TALK TO YOUR CHILDREN ABOUT KIDNEY DISEASE

SUMMER FOODS
IT’S ALL ABOUT MAKING ADJUSTMENTS

After 27 months on dialysis, I was excited to restart my life post-transplant. My goal was to attend graduate school and begin a career ensuring healthy lives for people suffering from disease and illness. The adjustment to life post-dialysis was hard. Similar to when I started dialysis, I had to embrace the emotional, physical, and lifestyle changes that take time to adjust to. I also had to remind myself that kidney disease is lifelong — even now, almost four years after transplant, kidney disease is still my biggest priority.

This issue of Kidney Living emphasizes adjusting to your diagnosis and educating others about kidney disease. Whether you are recently diagnosed or have been living with the disease for years, this issue shares ways to explain your disease to others and remain optimistic about living with kidney disease.

Ewo Harrell

Ewo Harrell, MPH
Patient Advocate, Transplant Recipient, Former Dialysis Patient and Health Entrepreneur
Talking to Your Children

About Kidney Disease and Dialysis

When a family member develops kidney failure, the whole family is affected, even if they don’t all show it. Everyone has questions. For children, it may be hard for them to know what to ask or to understand what is happening to their parent.

Here we offer some sample questions and concerns a child might have—and answers to help guide you in talking with them.

1. Why do you not feel well sometimes?
   Kidneys do a lot of things to keep us healthy. A normal kidney works 24 hours a day, 7 days a week to clean the blood. Because your kidneys are not working as well as they used to, some of these poisons are building up in your blood. When the kidneys don’t work how they’re supposed to, it is a little bit like a washing machine that doesn’t work right. It may look fine from the outside, but inside there are many important things that do the work. If something doesn’t work right, the washing machine doesn’t do its job of cleaning the clothes.

2. Why are you in a bad mood sometimes?
   My being in a bad mood sometimes is not your fault, and does not mean that I don’t love you anymore. There are many reasons why I may feel “down” sometimes. If your child doesn’t express his or her concerns, the questions below may help you begin a discussion about concerns a child might have—and answers to help you and your child cope, talk with your social worker.

   Sometimes, I don’t feel well enough to play like I used to. Right now, I’m feeling too tired for active things. I’d like to be able to play like I used to, and maybe when I get used to my treatment and start feeling better, I may be able to do more. But right now, I’m not strong enough. In the meantime, we can try to think of other things we could do together, so that we can keep playing and having fun together. Maybe we can think of some things right now that we can do, like puzzles and games, maybe watching a movie or reading a book.

   1. Why do you not feel well sometimes?
   2. Why are you in a bad mood sometimes?
   3. Why don’t you play sports and run around with me like you used to?
   4. Why do you have to go to the doctor so much? I only go once a year or when I’m sick.
   5. Are you going to die?
   6. Will this last forever?
   7. Do I have kidney disease? Can I get it?
   8. How will I feel during treatment?
   9. Why do I have to go to the doctor so often?

   Sometimes, I don’t feel well enough to play like I used to. Right now, I’m
   feeling too tired for active things. I’d like to be able to play like I used to, and maybe when I get used to my treatment and start feeling better, I may be able to do more. But right now, I’m not strong enough. In the meantime, we can try to think of other things we could do together, so that we can keep playing and having fun together. Maybe we can think of some things right now that we can do, like puzzles and games, maybe watching a movie or reading a book.

   1. Why do you not feel well sometimes?
   2. Why are you in a bad mood sometimes?
   3. Why don’t you play sports and run around with me like you used to?
   4. Why do you have to go to the doctor so much? I only go once a year or when I’m sick.
   5. Are you going to die?
   6. Will this last forever?
   7. Do I have kidney disease? Can I get it?
   8. How will I feel during treatment?
   9. Why do I have to go to the doctor so often?

   Sometimes, I don’t feel well enough to play like I used to. Right now, I’m

   *National Kidney Foundation*
I’ve been on hemodialysis in-center for a few years now. My healthcare team has been talking to me about home dialysis. Why should I consider dialysis at home?

For many, doing dialysis treatment at home allows more independence and control over their treatment and schedule. You can determine what times work best for you and your care partner and fit the treatment schedule into your life and work schedule.

