

When the Clinician Becomes the Patient

—Shedding Insightful Light on Delivering Patient-Centered Care

By Brenda Gray, Pharm.D., BCNSP, CNSC, and Parenteral Nutrition Patient



As a clinician, I have provided home infusion therapy for 15 years—very effectively, or so I always assumed, until I recently switched roles and saw my practice through the eyes of the patient. Surprisingly, I found this role more challenging. Even as an educated clinician familiar with our model of care, learning to do my own home infusion therapy was more difficult than I ever imagined.

When I excitedly suggested to my prescriber that I could do this at home and get out of the hospital sooner, I was confident it would be simple. I taught patients telephonically every day and my care partners were a home infusion pharmacist and an ICU nurse. I was sure I would be the ideal patient—I knew the risks, and I would be more careful with my vascular access device than most patients. **[Editor’s Note:** NHIA member Kevn McNamara, Pharm.D., CNSC, is the author’s colleague and care partner. See the box on p. 21 for more on her point of view.]

On one hand, learning the ropes and adapting to self-care was probably easier for me than for many patients. But, on the other hand, it was an educational adventure that my caregivers and I did not expect. I had no idea the path I was really heading down. Looking back, I am convinced the many lessons I have learned along the way will make me a better clinician. Since all of us in this field strive to give patients the tools they need to succeed in the alternate-site environment, I wanted to share a few of my most significant lessons-learned here.

1. IT’S HARDER THAN YOU THINK

The first thing I discovered is that home infusion is harder for a patient than I ever thought. I have always instructed my patients by saying, “If you can pop a balloon and screw in a light bulb, you can learn to do infusion therapy.” While my analogy is true and those are the basic skills needed, it really diminishes the challenges a patient will face. There are many skills to learn and I had to accept that every part of my life is suddenly impacted by this therapy.

I came home late on a Friday afternoon after multiple days in the hospital—I was exhausted and

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ready to be home and recuperate. I opened my front door to excited greetings of lonely pets, piles of mail, and all the things I needed to catch up on. AND, oh yeah, now I had to welcome a stranger into my home to teach my tired brain all the things I need to do to care for myself. Fortunately, I only had infusion therapy; I can only imagine if I also had to learn wound care or how to use other medical equipment. Even as a trained clinician familiar with infusion therapy, I was overwhelmed! I cannot even imagine being a naïve patient trying to take all this in. Do we really expect a patient to learn this at 8:00 p.m. the night of hospital discharge?

2. IT DOESN'T ALWAYS GO AS PLANNED

And so my adventure began. That first night home before going to bed, I had to figure out where to put the bag between the dog and cat. Of course as I slept, the pump's alarm beeped and instead of pushing a button for a nurse, I had to figure out how to make it stop. It went off again and then I was afraid something was wrong, so I began troubleshooting.

The next day, I looked at the box of supplies and the bags in the fridge and just shook my head. Wow—*this is harder than I thought!* I need to be aware of this feeling of exhaustion and fear so that I can be a better clinician. I need to learn to better prepare my patients for this experience.

3. EVERYTHING TAKES LONGER THAN YOU THINK

The reality as a patient is that everything takes longer than you think. *I do mean everything!* As I said, being on home infusion therapy affects all areas of life, and every task seemed to take longer with the bag on my back. My schedule had to include time to: prepare my therapy, reset pumps, gather supplies, check bags, prime tubing, and flush lines—so many little tasks to do and each takes time. I also had to figure in the very important step of taking my bag out of the refrigerator to allow for the formula to warm up before infusing—vein spasms are painful!



Despite the many challenges that come with adapting to therapy—from being tired and overwhelmed to fitting so many steps into her schedule—author and parenteral nutrition patient Brenda Gray, Pharm.D., BCNSP, CNSC, has been able to take advantage of the freedom home infusion therapy offers. With her pump and medication in a backpack, she's mobile and can continue on her personal and professional journey, centered around quality of life.

On top of these tasks, my doctor wants me to keep a journal of what I can and cannot do, symptoms, bodily functions, etc. And, I have to schedule a weekly nursing visit—who knew labs and a dressing change could take almost an hour? There is no such thing as a quick shower either. I have to protect the line, but how? That was not included in the initial teaching instructions.

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4. IT'S EXHAUSTING

In addition to the challenges associated with this new treatment schedule, I found myself juggling follow-up calls and medical appointments—not to mention going back to work! When am I going to rest? The more tired I got, the longer everything took, creating a viscous cycle that was difficult to break.

I was not prepared for this constant state of fatigue. In hindsight the reason for this exhaustion makes perfect sense—but as a clinician, I often did not truly consider this outcome for my patients. The body is trying to heal at the same time it is dealing with foreign fluids and the presence of an access device. All this drains energy. Patients may also be anemic and/or deconditioned from their time in the hospital. They may be home, but there are a lot of demands on their time and energy. Even the positive things, such as caregivers trying to help or friends coming to visit, can be exhausting (see the Box on p. 21 for the caregiver's perspective).

The demands of therapy add up. Now I understand why my patients sometimes struggle to be compliant and often get frustrated with my questions. With this deeper insight, I am recognizing that, as a clinician, I need to be more sensitive to this reality, and overtly acknowledge it for my patients. I see now that patients are often busy, *even when home* “resting.” When I call patients in the future, I will begin with a question—is this a good time for us to talk?—rather than an assumption that any time convenient for me must also work for them.

When they are able to talk, I will remember that appointments and phone calls include multiple questions and challenging conversations. As a clinician, I need to be more aware of this and only ask the essential questions, being careful with the words I use. Even a highly educated patient may struggle to process information when they are tired—we must use uncomplicated terms and verify that they understand what we are saying to them (see the article on p. 33 for more).

