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Glaucoma: what every patient should know.

Part 4. How should I change my life? What does low vision treatment have to offer?

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Abstract

Being diagnosed with glaucoma tends to permanently change one's daily activities, but it is important for every patient to realize that glaucoma can be managed and generally kept from changing his life.

The first part of the article explains what everyday personal habits — such as aerobic exercise — might be useful for glaucoma patients, which of them to avoid (Valsalva maneuver, weight lifting etc.) and which have no effect on glaucoma whatsoever (diet, alcohol consumption, caffeine intake, reading and watching TV).

The second part of the article focuses on the importance of low vision rehabilitation services and understanding what treatments, practical aids, technology and training it has to offer. One of the two main options of the low vision rehabilitation is using special equipment to improve visual function, choice and variety of which is vast (lenses, special filters, cell phone technology, magnifiers with LED lights, video magnification, software, etc). Alternative approach is using adaptive strategies and techniques and "low-tech" solutions.

The author also reminds that psychological counseling and treatment may be in question in some cases, since glaucoma patients with substantial vision loss are prone to depression. The difference in life with glaucoma is often one's ability to adapt, and incorporating devices and adaptive strategies in to daily life might help with that.

KEYWORDS: glaucoma, quality of life, low vision rehabilitation, adaptive strategies.

Глаукома: что необходимо знать каждому пациенту.

Часть 4. Как изменить свою жизнь, если у вас глаукома? Возможности реабилитации пониженного зрения

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Резюме

Диагноз «глаукома» зачастую полностью меняет привычный жизненный уклад пациента, но необходимо помнить о том, что привнесение необходимых изменений в повседневную жизнь может помочь человеку адаптироваться к болезни и научиться лучше с ней справляться.

Первая часть статьи объясняет, какие ежедневные занятия (такие, как аэробная нагрузка) могут быть полезны для пациента с глаукомой, каких следует избегать (прием Вальсальвы, поднятие тяжестей и пр.), а какие не влияют на её развитие и течение (диета, алкоголь, кофеин, чтение, просмотр телевизора).

Во второй части статьи рассматриваются возможности реабилитации пониженного зрения, дается общее описание входящих в нее способов лечения, технологий, тренировочных программ и практической помощи. Одно из основных направлений реабилитации пониженного зрения — использование большого диапазона специальной технической помощи (линзы, специальные фильтры, использование мобильных технологий, лупы со светодиодной подсветкой и видеоувеличители, специальное программное обеспечение и т. д.). Альтернативный подход предполагает обучение адаптационным техникам и стратегиям и использование более низкотехнологичных решений.

В заключение автор также напоминает о том, что в связи с предрасположенностью пациентов с резким ухудшением зрения к развитию депрессивных состояний, в некоторых случаях встает необходимость включения психотерапии в общую схему лечения. Качество жизни пациента с глаукомой во многом зависит от его способностей к адаптации, и использование адаптационных стратегий и специальных устройств зачастую способно оказать необходимую помощь.

КЛЮЧЕВЫЕ СЛОВА: глаукома, качество жизни, реабилитация пониженного зрения, адаптационные стратегии.

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"You mean I'm going to have to take these drops for the rest of my life?" For those choosing eye drops, this is a major reality of how glaucoma will change your daily activities, though if it's one 5 minute period getting the drop in once per day, and the occasional refill of the bottle at drug store or prescription plan, that isn't a huge time commitment. More than anything, it is the knowledge that something (another thing) is wrong with our body that is depressing, at first. The more we realize that glaucoma can be managed and generally kept from changing our life, the less depressing it should be.

Often, I am asked: "What else can I do in my daily activities that will help my glaucoma?" In comparing glaucoma to other diseases, especially the major eye diseases, there are only a few things that you will wish to consider. We know, for example, that cigarette smoking and sunlight exposure are both big causes of the eye diseases called cataract and age-related macular degeneration. Interestingly, these are not related to glaucoma. You still shouldn't smoke and you shouldn't be outside without eye protection, because these diseases happen to people of your age, too. But, in extensive studies of personal habits, we and others have found that diet, alcohol consumption, and caffeine intake are pretty much unrelated to causing glaucoma or making it worse. Clearly, eating a healthy diet containing fruits and vegetables and limiting booze and caffeine to a small amount per day will help you to live longer and healthier. So do that for yourself and to last long enough to watch your grandkids grow up. If you drink more than one caffeinated beverage per day, knock it down to one and make the rest of what you drink caffeine-free.

