

2023

Home Dialysis Toolkit

Developed by the Forum of ESRD Networks
Medical Advisory Council (MAC)

This toolkit for health providers and practitioners is a reference tool that gives information about overcoming barriers to starting or growing a home dialysis program.



This publication is the product of a workgroup under the auspices of the National Forum of ESRD Networks, Inc., a non-profit organization of volunteers dedicated to improving the quality of care to patients with end stage renal disease (ESRD). This toolkit was conceived of and sponsored by the Forum of ESRD Networks' Medical Advisory Council (MAC). The toolkit committee was a multidisciplinary group of volunteers who generously contributed their time and expertise to this effort. We would also like to thank Kelly Brooks, Forum Coordinator, for her tireless efforts and administrative support of this second edition toolkit. The Forum would like to acknowledge the hard work of the original 2016 toolkit authors that can be found at the Forum's toolkit website. The current toolkit authors are listed as follows:

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This Toolkit is a guide, created by experienced professionals using the available evidence and produced by the Medical Advisory Council (MAC) of the Forum of ESRD Networks. The MAC anticipates revisions and additions to the Toolkit overtime. The Toolkit is meant as a resource and should not be referenced as a regulatory statement. This document is meant to provide practical strategies for creating a thriving home dialysis program with good outcomes and satisfied patients.

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Introduction: How Do We Overcome the Challenges of Providing Our Patients with More Opportunities to Receive Home Dialysis?

When tasked with updating the 2016 Home Dialysis Toolkit, it became readily apparent that the world is a different place than it was five years ago, and that the dialysis community is not immune to these changes. The public health crisis created by the COVID-19 pandemic took its toll on dialysis patients and led to mortality rates as high as 25% (at least 4-5 times higher than that of their non-dialysis peers) (Hsu, 2021; Taji, 2021). It also tested our disaster management preparedness whereby infection control and resource utilization became critical for our patients' survival. Telehealth took on a much larger role in dialysis care by helping fortify our communications when health care teams and patients were often apart.

Amid all this upheaval, kidney medicine was once again leading the charge in terms of helping introduce new value-based payment models in an effort to improve patient outcomes while simultaneously reducing the cost of care. The focus on home-based dialysis therapy has – along with improved access to kidney transplantation – become a central focus of this value-based medicine paradigm, further highlighted by data indicating decreased hospitalization rates for peritoneal dialysis patients compared to those receiving in-center hemodialysis during the COVID-19 pandemic (Weinhandl, 2021). During a time of heightened concerns regarding emerging pathogens and risk to the most vulnerable, offering dialysis in the home setting can provide many benefits in terms of less clinic visits, decreased patient-to-patient contact, alleviation of staffing shortages, and less burdens on medical transportation.

The original thesis of this toolkit was that fewer of the people who require dialysis in the United States are dialyzing at home than should be the case. We propose to try to understand and rectify this situation by examining some of the systemic and conceptual barriers that, in our view, restrain what would otherwise be the more widespread and appropriate use of home dialysis. In order to begin this process, we will briefly review the history of treatment of end-stage renal disease (ESRD) by chronic dialysis. We will see that home dialysis has been part of this history almost since the beginning. Guidance for writing this introduction was obtained in large part from a useful article by Blagg (2007), from which more complete references to original source materials may be obtained by interested readers.

We hope this second edition will maintain the solid foundations of its predecessor while also providing timely updates regarding home dialysis patient care, healthcare team best practices, and nephrology community policy changes in the midst of the myriad challenges – and opportunities – faced in 2023.

The History of Dialysis

Hemodialysis was first successfully used in a human case of acute kidney injury by Willem Kolff in Holland during World War II, but consistent technical success with his original apparatus and its successors was achieved only after he emigrated to the U.S. after the war (Figure 1). The technical aspects of hemodialysis were developed further under the pressure of another war, the Korean conflict, during which Paul Teschan and colleagues used the new technique in the 1950s to treat combat injuries that would previously have been fatal.

Figure 1: Kolff and Berk's First Artificial Kidney (Rotating Drum)

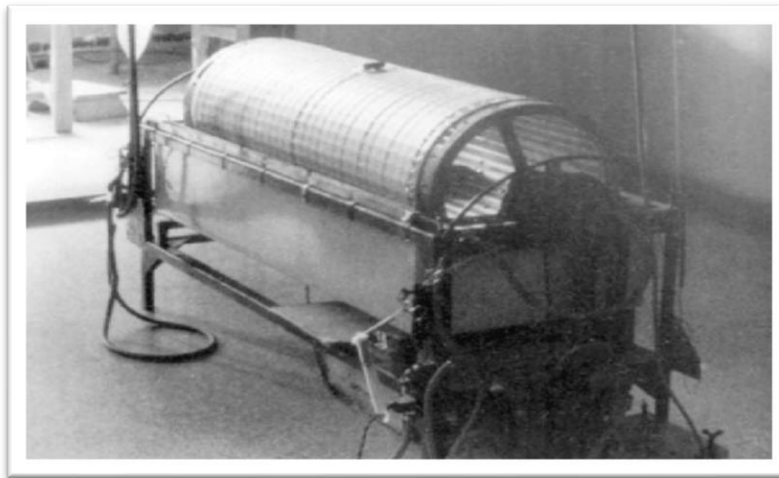


Image from: Crowther S M, Reynolds L A, Tansey E M. (eds) (2009) History of Dialysis, c.1950-1980. Wellcome Witnesses to Twentieth Century Medicine, vol. 37. London: Wellcome Trust Centre for the History of Medicine at UCL.

The concept of maintenance hemodialysis for chronic kidney disease was first implemented on a substantial scale by Belding Scribner and colleagues at the University of Washington in the 1960s (Figure 2). More than that of any other individual, Scribner's work contributed to saving hundreds of thousands of Americans otherwise doomed to die of uremia, not only because of his scientific contributions (including the concept of long-term vascular access), but because of the riveting testimony of Scribner and his patients before the U.S. Congress that led to the extension of Medicare to nearly all Americans with ESRD in 1973.

Figure 2: History of Dialysis

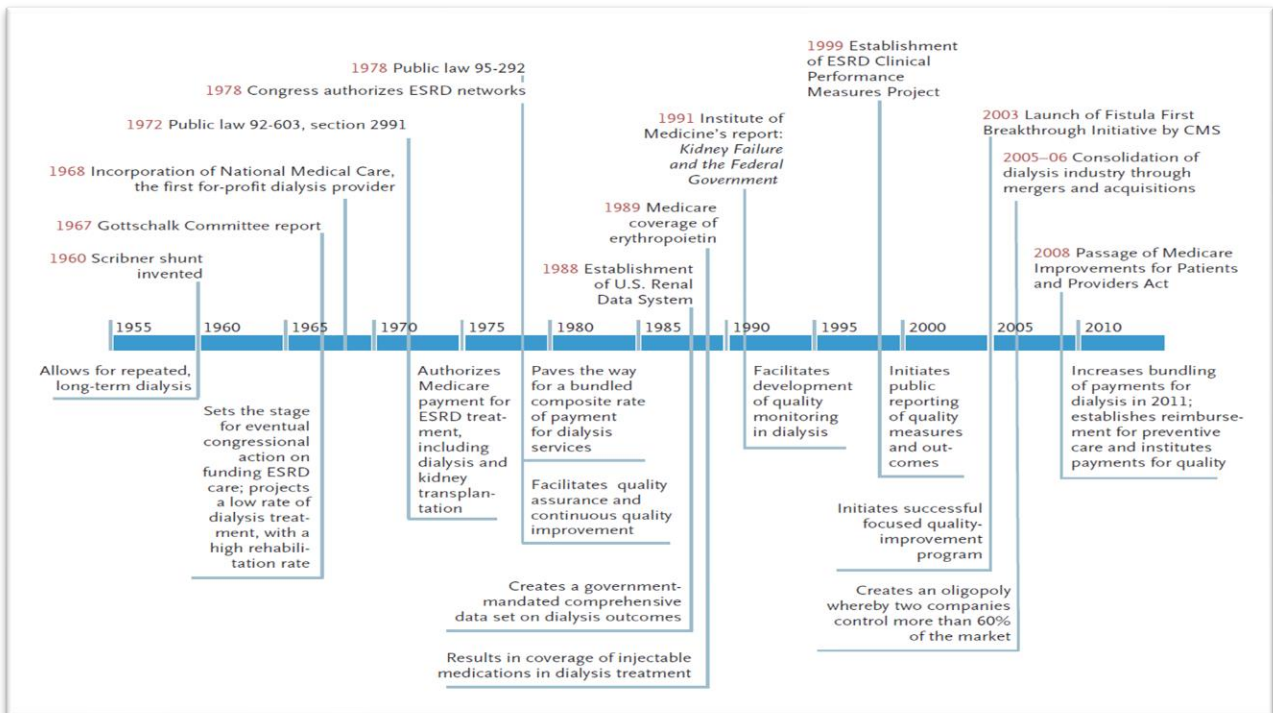


Image from: Himmelfarb J and Ikinzler TA. Hemodialysis. *N Engl J Med* 2010;363:1833-45.

Prior to the funding of the ESRD program by Medicare, however, many of Scribner's patients were treated at home, starting as early as 1963-4 (Figure 3). Shaldon introduced home hemodialysis in Great Britain in 1964 and in Germany in the late 1960s. After 1973, Medicare funding allowed the development of free-standing dialysis facilities in the U.S., but prior to that date, as many as 40% of all dialysis patients in the U.S. were dialyzing at home. It is apparent, therefore, that technical obstacles to home hemodialysis have not been insuperable, at least for some patients, for some 50 years. Despite exceeding 10,000 patients for the first time in U.S. history, the overall number of prevalent home hemodialysis patients still represented < 2% of the dialysis population (USRDS, 2020).

Figure 3: First Seattle Home Hemodialysis Patient with Kiil Dialyzer



Image from: Blagg CR. The Early History of Dialysis for Chronic Renal Failure in the United States: A View From Seattle. *Am J Kidney Dis.* 2007 Mar;49(3):482-96.

The Evolution of Home Dialysis Therapies and Present-Day Challenges

The initial successful use of peritoneal dialysis (PD) to treat acute renal failure was reported in 1951; however, its adaptation to support patients with ESRD, like that of hemodialysis, awaited the solution to the problem of chronic indwelling dialysis access (Figure 4). The first recorded patient with chronic uremia supported on home PD was treated by Russell Palmer in Vancouver, Canada, starting in 1964, using a peritoneal catheter conceived by Palmer and fabricated by Wayne Quinton, an engineer who worked with Scribner's group in Seattle, Washington. The PD catheter was subsequently improved by Henry Tenckhoff, again in the Seattle group, and the first report of a multi-patient home continuous ambulatory peritoneal dialysis (CAPD) program, by Robert Popovich and Jack Moncrief in Austin, Texas, followed in 1976. The subsequent introduction of premixed dialysate in plastic bags by Dimitrios Oreopoulos et al., the titanium connector by Karl Nolph et al., and the automated cycler by Jose Diaz-Buxo et al., increased the technical ease, safety, and convenience of home PD to the point that it became, and has remained, far easier to learn and sustain than home hemodialysis.

Figure 4: First Seattle Home Peritoneal Dialysis Patient

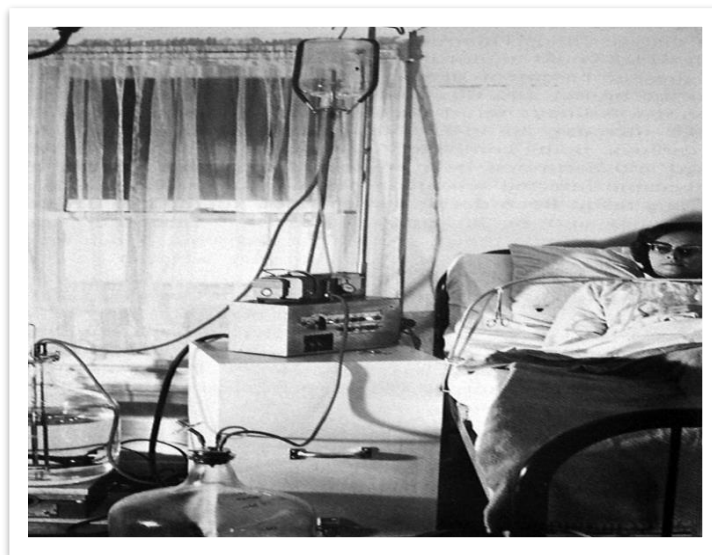


Image from: Blagg CR. The Early History of Dialysis for Chronic Renal Failure in the United States: A View from Seattle. *Am J Kidney Dis.* 2007 Mar;49(3):482-96.

Home PD experienced rapid gains in popularity soon after its introduction in the U.S., and its use as a percentage of all ESRD treatment reached its peak in the U.S. in the early 1990s. A subsequent long decline in the relative prevalence of PD use in the U.S. has started to reverse only since 2009. Despite the marked growth in the overall dialysis population since the early 1990s, the number of prevalent patients treated with PD in the U.S. (58,636) only represents 10.5% of the entire ESRD population (USRDS, 2020).

A Revitalization of Home Dialysis Therapies through Federal Government Policy

In recent years, home hemodialysis and continuous cycling peritoneal dialysis (CCPD) have made substantial relative gains in utilization in the U.S. Nevertheless, of patients starting dialysis in 2018, only 11.5% started any form of home dialysis (USRDS, 2020). This presumably represents a substantial failure of patient education and choice, since studies of pre-dialysis modality education reveal that 30-50% of informed patients choose home modalities (Lacson, 2011). Polls of nephrologists consistently show that the vast majority would choose a home dialysis modality for themselves in the event of ESRD, and they estimate that a home modality would be the optimal choice for approximately one-third of their ESRD patients (Merighi, 2012). Added to this discrepancy is the perception of nephrology fellowship trainees that most programs historically focus little time on home dialysis modality education and that they feel ill-equipped to encourage these therapeutic options to their patients when they themselves do not have a firm grasp of the subject matter (Gupta, 2021).

From a patient perspective, quality of life appears to be a major factor behind the decision to choose home dialysis for many patients. Table 1 shows examples of reasons that may support different dialysis modalities for a given patient with the underlying recognition that no one modality is superior to another overall. The ultimate goal should be a patient-centered approach that respects patient choice and autonomy through better medical education and infrastructure that supports the changing needs of any one patient as they progress through their dialysis journey.

Experience from numerous other countries around the globe, in fully developed and developing economies, supports the contention that a far larger number of patients in the U.S. could successfully dialyze at home, and do so at a significantly lower cost to our healthcare system. One major impediment to providing this opportunity to more patients is the lack of caregiver support that often limits choices for modality options. While some countries (e.g., Canada) already provide federal support for home-assisted dialysis, the U.S. is in just the early stages of legislation action. First proposed in September 2021, H.R. 5426 proposes to “amend Title XVIII of the Social Security Act to provide for Medicare coverage of staff-assisted home dialysis for certain hemodialysis and peritoneal dialysis patients and to ensure all patients are educated on modality options and receive the resources, information, and support to succeed on the modality of their choice, and for other purposes.”

Table 1: Advantages and Disadvantages of Home Dialysis Therapies

	Home Hemodialysis	Home Peritoneal Dialysis	In-Center Dialysis
Patient Privacy	X	X	
Schedule Flexibility	X	X	
Less Frequent Clinic Visits	X	X	
Avoidance of Sick Contacts	X	X	
Less Patient-reported Fatigue	X	X	
Less Frequent Treatments			X
Ability to Travel	X	X	X
Better Phosphorus Control	X	X	
Better Volume Control	X	X	
Ability to Perform at Night	X	X	a
Avoidance of Blood Exposure		X	
Peer Interaction/Socialization			X
No Supply Storage Concerns			X
Care Partner Mandate	b		
Lower Health Care Cost	X	X	
a. Some in-center dialysis centers offer nocturnal hemodialysis			
b. "Solo" home hemodialysis without a care partner is subject to state/local regulations and/or device labeling			

With evidence-based data now showing that peritoneal dialysis offers better 3-year survival at a cost of approximately \$14,000 less per patient per year when compared to in-center hemodialysis, the Centers for Medicare & Medicaid Services (CMS) has made efforts to transition dialysis from a fee-for-service to a value-based payment model (USRDS, 2020). The Prospective Payment System (PPS) that began in 2011 provided incentives to utilize peritoneal dialysis by equalizing the reimbursement for the once monthly peritoneal dialysis visit (“monthly capitated payment,” or MCP) to four in-center hemodialysis visits while also providing dialysis payment on the first day of peritoneal dialysis initiation.

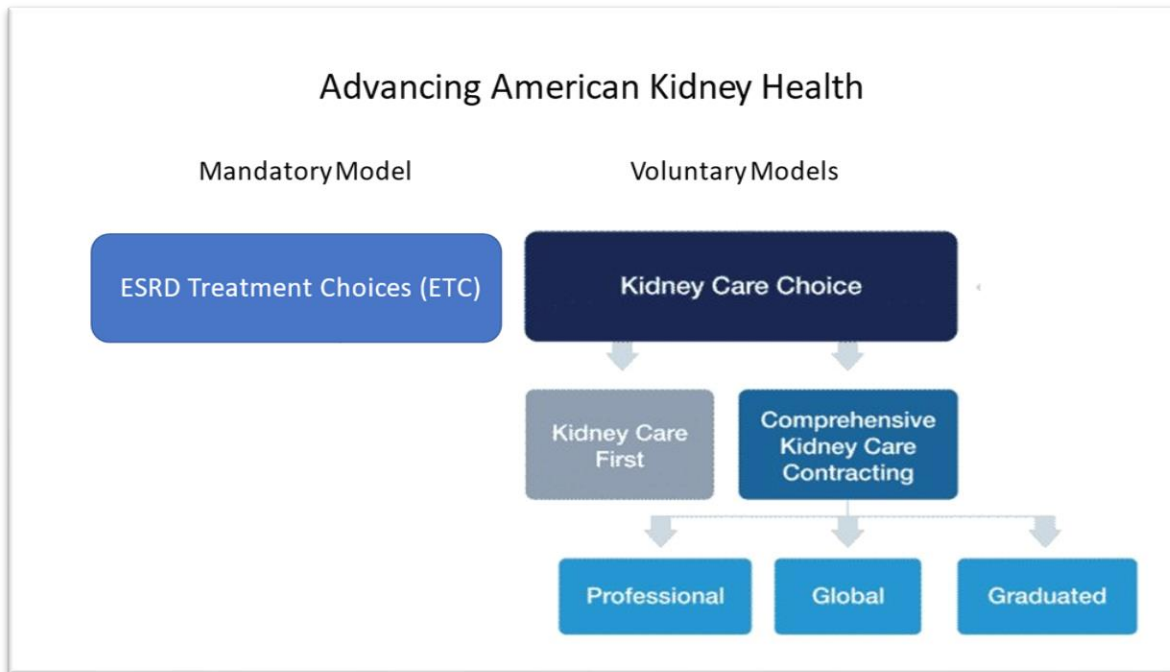
Building upon the PPS and Quality Incentive Payment (QIP), the Centers for Medicare and Medicaid Innovation (CMMI) began an advanced alternative payment model (AAPM) demonstration project in 2015 called the Comprehensive ESRD Care (CEC) Model. Under the CEC Model, dialysis facilities, nephrologists, and other providers partnered to form ESRD Seamless Care Organizations (ESCOs), the first disease-specific specialty-oriented Accountable Care Organizations (ACOs) that assumed financial responsibility for the quality of care and Medicare Part A and Part B spending of their aligned beneficiaries. ESCOs ultimately included 33 participants and over 71,000 ESRD beneficiaries (approximately 12% of the entire ESRD population) throughout the U.S. The fourth, and final, performance year (PY) completed in late 2020 and preliminary data from PY1 and PY2 reported a reduction in dialysis catheter use as well as a 1.8% reduction in Medicare spending achieved mainly through reductions in hospitalizations while having little impact on home dialysis utilization (Marrufo, 2020).

Some of the early successes of the CEC were focused on cost-containment with a “dialysis-centric” approach. The next generation of value-based kidney care models has begun, and with them will come stronger incentives to support home-based dialysis therapies. These care models will support the Advancing American Kidney Health (AAKH) initiative set forth by executive directive in 2019. In addition to goals set to delay the onset of dialysis in chronic kidney disease (CKD) patients as well as increased kidney transplant availability, the AAKH has outlined a goal to have 80% of new ESRD patients receiving home dialysis or a kidney transplant by 2025. This more “upstream” approach of aggressive CKD management and pre-emptive transplantation will hopefully yield greater patient outcomes and cost savings to the healthcare system.

The AAKH initiative is composed of five value-based care models supported through CMS. The mandatory ESRD Treatment Choices (ETC) model encompasses roughly 30% of all ESRD beneficiaries and their associated “managing clinician” (defined as those practitioners billing for the MCP) with positive payment adjustments made to the ESRD facility PPS base rate and managing clinician MCP reimbursement related to increased utilization of home dialysis and transplantation. Due to the lack of “downside” financial risk, the ETC model does not qualify as an AAPM. Patient attribution to the ETC occurs randomly via hospital referral regions throughout the U.S. and began in January 2021.

The other four value-based payment models are voluntary in nature and will effectively replace the CEC model (Figure 5). Collectively referred to as Kidney Care Choices (KCC), these models will have an ACO-like structure like the CEC while also encompassing late-stage CKD (stages 4 and 5), kidney transplantation, and post-transplantation-related care. While the general goals of KCC are similar to the mandatory ETC model, KCC participants will 1) qualify as AAPM participants and 2) receive capitated payments for the care of their late-stage CKD and ESRD patients and therefore participate in shared savings as well as risk. KCC models are further broken down into the Kidney Care First (KCF) and Comprehensive Kidney Care Contracting (CKCC) models. The KCF model will be relegated to nephrologists/nephrology practices only and receive performance-based adjustment measures based upon utilization and quality metrics. CKCC model participants will function as a “Kidney Contracting Entity” with a dialysis provider similar to the ESCO and will take on either partial or global shared risk/reward. At the time of this writing, the mandatory ETC model performance year had already begun as of January 2021 and has an expected completion date of December 2027. The voluntary KCC models were initially delayed but have since commenced as of January 2022. It is our hope that these types of incentivized approaches will at least play a part in the overall efforts to increase the use of home dialysis utilization.

