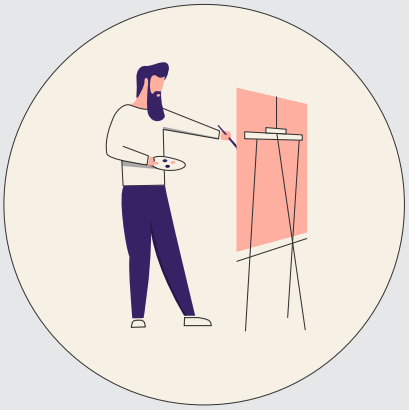


Holistic Care for Chronic Eye Conditions

Most doctors measure disease, some doctors measure health, but all patients measure life. —Prof. Denniston

By Annie Stuart, Contributing Writer

Physicians are sometimes so focused on the signs of a disease and laboratory test results that they miss the overall effects of the disease and treatment on a patient's life," said Gary N. Holland, MD, ophthalmologist at the University of California, Los Angeles. "And yet, if we take the time to consider the patient's overall well-being, we'll have better results in the long run," he said. "We can help patients better cope with their disease, adhere to their medications, and choose the treatment option that best fits the activities of their lives."

Three individuals—Ms. H,* Ms. B,* and Dr. G* —who are living with uveitis, age-related macular degeneration, and glaucoma, respectively, illustrate the diversity of the patient experience (see "Patient Stories," next page). They, along with four physicians, offer insights about providing holistic eye care and improving quality of life for those with chronic eye conditions.

See the Unique Patient

"When we do studies, we look at means and averages, but in the clinic we treat individuals," said Andrew G. Iwach, MD, glaucoma specialist in San Francisco. When patients have a chronic disease, it's especially important to form good long-term relationships, he said. "Our job is to keep people seeing for the rest of their lives, but at the same time to negatively impact their quality of life as little as possible."

Establish rapport, build a bond. In the flurry of a clinical practice, he advised trying not to lose sight of the following:

Speak directly to the patient. "Even when I was very young, my doctor spoke to me and not to my parents," said Ms. H. "The surgeon faced me directly and explained the pros and cons of the surgery in simple terms. It really made me feel as though I was a part of the process." It doesn't take a lot of extra effort to address your comments to a child at a level they understand, added Dr. Holland. And Ms. B. added that it helps to call patients by their first name, if appropriate.

Ask open-ended questions. You never know where open-ended questions will lead, said Dr. Iwach. For example, a patient might be in for a simple glaucoma check, but you learn they've been diagnosed with advanced pancreatic cancer—something that may completely change your approach to their glaucoma treatment plan.

Investigate behavioral cues. If the patient seems irritable or more quiet than usual, don't ignore it, said Albert O. Edwards, MD, PhD, retina specialist in Eugene, Oregon. You can say, "Betty, you seem different today. How are you doing?"

Encourage the patient, whether child or adult, to express what's bothering them and ask whether they understand what you've told them or if they have any questions, said Dr. Holland. If the patient is a child, he said, you might ask the parents if they've noticed a change in their child's behavior.

Philippe Nicolas

For example, is the disease or treatment affecting the child's schoolwork or relationship with peers?

Dr. Holland relayed a story about a child with uveitis who was very quiet and respectful during clinic visits but also seemed quite sad. After he discontinued a medication that had been ineffective, the child's behavior completely changed—he was "bouncing off the walls" and telling jokes. His mother then volunteered, "He feels so much better since he stopped taking the methotrexate."

Know your patient. You can't begin to figure out the best solution for your patient until you have an understanding of their concerns, said Dr. Iwach. "Even if a patient says everything's fine, it may not be." Are they actually taking their medications, or can they even afford them? Which side effects, if any, are bothersome? "Technicians may be your best radar because they sometimes spend more time with the patients," he said.

Learn about long-term goals and priorities. "My goal was to stay as normal as possible for as long as possible," said Ms. H. That translated into everything from choosing more aggressive treatment to using a lacrosse eye cage (goggles) in order to continue to play field hockey. "Through my nonprofit [see "A Long and Winding Road"], I met a patient from Australia who had the option to do a surgery similar to mine, but she opted not to due to the risks," she said. "She had come to terms with what the disease would do."

Don't underestimate your patient. When Ms. H. was 9 or 10, the doctor prescribed hourly eyedrops. "That might seem unrealistic for a child of that age," said Ms. H. "But if you understand your patients' barriers, as my doctor did, you can help them work through them in creative ways."

