**Fighting Blindness Canada Podcast
Season 1, Episode 2: Focus on Age-Related Macular Degeneration**

*(music plays)*

**Morgan:** Welcome to the Fighting Blindness Canada podcast. I’m your host, Morgan Ineson, manager of education at Fighting Blindness Canada.

In this series we will be interviewing researchers & physicians who focus on the treatment and prevention of eye diseases. We’ll go behind the scenes to learn not just about their research, but also why they are passionate about what they do.

In every episode we will also pose a question to the vision loss community to learn first-hand about how living with vision loss affects them.

On this episode we are focused on age-related macular degeneration, also known as AMD. AMD is the leading cause of vision loss in people over the age of 55, affecting approximately 2.5 million Canadians. In AMD, central vision is affected, making it harder to do activities like reading, driving, and distinguishing faces. There are two types of AMD, commonly known as wet and dry. Wet AMD causes bleeding and fluid to collect behind the retina causing vision loss. It is most commonly treated by the injection of medications, called anti-VEGFs, into the eye. Dry AMD is more common and typically does not cause significant vision loss until its advanced stages. At this time there are no treatments approved in Canada for dry AMD. In this episode we will discuss some of the physical, psychological, and practical challenges faced by individuals living with this condition.

First up we will be sharing an interview with ophthalmologist Dr. Deepa Yoganathan. Dr Yoganathan is a retinal specialist with a particular interest in helping patients learn to navigate the system to get the best possible care and support. Then, we will speak to Mary Campbell, a member of our community living with AMD who will share her experience with diagnosis and treatment.

The information provided in this episode is not a substitute for medical advice. If you have questions about your eye health, please speak with your doctor.

This is the Fighting Blindness Canada Podcast.

(music plays)

[2:22]

Dr. Deepa Yoganathan is retina specialist who has worked concurrently in both the United States and Canada for the last 13 years. She is currently in Windsor and Detroit. She is an Assistant Professor at the University of Toronto, an Associate Professor at the Kresge Eye Institute, Wayne State University, and an Adjunct Professor at the University of Windsor. In addition to her medical degree, she also completed a Masters of Science in Health Research Methodology at McMaster University. She enjoys teaching and he research interests include diabetic retinopathy, retinal trauma and patient navigation.

[2:58]

**Morgan:** Thank you for joining me Dr. Yoganathan. And it's a pleasure to have you on the Fighting Blindness Canada podcast. Before we talk about age related macular degeneration, I'd love to learn a bit more about you and how you got started in your career. Could you tell us about what made you decide to pursue a career in medicine and ophthalmology?

**Dr. Yoganathan:** I'd be happy to first thank you for having me on your podcast. Growing up, I would say that, you know, I just always had a general interest in helping people. When I went to medical school, my plan was to do family medicine or pediatrics. And then I got to my surgery, rotation and I really loved surgery. And I was I remember looking through the window of a pediatric, strabismus surgery case and I was mesmerised at you know, how tiny the muscles were and how they were doing surgery on all these small parts of an organ and kept, you know, watching more and more surgery including cataract surgery and cornea etc. But I was just, you know, just amazed at how these doctors were able to do such delicate surgery. Then during my ophthalmology residency, I just fell in love with the retina I love looking at the retina I was amazed at the idea that the retina could reveal so much about the body, you know, whether it's diabetes, or infection or inflammation, etc.

[4:29]

**Morgan:** Now I imagine being a retinal specialist, you see many patients in your clinic who are affected by age related macular degeneration, or AMD, could you briefly describe for us what this condition is and how it affects patients?