Figure 5: Value-Based Care Models of the AAKH



The purpose of this toolkit is to provide information and links to other resources to enable dialysis professionals to begin or grow a local home dialysis program. It has been produced by volunteers recruited by the MAC of the Forum of ESRD Networks and is intended for distribution by the ESRD Network program. The Networks support informed patient decision making in the choice of dialysis modality, as well as the mandate from the CMS Conditions for Coverage (CfC) that Medicare beneficiaries be made aware of, and offered access to, all modalities of ESRD treatment. It is our contention, as it has been the contention of numerous authors of previous publications in the field, that the promotion of home dialysis as the treatment of first choice for individuals for whom it is medically appropriate has the potential to increase quality of life, decrease costs, and improve clinical outcomes—areas that all would agree are in need of substantial improvement in the ESRD program. Because patient autonomy, and empowerment, is such a central tenet of healthcare, we thought that this current edition should begin from the perspective of the home dialysis patient. We asked a member of our Kidney Patient Advisory Council (KPAC) to provide a narrative describing her journey with home dialysis for over 20 years in Chapter 1. The chapter concludes with a list of “demands” that she and the KPAC feel would make the home dialysis experience more successful for patients with ESRD. The chapters that follow will address these topics and hopefully help healthcare professionals bring the goal of a better quality of life to reality for our ESRD community.

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Chapter 1: Making Home Dialysis Success a Reality by Learning from the Life Experiences of Our Patients



Dawn Edwards has had end-stage renal disease (ESRD) since 1992 and has been a devoted patient advocate to others on dialysis for decades. She joined the National Forum of ESRD Networks in 2018 and currently serves as Co-Chair of its Kidney Patient Advisory Council (KPAC). As the Forum discussed updating the home dialysis toolkit, we felt that a patient-centered approach was essential to helping providers and staff appreciate the life experiences of our patients to better serve them as we strive to make sure everyone is given the opportunity to be asked the question, “Why not home?” This chapter is dedicated to the patient voice. Dawn Edwards shares her personal story of several different kidney disease transitions in her life and offers a list of patient “demands” which she and her fellow KPAC colleagues felt must be met if we are to provide our patients with the best support for home dialysis.

“As a person who has chosen home therapies for over 20 years, transitioning to home must be individualized (taking into consideration all the factors that affect the patient’s life) for them to be successful and remain at home. Home therapies can be a truly rewarding, empowering experience, giving the patient better outcomes clinically and an overall better quality of life. However, without the assistance of the entire care team and appropriate training and preparation for transitioning to home, the patient can feel isolated, abandoned, overwhelmed, and never have the opportunity to reap the benefits and rewards of the home experience.

“I wish I had received proper, unbiased treatment options education before I started dialysis. When I was first diagnosed, I knew nothing about kidney disease, dialysis, or transplant. I was totally dependent on my doctor to inform and advise me on how I was going to manage the rest of my life after this life-altering news.

A New Illness and a New Beginning

“My life changed in 1992. I was 23 years old, with a few years under my belt at the post office. I was newly married and had a toddler at home. One day I went to the doctor for a pregnancy test, and I walked out with an emergency appointment to see a nephrologist. The nephrologist told me I had a little time, but not much. He didn’t ask me anything about my life. He told me that I needed to have a surgery to get my arm prepared for ‘treatment’ and that dialysis would be three times a week for four hours, and all I had to do was show up. I was told there was another way to do dialysis at home, but that had to be done seven days a week, and I had to do it all myself. I will never forget the words he then said to me: ‘You don’t want to do treatment that way because you’ll get an infection and die.’ So, I went and got my fistula and stopped eating a lot of meat (as instructed) and waited.

“Looking back at what I received from that doctor makes me angry and bitter. We never spoke about transplant. I didn’t know I had to do something to be on the list. He didn’t ask if I knew anyone who might

donate to me. Why didn't he ask me about my life or goals? Why didn't he give me unbiased information so I could make the choice myself? I'll never know the answers to those questions, but the choice to go in-center ruined my life as I knew it. I was miserable in that environment at my age, and I could barely make it to work for my shift at midnight. Since I was new at the dialysis facility, I was started on the fourth shift, finishing treatment at 10pm and trying to make it to work on public transportation; sometimes I made it, most times I didn't. Back then, people coded during treatment regularly. Everybody, including me, was puking and passing out and cramping all the time. I never saw my daughter because I was too sick; forget about being a wife (that part of life was over). My husband and I eventually separated and divorced. I skipped treatments because I needed to go to work. I was placed on restriction because of my work attendance. I finally gave up and went on disability because I thought my life would always be that way. I spent three and a half years on that roller coaster, still not receiving transplant education, I guess because I was 'noncompliant'...

"What finally changed things for the better was when I listened to another doctor rounding at that facility who convinced me to try peritoneal dialysis (PD). He had been trying to talk to me about it for three years; every time he came in, he stopped to see how I was doing and told me I could be doing so much better at home. I shut him down every time because of what 'my doctor' had once said. I was so sick and miserable that I couldn't hear what he was offering me. It took me hitting rock bottom for me to really get it. I decided to withdraw from dialysis at 27 years of age. I felt like I didn't have anything to offer and had given up. I refused to go back to the dialysis center, and I stayed home for the next week. That doctor called me at home and begged me to try PD and said that if I didn't like it, I could go ahead and withdraw. I decided to try it. I went back to dialysis with an appointment to have my PD catheter placed. I told the patients and staff at my dialysis center that I was going to do PD. I was discouraged by both groups and was told I would hate it and be right back at the center before I knew it. That made me even more determined to succeed.

"When I left that facility, I never came back. PD was an amazing experience for me. I learned so much more than how to perform exchanges and operate the cyclor. I learned about disease management and being in control over how I felt. I learned the meaning of my lab values and why they were important. I was taught about how my diet affected the labs and, ultimately, how I felt from day to day. All this learning and insight came through the relationship that formed between the training nurse and me. I was so empowered that the social worker made me the patient advocate. I was introduced to my ESRD Network and have been an advocate ever since. I have dedicated my life to mentoring patients and advocating for patients to be taught about their options and being in control. I hope that no other patient has to learn the way I did.

Optimizing Transitions to Home

"In my opinion, having the opportunity to directly transition to home therapy is the ideal way to be introduced to a home modality. This is the time when a new ESRD patient is totally dependent on the information they receive from their doctor and those appointed to help them plan the rest of their lives. They haven't experienced the in-center dynamics and influence from other patients and staff yet, and with guidance it may never be necessary. Home therapy from the start can be the bridge to transplant with the patient retaining their autonomy. It also can prevent patients from developing the dependent traits that many succumb to after years in in-center dialysis.

“In order to help your patient make the most informed decision about dialysis modality, it is critical for the dialysis provider to take the time to get to know the patient and understand particular details about day-to-day life:

- Details about family and personal life that makes a person feel fulfilled
- Discussing the things about dialysis that worry the patient most
- Work-life balance and what dialysis schedule would fit best
- Establishing goals for the future

“Having kidney disease should not interfere with a patient’s lifestyle or goals unless they are a matador or contact sports athlete. Your guidance is so important now because they are at a vulnerable point in life, so make sure they get the full story on all their treatment options (including transplantation) and how each one could affect their life. These patients may know a little about the dialysis experience from what they’ve heard, but you can give them the real deal and help them make this important decision. With the growth of CKD programs, transitional dialysis units, and incremental introduction to dialysis (as well as pre-emptive transplants) patients have more options and opportunities to gradually be introduced to life with kidney disease and explore their options to make shared and informed decisions on how to manage and live with kidney disease.

“From my own personal experience, transitioning to home from in-center dialysis can be challenging but not impossible. There must be the right set of circumstances to be successful at leading a patient to a home therapy:

- Timing – As soon as possible would be ideal (vascular access and getting adjusted can wait). Removal from the in-center culture and dependency is crucial to a successful transition.
- Support at home – Home dialysis requires time, organization, and support. Burnout, to some degree, is inevitable, making it necessary to have some sort of support to catch the patient when it happens. Some patients do very well independently at home, only depending on the support from the facility for respite in case of hospitalization or some other circumstance. Every patient is different; find out if support is available or even necessary.
- Education – This is the most important component. Patients need to understand the clinical and lifestyle differences between in-center and home dialysis. Most patients think home therapy will be the same as the in-center experience, when in actuality, it is quite the opposite. Many of the things that they had to give up as an in-center patient, they may be able to regain at home.
- Be sure to explain some of the potential benefits of more frequent or slower dialysis:
 - Gentler ultrafiltration can be easier on the heart
 - Possibility of a less stringent diet
 - Improved lab results (and often a better overall sense of well-being)
 - More flexibility and control of your life
 - Assurance that support and respite care are available for you and partner

Keeping Patients Informed and Involved in Their Care

“Many patients will be disillusioned by stories they have heard from staff and other patients returning from unsuccessful home experiences. It will take a multidisciplinary approach to encourage a patient to let go of the dependency of the dialysis center and venture into the world of independence and wellness

with kidney disease. Different members of the dialysis team can play critical roles in making sure that their patients are informed and prepared to make the modality choice that best suits their interests and needs:

- Nephrologist – To explain the clinical benefits.
- Training Nurse – To describe the training process, show patients the machine (and how it works differently from the in-center process), and discuss access, cannulation training techniques, buttonhole technique, EMLA cream (for HHD), and the simplicity of PD catheter placement. Explain that PD catheter placement is nothing like vascular surgery!
- Social Worker – To communicate with and educate family members about the possibility of improved outcomes and their loved one feeling better and not focusing so much on the aesthetics of the house and boxes (you can work all of that out). Health comes first.
- Dietitian – To review current labs and explain how they can improve with home therapy. Discuss mineral balance, bone health, and cardiac benefits along with the possibility of being able to enjoy a more diverse diet with less medications.
- Patient Care Technicians – Knowledge about home therapies can help to reinforce all the above with a positive attitude and encouraging support of the patient's choice. They can even help with self-cannulation or removing needles while still in-center.
- Patient Advocate/Home Ambassador/Home Patient – Perhaps the most important role on the team. A patient can actually explain how it feels and how they personally have benefitted from going home. The potential patient can ask candid questions and get answers from someone who has been there and is successfully managing at home.

“Converting a patient to home may not happen immediately; some patients want to go home, while others may not be ready to make such a choice right away. The fear of change and not knowing what to expect can be overwhelming. A patient may feel that they aren't competent enough to perform their own dialysis and will only overcome these fears through the encouragement and support of the entire dialysis team.

From Transplant Back to Home

“I felt horrible when I got the news that they had done all they could to save my transplanted kidney and I would have to return to dialysis. What had I done wrong? I followed instructions, ate right, took my medications; it was only six years, and I knew people who had their transplants for decades. I had to face going back to dialysis. I wasn't well; I had bone disease and a fractured hip, I couldn't get listed for another kidney transplant because I had the early stages of colon cancer, and I had a catheter because my access stopped working. I hoped I would be able to go back to PD because I loved that therapy, however the aftereffects of my colon surgery made PD no longer an option. So, in addition to returning to in-center dialysis, I was in a wheelchair from a fractured hip while learning how to manage an ileostomy. I was clearly depressed, but that wasn't my greatest concern at that time. Going back to the dialysis center was sad, almost degrading. I was sick, and I felt as if no one really wanted to know what happened to the transplant (I didn't feel right about telling other patients, as I didn't want to scare them). So there I was, back in-center after leaving 16 years ago. I knew I couldn't live the rest of my life this way. After a month or so, I had a bloodstream infection and was in the hospital and nursing home for months. When I recovered and received a hip replacement, I returned to the dialysis center and asked about home hemodialysis. It wasn't offered at my center so they asked me to wait, and I could be their first patient. Months later, I couldn't wait anymore and found a program on my own. I guess you could say the rest is history. I'm still doing HHD to this day. In fact, I asked for nocturnal HHD and became the first nocturnal HHD patient in my area. Ten years later, I'm back to work, advocating, and living my best life.

“Returning to dialysis after a failed transplant can be an extremely traumatizing experience. Having a transplant, although not a cure for kidney disease, may feel like life has gone back to ‘normal’ and dialysis is a distant memory. Rejection and return to dialysis feel like a personal failure, and patients may feel like giving up altogether. It is during this time when compassion for their loss must be considered and appropriately addressed with depression screening, and the introduction to home therapy as an alternative must be done with care. Along with encouraging returning to the transplant list or finding another donor, home dialysis while waiting can be an uplifting step in a patient’s journey. Most patients never want to see dialysis centers again after receiving a transplant, which provides fertile ground for home therapy education. The patient has adopted an independent lifestyle and may be back to work or school and want to keep their independence. Time has become valuable and travel, intimacy, and pursuing life goals are important again. Home dialysis may help the patient keep the things they worked so hard to regain during the transplant experience. You may need some or all the resources discussed previously for the in-center patient, but the transplant patient is at a different place in the journey and will be more like the direct transition patient, looking to their doctor and care team for answers and direction to help them through the grief and process of regaining their quality of life. This transition is the true ‘bump in the road,’ and shared, informed decision making is crucial. Peer mentoring and mental health support can help in this transition and is likely needed. Whatever the patient decides to do at this point (e.g., try for another transplant or maybe never wanting to hear the word “transplant” again), home dialysis can be the next level of the journey.”

A Call to Action for Better Home Dialysis Support: A Wish List from the Kidney Patient Advisory Council

1. Make home dialysis programs accessible to all; if home therapies are truly to be an equitable option, they should be in underserved communities as well as affluent neighborhoods.
2. Training materials need to be translated into multiple languages.
3. Assistance for patients with financial needs should be provided for chairs, storage containers, minor adjustments to the home (e.g., 3-pronged outlets, sink adapters).
4. Every home program should have trained PCTs to assist nurses with
 - a. Patient training to reduce wait times
 - b. Patients adjusting to home therapy post training
 - c. Troubleshooting machine malfunctions
 - d. Performing equipment maintenance and testing
 - e. Providing emergency respite care after hospitalizations and illness
 - f. Staff-assisted treatment to patients who have been at home for years, and are now elderly and unable to perform treatments themselves
5. Treatment options education should be standardized and mandatory for *every patient* in a way that is measurable for every facility, even facilities without home therapy programs on-site. Home dialysis programs should be encouraged to partner with such facilities in order to make sure patients are able to receive these dialysis modality education options from experienced staff.
6. Every home patient should be provided with a peer mentor they can reach out to if the patient should so choose.
7. Home therapies should be a mandatory subject for all nephrologists and taught to all PCTs and in-center dialysis staff. Reassure staff that promoting patient modality choice is not only good for patients but also good for those who care for them. Given the ongoing growth of chronic kidney disease, job security for staff with your specialized skills is a certainty!
8. Home dialysis training rooms should not be in backrooms of in-center facilities. They should be clearly visible to in-center patients while providing the privacy and sanitation required.
9. For patients transitioning from in-center to home, some training should begin immediately after consent on the treatment floor to shorten training times and to keep the patient enthusiastic about going home.
10. Train physicians to provide “precision home dialysis,” as not all patients require the same prescription.

Chapter 2: Overcoming the Barriers to Starting or Growing a Home Dialysis Program: Administrative Aspects

Chapter Synopsis

- Home dialysis modalities are generally less expensive to provide than in-center hemodialysis, mostly due to overall lower costs of labor, making the financial viability of home programs a more attractive option.
- CMS also provides financial incentive to use home modalities. Newer value-based payment models such as the Advancing American Kidney Health (AAKH) initiative will also likely add to ongoing home growth and success. As facility reimbursement by CMS is anticipated to decrease in the future, the financial position of home therapies relative to in-center treatment will become even more favorable.
- New home dialysis facilities must be certified by CMS and pass inspection by the state agency in order to bill Medicare (and Medicaid) for home training and treatment. The regulatory requirements, as specified in the Conditions for Coverage (CfC), are similar for home and in-center dialysis facilities.
- Desirable attributes for a home dialysis facility include adequate space for conferences, room for staff offices and breaks, and a home-like environment to facilitate the patient's transition to treatment.

What are the requirements for a successful home dialysis program? Like an in-center unit, the three required elements remain patients, staffing, and a facility. Detailed recommendations for helping identify best suited patients and staff are provided in later chapters of this toolkit. However, it is self-evident that without a financial and administrative structure, these elements cannot be assembled or maintained.

The administrative infrastructure for a new home dialysis program is generally much easier to put together if there is an existing in-center program. Historically, this favored larger dialysis organizations (LDO) that already had experience performing home dialysis elsewhere, however, present-day economics are now favoring home dialysis for non-LDO providers and/or hospital-based units as well. There are several published reports of successful home dialysis programs at both academic medical centers and within the Veteran's Administration that deserve notable attention for the lack of LDO involvement as well as their "grass roots" approach with regard to forming a strong foundation of patient and staff education from which success has been achieved (Ahmad, 2020; Jones, 2021).

One other movement that will undoubtedly help further the growth of home dialysis in LDO- and non-LDO-supported settings is the value-based program referred to as the Advancing American Kidney Health (AAKH) initiative set forth by CMS that actively incentivizes physicians and dialysis providers alike to encourage home-based dialysis therapy. The hope is that some of the associated financial incentives (referred to as *home dialysis payment adjustments*) will lessen the burden of smaller home dialysis programs which are at least partially driven by Conditions for Coverage (CfC) requirements for all dialysis units (in-center or home) to have a fully trained and certified interdisciplinary team consisting of a dietitian, social worker, dialysis nurse, and nephrologist. It should come as no surprise that a new, relatively small home dialysis unit is much more likely to be financially viable if it can share the services of renal dietitians, social workers, and technical staff with an existing program.

In general, the economics of home dialysis should be relatively favorable, given diminished nursing resource requirements. Staff support for training and troubleshooting is required, but the staff is generally not required to be present during treatments after patient training is complete. Most LDOs aim to have the home dialysis nurse caring for 20-25 patients at any one time (see Chapter 4 for a more detailed discussion regarding dialysis unit staffing recommendations). Many of the other costs of a home program are relatively fixed, however, making the financial incentivization through the AAKH a significant factor in long-term success. Regardless, to the extent that business models in general are often highly dependent on local factors, economies of scale are usually necessary to reach the financial break-even point. In areas where individual dialysis units are small and dispersed, it may make the most sense to have a regional home dialysis program. It is much less troublesome for patients to travel some distance to a regional unit twice a month than it would be to attend in-center hemodialysis three times weekly, even if the unit was closer to home. While local factors may vary, a home dialysis population of about 20 patients seems to strike many authors as a viable minimum to sustain a dedicated facility and full-time nursing presence. Smaller numbers may work for a new program if home dialysis staff also work in the in-center program, if space for the home program is available from the start, or if a substantial proportion of prospective patients are commercially insured.

Administrative Requirements at Start-Up

New facilities must become certified by CMS to offer home dialysis. After the initial application (form CMS-855A) is submitted to the regional Medicare administrative contractor, a state survey will be required and must be requested. In many states, there is also a Certificate of Need (CON) process required for approval of any new facility, even for the simple re-dedication of space within an existing in-center facility. Provision of an agreement with the administrative contractor to allow the facility to bill Medicare will be contingent on passing the state survey and any other state requirements; at that point, an application can also be made to bill Medicaid.

A governing body is required for a home dialysis unit, just as it is for an in-center unit (Dept. of Health and Human Services, 2008). A robust quality assurance and improvement (QAI) program, supervised by the medical director, will ensure compliance with the CfC and help to produce good patient care outcomes, but several of the parameters subject to QAI in a home program will need to differ from those followed in the in-center unit. For example, the measurement of dialysis adequacy differs greatly among in-center hemodialysis, home peritoneal dialysis, and home hemodialysis, and appropriate individual targets will need to be established for each modality. On the other hand, anemia management targets generally need not differ (recognizing that the administration of erythropoietin-stimulating agents and intravenous iron may be administered at home or during clinic visits based upon different factors). In general, one should plan a dedicated monthly QAI meeting with individually maintained minutes, even in a home therapies unit that is administratively attached to, and shares a medical director with, an in-center hemodialysis facility.

Physical Plant

A home dialysis facility requires dedicated space. Because of the needs for patient privacy, maintenance of sterile technique, and a distraction-free teaching environment, training for home dialysis is done in individual rooms. Attempting to train patients in a typical in-center hemodialysis space would predictably result in high complication and technique failure rates, as well as the loss of staff and patient buy-in. Training rooms can also be used for clinic visits with physicians and unit staff once patients are dialyzing

at home, but at the minimum, there must be enough capacity to train new patients and sustain clinic visits simultaneously. This must include provision for urgent, unscheduled clinic visits and treatments, particularly if accommodation is to be made for “urgent start” PD (see Chapter 4), which we would recommend as a substantial source of patient recruitment for programs with adequately trained staff and surgical/interventional nephrology support. Patient training/treatment and clinic space must be secure and access available only to authorized individuals. It is also worth noting that space availability for respite treatments is critically important as it can help alleviate the inevitable burden of fatigue on caregivers while also helping to avoid home modality loss/transfer. In dialysis units with combined in-center and home dialysis, this respite area should be part of the home dialysis treatment area.

