



Nutritional Advice for Dialysis Patients: A Patient's Perspective

I was diagnosed with kidney failure secondary to Atypical Hemolytic Uremic Syndrome (aHUS) in July 1997. I received hospital-based hemodialysis, underwent a kidney transplant which failed quickly due to recurrence of aHUS, was on peritoneal dialysis, and eventually on daily nocturnal home hemodialysis. Therefore, I have received various forms of dialysis for the last 27 years.

When an individual is asked to start dialysis, it comes as a shock. Life is no longer the same. Suddenly, life starts revolving around dialysis treatments for the patient and often for their family. Going for dialysis treatments, traveling multiple times a week for several hours, having to take many medications, being unable to work, due to the fatigue and the time demands of treatment, and so on, is onerous for many. Dialysis patients also face the challenge of adhering to fluid and diet restrictions. For some, these limitations can be even more daunting than dialysis. Dietary advice can play an essential role in helping patients navigate this tortuous journey.

Fluid restrictions

For many dialysis patients, fluid restrictions stand out as the toughest of all limitations, often surpassing even the challenges posed by diet restrictions.

When I was put on dialysis in 1997, initially, my care providers told me I could drink only enough water to swallow my tablets. That was extremely difficult to follow. Later, that limit was relaxed to about a liter of all fluids put together daily. No tips were ever given on how to adhere to that limit. Some advice on managing with only that much fluid, like using a spray bottle, could have made that a little easier.

I decided to switch to daily, nocturnal home hemodialysis in 2006. My primary motivation was the more relaxed fluid allowance apart

from the lower cardiovascular stress that was reported online despite the modality being significantly more expensive.

Dietary advice

When I was put on dialysis, I met a dietician only when I was admitted to the hospital. Stringent dietary restrictions were imposed on me. No suggestions were given on how to make food palatable. No questions were asked about what we usually eat, like rice, chapatis, etc. A preprinted diet chart was given with no customisation. Salt was severely limited. No suggestions, such as adding lime or herbs to make food tasty, were ever mentioned. Looking back, I feel that diet could have been handled much better. There was no focus on trying to make food more enjoyable. As a result, eating was a punishment and I used to hate my meals. I lost appetite, and as a result a lot of weight. Had the focus been on what I could eat and how, rather than what I should not be eating, things could have been much better.

Cultural context

Rice, containing nearly 60–70% water, becomes something patients are asked to limit. For many patients, rice is a staple in their diet. This social and cultural context is something that care providers need to keep in mind while advising patients on their diet. Often, providers are from the same region as the patient. Despite that, these dietary habits are not considered while prescribing diets. Rather than putting blanket restrictions and giving standard diet charts, guidelines on the type of food, the quantities, the food categories, how to mix and match to make food interesting would be more helpful.

Vegetables and fruits

I always felt that care providers overemphasized the restrictions on potassium and phosphorus. Blanket

Kamal Shah¹

¹Department of Clinical Research, NephroPlus Dialysis Centers, Hyderabad, Telangana, India

Corresponding author: Kamal Shah, Department of Clinical Research, NephroPlus Dialysis Centers, Hyderabad, Telangana, India. E-mail: kamal@nephroplus.com

DOI: 10.25259/IJN_588_2024



Received: 01-10-2024
Accepted: 27-10-2024
Online First: 22-11-2024
Published: ***

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, transform, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

How to cite this article: Shah K. Nutritional Advice for Dialysis Patients: A Patient's Perspective. Indian J Nephrol. doi: 10.25259/IJN_588_2024

restrictions on foods such as fruits, leaching of all vegetables, and avoiding dairy products are given, which I now understand do not have a sound scientific basis.

Given the multiple health benefits of fruits, and their being a rich source of fiber and thus help with constipation, providers should suggest ways in which patients can incorporate fruit smartly into their diet. Since I usually had normal potassium and was undergoing regular treatments, I was allowed an additional serving of fruit in the first hour of dialysis. This became something I looked forward to. While such occasional indulgences help to bring cheer to patients, unfortunately, few people are encouraged to do this even today. It is almost as if it is a crime for dialysis patients to enjoy their food!

Dietary advice may need to be changed occasionally based on the changing circumstances in the patient's journey. A patient with normal potassium may be hyperkalemic after a few months due to the addition of certain drugs, for instance. This periodic review is critical and rarely happens.

Travel challenges

All these diet and fluid restrictions often become quite a deterrent for dialysis patients, preventing them from travelling or going on vacations. I was told to follow my diet restrictions strictly without being given specific tips on how to do so. This would be really useful if guidelines could be provided on how one can safely eat while going out. For example, requesting a salt-free dish and adding a

small quantity of salt if needed, restricting my potassium hard for the rest of the day in anticipation of an outside dinner where I might indulge are all small suggestions that help.

Summary

I would much rather receive "diet guidelines" from providers rather than a prescriptive diet plan that does not give much room for experimentation and variety. This would empower me to decide what I want to eat rather than just be bound by a one-size-fits-all solution. These guidelines could provide broad inputs on how much of each nutrient is safe along with a reliable source of knowing what foods contain how much of each nutrient.

This would go a long way to enable me to take control of my diet in my own hands and give me much more freedom in tailoring my meals to my needs and preferences rather than adhering to a single-page diet plan that does not consider these aspects at all.

Diet is a critical part of a dialysis patient's treatment. If I were involved along with my provider in arriving at a nutrition plan, this would go a long way in helping me to enjoy my food in a safe manner rather than mealtimes becoming monotonous and boring.

Conflicts of interest

There are no conflicts of interest.