Doing dialysis at home means you can get more frequent dialysis, which has been shown to decrease the need for medications to control blood pressure and phosphorus. Also, patients report feeling better with longer, more frequent dialysis.

Some people may be afraid to have dialysis treatments with blood and needles at home. This is a common concern. Try learning to stick your own needles during your in-center treatments. Have staff teach you and then watch you try yourself until you are comfortable. This will make the transition to home easier once you feel more confident. However, you do not have to stick your own needles to do dialysis at home. Most centers require that you have a care partner trained and present during your treatments. Your care partner will be trained alongside you so you both know how to do everything required during treatment.

It’s also a good idea to talk with someone who has done hemodialysis at home – talk to your social worker to ask about support groups in your area or call NKF Peers 1.855.653.7337 to get connected with a peer mentor by phone. The fears and concerns you have are normal and others have also faced them. Talk with someone who has overcome them and successfully does hemodialysis at home.

Once you go home, you are not alone! Your healthcare team at the dialysis center will continue to follow you and be available to support you. You will need to see them in the center at least once a month. You will also be given a 24-hour emergency number to call, if needed.

Doing dialysis at home is not for everyone, but it is a great option to consider. The most important thing to remember is you have options! Learn more about them and decide what is right for you and your family.

**Dialysis is done in the comfort of your own home.**

You do not need to travel to a dialysis center.

You have more flexibility to choose the time of day to do dialysis.

You and your dialysis care partner learn how to do treatments independent of the center staff.

**PROs**

In home hemo

You must have enough space in your home to keep the machine, a water system, (if needed) and supplies

Your electric and water bills may increase

You will need a dialysis care partner

Both you and your dialysis care partner must take time off work or your regular routines to attend training.

**CONs**

In home hemo

You need to have a dialysis care partner

Some people may be afraid to have dialysis treatments with blood and needles at home. This is a common concern. Try learning to stick your own needles during your in-center treatments. Have staff teach you and then watch you try yourself until you are comfortable. This will make the transition to home easier once you feel more confident. However, you do not have to stick your own needles to do dialysis at home. Most centers require that you have a care partner trained and present during your treatments. Your care partner will be trained alongside you so you both know how to do everything required during treatment.

It’s also a good idea to talk with someone who has done hemodialysis at home – talk to your social worker to ask about support groups in your area or call NKF Peers 1.855.653.7337 to get connected with a peer mentor by phone. The fears and concerns you have are normal and others have also faced them. Talk with someone who has overcome them and successfully does hemodialysis at home.

Once you go home, you are not alone! Your healthcare team at the dialysis center will continue to follow you and be available to support you. You will need to see them in the center at least once a month. You will also be given a 24-hour emergency number to call, if needed.

Doing dialysis at home is not for everyone, but it is a great option to consider. The most important thing to remember is you have options! Learn more about them and decide what is right for you and your family.
Most teenagers are preoccupied with issues such as school, parents, friends, and what’s happening on Facebook or Instagram. But for 15-year-old Thalya Onelin, dealing with kidney disease is her biggest priority. In 2014, after suffering from nausea, weight loss, and rashes, Thalya was admitted to the hospital and diagnosed with stage 5 kidney disease. Her mother, Chantal, knew something was off, but did not realize the extent of the problem until they went to the hospital.

“As parents, we make it our mission to protect our children, and to know when something is wrong,” said Chantal. “When she was experiencing these strange symptoms, we decided to seek out medical assistance right away.”

It was then that their world was turned upside down. While they attempted to digest the diagnosis, and understand kidney disease, Thalya’s parents knew they needed to remain calm so that they could figure out what to do next. Fortunately, Thalya was much more positive than her parents expected. She was very compliant with her doctors, and always did everything she was told. She was even more concerned about her parent’s well-being, constantly asking if they were alright. It was then that their world was turned upside down. While they attempted to digest the diagnosis, and understand kidney disease, Thalya’s parents knew they needed to remain calm so that they could figure out what to do next. Fortunately, Thalya was much more positive than her parents expected. She was very compliant with her doctors, and always did everything she was told. She was even more concerned about her parent’s well-being, constantly asking if they were alright.

