

Navigating the Unexpected

Noah Kromer | Gresham, OR

“Chronic illness is hard to survive, and friendships often disappear due to the fact that all I have to talk about is the medical problems I am going through.”

After Noah Kromer's long-time doctor retired, his new doctor took him off a diuretic. As a result, he experienced intense weight gain.

Noah's doctor had been monitoring him for kidney disease for nearly ten years. His new doctor ordered a series of tests and they indicated serious problems with Noah's health.

Still, Noah was not formally diagnosed as having kidney disease.

During a weekend wine tasting trip, Noah became very sick. He thought he had pneumonia and visited an urgent care clinic when he returned home, where he was redirected to an emergency room at a local hospital.

It was only then that Noah was officially diagnosed with chronic kidney disease, heart disease, thyroid disease and (incorrectly) as diabetic. He received his first dialysis treatment in the hospital immediately following his diagnosis.

Shortly after, Noah connected with a nephrologist at a DaVita clinic who helped him develop a kidney care plan. This connection began a long journey of learning how to navigate a complex health care insurance system all too familiar to many patients with chronic conditions like kidney disease.

Falling through gaps in the system

Like most people, Noah received his health care coverage through his employer. So, when Noah lost his job, he was left with no health insurance. For a time, Noah got by with minimal care and relied on a faith-based community medical center which was not properly equipped to administer the care he needed. Noah eventually qualified for the Oregon Health Plan and was able to get current lab results in 2011. His tests showed his kidneys had failed.

Daily life became a struggle

Noah later had a double nephrectomy – something rare in the dialysis community. Sleep and dialysis schedules are difficult to anticipate, making normal day-to-day tasks difficult. His kidney disease led to bone spurs in his spinal column which required surgery to remove and limited his mobility. As a result, Noah cannot work.

“Kidney failure started a bunch of dominoes,” Noah said. “I really want to [work]. I miss having something to do outside of my dialysis. I've often wanted to teach a class called ‘everything your nephrologist hasn't told you yet.’”

Noah now uses a wheelchair due to the spinal surgery, which has also made it very difficult for him to qualify for a kidney transplantation, due to his restricted mobility and ability to exercise.

The stigma is strong

Socially, Noah feels like there is still a large stigma around chronic kidney disease.

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At the end of the day, Noah wants other people to see him as just Noah and not Noah-with-chronic-illness. In early 2021, Noah switched to at-home peritoneal care which helps with his mobility and access issues. At home dialysis freed up time that Noah would have spent commuting to a clinic. Now he has more time to pursue his personal hobbies like raising his plants in his local community garden plot and socializing with his neighbors. Noah is particularly fond of his neighbors who have pet dogs.

Treatment for ESRD will often disrupt someone's life to the point where it can be challenging to maintain a career, and in turn makes it challenging to afford health insurance. While many ESRD patients would like to keep working, they're often left with no choice to but to file for disability to qualify for Medicare.