Some new home dialysis units might initially be accommodated within currently unused space in buildings that already house in-center units. For example, advance planning might have resulted in the construction of an in-center unit with suitable extra space for a home dialysis start-up in the future. However, in most cases, a building addition or a separate building will probably need to be constructed or acquired. Experience with new construction for existing programs has suggested that making the environment of a new facility as home-like as possible will markedly enhance patient training success and recruitment. Indeed, it might seem attractive to acquire and remodel an existing residence as a home training facility, rather than pursuing de novo commercial construction. However, commercial construction may make it easier to comply with construction codes and life safety regulations, particularly when one factors in the needs for parking access and safety for patients with physical disabilities, as well as the requirement to pass periodic inspections by the various regulatory agencies.

Optimally, a home dialysis facility will also contain or have access to space separate from training and examination rooms for patient waiting areas, nursing offices, storage, conferencing, and staff breaks. Home dialysis supplies are surprisingly bulky, so storage space is a significant consideration, which is best addressed prospectively. A pleasant conference space is useful not only for staff meetings, but also for group chronic kidney disease (CKD) patient education concerning ESRD treatment options, an activity which is potentially reimbursed by Medicare and of documented effectiveness for patient recruitment. Needs for larger programs might include offices for other staff (e.g., physicians and administrative support).

Historical and present-day data would indicate that the large majority of home dialysis patients perform peritoneal dialysis (USRDS, 2021). The training hurdle for patients to start dialyzing at home is much lower for PD than for hemodialysis and the equipment less elaborate. While a significantly different skill set is required for PD nursing compared with hemodialysis, many new programs often choose to offer PD first. However, recall that the CfC require all modalities to be offered to patients. Therefore, if one wishes to retain home hemodialysis patients, adequate space, equipment, and technical expertise will need to be provided for their needs. In at least some certificate of need (CON) states, the maximum number of hemodialysis stations in each region is specified, and any hemodialysis stations in the home training unit will ultimately subtract from the capacity of local in-center units. Depending on the hemodialysis equipment chosen, the electrical or plumbing capacity of the home dialysis unit might also require upgrading.

Reimbursement Issues Specific to Home Dialysis

New ESRD patients not previously enrolled in Medicare and who start home dialysis immediately become eligible for Medicare; in fact, their Medicare coverage will be backdated to the first day of the month in which they start. Under the CMS PPS (Prospective Payment System), which most dialysis clinics elected to start using in 2011, the current per-treatment reimbursement rate is 151% of the standard rate for the first 120 days of dialysis. This adjustment should be applied automatically by the facility's regional Medicare administrative contractor. Thus, the home training facility can be reimbursed at this more generous rate for the entire 120-day period, known as the "onset of dialysis adjustment." While comorbidity and training adjustments do not apply during this period, the onset of dialysis adjustment more than makes up for any deficit.

The first 60 to 90 days of in-center hemodialysis, in contrast, are not covered by Medicare (i.e., Medicare coverage begins on the fourth month since dialysis initiation), thereby shortening the period during which the onset of dialysis adjustment (and, indeed, any reimbursement at all) applies. For programs that see a high proportion of otherwise unfunded patients, this built-in Medicare encouragement for home dialysis can make an enormous difference to overall financial viability. This is particularly true if one recognizes that a patient switching from in-center hemodialysis to a home modality within the first 90 days restores the Medicare eligibility to the first day of the month in which chronic dialysis commenced.

For patients covered by commercial insurance, the coverage varies, but is often present from the start of dialysis, covers training, and usually covers the monthly billing of supplies and support, including the nephrologist billing, at a higher rate than Medicare. The number of patients required for financial viability of the program is, in general, substantially decreased by having even a few patients who are covered by commercial insurance. In areas with substantial penetration of commercial insurance among ESRD patients, it may be possible to start a program with a relatively small number of commercial patients while awaiting Medicare certification.

Patients who are already enrolled in Medicare prior to initiating home dialysis, or those returning to Medicare after renal transplant failure, are not eligible for the onset of dialysis adjustment. Such patients, as well as those training for home dialysis after a longer period of in-center hemodialysis, are eligible instead for a (relatively modest) training adjustment for treatments done in the home dialysis unit. This adjustment is currently limited to 15 treatments for PD (i.e., three weeks of 5-day-per-week in-center cyclor training). In our experience, most patients and caregivers can complete training within this timeframe.

Home hemodialysis training is covered by the training adjustment for up to two months, though this is usually reimbursed on a 3-treatments-per-week basis, even for those patients performing a more frequent dialysis regimen. When one factors in staff time and equipment complexity, most home training units may not recoup expenses on home hemodialysis training itself. Legislative solutions to resolve this issue and thereby promote home hemodialysis penetration have been proposed, but at the time of this writing, no passage or implementation appears to be imminent. Of note, training expenses for patients who switch home dialysis modalities are reimbursed in a similar fashion to those switching to home dialysis from in-center. Medicare will pay for such "retraining" of a patient for home dialysis or PD under the following certain circumstances:

- The patient changes to a *different* type of home dialysis
- The home dialysis *equipment* changes

- The *setting* where the home dialysis occurs changes
- The dialysis *partner* changes
- The patient has a *change in medical status* that would not keep him or her from doing home dialysis—but would require additional training (examples can be found in the Medicare Claims Processing Manual (<https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/clm104c08.pdf>))

Certain medications are currently included in the reimbursement “bundle” (PPS) for both home dialysis and in-center dialysis, including erythropoiesis-stimulating agents (ESA), intravenous iron, calcimimetics, and vitamin D analogues. In our experience, home dialysis patients, particularly PD patients, tend to use lower doses of ESA per capita, at least in part due to subcutaneous administration; therefore, there should be no financial disincentive to expanding the use of home dialysis from the medication expense standpoint. At the time of this writing, phosphate binders, which are used by home dialysis patients and in-center hemodialysis patients alike, are not included in the bundle, and their inclusion has an anticipated date of January 1, 2025 (Medical Claims Policy Manual, 2019).

Chapter Summary

- Home dialysis is generally less expensive to provide than in-center hemodialysis, mostly due to overall lower costs of labor. Since it is reimbursed by CMS at a similar rate to in-center dialysis, the potential operating margin for the facility is greater once economies of scale are realized.
- New home dialysis facilities must be certified by CMS and pass inspection by the state agency in order to bill Medicare (and Medicaid) for home training and treatment. The Certificate of Need (CON) process also provides a significant hurdle in many states. The requirements for a governing body, medical director, quality assurance process, and interdisciplinary patient care team, as specified in the CfC, are similar for home and in-center dialysis facilities.
- Dedicated space for patient treatment, education, and clinic visits is required for a viable home therapies program. Desirable attributes of the facility include adequate space for conferences, room for staff offices and breaks, and a home-like environment to facilitate the patient’s transition to treatment in his or her own home.
- The human resources aspects of a home training program are covered in more detail in a later chapter. Nursing staff time dedicated to the home program is mandatory, and specific nursing qualification requirements are also discussed later. On the other hand, many successful programs share the services of the renal dietitian, social worker, and facility administrator (as well as the medical director) with in-center hemodialysis facilities.
- CMS provides some financial incentive to patients, physicians, and dialysis facilities to use home modalities, particularly at ESRD onset. The facility incentive has increased with the advent of the PPS (the “bundle”). Newer financial incentives through the AAKH that encourage home dialysis (through a home dialysis payment adjustment) will also likely add to ongoing home growth and success. As facility reimbursement by CMS is anticipated to decrease in the future, the financial position of home therapies relative to in-center treatment will become even more favorable.

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Chapter 3: Overcoming the Barriers to Starting or Growing a Home Dialysis Program: Educating Clinicians and Medical Directors

Chapter Synopsis

- The Advancing American Kidney Health (AAKH) initiative was established by the federal government in 2019. It places a strong focus on home dialysis and transplantation.
- Home dialysis training during nephrology fellowship has not been a priority until more recently. This sub-specialized area of nephrology is critical to improving the quality of care provided by the nephrology community going forward in order to ensure that all patients are educated and offered access to all kidney replacement therapies.
- In this chapter, we identify and discuss how to overcome the many barriers to training nephrologists in home dialysis therapies, in addition to discussing different approaches that may help reduce physician burnout.
- We also discuss different programmatic and personnel considerations (which include staffing and administrative issues) that all nephrologists and home dialysis medical directors should consider when starting or maintaining a home dialysis program.

The Advancing American Kidney Health Initiative (AAKH) Executive Order, first released in July 2019, includes ambitious goals for management of patients with ESRD on home dialysis. These goals will require ongoing recruitment of dedicated healthcare professionals and expansion of existing programs. Many of the barriers that were identified in the first edition of this toolkit published in 2016 remain today and will need to be addressed if the nephrology community is to marshal the resources necessary to achieve the AAKH initiative goals and ensure informed patient choice when making decisions for dialysis modality. This chapter will address both those barriers that are under the purview of the medical director or individual practice thought leaders as well as those that are potentially not under their control. It is recognized that dialysis programs need to be able to support patient access to both home (home hemodialysis and peritoneal dialysis) and in-center options, even if a specific dialysis unit may not provide all such options. Ideally, in-center options would include different approaches to hemodialysis that best meet the needs of the patient (e.g., conventional thrice weekly hemodialysis (HD), daily short HD, or nocturnal HD). It is imperative that all nephrology providers are educated (to the minimum extent) so that they can counsel patients on all kidney replacement therapy options and (to the maximum extent) that they can directly provide such therapy and be able to perform the necessary medical director responsibilities to achieve adequate oversight.

This toolkit will address:

1. Regulatory requirements of the medical director
2. Barriers to training of nephrologist and nephrology fellows with the requisite skills required to build/nurture a home dialysis program.
3. Programmatic and personnel considerations that address resource barriers that are under the purview of dialysis providers and Medical Directors to help grow and sustain a successful home dialysis program.

4. Programmatic considerations for eliminating or reducing burnout, including burnout experienced by medical professionals (nurses, technicians, and physicians/physician extenders) as well as by home dialysis patients and their care partners.

Regulatory Requirements of the Medical Director

In general, the Medicare Conditions for Coverage (CfC) do not make many distinctions between home and in-center dialysis programs with regard to regulatory requirements. The role of the medical director in the two settings is therefore quite similar. The medical director of a home dialysis program, like his/her/their in-center counterpart, is responsible for quality assurance and performance improvement (QAPI) activities and staff education, as well as for making sure that patients are seen by their attending nephrologists and other members of the interdisciplinary team and that care plans are completed for those patients. A home program, like an in-center facility, must have a governing body to which the medical director reports, and of which the medical director is usually a member. In the frequent case in which a single dialysis unit hosts in-center and home programs, the same individuals may serve on the governing bodies of both, but it is recommended that separate governing body and QAI committee meeting minutes be maintained. Some appropriate subjects for performance improvement projects in home dialysis do not apply to in-center programs, and vice versa.

Shortcomings of U.S. Nephrology Fellowship Training in Home Therapies

One important barrier impeding the uptake of home therapies may be the lack of sufficient comfort of nephrologists with home dialysis modalities to recommend or even offer home dialysis treatment options as a choice to their patients. A frequently referenced 2010 survey of over 600 practicing nephrologists reported that only 6% would choose in-center hemodialysis for their modality if they were to personally require kidney replacement therapy and knew they had five years to wait for a kidney transplant (Merighi, 2012). The fact that these results were published at a time when 92% of prevalent dialysis patients were receiving in-center hemodialysis in the U.S. is of particular note and has raised many concerns of which the adequacy of home dialysis training during nephrology fellowship has come to the forefront. It is also worth mentioning that nephrologists in the survey who received more fellowship training in home dialysis modalities, or who sought out additional training during or after the time they achieved board eligibility, were more likely to offer home therapies.

The American Society of Nephrology (ASN) convened a Home Dialysis Taskforce in 2021 with the purpose of evaluating the current status of home dialysis education in U.S. nephrology programs and identifying a pathway forward to improve fellow training, patient access, and policy supporting home dialysis therapies. They recently published a nationwide survey that reported 72% and 30% of program directors and division chiefs, respectively, believed that their current fellows would be capable of providing PD and HHD care independently upon graduation (Yuvaram, 2023). Nephrology fellow perceptions of competency would support this viewpoint as well. A 2017 survey of U.S. nephrology fellows reported that the two areas where fellows would want further instruction prior to graduation were home hemodialysis (51%) and peritoneal dialysis (49%) (Rope, 2017).

One persistent factor in the lack of penetration of home dialysis in the U.S., therefore, appears to be the lack of training in, and exposure to, home dialysis in many nephrology fellowship programs. One aggravating factor contributing to this issue is the overall low prevalence of home dialysis in the U.S. Nephrology fellowship programs may not have enough patients to satisfy the training requirements in home dialysis. It is therefore imperative that the training programs adopt home dialysis to an even larger

extent than other nephrology centers in order to promote training in home dialysis. Gupta and Miller recently published their viewpoints on what may constitute a successful home dialysis training program. A paradigm shift in what constitutes a standard “rotation” during fellowship training was offered in terms of creating dedicated home dialysis rotations that expand beyond typical longitudinal continuity clinics with a goal of not only increasing the volume of exposure, but also giving fellows the opportunity to better understand the underlying mechanisms of home dialysis and troubleshooting complications (Gupta, 2021). Most nephrologists having completed training likely have little knowledge in terms of how a PDycler is set up, or how to manage a contamination event, or troubleshoot and address failure of the modality as prescribed to provide adequate outcomes including clearance, never mind how (and when) to consider offering respite care for a patient with a fatigued care partner. The authors (and others) have also described the idea of creating home dialysis fellowships at “centers of excellence” where experienced nephrology educators can offer high-volume, high-quality opportunities to train the next generation of home therapy medical directors.

While attempting to directly address the deficiency in knowledge of home dialysis is beyond the scope of this toolkit, several continuing medical education programs and other resources have been developed for the practicing clinician. One must recognize that over the last many years since the first installment was published there has been a great deal of change in terms of how our nephrology fellows learn. Traditional in-person didactic learning has given way to mock clinical assessments/OSCEs, podcasts, and on-line training courses (e.g., Home Dialysis University) (Yuan, 2023). A list of links, current at the time of publication, to some of these is provided in Appendix I. In particular, the large dialysis organizations, which have a vested interest in increasing the penetration of home therapies, are generally eager to offer education and programmatic expertise for those nephrologists who hold admitting privileges or medical directorships at their facilities.

Ultimately, training that creates comfort and familiarity with the many modalities of dialysis therapy will be the best way to assure success in allowing our patients to make informed decisions. This is a significant challenge that can only be overcome with changes in the structure and scope of training with the hopes of eliminating some of the biases that exists amongst nephrologists that ultimately take away from the prime focus of allowing patients to make these individually centered informed decisions. Many of these biases still exist in the current climate of nephrology fellowship training and must be recognized (and addressed) in order to better educate current and future nephrologists:

- Failure to provide adequate exposure to home therapies
- Failure to explore the evidence supporting home therapies
- Failure within nephrology research to develop such evidence
- Failure of nephrology fellowship programs to require demonstration of the skillsets required for privileges in home dialysis care

One might think that the training environment for dialysis has improved in recent years, however trainee surveys and an unbalanced landscape of in-center and home dialysis therapy opportunities during (and after) graduation would seem to indicate otherwise. At present, it is our perception that many nephrology training programs have a much larger dialysis component than they previously did, because of the growth of the ESRD patient population, the recognition of the dominant role of dialysis in the clinical practice of nephrologists, and the increasing dependence of most academic medical centers on clinical revenue. Updated USRDS data describes the overall percentage of incident patients on home dialysis having grown from 6.8% in 2010 to 13.3% in 2020, while the percentage of prevalent patients on home dialysis grew from 9.1% in 2010 to 13.7% in 2020. Despite evidence of home growth over the last decade, the annual

report indicated that nearly half (45.6%) of the 8,088 Medicare-certified dialysis clinics in 2020 were *not* certified to perform peritoneal dialysis or home HD. Of those clinics certified to provide home therapies, 10% had no active patients at the end of 2020. In addition, more than 50% of PD programs and almost 87% of home HD programs had 10 or fewer patients (USRDS, 2022).

A survey of fellowship training directors published by Wadhwa revealed persistent, systematic deficiencies in PD experience. Factors cited included not only the lack of patients, but also the lack of qualified faculty (Wadhwa, 2013). Given the current rarity of home hemodialysis patients in the U.S., no publications were found that specifically addressed fellowship training in this area, but we suspect that most nephrology training programs offer very limited exposure to such patients and that faculty members with special interest or expertise in home hemodialysis are few and far between.

Additionally, some legacy training programs still emphasize in-hospital nephrology care, followed by outpatient continuity clinic providing CKD care, with less emphasis on a robust, realistic exposure to all forms of ESRD care. It is hoped that the changes in fellowship training advocated by ASN and other national thought leaders will lead to a cultural change emphasizing home modalities. It is likely that any changes in certification that would require demonstration of attainment specifically of peritoneal dialysis and home hemodialysis professional skills would accelerate such changes. Importantly, this may require consideration for a period of time of a unique and separate component of the certification to highlight the importance of these skills. To this end, the ASN's Taskforce on the Future of Nephrology published a report in February 2023 entitled "Reimagining Nephrology Fellowship Education to Meet the Future Needs of Nephrology" wherein recommendations were made to emphasize more personalized training that includes the ability to focus on specific areas of nephrology (e.g., home therapies) while de-emphasizing areas of training that have historically been a major focus of training (e.g., non-tunneled dialysis catheter placement and percutaneous kidney biopsy) (Rosenberg, 2023). Table 2 offers recommendations for skill training and core knowledge in home dialysis training.

Table 2: Attainment of Entrustable Clinical Skills and Core Knowledge Recommended for Nephrologists Managing Kidney Patients on Home Dialysis (adapted from Gupta et al)

Peritoneal Dialysis	Home Hemodialysis
PD Catheter Management; Pre- and Post-Insertion: <ol style="list-style-type: none"> 1. Understand proper catheter insertion and location; and complications 2. Diagnosing and managing catheter failures 3. Diagnosis and management of failure to instill or drain PD fluid 4. Diagnosis and management of exit site, tract, or catheter infections / abscesses 	Procedural Skills: Understanding Key Components of Patient Training <ol style="list-style-type: none"> 1. Hemodialysis machine set up 2. Actions to be taken when alarms sound 3. Vascular access care and optimal techniques for cannulation 4. Physical examination of / clinical measures to monitor vascular access 5. Certification of patient skills to conduct HD
Prescription and Management of PD Procedure: <ol style="list-style-type: none"> 1. Understand the goals and limitations of CAPD /CCPD; tidal versus regular PD 	Prescription and Management of HD <ol style="list-style-type: none"> 1. Initiation of HD / or transition from in-center dialysis 2. Adjustment of prescription
Management of PD Prescription: <ol style="list-style-type: none"> 1. PD fluid volume, fluid composition and duration for: Initiation, Urgent start, maintenance PD 2. Urea Kinetics Measurement and Interpretation and adjustment of prescriptions to meet goals 3. Peritoneal equilibration Test 4. Management of patient volume and BP with PD net UF 5. Understand the role of alternate PD solutions 	Management of HD Prescription: <ol style="list-style-type: none"> 1. UF goals (UF rate), dialysate composition and duration for: Initiation, maintenance HD 2. Urea Kinetics Measurement and Interpretation and adjustment of prescriptions to meet goals 3. Home dialysis water treatment 4. Nocturnal Home dialysis
Diagnosis and Management of Complications of ESKD in Patient Managed with PD: <ol style="list-style-type: none"> 1. Dietary control of protein and electrolyte abnormalities; measurement and management 	Diagnosis and Management of Complications of ESKD in Patient Managed with HD: <ol style="list-style-type: none"> 1. Dietary control of protein and electrolyte abnormalities; measurement and management 2. Management of BP and intravascular/ total body fluid volume
Diagnosis and Management of Complications of PD: <ol style="list-style-type: none"> 1. Peritonitis and catheter site infections / prevention, diagnosis, and management 2. Management of exit site for proper maintenance of PD 3. Hypoalbuminemia and protein malnutrition 4. Hyperglycemia especially complicating diabetes management 5. Unintentional weight gain or loss 6. Hernia prevention, surveillance, and treatment 	Prevention, Diagnosis, and Management of Complications of HD <ol style="list-style-type: none"> 1. Calcium and mineral metabolism 2. Potassium mass balance and removal
Understanding of the Patient and Treatment Issues Key to Sustaining PD Long-Term	Understanding of the Patient and Treatment Issues Key to Sustaining HD Long-Term
Demonstrate Understanding of the Components of Physician Programmatic Oversight: <ol style="list-style-type: none"> 1. PD technique training of patients 2. PD nursing qualifications and training 3. Unique roles and responsibilities of PD program Medical Director 	Demonstrate Understanding of the Components of Physician Programmatic Oversight: <ol style="list-style-type: none"> 1. HD technique training of patients 2. Home HD nursing qualifications and training 3. Unique roles and responsibilities of Home HD program Medical Director

Gupta N, Miller BW. Training nephrology fellows in home dialysis in the United States. CJASN 2021; 16: 1749-1751. Doi: <https://doi.org/10.2215/CJN.03110321>

Potential Programmatic and Personnel Considerations

Within medical practice, dialysis is among the best examples of a “team sport.” It is universally recognized that professionals from several other disciplines (e.g., registered nurses, social workers, and dietitians) aside from patient providers are required for dialysis patients to successfully receive treatment, and minimum training and certification requirements for individuals in these professional roles are specified in the CfC. Because many of these interdisciplinary team members come from in-center dialysis programs, nephrologists who wish to start home dialysis programs may encounter resistance from some of these individuals. Research has shown that, even in the most seasoned of home dialysis programs, interdisciplinary team members can have widely different views regarding patient candidacy for home therapy (Poinen, 2021). A major role of the medical director may be providing structured and focused education to these home dialysis team members in order to dispel certain misperceptions and to provide a consistent approach for all patients. The lack of an acknowledged and consistent evidence-based approach for all patients will provide an opportunity for the introduction of cognitive bias. This bias can lead to inequities in how dialysis modalities are discussed with patients and the breadth of modality choices that individual patients are given. Some of this bias may arise from misconceptions about patient-specific predictors of success with the home modalities and may contribute to the observed disparity of how each patient is offered, and potentially transitioned, to home dialysis modalities (Qamar, 2009).

