Dealing with the Emotional Impact of Vision Loss
June 28, 2017
Transcript of Teleconference with Dr. Deirdre Johnston

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

MICHAEL BUCKLEY: Hello, I am Michael Buckley from BrightFocus Foundation. Welcome to today's BrightFocus Chat, “Dealing with the Emotional Impact of Vision Loss.” If this is your first time on a BrightFocus Chat, welcome. Let me tell you a little bit about BrightFocus and what we will do today on our Chat.

BrightFocus Foundation funds some of the top researchers in the world. We support scientists trying to find cures for macular degeneration, glaucoma, and Alzheimer’s disease. We are able to share the latest news from these scientists with families who are impacted by these diseases. These BrightFocus Chats are another way of sharing this information. We are very fortunate today to be joined by Dr. Deirdre Johnston. Dr. Johnston is a geriatric psychiatrist at Johns Hopkins University in Baltimore. Dr. Johnston, thank you so much for joining us today. On some of our other Chats we’ve had ophthalmologists, we’ve had people who help make your home as safe as possible, and we’ve talked about topics such as driving and when to continue or not to continue that. This is the
first time we have had this topic. I am really excited today about discussing the emotional impact of vision loss. Dr. Johnston, in your opinion, what do people fear the most in old age?

**DR. JOHNSTON:** Hi. Thank you for inviting me, Michael. In my practice, I see a lot of older people, primarily, as I am a geriatric psychiatrist. One of the themes that comes up quite often is fear of losing their independence. Fear of losing function. Often, of course, the fear of loss of function leads to the fear of loss of independence, because people think that if they cannot do something they have always done that they may need to rely on other people to do it. Some people are terrified of that. It varies from one person to another. Some people find it very anxiety-provoking, and others can ease their way into a new situation like this and adapt to it. It is an adaptation. It is a challenge. People can experience actual anxiety symptoms. They can experience depressive symptoms. How you deal with these changes is the important thing.

Often, having the diagnosis early enough to plan ahead and learn what is going on—and be prepared—can be your greatest asset. So facing it and learning early is one of the best approaches.

**MICHAEL BUCKLEY:** That makes perfect sense. I was wondering, all of us are getting older every day and many people get a little bit of vision loss as they age. What does that do for the impact on your mood, the natural aging process? What is the impact on someone’s mood?

**DR. JOHNSTON:** For the most part, we get presbyopia, vision loss, as we age. That isn’t a disease. It is not pathological. It is normal and that doesn’t really affect our mood too much. It is really just a nuisance. However, conditions that lead to loss of actual vision can actually affect a person’s mood. In fact, it doubles the risk of depression, and macular degeneration actually accounts for 45 percent of low-vision cases, so it is a risk factor for depression. That doesn’t mean that you are going to get depressed because you have it. It does mean that you may be at increased risk. Being aware of that is sometimes helpful, too.

Sometimes, people ask if people with low vision develop seasonal affective disorder (SAD), where people develop low mood during the
winter time, when the light is low. That is an interesting question because people with low vision, the same as anybody else, can develop seasonal affective disorder. It turns out that they don’t experience it any more than other people because the receptors in the eye that detect blue light—which is the light that is involved in seasonal affective disorder—those receptors are often preserved in people with macular degeneration. You’re not really at increased risk of seasonal affective disorder any more than you would have been before developing the visual impairment. But depression, yes.

MICHAEL BUCKLEY: I appreciate that. As these changes happen and, as you mentioned, the mood changes that can happen, how does somebody re-engage with activities that they enjoyed?

DR. JOHNSTON: There is a natural grieving period for a lot of people. Some people take it on the chin, they are very stoic. Other people need time to grieve. I think that is most of us. You have to go through normal acceptance and dealing with the loss and new situation. Even being sad about losing some faculty or some function, that is normal. But the best way to cope with it is to learn adaptive techniques and to find out what is there to help you.

There are a lot of resources to help people with low vision. So, empowering yourself by finding the tools and learning about the tools, using them, so that you maximize your own independence—that is key and that can really help keep depression at bay. The other thing is that your doctor who has diagnosed the eye problem needs to be communicating with other providers and can bring in other providers. Your primary care doctor can bring in other people to help you manage depressive symptoms if you develop them, such as therapists and occupational therapists, who can help you adapt and help you manage the depressive symptoms and the anxiety that goes with it.