The family had to make a few lifestyle changes after Chantal’s diagnosis. When Thalya began dialysis, Chantal changed her work schedule from full-time to part-time to attend dialysis treatments with Thalya for three hours, three times a week. The family also had to change their diet. They now had to make sure they were mindful of their sodium intake and had to limit the consumption of foods that contained potassium and phosphate. They experimented with different spices to enhance the flavor of dishes, and found some great substitutions for some of their favorite meals.

“Everyone joined in and celebrated with new recipes. We didn’t want to turn the kidney diet into a chore,” said Chantal. “We opted to turn this lifestyle change into a discovery of how creative you can be when you’re faced with limited options. We were determined to make it a fun experience!”

While Thalya is patiently waiting for a new kidney, her mother is determined to raise awareness about kidney disease and the importance of organ donation. For one reason or another, Thalya’s family members were not a match, and so they have begun to look elsewhere. Concerned about the long waitlist, Chantal has started a Facebook page to raise awareness and help them in their journey as they seek a living kidney donor. Utilizing the resources from the National Kidney Foundation (NKF) and the new The Big Ask, The Big Give campaign, the family has developed a better understanding about kidney disease and organ donation, giving them the confidence to speak about it to others.

When speaking to her daughter, Chantal says she always reminds Thalya of the importance of perseverance, explaining, “This is a serious challenge but she’s going to learn from this. And moving forward, she can tackle anything.”
Summer means picnics, BBQs, and a lot of gatherings with friends. As well as foods full of potassium, phosphorous, and sodium. So, whether you are grilling at home or packing a POTLUCK for the park, use these low-so good and KIDNEY FRIENDLY recipes to add flavor and color to your meals. And keep all the foods you love on your table (or PARK BLANKET!).


**KIDNEY KITCHEN**

## CAULIFLOWER “RICOTTA” SPREAD

Makes 8¼ cup servings

**INGREDIENTS**

- 2½ cups roughly chopped cauliflower florets
- ¾ cup unsalted, pine nuts or cashews (soaked for 1 hour)
- ¼ tsp ground nutmeg (optional)
- ¼ tsp dried parsley
- ¼ tsp salt-free garlic powder
- ¼ tsp freshly ground black pepper
- ¼ cup fresh orange juice

**DIRECTIONS**

Steam the cauliflower until fork tender, 6 to 8 minutes. Then transfer cauliflower to a high-speed blender and add the remaining ingredients. Pulse until you get a ricotta-like texture. Scrape the sides of the bowl with a spatula to get any missed nuts or cauliflower. Add a little water if mixture feels too thick. Pulse until well combined. Store in an airtight container in the fridge for up to a week.

**Notes:** Add nutritional yeast, other salt-free spice blends (like: BBQ, za’atar, curry!), and other herbs or raw vegetables (like: peeled beets, basil, spinach!) for varied flavors. Then use as a dip, spread, or even stuffing for a healthy collard green wrap! Basically, anything you would eat with hummus!bath to stop the cooking process.

**ANALYSIS**

- Calories: 31
- Carbohydrates: 2.9g
- Total Fat: 2.1g
- Protein: 1.1g
- Sodium: 10mg
- Potassium: 112mg
- Phosphorus: 61 mg

## QUICK FENNEL RELISH

Makes: 1½ Cups (8 Servings)

**INGREDIENTS**

- 1 medium fennel bulb
- ¼ small yellow onion, minced
- 1 cup unseasoned apple cider vinegar
- ¼ cup fresh orange juice
- ¼ cup water
- 1 tsp turmeric
- 1 tsp yellow mustard seeds
- ½ tsp caraway seed
- ½ tsp fennel seeds
- ½ tsp dried dill weed
- ½ tsp red chili flakes
- ¼ tsp freshly ground black pepper
- ¼ cup chopped flat leaf parsley (optional)

**DIRECTIONS**

Prepare the fennel by washing and cutting off the bottom nub and fronds. Remove outer layer if bruised (and if you care). Otherwise, chop the bulb lengthwise into a few thick chunks. Then use a food processor (or a box grater) to shred the fennel pieces. Place everything except the fresh parsley (fennel through black pepper) in a medium pot. Bring it to a boil and let it cook until the liquid reduces, about 5 to 8 minutes. Let it cool, about 10 to 15 minutes. Transfer to a clean glass container with a lid. Place in the refrigerator until use. Will last up to a week.

