Course 1

Toward Home: Understanding and Empowering Dialysis Choices

Universal Staff Education—Home Dialysis
Introduction
A person on dialysis spends more time interacting with the healthcare team than a patient with any other chronic disease does. This time together enables you, as a member of your facility’s team, to build a relationship with each patient and gives you the opportunity to use your clinical knowledge and personal insights to educate, encourage, and motivate patients to lead their healthiest and best lives with kidney disease.

You are in the best position to talk with patients about home dialysis. You may not yet feel comfortable in this role, but this home dialysis course, along with Courses 2 and 3, will give you the tools you need to open a conversation about home dialysis with patients.

You are not expected to be an expert on home dialysis. However, after taking these courses, you will know how to talk with patients about home treatment, recognize patient readiness, understand that many common obstacles can be easily overcome, and be able to discuss different home treatment options. You will also understand the bigger picture—national goals, progress toward meeting them, and what you can do to help. Most importantly, you will feel comfortable talking with patients about and referring them to home programs.
Overview

More than 37 million people in the United States have kidney disease, which was the ninth leading cause of death in 2017, costing an estimated $114 billion each year.\textsuperscript{1,2,3} Once kidney disease progresses to kidney failure, known as end stage renal disease or ESRD, then dialysis or a kidney transplant is needed.

Most people start their treatment at in-center hemodialysis clinics. The treatment includes three weekly treatments for three to four hours at a time, which can be taxing for patients and their families.

Home dialysis, including peritoneal dialysis and home hemodialysis, is another choice for patients with ESRD. This option offers an improved quality of life and similar survival rates, while allowing patients to dialyze in a familiar environment.\textsuperscript{4,5,6,7} Despite these advantages, home dialysis is underused. Only 2\% of hemodialysis patients receive treatment at home, even though 85\% are eligible.\textsuperscript{8,9} Furthermore, up to 40\% of patients would have chosen home dialysis had they received appropriate education.\textsuperscript{10} A clear opportunity exists to increase the number of patients offered home dialysis.

Informed Choice

Most patients are educated on the different types of dialysis treatments and transplant when they are told they will need dialysis. So, they are informed, correct?


These words and ideas, although complex, make sense to you because you have chosen dialysis as your profession. You have learned about these concepts over time. To patients just starting dialysis, this is all new information.

People want to understand their diagnosis and act on the best options available to them. However, they often make decisions without a complete understanding of the diagnosis and treatment options—and at a time when they are facing some strong emotions.

Think back to the last time you got hard news or faced a serious life change, like losing a job or the end of a relationship. How did you feel? You may have felt anxious about the future and imagined all the bad things that could happen. You may have felt angry—it doesn’t seem fair that this happened to you. You might have denied that this tough thing was really happening. Maybe you told yourself this isn’t real; things will go back to how they used to be.

*Do you recognize any of these things in the people new to dialysis and/or their families?*

Experiencing these strong feelings and reacting emotionally is totally normal and can be expected. But when a person just starting dialysis is in this emotional place, it’s hard for him or her to take information into the rational part of the brain. The emotions take over, and it’s harder for information to be really heard and understood.

Now, let’s put these two ideas together. Imagine trying to learn about something as complex and specialized as dialysis while being worried, angry, or shocked. Imagine trying to learn anything when you’re worried you may die.

You must consider all of this when talking with patients about home treatment.

You will also need to discuss the person’s lifestyle and quality of life, including his or her life before the kidney disease diagnosis. Many patients worked full-time and led active lives with their families and communities. Incorporating these factors into your discussions with patients, along with early education on home dialysis treatment options and easy-to-understand explanations of the diagnosis and treatment options, will prepare patients to make informed choices on the best treatment for them.
Studies show:

— 20–50% of pre-dialysis patients with chronic kidney disease choose home during education sessions\(^\text{11}\)

— 78% are both medically and psychosocially suited for peritoneal dialysis\(^\text{12}\)

— ~40% of patients could be on home therapies by home dialysis proponents’ estimate\(^\text{13}\)

— 94% of nephrologists surveyed would choose home for themselves if they required treatment\(^\text{14}\)

So, let’s say 40% of patients with ESRD are suited to home dialysis and would choose it.

• Why do you think only 14% are on a home dialysis treatment\(^\text{15}\)?

• How could the current system be changed to better educate and encourage people that home dialysis might work for them?

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Early Education

The University of Florida (UF) Comprehensive pre-ESRD Patient Education Protocol\(^{16}\) supports early education of patients on home dialysis. The protocol was piloted with established patients with chronic kidney disease of stages 4 and 5 severity and not on dialysis. The education provided decision-making guidance for patients transitioning to dialysis.

The pilot cross-walked three delivery methods for educating patients about their treatment options:

1. **Pre-ESRD group education** focused on reducing biases toward specific modalities and supported patients’ preferences and choices based on their concerns and lifestyles.
2. **Face-to-face counseling** used protocol-based discussions. These were designed to enhance group learning; gain an understanding of the individual’s lifestyle, living situation, and personal concerns; and assess health conditions.
3. **Life-style simulation discussions** on the modality choice occurred weekly. The life-style simulation brought patients closer to the treatment plan and allowed them the opportunity to compare their preferred lifestyle to the lifestyle transition needed to accommodate their choice.

Results told an impressive story of how education plays a meaningful and powerful role in helping patients transition from chronic kidney disease to a home treatment option. Of the 108 patients enrolled in the training, 70% chose home dialysis. Of these patients, 55% chose peritoneal dialysis, and 15% chose home hemodialysis. Perhaps an even greater achievement is that 25.3% changed their treatment preference after the first education session, and comprehensively, the program resulted in a 216% growth in home dialysis census. This nearly doubled home dialysis prevalence to 38% of all dialysis patients.

Your facility may not have the bandwidth to conduct group trainings or life-style simulations. However, by increasing your education and awareness of home dialysis, you can be comfortable empowering patients to make an informed choice about their care plan and how to best manage their renal disease.

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Benefits of Home Dialysis

Individuals who dialyze at home enjoy multiple benefits that include:

- More independence
- Greater control of life choices
- More freedom to fit treatments into personal schedules and to choose day or night treatment times
- Improved energy levels after treatments
- Better sleep
- Fewer food and drink restrictions
- Ability to maintain friendships, social activities, and work life
- Improved control over blood pressure and labs
- Fewer trips to and from the dialysis center

Doing my dialysis at home has allowed me to gain a sense of freedom and allows me to have the time and energy to do daily activities. I can do dialysis while I sleep and wake up and go about my day. I'm also healthier than I was on hemo because I feel good and dialyze daily.

