


# 12 Tips to Nephrology Teams Supporting Patients with Advanced Kidney Disease

## An Advocate's Dozen

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As a first-time contributor to the *Clinical Journal of the American Society of Nephrology*, I appreciate the special opportunity afforded to me as a patient advocate to contribute my candid thoughts on several issues I believe are of great importance to patients and those who love and care for them. Although these may seem somewhat simple, they are vital to improving the patient experience and to creating more effective engagements between patients and their nephrology teams.

After I read the article entitled *Emotional Impact of Illness and Care on Patients with Advanced Kidney Disease* (1), I took time to contemplate my own encounters with kidney disease and the lasting emotions and memories I have had from multiple vantage points. These include my role and responsibility as a caregiver to family members at risk of kidney failure, including one member who presently lives on dialysis, as a dedicated friend to several of my friends and colleagues who have managed their disease for decades, as kidney policy advocate and Board Member of the American Association of Kidney Patients, and as a United States Marine officer and attorney. I believe that the authors of this article have done a tremendous service to all kidney patients by bringing this topic into the spotlight, especially for veterans whose service experiences often add a far deeper layer of complexity to how they are perceived and understood as patients. I also believe they have done an equal service to caregivers and, most importantly, focused a laser on an issue the medical professional community would be wise to give greater weight to when assessing patient health, resilience, and potential outcomes. Through their work, the authors have provided valuable insight into the emotional toll of the disease, and the research methodology makes a sound case for why far more should be done to elevate and disseminate qualitative research in a field so heavily dominated by quantitative research.

### Reflections as a Caregiver and Friend

The authors captured so many of the raw emotions that kidney patients balance in their everyday life. Paraphrasing the article, these emotions include fear,

isolation, mistrust, abandonment, alienation, and the tendency among patients to blame themselves for their disease and health outcomes, even when evidence and logic clearly points to the contrary. I am familiar with these emotions, I have heard them voiced first-hand during private conversations or during late-night phone calls when the voices of disappointment and resignation were first burnt into my memory. There have been other times when I have seen these same emotions emerge from disciplined suppression and play out in acts of frustration or anger. Perhaps some of these emotions could be mitigated if more professional team members appreciated the following:

1. Patients understand, especially in a large, dialysis clinic setting, that schedules are tight and staffing levels are leveraged to reduce costs. However, do not treat patients as a piece of meat, meaning do not dismissively pat their ankle walking by or forget their name.
2. Patients can tell when they are the last thing between you and the door and they do not begrudge your time with your family. But remember, the patient may be headed home to an evening of exhaustion and a house filled with concern and apprehension, so show genuine concern for them each minute you are with them.
3. Not every patient has the desire or courage to question or contradict the person in the “white jacket,” so make it easy for them to ask questions. This starts by stating clearly there are no stupid questions, only the ones that are not asked.
4. When you are speaking to a patient, always remember that you have the power to effect their emotional health, confidence, and optimism, and that of all those who care for that person at home. Consider your words wisely.

### Reflections as a Marine

The United States Marine Corps does many things in addition to training one how to prevail when they engage the enemy under the toughest conditions, on the roughest terrains, and under most severe environments anywhere in the world. The Marine

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Corps teaches all members, and especially their Marine officers, that you must know the character and psychology of those with whom you serve, particularly all who serve under you. If you ignore the person, small unit cohesion, effectiveness in battle, and the odds of prevailing in a contest are severely diminished. So, take a page from the Marine Corps and consider the following:

1. Do not BS the troops. Life is filled with tough conversations, and the chances are kidney patients have had many before they met you. Be honest, be direct, and be supportive, and never sugarcoat the truth. If you do, you will lose the confidence of the patient and your credibility to guide their care.
2. Problems at home translate into a divided focus on the front line (*i.e.*, their own care). Get to know your patients, look for behavioral aberrations, and understand that the emotions of home life run deep and can distract even the most focused and compliant patient.
3. Respect the instinct to assume blame or responsibility for problems. Among troops, this is a positive response and the first step to developing a solution to a problem. Although patients may have a misplaced sense at times, appreciate their desire to own a problem. With the right guidance, it can translate into a greater personal investment in managing the medical regimen, which equates to improved health outcomes.
4. Leave nobody behind. Never underestimate the innate human desire to live and prevail, and remember your responsibility to make certain your patients are not set adrift in the care system or left to fully coordinate the burden of their own care.

### Reflections as a Fellow Professional

As fellow professionals—speaking as a member of the legal profession to the medical profession, which I am fully aware carries a unique risk—we should consider the respective professional worlds in which we operate and ask some basic questions of ourselves before we interact with patients. I do this in my own interactions as a *pro bono* legal counselor for my fellow veterans, from all walks of life, through my work with the Inner City Law Center and the California Veterans' Association.

1. How would we want to be treated by fellow professionals, and do we treat patients in any lesser manner?

2. In my law practice or in your medical office or on your rounds, would we tolerate vague answers to our questions, lack of listening, or a lack of responsiveness?
3. I am responsible for maintaining clients and customers—do your interactions with patients and their caregivers help to keep them as clients or do they become disaffected and seek services elsewhere?
4. Have I fully answered my client's questions?

Through their work, the authors have provided valuable insight into the emotional toll of kidney disease. Ultimately, I would hope to see more of this qualitative research produced and disseminated through plain language guides and simple discussion tools for use by both patients and their nephrology teams.

As I match what I know to the feelings chronicled by the authors, my recurring thought is how little cost there is to professional nephrology teams to listen more closely and to respond more attentively to the underlying concerns of patients. What a vastly different world it would be for kidney patients if each of them experienced an even greater degree of empathy and understanding—as fellow human beings, they deserve no less.

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E.V.H. is a member of the Board of Directors of the American Association of Kidney Patients (AAKP) and serves as Chair of the AAKP Veterans Health Initiative. He serves as the Director of Staff Attorneys at the law firm O'Melveny & Myers. He is based in Los Angeles.

### Disclosures

None.

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See related article, "Emotional Impact of Illness and Care on Patients with Advanced Kidney Disease," on pages 1022–1029.