

LIVING WITH GLAUCOMA

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DOCTOR/PATIENT RELATIONSHIPS

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Part I

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In our lifetime we form many relationships, some intimate as with our partners and our children, some sharing as with friends, others distant but necessary as with our health professionals, a relationship that can be a life or death issue, but is more often a healing relationship. Many of our illnesses are short term, but some as with glaucoma, a chronic illness, require a life-time relationship in order to preserve our vision. And therein, is the problem. Both doctors and patients need to exchange important information, the doctor on the state of the condition, the patient to report accurately the effects of the treatment.

Sharing information is an important aspect of treatment. The doctor is not clairvoyant and the better the patient is able to observe and relate observations and health issues helps the doctor to steer the course of treatment.

The doctor-patient relationship is beginning to shift away from a one-sided affair, as both patients become more knowledgeable about their conditions and younger doctors invite patient participation. In fact, some doctors now openly advocate it as expressed in a recent article by two Emergency Room doctors at Brigham Women's Hospital in Boston, Massachusetts. They observed that it really is up to the patient to tell the doctor what's going on. Saying you have a pain, for example, does not provide much information. If you tell your doctor, however, the circumstances surrounding the pain, when you became aware of it, how often it occurs, and other pertinent information relating to it, the doctor may be better able to diagnose your condition.

Many doctors are now using a more patient informational approach. Recently I had that kind of experience. I was referred to a specialist. At my appointment I was not subjected to a series of tests before I saw the doctor, rather the doctor asked me to tell him the circumstance of my

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symptoms. I spoke for about fifteen minutes and only then did the doctor order tests. I will return to this doctor. On the other hand my former GP could no longer practice and I found a new GP who immediately ordered a series of tests, which I didn't take. Challenged, he advised me he could not treat me since I obviously disobeyed him. Subsequently, I found another GP who listened and respected my decisions. Incidentally, research recently revealed that patients didn't need the evaluative tests I had turned down provided the patients were symptom free.

Another problem the ER doctors discussed was exactly the above situation. A doctor hands you a list of tests and you have no idea why you need them. Does the doctor suspect a malevolent condition? Some of these assessments are invasive. Why does your the doctor recommend them?

Alternately, you may be too nice to say anything and simply obey like a good patient. Some alert physicians have noticed how nice their patients are. We're nice, really nice. We don't want to hurt our doctor's feelings. A doctor will say something, and we'll accept it, even though we have misgivings about undergoing this or that procedure but we

don't want to challenge the doctor. I knew a remarkable dentist at one time who said to me, "You know your own body." She was right, of course. In the end we are the arbiters of our bodies. We live in our bodies and oh, do we know it. So, if you think something won't work for you and you're too nice to demur, you may doing both yourself and your doctor a disservice.

Learning the terminology is a step forward in the doctor-patient relationship. The doctor will say, you need a trabeculectomy, or you need an operation. An operation today could be any number of procedures. It can be a shunt, a trabeculectomy, canaloplasty, laser procedure and so on – they're all operations. You need to know what is suggested or is going to be done. If the doctor says, I think we'll do an eye stent. What the hell is an eye stent? You have no idea. But again you're too nice to ask what an eye stent is, and how it is performed, and what you need to do following the procedure. Despite these issues, most of us respect and appreciate our doctors for if we do not feel comfortable with our doctors, we very often seek another doctor.

At times, however, your doctor may suggest that a specialist be consulted, or you may ask to be seen by a specialist.

Now this highly qualified doctor takes a quick look and as quickly announces we'll do this, this, and this. You don't understand what you are being told and, furthermore, it all sounds frightening. And maybe you don't want any further intervention. You never return to that doctor although some of the recommendations might have helped. On the other hand, and here we return to being nice again, you may not want to hurt the feelings of the doctor that you really like and may not seek out other treatments that may be beneficial.