Patient

Home Dialysis and Transplant

Dialysis is far from sustainable. One hundred thousand Americans begin dialysis each year, and approximately one in five of them are likely to die within a year. The best option for those with kidney failure is a kidney transplant, but approximately 93,000 Americans are currently on a waiting list for a new kidney.

The self-sufficiency of home dialysis offers a bridge to transplant for patients preparing to be waitlisted or already on the waitlist. Patients dialyzing at home have control over their treatment schedule and independence from the in-center regimen. This autonomy seems to support a better sense of well- and physical-being, providing greater patient empowerment and motivation to adhere to the care plan, while keeping patients as healthy as possible as they prepare for transplant.

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Considering Benefits
When deciding on which treatment option would work best for them, patients should consider the benefits of home dialysis as well as their physical and psychosocial situations, such as family support. You should share the benefits of home dialysis when patients show an interest in this treatment choice.

Approximately 90% of nephrologists and nephrology nurses surveyed would choose home dialysis if dialysis was needed.20

- Why do you think more nephrologists would choose home dialysis over in-center dialysis?
- Knowing what you know now, if a loved one needed dialysis, what might you tell them?
- Why might there be a gap between doctors choosing home dialysis for themselves but most patients being on in-center hemodialysis?

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Patient Education: Right Time, Right Tone, Right Way

Education can happen anywhere at any time. For example, while a patient is preparing to start dialysis, she may pose a question or two about something she was told or read. This is a great time for you to respond and make the moment a positive encounter by replying in an informative and educational way.

People on dialysis are quite ill and may not always remember what they have been told. You may have to share information during several encounters until the patient fully understands.

You will achieve the best results when you are meeting the patient’s needs. If you teach only at a time that fits your schedule, the education may not be as effective. However, dialysis facilities are busy, and it may be difficult to find the time that you would like to spend with a patient. To overcome this challenge, try this:

- Provide the patient with some resources before you begin teaching. He or she can review these beforehand to get an initial understanding and be prepared with questions.
- Deliver the patient teaching in small chunks. This will help you to fit the teaching into your schedule and will avoid overloading the patient.
- Try using the teach-back method. After you explain something, ask the person to say what he or she learned in his or her own words. This gives you a chance to check for understanding and clarify information.

According to the CMS Conditions for Coverage for ESRD Facilities, an initial comprehensive assessment must be conducted on all new patients within 30 calendar days or 13 hemodialysis treatments. A follow-up reassessment must occur within three months after the initial assessment and annually thereafter.

Part of this comprehensive assessment includes presenting to each patient all options of modalities (including peritoneal and home hemodialysis). If a patient is not suitable or declines home therapy, the reason must be documented in the plan of care.

Your facility may choose to have more frequent education about home dialysis.

It is equally important to use the right tone of voice and make the appropriate eye contact when talking with patients. If possible, sit down at the same level as the patient instead of standing and looking down at him or her. Refrain from judging and rushing the patient. Promote an environment of respect and understanding by stopping to ask if the patient has questions. This is a great way to make sure that the patient understands the information.

Encourage the patient to continue talking. Use verbal comments, like “yes” and “okay,” and then wait to respond until you’ve listened fully to the patient’s thoughts. Try not to interrupt while the patient is speaking, so that you can fully hear the concerns or questions.

Every engagement with a patient can be a teaching moment. Listen—it is your most powerful tool. Remember, every patient is at a different place in his or her journey.
**What can you do to support patients to get ready to be referred to home peritoneal dialysis or hemodialysis?**

Strategies include the following:

- Boost patients’ confidence by empowering them to take full responsibility for their treatment and engage with them while starting their treatment.

- Observe patients to uncover if they have a reliable friend or family member (care partner) who is supporting them in their in-center treatments. Learn whether the care partner would be available to help them when they initially transition to home dialysis.

- Assess patients’ activities during dialysis. Do they read a book? Are they attempting to take an online course as a hobby or for a degree? Do they engage with other patients during treatment? These activities can help assure you and the patients that they can undergo training, including up to eight weeks of training to transition to home hemodialysis.

- Talk with patients about their home environment, when appropriate. If storage is a concern, ask them to think of ways that they may be able to rearrange the interior design of their home to accommodate home dialysis.

- To help gauge patients’ interest in home dialysis over time, consider asking them, “On a scale of 1 to 10, how interested in home dialysis might you be?” Ask open-ended follow-up questions about what parts interest them and what they are unsure of. Then ask them, “On a scale of 1 to 10, how ready might you feel to start home dialysis?” Follow up with open-ended questions about what it might take for them to feel ready. Then provide information or refer them to someone else on the team to answer those questions. For people who answer with low numbers on this scale, try to ask these same questions every few months and see how their answers might evolve.

Specifically, for home hemodialysis:

- Support patients in making sure that they maintain a healthy working vascular access for hemodialysis.

- Discuss the water and electrical supply access for home equipment. Help patients feel assured that the changes can be accomplished, especially if they own their homes or live with someone who does. If they rent, encourage them to talk with their landlord about their options. Provide a list of suppliers in your area that you know have completed the work for other patients who transitioned to home, if such a list is available.

*People get in-center and establish a pattern they don’t want to break, especially in a difficult time.*

Home Program Manager, Washington
Peritoneal Dialysis
Peritoneal dialysis is a way to remove waste products from the blood when the kidneys fail. These treatments can be done at home, at work, or while traveling. Patients considering peritoneal dialysis will need manual dexterity. It is recommended that patients undergoing peritoneal treatments have a reliable family member or friend nearby for support.

Types of Peritoneal Dialysis
There are two types of peritoneal dialysis:
- Continuous ambulatory peritoneal dialysis (CAPD)
- Automated peritoneal dialysis (APD)

These methods remove waste and excess fluid from the blood, and both can be done at home. Both types of peritoneal dialysis require a catheter to be surgically placed in the abdomen, which is not a difficult procedure. Most patients who undergo the procedure go home the same day.

Continuous Ambulatory Peritoneal Dialysis (CAPD)
During CAPD, the patient performs an “exchange” four to six times throughout the day. During an exchange, a liquid—dialysate—is put into the abdomen through the catheter. The dialysate pulls wastes, chemicals, and extra fluid from the blood through the lining of the abdominal and pelvic cavities or the peritoneum. The peritoneum works like a filter as the wastes are pulled through it. The process of filling and emptying the abdomen with dialysate is called an exchange. The exchange is accomplished by using gravity to fill and remove the fluid. Each exchange takes between 30 and 40 minutes and needs to be completed every four to six hours.

