patients as ineligible for home.

Data show gender, racial, and ethnic disparities exist in the rates of people on home dialysis modalities. One study showed that “every racial/ethnic minority group was significantly less likely to be treated with home dialysis than whites.” One of the factors that could affect referring patients was “physician or provider perception of patients’ ability to perform home dialysis.”¹

- *Ensure that the demographics of those referred to a home program represent the demographic make-up of the total patient population.*
- *Think about your own biases. They may be about the person’s level of formal education, the type of home they have, or how they dress or present themselves at treatment.*
- *Challenge yourself and your team’s perceptions to ensure all people can explore how home dialysis might work for them.*

Use these communication tips to encourage patients and caregivers to consider home dialysis options.

- Always ask yourself, “Why shouldn’t this patient be on home dialysis?”
- When approaching a patient to introduce home dialysis options, ask, “Has anyone ever talked to you about all of the different ways you can get dialysis?” instead of “Do you know about home dialysis or home modalities?”
- Share the “[My Life, My Dialysis Choice](#)” video with in-center patients. This video shows home hemodialysis and peritoneal dialysis patients receiving treatment.
- Create a facility-wide mindset that everyone is a potential candidate for home dialysis. This ensures that all in-center staff members can identify and recommend candidates for home dialysis.
- Allow the home dialysis team to make the final decision on suitability for home dialysis.
- Identify the patient who could potentially use peritoneal dialysis where others may not see him or her as someone who could manage home peritoneal dialysis.
- Discuss the possibility of home dialysis at every assessment and plan-of-care meeting.

¹ Mehrotra R, Soohoo M, Rivara M et al. Racial and ethnic disparities in use of and outcomes with home dialysis in the United States. *JASN*. July 2016;27(7):2123-2134. DOI: <https://doi.org/10.1681/ASN.2015050472>.



Acting on the reasons why someone could do home dialysis is essential to improving the quality of life for patients on dialysis.

- *As you engage with patients, ask yourself, could this patient do home dialysis?*
- *If you find yourself pulling away from the opportunity, ask yourself why? Be reflective and consider options to overcome the perceived barrier.*
- *Also ask yourself: How can I approach the conversation of home dialysis with this patient?*
- *And finally: Who can I ask to help me better understand home dialysis, so that I am confident in talking with patients about home dialysis options?*

Failure Rates

The positive result of higher-than-expected failure rates means people were given the chance to try home dialysis. It is important that dialysis centers examine and use the lessons learned from failure rates to better understand how they might sustain patients in home programs. Identifying clinical and psychosocial reasons for patients returning to in-center dialysis is key to considering a different home dialysis option before establishing in-center dialysis as the only treatment option. Remember, patients are able to consider three types of home dialysis treatment options.

What can you do?

You've probably seen patients who are temporarily in-center due to infection or another medical issue, or who were not able to stay on a home dialysis treatment. Individuals have said that being at home made them "better" patients, meaning that they were better informed about their labs, engaged in their treatment plan, and more comfortable asking questions and relaying their needs to their healthcare team. That doesn't sound like a failure! Think, as you interact with these patients, how you can tell or reframe their stories with hope and inspiration.



Common Barriers & Misconceptions

Psychosocial issues can be significant barriers to home dialysis use. These may include fear, anxiety, finances, living conditions, availability of storage space, stress, job layoffs, relocation, divorce, loss of caregiver support, native language, and burnout. These issues affect patients and caregivers alike and may stop patients from starting home dialysis. Opportunities to maintain a treatment plan may be jeopardized as well by such outside influences as inconsistent transportation, caring for children or grandchildren, or other psychosocial issues.

Patients may also have physical conditions that they or the staff view as roadblocks to home dialysis. These barriers could include age, body size, vision or hearing loss, and diseases such as diabetes. Even the type of access can be seen as a hindrance.

I got inspired by others. I saw many that were worse off than me – and I realized that I could do it.

Home hemodialysis patient,
Mississippi

None of these should be automatic disqualifications for home dialysis.

Teams all over the country, right now, are helping people overcome barriers to exercise their preferred dialysis treatment choice.