I read about a woman with Stage 4 breast cancer. She was told that at best she'd live 5 years. She talked with her oncologist, and decided she didn't want chemo and radiation with its associated ill effects. She was not unduly suffering and she preferred to go as long as she could in her present state, but her oncologist suggested making an appointment with a well-known specialist, tops for her condition. Being a "nice" person she went to see him and he proposed the chemo, radiation, the whole works. He said, "That's the protocol for all my patients." She said, "I don't want radiation. I'm living a decent life." She stood

her ground and again refused the standard protocol.

MEMBERS OF THE GROUP SPEAK UP.

–I think doctor/patient relationships should be good. I've had some issues with doctors; specifically they wouldn't let me alone. This was a gynecological issue, a D&C, but the doctor said that I needed a hysterectomy telling me that she wouldn't put me through a D and C. Someone else told me to go to another doctor, the chief of the staff. And although I was not happy with him, he performed the D&C. (Editor's note – doctors perform more hysterectomies in this country than any other country in the world).

PUSHING THE ENVELOPE: With internet and television, some of us become overnight experts in our conditions. We take information we have gathered to our doctor. We glibly toss out medical terms. There was a wonderful cartoon in The New Yorker. A big sign on the doctor's wall read: PLEASE DO NOT MENTION DR. OZ. We arrive with these bits of information, smug in the knowledge that we have become an informed patient and we present our findings to the doctor expecting praise for our efforts. Chances are your doctor

will ignore your efforts as a threat even though you may not mean it that way. This doctor may be very effective in treating your condition. So do you drop your attempt to interact on another level or do you revert to an old-fashion doctor-patient role? There is no standard answer to these questions, but they do require thought.

Another problem may arise when you find yourself dithering about having a procedure. Is it because you don't understand exactly what is involved and your questions may be simply answered if you just ask them. You may want to know when you can go back to work, what steps do you need to take while the eye is healing, why you need to take so many drops before and after the operation, if certain foods or liquids will affect the healing process, what exercise level. If you have trouble remembering what you need to ask, write them out and hand them to your doctor.

Not too long ago I fractured my ankle. Immobilizing a fracture limb no longer requires it being encased in a plaster cast. Instead a plastic brace is attached with a Velcro fastener. As the medical assistant brought out the plastic brace I reached for my sock. He shook his head and affixed the plastic brace to my bare skin. I

was doubtful but didn't insist on the sock. Within a day I experienced severe contact dermatitis. When I told the orthopedist he said I should never use plastic directly on the skin. I didn't insist forcefully enough with the assistant.

Several people discussed problems associated with surgery such as the operation failing immediately or within a month or more. One member said she was a total medical wreck. In addition to the affected eye, she found other problems occurring that she attributed to fear.

Another member who had been a caseworker empathized both with the doctor and the patient, for in her work she experienced the trauma of being involved in such cases. As a result she had to leave her job because of burn-out.

It is frightening not to do a procedure. And then after the procedure to be told that it didn't work out right and the procedure needs to be redone. The doctors are trained not to be involved in your emotional responses for if the doctor loses his/her objectivity, s/he may lose perspective. It's a necessary defense to prevent burn-out.

SECOND OPINIONS: One doctor advised his patient to go to

Philadelphia for a second evaluation. She considered that a sign of a good doctor. Medicare will pay for one second opinion but in most cases not for a third and fourth. You won't hurt your doctor's feelings if you ask for a second opinion.

If your doctor doesn't suggest a second opinion, you are within your rights to suggest one. A number of people choose Dr. Quigley at Johns Hopkins in Baltimore for a second opinion. One of the members found it was less expensive even including the transportation and an overnight hotel than having a second opinion with some doctors in New York.

CHOOSING A DOCTOR:

Perhaps the problem lies in the initial choice of doctor. What is the criterion for choice? On what basis do we decide to choose a doctor to treat our condition? There is a very good site on the Internet. It's a NYS Physician profile that lists every physician who practices in New York. It provides information about malpractice suits, education and also where the doctor practices and other pertinent information. While it may be difficult to choose a doctor based on cold facts, this site can be quite helpful in making a choice. One of the members detailed how she went

about choosing a doctor. She said she would rule out some doctors advanced in years for since her condition is chronic, she knows she will be with that doctor for the long haul. Younger doctors who had already built up a background of experience might be a better choice for they would probably be more adept in the new technologies and familiar with recent research findings.

