

The Keto Diet and Epilepsy...Let's Get to the Guts of It! Transcript

- Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, CURE.
- Kelly Cervantes: 00:18 On today's episode, we are joined by Robyn Blackford and Breanne Fisher from Ann & Robert H. Lurie Children's Hospital of Chicago. Both work in the hospital's Epilepsy Center where they advise patients on the use of the ketogenic diet as a treatment for seizures. Robyn is a registered dietician, while Breanne is an advanced practice nurse. As medical professionals, they work together to monitor patients' vitals and ensure they use the ketogenic diet safely.
- Kelly Cervantes: 00:43 Robyn, Breanne, thank you so much for coming and joining us today to talk all things ketogenic diet.
- Robyn Blackford: 00:50 Thanks for having us.
- Breanne Fisher: 00:50 Thank you for having us.
- Kelly Cervantes: 00:51 Of course.
- Kelly Cervantes: 00:52 I think most people understand a general-level ketogenic diet is high fats and low sugars. What does it mean more specifically than that?
- Breanne Fisher: 01:05 There is a classic ketogenic diet, and then there's the modified version of the ketogenic diet. I think what the definition of a classic ketogenic diet would be is the amount of fat to non-fat that is in that diet. What you're doing is calculating ratios of a ketogenic diet, so that the ratio of fat grams to the ratio of grams of protein and carbohydrate when added together, create this dose, in regard to the diet. The modified version of a ketogenic diet is a high-fat, low-carbohydrate diet where you do some carbohydrate counting so that you keep your diet within a certain amount of carbohydrate grams that still puts your body into ketosis, which is why we call it a ketogenic diet.
- Breanne Fisher: 02:11 It doesn't matter how you get there, in terms of the amount of fat to non-fat or carbohydrate in your diet. Each diet is going to get you to the same point. And that is being in ketosis and burning fat for energy instead of burning carbohydrate for energy, which is what our bodies normally do. When you eat enough fat in your diet and take down the amount of

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carbohydrate, then your body will be forced to burn fat for energy instead.

- Kelly Cervantes: 02:45 Which is why it can be used as a weight-loss diet as well.
- Kelly Cervantes: 02:51 I can't tell you how many times I've seen people on Facebook talk about their ketogenic diet that they're doing for weight loss, and my head starts spinning because I think of how much work we did for Adelaide when she was on the ketogenic diet. What is the difference there? Is it the extremity of it from one to the next? What is the difference between me just wanting to lose weight and doing a ketogenic diet versus Adelaide using it as essentially a prescription treatment?
- Breanne Fisher: 03:22 It is kind of a step in that direction. It's kind of the gold standard for treating seizures when it comes to diet therapy. With the amount of fat to non-fat, the higher the ratio, the more potent the diet. I think of it as if you are taking a certain dose of a medication, and you start at the lowest dose. That would be like a ketogenic diet at a lower ratio of fat to non-fat. So less fat, a little bit more carbohydrate, then the higher the ratio you get would be like the dose of your medicine increasing. We certainly have people who are on a ketogenic diet and don't calculate ratios, but they're counting grams of carbohydrate. That kind of a diet could be a weight-loss diet or even a diet that could be treating some other disease.
- Breanne Fisher: 04:34 In terms of treating seizures and people with epilepsy, we do like to do a classic ketogenic diet, which is where you weigh everything on a gram scale. For those who are familiar with doing those things, you go into the hospital for a 4-day admission, and you work your way up to that dose of the diet. When your body finally goes into ketosis, that's when we find it the most therapeutic. Where people with seizures could have some kind of reduction in their seizures, or have some seizure control, is when they're in ketosis.
- Kelly Cervantes: 05:22 You bring up something that I think is a slightly common misunderstanding. You mentioned that, when an epilepsy patient gets started on the ketogenic diet, they're going into the hospital to do it. That's a big deal because you're essentially changing the way your body burns energy, or you're changing the chemistry in the brain. Why do we have to go into the

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hospital? What, exactly, are the risks? What are you monitoring when the patient is in the hospital?