Another chapter in this toolkit is devoted to a more detailed description of features of a home program from the standpoint of nurses and other members of the interdisciplinary team. This discussion will, therefore, focus on the potential role of a prospective medical director of a home dialysis operation, as a team leader engaged in consensus building. The nephrologist who intends to be successful in starting or growing a home dialysis program should enter the process with an understanding of the potential demands on the medical director and the other members of the team, and the purpose of this section is to describe these demands.

Administrative Issues

Among the first questions that need to be answered in starting a home dialysis program is the potential independence of the program; that is, should the program be started within an existing in-center hemodialysis operation, or will it be separate? Most dialysis units in the U.S. are now owned and operated by one of two large corporations, and most of the remainder belong to smaller chains. In theory, a multi-unit dialysis operation of any size should be willing to host a home program, since the financial margin on home treatment is favorable, compared with in-center treatment, and likely to become more so in the future. If the prospective home training unit is not part of a national or regional chain, the nephrologist may need to overcome a lack of local expertise in home therapies, a fear of risk taking, or concerns that the patient base will not support a home operation. Further issues may involve potential diversion of the effort of already oversubscribed local staffing or potential diversion of the patient base of an in-center unit whose margins are already thin. In the case of practices located in certification of need (CON) states, opening a home dialysis facility requires state approval, with associated delays and costs, and could result in the loss of approved dialysis stations from the in-center unit. In all states, acquisition of suitable space for patient education, treatment, and training (separate from the in-center dialysis treatment space) is absolutely required from the practical standpoint, and in some states by regulation (e.g., Texas) (Texas Regulations, 2023). If patients are to be attracted to home therapies and trained to succeed at home, making the training environment as “homelike” as possible is an important consideration.

In dealing with these concerns (and the inevitable associated start-up costs), the nephrologist should recall that patients must, according to the CfC, be informed of and offered a choice among all modalities of ESRD therapy, including home therapies. If the program cannot offer home therapies, it is obligated to refer patients to centers that do offer such modality options, even if they need to come under the care of another nephrologist.

In the case of a dialysis company that runs multiple in-center units in the same geographical area, starting a home dialysis program in a central location has often proven successful. Stable home dialysis patients generally need to be seen by their dialysis team only once or twice a month, so the overall travel burden is potentially much less than that experienced by in-center patients, even if the distance from home to the dialysis unit is significantly greater.

If a home dialysis operation that is administratively separate from local in-center facilities appears to be the best solution, the nephrologist must recognize that PD patients, and even home hemodialysis patients, may periodically require in-center hemodialysis for any of a number of changes in medical or social circumstances. Therefore, a home dialysis program cannot be safely and successfully operated unless there is a provision for back-up in-center treatment for its patients.

Another consideration is the availability of PD in local hospitals. All dialysis units, whether home units or in-center units, are required by the CfC to have an agreement with a hospital to provide inpatient dialysis when required. While it is clearly suboptimal to offer only hemodialysis to inpatients who were doing home PD before admission, many smaller hospitals will not have any nurses with PD expertise. In such cases, an agreement from the hospital may be required to allow the outpatient home dialysis staff to do CCPD for patients who are too ill to dialyze themselves in the hospital, and the hospital will need to acquire PD apparatus and supplies compatible with the patient's catheter extension set or arrange to obtain them through the outpatient home program.

Staffing Issues

From the professional perspective, nursing in a home dialysis program can be intensely satisfying, but it is self-evident that the skill set for home dialysis requires significant extension of that required for in-center hemodialysis. The foundation of any successful home dialysis program is the nursing staff, who have by far the largest role in interfacing with patients of any of the interdisciplinary team, including the nephrologist. Thus, a home dialysis program requires nurses who have made the extra effort to acquire additional skills in PD and in the specifics of home HD performed by the patient or their care partner including operation and troubleshooting of the equipment for either home modalities, who enjoy teaching, and who are willing to go on patient home visits and to be available to patients both inside and outside of regular working hours. Ideally, home dialysis nurses need to have home dialysis patient care as their prime responsibility lest demands of shared in-center hemodialysis care prevent them from managing home dialysis patient needs. Unless such individuals can be identified and appropriately compensated for their extra effort and expertise and provided adequate time to perform their specific responsibilities, no home dialysis program can be a success. On the other hand, it has been many of the authors' experience that, once nurses are recruited, the professional satisfaction associated with home dialysis leads to greater retention of the nursing staff in home units than in-center.

Dietary management differs significantly for patients who dialyze daily at home than for patients on standard 3-times-per-week in-center regimens. Additionally, nutritional requirements for patients on home HD and PD may differ depending on the exact modality and intensity of prescription chosen by the

patient. The ideal home dialysis dietitian recognizes and incorporates into his or her practice the additional flexibility that home dialysis offers. Indeed, it is this very flexibility that is one of the major advantages of home dialysis from the patient standpoint, and one should take care not to lose this significant advantage in quality of life by reflex prescription of a “renal diet.” For example, no dietary potassium restriction may be required of many patients who dialyze daily, whether on PD or HD. On certain intensive home HD regimens, phosphorus supplementation rather than phosphorus binders may be indicated. These situations may require significant conceptual adjustment on the part of both the nephrologist and dietitian. At the same time, dietary prescription for PD in particular poses significant challenges, since protein loss through the peritoneal membrane represents a significant source of negative nitrogen balance that is not present in hemodialysis patients. Unless the PD patient can maintain protein anabolism outside the peritoneum, protein wasting can result in technique failure. In summary, there is a far greater need for creativity in dietary prescription—thinking outside the box—in a home dialysis program than in an in-center program. The medical director who wishes to retain home dialysis patients should recruit a dietitian with this ability and encourage the required creativity. The dietitian may well need to become accustomed to generating different approaches to fulfill individual dietary recommendations for each patient.

Likewise, the challenges faced by the social worker in a home dialysis program differ in several respects from those seen in-center. The average age of home dialysis patients is likely to be lower than that of the in-center patients, and many individuals elect to do home dialysis so they can stay in the work force or provide family care (e.g., childcare or eldercare). The social worker should be prepared to interact more with employers and vocational rehabilitation counselors. It is the practice of the authors of this toolkit to make every possible effort to accommodate the time and lifestyle requirements of those patients who continue to work or attend school, and the social worker is obviously an integral part of these efforts.

Resources from the community may also need to be mobilized to alter a patient’s home physical environment to allow for home dialysis. Many more home dialysis patients should also be suitable candidates for renal transplantation, and the social worker may be involved in helping patients overcome personal or social obstacles to achieving placement on the waiting list. In general, most dialysis social workers should enjoy working with home dialysis programs, in which patients are (by definition) more independent and generally face fewer physical challenges.

Nephrology Providers: Improving Collaboration and Preventing Burnout

Like other physicians in acute care specialties, nephrologists have tended to aggregate into groups, and relatively few are in solo practice any longer. Most large group practices will already have active home dialysis programs, but in smaller practices, inside or outside an academic setting, a nephrologist who develops an active interest in home dialysis may acquire a level of commitment and expertise not shared by his/her care partners. Development of a “local expert” is undoubtedly a favorable influence on a home dialysis program and, in fact, is recommended. However, it should be recognized that this individual may face demands on his/her time that are not shared equally among partners. Other perceived inequities may develop. Patients who want home dialysis will (and should) tend to gravitate toward the local expert. Practice revenue patterns may change; those practices that see their in-center HD patients four times monthly will not be able to bill home dialysis patients for quite the same level of reimbursement (unless participating in some of the newer advanced alternative payment models). A partner of the local expert might be asked to admit a PD patient with peritonitis during the night and make decisions about antibiotic treatment and cyclo orders that they might not have thought about for quite some time. If such issues are anticipated, their exploration in advance should enable straightforward solutions in most cases.

The additional professional demands if not addressed may contribute to physician burnout. In a cross-sectional survey exploring the burden of, and risk factors for, burnout among nephrologists in the U.S., Nair and colleagues reported this symptom in nearly one-quarter of the 457 respondents. Among the many complaints cited, a perceived lack of control over work, frustration with the time spent on electronic medical records, and not being able to cure patients were highlighted as issues weighing heavily on these clinicians (Nair, 2022). Success in a home dialysis program not only requires emotional and clinical support for patients and their caregivers (also known as care partners), but also those clinicians caring for these patients. Efforts to maximize the roles of the interdisciplinary team, better educate colleagues to help better share patient responsibilities, and establish high-quality, reliable dialysis access support are but just a few examples of areas of focus to help alleviate the burdens put upon the home dialysis provider/medical director.

Well-trained PD nurses will be able to manage most nighttime patient calls, and pre-prepared protocols for peritonitis treatment and other anticipated technical problems should reliably facilitate management after hours. Efforts to lessen the on-call burden for nephrology providers is one significant way of improving the quality of life of the nephrologist. In addition, while physician monthly capitated payment (MCP) reimbursement for home dialysis patients is somewhat less than for the 4-visit monthly in-center patients, the difference in long-term revenue will, in many cases, be partly offset by immediate Medicare eligibility for home patients, and a home training charge that can be billed by the physician who personally supervises patient training. In fact, the average face-to-face management time is less also, and the physician may be able apply the time saved towards other clinical (or non-clinical) endeavors that either bring in better remuneration or personal satisfaction to one's career.

Peritoneal Dialysis Access Support

In some areas, lack of local surgical experience with PD catheter placement and maintenance may represent an obstacle to establishing and sustaining a home dialysis program (Crabtree). While Tenckhoff and other PD catheters can be placed blindly into the pelvic peritoneal cavity, it is our belief that laparoscopic placement is responsible for the much higher success rate we have observed in recent years. Omental adherence is a relatively common cause of drain failure of blindly placed catheters; this can be minimized by laparoscopically visualized placement of the catheter tip in a paracolic gutter, away from the omentum. Some interventional radiologists and nephrologists have recently reported high success rates with percutaneous placement under ultrasound and fluoroscopic guidance, and dissemination of this skill set among training programs may decrease the need for laparoscopic placement in the future, at least in uncomplicated clinical scenarios.

A few nephrologists have sought training and achieved competence in laparoscopic PD catheter placement. However, most nephrologists in the U.S. currently rely on surgeons trained in laparoscopic abdominal surgery for catheter placement. While the operation is not technically difficult (by the standards of an experienced laparoscopic surgeon) in most patients, a learning curve may be anticipated, with an initially high rate of exit site leaks, drain problems, cuff extrusion, etc. A survey of surgical training programs in the U.S. found that most programs offered the procedure but that most residents finished their training having performed less than five catheter placements (Wong, 2010). The procedure can also be performed by interventional radiologists who have experience in performing these procedures. Here the peritoneal dialysis catheter is placed using ultrasound or fluoroscopy guidance (Reddy, 2010).

When PD catheters malfunction, some patients may require a more advanced technical surgical approach that may include omentopexy, alternate (e.g., parasternal) exit site placement, or takedown of intraperitoneal adhesions. Occasionally, a malfunctioning catheter can be salvaged by stylet placement and repositioning by an interventional radiologist, nephrologist, or other appropriately trained physician. If appropriate local expertise in PD catheter placement is not available and cannot readily be developed, it may be worthwhile to establish a referral relationship with a center that supports an established program. A useful webinar with video illustrating some of the finer points in laparoscopic catheter placement, featuring surgeon John Crabtree, MD, is available to interested parties on the Internet (Crabtree, 2010).

While initial placement of the PD catheter is an important juncture in a patient's modality success, transitions of care can also jeopardize PD longevity when a patient is hospitalized. In facilities without proper registered nurse PD training and experience, the risk for either technique failure or catheter/exit site infection can increase. Likewise, many patients nowadays find themselves having to change modality due to a lack of rehabilitation facility options with PD experience. All of these factors affecting the success and empowerment of dialysis patients clearly have repercussions on home dialysis team success and physician frustration/burnout. Ensuring both expertise in dialysis access support and as well as in-hospital (or post-hospital acute care) modality access are all areas of focus that can improve patient and provider success.

Chapter Summary

- The medical director of a home dialysis program is integral in providing the oversight and educational support to the program. The CfC do not make many distinctions between home and in-center dialysis programs with regard to regulatory requirements.
- The nephrologist who is interested in starting or expanding a home dialysis program currently faces several obstacles. Among the most prevalent of these is lack of training and experience in home dialysis patient care, which many nephrology fellowships still do not offer to a suitable extent, but which can be overcome with continuing medical education (CME) offerings, published materials, and Internet resources. Efforts to improve the nephrology fellowship training experience are needed.
- In order to create a successful home dialysis operation, one must also have a facility that can provide space and time for patient care, and training will be needed. Professionals in other dialysis disciplines will need to be recruited, and among these the nursing staff is the most crucial, though buy-in will also be required from a facility administrator, dietitian, and social worker. Though the interested nephrologist may intend, through self-directed learning and accumulated experience, to assume the "local expert" role in home therapies, support from nephrology colleagues, as well as local hospitals, hemodialysis facilities, and a surgeon or interventionalist will also be required.
- Efforts to reduce physician burnout in nephrology could include support systems via interdisciplinary teams, other nephrology colleagues, and establishing high-quality and reliable surgical access care.

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Texas

Regulations:

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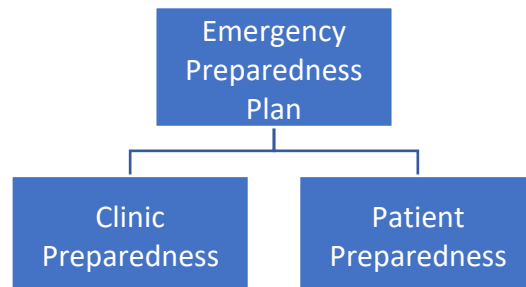
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Chapter 4: Emergency Management for the Home Dialysis Program

Chapter Synopsis

- Emergency preparedness for home dialysis requires communication and planning for both patients and staff.
- CMS emergency preparedness requirements state that each program should include four major elements: risk assessment and emergency planning, policies and procedures, communication planning, and training and testing.
- For home dialysis staff, emergency preparedness training, back-up communication planning, and coordination of patient care are critical aspects that must be provided at both the general and individual level.
- For home dialysis patients, emergency preparedness means involvement with training and preparation with the home dialysis unit, continuous readiness with emergency and dialysis supplies, and planning for scenarios of when one *cannot* leave the home as well as when one *must* leave the home.
- The National Forum of ESRD Networks works closely with the Kidney Community Emergency Response (KCER) Coalition during emergencies, and both are important resources for up-to-date information, communication, and directed support.

Preparation for a disaster or emergency event as a home dialysis provider has many similarities to that of the in-center hemodialysis program but with the critical caveat that home dialysis patients are dependent upon their own personal residence (which could be their actual home or even a nursing home) for the shelter, electricity, and water typically necessary to perform dialysis safely and effectively. For a clinic manager or medical director, emergency plans must include strategies to support the continuity of operations at both the clinic and in support of the patient continuing therapy at home if possible, and elsewhere if necessary.



In this chapter we will discuss emergency management aspects specific to a home dialysis program. For further information regarding the general principles of emergency management in the dialysis population, the reader is referred to the “Outpatient Medical Director Toolkit” that is available at our National Forum of ESRD Networks website: <https://esrdnetworks.org/toolkits/professional-toolkits/outpatient-medical-director-toolkit/>. Two other important source of dialysis disaster management education can be found at the Kidney Community Emergency Response (KCER) Coalition website (<https://www.kcercoalition.com/en/>) and the American Nephrology Nurses Association (ANNA) website (<https://www.annanurse.org/professional-development/practice/disaster-preparedness>).

Dialysis Emergency Management: What Are the Rules?

Emergency planning is a requirement noted in the CMS ESRD Conditions for Coverage (CfC) Emergency and disaster preparedness (V408-416) regardless of the type of dialysis a clinic provides and is specifically stated as follows:

V768 (Rev. 200, Issued: 02-21-20; Effective: 02-21-20, Implementation: 02-21-20) (g) Standard: Emergency coverage. (1) The governing body is responsible for ensuring that the dialysis facility provides patients and staff with written instructions for obtaining emergency medical care.

- “42 CFR part 405, subpart U regulations require dialysis facilities to have written policies and procedures for handling emergencies with annual reviews, testing, and revisions, and staff training to handle any emergency or disaster. This final rule requires that the staff be able to demonstrate the ability to manage emergencies that are likely to occur in the facility’s geographic area.
- “V408: (d) Standard: Emergency preparedness. The dialysis facility must implement processes and procedures to manage medical and non-medical emergencies that are likely to threaten the health or safety of the patients, the staff, or the public. These emergencies include, but are not limited to, fire, equipment, or power failures, care related emergencies, water supply interruption, and natural disasters likely to occur in the facility’s geographic area” (Forum of ESRD Networks, 2021; Centers for Medicare and Medicaid Services, 2020).

The CMS Emergency Preparedness Requirements state that each program should include four major elements that are listed below and will serve as the four primary areas of focus in this chapter:

- Risk assessment and emergency planning
- Policies and procedures
- Communication plan
- Training and testing (Medicare and Medicaid Programs, 2019)

Conducting a Risk Assessment and Emergency Planning

Emergency Management Limitations

Any disaster event must be approached from the point of view that there may be multiple limitations to conducting pre-formed strategies. Assistance is not guaranteed, and plans need to aim to include a variety of contingency plans. Every emergency will be managed in a way where there is a prioritized response and recovery. There can be no assumptions in terms of how quickly outside help will arrive. As a result, individuals must be prepared to take care of themselves for an extended period of time in order to maximize the best possible outcomes for all patients and staff involved.

Hazard Analysis

- **Hazard Identification:** A hazard is an act or phenomenon that has the potential to produce harm or other undesirable consequences to a person or thing. Health care providers should make every effort to include any potential hazards that could affect the facility directly, or indirectly, for the particular area where their patients are located. Indirect hazards could affect the community, but

not the provider, and as a result interrupt necessary utilities, supplies, or staffing upon which a home dialysis patient depends.

- **Maintaining Awareness of Events as They Happen:** Some states have their own emergency operations centers which have tools to help identify hazard risk based on location. As an example, California has developed a tool where a person can input their address and receive information regarding hazards that exist in their location. For more information on this specific resource, go to <https://myhazards.caloes.ca.gov/>.

However, most states don't have this level of hazard analysis system. Instead, consider using FEMA's Geohazards resource center at <https://gis-fema.hub.arcgis.com/> in your planning.

Power outages can happen everywhere, and depending on a patient's location, a disruption may last weeks to months. As a home dialysis provider, be sure to help your patients sign up for their power company's priority restoration list. The plan can also include generators for patients, especially in power outage-prone areas.

- Patient and Provider Resource: SCE Medical-Baseline: <https://www.sce.com/residential/assistance/medical-baseline>
- Energy.gov <https://www.energy.gov/>

Hazard Mitigation

Hazard mitigation includes any action taken to eliminate or reduce the probability of the event or reduce its severity or consequences, either prior to or following a disaster or emergency.

- **Preparedness:** Preparedness includes developing a plan to address how the provider will meet the needs of patients and residents if essential services break down because of a disaster. A completed preparedness plan will be the product of a review of the basic facility information, a hazard analysis, and an examination of the provider's ability to continue providing care and services during an emergency. It also includes training staff on their roles in the emergency plan, testing the plan, and revising the plan as needed. For patients on peritoneal dialysis with aycler, for example, training should include initial, and periodic, manual exchange training with the patient and any caregivers.
 - **Examples of Key Considerations for Home Dialysis Clinics:**
 - Patient-level risk assessment is an important part of an emergency plan and should be included in the patient rosters maintained in accordance with the plan. Patients can be categorized for "triage" according to their need for services. This enables providers to determine how to best utilize limited staff and resources during an incident to ensure that the most vulnerable patients get the assistance they need. Assign every patient a risk categorization at admission and update at least annually (or as frequently as the patient's condition requires) as part of the update to the patient's comprehensive assessment and plan of care. Monitor the process at predetermined time points throughout the year and as part of emergency preparedness program evaluation and testing.
 - Alternative Office Location - Having a site to offer back-up dialysis treatments with considerations for different power and/or water grid emergencies.
 - Vendor Management - Making sure there are extra dialysis supplies at the patient's home and in the home unit.
- **Response:** Activities immediately before (for an impending threat), during, and after a hazard impact must address the immediate and short-term effects of the emergency.

- **Recovery:** Activities and programs implemented during and after response are designed to return the dialysis location back to its usual state or a "new normal." This could include the home dialysis training unit or the actual patient's home/site of dialysis.

Patient-Level Planning

Every home dialysis patient and associated caregiver should be trained and prepared to manage events that could lead to disruption in their ability to perform dialysis at home in the way that they have become accustomed. While most dialysis providers offer their own specific patient training program and recommendations for disaster management, the KCER Coalition website (<https://www.kcercoalition.com/en/>) also offers online resources to help in such preparation. At a minimum, proper patient preparation should include the following:

- Appropriate documentation at the ready in the event that the patient should have to suddenly leave his/her home. This should include:
 - Dialysis prescription
 - Medication lists
 - Health history
 - Advanced directives
 - Personal identification
 - Insurance and credit cards
 - Contact numbers of loved ones
 - Home dialysis facility information

Patients should be reminded that one of the easiest and safest places to keep emergency information is on one's smart phone.