One major thing you can do that is proven to lower eye pressure and improve blood flow to the brain and the eye is aerobic exercise. This means doing something at least four times per week for more than 20 minutes that raises your pulse rate to a level that makes your heart work. Generally, it means walking, swimming, biking, or stationery machining at a level that keep you a bit out of breath. You should be able to talk to the person with whom you're running or walking, but with difficulty. First, check with your medical doctor before starting anything. Second, you may wish to be referred to a physical therapist for good hints on what and how to do it. Third, pick something that you really will do four times a week. If you hate to swim, don't try that. If you can't afford a health club membership, pick walking. Fourth, get a partner. When I ran marathons, one of my training systems was that I knew two guys were going to show up to run with me at my back door every dark, cold morning. If I thought that rolling over in bed and going back to sleep was a good idea, having them bang in the kitchen door reminded me to get my running shoes on. You will enjoy walking and talking with someone or a group more than solo. Fifth, make a standard time when the exercise is going to happen. With my busy schedule of job and kids, I had to simply get up 45 minutes earlier every day. In studies with older adults with early glaucoma, eye pressure fell by two points or so as they began consistent exercise. It's almost as good as adding another eye drop to protect your vision. Get off the couch!

Exercises which you should avoid are anything in which you are upside down or your head is below your heart during the exercise. For example, head stands or down-facing dog pose in Yoga cause your eye pressure to be twice or three times higher than normal. While there has been no study to show that yoga leads to worsening of glaucoma, there are plenty of other Yoga poses to decrease your stress level. In fact, our research group is now studying whether practicing yoga could lower eye pressure. Holding your breath while exerting yourself (called the Valsalva maneuver, like straining on the toilet) is also a time when your eye pressure goes sky high. So, if you lift weights for exercise, which is generally a good idea to maintain bone density, make it low weights with more repetitions of lifting, rather than heavy weights that make you grunt. A similar breath-holding problem applies to those playing the larger wind musical instruments like the French horn. One study suggested that there was a greater chance of glaucoma in symphonic wind players. If you play a brass instrument, it makes sense to have frequent checks of pressure, optic nerve head and visual field.

Your Mom may have told you not to read so much or you'd ruin your eyes. Mom was right about a lot of things and here she was only half right. Persons between the ages of eight and 15 develop more near-sightedness from close eye work if they have some inherent tendency to it. But, for the adult glaucoma patient, there is no reason to think that using the eyes is harmful. Read away. You can rot your brain by watching reality TV, but it won't hurt your glaucoma.

What does low vision treatment have to offer?

Some years ago, my godmother, whose art projects had always graced her home, developed a severe vision problem in her 80s. Unable to read normal print with standard glasses, she felt that it might be no longer possible to lead a "normal" life. Fortunately, two things made it possible for her, now 97, to continue to send me lovely hand-written letters, to do her finances and to surf the Internet. First, she has the wonderful capability of adjusting to change. That isn't easy for all of us, as I realize with every passing year. Persons whose vision has changed forever for the worse, can easily fall into the trap of feeling sorry for themselves. People keep searching in vain for a cure and a way to make it like it always was. I hear them just keep asking for "a different pair of glasses that will let me see normally." There are no magic glasses. My godmother was willing to try something new if it let her enjoy life more.

She fortunately had an eye doctor who recommended that she seek Low Vision consultation and she lives in a city that has a fine office for that. Many eye doctors try their medicines, their lasers and their surgery, and, when no further "treatment" will help,

the patient hears the message: “there’s nothing more I can do.” That’s hard for doctors to admit, since we spend our whole lives trying to help and (like everyone else) we’re lousy losers. However, it is not the end of the line. After the initial shock wears off and acceptance begins, the next step is to seek low vision rehabilitation services.