**Dr. Yoganathan:** Absolutely. So, as the name says, age related macular degeneration is merely a risk of getting older. The percentage of patients who have AMD who are who are over the age of 80 is quite high. So it's simply just by aging. Of course, there's other risk factors including smoking, you know, race, genetics. And so there's most of which is non modifiable. Obviously, if you're a smoker, the first thing to do would be to get all the help and aid that you need to try to quit smoking. But it's a disease where there, wet macular degeneration is a disease where you have abnormal blood vessels that are growing underneath the retina. And that can leak fluid or blood and blur the vision in the center of the retina called the macula, or more specifically, the fovea. Dry macular degeneration may not have any symptoms at all. There, they could just be deposits in the retina or areas of atrophy, meaning the cells are not working anymore in the retina and patients may not have any symptoms. So those are the two general categories wet and dry, macular degeneration.

[6:02]

**Morgan:** When you deliver a diagnosis of either wet or dry, AMD to your patients, what are some of the most common questions that people have for you?

**Dr. Yoganathan:** Let's start with the wet. Is this fixable? Should I have come in earlier? Is the needle going to hurt? How many needles will I need? Is this forever? What are the chances that this will happen in the other eye?

To answer the first question, is this fixable? So 90% the drugs are effective 90% in stabilizing or improving vision. So I would say yes, this is quite fixable, but if caught early. So unfortunately, patients oftentimes don't realize that what their symptoms are meaning central blur or vision loss or distortion is specifically a retina problem. Most of the time people think there's something wrong with your glasses or it's will just go away. But you know, I would advise seeking treatment, or at least an assessment with your optometrist or ophthalmologist, within a couple of weeks, the earlier the better.

In terms of how many needles everyone gets, you know, there are averages, you know, seven or eight in the first year and then a little bit less every year. So we treat the eye as an individual case, every patient gets what they need. We don't just use broad approaches to everybody, the general treatment is treat and extend. So we keep drying up the retina until it is completely dry, which is typically injections every month. And then we stretch out the visits, whether it's a to a month and a half to two months to three months to check whether the retina can remain fluid free during those intervals. So that's identifying the fluid free interval between injections.

Does this go on forever? Well, for some patients that goes on for a long time, and other patients it doesn't at all, they could be finished a treatment within a year or two. Other patients do need years of treatment and there are surprises along the way. So again, we do a checkup every time they come in, we take pictures every time the patient comes in, or let's say 99% of the time. And the technology and the pictures that we obtain give us a lot about the story of what has happened and a little bit about what will happen.

[8:32]

**Morgan:** Those were some common questions patients have when being diagnosed with wet AMD, how about dry AMD? What sort of questions do patients have when they are diagnosed?

**Dr. Yoganathan:** Sure, so in Canada in May of 2023, there is no drug available for dry AMD. There are two types of dry AMD, there's disease that is just you know, deposits of drusen within the retina. And then the other type is geographic atrophy. And in the United States, there is a drug that was just released a few months ago called Syfovre.

It is also an individual injection, just like all the other anti VEGF injections that we inject for wet macular degeneration, but the molecule and the target is different. As I work in the United States, I just injected, I just started injecting patients last month the and it's going well. The conversation is very different for a patient with geographic atrophy and treatment. Syfovre does not improve vision, it reduces the speed of future vision loss.

If there is this treatment that becomes Health Canada approved in Canada, then all the eye doctors the optometrists will be will be made aware that there's a new treatment and now they'll start referring their patients with geographic atrophy to the retina specialists, or to those that inject retinal disease. Currently since there's no treatment, there's not much to do. And so we don't see a lot of patients with dry macular degeneration in our offices, because, you know, it's simply a yep, that's what you have, but, you know, continue to eat healthy and, you know, use eye protection, kind of don't smoke mitigate those kinds of risks, but we don't have treatment in Canada at this time.

[10:30]

**Morgan:** I know that in addition to your clinical work, you're very passionate about patient navigation. Could you describe for us what that term actually means and why it's so important to you?

**Dr. Yoganathan:** Absolutely. My first exposure to patient navigation was through a diabetic coach when I was doing my masters at McMaster University. Basically, the concept was that there is a need in certain populations, for example, let's take people with diabetes. That they need help Okay, going to the doctor and coming home from the doctor is not enough. This is a daily problem of you know, a having diabetes for some people is like you have to think about it morning, noon, and night. Every meal, every time you're hungry, every time you don't want to exercise, trying to manage your high blood pressure and cholesterol This is a lot to manage.