- Creating "In Case of Emergency" Medical Identification - New York City's "A Guide to Emergency Preparedness for Dialysis Patients" has step-by-step instructions on how to create an "in case of emergency/ICE" medical identification that is accessible to emergency personnel without having to unlock the phone at <https://www1.nyc.gov/assets/doh/downloads/pdf/em/emergency-prep-dialysis.pdf>.
- Helping Patients Create Emergency Dietary Plans - A dietary plan in the event that the patient may have to miss some dialysis treatments. The KCER Coalition website offers a 3-day meal plan for dialysis patients. One other example can be found at <https://comagine.org/sites/default/files/resources/esrd-emergency-diet-plan.pdf>.
- The Emergency "Go Bag" - An emergency "Go Bag" which every patient should have ready and reviewed/updated semi-annually. Examples of an evacuation checklist can be found on the KCER Coalition website at <https://www.kcercoalition.com/en/resources/patient-resources/emergency-preparedness/emergency-go-bag/> and may look something like the following:

Figure 6: KCER Coalition’s “Are You Prepared?” Emergency Go Bag Checklist



Are You Prepared? Get Your Go-Bag Ready Now!



Hurricane, earthquake, flooding, fire, or even a pandemic like Coronavirus 2019 (COVID-19) can strike at any time. Take steps now to prepare yourself if disaster hits your home!

<p>Water and Food</p> <ul style="list-style-type: none"> <input type="checkbox"/> Emergency 3-Day Diet (see reverse) <input type="checkbox"/> Bottled water, cranberry, or apple juice <input type="checkbox"/> Non-perishable foods, canned: <ul style="list-style-type: none"> • Carrots, green beans, peas, corn, yellow squash • Unsalted peanut butter • Vanilla wafers • Applesauce • Fruit cup, drained • Low-sodium or no-salt added tuna, crab, chicken, salmon, or turkey 	<p>Health Documents</p> <ul style="list-style-type: none"> <input type="checkbox"/> Picture ID <input type="checkbox"/> List of medications <input type="checkbox"/> Treatment prescription details <input type="checkbox"/> Insurance/Medicare card <input type="checkbox"/> Copy of monthly lab results <input type="checkbox"/> Contact list of healthcare members/facility staff <input type="checkbox"/> Personal emergency contacts 	<p>Emergency Tools</p> <ul style="list-style-type: none"> <input type="checkbox"/> Face coverings <input type="checkbox"/> Disinfectant wipes <input type="checkbox"/> Flashlight <input type="checkbox"/> Manual can-opener <input type="checkbox"/> Spare glasses <input type="checkbox"/> Battery-powered radio <input type="checkbox"/> Cell-phone <input type="checkbox"/> Cell-phone charger <input type="checkbox"/> Warm blanket <input type="checkbox"/> Hand sanitizer <input type="checkbox"/> Whistle <input type="checkbox"/> Note pad and pencil <input type="checkbox"/> Disposable gloves <input type="checkbox"/> Medications (allergy) 	<p>Clothes and Toiletries</p> <ul style="list-style-type: none"> <input type="checkbox"/> Change of clothes appropriate for your climate <input type="checkbox"/> Sturdy shoes <input type="checkbox"/> Towel <input type="checkbox"/> Toilet paper <input type="checkbox"/> Toothbrush/toothpaste <input type="checkbox"/> Feminine personal hygiene supplies <input type="checkbox"/> Sunscreen
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Source: [Are You Prepared? Get Your Go-Bag Ready Now! \(kcercoalition.com\)](https://kcercoalition.com)

- Extra home dialysis supplies to last at least seven days
- Dialysis decision-making based upon the need to stay at home versus having to leave the home:
 - When the patient can (or must) stay at home, having adequate dialysis supplies, water, and electricity are critical to maintaining safety. Contact information for water and electricity providers (to make sure they are aware that the patient requires electricity and water for life-saving dialysis) should be readily available.
 - Home dialysis patients should be familiar with how to terminate their dialysis treatment safely during an emergency and how to protect/take care of their dialysis access.
 - Peritoneal dialysis patients should be comfortable performing manual exchanges and have supplies for adequate hand hygiene in the event that electricity or water are compromised.

- Home hemodialysis patients should have emergency power back-up and/or ways to communicate with local authorities to make sure that they are prioritized for power restoration.
- If the patient must leave his/her home, keeping in communication with family, friends, and the dialysis unit is a priority. A home dialysis unit (or local in-center unit) may be a safe place for treatment and respite.
- Specific details about what to pack and how to prepare for an evacuation can also be found at the KCER website.

National Voluntary Organizations Active in Disaster (VOADs) Access and Functional Needs Coalitions:

- National Voluntary Organizations Active in a Disaster: Local VOADs List: <https://www.nvoad.org/state-territory-voad/>
- Help Patients Sign up for Access and Functional Needs Emergency Registry Websites: <http://www.jik.com/d-rgt-links.html>

Emergency Preparedness Policies and Procedures

The CMS ESRD CfC and accompanying Interpretive Guidance from 2008 is a standard on Emergency Preparedness (V408): “The dialysis facility must implement processes and procedures to manage medical and nonmedical emergencies that are likely to threaten the health or safety of the patients, the staff, or the public. These emergencies include, but are not limited to, fire, equipment or power failures, care-related emergencies, water supply interruption, and natural disasters likely to occur in the facility’s geographic area.”

- Patients/designees should be instructed about the facility disaster/emergency plan.
- Home dialysis providers and suppliers should review their emergency program every two years.
- Document in the medical record completion of education in emergency evacuation and emergency preparedness, to include some measure of patient understanding, such as return teaching or demonstration annually or as needed.
- “Emergency physician coverage and hospital care (V770) Each dialysis unit is required to have a signed agreement with a hospital in the area, or at least a letter from a hospital, which states that the hospital agrees to provide access for the unit’s patients to 24-hour emergency services and facilities for inpatient care, including inpatient dialysis. In addition, the unit must have a roster that enables contact of the physician or licensed practitioner responsible for each patient at any time, including details of cross-coverage arrangements.” (Forum of ESRD Networks, 2021; Centers for Medicare and Medicaid Services, 2020).

Patient Living in Long-term Care (LTC) and Skilled Nursing Facilities (SNF)

Because CMS has considered LTC facilities as the patient's home for purposes of the ESRD benefit, dialysis providers need to determine if the LTC facility ensures that there is an emergency electrical system available in the rooms used for dialysis and that the plan for an emergency water supply addresses provision of additional water for dialysis treatments.

The CMS ESRD Survey and Certification Memo 04-24 states that for patients living in a long-term care facility:

- “A14. The ESRD facility and LTC facility are expected to define responsibilities for emergencies in the written agreement. The ESRD facility is required to have specific policies and procedures for handling medical and nonmedical emergencies that threaten patient health or safety related to the patient’s dialysis treatments. ESRD facilities are governed by regulations at §405.2136(f)(1)(v), 405.2136(g), and 405.2160(b) that require the facilities to have policies governing the care of patients in emergencies and to arrange for physician services and hospital services for emergency care.”

Responding During an Emergency

Part of responding to an emergency is the ability to identify what type of emergency (and where) is potentially impacting your dialysis patients. The Federal Emergency Management Agency (FEMA) offers many different on-line resources to include updated information on specific disasters, power outages, and evacuation zone maps at <https://gis-fema.hub.arcgis.com/>.

Continuity of operations at the home dialysis unit is a critical function of the emergency command structure during a disaster. Specific functions are necessary in order to ensure dialysis patient well-being:

- Maintaining a list of home and emergency contact numbers for all patients and staff.
- Communication with emergency operations centers and health care coalitions. It is an essential best practice to know whom to contact when an emergency strikes. Home dialysis providers should keep documentation of local, tribal, regional, state, and federal emergency preparedness points of contacts in an easy-to-use format for all staff. Home dialysis providers should work to include these organizations in planning and training efforts.
- Downtime/ charting forms in the event that the electronic medical record is not available. Such documentation should include patient insurance, dialysis prescription, and medication lists and allergies.
- Frequent monitoring of patient location and health status. Dialysis providers should contact patients in impacted areas and make sure that they are aware of an impending emergency and that it may impact their treatment.
- Provision of non-expired emergency/evacuation supplies, including site dressings, saline, intravenous tubing, and dialysis solutions.
- Assistance to patients in obtaining replacement supplies or alternative dialysis clinic care in the event that the home dialysis unit services are disrupted.
- Assistance with shelter in place planning:
 - Ensuring patient safety with adequate heating or air conditioning
 - Ensuring a patient strategy for proper sanitation and infection control practices
 - Emergency diet needs
- Assistance with evacuation planning:
 - Where to go: Will your patients stay with friends or family instead of a shelter?
 - Evacuation of homebound patients may require help from local rescue or disaster response agencies
 - Notification of local shelter staff of the need to perform life-sustaining medical treatment
 - Patients may require assistance with alternate transportation planning if they don’t have their own vehicle. Volunteer disaster assistance organizations (VOADs at

<http://www.nvoad.org/>) as well as FEMA’s Community Emergency Response Team (CERT at <http://www.fema.gov/cert>) are important volunteer resources to help support patients with such needs.

Communication Planning

The dialysis facility must maintain communications with local disaster management agencies, in the form of a letter that is sent at least annually to the agency, reminding them of the unit’s presence and potential patient needs. Periodic reminders should be sent to power and water utilities as well.

ESRD Networks also need to be made aware of any disruption in dialysis services in their area as they report to CMS/KCER. ESRD Networks play a major role in communication for dialysis units and patients during a disaster. Information and resources provided by each individual ESRD Network can be found at <https://esrdnetworks.org/resources-news/disaster-planning-resources-links/esrd-network-resources/>. Home dialysis units should familiarize themselves with their local ESRD Network and be aware of their reporting requirements.

Home dialysis units must also have plans in place on how to share information with other providers (including hospitals and clinics) in the event patients must seek care outside their treatment area. Such considerations should include:

- Referring patients for treatment (including establishing care between patients with available providers in areas where the patients have relocated)
- Coordinating patient care with others (such as emergency relief workers or those who can help in finding appropriate health services for patients, perhaps including transportation)

Each home dialysis unit should have multiple methods to communicate with both staff and patients:

- Home dialysis clinic communication/phone tree whereby there are clear steps on whom – and how – to get in touch with in the clinic chain of command.
- Have back-up plans if the internet is unavailable, especially emergency contact numbers for patients, staff, and local hospitals.
- Patients/designees should know how to contact their facility during off hours.
- Facilities should provide patients/designees with an alternate emergency phone number in case the facility phone is not answered and/or the facility is not functioning during a disaster (e.g., back-up dialysis unit).
- Information regarding FEMA Emergency Alert Systems can be found at <https://www.fema.gov/emergency-managers/practitioners/integrated-public-alert-warning-system/public/emergency-alert-system>.

Patient Communications

- The American Red Cross offers a “Safe and Well” searchable database to enable friends and family members to locate each other after a disaster at <https://safeandwell.communityos.org/cms/index.php>.
- Contact your water and power companies to register for special priority to restore lost services. Keep their phone numbers up-to-date and in your emergency kit.
- Identify potential back-up treatment locations both near and far from your home.

- Identify an out-of-state/area “check-in contact.”
- Contact the transplant center if the patient is evacuated to another area in the event a kidney transplant offer should become available.

After a Disaster

- Improve, Adapt, and Overcome: Strategies for Recovery and Resilience
 - Getting replacement supplies
 - Getting dialysis in-center or at the hospital/clinic
 - Get involved: Participate in local emergency trainings and response programs.
 - Collaborate with local rescue agencies to ensure the home environment is prepared for potential disasters and the patient is able to contact help.
 - Practice what you learned with friends, family, neighbors, and your dialysis clinic.

Training, Testing, and Continuous Improvement in Emergency Preparedness

CMS CfC specify that dialysis programs meet specific criteria with regard to emergency preparedness and can be highlighted as follows:

- V409 (1) Emergency preparedness of staff. The dialysis facility must provide appropriate training and orientation in emergency preparedness to the staff. Staff training must be provided and evaluated at least annually and include the following:
 - (i) Ensuring that staff can demonstrate a knowledge of emergency procedures, including informing patients of—
 - (A) What to do; *Staff must have sufficient knowledge of emergency procedures to educate patients/designees about how to handle emergencies, both in and outside of the facility.*
 - (B) Where to go, including instructions for occasions when the geographic area of the dialysis facility must be evacuated.
 - “42 CFR part 405, subpart U requirement that the staff inform patients of where to go during an emergency.”

In addition, training should include:

- V409 (1) (i) (C) Whom to contact if an emergency occurs while the patient is not in the dialysis facility. This contact information must include an alternate emergency phone number for the facility for instances when the dialysis facility is unable to receive phone calls due to an emergency situation (unless the facility has the ability to forward calls to a working phone number under such emergency conditions);
- In the Clinic V769 (Rev. 200, Issued: 02-21-20; Effective: 02-21-20, Implementation: 02-21-20) (2) The dialysis facility must have available at the nursing/monitoring station, a roster with the names of physicians to be called for emergencies, when they can be called, and how they can be reached.

Home dialysis providers must conduct one testing exercise annually. This training and testing can include a community-based full-scale exercise, or an individual facility-based functional (“tabletop”) exercise, which should alternate year-by-year. Providers may choose the testing exercise of their choice. Facilities should develop and maintain a training program based on the facility's emergency plan annually. In addition, it is required that additional exercises occur when the emergency plan is significantly updated.

Organizing Home Dialysis Emergency Preparedness Training

Training programs do not have to be time-consuming or costly. There are several free resources that combine trainings into routine care or quarterly check-ins.

- As a clinic, you can save staff time by designating certain staff and patients to participate in training and testing throughout the year.
 - For example, training and testing can be done on the individual facility-based level with a functional exercise every other year.
 - For home dialysis providers, this can include emergency disconnections (in the clinic and over the phone), identification of evacuation routes, how to obtain back up supplies, or coordination with EMS to reduce hospitalization.
 - Another example could include conducting a case review and include home dialysis patient emergency preparedness trainings into your regular QAPI meetings.
- Another way to organize trainings is to consider the information gathered from your risk assessment, focusing first on the highest risk patients, or those frequently impacted by loss of utilities (e.g., electricity or water) at home. This triage approach will allow the team to focus on high-risk patients first, while also maintaining a plan to progress toward addressing those patients at moderate and low risk.

Training and Testing Your Home Dialysis Emergency Preparedness Plan with Your Community: Why Train with Others?

Social capital is the value we place on our relationships with one another. Studies have shown that communities that possess a high amount of social capital bounce back much more efficiently after a disaster and tend to rely less on outside resources to return to normal.

Patient Training Specific to Home Dialysis

Several areas of CMS CfC provide guidance and expectations that apply to home dialysis patients and are highlighted below:

- § 494.100 Condition: Care at home. V583 The training (*home dialysis training*) must be conducted for each home dialysis patient and address the specific needs of the patient, in the following areas:
 - (vi) How to handle medical and non-medical emergencies. “Training for non-medical emergencies may include those related to mechanical/technical equipment failures, as well as preparing for natural or man-made disasters that may result in the inability to dialyze at home as scheduled and/or delays in supply delivery.
 - Technical problems to be recognized, managed, and reported would include power outages, failure of the PD cyclor or HD machine, failure of water treatment components (e.g., chlorine/chloramine breakthrough), clotting of the hemodialysis circuit, dialyzer blood leaks, line disconnection, water supply problems or leaks, and problems with supply delivery.”
- V412 (2) Emergency preparedness patient training. The facility must provide appropriate orientation and training to patients, including the areas specified in paragraphs (d)(1)(i) of this section.

- V412 Patients must have sufficient knowledge of emergency procedures to know how to handle emergencies, both in and out of the facility. Refer to V409 for the required areas of patient emergency education.
- V598 (vii) Identifying a plan and arranging for emergency back-up dialysis services when needed. The facility should assist each home dialysis patient in developing a personal disaster plan that identifies actions to take in the event of a natural or other disaster affecting his/her home treatment.
 - Individual plans should be in writing, included in the medical record and patient and caregiver provided a copy
- V409(1).(i).(D) states that patients will need to know how to disconnect themselves from the dialysis machine in an emergency. This includes when they are at home or in the clinic. Staff should be properly trained to guide patients through the process.

Chapter Summary

- Emergency Preparedness is not only a federally mandated requirement of all dialysis units, but also part of a readiness mindset for which all patients and dialysis caregivers should have familiarity.
- Policies and procedures adopted for emergency preparedness should be based upon CMS' Conditions for Coverage and reviewed on a regular basis.
- There are multiple resources available for patients and caregivers alike when it comes to dialysis emergency management. A key feature to success ultimately relies on establishing good lines of communication for all involved.

Provider Resources:

- National Voluntary Organizations Active in Disaster: <https://www.nvoad.org/state-territory-voad/>
- IS-368: Including People with Disabilities & Others with Access & Functional Needs in Disaster Operations: <https://training.fema.gov/is/courseoverview.aspx?code=IS-368>
- VTAGs cheat sheets: ESRD Core Survey Interview Worksheet: Home Hemodialysis Patient
- SOM - Appendix H (cms.gov) https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_h_esrd.pdf
- ESRD VTAGs: CFC 494.100 Section V580-V599
- CMS Home Health CoP: <https://www.federalregister.gov/documents/2017/01/13/2017-00283/medicare-and-medicaid-program-conditions-of-participation-for-home-health-agencies>
- State Operations Manual Appendix B - Guidance to Surveyors: Home Health Agencies (Rev. 200, 02-21-20) https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/som107ap_b_hhapdf
- CMS Manual System Department of Health & Human Services (DHHS) Pub. 100-07 State Operations Provider Certification Centers for Medicare & Medicaid Services (CMS) Transmittal 200 Date: February 21, 2020. <https://www.cms.gov/files/document/r200SOMA.pdf>
- ICS 100, ICS 700, FEMA Emergency Management Institute: <https://training.fema.gov/>
- ESRD Interpretive Guidance Version 1.1 (cms.gov): <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/esrdpgmguidance.pdf>
- State Operations Manual Appendix B - Guidance to Surveyors: Home Health Agencies (Rev. 200, 02-21-20) https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/som107ap_b_hhapdf
- Healthcare Ready CMS Emergency Preparedness Knowledge Center: <https://healthcareready.org/cms-emergency-preparedness-knowledge-center/>

Patient Resources:

- KCER/NCC: Preparedness Checklist: <https://www.kcercoalition.com/contentassets/b039229275ad4b4d9ad3dd44b0d53d65/kcergobagflyer508.pdf>
- Medical Education Institute: <https://homedialysis.org/news-and-research/blog/302-emergency-planning-for-home-dialyzors>
- Training for Caregivers: Learn How to Be the Help Until Help Arrives: <https://community.fema.gov/until-help-arrives> .
- Community Emergency Response Team: <https://www.ready.gov/cert>
- FEMA: 12 Ways to Prepare Checklist: https://www.ready.gov/sites/default/files/2020-11/ready_12-ways-to-prepare_postcard.pdf Other languages: <https://www.ready.gov/collection/12-ways-to-prepare>
- NKF: <https://www.kidney.org/sites/default/files/docs/disasterbrochure.pdf>
- FEMA app: <https://www.fema.gov/about/news-multimedia/mobile-app-text-messages>
- Individual and Household FEMA Disaster Assistance: <https://www.fema.gov/assistance/individual/program>
- Know which disasters could affect your area and learn what to do before, during, and after each type of emergency: <https://www.ready.gov/be-informed>
- Find activities that are happening near you: <https://community.fema.gov/be-counted>

- Preparedness Calendar: <http://do1thing.com/individuals>
- Medical Education Institute: <https://homedialysis.org/life-at-home/articles/disaster-planning-for-pd-and-home-hd>

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Centers for Medicare & Medicaid Services. State Operations Manual Appendix H - Guidance to Surveyors: End-Stage Renal Disease Facilities. 2020. https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_h_esrdpdf.

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Michigan Department of Health and Human Services, Bureau of EMS, Trauma and Preparedness. *Home Health Emergency Preparedness: A Handbook to Assist Home Health Care Providers in Emergency Preparedness Planning*. https://www.michigan.gov/documents/mdch/FINALHOME_HEALTH_EMERGENCY_PREPAREDNESS_PL_2FINAL_484105_7.pdf

Chapter 5: Overcoming the Barriers to Building, Growing, and Sustaining a Home Dialysis Program: Staffing Considerations

Chapter Synopsis

- Nursing staff are a key component to the success for a home dialysis program. Interpersonal skills, flexibility, professional dedication, and an interest in teaching and learning are among the characteristics of successful home dialysis nurses.
- The dietitian and social worker are two other foundational members of the home program. In addition to their core obligations, they should also be advocates for home dialysis and patient self-care and must recognize the special and often individualized requirements of home dialysis patients and incorporate them in their professional spheres of expertise.
- Dialysis patient care technicians are quickly becoming indispensable members of the home dialysis team. While their scope of practice is limited in terms of new patient training, they otherwise have the same abilities as their counterparts in the in-center hemodialysis unit.
- Since most home dialysis patients are dialyzing outside of normal working hours, nursing and technical support must always be available to patients. For PD patients, their chosen modality should be available in the hospital, and nurses trained in providing peritoneal dialysis should be available.

The Conditions for Coverage (CfC) for ESRD facilities (2008) require the training of home dialysis patients to be provided by a registered nurse who meets the practice requirement of the state in which he or she is employed. The nurse must also have at least 12 months' experience in providing nursing care and an additional three months of experience in the modality (HD or PD) for which he or she will provide training. In home dialysis, the CfC regarding dialysis staffing (42 CFR 494.140) do not specify maximum patient-to-nurse ratios, though state regulations may apply in this regard as there are several states that either have or are trying to establish mandatory maximum staffing ratios (Rastogi, 2018). For established programs, staffing ratios of registered nurses to patients vary, generally falling into the range of one registered nurse per 15-25 patients. This can include both PD and HD patients. Programs that include pediatric patients or a large proportion of home HD patients may be able to justify one full-time registered nurse position for as few as 10 patients.