Automated Peritoneal Dialysis (APD)
APD is also referred to as continuous cycling peritoneal dialysis or CCPD. APD differs from CAPD in that a machine, referred to as a cycler, delivers and drains the dialysate to and from the abdomen. The treatment is usually done at night while the patient sleeps but may also require additional daytime CAPD exchanges.
The illustration on the left, below, shows an example of the position of the catheter to be used for peritoneal dialysis. The illustration on the right shows how dialysate enters the abdomen through the catheter and how wastes and fluid leave the body into a drainage bag.

**Peritoneal Dialysis**

**Training – Peritoneal Dialysis**

Training will take place at the home program facility, and each session will last anywhere from four to seven hours. The training is conducted by a trained home dialysis nurse. Training will differ from patient to patient but usually takes between one to two weeks to complete. Once the patient can do the exchanges comfortably and his or her lab work is within range to support peritoneal dialysis, the patient can convert from doing the treatments at the facility to doing the treatments at home.

After the patient completes the training and is at home, the home program nurse will provide support either in person or by phone as needed. The patient is still required to be seen by the healthcare team monthly either via telehealth or in person.
The picture on the left shows a peritoneal dialysis cycler machine in a patient’s bedroom. The picture on the right shows a patient getting ready to be connected to the peritoneal dialysis cycler machine prior to going to bed for the night.

This link provides helpful information about peritoneal dialysis: “Home Dialysis—It Could be the Right Treatment for You.”
Home Hemodialysis
Hemodialysis usually takes place in a facility three times a week, but it can also be done safely at home. Home hemodialysis gives patients more control over their treatment schedule and reduces the number of trips they must make to and from the dialysis center. When dialysis is done at home, the patient might need a family member or friend to help.

There are three different types of home hemodialysis:

1. Standard home hemodialysis (three times a week)
2. Daily home hemodialysis
3. Nocturnal (night-time) home hemodialysis

The number of treatments a patient will need may vary from three to seven times per week, and the number of hours needed to receive treatment will be based on the number of treatments per week and the patient’s medical needs.

Both pictures show patients alongside their dialysis machines in the comfort of their own homes.
**Training – Home Hemodialysis**

Home hemodialysis patients and their care partners are required to complete comprehensive training at the home program facility. They will learn about how to safely perform the dialysis treatment, keep accurate treatment logs, clean and operate the equipment, and self-cannulate. The training usually takes from four to eight weeks and is conducted by a home dialysis nurse. After the patient completes the training and is at home, the home program staff will provide support either in person or by phone as needed. The patient is still required to be seen by the healthcare team monthly either via telehealth or during an in-person visit.

In August 2017, NxStage (a maker of dialysis equipment) received regulatory approval for patients to perform home hemodialysis without a partner, if the treatments are done during waking hours. This means that patients can modify their treatments to their specific needs. Patients need a prescription from their nephrologists to perform solo home hemodialysis.

This patient is connected to a hemodialysis machine at home.

This link will take you to a video that contains a brief overview of the different types of home dialysis options: “[My Choice, Home Dialysis](#)”
A Home Patient Can Be Anyone!

To transition more patients from in-center to home dialysis, it takes a mindset that home dialysis is possible for everyone. Operating from a belief that all patients can be considered and referred for home modalities is essential to the success of any home program. Effective programs cast a wide net to receive referrals. They also rise to the challenge of accepting as many patients as possible and avoid dismissing patients prematurely as ineligible for peritoneal dialysis.

Many patients lean into dialysis professionals, seeking confidence that the situation can be better. Openly and regularly communicating about home dialysis choices removes the patients’ mistaken belief that they have not been offered information about home options because they are not a candidate for the options. This means that you need to be equipped with knowledge and understanding to help patients select a home treatment option. Education can fortify your confidence and open pathways for you to discuss options with patients and better understand the benefits of home therapy.

Below, are examples of tactics you can use individually or with your team members to improve the number of patients using home dialysis.

- Suggest that your facility schedule routine calls with home programs to share confirmed in-center patient interest, education, and progress toward home modalities.
- Research and share clinical solutions to overcome challenges (e.g., peritoneal dialysis regimens, obesity, past abdominal surgeries).
- Allow the home team to make the final decision on suitability for home dialysis.
- See the potential peritoneal dialysis patient where others may not see him or her; see everyone as a candidate even if others have not in the past.
- Promote a facility-wide mindset that everyone is a candidate for home dialysis. This ensures that all in-center staff members can identify and recommend candidates for home dialysis.
- Do not ask, “Is this patient a peritoneal dialysis candidate?” Instead ask, “Why couldn’t this patient be on peritoneal dialysis?”
- Understand that uremia may affect a patient’s ability to make decisions or absorb new information and be persistent and empathetic in educating the patient.
- Accept that there will always be a percentage of people who will struggle with home dialysis. Work with these individuals on a case-by-case basis with a mindset toward maintaining them on a home modality. Encourage new patients to view the video, “My Life, My Dialysis Choice.” This will help patients choose the right treatment that fits their lifestyle.
• Ask open-ended questions about patients’ lives before dialysis and offer ways that a home modality could return them to a status more like before they were on dialysis.
• Do not ask patients if they know about home modalities. Instead, ask, “Has anyone ever talked to you about all the different ways you can get dialysis?”
• Bring up the possibility of home dialysis at every assessment and plan-of-care meeting.
• Start an “Experience the Difference Program” in which a dialysis facility partners with a home program to offer a two-week in-center trial of a home dialysis machine and schedule, coupled with intensive patient and family education about home modalities.
• “Have faith” in the home team if they want to give a patient an opportunity to be successful.
• Work with the family and support system.
• Show new in-center hemodialysis patients the “My Choice, Home Dialysis” video, which depicts home hemodialysis and peritoneal dialysis patients. The video has an emphasis on African American and Hispanic patients who explain why they chose their modality.
• Share a vision for home suitability, e.g., “Anyone with a peritoneum and a home can do peritoneal dialysis.”
• When an in-center hemodialysis patient reports a significant life change, ask him or her follow-up questions and connect the patient to his or her nephrologist, educator, or home nurse; look for an “entry point” for a patient to consider a home modality.
• Be proactive in assessing possible barriers by observing a patient’s body language, tone of voice, if he or she is acting in a way different from his or her typical manner, and responses to non-clinical questions. Ask follow-up questions to investigate.
Talking Points
Talking points provide a quick and easy way for you to stay on track and make sure communications with patients are consistent. Talking points can also affirm or negate a situation. When you talk with patients about their treatment options, it is important that you remain open and positive toward the options that a patient may wish to explore. The talking points below provide consistent messages for you to use when working with patients who are considering home dialysis.

