

PATIENT CARE IMPROVEMENT PROJECT

# Pearls to Improve Patient Compliance



American  
Glaucoma  
Society

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*This initiative is made possible by an unrestricted educational grant to the American Glaucoma Society from Pfizer Ophthalmics.*



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# The Challenge of Noncompliance

Why do glaucoma patients fail to take their medications as prescribed? Why do so many of them miss their appointments or fail to refill prescriptions?

In glaucoma care, the issue of non-compliance continues to be a frustrating, seemingly intractable problem. Despite evidence that pressure control is instrumental in protecting against vision loss, far too many patients don't comply with their medication regimens, fail to refill prescriptions and are no-shows when it comes to their follow-up appointments.

Even worse, physicians and their staff routinely underestimate the scope of the problem in their patients. Often, only subtle clues to noncompliant behavior are evident: an occasional missed appointment, an admission of a missed drop several days ago, a complaint of a bothersome drop side effect. When such a clue is detected, the wise physician targets that patient for extra efforts in improving compliance. Research extending back for more than 20 years has repeatedly demonstrated that physicians are poor judges of which patients are compliant and which are not.

## In Search of Solutions

In an attempt to develop strategies to address and overcome the problem of noncompliance, the American Glaucoma Society (AGS) initiated the Patient Care Improvement Project. The project, which was the first large-scale patient care initiative conducted by the AGS, is supported by an unrestricted educational grant from Pfizer Ophthalmics.

The project's initial goals were as follows: 1) Identify "best practice" ideas for enhancing and supporting patient compliance and 2) develop and disseminate a

printed compendium of the winning ideas. These two goals have been accomplished.

A third component of the project—to stimulate further research on compliance—is under way. Under the direction of the AGS Research Committee, a grant of \$50,000 has been awarded for research into novel ideas in the area of compliance, adherence and persistence to therapy.

## Identifying Best Practices

The AGS Patient Care Committee began by soliciting ideas from ophthalmologists, allied health personnel (ophthalmic nurses and technicians) and patients themselves regarding barriers to compliance. A number of print and online sources were used to advertise the project and solicit participants, including the AGS-net, the American Academy of Ophthalmology's *Academy Express* and *EyeNet Magazine* and the Glaucoma Research Foundation's patient information newsletter, *Gleams*.

The AGS contracted with investigators at Vanderbilt University to construct an interactive Website, which was used to collect respondents' descriptions of common reasons for noncompliance and recommended solutions for solving each problem. The Vanderbilt investigators (David G. Schlundt, PhD, and James W. Pichert, PhD) are noted for their research on non-compliance, particularly in diabetes care.

Respondents were asked to identify as many problems as they could in the general categories of appointments and medications. For each problem, they were then asked to generate from one to three solutions. Initially, many of the responses were overly brief, so the Website was modified to request a longer and more detailed response. The responses were coded using

a hierarchical coding system used in past research on barriers to self-management. They were then evaluated and ranked by an AGS-appointed committee according to their potential impact on patient care. The committee consisted of glaucoma specialists, general ophthalmologists and patients.

In all, the Website received ideas from 400 registered participants—144 physicians, 120 support personnel and 136 patients. Forgetfulness emerged as the leading barrier to compliance, with 31 percent of physicians, 26 percent of support personnel and 24 percent of patients identifying it as a significant barrier. Other common hurdles included patients' lack of strength or dexterity, which prevents them from being able to open and use eyedrop bottles as directed, difficulties with timing and scheduling, medication side effects and the cost of medications.

All told, 43 winning suggestions were identified (see "Honoring the Winners"). While some clearly require further research and development, others could easily be implemented by patients or in ophthalmology practices right away.



## SAMPLE QUESTIONS

Three questionnaires—one each for MDs, providers and patients—were distributed. The questions for patients were as follows:

1. What are the situations that prevent you from using your eyedrops as you are supposed to? Put down the real situations, not situations you think others might find acceptable.
2. What do you find helpful to be sure you use your eyedrops as you are supposed to?
3. What kind of support would be most helpful to enable you to use your eyedrops as you are supposed to?
4. What do you think would improve your ability to obtain medical follow-up at the intervals recommended by your doctor?