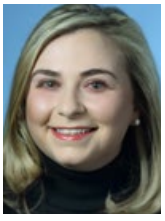
Remember: Circumstances can change. If you've seen a patient for a long time, said Dr. Iwach, you may tend to forget that the patient's overall health or even living situation may have changed. Has someone in the family died or become seriously ill? Has the patient lost his or her support system? Has the patient taken a fall recently? "As we age, falling is one of the biggest risks for quality of life and survival," said Dr. Iwach.

Likewise, don't assume that the source of a patient's vision problem always remains the same. "When I had declining vision in my right eye despite well-controlled pressures," said Dr. G, "Dr. Iwach didn't just stay the course with eyedrops and glaucoma surgery. He suggested an MRI, which revealed that a brain tumor was compressing my optic nerve. Surgical resection of the tumor not only helped me regain sight in

Patient Stories

A Long and Winding Road

SARAH H.: Medical student at Johns Hopkins University in Baltimore, and has worked with Dr. Holland on advocacy projects.



Diagnosed at age 18 months with juvenile idiopathic arthritis and with uveitis and glaucoma before the age of 7, Sarah H., age 25, has undergone 15 eye operations for complications of uveitis—including cataract surgery and placement of two shunts in both eyes, and several cornea transplants. Since her uveitis diagnosis, she hasn't gone a single day without eyedrops—some of which have caused light sensitivity, redness, and pain.

Having exhausted most of the medications available at the time, Ms. H.'s parents anguished over whether to pursue a glaucoma shunt surgery when she was only 9. Should they agree to a surgery that had rarely been done on a child of this age and risk potential blindness from complications, or simply succumb to inevitable blindness over time?

Doctors disagreed on the right approach. "One doctor told my parents that if I had the surgery, I would not only become blind, but could also lose my eyeball," said Ms. H. With her input, her parents ultimately greenlighted a slightly different procedure performed by a different surgeon.

"Fortunately, I'm now in a good place with my vision," said Ms. H. She's just completed her first semester of medical school at Johns Hopkins and has raised more than $250,000 for a nonprofit she was encouraged to found by her ocular immunologist when she was just 10. It's called KURE: Kids Uveitis Research and Education (http://kure4eyes.com/).

Learning From a Family's Medical History

PAT B.: Retiree, and a patient of Albert O. Edwards, MD, PhD, in Eugene, Oregon.

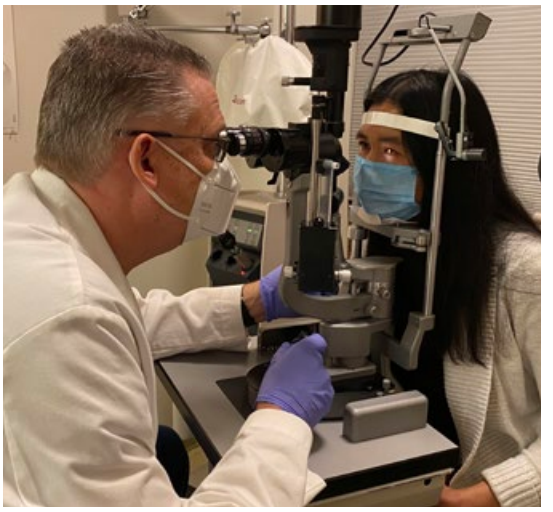
A resident of a small farming community just north of Eugene, Oregon, Pat B.

that eye but also potentially prevented a catastrophic stroke."

Ease fears, consider comfort. Have empathy for the patient's situation, said Dr. Edwards. "What does it feel like for a patient who is anxious or fearful, who has early dementia, who doesn't have the sophistication to navigate the health care system, or who doesn't have money or can't drive, due to vision impairment or some other reason?" he asked.

"Kindness goes a long way and doesn't cost anything," said Dr. Iwach. "Especially now, it takes everyone being sensitive—from the front desk to the technician to checkout to billing staff. Yes, you have to run a business, but make sure your patients' needs are being heard. Whenever possible, you want them to walk out feeling as though they are the only patient you ever think about." Ms. B. agreed, "A well-trained staff that is professional, yet personable, can really put the patient at ease."