**ANALYSIS**

- Calories: 49
- Carbohydrates: 11g
- Total Fat: 0g
- Protein: 1g
- Sodium: 17mg
- Potassium: 184mg
- Phosphorus: 87mg

Spreads and dips are staples of picnic season; hummus being the ultimate portable snack. And creamy cheese landing at a close second. But due to the phosphorous in beans and sodium in cheese, these two items don’t often make it into the kidney-friendly picnic basket. But don’t fret. Because this cauliflower-based spread not only saves the day, but will quickly become a new favorite for sunny afternoons to come. It is rich, creamy, and definitely healthy. And it goes with anything from crackers, to crudités, to a healthy collard wrap. It’s basically the new hummus (don’t tell hummus).
CARROT VEGETABLE NOODLE SALAD WITH SPICY SHRIMP
Makes 4 servings

Give your stove and your pasta noodles a summer vacation with this veggie-filled dish. It’s light, healthy, and bursting with spice. Not to mention a tangy avocado dressing to cool it all down (which you’ll end up using on everything). This dish can be served cold or at room-temperature, which is perfect for hot summer days and nights. And shrimp can be replaced by any protein that works for you and your diet. Note: it’s best to use frozen shrimp to be certain of sodium content, so be sure to look at and read labels to pick products right for your diet.

INGREDIENTS
5 medium carrots (rainbow if available)
¼ – ½ cup Avocado Green Goddess Dressing (see recipe, right)
4 oz snow peas, washed and trimmed
2 green onions, root ends trimmed, thinly sliced
2 red Fresno chile, thinly sliced
2 red extra-large, frozen shrimp with tails attached
1 lime, cut into 4 wedges
¼ tsp freshly ground black pepper
chili powder
1 tsp salt-free chipotle spice or paprika
¼ cup salt-free chopped peanuts
1 lime, cut into 4 wedges

ANALYSIS
Calories: 162
Carbohydrates: 12.3g
Total Fat: 11.6g
Protein: 4.5g
Potassium: 91mg
Sodium: 158mg
Phosphorus: 158mg

DIRECTIONS
Use a vegetable peeler to make carrot ribbons or the grater attachment on a food processor or a box grater to shred the carrots. Transfer to a large mixing bowl and add 1¼ cup of the dressing. Toss to coat well; taste and add more dressing, if desired. Add the snow peas, green onions, Fresno chile, jalapeno, basil, and cilantro. Toss to combine. Set aside.

In a medium mixing bowl, mix the garlic powder, chipotle powder, and pepper until combined. Add the shrimp and toss until coated with the spice rub.

Heat 1 tbsp oil in a large sauté pan or skillet over medium-high heat. Add the shrimp in batches and cook on each side until nicely seared and the shrimp are pink, about 3 minutes per side. Remove the shrimp to a plate and set aside. Wipe out the pan if it is watery from the shrimp. Repeat with the remaining shrimp until all are cooked, adding more oil, and adjusting heat as needed.

Serve the salad, accompanied by the shrimp, peanuts, and lime wedges in separate bowls and let guests dish up their own plates.

AVOCADO GREEN GODDESS DRESSING
Makes 1⅔ cups

INGREDIENTS
2 garlic cloves
1 small shallot, roughly chopped
⅓ cup tightly packed fresh cilantro leaves
⅓ cup fresh basil leaves
⅓ cup chopped fresh chives
⅓ cup lemon juice
2 tbsp lime juice
2 tbsp olive oil
⅓ medium avocado
2 tsp apple cider vinegar

ANALYSIS
Calories: 35
Carbohydrates: 2g
Total Fat: 3.2g
Potassium: 51mg
Sodium: 2mg
Phosphorus: 8mg

DIRECTIONS
Put the garlic, shallot, cilantro, basil, chives, lemon juice, and lime juice in a blender (or food processor) with 2 tbsp of the olive oil and puree until smooth. Add the avocado and vinegar and blend again until well combined. Add the remaining 1 tbsp olive oil as needed to get your desired dressing consistency.

