

BrightFocus[®]

Chats

Living with AMD: A First-Hand Perspective

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Transcript of Teleconference with Jill Adelman from New Jersey and Liz Tully from Toronto, Canada.

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Please note: This Chat has been edited for clarity and brevity.

MICHAEL BUCKLEY: Hello, I'm Michael Buckley with the BrightFocus Foundation. Welcome to today's BrightFocus Chat, "Living with AMD: A First-Hand Perspective." If you're not familiar with the BrightFocus Chats, let me briefly tell you about what we do. BrightFocus funds researchers all around the world that are trying to find better treatments and, ultimately, cures for macular degeneration and glaucoma and Alzheimer's. We want to share the latest news about these diseases and how to best manage them with our audience. That's why we put together the BrightFocus Chats. Also you can find a wide range of materials at our website, www.BrightFocus.org, where you can learn more about research that's going on in macular degeneration. You can learn tips about how to live well with these diseases and questions to ask your doctor and all sorts of information - just liked like we try to do on the Chats.

Now, let me tell you about today's guests. We have two people with us

today to give a first-hand perspective on living with AMD. We have Jill Adelman from New Jersey and Liz Tully from Toronto, Canada. This is a great opportunity to get a first-hand perspective on AMD and ask some questions about how they navigate daily life and vision health. With that, Jill and Liz, thanks so much for joining us. Let's start. Jill, can you just introduce yourself and tell us how you became active on AMD issues?

JILL ADELMAN: My name is Jill Adelman. I'm from New Jersey, and I was diagnosed with wet macular degeneration in 2014, and it changed my life. And I was looking for any information that I could gain, and quite honestly, my husband found the BrightFocus website that I did gain lots of information from early on, and it's important to me to get the information out to anybody else that's afflicted with this disease. So, I enjoy speaking with people and answering questions.

MICHAEL BUCKLEY: Thanks, Jill. Liz, would you like to introduce yourself?

LIZ TULLY: My name is Liz Tully, and I am from Toronto—born and brought up in the West Indies, moved to, first, the States, and then Canada. I'm approaching 80. I had a very different experience than Jill when I first got AMD, but like her, I am very committed to trying to help as many people as I can who's got this illness.

MICHAEL BUCKLEY: Several questions have already been submitted about that initial diagnosis. I was wondering if one or both of you could comment on: What did it feel like? Did you have fear or sadness? What were your emotions upon learning that you had macular degeneration?

JILL ADELMAN: I can start if you'd like. This is Jill.

MICHAEL BUCKLEY: Sure.

JILL ADELMAN: When I realized that there was something going on with my eyes and I got to an ophthalmologist, and he very

calmly explained to me that there was fluid and blood behind my eyes—and that’s what was causing my difficult vision—and that he was going to give me needles in my eyes to hopefully restore my vision. At the time, I was a registered nurse in a very high-volume trauma center, and I felt as though my life—my future—was over. I didn’t understand, nor was it ever explained to me in any detail, and once they told me what was going on and how the treatment was going to be, I heard nothing more. My husband was with me, and we were both in a state of shock, not knowing what was going to hold for the future.

MICHAEL BUCKLEY: That’s very powerful. Liz?

LIZ TULLY: I have to say that my experience was very different, and I’m very fortunate it was. I had an early warning that I might get macular degeneration, so I was on the [inaudible] for being aware that I needed to keep on top of how my eyes were progressing. So, when I got my initial diagnosis, it was in a very early stage, and, in fact, I was experiencing nothing. So, I was able to accept it quite calmly, and it carried on at that pace for a number of years. I’ve had macular about 16 years now, but my reactions were certainly different, as you would expect, when first I heard that I had wet AMD in one eye. And again, I was very fortunate because I knew my doctor well by that time. I had a lot of confidence in him. We got along well. So, after ... initially just, sort of, matter-of-factly saying, “Well, you know, you’ve got some leaking blood vessels in that eye now.” He went on to say, “I can give you your first injection now,” and then when he saw the fear streaming out of my eyes, he gave me just this little pat of reassurance on the shoulder. “I understand,” he said. “Well, maybe I’ll just give you a booklet on it and the treatments today, and then you can come back next week.” So, it was certainly different. It was certainly very upsetting, but again, I was experiencing nothing at the time, so I didn’t have that trauma on top of it all. But I did have that trauma when my left eye instantaneously went GA. I was looking at a recipe one second, and all of a sudden, I turn my head and I look back, and all I could see was a sea of gray. Again, I was