Strong home programs implement proactive person-centered strategies to work with patients and their caregivers to overcome barriers. Staff are educated on how to recognize the signs of a patient who may need assistance and are willing to consider a different treatment type for patients who would experience an improved quality of life on a home treatment option. Patients willing to transition to a home therapy are trained, able to perform and maintain home treatments, and improve their quality of life while on dialysis.

On top of potential barriers, patients and staff hold misconceptions about why patients cannot perform home dialysis. To improve access to home dialysis options, we have to address misconceptions not only with patients but also with dialysis professionals. Let's start with peritoneal dialysis and then look at hemodialysis misconceptions.



Misconceptions – Peritoneal Dialysis (PD)

Misconception: If a patient has had a previous abdominal surgery, he or she is not eligible for PD.

Reality: Routine abdominal surgeries, such as hernia repair, C-section, and some transplants, do not prevent PD as an option. The patient’s nephrologist and surgeon will help evaluate the options of peritoneal dialysis.

Misconception: Patients with vision or hearing impairments cannot do PD.

Reality: Assistive devices are available to help with most tasks involved in doing PD.

Misconception: Patients need to have a lot of space to do PD at home.

Reality: Patients do need some space for PD, but many people who live in efficiency apartments, trailers, and other small spaces find a way to make PD work.

Misconception: Patients who are overweight cannot perform PD.

Reality: While all PD involves having a special fluid in the abdomen, patients who are overweight should talk with their doctor about what is the best option for their circumstance.

Misconception: The risk of abdominal infection is great with PD.

Reality: When patients follow the procedures to perform their dialysis treatment, risk of infection is minimal. Shortcuts to the treatment process are never recommended for any reason.

Misconception: When patients do PD, they are free to take either a bath or a shower.

Reality: A bath is not permitted unless patients have a pre-sternal catheter placement. A shower is permissible, and patients are taught how to care for their catheter site before and after the shower.



Misconceptions – Home Hemodialysis

Misconception: Patients won't have an expert at home to help them.

Reality: With proper training for patients and caregivers, they become empowered experts at self-care. Plus, the home dialysis facility serves as a 24-hour telemedicine back-up. With the use of telemedicine on the rise, assistance is a phone call away.

Misconception: Patients are more likely to have a bleeding episode at home.

Reality: Machine alarms alert patients and caregivers to the detection of any problems with blood circulation. A safety device alarms and alerts the home hemodialysis patient if any blood is detected around the needle insertion site. Patients have time to react to the alarms, fix the problems, or disconnect from the machine.

Misconception: A home hemodialysis care partner needs a medical background.

Reality: Care partners don't need a medical background. In fact, in some cases, a care partner is not needed at all. Patients, and when needed, care partners, undergo extensive training before patients go through treatment alone.

Misconception: Patients can't have a pet at home because the pet may cause an infection.

Reality: Many homes where someone is dialyzing have a pet. Patients should clean the space in which they are dialyzing well and ensure pets stay out of the room when connecting or disconnecting. With proper care and training, pets can learn to adjust to the space set aside for dialysis, the machine noises, and patient responsiveness to treatment.

Misconception: Patients must buy the dialysis machine.

Reality: In almost all cases, the cost of the dialysis machine is paid by Medicare and/or a supplemental health plan.

Misconception: Patients have to pay out-of-pocket for home hemodialysis treatments.

Reality: Patients may have to pay for initial, minimal costs associated with making the home ready for home hemodialysis, such as shelving for supplies. But plumbing or electrical updates are not usually needed and basic supplies (dialyzers, lines, needles, tape, gauze pads, dialysate, home scale, laboratory supplies, etc.) are paid for by insurance, just as they are in a center.



What can you do to help patients overcome barriers and misconceptions?