MICHAEL BUCKLEY: That is great advice—to reach out.

DR. JOHNSTON: I was going to mention a specific type of therapy called cognitive behavioral therapy. This is a commonly and widely used type of “talk therapy.” We address assumptions and perceptions that people make
in their lives, and very often when we encounter adverse situations, sometimes we make assumptions and we approach these situations in a way that actually works against us instead of for us. What cognitive behavioral therapy does is it helps you learn to reframe these perceptions, to see these things that are so threatening and discouraging, to see them in a way that allows you to work with them and overcome them. It is a process. It is not a one-and-done treatment. It is an ongoing process. It can be very empowering, because you learn the tools to recognize when you are having difficulty coping with a situation and what the particular situations are that you tend to fall into negative thinking about. Then it teaches you techniques to move beyond that and to cope with the situation.

MICHAEL BUCKLEY: That is very helpful. I want to stay on that point of the negative thinking. A minute ago you said it was very common for people to have grief in a situation like this. I think another very common reaction is just that fearing the worst, the catastrophizing. We had a question from Jeff from Texas who basically asked that point. How do you deal with the constant thought that you might go blind?

DR. JOHNSTON: It is frightening. It is frightening for a lot of people. One of the things that you have to do is, first of all, be informed. Find out. Talk to your doctor. Make sure you are asking your doctor questions. Sometimes people are afraid to ask for the details because they are afraid of the answer. You are best knowing. It’s not guaranteed that you will go blind. I understand that it progresses at a different rate in different people. Learn to focus on what you can do, rather than what you cannot do. Learn to focus on how you make your environment safer, how you make things better for yourself, despite this challenge. That can make you feel better and can make you less fearful of what is going to come next. The truth of it is that none of us know what is going to come next. It is not helpful to worry that a little bit down the road, maybe something terrible will happen. The best thing to do is learn what you can do to be strong and be able to cope from day to day. That actually helps reduce the anxiety a lot. The anxiety is understandable, but you can learn to manage it and that can make a very big difference.
MICHAEL BUCKLEY: That’s great. Dr. Johnston, I wanted to get back to what you said about that honest communication being so important. I know that a lot of people take pride in being independent and are uncomfortable asking for help. I really appreciate the points that you make about that honest communication. I want to remind our listeners that BrightFocus has a free pamphlet called “Top Five Questions to Ask Your Eye Doctor.” Hopefully, that might facilitate a good conversation. Related to that, Dr. Johnston, it has got to be very challenging for someone who is in some stage of vision loss to live day-to-day, life in the community, the stores, and the supermarkets. For example, if I broke my leg or twisted my ankle, you would see me on crutches and would provide courtesy, care, and assistance if we crossed paths in the supermarket. What about someone who is having some vision challenges? How should they help themselves be a little more comfortable when they are outside of the home?

DR. JOHNSTON: That can be a tough one, particularly when you are adapting to a new situation. I think the important thing is to remind yourself to be calm. If you are calm, it reduces the likelihood that the other person is going to get irritated. Communicating with them that you have an impairment is okay, too. You may even help them by allowing them to understand that you have that impairment. The truth of it is, you cannot really change other people’s behavior, but by being aware and modifying your own behavior, you can actually influence their behavior to some extent. People can be very helpful if they know that you need help. Do not be afraid, I would say, to ask for help if you feel people are rushing you or to explain what the situation is.

MICHAEL BUCKLEY: I appreciate that. Related to that, do you have any tips for people in terms of maintaining their friendships? At some point, that must be a challenge if people are having vision issues, or others, in terms of continuing good friendships. Do you have suggestions for them?

DR. JOHNSTON: Yes. Keeping your friendships and family contacts, those are very important. Some people have an inclination to withdraw socially and think that they cannot do things that they used to do. One of the things that it is worth putting your energy into is fighting those inclinations. Your family still loves you. Your friends still love you. You are
still the same person. By not connecting yourself with them, by not staying connected, they are losing as well as you lose through the loss of that social engagement. In addition to that, you put yourself at increased risk of depression if you isolate yourself socially. Sometimes social isolation goes along with physical isolation, so if you are not interacting with other people, you are moving around less. You are less physically active. That combination of decreased social activity and decreased physical activity can increase your risk for other problems. It reduces your cognitive alertness. It can affect your cognitive function. It is well worth really being aware if you are noticing the inclination to withdraw socially and you are not feeling like doing things that you would normally enjoy because of the changed circumstances or change in your visual function. Reaching out to people and finding adaptive devices that can help you use your phone more easily, making arrangements with people to get places—I saw a really nice quote, “Keep playing golf. Your friends can watch the ball.”

