

# The Art of Effective Patient Counseling

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WITH JOSEPH I. MAGUIRE, MD, AND CARL REGILLO, MD

**A**s a retina fellow, it can be overwhelming trying to learn all of the clinical knowledge and surgical skills needed to be a proficient retina specialist. Because fellowship is often a very busy time, the importance of taking a few moments to properly counsel a patient can get overlooked. However, meaningful and effective patient counseling can mean the difference between a mutually satisfying doctor-patient relationship based on trust and one that is tense, hostile, accusatory, or even litigious. We asked two experienced retina specialists for their insights on this critical issue.

**How do you counsel retinal detachment patients? Are there any analogies or patient teaching tools that you have found useful? How do you approach patients with diabetes who are in need of surgery? How do you help your patients understand their clinical course and prognosis?**

**Joseph Maguire, MD:** My approach to counseling retinal surgical patients of any variety is to start from the beginning and assume that they know absolutely nothing about eye anatomy and physiology. Analogies and anecdotes that are familiar are most constructive, for example: The eye is like a camera, and the retina is the film in the camera; without film in the camera, there is no picture, and with damaged film comes a deficient picture. However, I am also certain to stress that the retina develops embryologically from the same cells that lead to the patient's brain and spinal column. As such, they are irreplaceable and, at present, non-transplantable from a practical standpoint. I recommend prompt repair of macula-threatening detachments to preserve central acuity and repair of macula-off detachments within 1 week to assure the best

chance of central vision return. My patients are informed that the mechanical goals of a detachment surgery are to restore the retina to its anatomically correct position. From there, good things can happen, but this does not guarantee visual perfection—that is left to the visual vicissitudes of central nervous system repair, much like in closed head trauma or concussion victims.

My macula-off patients are aware of the prospects of incomplete visual recovery and that improved vision can take place even a year after reattachment. To give them a benchmark, however, I typically invoke the *90 Rule*, in which 90% of patients will see 90% of their visual recovery within 90 days after their repair. Secondary developments contributing to visual reduction such as retinal redetachment, cataract, epiretinal membrane, cystoid macular edema, and loculated subretinal fluid are also reviewed as items that might require additional intervention if vision is less than expected.

When treating patients with diabetes, my approach is to invest in them an urgency to be intimately involved in their own medical care. If I ask them what their hemoglobin A1C is and they do not know, then there is work to be done. My counseling involves reviewing a few simple facts: one, that diabetic eye disease is the number one cause of permanent visual loss in working-age Americans; two, that it is driven by control over time; and three, that diabetic complications in the body concern the loss of blood flow, which I cannot give back to them once gone. These principles extend to the extremities and kidneys as well, and I inform them that the unifying theme is loss of capillary flow. Diabetic ocular therapy with laser, surgery, or injections essentially involves placing patches on diseased tissue and, therefore, cannot make things completely return to normal. All of my patients are aware of treatment complications, including total loss of vision. I find photo-

graphs, fluorescein angiograms, and optical coherence tomography (OCT) images extremely helpful in illustrating the degrees of severity, especially in individuals who have good vision, but due to an advanced disease, are at high risk of visual decline.

**Carl Regillo, MD:** When dealing with any retinal disease, I like to start with a brief educational session on the natural history of the condition and then explain how a given treatment may impact the course of the problem. With retinal detachments, we have a progressive, blinding condition, but surgery to treat the detachment is likely to preserve or improve vision; however, I always mention that the central vision and fine visual details may be affected by permanent blurring or distortion, regardless of the preoperative status of the macula. The camera analogy is usually a good one, and I often use it in patients with incomplete visual recovery after macula-off detachments by explaining that because the film is permanently damaged centrally, the image is not likely to ever be perfect or even as good as it was before the detachment. In patients with proliferative diabetic retinopathy, vision is threatened in many ways, including but not limited to vitreous hemorrhage and tractional detachment. Visual function may be affected by laser treatments such as with extensive pan-retinal laser treatment, which can sometimes lead to reduced visual field or reduced visual acuity. This can usually be avoided by aggressively treating any vision-threatening macular edema before the scatter laser, and staged or more peripheral scatter laser treatment can help minimize both transient and permanent decreased vision. Nonetheless, side effects can occur even with the best treatment approach, and patients need to be aware of this possibility before treatment begins.

**Have you noticed a change in recent years in patient expectations? Many patients are using the Internet to research their eye symptoms, eye disease, and eye doctors—and the information that they find can be misleading. How often does the Internet facilitate or hinder your counseling/education of your patients?**

**Dr. Maguire:** I think patient expectations for visual results have clearly increased over time. Again, this is a matter of patient education and informed consent. It is important that patients are aware that the results of refractive and cataract surgery do not translate to retinal issues. The “retina as brain tissue” analogy serves well to frame all treatment discussions. If a scleral buckle is employed, patients are made aware of the risk of initial induced myopia, especially those who have

pseudophakia or who previously underwent refractive surgery. If gas is to be used, they are informed of the expected visual obscuration and its necessity to immobilize the retina, being akin to a cast on a broken bone.