- Robyn Blackford: 05:52 There are many side effects to the classic ketogenic diet, as well as a ketogenic diet that somebody would use for weight loss. Part of the reason why we do the admission is to make sure that somebody tolerates going into ketosis. Not everybody will tolerate becoming ketotic, so we monitor that throughout their hospital stay, and even after they go home on the ketogenic diet. The patients that we start on the ketogenic diet, we do have frequent follow-ups, and follow-up on lab work as well as educating the parents about what to look for with regard to side effects. The main things that we look for in both their blood work, as well as what families report to us, is that the ketogenic diet can cause an acidosis in the body. If the carbon dioxide level goes low, somebody might not feel very well. They might have an upset stomach, with some spitting up or vomiting. Then it does put somebody at an increased risk for developing kidney stones, which is one of the things that we monitor very closely on the ketogenic diet.
- Robyn Blackford: 06:55 We also monitor something called carnitine, which is found naturally in the body. The diet can cause a decrease in carnitine levels, which help with energy. We often have to supplement with Carnitor when somebody is on the ketogenic diet. We also monitor cholesterol and triglycerides because of it being so high in fat. Our patients generally do very well with the cholesterol and triglycerides. You generally see an initial increase, but then those numbers level off.
- Robyn Blackford: 07:25 These are all things that we monitor very routinely for our patients who we put on the ketogenic diet. I don't think these are always monitored very closely for people who are just putting themselves on the diet for weight loss.
- Kelly Cervantes: 07:37 How often do you advise patients that they should be going in and meeting with the dietician and the APN?
- Robyn Blackford: 07:47 We have patients come and see us one month after starting the diet, and then every three months until they're stable on the diet. And we're getting lab work done at all of those appointments.

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- Kelly Cervantes: 07:57 Adelaide was barely eating by mouth. Essentially, we mixed baby food and butter together. For someone who is eating consistencies beyond pureed blends, what does a typical ketogenic meal recipe look like?
- Breanne Fisher: 08:13 In a classic ketogenic diet, that ratio of fat to non-fat is more important. We can actually use any food that a child likes in order to create that right ratio. Even if it is oatmeal in the morning for your child, then that amount of oatmeal is weighed on a gram scale according to recipes that the dietician gives them, and then we match the carbohydrate and protein amount in there with the fat source. Everything would be paired to the fat source.
- Kelly Cervantes: 08:49 When you're talking about that, just to clarify, a lot of the time it's like a 3:1 or a 4:1 ratio. So, you're talking about 3 units of fat for every unit of carb?
- Breanne Fisher: 09:01 Right, carb and protein added together.
- Kelly Cervantes: 09:03 Okay.
- Breanne Fisher: 09:05 Then, in a modified ketogenic diet, it might look a little bit more like eggs and bacon, sausage, with butter and cream on the side, just making enough calories so that the person eating it has enough to eat and isn't hungry.
- Kelly Cervantes: 09:25 You're talking, just to clarify, straight butter and straight cream that are just being consumed. I just want to make sure that people understand that, that you can have a tray and it's like mayonnaise, or...
- Breanne Fisher: 09:37 Yeah, yeah.
- Kelly Cervantes: 09:37 ... or just oil, and that you're just eating that straight as it is, like you don't have to put it on bread and then eat it with your bread. It's like, here's some butter.
- Breanne Fisher: 09:48 You can.
- Breanne Fisher: 09:48 You're mixing it in your eggs, or you are eating it as a side. What's nice about kids is they kind of eat whatever you give them, to a degree. I know there are limits to that, even in my own home, but they tend to really like their ketogenic diet, so

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you find the right foods that they really like. If they are good salad eaters, then maybe that is lunch. You have a Cobb salad kind of a lunch for them. Then your fat source can be an oil dressing. A lot of kids are used to drinking milk, so we just flip that and they start drinking cream instead of their milk. So it becomes their new keto milk, or some families just call it milk, and they know that they're giving them cream. It's still an 80-90% fat diet, regardless if you're using a classic ketogenic diet and weighing it on the gram scale or using a modified ketogenic diet where you're carb counting and adding extra fat.