## Honoring the Winners

After the AGS grading committee evaluated and ranked ideas, 43 winning ideas were identified from 10 physicians, 10 support personnel and 10 patients. The winners were honored and awarded monetary prizes—\$3,000 each to physicians, \$500 each to providers and \$250 each to patients—in November 2006 at Glaucoma Subspecialty Day, held in conjunction with the American Academy of Ophthalmology's Annual Meeting in Las Vegas.

**Physician award winners:** Nicholas Bell, MD; Peter DeBry, MD; William Haynes, MD; Inci Irak-Dersu, MD; Brian Jacobs, MD; Worldster Lee, MD / Bradford Lee; Paul A. Sidoti, MD; Joshua Stein, MD; Misha F. Syed, MD; Lisa G. Wohl, MD.

**Provider award winners:** Carol Anderson; Cindy L. Blachly; Tulay Cakiner-Egilmez;

Mona Carpenter, COMT; Kelly Cerrada; Wendy Houston; Amanda L. Lee, COA; Fredy Andres Otalora; Mary Preston; Patricia Weikert.

**Patient award winners:** Sari Aber; Christine Appert; Riva Aidus Hemond; Mary J. King; Ruth Meserve; Lorraine Miller; Naga Narayanaswamy; Mary O'Connor; Elise Tripp; Elizabeth Wolfe.

# Tools to Boost Compliance

It's the daily-ness of glaucoma care that seems to bog even the most conscientious of patients down—the need to keep track, to remember, to be organized, day in and day out. With that in mind, respondents had a number of pragmatic suggestions for jogging one's memory and other daily challenges:

## Memory aids

Patient Riva Aidus Hemond suggested associating the action of putting drops in with other automatic, habitual morning routines. “For example, put one drop in when you first get out of bed. Put the other bottles in your left robe pocket—because they are ‘left’ to take. Put another one in after you have started the coffee.”

Riva's own routine is to take her drops in alphabetical order. “After I put a drop in, I place that bottle on my nightstand.”

Provider Mona Carpenter also recommended making use of the power of association and habit: “Involve the patient in a plan of action. Listen carefully to what the patient does on a typical day. Then together write down a plan with them. Associate the drop with what is meaningful to their lives. If you say, ‘Use at bedtime,’ that is too vague. Bedtime is arbitrary, especially for older

patients with sleep disturbances. Give the patient something concrete to associate with the drop, something that hopefully carries over to vacations as well.” Vacations and weekends are often times when routine habits are abandoned and thus need special attention to ensure eyedrops get taken.

Other memory aids might include printed forms. “What is really great is to have a preprinted form that shows pictures of each of the glaucoma medications along with slots for scheduled times or examples

of when the patients should use the medications,” said provider Patricia Weikert. She added, “Pictures of the drops have been very helpful to our patients.”

Stickers might work as a memory aid, said provider Mona Carpenter. As she pointed out, “People love to fill in the blanks and check things off. Use this compulsion about list completion to help with forgetfulness. Give the patient a sheet with circles that need to be filled in, corresponding to the number and kinds of drops needed. Then give them a sheet of stickers [with the drug name]. When the patients take their drops, they put the corresponding round sticker on the paper to fill in or complete the sheet. If they forget, there is that hole to remind them.” She also noted, “If the patient cannot see well enough to read a logo on a sticker or to see the color, you can use different shaped stickers for each drop.”

Mona also suggested using an elastic bracelet as a memory aid. “If the patient is on only one type of drop, give them an elastic bracelet to move from one side to the next to help them remember if they've used the drop or not. The bracelet goes on the left wrist every morning when the first drop goes in [and is then moved to the right wrist after instillation]. If it is still on the left wrist at bedtime, then they forgot their evening drop and it reminds them to go use the drop. If this were manufactured, and depending on cost effectiveness, this



bracelet could even have a simple timer or beeper on it.”