--One member appreciated that some doctors presented the facts including the pro's and con's and as a result she became comfortable with the doctor. If a doctor knows his expertise and knows how to present needed information, the patient feels comfortable both with the doctor and the procedures offered.

--Another member reported that when she was first notified that she had glaucoma, she made an appointment with somebody known as a doctor's doctor, a glaucoma specialist. He was efficient. He told her she would need surgery, but she needed some questions answered such as how long she'd be out of work, the recovery time, the protocols she'd need to take. He was busy at the time so she called several times to see if there was a time when she could speak with him or possibly speak to an assistant. The idea of having surgery was frightening.

But neither he nor anyone in his office responded. So she wrote him a letter telling him of her experience with his office and that she probably was not the only patient that had this experience. She also stated that she would no longer be his patient, that she had found another glaucoma specialist. That's what you have to do. Let doctors know that the patient needs to be treated with common courtesy and respect. This member believes that it's good to either confront the doctor or write a letter to advise the doctor and his staff the effect they have on patients when the patient's requests for information are ignored. Subsequently this member did receive a phone call but by this time she had found another doctor. She learned later that her letter was effective in improving the procedures in his office.

One of the long-time members of the support group stated that she accepts her glaucoma so that the rest of her body doesn't get ill from it. But she will fight it to her last breath. She has visited doctors who have told her that she has so little vision in one eye she does not need to take drops. But she is determined to save what she has. She wants to know everything the doctor knows about her condition.

She urges patients to ask doctors what their pressures are. They have a right to know as they have a right to know the form of glaucoma they have. Patients need to take on a more activist role. The outside world will not advocate at the same level as the patient experiencing the prospect of potential blindness.

One patient described standing her ground when the doctor advised retinal surgery that required her head to be kept down for a period of time. She refused that surgery knowing that position might compromise her glaucoma.

QUESTIONS: We all have questions but they seem to vanish when we are with our doctor. Write out your questions. Bring them with you or send them to your doctor in advance. That way your doctor will be prepared to respond and allay your fears. Often, we worry needlessly because we lack information.

Alexander Pope, an 18th century English poet wrote "A little knowledge is a dangerous thing." Of course it's true as many of you have found, but in certain cases, a bit of information can help you shape an appropriate question. When a doctor says I see changes, ask what do those changes signify? The visual field is an excellent instrument for

measuring vision loss, but perhaps, you and the test are not compatible or you hadn't slept the previous night or a disaster had occurred in your family. You have a right to retake the test. If for some reason you cannot take the test you can ask your doctor to do a non-invasive test such as the Heidelberg or the OCT. Both are electronic devices that measure the nerve fiber layer and provide an accurate reading of vision loss. Teaching hospitals have these instruments.

Sometimes when you do a visual field, it comes back saying too many errors. One of the problems when first taking the test is that the medical assistant doesn't explain the procedure carefully enough or doesn't monitor you while doing the test. For example, if you tire, you can hold down the button and give yourself a little break. Another problem may be the distraction of people chatting within earshot. Not only do you have to speak up to your doctor but to the medical assistants or technicians as well.

A member reported on a recent experience that put the visual field test in perspective. She felt she was losing vision but two visual fields did not corroborate her impression. Her doctor told her that the visual field tests only the acuity range of

vision, but not contrast sensitivity, and color perception. She learned there were four components that comprise vision and then she realized that a different component had deteriorated one not tested by the instrument. With that knowledge, her anxiety about taking the test lessened.

One member stated she schedules visual fields early in the day, after taking her drops believing that her eyes are in the best shape at that time.

Another member added that it is helpful for the physician to use an Amsler grid. It's a quick way of indicating vision loss, and incidentally, legal blindness.

SELF TESTING: A member stated that she puts one hand over one side of her face to check each eye's peripheral range.

Lovett added that people find by self-testing that they can still do this or that.