In a hospital setting, before you leave the hospital, there's someone who makes sure that you have a home to go to that is safe, that you are able to follow up with your follow up appointments. There's, there's a person in charge of your well-being before you leave the hospital. In a community setting, there's nobody like that. I've been working not just with Fighting Blindness Canada, but now I have two Master's students at the University of Windsor through their new translational science program. And so we've been working on a ton of interventions to help first gauge the needs of the community, and then to try to implement them.

The last part of this puzzle is to work with the School of Social Work at the University of Windsor. So a social worker in a community setting like a retina clinic is, I think, the perfect solution to these issues. A social worker will know where to get help for the patient. There are community resources that exist, it's just hard for my staff or myself to really be able to navigate on the system. So the bottom line is that I feel that there is a lot of gaps in our wonderful healthcare system in Canada, and I'm not being facetious. I do think it's a wonderful health care system, and I believe that health care should be free for all. And unfortunately, there are certain things that don't, that are not covered. You know, there's certain technologies, certain things like caseworkers, social workers in this kind of community setting.

[13:05]

**Morgan:** How do you see a patient navigator being able to assist somebody who has wet AMD for example?

**Dr. Yoganathan:** So, several ways, first of all, transportation is a huge burden. For some patients, they are oftentimes dependent on their family member, their neighbor, their friend. Some people pay taxes to come, and they're truly limited by, so If this woman says to me, you know, the taxi cost me $80. So I can only afford to come every two months. And I'm like, $80? That's so much money, how can you pay 80 just to come to see me? I feel so guilty, you know, and even my wonderful staff, they'll be like, Oh, we want to pay for this patient's this or, or we want to pay for this patient's taxi to get to surgery, literally, that happened two weeks ago, where they all wanted to collect money to get a patient to their surgery, you know, and like, what a wonderful gesture. But you know, there's an underlying source of that, of that, of that of that issue. When I was working in Toronto, there were transportation, very reliable transportation companies that would drop off the patient, yes, they had to drop off, you know, when it's a three-hour span. However, you know, not every community has that. And so just being able to have a list of resources, or have a person, hey, I have this problem - Let me introduce you to my patient navigator. I would love to be able to have that follow through with our patients and be able to support them not just for their retinal condition, but in a holistic way.

[14:42]

**Morgan:** In the second half of today's episode, we're going to be hearing from an individual who had some difficulty navigating their diagnosis, especially at the beginning. So just to close off today, do you have any advice for people who might be struggling to get the information that they need from the medical system?

**Dr. Yoganathan:** At the time of diagnosis, it's very hard to come up with all the questions you're ever going to have about your condition. And it's hard when you're meeting a patient for the first time, it's hard to know what how the information you give them will land. And that's the art of being a doctor is to try to make sure that you treat every patient as an individual, and you give them the information that they need, in the way that they need it. And sometimes it's just a feeling and other times you're right, and other times you're wrong, about what kind of personality the patient, you know, has. And so I would just advise a patient, if you don't understand, make another appointment with a doctor, contact the doctor, you know, see if they're available by email, or basically, figure out which quite quick which questions are administrative which you can deal with the staff, and figure out which questions are medical that you know, you should sort of target towards the doctor.

**Morgan:** Great. Well, thank you so much for joining us today. It was really wonderful talking to you.

**Dr. Yoganathan:** Thank you so much. I really appreciate the opportunity. Have a lovely day.

**Morgan:** We'll be back after this short break to speak to an individual who's living with AMD to learn more about their experience.

(music plays)

**Jackie:** Fighting Blindness Canada is the largest charitable funder of vision research in Canada. To date, we have contributed over $40 million in funding for the development of sight-saving treatments for blinding eye diseases. With your support, we are advancing research to understand why vision loss occurs and how it can be slowed or restored. To learn more, visit us at: fightingblindness.ca.