absolutely terrified. I had no expectation that it could go that fast, but I was able to reach my doctor. It was on the weekend—the very first weekend before the pandemic shutdown in Toronto. He...I described my symptoms to me ... to him. He told me he wasn't worried. So, I replied, "Well, if you're not worried, I'm not worried." But I was terrified. And he was able to see me the next week, and that's when I heard that what had happened, that other eye had not gone wet, but the geographic atrophy had killed off a number of photoreceptors in the center of my eye. But by that time—again, so lucky—my eyesight was already beginning to improve a bit, and when I asked him how that could be possible, he told me it was all about the brain, and my brain was already trying to adjust for my new reality. I don't see as well now as I did before that incident, but I certainly see a whole lot better and a whole lot better than anyone would ever imagine based on the fact that I do have advanced macular in both eyes for different reasons.

MICHAEL BUCKLEY: Thank you, Liz. Liz and Jill, I've been fortunate to get to know you through the BrightFocus Foundation, and I know you've a lot of experiences with eye doctors and navigating the health care systems in your respective countries. I was wondering if each of you could offer, maybe, two of three tips that you've learned—either the easy way or the hard way—along the line on how to make a doctor visit go as well as it could? So, would one of you like to start off?

LIZ TULLY: Jill, do you want me to start this time?

JILL ADELMAN: Sure, go ahead, Liz.

LIZ TULLY: I took a very broad perspective in the whole thing, and I guess my tips would be, first of all, know yourself. Know your nature. Know what you're comfortable with. Know how you would feel most comfortable approaching a doctor. The other one would be, for me, be prepared. For me, it's just so important because I want to feel that my ask is reasonable and that I am reasonable. And so, I try to do as much prep as I can around what might be the

difficulties and how I can address them. The next one would be, Be comfortable. And by that, I mean as well as taking a comfortable approach and being prepared, it has to do with the environs you're having that conversation. Because my experience has been—and I know it's of others—is when you want to ask your doctor a question, the only time you're ever given when you ask that way was a few minutes after you've had an injection, which is not very conducive for the kind of conversation you might want to have. So, if you need a more in-depth one where you can see and feel relaxed, push for that. And I did actually do that recently, and I am getting an appointment that is separate from my eye injection. He initially was not very happy with it, but I think I found out why, and I've also given him a heads-up on why I'm asking what I am and why it's so important to me and why he's the guy who has to give me that information.

MICHAEL BUCKLEY: Jill, do you have a couple of pointers that you've learned?

JILL ADELMAN: From my perspective here, I think it's very important, number one, to be comfortable with your doctor, be comfortable with their processes. I, personally, had a conference before moving to this newest doctor beforehand. Being a medical professional, I need questions answered, and I need them answered when I'm asking them. And I needed to be sure that he was going to accept my way of getting my treatments. If I have questions, I want them answered, even if the answer is, "We don't know." And that's an okay answer. And that's important for people to understand, that sometimes the answer in this string is, "I don't know." The other thing is, it was important for him to realize that each and every appointment I want to see my pictures. I want to see the comparison from this month to last month. You're taking the pictures. They're of my retina, and I want to see how it is. And every couple of months, we also check to see if the GA is advanced. He has it on his computer. He clicks two pictures, and he needs to understand that I have questions, and I need communication. I can't do what I call the cattle shoots, where nobody talks to you—

they don't know who you are. It's also very important to know that if one procedure in getting your injections doesn't work for you, to let the doctor know because that can deter someone from wanting to go back, and the injections are so very, very important in wet AMD. Let them know because many times doctors can alter the way they do things to give you a little more comfort, but yet keeping you safe and keeping you non-infection because that's always the biggest concern. That's where open communication and advocating for yourself—because you are the patient, and you have that right—is so very important.