A sustainable home dialysis program must have adequate staffing. Ideally, two registered nurses are recommended to run even the smallest program. This allows for one nurse who is dedicated to home training while the other nurse can fill in as a backup as required (Counts, 2008). Although it may seem efficient for smaller programs to divide a nurse between in-center hemodialysis and home dialysis responsibilities, this does not provide the flexibility needed for training, follow-up, and recruitment of new patients into the home program. Furthermore, home dialysis nurses should ideally be available to patients at night and on weekends, and it would clearly be difficult to recruit and retain a nurse to work full-time during the day and be on-call all or most nights and weekends as well.

Recruiting registered nurses for home dialysis is a critical part of maintaining adequate (and high quality) staffing. Recruitment from the in-center HD staff may be optimum for at least three reasons: 1) patients converting from in-center hemodialysis will benefit from the continuity of care; 2) home dialysis can often provide more job flexibility and less stress for dialysis nursing staff and technicians when compared to in-

center treatment; and 3) the in-center nurse already has experience with renal disease and dialysis management. The opportunity to work with patients who are motivated to participate more in their own care and well-being can be an added benefit to nursing staff.

Characteristics of Successful Home Dialysis Nurses

The primary role of the nurse in the home program is to provide patients and caregivers with complete, accurate, and understandable information, which will allow them to perform dialysis safely and independently in the home setting. However, in viable and growing programs, nurses go far beyond this primary role. They become the primary interface between patients and the program, and since they usually know the patients and their home environment best, they are in the best position to direct the efforts of dialysis technicians, dietitians, social workers, and technical staff where they are most needed. As the public face of the program, they are often the decisive factor in the recruitment of new patients and new staff.

Given these considerations, several authors (Counts, 2008; Diaz-Buxo, 2003) have sought to define the attributes of successful home dialysis nurses. A survey of this literature suggests that these attributes include:

- Enthusiasm and motivation to inspire staff and patients to do their best while also showing cultural sensitivity to the myriad of patients who come from many different experiences and backgrounds
- Knowledge of learning styles to enable effective teaching to each individual
- Advocacy for self-care, combined with flexibility to adjust training and follow-up to accommodate differences in patient/caregiver capabilities
- Self-direction, with the ability to multi-task
- Comfort with evaluating, troubleshooting, and counseling patients/caregivers personally and by phone
- Confidence in the professional nursing role and sphere of expertise in working with physicians and advanced practice providers, combined with recognition of the appropriate time to contact them when the limits of nursing practice are reached
- The ability to develop innovative solutions to challenging (and often unforeseen) circumstances

Successful home dialysis nurses are avid supporters of home therapies and develop close bonds with their patients. They must be the ultimate patient advocate by helping motivate and support home patients and their families through difficult times while also recognizing when respite and changes in modality need to be considered. A review of the list above makes it clear that not all dialysis nurses, no matter how experienced in in-center dialysis they may be, are equipped to do well in the home setting.

Professional Development

Many excellent resources are available for nurses to begin and continue their education regarding home therapies. Conferences are offered by several organizations and special interest groups, and listservs organized by such groups are available online. Links to some of these resources are provided in Appendix I; we will refer to a few useful examples here.

Journals with timely information are available both in print and online. The [American Nephrology Nurses Association](#) is for nurses working with patients and families with kidney disease and publishes the

Nephrology Nursing Journal. For members of ANNA, a discussion site called “Home Therapies Special Practices Network (SPN)” offers information from practicing nephrology nurses on a variety of home dialysis issues including managing patient phone calls, staffing, and inpatient issues. Certification in nephrology nursing is available through the Nephrology Nursing Certification Commission (NNCC).

The [International Society of Peritoneal Dialysis](#) has a training segment entitled “[Teaching Nurses to Teach: Peritoneal Dialysis Training](#).” The series was developed in 2006 by the University of Pittsburgh. The lessons include videos, written material, and a post test. The purpose is to help home nurses organize and present training materials using principles of learning. All aspects of training are included.

A smartphone app that is useful to both nephrologists and nurses working with PD is [QxMD](#). A segment devoted to nephrology includes access care and complications of PD catheters and management of peritonitis.

Training for nurses new to PD is available through a number of avenues and is beyond the scope of this chapter. Suffice it to say, large dialysis organizations, as well as many smaller organizations, have found it advisable to assume responsibility for training nurses in home dialysis therapies, as well as for the start-up of new home programs within their facilities, with a general educational framework as follows (Witten, 2014):

- Management and monitoring of home dialysis patient in clinic as well as remotely
- Performance of the home dialysis procedure
- Reporting of appropriate medical data and participating in patient plan of care
- Monitoring and recording health status of patient
- Handling of medical and non-medical emergencies
- Education regarding infection control as well as water and dialysate management
- Ensuring that the patient has necessary equipment and emergency/back-up plan

However, online or classroom training will not suffice for staff being hired by a new home dialysis program. Because of the CMS guideline requiring three months of experience, nurses new to home dialysis will need to be mentored by an experienced nurse before being allowed to train home dialysis patients on their own. Therefore, a new program must either hire an experienced staff member from an existing program or make arrangements for newly hired staff to spend at least three months working in such a program.

Other Members of the Patient Care Team

The **dialysis patient care technician (PCT)** has become a critical member of essentially all in-center hemodialysis programs in the U.S. and is gaining traction as a valued member in home dialysis programs as well. While the dialysis PCT cannot perform home dialysis training, the job description per the CfC [42 CFR 494.140 (e)] for personnel qualifications of the dialysis PCT are outlined as follows:

(e) Standard: Patient care dialysis technicians. Patient care dialysis technicians must -

- (1)** Meet all applicable state requirements for education, training, credentialing, competency, standards of practice, certification, and licensure in the state in which he or she is employed as a dialysis technician; and
- (2)** Have a high school diploma or equivalency;
- (3)** Have completed a training program that is approved by the medical director and governing body, under the direction of a registered nurse, focused on the operation of kidney dialysis

equipment and machines, providing direct patient care, and communication and interpersonal skills, including patient sensitivity training and care of difficult patients. The training program must include the following subjects:

- (i) Principles of dialysis.
 - (ii) Care of patients with kidney failure, including interpersonal skills.
 - (iii) Dialysis procedures and documentation, including initiation, proper cannulation techniques, monitoring, and termination of dialysis.
 - (iv) Possible complications of dialysis.
 - (v) Water treatment and dialysate preparation.
 - (vi) Infection control.
 - (vii) Safety.
 - (viii) Dialyzer reprocessing, if applicable.
- (4) Be certified under a state certification program or a national commercially available certification program, as follows -
- (i) For newly employed patient care technicians, within 18 months of being hired as a dialysis patient care technician; or
 - (ii) For patient care technicians employed on October 14, 2008, within 18 months after such date.

A home program must have a **dietitian** registered through the Commission on Dietetic Registration with a minimum of one year of experience in clinical nutrition as a registered dietitian (Dept. of Health and Human Services, 2008). These are the same requirements as in-center hemodialysis. Dietitian responsibilities include initial and ongoing nutritional assessments, the provision of tools and education for diet management, and the active participation in the patient's plan of care (Diaz-Buxo, 2006). In practice, the dietitian role is often shared with in-center programs. Experienced renal dietitians recognize that dietary prescriptions and restrictions may be quite different for home patients than they are for in-center patients since most home patients dialyze more frequently.

The home program must have a **social worker** who has a master's degree in social work from a school accredited by the Council on Social Work Education. As in the in-center dialysis unit, social workers are responsible for the evaluation and documentation of a patient's psychosocial status and assessment of patient satisfaction with the program. The special expertise of the social worker in both in-center and home dialysis is the identification and mobilization of family and community resources needed to achieve and maintain the best possible patient functional status and quality of life. The need for, and availability of, such resources may differ substantially between in-center and home dialysis patients, even in the same geographic area, so there is not complete overlap in the knowledge base required to serve these potentially disparate groups. The home program social worker must be prepared to incorporate the patient's employment, level of education, or childcare responsibilities into individually customized financial, psychological, and modality choice counseling. The social worker in the home program is also the key to early identification of potential changes in the home that may lead to patient (or caregiver/dialysis partner) burnout or dropout (Luongo, 2009).

After-Hour Availability

It is essential that patients know how to contact the correct person for questions or problems at all times. The CfC do not specify the need for registered nurse availability on-call, however they do discuss the need to provide adequate patient support. Though programs may use on-call dialysis nurses, nephrologists, advanced practice providers, renal fellows, and corporate technical help lines, in our experience most

successful programs utilize the nursing staff as the initial point of contact for patients, whether the contact occurs during or after working hours. Continuous and prompt on-call support improves patient outcomes through rapid response, preventing waste of resources, and maximizes the patient's confidence and satisfaction (Counts, 2008). If emergency care is required, emergency departments need protocols for managing dialysis-related problems, such as peritonitis or catheter malfunction, and this information is best provided in advance by the home dialysis nursing department, in concert with the medical director and/or the primary nephrologist. The means to provide PD in the hospital, including technical assistance for the hospital nurses and the management of EMR, PD cyclers, and connector compatibility issues, is also far better planned by the home dialysis nursing staff, in detail, in advance, and during normal working hours, than on an urgent basis during on-call hours when hospital staff and providers less experienced with PD may be involved.

Patients who are normally highly capable of self-care may be temporarily too ill to dialyze themselves in the hospital. In order to avoid the potential for technical or infectious complications resulting from the hospitalization, it may be better for the home dialysis nursing staff to be credentialed to provide this care in the hospital, than for hospital staff nurses to attempt cycled PD on the basis of occasional exposure to the technique and equipment. Well-trained patients who are well enough to dialyze themselves in the hospital should be permitted and encouraged to manage (or at least participate) in their own dialysis care. We have occasionally encountered hospitals that consider patient self-dialysis in the facility to be potential liability risk, but typical home PD patients are likely to have a much higher level of expertise, including meticulous infection control technique, than the nursing staff of a general medical-surgical ward, where PD volume may be relatively low. In these settings, it should be the responsibility of the inpatient dialysis medical director to make sure that there is staffing with adequate experience available to take care of this vulnerable population.

Starting a Rural Home Hemodialysis Program

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Rural home dialysis programs face multiple challenges, especially when one considers issues regarding patient accessibility and access to services. Both patients and staff may drive many miles to dialysis clinics. For patients who qualify for transportation assistance, coordinating transportation to and from rural homes (which may be on gravel roads and in poor condition during winter months) to the dialysis clinic is another challenge.

Home hemodialysis (HHD) can help reduce many of these barriers. For the appropriately selected patient, performing hemodialysis at home can be life changing. For the purposes of our experience (which only offers one specific home modality), HHD significantly reduces travel time to and from the dialysis clinic while also helping decrease the chance of missed treatments due to inclement weather, poor road conditions, or other unforeseen circumstances. For instance, prior to our opening a HHD program, there was an alternate HHD program approximately 75 miles away from our clinic, but this was not accessible to the vast majority of patients due to the amount of time required to travel to and from the clinic for training and monthly doctor visits.

Our dialysis organization, Southeastern Renal Dialysis, is located in southeast Iowa, and there are five clinics, each approximately 30 miles apart. The central location is the small town of Mount Pleasant (population 9000, 2020 data), and is located 50 miles from Iowa City, IA, 85 miles from Davenport, IA, 135 miles from Des Moines, IA, 210 miles from St. Louis, MO, and 260 miles from Chicago, IL. Our other clinics are located in Fairfield, West Burlington, Fort Madison, and Keokuk, IA and cover seven counties, with a total population of approximately 150,000 individuals covering nearly 3,300 square miles. Our organization offered peritoneal dialysis (PD) for many years, but due to interest voiced by patients, our organization began a HHD program in 2022.

Following are some steps that our organization took to build and sustain a successful dialysis program. We recognize that not every point will be applicable to all readers, but nevertheless, we felt these to be the most important takeaways from our experience.

Steps in Starting a Rural Home Hemodialysis Program

We were initially unsure of patient interest in this modality, but our team felt strongly that if HHD was offered, patients would be more apt to choose home therapy. There was strong nursing interest early on, which was essential to the success of this program.

Once patient and organizational interest in offering home dialysis was established, we reviewed current FDA-approved home dialysis machines on the market. We contacted company representatives from one well-established home therapy device company and another that was relatively newer to the market. We had several meetings with each company to learn the pros and cons of each HHD system. Involved persons included the administrator, medical director, and nurse manager (who eventually would take on the home hemodialysis nurse role).

Budgets were carefully reviewed. Cost analysis was conducted to determine anticipated insurance reimbursement and payoff time after the initial upfront cost of the machine purchase. In addition, our independent, for-profit dialysis organization required approval from our Board of Directors prior to proceeding with contract negotiations and machine purchase. Ultimately, we elected to purchase Tablo machines from Outset Medical. Although the start-up costs were higher compared to the other vendor product, we felt that the machine was easy to use, had a clean design and an intuitive touchscreen, and was overall more patient-centered and user friendly than the alternative. If we truly wanted to grow a HHD program, we needed a modern HHD machine that patients could use long-term and not suffer from burnout.

Since HHD was a new modality to our organization, the HHD nurse underwent extensive training from the machine manufacturer. This included online training and face-to-face training with a company representative. A second nurse also underwent training for HHD to serve as a backup to the primary HHD nurse if she was unavailable. Nephrologists reviewed company-supplied information on HHD prescription and training.

Patient Recruitment

Three to four months prior to our anticipated start date for HHD training, dialysis clinics started working on patient recruitment. Physicians discussed this new dialysis modality availability during monthly physician rounds with staff and patients. Handouts were provided to interested patients (marketing materials received from the machine manufacturer and from QSource ESRD Networks ([Kidney Treatment Options – ESRD Networks \(qsource.org\)](http://qsource.org))). Videos about HHD were preloaded onto an iPad at each dialysis unit so patients could watch educational material during hemodialysis treatment. Educational bulletin boards were created in the waiting rooms of each dialysis clinic. A query of patients revealed approximately 10% of our incident in-center dialysis patients reported interest in pursuing HHD.

Interdisciplinary Patient Selection Team

We decided to use an interdisciplinary team for patient selection similar to the way that patients are selected for kidney transplantation. Our interdisciplinary team consisted of individual clinic nurse managers (who were most familiar with patients), the dialysis social worker, nurse practitioner, and nephrologist. At monthly QAPI meetings, potential candidates for HHD were discussed. If there were any challenges identified, the team discussed ways to overcome the challenges. The most common challenges involved housing situations (i.e., living in a small apartment, no storage space) or lack of a care partner. Noncompliance with in-center treatment was *not* considered a contraindication, as we have noted that patients are more successful at home dialysis than in-center hemodialysis due to increased flexibility and autonomy.

If the patient was felt to be a good candidate from the interdisciplinary team evaluation, he or she was contacted and invited to schedule a meeting with the HHD nurse to review the home dialysis machine, the requirements for home therapy, and required responsibilities.

If a patient decided to proceed with the HHD modality, he or she signed a contract at the end of training that expressed that they felt comfortable to perform dialysis treatments in their home.

They acknowledge that they had access to 24/7 nurse support for any patient issues, vendor support for machine issues or ordering, and should call EMS if they were experiencing a medical emergency.

Development of Policies and Procedures for Home Hemodialysis

Instead of designing policies and procedures from scratch, we utilized our contacts in the industry, and a dialysis clinic manager generously shared the policies and procedures from an existing HHD program. We modified those as needed to fit our practice, while remaining within regulatory standards of care. Current policies and procedures from in-center hemodialysis were carefully reviewed and modified as appropriate. Specifically, emergency policies and procedures were modified as appropriate for HHD.

Vascular Access

Ideally, patients would have an AV fistula or AV graft present at the start of training. However, some patients were converting from PD to HHD and had a central venous catheter while their AV fistula or AV graft matured. Our team reviewed the evidence and risks and benefits of allowing patients to dialyze with a central venous catheter. Ultimately, we felt that if our program were to grow and be successful, we would need to include patients with central venous catheters. Patients were initially trained in how to access their central venous catheter, and once their AV fistula or AV graft was ready for use, they came back to the home clinic for cannulation training.

Decisions about Solo Home Hemodialysis

While ideally every patient would have a care partner living at home with them or available continually during HHD training, this was not always practical. Our organization had to decide about allowing solo HHD treatments. The state of Iowa does not have specific regulatory requirements for solo HHD, and the medical director is responsible for deciding about patients performing solo HHD. After reviewing available evidence and discussion with HHD experts, our medical director/organization elected to evaluate patients for solo HHD on a case-by-case basis. We feel that carefully selected patients can successfully perform solo HHD. We set up additional safety procedures, including requirements that patients have a cellular telephone with them at all times in case of emergencies. We encourage patients to reach out for support from their family and friends, for example, notifying neighbors so they can assist if needed or having a close relative or older child present to call for help if necessary. Solo HHD patients need to perform treatments during the daytime (we don't have any patients performing nocturnal HHD). Other things to consider would be if the patient has any prescriptions for potentially sedating medications or a diagnosis of sleep apnea.

We currently have one patient performing solo HHD (out of a total of four current patients, at the time of writing in June 2023), and his access is a tunneled catheter. If we had a patient performing solo HHD using an AV fistula or AV graft, we would consider using a wet/blood monitor under the access for additional safety precautions, but to-date we have not encountered this situation.

Our medical director would also seek guidance from established HHD programs and Outset Medical.

Nurse Challenges

Challenges for training the HHD nurse included learning an entirely new dialysis machine and becoming comfortable teaching a patient on how to perform HHD. Nursing staff also had concerns about patients' ability to respond to emergencies at the home, and policies and procedures were created specifically to address home emergencies, such as potential for air embolism, needle dislodgment, arrhythmia, seizure, etc.

Our existing staffing model is one nurse for PD, one nurse for HHD, and five nurse managers for our in-center clinics. Call schedules for our home programs were created utilizing both PD and HHD nurses. With the addition of patients to the HHD program, we have added a patient care technician (PCT) to help with supply and lab preparation and collection of water and dialysate cultures. The PCT will be trained to assist the nurse with HHD treatments that are performed in the clinic. At the beginning of our HHD program, we just had one HHD nurse managing the entire program but quickly realized that we needed to cross train other nurses for both home therapies (PD and HHD) so that we would have coverage when the primary nurse needed to take time off, especially as we anticipated growing our home therapy programs.

Lessons Learned

HHD therapy takes a great deal of commitment from the patient, caregiver, and staff members, yet has turned out to be incredibly rewarding. We have patients who are feeling better than they have felt since starting dialysis. The flexibility of home therapy has opened many opportunities for patients that they would not have had with traditional in-center HD. Many have returned to work or volunteering opportunities. Some have been able to resume their social engagements and have more time with family. It is also rewarding to the nurses, dietitians, social workers, and physicians to see patients take charge of their own health and have the freedom to perform therapy in their own environment. It has been a win-win situation for our dialysis patients and our community.

Chapter Summary

- High quality nursing staff is one of the keys to success for a home dialysis program. Interpersonal skills, flexibility, professional dedication, and an interest in teaching and learning are among the characteristics of successful home dialysis nurses. While fulfilling the responsibilities of a home dialysis nurse is professionally rewarding, it is also demanding, and staff-to-patient ratios that recognize this reality must be maintained. Many in-person and web-based training resources are available for nurses who wish to acquire the home dialysis skill set and enter the field.
- The CfC requirements for staff other than nurses are as stringent, and for nursing staff somewhat more stringent, than those for in-center dialysis personnel. While the responsibility for patient training ultimately falls upon the medical director, the actual teaching and patient education is performed by a registered nurse with at least three months of home dialysis experience. The home program dietitian and social worker, as well as the nursing staff, should be advocates for home dialysis and patient self-care and must recognize the special and often individualized requirements of home dialysis patients and incorporate them in their professional spheres of expertise.
- Since home dialysis patients are often dialyzing outside of normal working hours, nursing and technical support must be available to patients 24 hours a day, seven days a week. For PD patients, their chosen modality should ideally be available in the hospital, with compatible cycling equipment and supplies. Hospital nurses may need to be trained in cycling PD, or the hospital may need to contractually arrange for outside home dialysis staff to service patients in the hospital (or rehabilitation) setting.

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Chapter 6: Overcoming Barriers to Patient Success with Home Dialysis

Chapter Synopsis

- All patients actively performing, or anticipated to require, renal replacement therapy should receive education and participate in shared decision making for dialysis modality choice.
- The success of a home dialysis program not only includes patient recruitment, but also support of the patient and caregivers to help maintain retention of their modality of choice.
- This chapter reviews the make-up of the home dialysis team and discusses the assessment of potential home dialysis candidates.
- A critical aspect of home dialysis care also includes management of caregiver fatigue/respite and the potential for care transitions to other modalities. A successful home dialysis program should be able to adapt to the many changing circumstances of the kidney patient and his/her support system.

The Advancing American Kidney Health (AAKH) initiative aims to have 80% of incident ESRD patients receive either home dialysis or a kidney transplant by the year 2025. In order to realize this lofty goal of increasing home dialysis use, it is very important to eliminate and minimize all potential barriers for home dialysis.

ESRD patients who are interested in performing home dialysis typically have two choices – peritoneal dialysis (PD) or home hemodialysis (HD). Home PD regimens may be entirely cycler-driven (continuous cycler PD, or CCPD), entirely ambulatory (continuous ambulatory PD, or CAPD) with manual exchanges, or hybrids of the two; assuming that the home environment is suitable for PD in general, individualizing prescriptions among these choices is not likely to run into technical constraints.

The options for home HD equipment and regimens are somewhat wider, and both the physical and social aspects of the patient’s home situation might constrain some of these choices. In earlier eras, patients who were in Veterans Affairs (VA) home dialysis programs, for example, might have had their homes renovated by the VA to install electrical and plumbing systems capable of accommodating standard hemodialysis machines and water treatment devices. In some cases, professional dialysis staff were hired to travel to the patient’s home and perform dialysis there as well. The availability of such resources is rather unusual at present, as Medicare does not pay for assistants for dialysis. However, the “Improving Access to Home Dialysis Act of 2021” hopes to change that by making a provision for Medicare to reimburse the cost of in-home assistance for home dialysis care. The advent of hemodialysis machines specifically engineered for home use has greatly lowered the potential technical obstacles to performing hemodialysis in many patients’ homes.