Talking Points – YES
Say things like,

- “Choosing a treatment option is a personal decision. It is important that your treatment choice supports your lifestyle and values.”
- “Every patient can be considered a home dialysis candidate.”
- “There are advantages and disadvantages to home hemodialysis and peritoneal dialysis options. The good news is you aren’t ‘locked in’ to any one of these options.”
- “Although peritoneal dialysis is every day and in APD, throughout the day, it most likely takes less time than traveling to and from and receiving treatment in-center.”
- “Studies indicate that receiving dialysis treatments more frequently can significantly improve patient outcomes. This may mean better survival of kidney disease for you.”
- “If you dialyze at home, you can travel with greater ease because your equipment and supplies are with you or are shippable to and from your destination.”
- “Home modalities are a bridge to transplant.”
- “You will always have other treatment options if home dialysis does not work for you.”
Talking Points – NO

Don’t say things like,

• “Home dialysis requires you to take full responsibility for your treatment.”
  o Explanation: This may give patients the wrong impression. Patients are not alone. They will have team support and may have a caregiver that can help as well.
• “You will need many hours of training to begin home dialysis.”
  o Explanation: It would be better to discuss what is needed in the training and emphasize that the patient will get all of the training he or she needs to feel comfortable at home.
• “Dialysis supplies take up a lot of space.”
  o Explanation: The team will work with the patient to accommodate his or her home environment.
• “If you rent, your landlord may not allow the water and electrical connection changes required for home dialysis.”
  o Explanation: Not all of the equipment needs to have water or electrical changes.

These negative talking points may have some truth in them, but they certainly don’t make home dialysis seem like a real possibility for someone. People all across the country have figured out solutions for many of these issues. Solutions are out there! It takes a positive mindset to frame the downside of any situation to present the information in a real and meaningful way without making the information seem impossible or out of reach for the patient.

When patients ask questions that have complex or complicated responses, try responding with a question before using a negatively positioned talking point. For example, a patient may ask about training for home dialysis. A staff member might observe that the patient has been asking about placing herself on the machine and respond by asking, “Would you like me to connect you with a home program nurse who can talk with you about the training?” This response is helpful and refrains from making the training seem overwhelming.

• Don’t share stories in a negative light about people who return to in-center.
• If you don’t know something, don’t guess—tell the patient you’ll ask or look it up and get back to him or her.
• Don’t feed into someone’s fear or negativity. You can always say things like, “Well, for some people home dialysis works out really well.” Or, “That’s okay, we can talk about home dialysis later. The choice to look into home dialysis is always open.”
Tips

• Think “why shouldn’t this patient be on home dialysis?”
• Look for opportunities to be successful with each patient referred, e.g., assistance from family members.
• Ensure all training, education, and patient interactions are upbeat and encouraging.
**Patient Case Study**

You work in a small town in Mississippi. Tom, who is an in-center dialysis patient, says to you, “I am interested in learning about peritoneal dialysis. Am I a good candidate?” You know that Tom cannot read.

**What would your reply be to Tom?**

You think that Tom is not a candidate because he must be able to read to be trained for peritoneal dialysis. You tell him that he has to be able to read to do dialysis at home. Tom stays in-center for his dialysis.

**Is this the best response to give to Tom?**

No. It might better to ask Tom:

“What do you know about peritoneal dialysis?”

“What information have you received about home dialysis?”

Then consider: Are there resources you could share with Tom that would not require reading, such as pictorial flyers? Are there videos about peritoneal dialysis that he could watch? Who could help Tom?

You talk with Tom about home dialysis. You connect with the home program to find pictorial flyers, videos, and other material on home dialysis. You share these with Tom. You also ask Tom if he has a family member or friend who could read materials to him.

Tom watches videos and takes the materials home to a family member. On his next visit, he tells you that he wants to do home dialysis.

**What is the next step?**

You refer Tom to the home program nurse or facility for evaluation. You realize that a patient’s inability to read does not make him ineligible for peritoneal dialysis.

**Consider these solutions:**

- **Consult with the home program:** Some home programs have trained blind patients to do home dialysis.
- **Use technology:** Many of the peritoneal dialysis cycler machines talk patients through setting up the machine. Some have modems that can upload data without the need for a flowsheet.
- **Get creative:** One home staff nurse audio recorded step-by-step instructions on how to operate the cycler. Because this nurse was able to think outside the box, this patient is now on home dialysis.
- **Utilize pictures:** This can be another useful tool for training patients who cannot read.
Facility Case Study
“Isn’t this the MSW’s job? We don’t even have a home program.”

You work in a dialysis facility that does not have a home program attached to it. One day while you are working, Suzie, who has been a dialysis patient there for three years, asks, “How do I get information about home dialysis?”

You respond to Suzie, “We don’t have a home program here at our facility. It’s not my job to know about home dialysis. I only know in-center dialysis. You would need to ask the social worker about that.”

Is this a good response to Suzie?

The clinical manager overhears this conversation.

What do you think the manager should do?

The clinical manager recognizes this is a problem and develops a plan to educate all staff about home therapies. The manager meets with all of the staff to share detailed training/education on home dialysis options. She also tells the staff what steps to take to start the referral process for patients who are interested in home dialysis.

The manager partners with a nearby facility that has a home program to assist with training of the in-center staff, including front office, biomedical, social workers, and dietitians.

Oscar, a new patient to the clinic, asks, “How do I get more information about home dialysis?”

You give him an overview about the home therapy options. You also share educational resources and connect him to the home program nurse for more information.
Resources to Learn More
As you explore home dialysis, these downloadable resources, including continuing education units (CEUs), are available:

- ANNA CEU events available for members only at a cost: https://annanurse.org/
- DaVita: https://www.davita.com/education/kidney-vocabulary/home-hemodialysis
- Fresenius Kidney Care: https://www.freseniuskidneycare.com/tools-and-resources
- Home Dialysis Central: https://homedialysis.org/
- NANT, available for members at a cost: https://www.dialysistech.net
- National Kidney Foundation home dialysis course with a $35 fee: https://education.kidney.org/content/connected-health-home-dialysis
- NxStage Home Hemodialysis: https://www.nxstage.com/hcp/training-resources/education-videos/

Next Steps
Congratulations, you have completed Course 1. You may begin Course 2.
Course 2

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

Universal Staff Education—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.
New ESRD patients choose home dialysis
• 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.

