Hadley

Getting the Most Out of Your Eye Doctor Appointments

Presented by Ricky Enger

**Ricky Enger:** Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, we discuss strategies for successfully managing appointments with the eye doctor, and our guest is Judy Box. Welcome to the show, Judy.

**Judy Box:** Good morning.

**Ricky Enger:** So, delighted to have you here. We've had discussions on this show from the perspective of various eye specialists, like what kinds of eye conditions they treat and what you might expect during an exam, but what we haven't done yet is to talk about things from the perspective of the patient who's walking in and looking for answers and might be feeling a little bit vulnerable or uncertain about things. So, I'm delighted to have you here so that we can just kind of talk through some of those strategies that people might use to make sure that their needs are being met during appointments like this. Before we get into that, why don't you just tell us a bit about yourself, your background, and maybe a bit of your vision loss journey, if you're comfortable with that.

**Judy Box:** Sure. I grew up in Australia, rural Australia with 6,000 sheep on a farm that's still in the family for the fifth generation. Then went to boarding school, and then medical school in Melbourne, and came to the United States in 1972. Practiced medicine for 45 years, married twice, widowed first time, remarried six years ago, bunch of kids, step kids, grandkids, all the rest of it, enjoying life. I got macular degeneration about two years ago. My mother had it, so I had anticipated that that might be my future. And the symptoms first became very noticeable about two years ago. A year later, it went into shots, and I've been getting shots in both eyes now every month for a little over a year. So, there we go.

**Ricky Enger:** Like it or not, it sounds like you have had a number of experiences going to these eye appointments, whether accompanying your mother to them, and then certainly going yourself. So, as you are heading into an appointment like this, do you think it's a good idea to take someone with you, someone who could be an advocate, friend, family member, that kind of thing?

**Judy Box:** Yes. Yes, there is. But let me just phrase that a little bit. If you're going into an appointment with a doctor for a condition that's chronic and you already know what's going on, no, you don't need to take someone with you. But a first appointment or something new, and particularly if you're feeling anxious about what the something new might be, yes, I really do recommend taking someone with you. And if you've got a family member or a friend who has a medical background and speaks some of the language the doctors are using, that's a huge help. Nurses are gold. If you have a daughter, a niece, or a neighbor who's a nurse, I really suggest that one.

**Ricky Enger:** And do you think people who come in with you, what purpose do they serve beyond just another set of ears? Are there other things that they can do during that appointment for you?

**Judy Box:** Yes. In fact, I go with neighbors to doctors sometimes, and what I do is just keep quiet. And then if there's something I don't understand, I ask the doctor to explain it to me, and then I can help the patient afterwards if there's something they don't understand. But we don't need the accompanying person to be butting in and being difficult and asking lots of questions. I think the appointment belongs to the patient, but the second pair of ears is really helpful for clarifying things. And sometimes you'll notice that the person you're with didn't understand. You recognize the puzzled look on their face, or they lean forward as though they didn't understand something that would be a prompt for the accompanying person to ask a clarifying question too.

**Ricky Enger:** Right. That makes sense. And it actually leads quite nicely into my next question, which is that sometimes these appointments are not very informative for whatever reason. Either the doctor is talking in a bunch of technical jargon that you don't get, or they're just saying very little and assuming a lot of knowledge on your part, or any number of things that can happen. How do you cope with feeling overwhelmed and having so many questions during an appointment like this? What are some strategies you can use?

**Judy Box:** It's a bit different if it's a first appointment, or if suddenly you've got something told to you that you weren't anticipating because you can't be ready for that. But let me talk more about what goes on perhaps in the next appointment. I wanted to know what does this diagnosis mean for me, and what can we do about it? Because all the jargon described to me what's going on behind the eye and blah, blah, blah, tends to be foreign to most people. And perhaps I'll stick with macular degeneration just as an example, but what I'm saying would apply to other people too. Well, the doctor I've got now was wonderful. He used language that I understood. And then when he got into the weeds, which is my language for he's getting into language I don't understand, he flipped to using common language. And I think it's important, there are times when he'll use a word and I'll say, "I don't know that word." So, he uses a different word. I think it's important to ask the doctor, "I'm sorry, that's a word I don't understand."