PART 2 ADVOCACY/AWARENESS

Joe Lovett, producer of the documentary **GOING BLIND**, joined the Group. He has been showing the documentary worldwide to raise awareness of glaucoma. He brought a special message to the Group – Advocacy. While we do at this stage accept

inevitable vision loss, we cannot be passive about it. We need to demand more research. Lovett began his medical reporting at 20/20 with the AIDS epidemic where young patients did not accept the death sentence of this illness. They hammered the government and the doctors until research for effective medications was developed.

Lovett announced that there would be a state house screening of Going Blind at the State House in Albany on April 30th at 5pm. He invited glaucoma patients to come. Before the screening, people can meet with their representatives to discuss the issues facing those who are blind or have low vision. Legislators need to know that there is a community of people afflicted with this debilitating condition and who care about these issues and are displeased with the dearth of interest and support.

Lovett also announced that he was in touch with Dr. Ritch and reported that Dr. Ritch aggressively pursues possible cures or remediation of glaucoma problems. Dr. Ritch supports an active research team. As well he is in close touch with the best in the field. Lovett feels there's a disconnect between treatment and quality of life in ophthalmology. The problems

associated with vision loss seldom enter into the treatment plan. How often has a doctor asked you, "just what are you seeing?"

Lovett addressed the medication issues. Drops have been the first standard of treatment for a long time. Some professionals refer to glaucoma as a benign disease implying all that needs to be done is to keep the pressure in check through the various procedures of medication and operations. At conferences, however, glaucoma is referred to as a relentless disease.

Lovett advocated more basic research into glaucoma especially since it is now increasingly evident with brain research science that there is a connection in the neural pathways with such diseases as Alzheimer's, MS, autism and possibly other behavioral diseases.

But there are some treatments not approved by FDA that exist in other countries and these might benefit us. He mentioned a form of treatment in Germany that acts on nerve cells and establishes new connections in the brain to stimulate better processing of the object viewed. The treatment is called alternating current stimulation. The laboratory is a two-hour train ride from Berlin to the University of Magebourg. It is directed by Dr.

Bernard Sabel. Lovett speculated that if the theory works, perhaps the protocols could be extended to the other brain diseases mentioned above.

He has seen results of the therapy. When he began the therapy, he couldn't see his left pupil with his left eye when he looked in the mirror. After the therapy, he was able to do so. He also attended a ballet in Berlin and was able to read the program with his left eye with and without his glasses. Normally he couldn't read with his left eye very well at all. And, adding to his enjoyment, he could see the details of the dancers' faces on the stage.

The improvement diminishes over time, but it appears to improve the sight in the long run. The treatment regimen requires daily treatments for 10 days at six-month intervals. It is designed for optic nerve damage and is used for glaucoma, trauma, stroke and tumor. There's a little video on UTube about it. <http://bit.ly/ZGRO7W>.

Lovett also stressed that as a group or as individuals we can have an impact on the FDA. We needn't sit around waiting for something to happen but can lobby the FDA to make a move. It is within our right to make an appointment and be heard. We can go as a delegation.

Lovett cites an all too familiar story about receiving a phone call from a 67-year-old man who went in for a routine contact lens exam in upstate New York and discovered that he has tunnel vision. His visual fields showed profound vision loss, but the doctor had told him that he had moderate glaucoma and given him drops and set up a follow-up appointment in a few months. The man went on the web, found information and also Lovett's film and expressed his dissatisfaction with the information available. Lovett referred him to a glaucoma specialist in New York City who, of course, diagnosed very severe loss.

Another man who has had glaucoma for 35 years, and has lost a great deal of sight visited the Lighthouse for help in best dealing with his situation was advised to call Lovett. There is a disconnect here that needs to be addressed. When the pre-eminent place for Vision Rehab the Lighthouse refers the patient to a documentary filmmaker rather than more help at the facility, something is wrong.

Further in this man's travails a doctor at The New York Eye and Ear also suggested calling Joe Lovett. (Editors Note: I receive these so called "referral" calls on an ongoing basis. GSEG has

repeatedly asked doctors to refer patients to members of our Group for assistance since our Group has become a reliable source of available resources for information and support).