This is the Fighting Blindness Canada Podcast.

(Music fades)

[16:47]

**Morgan:** Our second guest on this episode is Mary Campbell. Mary is a vibrant, independent 76-year-old woman who lives in Toronto with her husband. She has three children, six grandchildren and loves to stay active by walking, taking online classes and listening to music.

When Mary was 65 at a routine visit to her optometrist she was diagnosed with dry AMD. She knew nothing about the condition at the time and was shocked to find out both of her eyes were affected and by how little information she was given at her appointment.

**Mary:** Fortunately, there was an optometry student with him in the room. And I said to her, I, you know, I'm devastated. I don't know what this means. And so she kindly went and got a pamphlet on it. And she gave me an Amsler grid. And she said, that I should check my vision, from here on in looking for any changes. So that I did start doing that. And so the next year in 2012, I noticed I was I was either trying to read or watching TV, and I thought something was a bit blurry. So I got up my answer grid, and I looked at it. And I thought, I can't see the bottom half of this grid. So I thought, oh, something's wrong. So I called the optometrist and got an appointment.

[18:10]

**Morgan:** When Mary saw the optometrist this time, they told her that there was some bleeding in her eye, and she would need to see a retinal specialist. The appointment was for 8 weeks later, and Mary was sent home. As Mary waited to see the specialist, she worried that her vision was getting worse.

**Mary:** I was there alone at the appointment went home. I didn't know anybody who had this. AMD, I didn't even know what it was then. I have no family history of it that I knew of. So I kept checking my eye on the Amsler grid, and I noticed that the I was seeing less and less of the grid.

**Morgan:** When Mary finally saw the retinal specialist, the news wasn’t good. She had significant bleeding and fluid in her eye. She was told she would need to start injections immediately in order to stop the bleeding and prevent further vision loss.

**Mary:** And he said, you need an injection today, here's a prescription, go down to the pharmacy and get it and bring it back up and sit in the waiting room. Didn’t tell me what the medication what the name of it was, what it was for. I think he told me the risks and benefits, you know that, but not exactly how it worked. So I was sitting in the waiting room and waiting, gives a busy clinic and finally called in and assistant kind of prepped my eye. And then he came in to give me the injection, and I asked, you know, I was just like, gonna hurt like, I had no idea what to expect. And he said, Well, I've been doing injections all morning. Have you heard anybody screaming while you've been sitting out in the waiting room? And I said, No, no, hadn't. So he proceeded to give me the injection. And I, you know, that was it. I was I would like to send home and it was sent home and absolutely, you know, shock, stunned. I didn't know what had happened. I didn't know what this would mean, for me, I was scared. Just a whole lot of thoughts floating around in my head.

[20:07]

**Morgan:** Mary continued getting injections for the next three years at this clinic. Her vision improved slightly in the affected eye, but significant damage had been done. She felt adrift and still didn’t have a full understanding of her condition, but she knew that the injections were helping. Fortunately, she soon met an individual who would influence her approach to her diagnosis and treatment.

**Mary:** I continued to see him and I still didn't know anybody who had this AMD. I would sometimes talk to patients beside me about how long they've been coming, and you know, where they lived, etc, etc. But I was singing in a choir at that time and I learned that someone else in the choir had this AMD so I talked to her and asked her what her routine was like. Now, the doctor I was seeing never looked at my good eye. He just concentrated on my “bad” eye. So she told me that she got scans every visit, and that she always checked her good eye. And so I asked this doctor, at one of the appointments, what happens if I have a problem with my other eye when I notice I can't see. And he said to me, well, you'd have to go back to your optometrist and get another referral to see me. And I thought, I can't do that. I can't continue to see this doctor anymore. This is I have one good eye left. So I did I, I changed optometrists, I and I got a referral to the retinal specialists from my friend in the choir. And it was like, night and day.