You have taken the first step by taking these courses. Other ways to prepare yourself include:

- Keeping an open mind. Increasing patients' access to home dialysis means changing your own beliefs and patterns about referring patients to home dialysis. When you keep an open mind and seek to understand patient barriers to treatment plans, you are better positioned to help patients overcome barriers and refer patients to a home dialysis option.
- Asking people about their worries or fears. This gives them a chance to share openly and a chance for you to help them find answers and information.
- Getting training on home dialysis and communicating with in-center and home program staff, so you can help patients manage their fears and concerns, and home dialysis can become a new way of life for in-center patients.
- Listening to and validating patients' concerns and helping clarify any misinformation about home dialysis.
- Talking with a home dialysis nurse to learn more about how to answer patient concerns about home dialysis.
- Reaching out to patients who have transitioned from your in-center dialysis care to a home treatment option to learn first-hand what fears they overcame to transition to a home treatment option.

Remember, when sharing a patient success story with someone, do not share personally identifiable information, including the patient's name.



Staff Roles

Every in-center and home program staff member has an important role in understanding the details of both in-center and home dialysis options.

Each contact between you and a patient is an opportunity to improve awareness, transfer knowledge, and ultimately improve the quality of life for people receiving dialysis. While you may not know everything about the variety of treatment options, the more informed you are, the better prepared you will be to support patients' empowerment and self-efficacy.

- In-center staff role:
 - Educate patients about the benefits of home dialysis.
 - Provide educational brochures to support home dialysis.
 - Show real-life videos of patients performing home dialysis.
 - Invite current home patients to share their personal experiences with interested patients to dispel any myths and misconceptions.
 - Refer patients to a home program over evaluating patients' readiness for home.
 - Foster a culture of physician support for home dialysis.
 - Stay connected to local home programs by inviting their staff to come to the clinic, share patient referrals, and follow up on progress of patients who transitioned to home.
 - Work as a team in-center to create a culture that supports patient choice, empowerment, and engagement in their care for the span of their kidney disease journey.

- Home program staff role:
 - Prepare patients for home dialysis through orientation and training.
 - Coach families and friends (non-professional caregivers) to be available and supportive, especially during the initial transition from in-center to home dialysis.
 - Monitor and track patient concerns and provide guidance to overcome barriers on a one-to-one basis.
 - Utilize patient questions, concerns, and feedback to update resources, enhance orientation, and improve the home training program.
 - Connect with local in-center facilities to share experiences, success stories, and support to staff and patients.



Future of Dialysis, Future Careers

It's possible that some in-center staff may worry, "If my patients go to home dialysis, is it possible I could have my hours cut or even lose my job?" The truth is many people are diagnosed with ESRD every year. There will always be many patients for whom home dialysis is not possible or does not fit their lifestyle. While centers are always looking for ways to make in-center treatments/center operations more efficient, until bigger system changes or technological advances occur, many people will need in-center dialysis. You will continue to be needed in your role. And, working in dialysis is a special job that not everyone might like or be good at. As such, your specialization makes you unique—people rely on your set of skills to stay healthy, and those skills aren't picked up quickly. You matter.

In short, don't feel that encouraging people to explore home dialysis means you are jeopardizing your job.

In some areas of the country, not enough home dialysis nurses are available to meet the demand of patients wanting to train for home dialysis. With bold home dialysis goals for the country and the provider landscape changing, more opportunities are available to work in home programs than ever before. Some programs hire patient care technicians (PCTs) to reinforce nurse education, assist with tracking of labs and supplies, and help during clinic visit days.

Nephrology nurses, as you progress through your career, consider learning more about home dialysis as a career choice.

To be a peritoneal dialysis nurse you must:

- Be a Registered Nurse
- Have at least 12 months of experience as a Registered Nurse
- Have an additional three months of experience in the specific modality of PD (most home programs will train nurses)

To be a home hemodialysis nurse, you must:

- Be a Registered Nurse
- Have at least 12 months of experience as a Registered Nurse
- Have an additional three months of experience in the specific modality of home hemodialysis

If one Registered Nurse is responsible for both home hemodialysis and PD programs, the nurse must have 12 months of experience as a nurse plus at least three months of experience in each respective modality. Pursuing home dialysis nursing is an opportunity for career growth and advancement.