- Kelly Cervantes: 10:56 I'm remembering it was important that Adelaide eat the entire meal. It wasn't just like you eat until you're full. Because everything is measured out, you really have to eat everything that's on that plate.
- Breanne Fisher: 11:12 Right. We're using grams worth of food, so you have to consume that many grams of that fat, that carbohydrate, that protein to make sure that your dose of the diet is correct, and that's what you're ingesting. If you're on a 3:1 ketogenic ratio, you have to eat your entire meal. The good news is you get more bang for your buck with the fat, so your portion sizes can be a bit smaller.
- Robyn Blackford: 11:43 It really fools your eye because you're looking at food and you're not thinking that that amount of fat has that many calories in it, but it really does. It takes up a lot of the calories that a person would eat, so you're really satisfied because you're eating those same number of calories that you're used to eating, but it just looks very different on a plate.
- Robyn Blackford: 12:09 Also, for patients who are tube fed, you can still do the ketogenic diet. It doesn't have to be on a plate. There are baby food purees that we can use, and there are ketogenic formulas that are available so we can use that for tube feeds for patients who are on the diet as well.
- Brandon: 12:30 Hi, this is Brandon from Citizens United for Research in Epilepsy, or CURE. If you want to know more about advances in our understanding of diet and epilepsy, tune in to our Epilepsy and Dietary Therapies webinar on June 13th, at CUREpilepsy.org/Diet.

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- Kelly Cervantes: 12:45 Are there ready-made meals for patients out there who are eating by mouth that make it a little easier to manage the diet? Or are you just in there with the recipes weighing it out and making the food?
- Breanne Fisher: 13:01 I think most of the time that's what our families are doing. I'm not aware of too many places where they can get ready-made ketogenic meals that are according to their ratio and the number of calories that they need. It's so very specific for each individual patient. They'd probably have more luck if they were on a modified version of the diet while still knowing how many grams of fat and protein and carbohydrate are in each thing because they're counting those things on a daily basis anyway. So, they could probably use those resources.
- Kelly Cervantes: 13:39 Just because they go to the grocery store and the label says 'keto friendly', that does not mean that when you're on the prescription diet at a specific ratio that is something you can use that is more for the modified version?
- Breanne Fisher: 13:53 Right, right, right.
- Robyn Blackford: 13:54 One of the benefits of the ketogenic diet being so popular right now for weight loss is that there are a lot of products being created that somebody on the classic ketogenic diet can't go to the store or order them online and just eat them. They still need to be calculated as part of the meal plan. There are at least options to incorporate some other things into their meals.
- Kelly Cervantes: 14:16 How do you know when someone is in ketosis?
- Robyn Blackford: 14:18 Ketone bodies can be checked through blood and through urine, so, whenever patients come in to see us in the ketogenic diet clinic, we will get their blood beta-hydroxybutyrate to see what the ketone level is in their blood. Routinely at home, they can check their urine for ketones. That's what we have them routinely check and report to us.
- Breanne Fisher: 14:43 Of course, it's more important for patients to find their level of seizure control than where their ketones are at, even though that is our therapeutic marker of how we know that a patient is on the ketogenic diet. There are some patients who don't go into ketosis who still have some seizure control. The only way we know how to prove that a patient is on the diet is by

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checking their urine ketones. Since seizure control is a priority, then we'll check and see if they're in a certain level of ketosis to see if it's at a therapeutic level.