MICHAEL BUCKLEY: Thanks for the great tips. Along those lines, to Jill and Liz, a lot of us can feel pretty awkward either kind of quote, "breaking up," with a doctor or maybe asking for a second opinion. It's something that just ... for a lot of us just don't always feel that comfortable in those situations. Have you been in those situations? Do you have any tips for how people might either tell the doctor they want to see a different doctor or get a second opinion? I mean, do you have tips or experience that you can share with our listeners today?

JILL ADELMAN: I'll go first on this one, Liz. I have moved to ... four different times. I started at one location, and the doctor and I just did not get along. He didn't want to answer questions during my injection visit. He would walk in the room, say hello, didn't know my name, tell me, "Eat the rainbow. Shh, shh, shh. Put your head back, open your eyes," put the injection in, and out the door he would run. Even though I did continue going there until I found someone else, that was not the kind of treatment that I was going to get. And he only had to take over because the doctor that did my original diagnosis, who was as sweet as could be, became critically ill and could no longer practice. When I left that practice, I just left. I did not make another appointment. I found someone else, totally coincidentally. He happened to be on a news channel because of a very promising device that he had used on someone, and just listening to this doctor on the news, I called his office, asked a million questions, set up a consultation first—again,

I wanted to go talk—and he was the kind of office that I wanted to go to. So, I moved to him, and I remained with him for almost five and a half years until, unfortunately, he became ill. And that office I had the relationship with that I was able to say, “Listen, I’m going to go to such and such office first, and see how they are.” That office didn’t work out for me either because I didn’t like their procedure. I was down and out for the entire day after getting an injection, where I was used to getting my injections and going out to lunch, going food shopping, doing what I had to do. I went back to the office that I’d been to for quite some time and, again, had a consultation with the new doctor that was taking over the practice, and his practice was the same exact family—patient...just being so congenial to their patients and having the time. And that’s where I’m at now, and it’s very comfortable. So, your comfort is important but an actual break-up, nah, I just don’t make an appointment.

MICHAEL BUCKLEY: Liz?

LIZ TULLY: That sounds rather familiar.

MICHAEL BUCKLEY: Liz, your perspective?

LIZ TULLY: I have only had one experience and that was very early on, and it was when I had early AMD—actually, I was the one that diagnosed my condition. He kept talking about tired spots, and I finally asked him, “Are your tired spots what I know from what I’m reading are called drusen?” And he said, “Well, yes.” So, I said, “So I’ve got early macular?” And he said, “Well, yes you have, but don’t worry. Be happy because you’re doing all you can do—know that.” Now, in 2005—I’m almost 80 now—when that was first ... when I was first diagnosed, anti-VEGF treatments ... we didn’t know a fraction of what we know today, so he was basically just trying to help me feel good, and I didn’t like that because you can help a person feel good but still be honest with them. And so, what happened was I lost trust in his ability to tell me what I needed to know when I needed to do it. So, like Jill, I did not make another appointment, neither did they call me back. And by sheer

good luck, when I was having cataract surgery, the clinic I was in also had a retinal specialist, and it turned out to be the person I'm with now, and I do feel very relaxed and comfortable with him. The only thing I know I need to know now, and I know I need to do it because I have full faith in his clinical skills. And I also know he's basically a very nice person, but he is under a lot of pressure—time, family, all kinds of things, never mind the nature of the practice and the other things they do besides putting needles in people's eyes. So, bearing all that in mind, I have set up the appointment. I have given him a clue about what I want to know, and I do have faith that, going forward, he will give me what I'm asking for. I didn't ask earlier because this only became an issue after that huge experience that I had in the summer—or early, I guess, spring it was—and I didn't want to interfere with his processes while we were in the pandemic because I was just so grateful that he was still giving people all the eye injections that they needed. So, I waited for my moment, and it has come.

MICHAEL BUCKLEY: Thank you. Both of you were very helpful there about tips for advocating for yourself and taking a lot of the right steps. Related to that, I wonder if either of you have had experience with getting any type of services from a low vision specialist or vision rehabilitation. I know both of you are in different health care systems. I was wondering if either of you have worked with a low vision specialist, and what have ... if yes, what have they helped you with, or how would you describe that experience to our listeners?