No one wants to think of themselves as “low vision” or “blind”, and the images of white canes, seeing-eye dogs, and dark glasses may even invoke our pity, but, surprisingly, our research has shown that 37% of people seeking low vision services nationally have only mild visual impairment and are simply not satisfied with their present visual function. Even a little vision problem can become frustrating when you just need to read the account number off a credit card. I find that many of my patients simply don’t want to give vision rehabilitation a try. My argument is that they have little to lose and a lot to gain. You don’t know what can be done to make your life better without finding out what’s out there. Understanding what treatments, practical aids, technology and training that physicians, occupational therapists and orientation and mobility specialists have to offer, can be empowering. With that said, one visit to a low vision clinic will not undo the effects of vision loss from glaucoma nor will it cure you. Like any treatment, if you are told about things to do and you don’t want to do them, you can walk away. In fact, a vast majority of my patients who have gone to our Wilmer Lions Vision Center for consultation tell me that there were beneficial treatments and suggestions that improved the quality of their lives. Like any form of rehabilitation, success may involve change, and that may be a lot to ask for. This is where the rubber meets the road. A positive attitude, an open mind and good support can make a world of difference during this process.

Problems reading, driving, and walking in dimly lit restaurants are common complaints. Low vision rehabilitation addresses each activity by using lenses, lighting, reverse telescopes, special filters, camera, cell phone technology, and adaptive strategies. Nowadays, there’s a lot of equipment out there to improve visual function — magnifiers with LED lights, video magnification, software, etc. To assess rehabilitation potential and make treatment recommendations, specialists can be helpful in directing the approach before spending money on devices that are not right for you. Buying things off the Internet might sound simple, but you can’t tell what you need and everyone wants to sell you their product. I wouldn’t think of buying a new car without test-driving it first. Devices may not be the solution. Training on adaptive techniques and “low-tech” solutions may be what’s necessary. You really don’t need your vision for everything — someday we’ll be able to drive without it. For now, however, instead of getting frustrated with getting the toothpaste on the toothbrush, just squeeze the paste on your finger first and then wipe it on the brush. A low vision specialist has only your best interests at heart and is the best person to direct this part of your care.

Before vision loss, you probably used reading glasses either as part of “bifocals” (now mostly progressively changing power lenses) or separate reading glasses. Glaucoma often leaves the ability to read individual letters or words pretty much intact, but constricts the usable area of reading vision to a tiny tube of good vision in the center. On occasion you may notice that you miss the beginning of words or it is harder to keep your place when going to the next line of print on the left. When my glaucoma colleague, Dr. Pradeep Ramulu, developed special tests for continuous reading, he found that glaucoma patients start out okay, but slow down much more than others their age by 15 minutes into their reading. This is exactly what we had heard from patients over many years: “I get really tired quickly when trying to read.” This is where careful examination can make all the difference, as it may be dry eye or cataracts that are causing the problem, rather than the glaucoma. Fortunately, the ability to see small print is often retained, but it is the loss of contrast sensitivity, the sense that someone has taken some of the ink out of the printer that’s annoying. You may find reading red writing on a blue background is impossible. This loss of contrast sensitivity is often the culprit in problems driving at night and recognizing faces at a distance.

Low vision specialists make things better through a variety of “work-arounds” and solutions, such as better ways to light the page you’re reading, and moving the book to the optimal distance for what you’re trying to see. Task lighting is often the most effective solution to enhance reading. Directed-source lights, like the full-spectrum and LED, positioned properly and close to the book, may dramatically improve reading ability. Some of our patients even contract with electricians to make lighting modifications in their home that can make all the difference. For the most part, people with glaucoma need a lot of light, but undirected light can be troublesome in certain situations.

Glaucoma patients are very bothered by glare, meaning light that comes into the eye from the side or the top, away from the center part you’re trying to use to see. Indoor fluorescent lighting at superstores, driving in and out of shady areas or adjusting to changing light when walking out of a movie theater can be worrisome and even scary at times. Understanding the effects of changing light and preparing accordingly can be helpful. Glare outdoors is best handled by hats with a brim (baseball caps or a visor are great). Sunglasses that are too dark can be worse than not having them on. They cut down the light coming directly where you want to see, but let in light coming in from the side (the glare producing stuff). If you don’t like hats to block glare, get wrap-around glasses where either the lenses or the frames block light coming from the sides. Each person is different, and the choice of filter color and light transmission can make a difference. Glare evaluations can be performed as part of low vision assessment.