MICHAEL BUCKLEY: Mine wouldn’t have to look that far!
DR. JOHNSTON: Exactly. I know, me too. I think that is a very good way to think about it. Your friends are your friends. Your family is your family and that doesn’t change. Don’t shut them out.

MICHAEL BUCKLEY: That is wonderful advice. A lot of the research funded by BrightFocus and others on Alzheimer’s and other age-related vision diseases gets back to that point of the importance of staying mentally and physically active and eating well. I think that you raise some really good points about how to not have vision disease work against that. What about reaching out to new people in the community, for example, a support group or the role of your faith-based community?

DR. JOHNSTON: That actually is also very important. Support groups can be hugely helpful. The original support groups were developed for people who had tuberculosis years ago, many years ago. They hadn’t been used as psychotherapy. They hadn’t been used for people with depression or other conditions before that. It turns out that the people who were really involved in the support groups—despite the fact they had this terrible illness and were sick because of it or were depressed because of it—they actually all improved. Their moods got better and their depression
resolved. That is where group therapy started. These were peer-led support groups. Meeting with people who are dealing with similar issues on a regular basis can be a very powerful way to cope. You are getting the support. You are talking about some of the things you are going through. You are able to ask questions of people who have been through it and you can get feedback and guidance from them. I would strongly recommend engaging in support groups.

Some churches and synagogues and other religious organizations may have resources you don’t know about until you ask. It is also worth considering.

MICHAEL BUCKLEY: We actually have two questions related to some of these depression issues that you mentioned. One is from Kay from Los Angeles, who would like you to elaborate a little bit more about the talk therapy that you mentioned at the outset of this call. Can you tell us more about what that is and why you think it works?

DR. JOHNSTON: Talk therapy is another name for psychotherapy and, really, what that involves is meeting with a therapist—a mental health therapist or counselor—on a regular basis. There are different types of talk therapy. Sometimes what a person just needs is support. That is called supportive therapy—just to touch base and be supported in dealing with everyday challenges. There is a time for everything and there is a time for that. When a person is going through grief, in the acute phases of grief, that would be a time for supportive therapy. However, the most useful type of therapy, and the one that is most widely used, is called cognitive behavioral therapy. That is where people are helped to learn about perceptions and assumptions that are working against them. We all are inclined to make them. We are all inclined to get discouraged about things, or we get into a mode of thinking that can be negative because of some bad experiences or because we’ve been discouraged in attempting a certain thing. We start to assume that that is how it is always going to go. It can take an effort of will to see it otherwise. It can also take a lot of support to see it otherwise.

In a lot of situations, learning to see these things, these challenges—and I’m not talking about big challenges, having macular degeneration is a big challenge—I am talking about the little day-to-day challenges that can be just as frustrating. Focusing on the big challenge can actually get in the
way. Focusing on the day-to-day issues that are difficult and challenging really is challenging for a start and is a great way to help change things. So cognitive behavioral therapy helps you do that and helps you develop new strategies and techniques so that you are feeling more in control of things.

MICHAEL BUCKLEY: We have a few more questions on the depression angle here. One is, “How can someone know the difference between sadness or grief about a diagnosis versus what might be a diagnosis of depression?” Maybe I am not phrasing that the right way, but how do you know when you are crossing a line into a more serious condition that they need to address?

DR. JOHNSTON: That is a very important question, because there is a distinction. Grief and loss are often associated with symptoms that are very similar to depression. A person might have trouble sleeping, their appetite might drop off, and they might not be interested in doing things. They might be sad, they might cry. All of that is a normal part of grief in the early stages. If those symptoms, however, persist beyond a few weeks to months and the person becomes socially withdrawn and if they change their level of engagement with people that they could be talking to or that they would enjoy engaging with, and that doesn’t get better—if that persists beyond weeks to months—we see this all of the time with grief, but people who grieve recover from grief. When it interferes with their function, their daily function, then that is when it is depression.