But Lovett rightly suggests there's something wrong when available information is not readily shared on the web sites of organizations involved in the disease.

Another problem that surfaced at least thirty years ago is the need to add a clause or establish a new category in addition to the definition of legal blindness addressing low vision. Until the legislation is passed, the insurance companies including Medicare will not reimburse for low-vision therapeutic devices.

Perhaps if we address vision loss rather than generalized glaucoma, the people suffering from these conditions would likely be more activated to pursue research and activation. People with other eye conditions also suffer severe vision loss and need accommodation.

Lovett believes that part of the problem is fear of blindness. Actually this non-sharing of information with the patient is prevalent throughout the health field. It's only with the advent of the Internet where patients can research facts about their own

diseases have doctors become more forthcoming about the nature and prognosis of the illness. Perhaps because of our terror of blindness, we avoid the subject. Since a small percentage of glaucoma patients develop serious vision loss, to find out more does not become an issue. Lovett posited that this reluctance to face blindness may lie with a prevailing prejudice against the blind and that we may inadvertently incorporate this prejudice, feeling "less than whole" and embarrassed or ashamed by our visual inadequacies.

Losing vision produces anxiety, possibly depression and despondency, and we may just retreat. Where there is a strong advocacy group for a disease, more support both governmental and community exists. At the World Ophthalmology Conference in Berlin in June 2010, an individual approached Lovett and suggested an experimental treatment asking if Lovett was interested. Lovett, of course, wanted to know more. And this is how he found out about the treatment In Germany.

The various glaucoma foundations are now directing their resources to research and provide little room for support systems for patients.

There's strength in numbers and we need to bring the baby boomers into the fray. Glaucoma knows no boundaries and there is a need to work with the World Glaucoma Support Organization. January was Glaucoma Awareness Month. More publicity is needed.

We want to thank Joe Lovett for reviving awareness of the need for patient self-advocacy. This has also been one of the missions of the GSEG. One of the long-time glaucoma patients now blind from the disease began work on legislation issues many years ago. Despite her blindness she is still working on the issue. Her analysis of the situation lies in the fact that the doctors are no longer required to fill out a form reporting legal blindness. It is up to the patient to request that the doctor's office submit the paperwork to the NY Commission of the Blind in order to receive services. She is working at this level. The second level and this is much more difficult is legislation that includes low-vision as a handicapping condition to make this condition legally entitled to services. This legislation requires a bill to be prepared by our congressional and senatorial representatives and presented to Congress for a vote. Such a bill

requires lobbying a particular congressperson to this effect.

On a grassroots level screening for glaucoma needs to be revitalized. With the portable visual field instrument it is possible to screen a large number of people within a given period of time. About six or seven years ago, this kind of screening was conducted by a number of "vision" agencies. This level of screenings has dropped considerably.

Lovett suggests going directly to the State House with a NY delegation. He has spoken with Carl Jacobsen, president of the National Federation of the Blind, New York chapter, who expressed an interest. This is an important issue. Blind people have representation. They were one of the first disabling conditions to receive services, but people losing vision tend not to have a voice. Legislators need to realize that loss of vision does not equate total blindness but is a serious handicapping condition. Most people with vision loss fall somewhere along the spectrum between sighted and non-sighted. This is a difficult concept for others to understand, but it is our job to raise awareness.

OTHER INFORMATION:
Citicoline is a form of B vitamin that has shown positive results to

retain nerve function. It can be purchased over the counter.

Lovett Website:
www.goingblindmovie.com also they are on Facebook.

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Please note: We began our workshop speaking about doctor-patient relationships but it morphed into a call for creating public awareness of the disease. This is a good thing, for in the course of this workshop, we discovered with the aid of Joe Lovett that while we depend upon our doctors for medical care to receive the services and support we need, it is up to us to become advocates for glaucoma awareness and general support.
Edith S Marks, Moderator

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Please note: The contents of this newsletter are for informational purposes only. The Content is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

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