[21:48]

**Morgan:** With her new doctor, Mary got OCT scans every visit. The doctor checked her regularly for glaucoma and she was diagnosed at one of these screenings. Her doctor also caught the start of wet AMD in her other eye before she exhibited any symptoms. She was started on injections in that eye immediately and her vision was, and continues to be, preserved in that eye.

Mary’s story is reflective of many individuals who are living with AMD. In 2020, a survey conducted by Fighting Blindness Canada of people affected by AMD shared similar statistics: 77% of people worried that their condition would worsen, leading to a significant emotional burden. Like Mary, 31% also shared that they were challenged by long wait times for appointments and a common theme in these discussions was the lack of time and information from patient’s doctors around the diagnosis and start of treatment.

Thankfully for Mary, she lives close to her doctor’s office and does not share the challenge of many who may have to travel great distances to their appointments. In fact, 85% of respondents to the survey indicated that they required help to attend their appointments. In addition to the practical and financial barriers to attending these appointments many identified anxiety or fear about the injections.

I asked Mary how she felt about injections now – and if the procedure has become less frightening over time.

**Mary:** I think what really helps me with the injections is first of all, before you get the injections, you have all these screening assessments, you have to read a chart, check both eyes, you have your glaucoma check, you have your OCT scans. And so for me when I go every six weeks, the fact that I hear back and see my vision hasn't changed from the previous visit. I always say did I read the same line as I read the last time? That's I'm just so anxious to know that that things are still stable. And so that getting the injection is less of an issue now. Because once I know that things are good, I'm fine with the injection.

It's really a quite painless, surprisingly painless, experience. And I think every ophthalmology office is probably a little bit different as to their technique and how they use it. But my experience is that I get you know, anesthetic drops put in my eye by one of the technicians after I've had my OCT scans. And then I go into the office and the retinal specialist after he's looked at my scans, he gives me an injection in my eye of more freezing. Now some people apparently don't get that needle, but by the time your eye is already numbed with the drops, so you barely feel, a little bit of pressure. And then he comes back in five minutes, and he gives me the injection. It takes about 10 seconds to give the injection, very fast, very quick, and you just feel, sometimes I feel nothing, sometimes a little bit of pressure. But I know the needle is very, very fine that they use, and I've asked if there's scar tissue that builds up on the cornea and there isn't. So, I am very comfortable. And I think he's got a very good technique.

[25:03]

**Morgan:** Although Mary had a difficult time at first, by speaking to someone else who shared her diagnosis she was able to turn her treatment journey around and learned how to become her best advocate. Mary now works with patient groups and is outspoken about her experiences with the hopes that others will not have to go through something similar.

**Mary:** You know, I'm feeling very positive about the future because of the research that's going on, and the good things that are happening. And I think my children are at risk for developing AMD. The three of them. And I think, you know, I don't know what will be out there for them if one of them was ever diagnosed when they're a bit older. But, you know, I'm just so glad that there is all this research going on. Just have really appreciated Fighting Blindness Canada, for the work you do. And like, the education and once I, you know, once I started to learn more about it, then you get empowered, right? To ask questions, and speak up and feel more confident about everything. I can't believe looking back now, and I was preparing for this talking to you today, I kept thinking, I can't believe how I was so ignorant when I first started on this journey, didn't know anything. And was just didn't know anybody, and didn't know what questions to ask. And, you know, I've come a long way with living with this disease to become, you know, better and much better educated, and, you know, advocating for myself and just, you know, doing everything I can to preserve my vision.

*(music plays)*

**Morgan:** Thank you for joining us for this episode of the Fighting Blindness Canada Podcast. I want to thank Dr. Deepa Yoganathan and Mary Campbell for joining me and sharing their perspectives. Stay tuned for our next episode on advocacy, coming soon. I’m Morgan Ineson. Thank you for listening.

**Jackie:** This podcast is brought to you by Fighting Blindness Canada.

If you have an idea for a future episode or have a story you would like to share, please contact us at education@fightingblindness.ca. For more information about us, visit us online at fightingblindess.ca/podcast