Your primary care doctor is trained to recognize and treat depression, but not all are comfortable doing that. Sometimes they will refer you to a mental health therapist to see if this is depression that should be treated. Of course, one of the treatments that can be long-term or can be for as long as you need it is cognitive behavioral therapy, which I mentioned. There are also other treatments. The cut-off for using other treatments, such as medications, really has to do with how severe the depression is and how badly it is affecting you. Sometimes it is clinical depression, but it is not bad enough that medication is needed.

MICHAEL BUCKLEY: We actually just had a follow-up question about the anxiety. You talked about the importance of sleep and eating well. At some point, could anxiety get in the way of adjusting to the actual macular degeneration?
DR. JOHNSTON: Yes, and of course, anxiety and depression go hand-in-hand. Anxiety can occur as a symptom of dealing with a new situation, and there is such a condition as adjustment disorder with depressed mood that can have anxiety associated with it as well. Anxiety is important to manage, and one of the ways you can do that—there are a whole range of ways like mindfulness, meditation—the last thing ever you would want to do for anxiety is take medication, unless the anxiety is a symptom of a more severe depression. Then there are medications that are appropriate. But exercise is actually good as well for anxiety. It can reduce anxiety.

MICHAEL BUCKLEY: Since you mentioned the medication, what about people who may have concerns that some medication might increase their risk of falling at the same time that their vision diseases are increasing the risk of falling? Is that something that somebody should be concerned about?

DR. JOHNSTON: That is a very valid concern, and I actually have that concern with all of my patients. Again, this is a situation where if somebody suggests prescribing medication to you, you want to get all of the information you can about that medication. You want to find out what the medication is and how to take it, what the side effects are, and ask the question about falling. Some medications are more likely to increase your risk of falling than others, and the golden rule for treating depression in older people is to “start low and go slow.” Most of us in geriatric psychiatry will look for the lowest dose of any medication we are considering prescribing and half it and start the person on that. When you do that, there is less of a chance of the person falling, although with these medications there is always some degree of risk.

You have to be a little bit more careful. One of the things you can do, because falling is always a concern with low vision—I think most people who have already been diagnosed with low vision would already be making sure their environment is safe. That is an important thing to do, because if you have a safe environment where you have clear paths to move about in the house, you have objects to hold onto that you know where they are, and you know about your medication, you are staying hydrated so your blood pressure doesn’t drop when you stand—that will...
reduce your risk of falling. That is a whole topic in itself that we could talk about for half an hour, I think. But ask your doctor.

MICHAEL BUCKLEY: That is very important. I am glad you mentioned the changes in the physical environment. Again, that is such an important part. Related to that, if there is somebody else or a caregiver that lives under the same roof or visits often, how should a person who is going through macular degeneration—perhaps has some depression or other issues—how should they interact with their caregiver to make this as constructive as possible?

DR. JOHNSTON: I think they should be upfront with them about what they are going through and make it okay for them to ask you how you are doing and make it okay to talk about it. For one thing, it does help to talk about it. For another thing, if a person feels like they cannot acknowledge that you are having difficulties, that doesn’t help things. Your family, friend, or whoever is there with you—I think most people who have impaired vision know that it is best if their family or people who are in the house with them understand that stuff can’t be moved around or left lying around or left in the way. That is a given for most people in this situation. If depression is part of the picture, then your main support system is usually your friends and family. So let them know. If you are trying to change your behavior, if you are working on the depression and you are trying to keep up a level of activity, they are your biggest ally. They are your team, so keep them in the picture. For persons who live alone, remember you have a telephone.

MICHAEL BUCKLEY: That is a great point. It seems like in all of these issues there is a cloud of stigma that may cover over some people. If I am hearing you correctly, it seems like through all of this, people should try to fight that stigma. How would you address that?

DR. JOHNSTON: Absolutely. I would totally agree with you. I think that we are our own best advocates. Anybody who has a chronic or severe condition is really one of many—especially these days. Society is aging and we are all aging. The more open we can be about the conditions associated with aging and about the challenges of aging, the more we can bend society in the direction, I think, that it needs to go. That is my
personal belief and it is what I recommend to my patients, because if you pretend these things don’t exist, they aren’t accommodated. I believe that all of us would be better off if people would acknowledge that everybody is not perfect.