- Kelly Cervantes: 15:27 I remember we had, when we were in-patient, a big training session about how to prepare to bring the keto diet home because it is a lot of work. We got our food scale, and we got all our menus about how to prepare the food. What are other ways that you help families prepare for what they're about to embark on, and what should people know about the diet in preparing the food, and how all that's going to go?
- Robyn Blackford: 16:02 I think it really starts with our initial clinic. We ask families to come in to be educated about the diet before they ever get admitted to the hospital. During that clinic visit, they might meet with a nurse practitioner, a dietician, and then a social worker. We really discuss what the diet looks like at home, and the barriers to the diet at home so that families can really start to get things in order to be prepared for the diet, even before their admission. Then, when they get admitted to the hospital, they have very intense education with the dieticians.
- Breanne Fisher: 16:37 During the admission, we have it set up where we have certain topics that we would talk about every single day. The dietician is part of the medical team that's in-patient, and then that person would go and meet with the family and do all the nutrition education that's required before discharge. They're not only doing all the education with the families and giving hand-outs and going through every single menu and gram of food that the child is eating. They're also thinking about once the family goes home, and how to set them up to be the most successful in doing that at home because this is not an easy diet to do at home. I think that it is helpful that they're thinking about it ahead of time. They know what to expect once they're in the hospital, and then we are helping them overcome any of those barriers once they go home, the things that they are most fearful of doing.
- Breanne Fisher: 17:46 We also have a social worker who works with our team as well. She is more than just a case manager and trying to get stuff for home, but also meets with families to see what it is that we can be most helpful in doing when families are ready to go home on the diet. That could be a variety of things. Maybe there are families that have more than one child, so they have to think

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about others when they're feeding their own keto kid. Maybe how to manage school issues along with the diet. Birthday parties or any kind of family event that's also going on, where they have to weigh all their food on a gram scale and take all their food with them. How do you handle all those things? Our social worker is helpful as part of our multidisciplinary team to be able to overcome some of those barriers.

- Kelly Cervantes: 18:51 It can be a lot of work. It is a huge change, but, if it works, I mean, it's worth it. Let's talk about that. What is the success rate? How often do you see this work?
- Breanne Fisher: 19:08 In all of the published literature since the 1920s, we see that the success rate of the diet is anywhere between 50-75% helpful for seizure control for all of the studies taken together. I think that, even when you try one medicine and a second medicine and a third medicine, that the percentages of seizure control and success with those additional medicines decrease and decrease and decrease. You will not see the same thing happen with a ketogenic diet. You will see that same 50-75% success rate.
- Kelly Cervantes: 19:55 Regardless of where you try it in your treatment plan?
- Robyn Blackford: 19:58 Right, right.
- Kelly Cervantes: 19:59 I imagine it's probably more common for people to come in to start the diet who are already on meds. Do you see people come off their meds? Have you seen people get full seizure freedom?
- Robyn Blackford: 20:11 Absolutely both. The best-case scenario is that somebody comes in and wants to start the ketogenic diet, we put them on the diet, and they become seizure-free and are able to wean off their medications. We'd leave them on the diet for about 2 years, check an EEG, and then wean them off the diet and have them go on and have a normal life without seizures. Certainly, more often than not, it's somebody comes in and they start the diet, and they've had either complete seizure control, or at least a good reduction in seizures, and are able to be on less medication than they were on previously.
- Kelly Cervantes: 20:48 Are there certain types of seizures, or certain ideologies for epilepsy, be it genetic or brain malformation or post-traumatic epilepsy that you have seen, either clinically or in research

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studies, against which the ketogenic diet can be more useful or more effective?