In the search engine age, I think it is always important for the retina specialist to initially direct the conversation and outline the issues at hand. This often answers any questions and dispels any misinformation that a patient may have on arrival, no matter what the source. Although the Internet can be a problem in disseminating erroneous information, at Mid Atlantic Retina, we utilize a robust website to aid our patients. In addition, pamphlets and information sheets are clearly visible and available throughout our office.

**Dr. Regillo:** There has been a definite change in patient expectations over the past 10 to 15 years. Patients are aware of the various advances and improved outcomes associated with both general ophthalmic conditions and retinal problems. With retinal surgery, it is common to have transient worsening of visual acuity immediately following vitrectomy or scleral buckling. I always let patients know that their visual acuity is likely to be worse immediately after surgery and that any improvement is likely to occur slowly over time, usually in the order of weeks to months, depending on the problem at hand. Because an air or gas bubble may be used in vitrectomy surgery, I always inform the patient and family of the bubble and describe how it will interfere with his or her vision. With regards to the Internet, there has been a definite increase in its use by the patients or their families seeking to gain more information about a condition or treatment. In the counseling and education process, the Internet is generally beneficial because patients often come already familiar with what a specific condition can do and how treatments might help. It makes the initial encounter less overwhelming for the patient and easier for the provider. One significant problem, however, is that the information on the Internet may either be incorrect or outdated. For example, it is not uncommon for patients to find a website that recommends 2 to 3 weeks of face-down positioning after macular hole surgery when many of us are now recommending much shorter time frames. Furthermore, patients sometimes get off track by researching the wrong ocular condition. I have had patients come with information on macular holes when they really have macular pucker or who think they have age-related macular degeneration (AMD) when they really have a macular hole. Therefore, it is important to know if a patient has

used the Internet and what he or she has found in order to ensure that his or her information is accurate and up-to-date.

**How have digital fundus photography, OCT, fluorescein angiography, and wide-field imaging changed your methods of counseling patients?**

**Dr. Maguire:** Epistemology is an interesting subject, but I find that most individuals today respond to visual learning cues and the use of digital photos, fluorescein images, and OCT scans, especially on viewing stations, which can be enlarged. A patient with significant reduction in retinal edema due to AMD, venous obstruction, or diabetes can clearly grasp the before and after effects of treatment. Even in difficult or slow-responding eyes, positive reinforcement with structural improvements tends to keep patients positive and engaged in their therapy, especially over many recurrent visits.

**Dr. Regillo:** Digital imaging with fundus photography, fluorescein angiography, and OCT has made a hugely positive impact on patient counseling and education. It is very useful to have normal images for the various tests and to show patients how their images deviate from normal. This often gives patients an interest in their condition and treatment response; this is especially true with the use of OCT in the diagnosis and management of macular problems.

**Forming a therapeutic doctor-patient relationship is very much about establishing trust, providing patient education and counseling, and managing patient expectations. In a busy practice, retinal detachments and other retina conditions can become routine, making it easy to forget how devastating these diseases can be for patients. What advice would you offer to young retina surgeons in this regard?**

**Dr. Maguire:** We are fortunate in the present era to have a surfeit of technology to aid in the diagnosis and treatment of many common medical and surgical retina issues. However, over-reliance on technology can cause an erosion of physical diagnostic skills and, by extension, create a layer of separation on a human level. Establishing a personal connection and maintaining a sense of empathy, or the "laying on of hands," is especially important in treating patients with chronic diseases such as AMD and diabetes. It only takes a few seconds to make eye contact, offer a hand shake, acknowledge family members, and ask open-ended questions like "How are you today?"; however, all of these actions help form the foundation of a doctor-patient relationship that is long-lasting and mutually supportive.

**Dr. Regillo:** To optimize the doctor-patient relationship in our field, it is important to remember that eyesight is valued very highly; therefore, eye problems, even those that are not critical, are associated with great anxiety. Doctors and support staff alike need to keep this in mind, as this will help promote a greater degree of empathy and understanding. In communicating information about the condition and its treatment, perspective is key. Patients want and need to know the likelihood of both favorable and unfavorable results or events associated with their condition and its treatment. As I discussed earlier, it is often useful to start counseling the patient about his or her condition by first explaining the natural history and then discussing how treatment may help. It is important to be clear and concise and to avoid bombarding the patient with too much information at once. The relationship is an ongoing educational process and, with that in mind, a greater understanding in the setting of a trusting relationship is established. It is also important to make sure that patients understand the meaning of the term "treatment." More often than not, when a patient hears "treatment," he or she often misinterprets it as "cure." Therefore, word choice is very important. For example, when starting a patient on a course of anti-VEGF therapy for AMD, I make sure that the patient understands that the treatments help to control the condition, not cure it. ■

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