New ESRD patients start in-center dialysis
• 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.

New ESRD patients “crash” into dialysis
• 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.

A transplanted kidney is no longer working and now dialysis is needed
• 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.

Individuals decide to change from home to in-center dialysis
• 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.

Individuals decide to change from in-center to home dialysis
• 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

1. Provide education to the patient.
2. Refer the patient to the home program, which assesses the patient's suitability.
3. Assess for and place appropriate access.

Training for and sustaining home dialysis

1. Patient accepted for home training
2. Provide home hemodialysis training overview.
3. Provide peritoneal dialysis training overview.
5. Transition the patient to home.
6. Provide ongoing support, monthly education, 24/7 nurse support, monthly lab review, and in-person or virtual visits. Monitor remotely if available. Troubleshoot issues and barriers to help resolve them.
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.

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.

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.
Course 3

Putting It All Together to Make a Difference

Universal Staff Education—Home Dialysis
Introduction

After taking Courses 1 and 2, you are able to discuss what home dialysis involves, its benefits and perceived barriers, and your role. You are prepared to recognize patient readiness, talk with patients about home dialysis, and help with the referral process by sharing your insights on the patients with the rest of the team. This course looks at the broader picture—national goals, progress toward meeting them, and what you can do to help.

Renal Community Goals

In 2019, the U.S. Department of Health and Human Services (HHS) launched the Advancing American Kidney Health (AAKH) Initiative, which outlines goals to address kidney disease in the United States.¹ The AAKH Initiative focuses on fewer patients developing kidney failure, fewer Americans receiving dialysis, and more kidneys being made available for transplant. The Centers for Medicare & Medicaid Services (CMS), an agency of HHS and the majority payer (~90%) for individuals diagnosed with end stage renal disease (ESRD),² is concentrating efforts on these goals.

This makes HHS and CMS goals meaningful to everyone in the renal community—patients, providers, nephrologists, and staff—as we work together. Dialysis clinics, kidney care stakeholders, and partners across the continuum of care will be needed to create this level of systemwide change. Importantly, you, as a frontline staff member in close contact with patients, are in a vital position to help meet these goals.

The AAKH Initiative has set a goal of 80% of patients newly diagnosed with ESRD receiving dialysis in the home or receiving a transplant by 2025. As you will see in the next section, based on the current trend, only 29% of patients new to ESRD will receive a transplant or use home therapy within 180 days, falling far short of the 2025 goal.

We can do this!

It will take all of us—nephrologists, clinic managers, nurses, patient care technicians (PCTs), social workers, and dietitians—working together to reach the goal, so that more people can lead the kind of lives they want—to thrive, not just survive.

The focus on home dialysis as an avenue to improved quality of life and patient engagement is not just being promoted at the government level. Dialysis companies, large and small, have also been encouraging home dialysis.

- What has the dialysis provider you work for done to promote home dialysis?
- Have you noticed a difference in the way people are talking about home dialysis?
- Have you received more education on home dialysis lately?

One way to support the goal to increase patients dialyzing at home is to ensure that in-center dialysis professionals, such as nurses, renal dietitians, social workers, dialysis technicians, and assistants, are knowledgeable about home dialysis treatment options. As an in-center dialysis staff member, you can promote home dialysis treatment options and talk with all patients about how home treatment could work for them. Your knowledge and awareness of home dialysis can empower conversations between the patient and the nephrologist or the home dialysis nurse.
Progress Toward Goals for Home Dialysis
In January 2020, the ESRD National Coordinating Center (NCC) calculated the future progress toward the 2025 goal, which is for 80% of patients newly diagnosed with ESRD receiving dialysis in the home or receiving a transplant. As you can see in the graph, on the current track, we won’t reach the goal by 2025. If we, as a community, continue along the status quo, we will not reach the goal. We must all take action.

Based on the current trend, by 2025:

- Only 29% of patients new to ESRD (incident patients) will receive a transplant or use home therapy within 180 days.
  - 25% – will receive home therapy.
  - 5% – will receive a transplant.
  - 1% – will receive both.
- The average annual projected improvement rate is 1.3%.

To meet the 2025 goal, the following is needed:

- **An additional 51%** of patients will need to receive a transplant or use home therapy.
- **An additional 63,630 patients** will need to get a transplant or start home therapy.
- **The average annual improvement will need to be 7.3%**.
Moving Forward

In Course 2, you learned ways to address barriers and misconceptions to home dialysis that both patients and professionals hold. You also have to consider environmental factors. For example, patients will need adequate space to perform home hemodialysis, or to adjust their sleeping environment to make room for a cycler while they sleep. And new environmental factors, such as managing treatment during a pandemic, like COVID-19, need to be considered.

While there is much to learn about COVID-19, the onset of the pandemic has opened new communication channels for patients and providers. For example, the use of telemedicine and telehealth reduces patient and provider exposure during routine check-ups. The pandemic may also provide a pathway to increase access to home dialysis. Patients who are concerned about their exposure to COVID-19 may want to consider home treatment options. With social distancing and gathering restrictions in place, now is a good time to ensure you are comfortable with presenting home dialysis options to patients and discussing how they can make the transition from in-center to home dialysis.

Still, obstacles must be overcome. Some obstacles, such as managing a certificate of need,\(^3\) are regulatory, while others include insufficient staff to train on home dialysis options. However, since the onset of COVID-19, the healthcare community has witnessed numerous federal, state, and local restrictions being lifted. If facilities implement staff awareness training, the dialysis community may be better positioned to meet the robust goals to increase kidney patients’ access to home dialysis, especially during these rapidly evolving times.

Success Stories

Success stories from the field are another way to advance home dialysis for more people. This brings better quality of life to more people and advances us toward our national goals outlined in the AAKH Initiative.

Success stories can provide inspiration for you as you look to adapt your facility’s services to include home dialysis options. They can also inspire hope for patients who want to dialyze at home but don’t currently have that option.

Here are two brief examples:

- Nephrologists play a significant role in supporting dialysis staff in promoting home programs. Nephrology leaders at Kaiser Permanente, East Bay, work closely with the Satellite WellBound home team members to ensure home dialysis is always the first option for patients in their programs.