Case Studies

Case Study #1

Jonathon, a 68 year-old, has had only one kidney from birth, and it failed after a motorcycle accident. He asks the nurse in the hospital about treatment options, but she only knows in-center options. Jonathon starts dialysis at your small independent clinic, and he tells you he is interested in learning more about home dialysis.

You see that Jonathon has diabetes and is 68 years old. You think he is not a good candidate, so you make a note of his request but don't do anything else. Jonathon continues to get dialysis in the facility a year later.

How could you have handled this differently?

Inform team members. Share Jonathon's request with his nephrologist, the social worker, and the nurse. Raise the home dialysis question at Jonathon's next care planning meeting. If your facility has a home program, inform the home training nurse.

After the next care planning meeting, Jonathon gets referred to a home dialysis program. He is struggling a bit with all of the information.

How can you help Jonathon?

Understand that the overwhelming nature of chronic illness may affect his ability to make decisions or absorb new information. Be persistent and empathetic in educating him.

Jonathon is worried he does not have enough space to store the supplies that get delivered once a month.

The facility contacted the supply company and arranged for every-two-week delivery of supplies.

How can you help Jonathon make a successful transition to a home treatment option?

Work with Jonathon to identify and resolve other barriers with a mindset of maintaining what is in Jonathon's best interest. Separate the barriers or issues from the patient.

Work with the family and support system.

After completing his training, Jonathon moves to home dialysis. He is now one of the patients who visit the clinic to talk to other patients about home dialysis.



Case Study #2

You work in a 24-station, 140-patient in-center dialysis facility. During the monthly staff meeting, the manager shares that the goal of the facility is to increase the number of patients transitioning to home therapy by 15%. When exploring potential barriers to reaching the goal, it comes to light that the staff feel the reason why there are not more in-center patients going home is because “all the patients are too old.”

Which of these statements are appropriate for the manager to make in response to that statement?

“Every patient is an individual and should be discussed during the care plan meeting.”

“It is not for us to decide whether a patient is ‘too old’ for home dialysis. The home program can assess whether home dialysis could work for that patient.”

“Let’s talk about setting up a process to refer all patients who are interested to a home program.”

If you answered that everything the manager said was appropriate, then you are on track to support your facility in helping more patients dialyze at home.

- Consider all patients for home dialysis regardless of age and refer them to a home program if they express an interest and if their nephrologist agrees.
- Have the mindset that all patients should be considered as candidates for home.

Which of these could help your facility meet the goal?

Partnering with an established home program.

Yes. This is a great way to expand the home referral number. The home training nurse can provide education to all the staff and conduct individual option classes for patients. When possible, the home training nurse can also participate in home lobby days.

Showing the “[My Life, My Dialysis Choice](#)” video.

Yes. This video depicts home hemodialysis and peritoneal dialysis patients.

Inviting patients to attend support groups.

Yes. Current home patients can provide insight and peer support on home dialysis.

Encouraging patients to participate in peer mentoring.

Yes. This will allow them to receive support and education.



Increasing home therapy awareness.

Yes. Strategies could include holding lobby days focusing on home dialysis to expose patients to home dialysis and posting educational material on bulletin boards in the lobby and by the scale.

Sharing educational flyers and resources.

Yes. Patients will learn the different types of home dialysis and whether or not home dialysis is what they want. Here are resources to consider:

- [Uncovering Myths About Home Dialysis](#)
- [Choosing Home Dialysis](#)
- [Know the Facts About Home Dialysis Choices](#)
- [Treatment Options: Peritoneal Dialysis](#)

Inviting patients' families to come to the facility to meet the home dialysis staff.

Yes. This will involve the patient's support system in the decision-making and will educate them about what will be needed for successful home treatment. Sending educational material home to review with the family and caregiver is also helpful.

What is the best way to approach a patient? Do you think asking a patient what she knows about home dialysis modalities would work?

This could limit the conversation. Instead, ask, "Has anyone ever talked to you about all the different ways you can get dialysis?"

Ask open-ended questions about a patient's life before dialysis. Offer ways that a home modality could return her to a status more like before starting dialysis.



Next Steps

Congratulations, you have completed Course 2. You may begin Course 3.

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