Store in an airtight container, with a little water on top to prevent browning, in the refrigerator for up to 4 days. Pour off the water before using.

HARISSA HOT SAUCE
Makes 7½ cups

Most store-bought hot sauces will contain more than 100mg of sodium per 1 tsp. But you can harness the same heat with the help of dried chilies, fresh chile peppers, and a blender. And by having this sauce on hand, you can quickly spice up any summer dish, from a pasta salad to grilled skirt steak to roasted asparagus. And don’t forget about a DIY pizza, burgers, or taco night!

INGREDIENTS
1 dried ancho pepper (or chipotle, pasilla, guajillo)
2 red bell peppers
2 tbsp lemon juice
⅓ cup canola or olive oil
1 tsp ground cumin
⅓ tsp salt-free garlic powder
2 tsp fresh lemon juice
1 small shallot, roughly chopped
2 garlic cloves
¼ cup canola or olive oil
2 red bell peppers
2 tsp lime juice
1 small shallot, roughly chopped
2 garlic cloves
¼ cup canola or olive oil
2 red bell peppers
1 small shallot, roughly chopped
2 garlic cloves
½ tsp paprika

ANALYSIS
Calories: 331
Carbohydrates: 1g
Total Fat: 2.8g
Potassium: 17mg
Sodium: 0mg
Phosphorus: 5mg

DIRECTIONS
Put the dried chiles in a small heatproof bowl and pour boiling water over them, just covering them. Let soak for 30 minutes.

Meanwhile, preheat the oven to broil and line a baking pan with aluminum foil.

Cut the bell peppers in half and remove the stems and seeds. Lay the pepper halves in the prepared pan, cut-side down. Broil the peppers until the skin is charred, 15 to 20 minutes. Remove from the oven and, using tongs, put them in a medium bowl. Use the foil pan liner to cover the bowl and let the peppers steam for about 15 minutes. When cool to the touch, use your hands to remove the charred pepper skins and discard. Set the peeled peppers aside.

Drain the rehydrated chiles, and reserve the soaking liquid. Use a knife (and wear gloves) to remove the stems and seeds. Put the chiles and bell peppers in a food processor (or blender), and add the lemon juice, canola oil, cumin, garlic powder, ground coriander, and 2 tbsp of the chile-soaking liquid (or add more if you want it spicier). Blend until smooth; add a little water, as needed, for the desired sauce consistency.

Store in an airtight container in the refrigerator for up to 7 days.
For the first time ever, patients with chronic kidney disease were at the forefront of deciding national research priorities. This past April, the National Kidney Foundation’s Patient Centered Outcomes Research Stakeholders’ Conference brought together 100 patients, caregivers, stakeholders, and academics to identify patient-centered research priorities—and challenges—for kidney disease.

Many patients have never been involved in research. Even those that are interested often don’t know where to start. The goal of the conference was to identify barriers to patient’s involvement in research and start brainstorming how to address and overcome those barriers.

“Over the last few years, research with patients and caregivers as active members of the research team has become increasingly important,” said Teri Browne, PhD, associate professor at University of South Carolina College of Social Work. “But unfortunately, there’s been limited growth of such methodology in kidney disease research and very few studies that actively engage patients in the development and execution of kidney disease research,” added Dr. Browne, who will serve as project lead for the Stakeholders’ Conference.

The Stakeholders’ Conference was facilitated by both a patient and researcher and featured patients, caregivers, and researchers on a panel discussion and breakout groups. Attendees gained insight into the experiences of patients, caregivers, and researchers, learned more about the importance of patient centered outcomes research (PCOR), and identified best practice strategies for actively engaging patients in kidney disease research.

As part of NKF’s commitment to the Stakeholders’ Conference, the Foundation will provide a minimum of $40,000 towards funding a 2018 Kidney Disease Patient Centered Research Grant. The grant will focus on the top kidney disease priorities identified by patients at the Conference. The Stakeholders Conference is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award.

In addition, NKF hopes that many projects, resources, and research opportunities grow from this conference and that discussion will continue among all stakeholders. We asked our readers to give their feedback too! See the following page for responses. Join the conversation online at kidney.org/kidneyliving