Assessment of Potential Home Dialysis Patients

Traditionally, many nephrologists and dialysis professionals have mainly advocated home dialysis to healthier, and – oftentimes – younger patients. However, over time we have seen that many patients who traditionally may not have been considered “good candidates” for home dialysis do also benefit from

home dialysis. For example, an older patient with significant systolic congestive heart failure may not be able to tolerate the intensity of standard thrice weekly in-center hemodialysis but may do very well with PD or home HD given the lower ultrafiltration rates associated with more frequent treatments. Patients with impaired mobility (e.g., history of amputation or stroke) are yet another example of individuals who may benefit from a home-based therapy. These patients often have difficulty with transportation to and from dialysis, and home dialysis may lead to improvement in their quality of life. In addition, many patients are labeled “non-compliant” for reasons that are out of their control. This label has historically led to such patients not being considered candidates for home dialysis despite the fact that home dialysis can alleviate many of the barriers associated with in-center dialysis that often lead to patients’ inability to adhere to medical advice.

All patients (with rare exception) actively receiving, or about to initiate, renal replacement therapy should be offered education regarding home dialysis. These exceptions generally would include patients with advanced dementia (unless they have a care partner at home who can train with them and perform all of their home dialysis), patients without a stable home environment (who may still be candidates for self-care dialysis in-center), and patients who reside in skilled nursing facilities (SNF) if the SNF does not offer home dialysis. Growth in a home dialysis program depends on retention of patients as well as recruitment, and the ideal shared decision-making process regarding modality choice may well lead to the realization on the part of the patient, as well as the dialysis team, that home dialysis is not in accordance with the patient’s goals or wishes.

The assessment and planning by the dialysis team should include the following:

- Evaluate the home environment: overall safety and cleanliness, living arrangements with others, access to clean water, adequate space for equipment/supplies, and electricity.
- Consider the potential need for a dialysis care partner: screen for memory deficits, physical debility, developmental delay or learning disabilities, severe mental illness, or alcohol and drug abuse. Patients without a care partner may still be successful at home dialysis if they are competent and able to comply with training and home dialysis care requirements.
- Recognize that some dialysis centers even offer remote patient monitoring technology which can help serve as a “virtual care partner” and may help to improve safety, as well as provide additional support to the patient dialyzing alone at home. With widespread use of multiple online meeting tools after the COVID pandemic, virtual visits are now even more commonplace. Several new PD and home HD machines contain technology for potential remote monitoring of dialysis treatments either in real-time during dialysis, or the ability to transmit treatment data to the home dialysis facility remotely through the cloud. Depending on the patient’s dialysis facility and whether broadband service is available to the patient, remote monitoring may or may not be available. If a patient would be more comfortable with remote monitoring and their home dialysis facility does not offer it, the patient should be offered the option of going to the closest dialysis center that offers this technology.
- Complete an individualized patient assessment to include literacy, language fluency, age, weight, physical health, eyesight, mobility, manual dexterity and strength, employment status, and transportation. None of these topics should be a contraindication to performing home dialysis, but recognition of different barriers and needs of the patient early on can help make the home experience as successful as possible.

Many potential barriers can be adequately addressed and managed during the training sessions if they are planned for prior to the initiation of training (Czajkowski, 2013; Koester, 2013). Monthly clinic visits

offer the opportunity to address new or potential changes before they become problems. Both patients and partners need to feel safe about discussing concerns and asking for help. Having clear written expectations of both the patient/caregiver and the staff is useful to avoid potential miscommunications.

Incident Patient Recruitment

Potential candidates for home dialysis are typically recruited from one of two groups: those patients new to dialysis (including pre-ESRD patients and incident ESRD patients) and established ESRD patients who desire or require a change in modality. Mechanisms for identifying and recruiting patients from the two groups must differ, and successful programs are likely to have strong pathways for patient intake from each group, recognizing the need to tailor patient education programs to local needs and conditions.

Patients are more likely to choose a home modality if that choice occurs prior to starting in-center hemodialysis (Poinen 2021). Even with very intensive and enthusiastic home education days both in groups and with individual sessions, many patients already performing in-center dialysis are reluctant to change (Schiller, 2011). Reasons include comfort with their current therapy, concerns about the safety of performing dialysis at home, disruption of family life (patients sometimes describe not wanting to “bring dialysis home”), concerns about ability or benefits of changing therapy, and loss of socialization with a group of people with the same modality. As a result, there has been an increasing amount of interest in using transitional care dialysis (TCD) as a potential means to improve home dialysis uptake. The goal of TCD is to provide comprehensive patient education on all forms of renal replacement therapies (as well as transplant education) for all new-start patients, typically over a 4–6-week period while the patient is receiving dialysis in an environment with a dedicated educational program and a higher staff-to-patient ratio. For a more in-depth explanation of TCD, see Chapter 7.

Patients often first learn about home dialysis therapies through their nephrologists. While pre-dialysis modality education is reimbursable to physicians by Medicare (CMS ESRD Kidney Disease Education (KDE) sessions), studies have shown that physicians are more likely to discuss home options if structured education classes led by home dialysis nurses are readily available (Czajkowski, 2013). While CMS typically only reimburses for KDE if performed or led by a nephrologist or APP, the AAKH payment models, including the ESRD Treatment Choices (ETC) model, do include waivers allowing for education by dietitians or social workers as well. Those presenting the information should be knowledgeable and enthusiastic about all modalities (PD and home HD, in-center, transplantation, and conservative management) yet respectful of patient and family choices. Biasing a talk towards the “best” therapy negates the concept of informed patient-centered decision making. Attendees expect accurate information and can plan more realistically if detailed information is available. Examples may include dialysis access surgery sites, expectations for healing and maturation procedures, and expected time to full recovery (and use); available dates to initiate training and anticipated length of training; and potential barriers to successful home therapy.

A focus group of PD and home HD patients found five themes important in establishing and maintaining successful independent programs: 1) patients need to know that the team hears their fears and concerns; 2) their own treatment choices will be supported; 3) training and education materials will be comprehensive and realistic; 4) 24-hour support for clinical or technical problems will be available; and 5) peer support is available (Sondrup, 2011).

Well-organized patient education material may be available through the local ESRD Network (link to each ESRD Network through the Forum website at <https://esrdnetworks.org/membership/esrd-networks-contact-information/>), the ESRD National Coordinating Center, or the dialysis organization. In addition,

there are patient educational materials available from multiple patient and dialysis non-profit advocacy organizations online (links are provided in Appendix I). Therefore, there should be a very limited need for individual facilities to develop their own material. Compliance with CMS ESRD regulations around KDE must be met to bill Medicare for the activity, and the use of structured materials provided by public organizations may assist with compliance.

Recruitment of Established ESRD Patients

In some areas of the U.S., access to local nephrology care prior to the onset of ESRD may be limited, and patients therefore may present to the facility or hospital with irreversible uremia, no prior CKD care or education, and an immediate need to start renal replacement therapy. In other instances, the patient may not have been referred, or has been referred but has not chosen a modality. If there is no urgent start PD program in place, such patients typically start with in-center hemodialysis.

The ESRD Conditions for Coverage (CfC) mandate education for all new ESRD patients, including education about all possible modalities of treatment, which includes home dialysis and transplantation. Unfortunately, many patients still face the need for dialysis without the opportunity for adequate preparation. Given the sudden and disruptive changes in lifestyle, information overload, and general atmosphere of fear and uncertainty that is likely to prevail under these circumstances, such patients may not be in a position to make the best informed choice about treatment modality at that time. Although handing the patient vast volumes of educational material while checking boxes on checklists in the electronic medical record may satisfy CfC obligations for modality options, it is unlikely to help the patient to ideally make the best decision about whether to pursue home dialysis or not.

If the above scenario prevails locally, patients may be able to make a better choice if they are visited in the dialysis unit by home training staff, perhaps after some initial adjustment period. It may also be helpful if new dialysis patients are offered the opportunity to visit the home training facility and participate in the same educational program offered to pre-dialysis patients. Although this education may not be reimbursed by CMS for most dialysis facilities, if the nephrologist or facility is involved in the ETC Payment model or voluntary AAKH payment models, they may be able to bill for this education for new dialysis patients. Identification by, and positive reinforcement from, the nephrologist of patients who would be good home dialysis candidates is undoubtedly helpful as well. A home training facility that is itself “home-like” may be an excellent recruiting tool, in that it may provide a striking contrast to the busier (and often less personal) in-center hemodialysis environment. In addition, ongoing discussions with dialysis patients about home dialysis should occur by the dialysis interdisciplinary team (IDT) during the patient’s initial and 3-month comprehensive interdisciplinary assessment (CIA) and Plan of Care (POC) per CMS CfC and Interpretive Guidance (IG).

Dialysis patient support groups are also a tremendous potential source of education for the modality decision making process. The ESRD Network program scope of work includes the promotion of patient mentors for other patients at the local facility level through identification and promotion of patient facility representatives (PFRs). The dialysis facility should encourage the involvement of committed and successful patients in such activities, as they can be helpful in educating and encouraging patients to consider home dialysis. Numerous online home dialysis resources are also available to dialysis patients, including educational material through the ESRD Networks at <https://esrdnetworks.org/membership/esrd-networks-contact-information/>.

One of the more rapidly growing sources of new dialysis patients in the U.S. is those with failure of a kidney transplant. Previously transplanted patients may be more knowledgeable about dialysis and modality choices than those with new onset ESRD. This potential source of patients should not be overlooked by home training programs. Even if the transplant patient never dialyzed at home previously, he or she is likely to place a high value on the freedom from in-center dialysis schedules that he or she enjoyed when the transplant was functioning. Cultivation of a good relationship with local transplant programs is therefore important for the home dialysis program in order to make it easier for patients to transition from transplant to home dialysis.

Urgent Start

“Urgent start” PD (USPD) refers to the practice of initiating dialysis within two weeks of catheter placement. In patients requiring unplanned dialysis, it allows for the avoidance of central venous catheters, facilitates uptake of a home-based modality, and is considered cost-effective in both the short and long term (Liu 2014, Lok 2016). Use of PD as a first modality choice in patients newly dependent on chronic dialysis, most often in the hospital setting, also allows patients without other resources immediate coverage by Medicare. Urgent placement of PD catheters can be performed either by open-surgical or laparoscopic techniques or percutaneously using peritoneoscopic or fluoroscopic guidance depending on local expertise. Patients are generally initially dialyzed with low volumes (500 to 1000 mL) every 1-2 hours in the supine position. Gradual increases to full volume and postural freedom are usually achieved within two weeks (Ghaffari, 2013). PD can be done with a cycler or by manual exchanges. Because of the low volume of dialysis, patients typically need to produce at least 500 mL of urine per day and a residual urea clearance of 5 mL per minute in order to avoid complications of underdialysis.

If PD is urgently started in the hospital, the patient is immediately referred to the home training program upon discharge; initial outpatient PD “runs,” usually CCPD-driven, are performed during working hours in the home training center, and the patient can be simultaneously or intermittently instructed in the performance of his own dialysis. Planning for an urgent start program requires nursing input for staff training and protocol/procedure development (Ghaffari, 2013). The accepting program needs to have sufficient staff, as well as a fully reclining chair or bed, along with the room to offer PD and training with little advance notice, while meeting the needs of previously scheduled patients for training and outpatient visits.

Casaretto and colleagues have described their USPD experience in detail. They recommend at least two dedicated registered nurses to ensure that any other planned training is not disrupted (Casaretto, 2011). They also suggest the need to hire a nurse before the program grows since “urgent start” is a new nursing responsibility. As long as the patient can be monitored (e.g., via a window, multi-site training room, or intercom), the nurses can continue to work with other patients. The fresh urgent start patient may dialyze in a supine position for six hours three days a week (e.g., Monday, Wednesday, and Friday) with 1000 mL dwell, with exchanges occurring up to hourly. Patients are drained completely before sitting or standing for any reason in order to avoid mechanical complications such as catheter leaks. For a thorough review regarding how to build a USPD program, we also refer you to Rajora, et al. (Rajora, 2020).

Impact of Unexpected Events, Complications, and Technique Failure among Home Dialysis Patients

A major component of a successful home program is the flexibility to deal with the unexpected. Patients may need temporary in-center dialysis, either HD or PD, for reasons such as acute illness, respite for

caregivers, peritonitis, or access problems. Therefore, home dialysis nurses need to have working relationships with the local in-center hemodialysis units and hospital-based dialysis staff. Patients need to be able to transfer back and forth between therapies with ease to continue their care. Factors to consider when establishing procedures to provide respite or urgent care plans include billing mechanisms, the location of respite dialysis, and the authorization to proceed with this care with a minimum degree of difficulty. The CMS CfC and IG require that dialysis facilities provide home dialysis patients with in-center back-up treatments when needed.

Failure to achieve or maintain acceptable clinical outcomes with home PD is reported in up to 50% of cases at one year. Proximate causes for technique failure are often medical in nature (e.g., recurrent peritonitis or transdiaphragmatic hernia), but social and demographic factors are known to increase the risk as well (Shen, 2013). One factor that may not be appreciated in advance is the potential for patient or caregiver burnout, particularly as dialysis regimens are intensified in response to ongoing loss of residual kidney function.

Preventing burnout is vital to the success of home dialysis programs and patients. In a study of patient and care partner couples who completed at least six months of short daily HD (SDHD), patients who did more SDHD self-care, particularly self-cannulation, were more likely to experience long-term success (Wise, 2010). It also appears that several large successful home dialysis programs encourage patients to do the majority of the home dialysis care with little help from care partners and have noted lower rates of burnout (personal communication). In addition, dialysis units should offer the ability for patients to come to the home unit and perform dialysis if they or their care partner need respite. Hopefully, the “Improving Access to Home Dialysis Act of 2021” will eventually make the provision of respite care easier by allowing Medicare to reimburse staff for in-home dialysis assistance.

Remote monitoring (RM) technology is now increasingly used to improve safety, reduce burden of care, and provide support to patients and caregivers. In a study looking at the relative risk of home HD attrition in patients using a telehealth platform, adjusted hazard ratios (AHRs) of all-cause attrition, dialysis cessation, and technique failure were 0.80 (95% confidence interval, 0.68–0.95), 1.10 (0.86–1.41), and 0.71 (0.57–0.87), respectively, for those using the telehealth platform vs. matched control (Weinhandl, 2018). Another study of PD remote management concluded that “despite the perceived benefits of RM in recording and transmitting treatment data and the potential for more responsive treatment adjustments, patients/care partners did not view it as fully alleviating daily treatment burdens.” However, RM technology can provide formal and informal support which were recognized by patients and their care partners as important components of PD treatment. Overall, further advancements in RM technology are expected to improve patient safety, experience, and burdens of care which may translate to a lower burnout and home dialysis attrition rate.

The dialysis clinician may recognize factors at the initiation of chronic dialysis support that would make success with home dialysis difficult or unlikely. It is our belief, however, that motivated patients deserve a chance to perform home dialysis if the factors that mitigate against success are not overwhelming. Experienced clinicians will recognize that technique failure cannot always be predicted with accuracy. PD and in-center hemodialysis are not modalities forever slated to be mutually exclusive for a given patient; patients may benefit from their consecutive use. If one never prescribes PD for patients considered at some risk for technique failure, many candidates who would do well for a long period of time would be excluded, and the growth of the home program unnecessarily constrained as a result.

If the home program Medical Director recognizes and accepts the possibility of PD technique failure, a corollary question that frequently arises is when PD patients should ideally have an arteriovenous (AV) fistula placed, and whether the patient should be educated then about hemodialysis and prepared for possible transition to home HD. The need for a technique switch, or respite from PD, often comes up rather suddenly, and one would like to avoid the necessity of placing hemodialysis catheters; yet routine AV fistula surgery creates morbidity and expense for patients who might never require the fistula to be used. Evidence of PD failure (e.g., inability to consistently achieve dialysis adequacy or ultrafiltration failure) should be recognized early, and in such patients, consideration should be made to place AV access and re-educate the patient regarding alternative modality options. Rather than returning to in-center hemodialysis, patients who are no longer finding success with PD would often be strong candidates for home HD, and vice versa. Shared decision making with patients and families allows for the development of a “life plan” that addresses many of these issues upfront and provides guidance for the patient’s care team in these circumstances. A link to Michael J. Schreiber’s article, “The ESRD Patient’s Life Plan: Extending Survival by Managing Health,” is provided in Appendix I. Additionally, Chapter 7 of the Forum’s Transitions of Care Toolkit expands on many of the concerns that prevalent patients have about changing modalities and suggests ways to address them. A link to this toolkit is provided in the Appendix.

Chapter Summary

- All patients actively performing, or anticipated to require, renal replacement therapy should be educated on home dialysis modalities and considered a potential candidate for home dialysis with few exceptions (i.e., advanced dementia, homeless patient, SNF patient if SNF doesn’t offer home dialysis). Growth in a home dialysis program depends on retention of patients as well as recruitment. Ideally, a shared decision-making process regarding modality choice should take place to help the patient and dialysis team choose the most ideal treatment for each patient. Making a good, informed choice does require more than the simple provision of printed information. Programs to promote exposure of all potential home dialysis candidates to committed home dialysis staff and patients should be strongly considered.
- Kidney Disease Education (KDE) for pre-ESRD patients and patients new to dialysis is critical to help patients receive adequate education and make the best decision regarding modality choice for dialysis. Transitional dialysis care (TDC) is a process in which patients begin outpatient chronic dialysis treatments on a home dialysis machine for several weeks, while receiving comprehensive education about treatment modalities. Transitional dialysis programs help provide comprehensive education to patients and their caregivers so they can make educated decisions about renal replacement therapy modalities and other aspects of their care.
- Urgent start PD may provide a meaningful resource for patients to programs that serve sizable hospitals, populations with previously limited access to care, or both. A defined urgent start pathway, supported by adequate reserve capacity of staffing and space within the home training unit, is required.
- Patient retention is as important as recruitment for program success. Realistic assessment of patient functional capacity, social support, and home environment is a crucial component of the optimal shared decision-making process regarding modality choice. The process of overcoming barriers to home dialysis success is equally important.
- Having arrangements in place for respite in-center care or the possibility of technique failure is highly recommended as an important contribution to patient accrual and informed mutual decision making. Prospective placement of an AV access and proactive discussions with PD patients who may be experiencing early PD failure about home hemodialysis options is critical. If a PD patient is starting to experience PD failure and is interested in possible home hemodialysis,

arrangements should be made early to begin training and transition of the patient to home hemodialysis to avoid in-center hemodialysis altogether if possible.

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Chapter 7: Transitional Dialysis Care Units

Chapter Synopsis

- Transitional dialysis care (TDC) is a term more recently used to describe the provision of hemodialysis to dialysis patients using home equipment in an in-center setting, supplemented with thorough patient education on the psychosocial issues associated with dialysis, as well as nutrition and vascular access.
- TDC units provide education over several weeks to patients and caregivers regarding dialysis modality options as well as transplant referral during a critical transition period from chronic kidney disease to end-stage renal disease. Such units can either intermingle with the dialysis unit's in-center hemodialysis program or be physically separated.
- A key aspect to a successful TDC program is a robust educational curriculum that offers dialysis patients all dialysis modality opportunities through a shared decision-making process.

What is Transitional Dialysis Care?

Transitional Dialysis Care (TDC) is a process first described by Joseph Eschbach (termed a “hemodialysis orientation unit” at the time) at the University of Seattle in 1983. The goals of TDC are to provide education, emotional support, and comprehensive multidisciplinary care to patients (and their caregivers) during the period of hemodialysis initiation. “Initiation” does not necessarily mean that only incident patients should be offered TDC. In fact, any transitional point in care (e.g., recent failure of the kidney allograft or modality loss from PD) can be viewed as an opportunity to offer TDC. As patients progress towards ESRD, many report a sense of feeling overwhelmed by the complexities of their disease process. Dialysis modality education, dialysis access referrals, discussions regarding kidney transplantation, as well as dietary and medication changes are just a few of the many factors that must be addressed during a time when uremia can severely impair one's ability to make decisions and follow through on multiple tasks. Historically, many of these patients have been sent to in-center dialysis units and often were never given the opportunity to make an informed decision regarding many aspects of their care.

For those patients who preemptively choose home dialysis, a referral directly to the home dialysis unit for training is recommended, as these patients will receive dedicated education from multiple disciplines. But for those who choose in-center hemodialysis (or are simply undecided), the TDC can be an opportune environment to give a patient and his/her caregiver focused attention as he/she begins to process the many choices and changes associated with renal replacement therapy. Typical TDC units generally provide a 4-week curriculum that begins with education regarding kidney disease and dialysis. Subsequent treatments are associated with discussions regarding dialysis modality options, transplant education and referral, and an introduction to the roles and services provided by the social worker and dietitian. This is all meant to be done in an environment where the patient is gradually beginning to feel better (from their dialysis treatments) and is more capable of making informed decisions regarding the best pathways for care to meet their needs. In many TDC programs, patients receive dialysis on a home hemodialysis machine four days a week with shortened duration in order to provide them with a “gentler” introduction

to dialysis (Bowman, 2019). The goal of a TDC program is not to transition all patients to home dialysis. Rather, the intent of such a program is to perform the following:

1. Help patients to feel better during the transition to ESRD when starting chronic dialysis
2. Provide comprehensive education to patients and their caregivers to help better inform them to make educated decisions about modalities for treatment of ESRD and other aspects of their care

As mentioned, the ability to slowly transition a new ESRD patient on a home dialysis machine can have several advantages over the use of standard in-center hemodialysis prescription. By initiating dialysis in such a way, patients can ease into dialysis with dedicated attention from staff with pre-specified education. More frequent (and shorter) dialysis treatments result in less aggressive solute and volume removal, potentially helping patients experience less post-procedure fatigue. Dialyzing in such an environment can break down many barriers that people often feel with regard to home dialysis and begin to appreciate what treatment would feel like at home (Morfin, 2018).

