

BEH PODCAST EPISODE 38

IF I DO NOTHING WHAT ARE THE RISKS OF BLEEDING

This is the next in the series of questions we've been doing over the last couple of weeks that I call the "should ask" questions. You've heard of frequently asked questions, you know answers to questions that people ask frequently. Well these are questions that I drew up that I want people to ask, but that they don't often think of. This is a little off how its normally done, but it's working for me, so we are going to do it. I hope it's working for you as well.

The question for today applies mainly to people with Macular Degeneration and Stargardt. If you have Macular Degeneration or Stargardt and you don't do anything, except take the vitamins that your eye doctor recommends, what are the chances that you'll become exudative, or develop wet degeneration or wet Stargardt.

Let me preface this discussion with two things that may not be evident to people. First, Macular Degeneration and Stargardt are very closely related. Stargardt is the juvenile form of Macular Degeneration and the genetic predisposition for that is maybe you have two abnormal genes instead of one. That could be why it shows up when you're younger. The other thing is that a lot of people think and this is in part because of the way eye doctors think about this. They somehow think that wet Macular Degeneration or wet Stargardt disease is a different entity than dry Macular Degeneration or dry Stargardt disease. The truth is they are the same disease.

The example I like to use is if you think of another common disease, something like diabetes, which has been around for a long time and you progress into a stage where you start having the complications that diabetics can get. Things like heart problems or poor circulation in the legs or kidney failure or diabetic retinopathy, the eye problems associated with diabetes. It's all still just diabetes. It's diabetes in a more advanced stage, now with complications. The same is true for the eye diseases. If you have wet macular degeneration, you have good old Macular Degeneration, only now it's progressed to a point where you have the complication of leaking and bleeding.

I'll finish this topic and then I'll have another little conversation about when they decide to inject your eye. The data is clear for people with Macular Degeneration that the odds that you will convert from dry to wet only about 10 or 15%. That doesn't mean that everyone with Macular Degeneration, because it all starts out as dry, is going to convert to wet Macular Degeneration. The odds are in your favor that you won't. You can have a lot of what geographic atrophy. You can continue to lose vision, but you may not have the problem with leaking and bleeding.

The leaking and bleeding can be catastrophic. It can lead to sudden and dramatic loss of vision because of the damage that that fluid and blood leaking into the retina. The damage that that can cause can be quite severe, and it can happen very quickly. When

you hear about the treatments for macular degeneration, really, they're not talking about treatments for the disease. All that language is talking about treatments for the complications. Ophthalmologists still really have no treatment for the disease.

Some are looking at injecting stem cells and they keep saying that's years away. There's some people that are trying it now, but most of the people who are trying it's not an approved technique. The clinics that do it aren't supervised or registered or licensed to do it. There's a bit of a scandal going on now with a lot of stem cell therapies where stem cells are being injected. It's not fraudulent, but it's not a controlled procedure, and people spend a lot of money for that. They can charge you tens of thousands of dollars to inject stem cells into you and you'd like to think it's going to work if you're going to spend that kind of money. But a lot of people aren't doing it well or don't know what they are doing, so the results aren't very good. So I'm going to end that simple statistical thing.

The next conversation I wanted to have though just briefly though. Just briefly because it relates to this is that because the only tool that the ophthalmologist have is these injections, they tend to do them a lot. In fact, they do them often when they are not indicated or called for.

Often, you know people don't even know that they have Macular Degeneration until they have some sort of catastrophic event like a bleed or a leak. They may know that their eyesight is declining, but no one's ever used the words Macular Degeneration before. This gets into you know a whole other thing that is a sorry thing that doctors still do. That they've always done is they don't want to worry their patient. They don't want to worry their client. If your eye doctor sees loss of pigmentation, geographic atrophy, maybe some droozen, you know, the kind of debris you left behind because of all the cells that are dying off, they may know oh this is an eye with Macular Degeneration most likely. But they don't say anything and then you will one day wake up and you can't even really see in one of your eyes. And they will say, oh you bled and this is Macular Degeneration and it's not new, just nobody ever told you were having problems with your eyes. The reason they don't tell you is that since they have nothing to offer, they figure why worry this person. Why upset them. It's not doing a good service to you when they do that.

To get back to what I was saying, there are a lot of people who I see now who are getting these injections and they are not really indicated and there is evidence now that those injections can do some damage in your eye. If you've had a big leak or a bleed and its causing a lot of damage into your eye. Yea, you want to do some first aid, some emergency thing to try to cut it back. But getting injections every month for years on end ultimately leads to problems. This is a bigger discussion, so let's come back to this in the future.

I'll put it down on this list of topics for coming weeks. But I'm going to end there with the just thought that getting these injections in your eye when you don't need them can be damaging. Wet and dry are the same and sometimes the first time you even notice you have macular degeneration is because of a bleed, but it's always preceded by a dry

form. You've had degeneration in your eye before you had the bleed. It's just that no one told you or no one diagnosed it. We're going to open the Q&A now.

As an addendum, I want to mention two important references about the risk of repeated eye injections. The first reference is from one of the bigger ophthalmology journals called Retina in 2014, July, volume 34, number 7, pages 1308 – 1315. The primary author was Young. There's another article from the journal Ophthalmology from 2013. Both showed the risk of geographic atrophy in people who received multiple injections of these drugs. That's a bad thing, so I wanted to make sure that people were aware of those findings.