



Practical Tips & Tricks for Patients Preparing for Cabozantinib

I am Lisa Yen, Director of Programs and Outreach for the Neuroendocrine Cancer Foundation. And I support my husband who's also living with neuroendocrine tumor. So today I wanted to share with you some of the tips and tricks about Cabozantinib a medication that was just FDA approved in March 2025, and it's been coming up quite a bit in our support group.

We discuss this almost every single week because people have questions about it. And for us, in my husband's treatment journey, this has come up. So, this is personal for us too. So, I wanted to share some of the tips and tricks that we've learned along the way. So, the top two resources that we found very helpful for us was number one, talking to a pharmacist, specifically an oncology pharmacist.

And so, for us, we talk to one through our specialty pharmacy and you can also perhaps find one through your institution or hospital, wherever you get medical care. We recently released a podcast episode on that, so you can listen to that and learn more about what an oncology pharmacist does. The second resource that we found really helpful was a free patient care kit from the manufacturer's website, so the manufacturer is Exelixis. You don't have to memorize that. You could just Google search the name of the medication. The brand name is Cabometyx (or Cabozantinib or Cabo) care kit or Cabometyx, and you should be able to find the website and sign up to get the free patient care kit.

Inside is a lot of helpful things. We found this to be hugely helpful and samples of things that you might need to help with side effects and symptoms.

So, I'll open it up and show you what's inside. So, one thing is that the medication can cause nausea so that it comes with some sugar free lozenges in different flavors.

So, in case you experience nausea, there's this. Also, diarrhea is a possible side effect. Again, not everyone experiences these things, but this is just in case. So, there's anti-diarrhea tablets already in this kit. And the other common thing is hand foot syndrome so your hands and feet can get red and painful.

So, there's this urea base cream called Utterly Smooth. And there's a sample size in here. We like this so much that we got larger, bottles of this. And it is a really nice cream that is made for rough dry skin and it's not really greasy and it's pleasant to put on. So especially putting it on at night before you go to bed is a reasonable time to put it on.

So those are the things that come in the kit in terms of samples. And then there's also some information in here. So, information's helpful. Information about the medication, information about side effects and tips of how to manage the side effects, and also a treatment journal so you can, keep track of information and keep track of how you feel while you're taking the medication. And also a handbook as well. So, these things are really important. Really tracking your symptoms is super important because things can change and it changes day by day and we may not remember it. And the most important thing that we found in taking this medication is communicating with your healthcare provider.

And it's really important to meet with them, to talk with them, to tell them how you feel and they wanna know how you feel because there might be a need to adjust the dose or to, do something to manage the side effects or to take a break from the medication. So, a lot of this is in the open communication, so keeping track of how you feel is super important.

And there's, there's a place here in the treatment journal to track your symptom date, who you spoke to and their recommendations. So, things like this is really helpful. And there's also another resource called Be Connected. They also offer a support program designed to help with other educational information while you're on the medication. So those are the resources that are available in this patient care kit and through the manufacturer's website, which we found really helpful.

Now, some of the other tips and tricks that were provided to us by the pharmacist included other things that might be helpful. One big thing is that a major side effect might be that it changes your blood pressure, namely it could increase your blood pressure. So they told us to take your blood pressure every day, usually the same time of the day, preferably in the morning.

And so, we got a blood pressure cuff. And again, you can track that in your treatment journal and it's important to write that down and also know what the parameters are of when you should call your doctor. Some people complain of dry mouth or mouth sore so you can get

over the counter oral rinse, Biotene to help rinse out your mouth, usually before eating, and that might be helpful with any mouth dryness, mouth sores, or anything like that. Another thing that we found is that it can affect your voice and it can cause a hoarseness in the voice. So again, if that happens, it doesn't happen to everyone but talking to your doctor about that.

The pharmacist also told us when not to take the medication, and also what not to take it with. So, it's important not to take it, don't take it with grapefruit juice or grapefruit or grapefruit like products. I think the most important thing that was helpful for us was what time to take it and how to take it.

So, it's important to take the pill whole and not to chew or crush or dissolve the medication. And they told us to take it an hour before eating or two hours after eating. So, it has to be beyond an empty stomach an hour before eating, or two hours after eating, and the same time every day. It didn't have to be at a specific time of the day.

And then they told us if you missed a dose. Making sure that if you miss it for more than 12 hours, just to skip that dose, but making sure you're taking at the same time every day was the most helpful. So those are our tips and tricks. And again, I think the most important thing for us was to be noticing and to be tracking the symptoms and to have open conversation with our doctor.

And really to let that be a conversation. And I hope this will be helpful because I know that anytime that anyone starts a new medication, there's a lot of anxiety because of the unknowns. And hopefully this will help demystify that a little bit for you as it did for us.

Thank you so much.