- In Greenville, NC, a Fresenius clinic partnered with a local home program to transition patients with low literacy to peritoneal dialysis by creating a pictorial training guide for peritoneal dialysis.

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\(^3\) A Certificate of Need is a legal document that is still required in some states in order to build a new dialysis facility.
patients and their caregivers. One patient with no ability to read made the transition and has maintained his peritoneal dialysis treatment for nearly two years.

Success stories like these have the potential to increase patient and provider engagement through lived experience. Sharing lived experience through stories informs and connects the listener to new or additional ways of reaching a goal, while solving challenges that arise along the way.

Storytelling is powerful. It speaks to people’s hearts and minds. It sets up the listeners to imagine what can be in their own lives.

- Think about the last time you heard or read about one person’s journey to overcome difficulties. As the story described his or her setbacks, feelings, actions taken, people who offered support, and eventually a happier ending, how did you feel? Did you feel inspired? Did it make you think that more things are possible in life?

- Now think about how inspiring these stories can be to those with ESRD who feel hopeless, stuck, or lost because of this difficult diagnosis. And, think too about the kinds of stories you share with patients. Make sure you share the successes and highlight the uplifting parts.

Sharing Success Stories

You may not feel you have stories to share or are not sure of what to share. These tips may help:

- Ask home dialysis nurses you work with or meet in lobby days for success stories that you can share with patients.

- Do not share names, identifying details, or any personal or protected health information. Do share what the home patients feel are the benefits of being on home dialysis along with challenges they had and how they overcame them.

- Ask the home dialysis nurse how the home team supported the patients so they could be successful at home.

- Share stories often, but always remember—never share patient names or other personally identifiable information unless you have the patient’s written permission.
Stakeholders
Healthcare stakeholders are individuals, organizations, or other entities that have an interest in healthcare. They care about what is happening in the healthcare system. They also have an impact on the healthcare system or are affected by it. For example:

- A professional association educates staff on care guidelines, which improves the care patients get.
- Patients have a say in where they get treatment, which affects how many spots are available for others.
- A patient organization posts education on home dialysis on its website, so patients understand their treatment choices.

Major stakeholders are patients, doctors, providers like dialysis facilities, and government or private insurers. These stakeholders and others have unique or different points of view and areas of expertise to share with you.

Working with Stakeholders
Collaborating with stakeholders is critical to the success of any large-scale initiative, including getting more patients referred to home dialysis. When your facility or dialysis organization works with stakeholders, a basis of teamwork and partnership is created. This can lead to positive change.

There are other benefits too! These include:

- Pooling knowledge, experience, and expertise to create solutions.
- Respecting and valuing unique perspectives.
- Reducing the level of risk through a collection of lessons learned.
- Including multi-disciplinary individuals to generate value, reduce duplication, and move the marker toward the goal.

This example shows how stakeholders can work together:

To support getting more patients to dialyze at home, the ESRD NCC brings together stakeholders. Patients, dialysis staff (nurses, social workers, dietitians, etc.), organizations, and agencies contribute to Quality Improvement Activity Learning and Action Networks, human-centered design work to increase access to home dialysis, and projects such as this Universal Staff Education.
Home Dialysis Stakeholders
Who are the stakeholders in home dialysis? Patients, their families, and the dialysis facility staff members are ones you may think of first, but many more stakeholders play a role in supporting patients and staff in home dialysis. This list shows some of the home dialysis stakeholders:

- People with ESRD
- Professionals who treat people with ESRD
- Private or public organizations that support people with ESRD
- Private or public organizations that support professionals who care for people with ESRD
- Government agencies, for example, CMS, and contractors such as the ESRD NCC and ESRD Networks
- Community organizations, including local support groups and peer mentoring organizations
- Family members
- Friends
- Co-workers
- Caregivers
- Public insurance like Medicare and Medicaid and private insurance, for instance, Humana, United Healthcare, and others
- Equipment and medication suppliers

What materials on home dialysis do you share with patients? Are they mostly ones created by the dialysis provider or company?

Do you think patients or families would benefit from other resources created from a different point of view? For example, would a podcast with patients talking about their experiences be helpful?

How can stakeholders help you get more patients referred to home dialysis?
Stakeholder List
Look at the list of example stakeholder organizations below. The list is not intended to be all inclusive. Use the list to learn more about kidney disease, resources for patients, tools, and small- and large-scale events for networking; gain an understanding of home dialysis; and advance your skills.

ESRD Networks
You’ve probably heard ESRD Networks mentioned in your facility but may not be sure about what they do. This is how it works: The federal government contracts with quality improvement organizations to serve as ESRD Networks across the whole country in support of the ESRD Network Organization Program. There are a total of 18 Networks. Some cover one state; others cover more than one state or United States territory. You may be most familiar with their Quality Improvement Activities or working with patients who have questions about the care they receive. On behalf of CMS, Networks do this and much more to support patients and facilities. For example, they have a toll-free helpline, maintain a website, work with facilities on projects to improve the quality of care, and provide education to patients and staff on such topics as transplant and home dialysis.

Look for: Your Network’s website to find home dialysis information with resources, events, and region-specific topics.

End Stage Renal Disease National Coordinating Center (ESRD NCC)
Just as the 18 ESRD Networks support all facilities and patients, the ESRD NCC supports all Networks. Here are a few examples of how the NCC does this. The NCC helps the Networks with projects and collects and shares best practices—what works—on different topics, such as helping patients move to home dialysis. The NCC creates educational materials and programs for dialysis facilities, transplant centers, and patients with ESRD. The NCC also brings together patients with other stakeholders to make sure the patient’s voice is included in all patient resources and Network activities.

Look for: Downloadable Patient Mobile Tool with home dialysis information for patients’ mobile devices. Educational materials on home dialysis written with patients, for patients. Podcast and webinars featuring patients and caregivers talking about their home dialysis experiences.

American Association of Kidney Patients (AAKP)
“AAKP is dedicated to improving the lives and long-term outcome of kidney patients through education, advocacy, patient engagement and the fostering of patient communities.” AAKP places the interest of people with kidney disease at the forefront of advocating for informed treatment choice, including home dialysis and transplant options. AAKP also advances research and kidney innovation.

Look for: Center for Patient Research and Education, kidney-friendly recipes, and the benefits of choosing a home dialysis option.
American Kidney Fund (AKF)
AKF supports people living with kidney disease through financial assistance to improve their access to the care that they need. The organization also provides various programs to educate people with kidney disease and their families about prevention, early detection, managing kidney disease, and treatment options.

