

Patient Leadership Committee
Family Focus Series

Diet – What Me Worry?
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Is maintaining a diet stressful? In response to a questionnaire by The Renal Network, family members of kidney patients responded that coping with the renal diet was a major stressor especially during the first year of dialysis. Now remember, this was a survey of family members, those individuals trying to provide the best care and support for their loved one who is now requiring dialysis treatments. As support people, family members are usually involved in planning the family diet and in actual meal preparation.

In my experience, their major concern is that they will accidentally do something wrong with diet planning and end up harming the patient. In fact, the renal diet has become easier to follow in the past few years due to improvements in dialysis procedure and the removal of more toxins during treatment. Very few patients are harmed solely by diet choices. Such patients are in denial about their disease and are really ignoring their diet restrictions in a big way.

Most patients achieve good results with the renal diet and are still able to enjoy mealtimes with family and friends. You really do not need to be perfect in planning the diet! Right from the start, in the first months on treatment, good results can be achieved with help from the health care team and with normal efforts. In fact, in that same questionnaire, family members reported that the renal diet becomes only a minor stressor after time.

There are several things that you can do in the first weeks to help you get to this less stressful state. As a practicing renal dietitian, I will share some of those tips with you in this article.

The first step in reducing the stress for you, the family member, is education. The new patient will meet with the dietitian and receive information on the renal diet in the first couple of weeks on dialysis. Try to be there for this instruction. Or review the materials later with the dietitian.

Remember the renal dietitian is there to help your family to “live” with the diet plan. Let her/him know about your family’s eating habits, favorite recipes and traditions so that they can be worked into the diet as much as possible. When the diet plan is followed regularly, there is usually room for that special holiday recipe.

I especially like to work with the person who does the grocery shopping and cooking for the household to make the diet acceptable for the patient. Encourage the whole family to learn this new diet and to offer creative suggestions for

adapting it for your lifestyle. The new diet will be much easier to follow if everyone helps, especially in the first few weeks and months!

So, you have had your first instructions on the renal diet. Now you are home with your family and have a whole new plan to follow.

How do you start?

Take it slow at first. Get used to the new diet. It is common for family members to take over meal planning for the patient in the first few weeks as the patient regains their strength and appetite. However, the dialysis patient should be feeling better soon and should take control of their own meal planning then. The patient needs to understand why they need to follow this plan.

It is not healthy for the family or the patient if you become the “enforcer” of the diet. Especially when the patient is capable of handling it.

If the patient does not follow the diet and medical advice given, you should continue to offer your support but do not accept the responsibility for their actions. After all, we are able to make long-term changes best when they are accepted and not forced upon us. The commitment is an individual choice. Give the patient the chance to make the right choices for him/herself while providing lots of love and support!

You may find the first weeks of following the renal diet to be stressful since changing old habits require a determined effort. Change does not happen overnight for anyone! Grocery trips may take more time because you need to read the food labels of familiar foods. You may find that some convenience foods can no longer be used due to high sodium content. You will also be surprised to discover that potassium and phosphorus are not even listed on most food labels.

Questions will come up right and left as you learn this new diet. You may find yourself preparing “safe” meals of broiled or baked meats, plain vegetables and soaked potatoes because you are afraid to try anything else. Neither the patient nor family members will be happy with this situation for long!

This is the time to visit your dietitian again to find creative approaches to the diet. Now is the time to adapt the diet for the “long haul” of dialysis. The most successful and contented families will look for renal cookbooks, advice on shopping and help in changing favorite recipes.

Ask your dietitian for a “refresher course” if you have forgotten some of the diet guidelines. Write down any questions you have about diet and bring them to treatments to be answered. Please remember that all dialysis staff are not equally qualified to answer diet questions.

So be sure to ask for the registered dietitian who cares for your family member. If you are still overwhelmed by the diet, ask the dietitian to teach it “in pieces” so that you can understand each restriction that is needed and the reasons for it. Your dietitian will be happy to help you care for your loved one!

Experienced dialysis patients will tell you that it is very hard to change your diet habits for months and years. Think how hard it is to follow a diet for just a week! It becomes much easier if the patient and family have a lot of social support. Research shows that the most important factor related to good compliance is the positive support of others.

You and the patient should surround yourselves with persons with encouraging attitudes. I have found that many young patients do not want to admit that they are ill and so they will act like they are “invincible.” They often do not follow their diet, take their medications or come to treatment because they want to “fit into their crowd”. However, these patients may listen to people other than their family like teachers, coaches, co-workers or friends. On the other hand, older patients may not want to burden their family and friends with their illness but will talk to dialysis staff who care for them. Find more support people for your loved ones so that you don't carry the burden alone! Some other options for encouragement include church leaders, club members or neighbors. Support groups at your dialysis unit may also prove helpful.

Just remember that your family member is an individual unlike any other in the waiting room at the dialysis unit. Do not allow other patients and family members who are angry or discouraged to change your own approach to the diet and dialysis. The right attitude is a large part of the whole equation!

Veteran dialysis patients have suggestions for dealing with your diet and social life also. Your family member may feel like an outcast at social events if there are many restricted foods on the menu. This may cause them to turn down invitations and just stay home.

Do not pass up these events which will boost patient morale and help them accept their new life! Plan ahead by preparing an appropriate potluck dish, or checking with the dietitian if some “careful cheating” could be tolerated. Patients who follow their diet closely most of the time may have room in their diet plan for some “special foods” in moderate amounts.

Ask your dietitian for “Eating Out” guidelines and portion sizes. It is also helpful to offer a small meal or snack before going to the event to prevent poor choices due to extreme hunger!

As in many things, moderation is essential.

Successful dialysis patients have shared other hints with me over my years of practice. They suggest finding hobbies which distract the mind from food. Exercise can also serve this purpose.

Perhaps you can even join your family member in a new pursuit! Also, enough time should be allowed to plan appropriate meals, especially if they must be taken regularly to work or to school.

Unfortunately, there is not yet a “renal fast food” chain of restaurants available for meals on the run!

Patients who are successful also do not punish themselves with negative feelings when they do make poor choices. The entire diet plan need not collapse because you made a couple of mistakes! You just need to “get back on the horse and try again.”

Finally, both patients and family members should remember that although the behavior may not be good, that does not mean that the person who made the mistake is also not good. If you find yourself or your loved one with that attitude, take time to talk to your social worker about the “whole picture.”

You too can be one of the family members who finds stress from the renal diet lessening with time! You can find yourself enjoying a good meal with your loved one and discussing current events, rather than the amount of vegetable allowed for dinner in the diet plan. Your family will have found new favorite dishes to share together at the holidays.

Social occasions will again become the time to visit with friends that you don't see often enough.

Your renal team and your dietitian are there to make this vision become a reality for you!