Be adaptable. Don't deliver care the way you want to deliver it, said Dr. Edwards. Deliver it in a way that makes it easy, comfortable, and safe for patients. "Safety may encompass a wide range of things from a fear of needles and burning after injection to financial discomfort," he said. "If we think about things from the patient's perspective, we can compromise in many ways and deliver a more satisfactory level of care," he said.



EXAM. *Dr. Iwach and Dr. G at the slit lamp.*

Acknowledge and address fears. Much comfort comes from simply acknowledging and labeling a patient's feelings, said Dr. Edwards. "But if patients are miserable with our protocol, we have a duty to try to make them more comfortable." He gives the example of minimizing the use of betadine before injections—how much of the cornea is exposed as

was referred to a retina expert nine years ago at age 70, and she was immediately diagnosed with wet AMD. At the first appointment, her doctor asked, "Do you want to start treatment today?" She hesitated briefly and then said, "Yes."

Both her father and mother-in-law had been blinded by the condition, so she knew where AMD could lead without treatment. She might not go completely blind, but she might get to the point where she couldn't drive a car, do handicrafts, read recipes, and have the overall quality of life she had had before.

"We all have choices in life," said Ms. B. "I chose sight. Your eyes are precious, and you don't have any spares. You have to take care of what you've got."

The Art of Adaptation

TRINH G., MD: A family practice physician in Oakland, Calif., and a patient of Andrew G. Iwach, MD.

When Trinh G., MD, received a glaucoma diagnosis at age 21, it came as a shock. "My first thought was, 'All my hard work in college will have been for naught,'" she said. "For me, vision is everything, so I experienced a lot of anxiety." It didn't help that her first glaucoma specialist told her, "By the time you turn 50, you'll be blind."

Regular assessments had uncovered rising eye pressures and a worsening cup-to-disc ratio, which eventually led to many surgeries—from selective laser trabeculoplasty and trabeculectomy to placement of Ahmed glaucoma valves.

With a loss of depth perception and peripheral vision, and other visual deficits, Dr. G. has become skilled at adaptation: For example, unless familiar with a route, she avoids night driving; she explains to neighbors why she sometimes doesn't recognize them; and she's stopped playing tennis and swimming, even though she otherwise remains very active.

In medical school, she was recruited for vascular surgery, but she declined due to the fine work required of the specialty.

Today, she is 46 and practicing family medicine.

well as the length of time the solution stays on the cornea. "Use the minimum you feel comfortable with, but if a patient has problems, ask yourself if you can minimize it further for this particular patient."

Dr. Edwards also tries "Jedi mind tricks," such as having patients tell themselves there are no needles. Or, he'll use the art of distraction, asking the patient to take a deep breath at the time of injection.

Ms. B. noted that she has benefited from her husband accompanying her to most of her injection clinics, and she advises that physicians ask about the availability of support from family members.

Prepare and collaborate with the patient. Dr. Holland emphasized that children's fears may be amplified by a lack of understanding about their medical problem or the treatments they're undergoing. "This problem is especially true with very young children," he said.

Most adults also breathe easier when they know what to expect. Ms. B. explained how a simple overview of the injection process can help alleviate fears. She recommends telling patients something along the lines of the following: 1) Your injection is not to be feared. 2) Pain is minimal to nonexistent because drops are put on the eye to numb the injection site. 3) Just prior to the injection, comfortable holders are put under the eyelids to

Patient-Reported Outcome Measures

A recent glaucoma study found that providers only asked about glaucoma-related vision loss during 15% of visits and glaucoma quality of life during 13% of visits[1]—just one sign that ophthalmologists may need help uncovering key information about their patients' experience.

"With patient-reported outcome measures [PROMs], we try to capture what matters to patients, rather than doctors," said Professor Alastair Denniston, MA, MRCP, FRCOphth, PhD, at the University of Birmingham in the United Kingdom.

These quality-of-life measures are relatively new in medicine for two main reasons, he said. "One, quality of life is hard to define, let alone measure," he said. "Also, Western medicine has traditionally been about tackling disease, whereas it was more about wellness in ancient times. I think we've come full circle and really value wellness and health once again."