- Robyn Blackford: 21:09 With research, we are continuing to learn more about specific ideologies that the diet can be helpful for. For certain genetic conditions such as GLUT1 deficiency or pyruvate dehydrogenase deficiency, we automatically put those patients on the ketogenic diet. We find it to be very helpful for patients who have MAE, otherwise known as Doose Syndrome. We put those patients on the diet, generally very early on in their epilepsy course, as well as patients with infantile spasms, we tend to put them on early on in their course. Otherwise, anybody who's really failed two or more medications is considered a good candidate for the diet.
- Kelly Cervantes: 21:55 How long do you recommend typically that someone stay on the diet? Can you be on the diet for too long? How does that work?
- Robyn Blackford: 22:05 It really is all dependent on how useful it is for a patient. If we put somebody on the diet and they're doing very well from a seizure perspective, and they're tolerating the diet without side effects, we can have them stay on it for years. We've had patients on the diet for more than 10 years, as long as we feel that it's still helpful for them.
- Robyn Blackford: 22:29 On the opposite side, if we put somebody on the diet and we're really not feeling that it's helpful for them, or that they are having side effects, we try to get them back off the diet as quickly as possible, even within a few months of starting.
- Kelly Cervantes: 22:43 How does that look, to come off the diet? I remember we sort of weaned Adelaide off, similar to how we would to a pharmaceutical med, because it is still a chemical reaction that you are altering in the brain. Talk to us about what that weaning process looks like.
- Breanne Fisher: 23:02 It can be different for everyone, especially if a patient is having severe side effects of the diet, then we might want to wean the diet more quickly. There's no hard and fast rule about weaning, even in all of our consensus across the world when it comes to diet therapy. It could be slow, or it could be fast. There are some patients who might want to stay on it a little bit longer and have a longer weaning process, especially if the diet has

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been very helpful for them. Since we're kind of testing the waters, it's also like reducing a medicine. What is it really controlling? When we come down off that therapy, what's behind that door? We might go slowly to kind of see how the patient responds to being off the diet.

- Kelly Cervantes: 23:54 On the science-y side of it, how does it work? Why is this diet, why does being in ketosis, control seizures in some people?
- Breanne Fisher: 24:08 I think that's the million-dollar question.
- Robyn Blackford: 24:09 Million-dollar question.
- Robyn Blackford: 24:12 We don't really know exactly how it works. We have a lot of scientists working on this all of the time. There's a lot of research going into the ketogenic diet, and I think it comes back to the brain. It comes back to epilepsy, and that we don't yet have a cure for these things. So you have this therapy that you know is helping with symptoms of having epilepsy, and that is the seizures. But we also don't know how that is working. We can't predict who's going to be a good candidate for the diet, and who is going to be a responder. We have some good ideas, but we are not 100% accurate on it every time.
- Robyn Blackford: 25:04 Epilepsy could be genetic, or it could be inflammatory. Some of these things might be things that can be a target for the ketogenic diet, where you lower blood glucose. Maybe just stabilizing blood glucose could be helpful for seizure control. Maybe working on the hormones of the body, and sleep helps with seizure control. Some of those things that would trigger seizures, we think the diet kind of works with those things to make those symptoms of epilepsy a little bit better.
- Kelly Cervantes: 25:43 There could be one aspect of the diet that is controlling seizures for one person, and then it's a different effect of the diet that is helping another person? There's just no way to really know.
- Robyn Blackford: 25:56 Absolutely. And having so many different seizure types, too. There are different seizure types where it might work well but not for others. For every individual, it's so different and hard to predict.
- Kelly Cervantes: 26:11 It's a personal and hard-to-predict disease, so that sort of falls in line. Breanne, Robyn, thank you so much for coming and

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teaching us all about the ketogenic diet. We appreciate your time so much, and everything that you guys are doing for all the kiddos out there. Thanks.

Breanne Fisher:	26:28	Thanks Kelly.
Robyn Blackford:	26:32	Thank you.
Kelly Cervantes:	26:32	Thank you again, Robyn and Breanne, for exploring how the keto diet works for patients with epilepsy. If you want to learn more about the ketogenic diet, then check out the articles in the CURE news section, at CUREepilepsy.org/News . There you will find topics on the ketogenic diet and other research projects from researchers around the world who are working on finding a cure for epilepsy.
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