**Look for:** Home dialysis treatment options and support, financial assistance information for patients, resources for a kidney friendly diet, and much more.

American Nephrology Nurses Association (ANNA)
With a membership of over 8,500 Registered Nurses and other healthcare professionals, ANNA provides education and community forums to advance professionals’ expertise in the treatment of kidney disease. Members can find information on in-center dialysis options, home program treatment choices, and kidney transplantation.

**Look for:** The online library, education and resources for home treatment options, infection prevention, and kidney community publications.

Home Dialyzors United
Home Dialyzors United is the only dialysis patient organization dedicated to the home dialysis community. The organization’s mission is “to inspire, inform, and advocate for an extraordinary quality of life for the home dialyzor community.”

**Look for:** Partners in home dialysis, low-cost healthcare resources, advocacy posts, travel information for patients, special programs, and events.

Medical Education Institute (MEI)
This non-profit organization works to improve outcomes for people with kidney disease. One of MEI’s main roles is to create educational programs for patients and professionals.

**Look for:** Home Dialysis Central, which has easy-to-understand patient information on home dialysis basics, life stories, and locating a home program as well as a section on professional resources and tools. Kidney School, which is an interactive, web-based learning program to help professionals and patients learn about kidney disease. The web-based learning is an independent activity with resources, toolkits, and curriculums. **Look also for:** The Method to Assess Treatment Choices for Home Dialysis (MATCH-D) for Home Dialysis Central, which was developed “to help nephrologists and dialysis staff identify and assess candidates for home dialysis therapies (PD [peritoneal dialysis] and HHD [home hemodialysis]).” MATCH-D resources include a clinical calculator and decision support tool that can be used on mobile devices.
National Association of Nephrology Technicians/Technologists (NANT)
NANT offers education and networking for dialysis technicians who wish to become more proficient and increase their knowledge about dialysis treatment options.

Look for: Education programs, webinars, and publications representing home dialysis information.

The National Forum of ESRD Networks
The Forum of ESRD Networks is an independent, not-for-profit organization that supports the ESRD Networks in achieving CMS national quality goals. The Forum advocates to improve the quality of care for patients with renal disease and gains the patients’ perspective from its group of credible and engaged patients called the Kidney Patient Advisory Council (KPAC).

Look for: Home Dialysis Toolkit for professionals, the Transitional Care Operational Guide, and other resources and toolkits to advance the quality of care for people with kidney failure.

National Kidney Foundation (NKF)
NKF is dedicated to improving the quality of life of individuals and families affected by kidney disease. It offers information about kidney health, treatment options including home dialysis, getting a transplant, and being an organ donor. NKF is also a national convener of subject matter experts and researchers to advance clinical trials, improve adherence to the Kidney Disease Outcomes Quality Initiative (KDOQI) Clinical Practice Guidelines, and innovate future kidney treatment options.


Look for: Information on home dialysis treatment options, professional tools and resources to keep you informed, and other resources to support informed decision-making for patients considering a home dialysis option.

Renal Support Network (RSN)
“Renal Support Network is a national kidney patient organizations that empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and make friendships that last a lifetime.”

Look for: Monthly on-line support groups, Kidney Disease Health library, special events, and podcasts about transitioning to home dialysis.
Using Community Resources

In today’s rapidly changing healthcare environment, kidney professionals like you need access to community resources—people, events, educational materials and tools, and community services. Regardless of resource type, they are all central to helping you diversify your knowledge, enhance your professional support system, and connect patients with what they need.

No one dialysis company, organization, or individual holds all the answers and resources needed for every patient. The list of stakeholders in the previous section is a good place to start to build your own library of go-to information, sources, and expertise. You can also find community services through networking with social workers, faith-based ministries, and local support groups, just to name a few. And, of course, the social worker in your facility or program is an expert on community services like child or elder care, ride sharing or transportation to and from doctors’ appointments or dialysis treatments, and vocational rehabilitation to get patients ready to return to work.
Quality Assessment & Performance Improvement
Change happens at the local level. Dialysis facility Quality Assessment & Performance Improvement (QAPI) meetings are the perfect place to start. While each dialysis provider may have its own system or application to manage QAPI meetings (e.g., Facility Health Meeting, often called FHM, or QAPI meetings), the basics should be the same.

Have you attended a QAPI meeting? Do you know what these meetings are all about?
If you haven’t attended a QAPI meeting or been to one recently, speak with your clinic’s manager about attending or asking him/her to go over the data, goals, solutions, and progress toward goals with the team over lunch or during a stand-up meeting. Knowledge is power.

QAPI merges quality assessment (QA) and performance improvement (PI) into a comprehensive approach to quality management. QA is the process of meeting standards and ensuring care reaches an acceptable level. Performance improvement is the proactive, continuous study of processes with the intent to identify opportunities and test new approaches to fix the underlying causes of persistent, systemic problems. Data-driven QAPI programs may be customized to facility needs.

Key steps include:

- Identifying the problem and defining the goal.
- Deciding on a measurement to monitor improvement.
- Brainstorming solutions based on barriers and root causes or the most basic reasons something happens.
- Planning an intervention or an action meant to cause a positive change.
- Using plan-do-study-act (PDSA) to implement the improvement project.
  - You’ll learn more about PDSA in the next section.

Many metrics can be measured and tracked to make home dialysis successful. Some examples are:

- Metrics for interest, education, referrals, nephrologist input, and home program visits for all in-center hemodialysis patients. Collect, track, and share these metrics with the in-center hemodialysis and home teams.
- Real-time data related to physician home referral rates within a practice and across practices for benchmarking. Provide nephrologists with this information so they can see how their practice is doing compared to others in the region, state, or nation.
- The turnover rate from home dialysis back to in-center dialysis. Share with other staff and nephrologists that a higher than expected turnover rate means that people are being given a chance on home dialysis.
- Reasons for turnover. Address modifiable reasons, including peritonitis, psychosocial issues, and loss of caregiver support.
Learn more about QAPI
Go to the Forum of ESRD Networks website at https://esrdnetworks.org/resources/toolkits/mac-toolkits-1/qapi-toolkit/qapi-toolkit to learn more about QAPI. Dialysis facilities can contact their local ESRD Networks for assistance with PDSA principles and practices, questions about change strategies, and home dialysis resources. A complete listing of ESRD Networks can be found at https://esrdncc.org/en/ESRD-network-map/.
Taking Action with a Quality Improvement Mindset

A quality improvement mindset means you’re always willing to improve processes and products through implementation, testing, and feedback loops. To adopt a quality improvement (QI) mindset, start with improving something small. After each improvement, reflect on what you’ve accomplished and how this makes you and the team feel. Focus on what improvement strategies or tactics contributed to the greatest improvement. Consider new ways to get more of that improvement or behavior change. This positive feeling of achievement and understanding how it was accomplished is the fuel for your next improvement.