**Ricky Enger:** Right.

**Judy Box:** There's nothing wrong with that. They can then rephrase what they're describing. Then the important stuff we need, particularly in vision loss, is what do I expect for the rest of my life? In my situation, he said, "These shots should keep you with your vision the way it is now." I said, "Well, okay, I've adapted this far. I can live with that." Well, it turned out it didn't stay that way. It got much worse, and then it got better, and blah, blah, blah. But it's important to ask those questions because we have to plan life. Just being told, "Well, you've got this problem and it's going to affect your eyes for the rest of your life, doesn't tell you, am I going to be legally blind sometime? Should I learn now to use voiceover, so that I'm ready for it? And in fact, at that point, you've never even heard of voiceover. And a huge problem in this industry is there's no rehab. There's no good support one-on-one for people new to vision loss.

If I had a stroke, they'd have an occupational therapist in my house next week. But with vision loss, I'm cutting my fingers, my husband's promising to buy stock in Johnson and Johnson because we're going through so many band-aids, I can't see the screen on my iPhone. The doctors are of no help with that. They really aren't. Hadley is way more help with that, and Hadley now has a peer-to-peer program that I recommend people new to vision loss try and get involved with. Doctors aren't going to be much help with that.

**Ricky Enger:** Yeah, that's something incredibly common, unfortunately, that we hear, is you walk into the doctor's office, and they tell you what's going to happen or what they believe is going to happen, and then wish you luck and send you on your way.

**Judy Box:** Yeah.

**Ricky Enger:** It's not so helpful. So, it's essential that people find not just what has happened and understand the technical side of things, but then what do I do from a practical standpoint next?

**Judy Box:** I have a couple of other little things on that too. When I go back to the doctor, I have questions. I write them down and try and organize them in a way that I'm not asking five different questions, three of which are much the same. Try and make it simple.

**Ricky Enger:** Right.

**Judy Box:** I pay attention to the pace. Some days I go to see my doctor and I can tell he's super, super busy. The waiting room is packed. So that's the day when I might postpone my question to the next appointment. And remember, I see him every four weeks. So, if you see him once a year, it's a different story. Then the first thing I do when he comes in and says, "Good morning," I say, "Good morning. I have a couple of questions for you today," because that lets him know to budget a little bit of time for my questions rather than losing it now in chitchat. Now sometimes, he will just sit down, "Okay, let's have it." Other times, he's numbing the eye and he's coming back for the shots a little later. "I'll address that when I come back later." But giving him the warning that I want some time, I think is gold. Otherwise, you're at the end of an appointment. He's already got his brain on the next patient. "Oh, and by the way, I want you to explain X, Y, Z to me," that's not a good starter.

**Ricky Enger:** Yeah. What about the other people in the office? So, you might see a nurse or technician, and typically you might have a little more time with them than you do with the doctors. Where do they fit in? Are there things that they can do that maybe the doctor is not best suited for?

**Judy Box:** That varies widely. In family practice, the nurse gold. In my experience with the ophthalmology people, first, I see a technician who asks for medication changes, asks, "How's your vision going?" Checks the eye chart and puts drops in the eyes and checks for glaucoma. She's a technician. She's not going to know the answer to most of my questions. By all means, you can ask, but don't expect a whole lot. The next person in the pipeline, for me anyway, is the fellow or the girl who takes pictures of the back of my eye. And sometimes when I've asked them questions, I get the answer, "Oh, you're going to have to go over that with the doctor." Just this last week, I asked a question, and the technician not only took time to explain it to me, but he showed me on the pictures in a way that I understood what was going on, but that's the first time I've ever had that experience.