Provider Mary Preston came up with another way to use a bracelet as a memory aid: “Eyedrop bottles could have removable rings on them corresponding to the number of times a day they should be used. A bracelet or necklace is then used [to hold the rings]. For example, if they are supposed to use a drop three times a day, they would start the day with three rings on the necklace. As they put in their first dosage, they would put one ring back onto the bottle. At the end of the day, all rings should be back on the bottle.”

### Timing tools

Patient Lorraine Miller uses a household clock to time multiple drops: “I use a clock and add a drop every time the minutes are on five or zero, i.e., 35, 45, 55. Remembering the last number helps me space them properly,” five minutes apart.

Watches—and their alarms—also can help. Patient Elise Tripp suggested, “Use an alarm watch or alarm on a PDA to go off at a specific time to take the first medication and then five or 10 minutes later to take the second one.”

And patient Mary J. King reported that she wears “a watch that can be programmed with up to 12 daily alarms and text messages. When the alarm sounds, I can read the text message.” Since the watch is too large for her wrist, she wears it as a pendant.

Patient Sari Aber suggested that a special watch be developed, which she called a “drop watch.” This would be a “digital watch dedicated to my drops. It will be easily programmable to enter the name of the drop and the times of day to use the drops ... it will reward me with a smile after I click on a

button as I put my drops in on time.” She also suggested, “It will cost \$10 without a contribution to charity and \$15 with a contribution to charity.”

Finally, provider Mary Preston suggested “a talking bottle holder that could be set with a timer for specific times of the day for each medication.” Such a bottle holder would chime an alarm and then say the name of the medication to be used.

### Tracking tools

“When we have to work flexible hours, there isn’t a lot we can do about our schedules,” said patient Elizabeth Wolfe. “Recently, I have begun to keep a log of the times when I use the eyedrops and when I’m involved in other activities so that I can get a picture of what throws me off schedule and figure out ways to fix that.”

And patient Lorraine Miller uses a permanent marker to not only mark the date on the bottom of a bottle when she starts using it but also to note on a separate log the day she started using the two previous bottles. That gives her a sense of how long it takes her to use a bottle. If the timeframe is too long, it serves as a warning that perhaps she forgot too many times.

Several providers also had ideas for tracking tools. For instance, Kelly Cerrada suggested providing patients with “colored handouts that show pictures of the medications, with a drop schedule or easy-to-follow chart/graph.”

And Mary Preston suggested a “lami-





nated chart with medication names and time of day to take.” The patient, who would have a dry erase marker, could then cross out each instillation. This chart could be magnetic, to hang on a refrigerator, she suggested, and at the end of the day, the patient could just wipe the chart clean for the next day.

### Other organizational aids

Patient Sari Aber came up with the idea of a small purse—a lightweight, specially designed bag she called a “drop bag.” The bag “will have a place to put each bottle of drops used during the day. It will have a Velcro closure on top to secure the bottles within. It will keep those drops easily accessible in the handbag I carry,” she said.

### Ideas for drug companies

Behold the basic eyedrop bottle. It’s small, it’s disposable, it’s cheap to produce—and it’s driving patients crazy.

There’s no question that poorly designed eyedrop bottles contribute to poor compliance. Even if a company spends time and money developing a drop container, its use

drug companies could develop a “tilted eyedrop bottle.” Such a design would have the “dropper part of the bottle on an angle to the well of the drops.” That would make it easier to “get the bottle at the proper angle to the eye,” she noted, and patients would “never miss again.”

Another potential approach would be to “make the bottles out of a softer plastic, or better yet re-design eyedrop bottles altogether,” said provider Wendy Houston. Perhaps drug companies could design “a bottle you don’t have to turn upside down but has a sanitary disposable hooked neck that is changed after each installation,” she suggested.

A second problem posed by poor bottle design involves what Sari Aber described as “one of the constant worries that plague me: Do I have enough left until my next appointment, or do I have to get another prescription?”

Drug companies could alleviate this worry by positioning labels on bottles so that the label doesn’t obscure how much is left in the bottle, she said. Next, they could “put a measure ruler down the side of the bottle showing me how many drops are left in the bottle.” Finally, she said, the bottle should be clear for the length of the ruler, so that it’s easy to see exactly how much liquid is remaining in the container.