PROMs used in ophthalmology. A variety of PROMs are available. The EQ-5D is a widely used standardized instrument for measuring generic health status that has been used for more than 30 years.[2] Others are more specific to vision. For example, the NEI VFQ-25 is a visual measure typically used in clinical trials, and the EYE-Q measures vision-related quality of life and function in children.[3]

A research tool. Researchers are increasingly using PROMs in clinical trials, although rarely as the primary outcome measure, said Prof. Denniston. These tools range from simple questionnaires that provide symptom scores on a scale of zero to 10 to a more complex scale that measures how patients' conditions affect interactions with their families, for example.[4]

A role in the clinic. A few years ago, Prof. Denniston started using PROMs as a research tool in his uveitis clinic. "I was primarily trying to understand which treatments had made a difference," he said. But he soon found it to be one of the most useful tools in clinical care.

"I had thought I was an empathetic doctor who listened well," he said. But answers to patient questionnaires were often quite at odds with what the history or consultation had revealed. "The questionnaires ask a wide range of questions you might not think to ask or might be a bit shy to ask," he said, explaining that the surveys have changed his perception about what's really going on with his patients. Prof. Denniston now reviews the questionnaire before he consults with patients, making it a key part of a holistic assessment.

Improved decision-making. "I guarantee it will change how you practice medicine," he said. "It isn't easier, but it does make it easier to make better decisions and helps you share decision-making with the patient." And although he initially had concerns that the questionnaires would be a burden on his patients, he's never heard patients complain about them. He suspects that these tools may be routinely used in clinics within a matter of years.

1 Sleath B et al. *Patient Educ Couns.* 2017;100(4):703-709.

2 Euroqol: "EQ-5D." euroqol.org/eq-5d-instruments/eq-5d-5l-about/.

3 Angeles-Han ST et al. *Arthritis Care Res.* 2015;67(11):1513-1520.

4 Braithwaite T et al. *Patient Relat Outcome Meas.* 2019;10:9-24.

keep the eye open during the injection, and they're removed right after. 4) Remember to relax and sit perfectly still.

Be realistic, but offer hope. As a physician and a patient, Dr. G. can see communication challenges from both sides. And given her experience at the time of her diagnosis, she advises physicians to choose words about prognosis very carefully. "Offer hope, but don't promise too much," she said. For example, a procedure may lower pressure and save sight, but it may also reduce visual acuity.

Share decision-making. "Whenever possible, engage the patient in making decisions," said Dr. Iwach. "It empowers them and makes them partners with you." This partnership is especially important if and when challenges arise, he said.

"Doctors must impart their expertise, but it also helps to encourage patients to do their own due diligence, ask questions, and get input from other doctors, when needed," said Dr. G. When Dr. Iwach recommended a procedure for her that had a risk of permanent diplopia, he encouraged her to get a second opinion if she was at all uncomfortable with it.

Respect patient preferences. "Many of us are very rigid in our practices," said Dr. Edwards, "but sometimes we need to ask, 'What is the incremental harm in doing this a slightly different way—one that's preferred by the patient?'" If the patient's preferred approach is riskier, he suggested asking this question: "How does that risk compare with the patient dropping out of clinic and coming back nine months later with 5 to 7 lines of vision loss?"

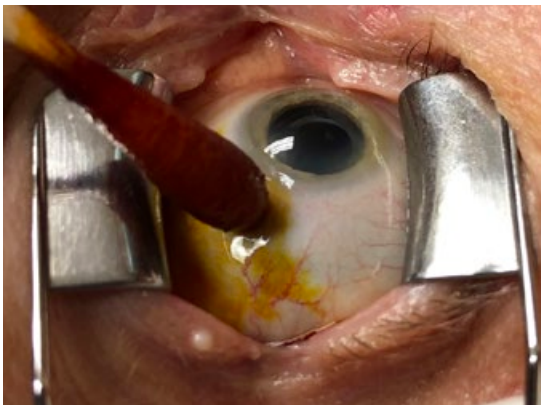
Thinking Outside the Clinical Box

Of course, many other considerations exist for patients and families outside the clinic.

Remember the family. People don't often talk about the impact that a chronic diagnosis can have on family and friends, said Ms. H, as she reflected on the pressure her parents felt to make the right decision about her first surgery. "The effects on the child have widespread effects on the parents and siblings," agreed Dr. Holland. "Start with compassion and empathy for both the parents and child and build on that."

Open-ended questions pertaining to family may help uncover important details, said Dr. Edwards, such as a death in the family. "Make a note of it in the chart," he said. "It doesn't take a lot of time. For many patients, particularly during the pandemic, we are the only people they see, and attention to these details will make a big difference." (For more on grief, see "Of Loss, Grief, and What Was Said," Opinion, April 2020, at aao.org/eyenet/archives.)