JILL ADELMAN: I have. I say my low vision specialist saved my sanity. The person that I go to was able to come up with an appropriate prescription for me to be able to function—daily wear, driving-wear. She's an ophthalmologist ... no, she's not an ophthalmologist, she's an optometrist, and her specialty is low vision. She works for a large organization, and she took my insurance, and she does a very in-depth visual acuity testing with all different types of devices that help her help me. And I can go to her yearly, every 6 months, as much as ... I can go to her as often

as necessary when I find changes in my glasses, and she works with me with different devices, with different coloring, because all of those things can affect what's going on because of what's going on in your eye. Different tints and different coloring can help, many times, with giving you better clarity. So, I have had a great experience with low vision. I did not have a good experience with a ... like, an occupational therapy-type situation, so I won't go there.

MICHAEL BUCKLEY: Liz, what's your experience been like?

LIZ TULLY: Canada is quite different. And at the time I was diagnosed, I just went directly to an ophthalmologist and made an appointment. Now, up here, you have to be referred by a family doctor, so that's how I got my ophthalmologist. I was never used to working with an optometrist. I was used to ... I mean, I never even thought about my eyes before I started to have problems. I went to an optician when I thought I needed new glasses, and that was it. So, after all of this happened, and I was talking briefly about some of the things I was beginning to experience with my ophthalmologist, and did he know an optometrist who specialized in low vision. He gave me the name of a person who was very good, and just as with Jill, he did prescribe some glasses, but that was basically it. Now, I've also tried to research this a little bit further because we don't call them low vision specialists, they are low vision optometrists. And when I went on a website for ... I research a lot on the internet because I can still see as well as I can, and I have someone who helps me with things that I can't, and I came across, sort of, guidelines for optometrists, and I think the reason I haven't had any more help than that with the person I'd been working with was because my eyes weren't bad enough. Sounds odd, but I'm at 20/50, so I could still, theoretically, drive if I wanted to. So, I can't really comment beyond that.

MICHAEL BUCKLEY: We have a question from our audience that really extends the topic of low vision specialists and asking for help, and it's more: How do you become comfortable asking for help,

whether that's a family member or a friend or a neighbor? A lot of us aren't really comfortable asking for help or maybe don't like to feel dependent. I was wondering if either of you could talk about that process that you went through.

JILL ADELMAN: Well, for me, being a nurse, I was the caregiver. I always took care of everybody and everything, so it was very, very difficult for me. I'm very fortunate. I have a husband. I've been married for 40 years, and he is by my side, and whatever I need—he's a first responder—but whatever I need, he changes his schedule. He is here for me. We get everything done together. I do have three grown children. They work, but they're always, "Mom, do you need anything? Do you...you know, we're going to the store; do you want to go?" I'm still independent enough to get to local areas, and I'm adamant that as long as I feel safe, I go. And when I say feel safe, as soon as I get in my car, I know if it's a good day or a bad day, and if it's a bad day, I get out of the car, and I don't go. Asking for help was the number one most difficult thing for me to do. Over the course of the last few years, friends that we associate with, they know that if it's dark, I can't get to different places, and arbitrarily somebody will just give me a call, "Hey, Jill. We'll pick you up at such and such a time." So, I'm very, very lucky with that, and that's for socialization. And, of course, my husband is my rock. I'm very, very fortunate there as well.

LIZ TULLY: I have quite a different situation. I live alone. I do not have any family nearby. I certainly have friends, but by the time you get to be my age, we are ... I don't have as many nearby as I used to have. And I, like Jill—well, maybe not because it sounds like it's still hard for her, but I have found it much easier now to ask for help or to accept help. Like her, I was very independent all my life until this all happened. I like to paddle my own canoe, and I was the one who gave, not the one who has received. But what I keep remembering is a phrase or an expression that my sister, who lives in Scotland, told me a friend of hers told her, "Ages and stages." And I'm at that age and that stage now where I cannot do all of the things I used to be able to do. So, I accept that. I still want to do

absolutely all the things I can, and I keep reminding my friends of that when they want to do things for me. But if I need help, I will accept it, being in a large city and using public transit and things like that. I've also found strangers very kind. Even young people—they might bolt past me on the stairs—realize I'm having difficulty as I'm crab-walking down, will halt, come back, and ask if they can help. I always say, "Yes," whether or not I need it because I want to encourage that kind of behavior in them, and we both feel better for it afterward. But I do try to maintain as much independence as I can while I can, and that's still quite a bit.