MICHAEL BUCKLEY: I appreciate that. Related to that, Dr. Johnston, you mentioned support and counseling services and other types of resources. How can someone find out that information?

DR. JOHNSTON: I mentioned your primary care doctor might be able to refer you to a local mental health therapist. Everywhere is a bit different, and different states have their own available resources. You could start with your primary care doctor. You could also go to your state department of human services. There are also resources like Lighthouse Guild, and of course, your BrightFocus website has wonderful information on it. If you look for your local resources in your own state, that is probably the best place to start.

MICHAEL BUCKLEY: I appreciate that.

DR. JOHNSTON: The Lighthouse Guild, and of course there is the Center for the Visually Impaired and the American Foundation for the Blind. I didn’t put the websites on my little cheat sheet here, but there are a number of websites that people might find helpful.

MICHAEL BUCKLEY: Great. We have resources at BrightFocus.org. I wanted to turn to the topic of hallucinations. I understand that that can be part of the adjustment. Is that something that you encounter in your practice?

DR. JOHNSTON: Yes. It is something we see, and I am sure some of the people listening may have had some experience with this. Up to about a quarter of people with macular degeneration, particularly in the later stages, can develop hallucinations. They are visual hallucinations. I think one thing to remember is that they usually are not scary. They are usually not menacing. Some of them, in fact, can be quite pleasant. I’ve had several patients who report flowers, seeing bunches of flowers, and that kind of thing. The hallucinations I think are almost more like an illusion
where your eyes are receiving stimuli and trying to interpret them, and they are creating bunches of flowers where there aren’t any, because of this stimulus that is not being received correctly. However, if a person has menacing or scary hallucinations—obviously any time you have a hallucination you need to talk to your doctor about it—if they are scary, it could mean that the person has depression because that would be consistent with other potential symptoms associated with depression.

MICHAEL BUCKLEY: Dr. Johnston, as we reach the end of our time together, do you have any concluding remarks or big picture advice from what you have seen during your time as a geriatric psychiatrist that you think would be useful for families impacted by vision disease?

DR. JOHNSTON: I’ve seen a lot of people through years of dealing with these illnesses and some of the things I’ve said, like allowing your family and friends to be part of the solution, not shutting them out, accepting when they want to help you, asking for help when you need it—but, most of all, learning about your condition. Learn as much as you possibly can about getting accurate information and not being afraid to ask your doctors for clear information.

Get somebody to write down your questions before you go to the doctor so that you are prepared, and get somebody to write down the answers so that when you leave there you have something to refer back to. It isn’t all about what happens at the doctor’s office either, but having the information and having accurate information can be a big help. Also, don’t isolate yourself.

MICHAEL BUCKLEY: Yes, that is all great advice. Both in terms of managing your time in a physician’s office, but also addressing the number of issues. Dr. Johnston, again, I just want to thank you so much. I think you’ve really been very helpful and very positive. I appreciate your candor and your understanding of how difficult these issues are. I want to thank you for that.

To our audience, thank you very much for being a part of today’s BrightFocus Chat. We have a number of resources available at www.BrightFocus.org and also publications that we can send for free.
through the U.S. mail, like Macular Degeneration: Essential Facts—the basics of diagnosis and treatment. We have a new publication about clinical trials that answers some of the questions you might have about whether to participate. We have materials on driving to help with conversations within your family. All of that is available at www.BrightFocus.org.

Dr. Johnston, on behalf of BrightFocus Foundation, I really appreciate the work you are doing to help families in your own practice, and through today’s Chat, helping families all across the country. Thank you very much.

DR. JOHNSTON: You’re very welcome. It was a pleasure.

MICHAEL BUCKLEY: This concludes today’s BrightFocus Chat. Thanks again for participating.
Useful Resources and Key Terms

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

- Information on research funded by BrightFocus Foundation
- Update on Clinical Trials for Macular Degeneration
- Clinical Trials: Your Questions Answered (PDF)
- Healthy Living and Macular Degeneration: Tips to Protect Your Sight (PDF)
- Macular Degeneration: Essential Facts (PDF)
- The Top Five Questions to Ask Your Eye Doctor
- Treatments for Age-Related Macular Degeneration