

The Josephine Way

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Do I contradict myself? Very well then I contradict myself. (I am large, I contain multitudes.)

— Walt Whitman

“I’ll take three pills,” Josephine told us. At that point, she was taking nearly a dozen prescription medications and a few more supplements and vitamins. “You guys can decide which ones, but I’m only taking three.”

The nurse practitioner, social worker, and I were sitting around her bed in the hospital. Warm, early-autumn sunlight did its best to shine through the grimy double-paned windows. A tray of mostly eaten blueberry pancakes and scrambled eggs sat on the bedside table, alongside empty cellophane wrappers from cookies and croissants from the café in the hospital lobby.

In her 60s with long-standing dialysis-dependent kidney failure, diabetes, and inflammatory bowel disease (IBD), Josephine was back in the hospital for the third time that September. After the first two admissions, she had gone home and disregarded the dietary advice so many of us had given her. Her favorite pasta and takeout upset her IBD, and she eventually felt too sick and weak to continue with her peritoneal dialysis exchanges. Without dialysis, it was only a matter of time until she was back in the hospital.

As part of the specialized kidney palliative care team seeing

Josephine, I had gotten to know her well over the course of 2 years. She was warm and funny, with a deep chuckle that started in her belly and went on to fill the room. Josephine had a way of drawing out of our team details about our personal lives that we wouldn’t normally have shared. She and I joked about the joys and challenges of raising little boys (hers was now in his 40s), and she freely dispensed dating advice to team members who weren’t wearing wedding bands. When she was feeling well, Josephine did more than hold court from her bed: she commanded the stage.

Despite our affection for her, caring for Josephine was not easy. She picked and chose the medical recommendations she would follow, often deciding to discount them entirely. And when she made up her mind, there was little we could do to change it. The previous year, she had been hospitalized with volume overload and a severe *C. difficile* infection. She needed daily dialysis and a few more days of IV antibiotics. She was getting better but needed to be in the hospital for at least another 48 hours or so. Josephine, though, had other ideas. “It’s my son’s birthday to-

morrow. I always make him my lasagna. I’m going home to make it for him,” she told us. “I know you’re worried about me. I’m not. I’m going home tonight so I can make that lasagna.”

Josephine left that evening, made lasagna for her son, and came back to the emergency department with worsening diarrhea 2 days later.

In medicine, we tend to subject people with chronic or life-limiting illnesses to what can seem like an ever-increasing list of restrictions. Though the first freedom to go is often food choice, the constraints don’t usually end there. We place limits on activity and, in some cases, where patients can live. We frequently worry that it will be “unsafe” for an older adult to go back to living alone, even if they’ve been doing so for years, if not decades.

For people like Josephine receiving dialysis for renal failure, the restrictions are even tighter. Patients not only have to strictly limit their salt and fluid intake, but also their potassium and phosphorus. Those receiving their treatments at dialysis centers are tied to a fixed schedule. Their “chair” is booked for 4-hour shifts on 3 days each week. The system is not very flexible. Patients undergoing peritoneal dialysis, as Josephine was, have slightly more control, though they must self-administer dialysis daily. In other words, dialysis is both a

full-time job and a lifestyle.

We can't be surprised, then, that people have trouble adhering to all these requirements. Even the most deferential patients bristle at the disruption dialysis brings with it. For Josephine, with her fierce independence, the restrictions were like a straitjacket.

When she told us she'd take only three medications, she wasn't only trying to gain back a modicum of control over her life. She was also pointing out, in her own way, the absurdity of everything we, as her extended care team, were telling her she had to do.

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"Look, all of you are always telling me, do this, don't do that. I hear you, and I respect your opinions. But I do things my way. The Josephine way." When Josephine wanted to go to the casino or take a trip to Maryland, she was going to do it, regardless of whether she'd miss dialysis. She'd eat what she wanted to eat, even if it led to stomach pain or fluid overload.

If Josephine had wanted to stop dialysis or to prioritize symptom control over everything else, we would have felt much more comfortable. But Josephine's goals

were muddy. They frequently shifted. She was tired of being on dialysis. But she was neither ready to discontinue it, which would shorten her life, nor willing to attend her sessions regularly. She came to the hospital when she wasn't feeling well, but then resisted the treatment we recommended. I'll admit it: she frustrated me. She became another consult note to write, another anxious medical team to talk down, another primary care doctor to reassure that he was doing all he could for her. Particularly in an era of overflowing emergency departments and inpatient

But how do they apply to a patient whose top priority doesn't fit neatly into either side?

Josephine reminded me that we, as clinicians, aren't the ones in control. Our patients decide how to integrate our recommendations into their values and worldview. It then becomes our job to care for them with both empathy and humility, recognizing that we can't really know what we would do if we were in their shoes. To be sure, this shift in perspective is easier in theory than it is in practice, since patients like Josephine can make us feel ineffective. But there was also something admirable in Josephine's defiance in the face of the chronic diseases that continually threatened to strip away her autonomy. She remained her authentic self. Josephine contained multitudes.

Eventually, clinicians from all of Josephine's teams met over Zoom. The discussion wasn't easy, but we were able to narrow her medication list down to three. Josephine felt heard.

Over the next year, things continued to be difficult for Josephine. She was in and out of the hospital, and she had several close calls. A few months ago, I saw her when she was briefly admitted with diarrhea and pain. "I'm worried my time is running out," she told me. I asked her if that scared her. "No," she responded. "I've lived a good life and I'll keep living it. By the way, how are your kids?"

Josephine eventually decided to stop dialysis, and our team set her up with hospice. But when the hospice came to drop off her hospital bed, she was nowhere to

wards, I know that if all patients were like Josephine, our already tenuous health care system would collapse. Of course, most patients are not like Josephine. Even if Josephine had followed all our advice, I'm not sure we could have kept her out of the hospital.

We're taught to think about the inherent trade-offs — risks versus benefits of a new medication, or prioritizing longevity versus comfort in a patient with serious illness, for example — as we apply evidence-based guidelines to our individual patients.

be found. She had gone with her son to the casino.

Disclosure forms provided by the author are available at NEJM.org.

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This article was published on December 10, 2022, at NEJM.org.

DOI: 10.1056/NEJMp2211162

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