Lifestyle issues. When she was younger, Ms. H.'s daily life was frequently interrupted for appointments, infusions, and urgent surgeries. "Toward the end of college, it was a pretty tumultuous time," she said. "It got to the point where I needed some accommodations in school."



COMFORT. *Consider the patient's perspective. Is it possible to use less Betadine to improve the patient's experience?*

Factor in lifestyle when scheduling surgeries, said Dr. G. "I had three children when I went through my eye surgeries, but I wasn't allowed to lift during a six-week period of recovery, so I needed to line up someone to help with tasks such as getting groceries and picking up my kids." To help the patient adequately prepare for the post-op period, she said, it's also good for the ophthalmologist to know the kind of work the patient does.

Consider other challenges. Patients may be dealing with many challenges that may interfere with their treatment. "Some people have to travel half a day to get to the retina specialist," said Ms. B. Also consider the cost and storage of medications, said Ms. H., recalling a time when her father put her eyedrops in his pocket, which were ruined by his warm body temperature.

If a patient doesn't want to continue with injections, don't just assume the problem is a fear of the injection, said Dr. Edwards. For example, the patient might be short of money. Dr. Iwach had a cash-strapped patient who thought the only solution was to treat his heart one month and his eyes the next. In a situation like this, Dr. Iwach said, it can be critical to at least recognize the challenge and explore alternatives with the patient.

A patient may also have trouble remembering to take medications. It may help to give tips such as linking the dosing to other routine activities such as eating meals or brushing teeth, said Dr. Iwach.

Reach out for other resources. With a condition such as juvenile idiopathic arthritis and uveitis, a patient may benefit from online self-help

support groups. A variety of eye health organizations also offer patient resources for a variety of eye conditions.[1,2]

Practice Management Is Key

As clinicians, ophthalmologists are a type of service industry, said Dr. Iwach. "It helps to think about how other service-based businesses succeed in making their customers feel comfortable so that they want to come back time and again."

"We need to consider what it feels like for patients coming in and out of our offices every six to eight weeks," said Dr. Edwards. Although his practice scores far better, he pointed to studies revealing injection clinic dropout rates of up to 25%, a sign that there's room for improvement.[3]

Learn lessons from the pandemic. COVID-19 has offered an opportunity to reevaluate how we run our practices—to look at our infrastructure, systems, and who the patient interacts with, said Dr. Iwach. "These things ultimately determine how patients view you and your practice, and this may impact how they respond to your recommendations."

Taking a cue from Disney and Walmart, Dr. Iwach's practice has hired more employees during the pandemic to make sure the quality of the experience doesn't suffer. For example, more employees were hired to handle extra phone screening, and a new "greeter" position was created to take patients' temperatures, sanitize hands, and take histories before the patients enter the office.

Consider the entire cycle of care. It's important to think about everything that is necessary to successfully see a patient, replace inventory, be ready for the next visit, and communicate with other doctors on the health care team, said Dr. Edwards.

"The weakest link determines the strength of the chain," said Dr. Iwach. "For example, if a receptionist is rude, unaccommodating, or lacking compassion, the patient may not even make an appointment with you. Or, if the technician isn't open and empowered to talk to patients, you may miss a great source of information." (For more about how to empower technicians and the entire team, visit the Lean Management resource page, courtesy of the American Academy of Ophthalmic Executives [AAOE], at aao.org/practice-management/lean-management.)

Prep the supply chain. Details matter. And they require a lot of close collaboration between reception, the clinic, and the rest of the team, said Dr. Edwards, pointing to important questions to ask: Are we ready for patients when they show up? Do we know what the patient's out-of-pocket costs will be? Do we have the prior authorizations? Do we have the medical records? Is the staff ready for managing the patients and efficiently dealing with any side effects or complications? Have they educated patients about how to deal with common side effects?

1 Ocular Immunology and Uveitis Foundation: "Online Support." https://uveitis.org/patients/support/.
2 EyeCare America: "Eye Health Organizations." aao.org/eyecare-america/resources/eye-health-organizations.
3 Rose MA et al. *Clin Exp Ophthalmol.* Published online Aug. 23, 2020. doi: 10.1111/ceo.13845.

* For privacy reasons, last names of patients are not included.

MEET THE EXPERTS

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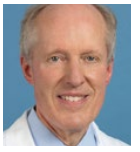

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For full disclosures, see this article at aao.org/eyenet.