Education and Programmatic Features of Transitional Dialysis Care

The education program as part of the transitional dialysis program should be structured and consistent. It often begins with basic kidney disease and dialysis principles and dietary education and includes efforts to address the emotional aspects of ESRD. The Forum of ESRD Networks website contains a Depression Toolkit developed by the Kidney Patient Advisory Council (KPAC): <https://esrdnetworks.org/toolkits/patient-toolkits/dialysis-patient-depression-toolkit/> which is meant for patients and other members of their support team. TDC education should also cover information about dialysis and how to care for the access safely. This is typically followed by dialysis modality education where different tools can be used to try to assess goals and priorities of patients. After learning what is most important to patients (such as spending time with family at home, feeling healthier to participate in other activities, being able to travel or work, etc.), the modality education can then be tailored to the patient's goals. This process helps to make education more meaningful to patients and is more effective than simply performing a "one-size-fits-all" educational platform. In addition, it is often effective to include videos of other patients' experiences and patient stories in education.

Education should also focus on transplantation options including living donor and deceased donor transplantation. One helpful resource for patient education on transplantation can be found within the Forum of ESRD Networks KPAC toolkit and is entitled, "Is a Kidney Transplant Right for Me?" This toolkit can be downloaded from the Forum of ESRD Networks website at <https://esrdnetworks.org/toolkits/patient-toolkits/is-a-kidney-transplant-right-for-me/>. In addition to the toolkit, this link also includes a video by the KPAC which highlights the toolkit from the patient perspective. Lastly, patients should receive education on financial aspects of dialysis. The Forum of ESRD Networks KPAC also has a "Financial Help Resources" toolkit that can be found at the following link: <https://esrdnetworks.org/toolkits/patient-toolkits/financial-help-resources/>.

TDC can either be provided in an integrated setting within an in-center dialysis facility or in a separate dedicated transitional dialysis unit. There are advantages and disadvantages to both settings. One advantage of including the transitional dialysis program in the in-center environment is that patients on transitional dialysis can easily see the contrast between their treatments on a home dialysis machine and that of the patients receiving treatments on a traditional hemodialysis machine. Another advantage is that having the home dialysis machines in-center will help to raise visibility of home dialysis and may help

existing hemodialysis patients become interested in home dialysis. In addition, having the home dialysis machine in-center may help with educating dialysis staff on home dialysis so they can better educate other patients and potentially develop interest in becoming a “home champion.” This type of staff exposure can offer staff different career opportunities and help create an avenue for staff to learn from one another. Lastly, the use of home dialysis machines in-center could potentially provide patients and the staff the opportunity to perform self-care within the dialysis unit as well as allow in-center patients the opportunity to try the home dialysis machine in order to see how they feel on home dialysis, which may also help with home dialysis exposure. In summary, TCD units may take some of the anxiety away from patients thinking about doing dialysis at home.

A separate transitional dialysis unit also has some potential advantages, including keeping transitional dialysis patients in a quieter, isolated environment, more reminiscent of home than the in-center setting. Such an environment may allow for a better focus on patient education (with less distraction), and it may also have the benefit of allowing for more flexible scheduling options such as more frequent dialysis (e.g., four or five days per week dialysis). The separate transitional dialysis unit may allow dedicated staff a better opportunity to become experts on the educational material, without having to worry about cross-training for home and in-center care.

The Forum of ESRD Networks website contains a “Transitional Dialysis Care Guide” at <https://esrdnetworks.org/resources-news/transitional-dialysis-care-operational-guide/>. This guide is meant to serve as a resource for any dialysis program considering starting a TDC program. The guide was not directly developed by the Forum MAC or KPAC as most of its toolkits are, but rather was developed by experts with experience in implementing a transitional dialysis care program. Although the guide itself was sponsored, in providing this resource, the Forum does not endorse any company or manufacturer mentioned. However, we are pleased to offer you access to this guide, which contains many useful principles and ideas to help any program starting a TDC program. Among the many resources, the guide contains a sample timeline and information for setting up a program, as well as a sample education program which can be used as a blueprint when setting up education in your TDC unit. While the guide focuses primarily on one particular dialysis machine and describes the clinical benefits of more frequent dialysis in detail, a TDC program can also be set up using other available home dialysis machines.

A TDC program does not necessarily need to feature more frequent dialysis for all of its patients in order to be successful. However, we would recommend at least offering more frequent treatments (more than three times per week) to individual patients who might have clear clinical benefits, such as a patient with significant volume overload, or the obese patient who is anticipated to not achieve adequate dialysis on a home machine with only thrice weekly dialysis. Even if a patient is not achieving “adequate” dialysis but has good residual kidney function when starting dialysis or transitioning from PD, “adequate” Kt/V or URR may not be necessary clinically (but may be from a regulatory or dialysis program standpoint, depending on your facility). If a patient has adequate residual kidney function, which most patients starting dialysis do upon initiation of dialysis, they may benefit from starting with incremental use of dialysis. For more information regarding the potential benefits of incremental dialysis, the reader is directed to the article by Vilar and colleagues referenced below (Vilar, 2022). Again, medical decisions regarding patient care should be individualized to the patient’s needs and decided clinically by the nephrologist and/or medical director.

Chapter Summary

- Different efforts have been proposed to help support patients' ability to make informed choices with end-stage kidney disease modalities. Transition Dialysis Care is one form of such support that provides more intensive education to the newly initiated dialysis patient.
- Transitional Dialysis Care should not only offer intensive education in home dialysis modalities, but also education in kidney transplantation, nutrition, social work-related support, and discussions related to dialysis access planning when needed.

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Chapter 8: Self-Care Dialysis

Chapter Synopsis

- There are many potential barriers to a dialysis patient's ability to dialyze at home.
- Self-care dialysis may be an excellent opportunity for the dialysis patient with a desire to dialyze at home to maintain autonomy and involvement in their dialysis care.
- There is limited data relating to outcomes in patients participating in self-care dialysis, but self-satisfaction and improved quality of life seem to be common findings.
- From a dialysis provider and nephrologist point of view, self-care dialysis may allow for more engaged patients, lower staff-to-patient ratios, and positive reimbursement in newer value-based care models.

Defining Self-Care Dialysis

Self-care dialysis is a form of dialysis in which a patient performs all or part of his/her dialysis treatment with limited levels of support from dialysis staff. The amount and type of dialysis performed by the patient which constitutes self-care dialysis is (to a certain degree) variable, however CMS has set expectations for in-center self-care. The Medicare Benefit Policy Manual (ESRD), Chapter 11, provides this definition in Section 10: "Self-Dialysis - Dialysis performed by an ESRD patient in-facility with the expectation that the patient performs their dialysis treatment with little or no professional assistance. The patient must have completed an appropriate course of training as specified at 42 CFR §494.100(a)." In the U.S., self-care dialysis has been applied to the motivated hemodialysis patient lacking the support to perform home HD, however several countries utilize home dialysis staff to assist patients in performing PD at home as well (Giuliani 2017, 2020). Both patient and facility characteristics help determine the extent of self-care dialysis performed by patients.

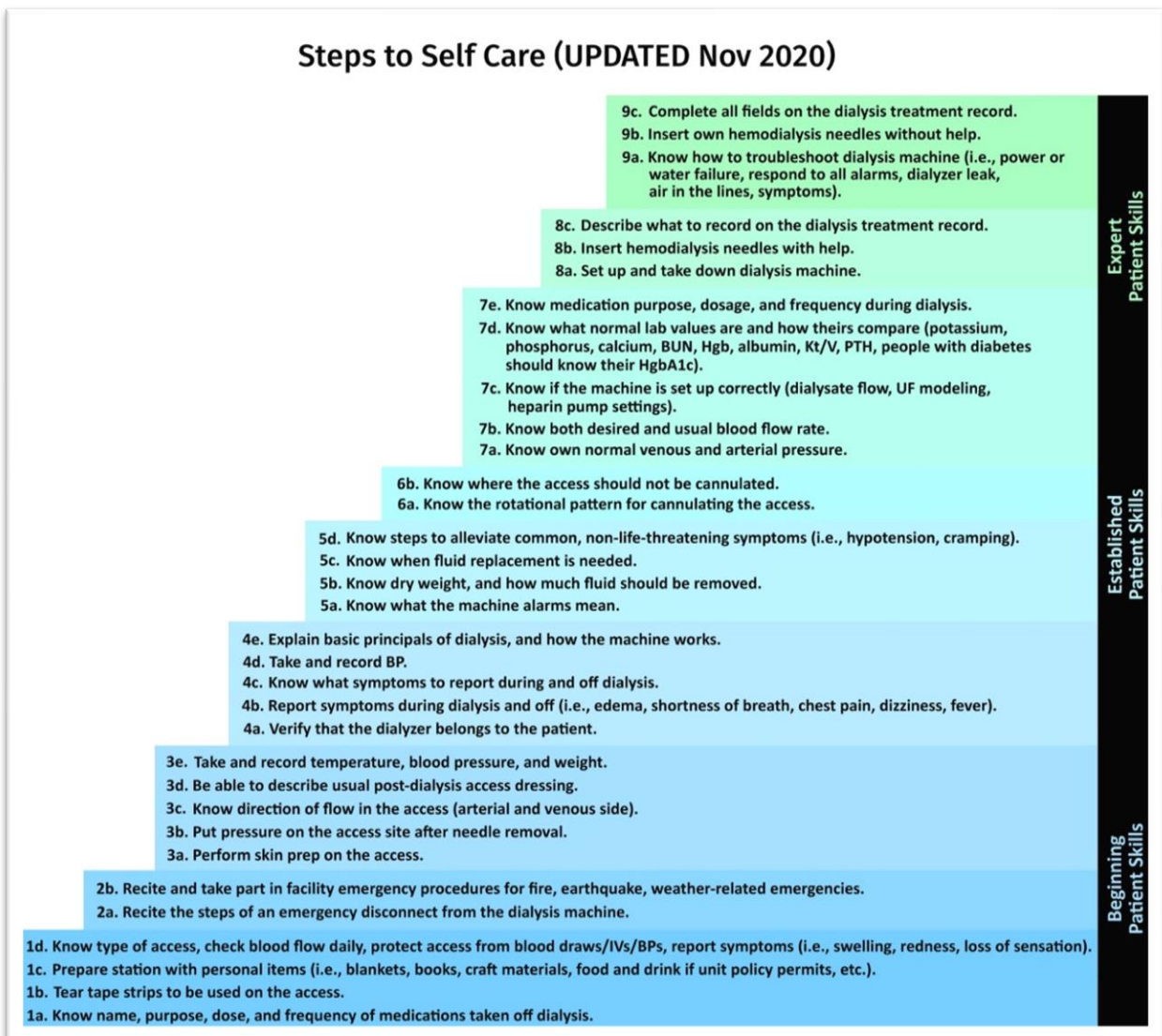
There are several advantages to patients performing self-care dialysis. Small case reports suggest that patients who perform self-care dialysis may have better clinical outcomes than other dialysis patients, including less hospitalizations and readmissions, less infections, and better volume management (Jones, 2016)/ It is also believed that self-care dialysis may be a bridge to home dialysis or be used as an alternative to home dialysis for patients who are unable or unwilling to pursue home dialysis. In addition, if enough patients perform self-care dialysis in a center (e.g., a pod or shift of patients), then the staffing for those patients may be able to be reduced in number or skill level.

There are many possible reasons patients may be unable, or unwilling, to pursue home dialysis. One such reason includes the lack of suitable home environment to pursue home dialysis (i.e., unstable living situation or lack of space for storage of supplies). The lack of a care partner remains another common reason preventing many dialysis patients from being treated at home. Patients may also have a fear of dialysis-related emergencies. Others state a preference to keep their medical treatments out of the home environment and may not want to expose their family members to dialysis treatments. Many patients also prefer the socialization that comes with performing in-center dialysis. They may value the interactions

they have with staff and other patients on a regular basis. Some patients may wish to perform home dialysis but are unwilling or unable to perfect self-cannulation. Self-care dialysis should be a consideration for all patients who fall into the above-mentioned situations.

Some dialysis centers with self-care programs have gradual education modules where patients start out with some basic aspects of self-care such as turning the machine toward them and observing their treatment data on machine or learning to respond to certain alarms. In these programs, patients who master the simpler aspects of self-care dialysis then progress to more complicated aspects of their dialysis care, such as initiating or terminating their treatments and setting up their dialysis machines. For many patients, self-cannulation may be their biggest barrier, but this too can be taught by dialysis staff to patients until they perfect it. Home Dialysis Central offers an organized approach to helping patients achieve proficiency in performing self-care dialysis (Figure 7).

Figure 7: Recommended Steps to Achieve Patient Proficiency in Dialysis Self-care



Achieving Proficiency in Self-Care Dialysis

A self-care dialysis program should be well structured and laid out prior to initiation. Facilities should have policies and procedures around self-care and educate staff on these prior to initiating such a program (Manns, 2005). In some centers, the training for patients for self-care dialysis may be performed by home-training registered nurses and is similar to home dialysis training. This may be a preferable approach if available since home dialysis nurses are experts in training patients on self-care already. With that said, many in-center nurses also enjoy the opportunity to educate their patients and can build from the rapport they may have already built with the dialysis patient. Regardless of the type of nurse, all involved should be well-trained and maintain competency in teaching patients to perform self-care dialysis. As patients progress on self-care dialysis and perform their own dialysis treatments, it will allow the staff to act more as coaches than technicians and will allow patients more independence. This can also help improve patients' quality of life in addition to the possible clinical benefits previously described.

The CMS ESRD Treatment Choices (ETC) payment model developed by the Centers for Medicare and Medicaid Innovation (CMMI) recognizes self-care dialysis patients in its final rule. If a dialysis facility is in a hospital-referral region of the U.S. chosen by CMMI to participate in the ETC payment model, the degree of home dialysis penetration can have a positive or negative impact on a provider's reimbursement. In the final rule, after comments from various stakeholders including the Forum of ESRD Networks, CMMI did decide to include self-care dialysis patients as one-half of a home patient in the numerator when calculating facilities' home dialysis rate as part of their modality performance score (MPS). This may be yet another incentive to nephrologists and dialysis providers to pursue self-care dialysis if they don't currently have such a program.

Chapter Summary

- A common experience of patients initiating dialysis is a loss of control and diminished quality of life. Active involvement in one's dialysis treatments can help address these feelings and is a major reason that many patients choose home dialysis. For those patients who are unable (or unwilling) to perform home dialysis, self-care dialysis offers an opportunity for patients to be more actively involved in their hemodialysis treatment while also providing in-center dialysis unit oversight.
- Evidence-based patient-related outcomes have yet to be established in self-care dialysis, however, greater adoption of this mode of dialysis therapy may at least offer great patient satisfaction while also benefiting staff support structure.
- Levels of patient involvement in self-care dialysis can be modified based upon patient needs and abilities. These different skill levels are outlined in the chapter and can offer structured guidance for patient and staff training purposes.

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Appendix I: Annotated Links

[Baxter International](#)

This site is obviously commercially sponsored, but the “Home Therapies Institute” tab links to a large number of educational videos and webinars that cover numerous topics in home dialysis, presented by experts and intended for physicians and nurses, without necessarily referencing to the company’s products. The intention appears to be the promotion of home dialysis in general. There is also a link to “Team PD,” an online and potentially face-to-face program developed by Baxter nurse clinical educators to train PD nurses; some of this material is specific to the company’s products and services.

[Home Dialysis Central](#)

A website created by the Medical Education Institute (MEI), a non-profit whose purpose, as expressed on the site, is to improve the lives of patients with CKD and ESRD. Much of the website (and other sites sponsored by MEI) is directed at patients, but it does have a “Professional Tools” tab that incorporates some useful and practical information about starting a home dialysis program, as well as resource links and FAQs. Also, please see [Match-D](#), an online tool for dialysis professionals to help assess the suitability of patient candidates for home therapies.

[RenalWeb Nocturnal and Home Hemodialysis](#)

RenalWeb is described on its website as a “neutral, non-affiliated” site that aggregates links to dialysis companies, products, and services; many of the links are commercial advertising, but there are also links to recent journal articles and non-commercial websites of interest. The site as a whole appears to rather aggressively promote the opinion that conventional thrice-weekly in-center hemodialysis is “inadequate” therapy of uremia, which continued use is sustained mostly by inertia and financial conflicts of interest among payors and providers. PD is not covered.

[Finances of Home Dialysis](#)

A useful slide deck generated by Thomas Golper, MD, for a talk at the International Society of Peritoneal Dialysis.

[Advanced Renal Education Program](#)

A website created and maintained by Fresenius Medical Care (FMC) that covers numerous topics of interest in home dialysis—founded in part by cycling PD pioneer Jose Diaz-Buxo, MD. The site offers “e-learning” modules for nephrology nursing continuing education credit. It also links to the ongoing live symposium series “Current Best Practices in Home Therapies,” sponsored by FMC several times each year in locations across the country, which can be attended by any medical professional without registration fees.

[QxMD Calculate](#)

A decision support tool for mobile devices that includes a number of modules of interest in PD, such as access care and peritonitis treatment, as well as a mobile version of the Match-D tool described above.

[American Nephrology Nurses Association](#)

The association website offers much material relevant to home dialysis therapies, including a specialty package of continuing nursing education (CNE) credits related to home therapies, an online library that includes webinars and archived meeting presentations, and modules from the Core Curriculum for Nephrology Nursing. Some resources are limited to members or provided to members (or local professional groups) at a discount.

[Implementing Hemodialysis in the Home: a Practical Manual](#)

The International Society for Hemodialysis has sponsored the formation of a committee (The Global Forum for Home Hemodialysis) in order to generate and disseminate this manual. It can be read online or downloaded in PDF format in its entirety, at no charge.

The committee is international in composition. It includes many leading experts from various disciplines in the field and includes at least one patient; the U.S. is well represented. Though the initiative was funded by a grant from Baxter International, care was evidently taken to keep the material free of commercial considerations. The manual includes references up through 2014; in fact, new modules were still being posted at the time of publication of this document.

[“New Concepts in PD Catheters and Placement”](#)

This YouTube video features John Crabtree, MD, and includes video taken through the laparoscope, demonstrating some basic and advanced techniques. The material is presented at a level intended for trainee and experienced physicians and surgeons. The video is approximately 90 minutes in length. Its production was sponsored by DaVita Kidney Care. Several other, briefer videos demonstrating basic Tenckhoff catheter placement, as well as material intended for PD nursing and patient training, are also available on YouTube.

[United States Renal Data System \(USRDS\)](#)

The USRDS produces the Annual Data Report on ESRD and CKD, providing yearly updated information on trends in dialysis patient demographics, modality use, costs, regional disparities, etc.

[The International Society for Peritoneal Dialysis](#)

This website has a number of links to online educational material for physicians and nurses, as well as links to meetings offered by the Society and others. A three-day meeting for nephrologists known as “Home Dialysis University” was sponsored by the Society and Wake Forest University, through a grant from Baxter International, at three locations in the US in 2015; future meetings, as well as sessions for fellows, surgeons, and interventionalists, are evidently in the planning stage, but the website does not contain information about future meetings at the time of this writing.

The Society’s journal is [*Peritoneal Dialysis International*](#). Most articles are limited to subscribers or purchasers, but some useful articles are free; see, for example, the article [“Infrastructure requirements for an Urgent Start Peritoneal Dialysis Program”](#) by Ghaffari et al. (2013).

[“The ESRD Patient’s Life Plan: Extending Survival by Managing Health”](#) by Martin J. Schreiber, Jr., MD

[Transitions of Care Toolkit](#)

The Transitions of Care Toolkit was developed by the Forum of ESRD Network’s Medical Advisory Council (MAC). This Toolkit for health providers and practitioners is a reference tool that gives information about challenges in transitions of care and suggestions to help create solutions.

[Are You Prepared? Get Your Go-Bag Ready Now!](#)

Developed by the Kidney Community Emergency Response (KCER) Coalition, this document helps patients prepare for emergencies both at home and away from home.

Appendix II: Home Dialysis Checklist

	Yes	Not yet	No	N/A
Certificate of need in hand?				
Appropriate space for unit constructed or obtained? Is it compliant with ADA and local life safety code?				
Application to Medicare fiscal intermediary submitted? (Form CMS-855A)				
State agency notified? (Certification for PD, HHD, or both may be requested) (Form CMS-3427)				
Governing body appointed?				
Medical director appointed?				
Nurse manager appointed?				
Nursing staff in place?				
Dietitian appointed?				
Social worker appointed?				
Technical staff available? (HHD)				
Quality assurance committee and program in place?				
Agreements with equipment/supply vendors in place?				
Agreement with hospital(s) in place?				
Nursing and technical call support available for patients 24/7?				
Nephrologist available 24/7?				
State agency inspection completed?				
Agreement signed by CMS regional office? Contact made with ESRD Network?				
Medicaid payments authorized? (Not necessary to start training patients, but advisable)				
Hospital staff capable of performing PD? Or home PD staff credentialed in the hospital?				
Compatible CCPD equipment/connectors in hospital?				
In-center hemodialysis unit available for respite/backup care?				
At least 2 qualified nurses on staff?				
At least 1 RN per 20 patients?				
(Optional) Space/staffing for urgent start program in place?				
At least 20 potential home dialysis patients? Referral sources/growth potential assessed?				
Attending physicians credentialed and appointed?				

Advanced practitioners credentialed and appointed?				
Qualified surgeon or interventionalist for Tenckhoff catheters available?				
Predialysis education/modality choice program in place?				
Modality choice education program for local in-center patients in place?				
Inpatient and outpatient protocols for infections, inflow/outflow issues, leaks, other urgent issues in place?				