MICHAEL BUCKLEY: We have a question from our audience related to that for one or both of you: How do you, I'll say, process or maybe negotiate with yourself about reducing driving or stopping driving altogether? How do you emotionally process? I know that Jill, you said you limit some of your places and times, but how ... is that emotionally difficult? I was just wondering what the emotions and the logistics of doing less driving or eventually no driving. How does that work for one or both of you?

JILL ADELMAN: Well, I think losing the entire ability to drive is the scariest thing that I look to in the future. I recently bought a new car with the total intention that when the day comes and I say, "Okay, I'm done," it'll go to my grandson, and he knows it. But I just take one day at a time with it, and it's a part of adjusting each and every day and accepting what's going on for that day. In my case with my eyes, they're different from day one of injection to day 28 prior to injection—it changes throughout the month. So, I just take one day at a time and accept that day for what it is and readjust in each way.

LIZ TULLY: I had a rather different experience and different options because of where I live. I actually drove for 50 years, but when I knew macular degeneration could likely be in my family because it is—I have a number of relatives who have it, which I have discovered over the course of years, I've started planning

ahead because I knew I lived alone. I knew where I lived, I would not be able to function nearly as well or be as independent as I moved closer to public transit, so that's what I did, and I can get around pretty well with that. I've certainly been more cautious during the pandemic because of the pandemic, but I feel comfortable doing it. I'm able to see well enough that I can. I have friends who will take me and who offer to when I need it. Often, I don't. I say, "No thanks. I'll be okay." I can walk to many, many things that I want to do. I'm a walker by nature, so this was a good move for me, and that was one of the reasons I made it.

MICHAEL BUCKLEY: Thank you. And staying on themes of independence and daily life, any specific tools or devices that have helped you in restaurants or stores or anywhere that you're out and about that you think could be helpful for our audience today?

JILL ADELMAN: A few years ago, at a low vision conference, I found an electronic magnifier that is my savior. I call it my ruby. It goes with me everywhere, and it changes colors. It makes things from actual size to very large size. It's lighted, so if I'm in a dark restaurant, I can see the menus. Sometimes, I just use it in every restaurant because the menu print is so small—that is my savior. Unfortunately, not covered by insurance, but it's definitely well worth the investment. I do have quite a few hand-held magnifiers that you can get on low vision device sites, and myself, I just had to play with different ones to see which ones worked best for me, so it was a learn-as-you-go type situation. In my home, I have lights in every closet that are motion-detected, so as soon as I open a closet door or a staircase, a light goes on, and that has helped a lot, especially with depth perception, like going from my first floor to my basement. The lighting is very important, and now they're all over the place where you can get the motion detector, and most of them are USB-charging availability, so they're constantly charged. Those have been very important to me through this journey.

MICHAEL BUCKLEY: Liz, do you have any tips to add to that?

LIZ TULLY: I don't have a lot because I don't need much help at this point in that respect. I do have a couple of digital magnifiers, which I certainly use when the need arises. I tend to look at menus before I go to the restaurant, so I have a sense of what I want to buy. I do when I'm out when it's darker, I take a flashlight with me because we now have very environmentally responsible lighting, but it's not that helpful with people with vision loss. And so, I have the same experience that Jill does with depth perception and contrast sensitivity, and being able to see, for example, the slight variations in slabs ... the slabs of a sidewalk. And to make sure I don't stub my toe and go flying forward, I take this flashlight, if I need it, and I'm always very aware that those two senses for me have really deteriorated with my macular degeneration. But other than that, no, I haven't really needed anything. I do have a right-handed glove for when I cut in the kitchen, so that I won't slice off a portion of my finger at the same time. But other than that, I'm still able to handle things pretty well.