Then after that, the nurses come in and do the initial shots and some of the more significant eye drops. That's an opportunity to ask some questions. But because I have a good relationship with my doctor and we speak the same language now, I haven't asked many of those questions of the nurse. I asked the nurses more practical questions, and frankly, they don't know. They've never had a problem cutting their fingers because they can't see where their fingers are. So, they really have no clue, and they're embarrassed about that. And that's another time to recommend they tell people about Hadley. I haven't found a nurse yet get permission from the administration to do that. That's the most frustrating part about all of this.

**Ricky Enger:** Yes, indeed. And sometimes there's a lot frustrating about the whole situation, and in fact, maybe things just are not working with your doctor, and that can be problematic, especially if you are seeing a specialist and there aren't too many other options for you. But do you have thoughts about how to navigate this? How do you decide when you should go through switching to another doctor? And then if you do make that decision, that opens up a whole new can of worms. So how do you navigate that with the new doctor?

**Judy Box:** I did all of that. And let me just tell you my story because it's pretty poignant and pretty distressing. I was referred to a retina specialist, and the first thing I told him was I'd heard about this little gadget called Foresee that could help know when my macular had become wet. He ordered that for me. I had two weeks to get a baseline set up in the machine, and it was already too late. I had too many wavy lines already. When I went back to him the second time, he was very brusque. He spent all of two minutes. And as he left the room, I said, "Oh, by the way, Foresee couldn't get a baseline." And he said, without even turning around, he said, "Well, some people just need more practice and kept walking."

**Ricky Enger:** Wow.

**Judy Box:** I won't use the words that went through my brain at that time, but I thought, "You," fill in the blank, "you know I thought this was important to me. You know I'm worried about my eyes turning wet. This machine was supposed to help me, and now you're telling me I'm too stupid to spend more time with it?" So that was enough for me to switch to a different doctor in the same practice. My husband's first wife who died some years ago had an eye operation by a different doctor in that practice, and that woman was no better. My left eye has barely any vision left in it at all. Meanwhile, they recommended shots in both eyes, and I didn't know why. And so I said to her, "Why are we doing shots in the left eye?" "Well, if you don't want shots in the left eye, you don't have to."

I said, "No, I just want to know what the goal is doing shots in the left eye." "Well, I can tell you if this was my eye, I'd want shots in it." Now, that was only about the fourth round with this woman. So I decided, okay, I am done with this practice. And here's the important point here. This relationship with an ophthalmologist is the rest of my life, and I need to be comfortable with whoever I'm going see. So that's my story on why I switched. It so happened that a friend of mine was about to have a very dangerous eye operation with the doctor she'd been seeing for a long time, and she thought he walked on water. And her descriptions of his behavior and his relationship with her and all the rest of it were enough for me to figure out, "I'll try with this guy." And he happens to be at Ohio State University. He's very good, and I'm very satisfied there.

So that's my answer to that. Now, how do you go about finding a new one? The same way I did. Ask around if you know anybody. Ask your family doctor, your family doctor might know someone. Or if you were referred by a general ophthalmologist to a specialist, ask the general ophthalmologist or the nurse in the general ophthalmologist practice, "Can you recommend somebody else? I'm not liking what I'm getting from the place you sent me to first." There's no right way to do this. There's no guaranteed outcome because we're really talking about personalities. But those would be my suggestions.

**Ricky Enger:** And what about when you go to that appointment with the new doctor? It can be tempting maybe to tell your entire history or to just tell a little bit and let them read the rest. What do you do?

**Judy Box:** I don't think it helps to go into a new doctor badmouthing the last one. In fact, I don't even know if he asked me why I was switching, but if he had... Actually, I did. I said, "I wasn't comfortable there," and he named the practice. So, he must have had other people come to him who had come from that practice. Now over time, bit by bit, I've told him some of those stories just because they're relevant to a chitchat we are doing, but you don't gain much by badmouthing the last guy. Besides, this is, again, a personality thing, and it may be you are the one who's difficult.