If reading small print has gotten harder, magnification may be helpful and prescribed in the form of spectacles, hand-held devices and computer

adaptations. For some with glaucoma, however, bigger print is not always better. If reading books and newspapers are important to you and magnification is not effective, than you may wish to attempt listening to Talking Books. They are read by wonderful actors and it is a great way to continue to enjoy the classics or the latest best sellers. Talking Books are widely available and many local libraries and many have converted from the traditional cassette tapes to providing very easy-to-operate digital players. The digital tapes of interest are sent to your home so there's no need to drive to the library. Because of computer use and the advent of Kindles and IPads, reading with vision impairment has been revolutionized. Best yet, when the eyes tire, turn on Text-to-Speech, sit back, relax, and listen. I always tell my patients, that there has never been a better time in history to live life with vision impairment.

The great thing about watching TV and using a computer is that you can make it easier with the right kind of lens correction and by changing the device. Often using glasses prescribed for the computer, changing your work distance, getting a bigger screen, or using the right kind of software that enhances the font or reads aloud will make it the activity less frustrating. Understanding what is effective for you can make life more fulfilling.

Judging stairs, steps, and curbs and walking safely can be challenging with vision loss from glaucoma. In studies that Dr. Ramulu and others working with us at Wilmer have done, we find that glaucoma patients who have significant loss of vision walk more slowly and, unfortunately, bump into things more often. People comment that they are more cautious when walking because they are afraid of falling. Orientation and mobility specialists, occupational therapists specializing in vision impairment and physical therapists can assist with fall prevention and balance, thus improving your mobility safety. Your doctor or therapist may recommend something as simple as removing the bifocal and prescribing distance-only glasses. You can be more confident while walking after low vision assistance by learning how to use your remaining vision, by scanning effectively within your limited view and by considering the use of a walking stick or cane when out at night or in unfamiliar places. Home safety is the key to avoiding a fall that breaks a hip and puts you in the hospital. You can have a therapist who visits your home and makes many helpful suggestions about how to live independently and as normally as possible with limited vision. Some of the logical things that we don't immediately think of, for example, are the removal of cords that trip us up or sliding rugs.

Driving is one of the most important abilities for many in our culture, allowing independent living in our present home setting. But how safe are you driving with whatever glaucoma has caused in your vision? Do you know what you don't see? Many people with visual loss modify their own driving by limiting themselves to driving in the daytime and or only in familiar areas. Even with these restrictions, critical errors may occur. In one study of seniors, our group found that a substantial number of glaucoma patients had given up driving entirely. For some of them, this was probably for the best, as they could not see well enough to drive safely. As older age is associated with slower reaction times and physical limitations, it may be a good choice to find other ways to travel and shop. However, some patients who we found had given up driving seemed to have vision and capability that otherwise should not have been limiting. Legal doesn't mean safe and safe doesn't mean legal when it comes to driving. Talk with your vision rehabilitation physician. There are facilities available for testing your ability to drive with your present vision that will show you and experts that you continue to qualify to drive safely (or not).

A very common thing that persons with significant vision loss from glaucoma and other eye problems have is seeing things that aren't there. As many as one third of those with major vision loss experience seeing patterns, shapes, objects, and even people that they know are not real. These are not a sign of dementia and are not hallucinations in the sense of having a mental problem. I'm always glad when a patient trusts me enough to mention this, as older people fear that if they tell their children what they are seeing that the family with think that they have "lost it". These images are quite simply the product of your brain not getting visual stimulation from big areas of the view of the world from which the brain was used to "hearing". The phenomenon is named after a French doctor, Charles Bonnet. Patients described seeing patterns like the shape of tiles in a floor, like leafless trees against a winter sky, or images of realistic objects. As opposed to actual hallucinations, where the person being seen might talk to you, these are all visual things. It's as if the part of your brain devoted to vision gets bored when it doesn't get enough input. So, it plays back patterns and "movies" of past experience into the blind zones. This happens most often when we are not thinking about much, and staying very engaged in other activities makes it happen less. However, there is no way to stop it, despite some suggestions that strong psychoactive drugs can decrease it. We tell patients that once you understand what it is, you can hopefully "enjoy the show" without worrying that you're losing touch.

Vision loss is scary and can lead to disability and depression in some cases. In our recent research, there is evidence of depressed mood in about 22-25% of people seeking vision rehabilitation services. Depression is more common among seniors overall, but having visual difficulties makes it more likely. Seeking psychological counseling and treatment is appropriate. Some of the frustration from vision loss can be decreased by seeking vision rehabilitation services and incorporating devices and adaptive strategies in to daily life. Just remember, people born totally blind have fulfilling lives. The difference in glaucoma is often one's ability to adapt, just like my godmother.

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