MICHAEL BUCKLEY: Liz and Jill, this has been a fantastic conversation. I think you've really given us a lot of tips to be better informed and more empowered, and also just staying safe and active in day-to-day life. So, in conclusion, is there something that you wish every ... people knew about AMD, whether early during the diagnosis, the patients or their families? Is there something that looking back you would have told yourself at that point or something you'd want to share with people who might be at that early, pretty anxious part of the process?

LIZ TULLY: I would say, for me, the most important thing ... and I was so fortunate that a chance remark of my mother's cousin alerted me of the possibility that I might get it. It's so important to be diagnosed as early as possible. I know you can go for eye examinations. And the days when I had it, it wasn't the done thing, but do try to keep on top of that, especially if you know there's a possibility you could get it because that can make all the difference. It really has for me, and that's why I firmly believe I'm able to see as well as I can now. I've done as much as I could all along my

journey, and I know I couldn't do ... can't do anything more. So, now it's kind of in the lap of the Gods.

MICHAEL BUCKLEY: Thanks. And Jill?

JILL ADELMAN: Well, I think that somebody just diagnosed with AMD, I'd want to tell them that it's important for them to realize that life isn't over, that there's so many things going on that can help to improve this disease and maybe even conquer it, and to take one day at a time. Be very conscious of your daily vision, have a great conversation with a wonderful retina specialist that you're comfortable with, and don't be afraid to ask questions. The question that was never understood by me in the very beginning is: What is this all about? What does this do? What can I expect? Where is the future? And it's okay for them to say they don't know, but accept it and not be afraid to ask the questions.

LIZ TULLY: I just wanted to add one other thing to what Jill was saying because that's all absolutely true, and I still have, I would say, a very full, active life—some different activities, but they're very fulfilling. The other thing is to bear in mind, especially early on: only about 10 to 15 percent of the people who are diagnosed go on to have a severe illness or disease. For the other 85 or 90 percent, it is all likelihood it really will not impact their vision as much. And so, just keep on top of it and know that that is important because it may well not affect you. But if it does, you're prepared.

JILL ADELMAN: As Liz said earlier on, early diagnosis is very important if you know that there's something going on in your family background—so, having that open discussion with whoever it is you see as an eye doctor. And I think that there needs to be more education to people to get those every 2-year eye exams, whether you have macular degeneration in your life change or not because you never know what's going to happen. had nothing in my genetics. So, everybody should be getting their eyes checked once they hit ... even a child, and that's not really promoted very well,

and that's important in the whole scheme of things because they're finding early diagnosis definitely does help.

MICHAEL BUCKLEY: That is great advice. And I think as we conclude the conversation to our listeners, a lot of the points that Jill and Liz made about learning more about macular degeneration and being as informed as you can about managing your vision health, you can find a lot of that information at our website, www.BrightFocus.org; one word, www.BrightFocus.org. So, I'd encourage other people to visit www.BrightFocus.org. If you don't have internet access, you can call us at (877) 4372423; again, (877) 4372423. Or go to the website, www.BrightFocus.org, and you can learn more about macular degeneration, glaucoma, and Alzheimer's.

Jill and Liz, I just want to thank you so much. It's been a really, impressive conversation. I think you've shared a lot of important tips, so thank you so much for giving up your time today to be with us.

JILL ADELMAN: My pleasure.

LIZ TULLY: You're very welcome. Take care.

MICHAEL BUCKLEY: On behalf of BrightFocus and our guests, Jill and Liz, thank you very much, and best wishes for the holiday season. Thanks.

Useful Resources and Key Terms

BrightFocus Foundation: (800) 437-2423 or visit us at [www. BrightFocus.org](http://www.BrightFocus.org). Available resources include—

- **Amsler grid**
- **BrightFocus Foundation Live Chats and Chat Archive**
- **Clinical Trials: Your Questions Answered**
- **Healthy Living and Macular Degeneration: Tips to Protect Your Sight**
- **How Low Vision Services Can Help You**
- **Macular Degeneration: Essential Facts**
- **Research funded by BrightFocus Foundation**
- **Safety and the Older Driver**
- **The Top Five Questions to Ask Your Eye Doctor**
- **Treatments for Age-Related Macular Degeneration**
- **Understanding Your Disease: Quick Facts About Age-Related Macular Degeneration (AMD)**