**Ricky Enger:** Yes. So, when you are looking for a specialist or you're looking for just a number of people who you can interact with, who can talk about the medical side and maybe some of the practical side, what do you think about teaching hospitals? There are certainly more people that you deal with in a teaching hospital. Is that a good or a bad thing?

**Judy Box:** Neither. Teaching hospitals, the professors tend to be more up to date with the latest research. And if you're interested in getting into research protocols, you've got quicker access to that. But you can follow the Foundation Fighting Blindness too, and they'll let you know what research is going on. I'm not a fan of having the latest treatment. I never prescribe the latest drug to my patients. I've never taken the latest drug. I leave it on the market for a while and see how it really shakes out. I do trust that the specialists you're seeing are staying up to date in their specialty. I don't expect a retina specialist to know anything about hemorrhoids, but I do expect them to know about the retina. So, I don't think there's an advantage or disadvantage. I occasionally see a fellow. Ophthalmologists do medical school, then they do ophthalmology, then they do a fellowship, which is a specialty. And by the time the fellow is learning how to deal with my macular degeneration, he or she already is a qualified ophthalmologist.

So, I'm quite comfortable if occasionally, my doctors backed up and the fellow is giving me the shots. They know how to give shots. They're not green. So, you see more people. But frankly, in my conversations with the fellows, I tell them more than they tell me. I give them an earful about my frustrations, that the ophthalmologists don't know anything about how to live with these disabilities, and they listen. And some of them are very interested, and one even wanted to have me come in and teach fellows, but it never happened. I don't understand why these outfits just don't want to learn this stuff. I don't get it.

**Ricky Enger:** Yeah, it makes very little sense. And as I said at the beginning of the episode, it's a common thing that happens. People go in and it feels like a one-way communication. The doctor tells you what they deign to tell you, and they're not necessarily always interested in learning something from you, which is unfortunate.

**Judy Box:** Yeah. By the way, there is another thing to remember here. All my doctor can do is look at the pictures and determine how frequently I need the shots, and he can tell me what to expect from those shots. He can't predict accurately what's going to happen with the rest of my eyesight, and he really doesn't know the answers to how do you stop chopping your fingers? But I think it's important to understand the scope and the limited scope of what your doctor can do. Because when I first went in, I thought, well, this guy's the miracle worker. My friend said he was. And I was expecting him to be able to do things that he can't do. We don't know how to do those things yet. It's important to clarify that.

**Ricky Enger:** That's a great point. We've covered quite a lot, I think, but is there anything that we haven't touched on that really is important for somebody who is trying to get their needs met and successfully navigate these appointments and might be struggling a bit?

**Judy Box:** Yeah, I've got a couple of tips here. One of them is the use of the word hallucinations. Most of us see things that aren't there, and most of us know we are seeing something that's not there. Understand that that is a hallucination, and it has nothing to do with being crazy. I practiced psychiatry for 45 years, and I can tell you I am yet to see a patient who has hallucinations as part of a mental illness except PTSD. But one day, I was sitting at my desk, and I saw what looked to me like a bunch of snakes swimming around in a babbling brook running with milk. When I mentioned that to my ophthalmologist, he said, "Did you have a headache after that?" And I had to think about it for a minute. And I said, "Yeah, I did, a couple of Tylenol worth headache."

He said, "That's an ocular migraine." Okay. Well, I've talked to other friends who have had visual hallucinations, and they're terrified to tell the doctor for fear they're going to get shipped off to a psychiatrist. Just stop and think for a minute. I'm worried about why I'm seeing snakes swimming in milk and my doctor answers that question. And if it happens again, don't worry about it. It happens. I'm relieved. I'm not worried. I'm not scared. I'm not going crazy, and I'm not scared. There's something horrible happening with my brain. Hallucinations do not equal you’re crazy. Okay? A psychiatrist just told you that. There's another thing I wanted to talk about, and that is doctors saying, "Call us if anything changes." That's where I really got into trouble and basically lost functional vision in my left eye. The first practice had given me a very nice handout, which described dry macular degeneration and the symptoms of it.