Below are strategies you can use to adopt and stay in a quality improvement and growth mindset.

- Participate in home dialysis education.
- Volunteer to be a home dialysis ambassador or champion.
- Pose questions about home therapies at monthly quality meetings.
- Recommend that a home program team member joins the in-center QAPI meeting.
- Suggest that your facility partner with a home program to hold lobby days.
- Propose the staff team utilize a tracking tool to track the patient’s progress for moving to home dialysis.
- Advocate for peer-to-peer mentoring from a home dialysis patient.
- Celebrate facility and patient successes such as graduation to home dialysis, length of time treating at home, and program growth.

The “QI mindset” doesn’t say, “I think we’re doing pretty good” or “We’re doing everything we can” or “This is the most we can do with our patients.”

Quality improvement relies on objective data, benchmarking, goal setting, and remeasurement to assess true progress and achieve ambitious goals.

The quality improvement mindset is curious, fact-based, and accepts that change is constant.

It is the continuous study and improvement of processes to improve outcomes and prevent or decrease barriers and issues. It does this by identifying areas of opportunity and testing new ideas to fix the causes.

Do you know your facility’s goals for home dialysis? What metrics are you tracking? Are you on track to meet your goals?
Quality Improvement Tools

Formal quality improvement tools are a great addition to QAPI. They provide a structure to create goals, track progress, and measure what interventions are working. They can also be used in small ways every week as you interact with patients and carry out all the roles in your job.

As you read about these, think, how can I use the quality improvement mindset to be curious, objective, and create new outcomes for patients and reach facility goals?

Plan-Do-Study-Act (PDSA) Cycle

The Plan-Do-Study-Act (PDSA) cycle is a method of testing change by planning the change, implementing it, observing the results, and acting on what was learned. PDSA incorporates learned experience into improvement and is designed to be used in short iterative cycles that move a project or process closer to providing measurable outcomes and impact.

Think about this:

Your facility tries a new process for home dialysis referrals. How do you know if it helps? Well, you might start the new process and later ask staff and patients what they think of it. Did the new process work? You could wait a few months and see if there is any difference, but you don’t know for sure, do you?

Now, try it with a “QI mindset” using the PDSA tool. Plan all parts of the new process, including who is doing what for how long, when, and how often and how you’ll measure if the plan is working. Then Do the new process. Following the plan you wrote, Check (or Study) to see if what you’re measuring is improving. Lastly, Act based on whether you see improvement. If you don’t see improvement or don’t see as much improvement as you were expecting, start over and make changes to the plan that you think are needed. Then, start the PDSA process again.

Remember, it’s best to try one new thing at a time if it’s significant. That way you can tell what interventions are making the difference.

The PDSA tool can be used in smaller ways, too, such as in patient education. Plan the education you’ll be providing. Do it. Check to see if the patient understands what you’re teaching. Then Act based on his or her response. If the patient didn’t receive the message you were sharing, it’s time to adapt it and try again.
The Five Whys

The Five Whys is used to drill down to the details of a problem. This method is asking the question "why" five times to identify the root cause. Answering the why can lead to new interventions with greater improvement impact.

Using the Five Whys in QI does not always happen all at one time. Sometimes, you may make more progress if you stop and study the successes and barriers to each why response. It’s easy to get caught up in the why, but you also want to better understand how to achieve more success and solve barriers. QI looks at the processes that caused these outcomes.

Imagine this:

At a staff meeting on home dialysis, a co-worker says, “Well most of our patients just aren’t interested in home dialysis.” Having just finished this course, you decide to try on a “QI mindset” and employ the Five Whys. It might go like this.

Why are most of the patients not interested in home dialysis?
Because patients haven’t received any education.

Why haven’t they received any education about home dialysis?
Because the staff has not received any training on home dialysis.

Why hasn’t the staff received any training on home dialysis?
It has not been a part of the ongoing/annual education for the staff.

Why has it not been a part of the education for the staff?
Because there is no home dialysis expert available to the dialysis unit.

Why isn’t there a home dialysis expert available to the dialysis unit?
Because it has not been a priority.

This is a missed opportunity to promote home dialysis and educate all patients on the benefits of home dialysis. The dialysis facility should partner with a current home program within their organization to provide education to all staff about home modality options.

This same 5 Whys or QI mindset could be helpful in working with an individual patient. As the patient shares his or her reasons for not considering home dialysis, continue to ask why. Asking why will eventually drill down to a benefit or potential barrier to overcome.
Case Study
Your dialysis facility only had two patients that converted to a home modality last year. During a recent quality meeting, the medical director recognizes that the facility has a low home referral rate. He decides he would like the facility to initiate a quality improvement project.

As the manager, you have just completed this module and decide to utilize the PDSA cycle to improve the outcomes.

What is the first step?
Do you start with staff education?
Or do you start with patient education?

No—you must start with the “P” phase or the planning phase of the PDSA cycle.

The team meets to set an achievement goal and agrees on “increase the number of patients moving to home dialysis by 5% by the end of the year.” The team also discusses “Why are we changing?” and “What are we changing?”

Once the planning phase is completed, the team focuses on the “D” or do phase. The team chooses to roll out a comprehensive home education program for the patients. It includes two educational flyers and a video. This takes place over four weeks.

Next, comes the “S” or study phase. For this, the team reviews how many patients are interested in or have moved to home dialysis. The team determines the plan was not successful because no patients expressed interest in changing to a home modality.

The last phase is the “A” or act phase. The team decides that changes need to be made to the plan.

What could have been done differently?
What other actions could have been implemented as part of the “D” phase?
What are the next steps?

You gather the team and return to phase “P” and develop a new and different plan that might result in success.

Ideas to consider include:
- Providing home dialysis education for the staff.
- Having a home program nurse provide an in-service to staff.
- Promoting home dialysis by hanging flyers in the lobby.
Next Steps

Congratulations, you have completed Course 3. Click HERE to complete the course evaluation. After submitting the course evaluation, you will be directed to the learning management system to take a quiz. Upon passing the quiz, you will receive 1.5 continuing education units (CEUs).