5. CHANGE IS A BIG DEAL

I never understood why patients would get so derailed when we had to modify their supplies or delivery schedule—now I do. Everything about successful infusion therapy management in the home depends on organization, consistency, communication, and schedule management. When something changes to a clinician, it's a blip in the radar—the new product simply looks and feels “different,” no big deal. However, to the patient—especially if they are blind-sided by the change—*anxiety and questions arise*. Did I receive the wrong thing? Do I have to do something differently? Am I confused? Did I do something wrong because this looks different?

We teach patients how to self-administer their infusion therapy using visual cues and hands-on practice, so even a minor modification changes what they have become familiar with doing and seeing. At the very least, changes can result in the patient stopping and double-checking everything, leaving room for doubt and anxiety. This often results in a call to the provider to ensure the new item is correct and used in the same way. This now impacts the amount of time and energy needed to prepare therapy and can derail the very critical schedule.

As a clinician, I will remember that change is a big deal and it's essential to communicate with patients about it—*ahead of time, whenever possible*.

6. PRIVACY IS FLEETING

Another surprise for me was how little privacy a patient actually enjoys. Clinicians often have to ask very personal questions, including questions about bodily functions. Patients are frequently not alone at these times, either due to caregiver presence, visitors, or appointments, and may not be comfortable discussing bodily functions—especially gastrointestinal

LESSONS FOR THE CLINICIAN—FROM THE CAREGIVER

By Kevn McNamara, Pharm.D., CNSC, and Infusion Patient Caregiver

As a veteran home and specialty infusion pharmacist, McNamara regularly talks with patients and caregivers about their therapy regimens. But after taking on the role of caregiver to her friend and colleague in the field, McNamara was inspired to share some of her insights with other clinicians, so they can better understand the experience and needs of the home-based care team:

1. Remember, I am just as exhausted and overwhelmed as the patient. If I tell you I don't have questions, don't believe me! But give me time to figure out what they are, and please keep checking in with me.
2. Be patient with me! I probably have no clue what a cap and extension set is.
3. Remember all the pieces kind of look alike. Please be very specific when you talk about the way the supplies work. I will also grasp a lot more when I can look at the supplies, while you tell me about them.
4. Provide the same teaching to me as you do the patient. I am probably doing a lot of the work, at least early on.
5. Everything takes 2-3 times longer than you think, so be patient and realistic. By the time I am an expert at this, we may be finished with this treatment.
6. If you are changing something, it is important to let me know as well as the patient—we are both at risk for the confusion and anxiety that can accompany unanticipated changes.
7. The pump is not as easy as it seems. You program infusion pumps every day; I only reset the bag volume, turn it on, and push go. When the alarm goes off, it is scary! Troubleshooting is not as simple as finding the kink and unkinking it. The tubing will re-kink, the alarm will continue, and my anxiety will escalate. Remember the goal is to help me help the patient receive his or her therapy, not skip it.
8. The tubing is hard to attach to the bag!
9. Priming can be a frustrating and time-consuming process.
10. A bag of parenteral nutrition will not warm to room temperature in one hour or two. Teach me to remove the bag from the refrigerator after I disconnect the current bag.
11. Time of discharge is very important—please give us only what we can handle late at night when we are exhausted. I will not remember what you tell me, so plan to come back the next day when we've had some rest and can absorb what you are teaching us.

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Gray and caregiver, Kevn McNamara, Pharm.D., CNSC, prepare to administer her therapy. Caregivers play a critical role in the provision of home and specialty infusion therapy, especially when the patient is first discharged and both caregiver and patient are presented with copious amounts of information on the supplies and steps necessary to perform this complex, and sometimes intimidating, medical procedure in the home.



Gray recently went from home infusion clinician to parenteral nutrition patient, affording her a rare, self-aware perspective on her practice which she says will make her a better clinician.

or urinary issues—in front of just anyone. Likewise, they may not be willing to ask certain questions in front of other people.

Clinicians need to keep this in mind and realize that patients may be resistant to answering questions or even provide false or incomplete information in order to preserve their privacy or minimize the embarrassment they may feel. We need to be more considerate and ensure our assessments are being done when the patient feels comfortable being open and honest. It's so easy to begin with "I need to ask you a few questions about how you have been feeling these past few days—would you prefer we speak in private?"

7 . IT'S ALL ABOUT QUALITY OF LIFE

Lastly, I was reminded that patients are people and have lives to lead. The therapy may impact all aspects of their life, but it should still be a full and rich life. All of these challenges—learning new skills, managing a difficult schedule, adapting to changes as therapy progresses, and the overall fatigue of being sick—have to be managed successfully so the patient can still enjoy the life they are fighting so hard to preserve.

Patients do learn and adapt. They still dream, and they still want a high quality of life. Patients have

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places to go—from simple trips to the store, to work, or on a vacation. They also have friends and family they want to interact with. In this field we are keenly aware that by keeping patients out of the hospital we greatly contribute to these pursuits. So, it is important for us to support them and help make their journey more successful.

Perhaps the most important thing I learned is that we **must respect** our patients. These folks are busy, tired, and overwhelmed by their new lifestyle. As caring professionals, we need to realize their main goal is to take the best care of themselves as possible, and ours is to help them achieve it.

My new role and firsthand experiences as a parenteral nutrition patient have truly helped to enhance my abilities to genuinely empathize with the patients that I

work with clinically. I have learned that clinicians actually play a smaller role in this process than we think. My patients live with it every day and my role is to support them. As an infusion professional, I need to “infuse” passion and compassion in my practice. I need to not only provide information and medication, but I also need to simultaneously be patient, listen, care, teach, and respect the journey they are taking. After all, I became a home care clinician to help patients in need—and there is no better way to do that than to see everything I do through their eyes! ▀

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