The most common way to know if it's become wet is if you're seeing wavy lines. Well, I did a lot of research online and understood what dry macular degeneration is and what the symptoms are, and so on. In the meantime, I ask a fellow. The fellows will sometimes stop and chat with you, and they can be good at answering questions. But I asked a fellow, "How do I know when to panic? So far, I'm getting vague information. I don't know when I should really panic and make a phone call." He said, "Oh, you'll know. There'll be a big black hole in your central vision." Well, for a start, that's not true, and that's another problem. But anyway, some months later, I noticed while I'm reading the paper on an iPad, my vision's really not as good as it was yesterday. And over time, it got worse.

I kept checking the research I had on what dry macular degeneration looks like. It's all consistent. I've been seeing wavy lines for two years, so that's not relevant. I don't have a big black hole. So, I waited almost two months for a routine appointment, and then got hell because I should have come in when this changed. Well, if I go outside on a sunny day, I can't see my iPhone. That's a change. So, what do you mean by if something changes? So, here's my suggestion on this. Figure it out for yourself. What is your baseline? For me, if I'm reading the morning paper, I can read the text without any trouble, I can increase or decrease the font if I need to, I can do all the things to the screen that you already know from Hadley, changing background colors and all that sort of stuff.

Now, I know my baseline. And every day for months and months and months, I read the paper. Same time of day. Same lighting. I've just had breakfast. I've just had a good night's sleep. But when that changes, that's a change. So, I'd encourage everybody listening to this to figure out what is normal for you in a stable setting, and then pay attention to it. And if it changes, call. Missing that cost me my functional vision in my left eye.

**Ricky Enger:** Absolutely. And I appreciate your description of not just finding a baseline, but how to do that. So, starting from a point where your routine is consistent, you have a consistent thing that you pay attention to each day, and then you can figure out what's deviating from that.

**Judy Box:** Right. If something has changed and you call in, say my example, I have been able to read the paper every morning on my iPad, and today I can't,-

**Ricky Enger:** Right.

**Judy Box:** ...that's the difference. Saying, "I can't read the iPad," doesn't tell them anything. What's normal for you?

**Ricky Enger:** Yes. That makes total sense. And anything else you want to add before we wrap things up?

**Judy Box:** Ask your doctor, "What do I do if I have an emergency? Where do I call? What about the weekends?" Because if you don't know the answer to that question, you might have a problem on Friday and put it off till Monday.

**Ricky Enger:** And that might be too late. Yeah.

**Judy Box:** Here's another example. I was sitting in the bathtub 20 years ago and realized with one eye closed, I couldn't see the faucet at the end of the bathtub. I waited till the next morning to call the ophthalmologist. And when I went to see her, she gave me all sorts of grief. It was a stroke, and it didn't matter that I'd waited till the next day. And she said, that might've been a retinal detachment, and that would've been a big deal if you'd waited till the next morning.

**Ricky Enger:** Right. So just being vigilant about those things and have an idea of what to do in an emergency.

**Judy Box:** If something changes, I can't see the faucet with my left eye closed, that's a change. And by the way, when you're testing your eyes, check one eye at a time, because with two eyes, you'll always see better than with one eye.

**Ricky Enger:** Right. That makes total sense. All of this has been incredibly helpful, Judy. I know that people who are listening are experiencing some or all of this in their own doctor's appointments, and I think that just having some of these strategies to what to do when something happens, it helps to have something in your back pocket to say, well, if this happens, I know what I can do next. It just makes things easier for people. This has been very, very helpful. Thank you so much.

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