A clear bottle is essential, concurred provider Tulay Cakiner-Egilmez. “This will give patients an idea of when to refill their medication.” She also wondered whether drug companies could modify the label in some way so that it turns another color after the bottle has been opened for two to three weeks. The color change would be an effective way to let patients know that it’s time for a refill.

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When it comes to bottle design, it might be time to do away with the traditional eyedrop bottle altogether and lobby the drug companies for unit-dose medications.

in real-life situations quickly points out its deficiencies. For instance, patient Sari Aber cited the perennial problem of getting drops to the eye consistently and accurately. In her own experience, she noted, “If I tilt my head back far enough, I never miss getting those drops into my eyes.”

To mimic this action, she suggested,



Provider Cindy L. Blachly suggested that it might be time to do away with the traditional eyedrop bottle altogether and lobby the drug companies for unit-dose medications. “Having Monday through Sunday packs for drops would clearly identify missed medications. If they can do it with birth control pills, they can do it with glaucoma drops!” A side benefit would be to get rid of sometimes irritating preservatives.

### Appointment reminders

When the standard appointment reminder doesn’t do the trick, here are some alternatives to consider:

“At the current appointment, have patients write themselves a note about their next appointment,” said Peter DeBry, MD. The office staff then drops the note in the mail 10 days before the upcoming appointment. The “novelty of getting a letter from yourself” reminds the patient of how important the visit is, he said.

Provider Amanda L. Lee also suggested the personal touch: “Make a list of non-compliant patients and give them frequent reminders, a note in the mail box, a courtesy phone call.”

Special pre-recorded telephone messages might be helpful, said Joshua Stein, MD. “Have celebrities [ideally a handful who themselves have glaucoma] pre-record telephone messages reminding patients of the importance of regular follow-up and proper usage of eyedrops. The patients can receive a friendly pre-recorded reminder from the celebrity prior to upcoming appointments. The patient would have to agree, in advance, to receiving the reminder [for HIPAA purposes and to avoid creating unwanted intrusions].”



And for at-home use by the patient, Nicholas Bell, MD, suggested developing a “calendar with a layman’s version of the American Academy of Ophthalmology’s *Preferred Practice Guidelines*.” One page

could have the guidelines for follow-up intervals, so that patients have a concrete, handy reminder of the need for return appointments. “Another page can be dedicated to visual fields, showing normal, mildly abnormal” and so forth, said Dr. Bell. The practice would have to adopt the guidelines of the PPPs, which isn’t a bad idea in itself.

Finally, Brian Jacobs, MD, recommended a high-tech appointment reminder, a PDA [personal digital assistant] device that could “keep track of upcoming appointments and alert patients of potential conflicts in their schedules.”

Additionally, he said, “an alarm can be set to not only remind the patients that they have an appointment that day but also to sound an alarm days to weeks ahead of time so they remember that the appointment is coming up.”

Dr. Jacobs also suggested that “the audio alarm be accompanied by a reminder on the screen that the patient must check to remove from the screen, therefore confirming that they received the reminder.” In addition, the display screen could be programmed to show the physician’s office phone number so that patients could call when they needed to reschedule. In the best of all possible worlds, this would solve the problem of no-shows.

# Supporting Self-Care

The efficacy of empowered self-care in boosting compliance has been noted time and again in a number of health conditions, with diabetes care leading the way. As numerous studies have found, involving patients who “buy in” to the idea of contributing to their own care tends to result in healthier patients.

As patient Mary O’Connor pointed out, “I notice there are counseling sessions for diabetics regarding strict diet and using their medications, so why not for glaucoma? This counseling should be mandatory and free.”

Respondents suggested a number of ways to encourage patients’ self-care efforts, including the following:

## Highlight the consequences of noncompliance

Any effort at patient education should appeal to the emotions by highlighting the consequences of not treating the disease, several respondents noted.

Patient Ruth Meserve suggested, “Have patients list the things they would miss if their vision deteriorated.” Many people

don’t connect loss of vision with the inability to do specific things, such as watching their grandchildren grow up.

The voice of experience also could be tapped. “Expose patients to the experience of others who may have lost functional vision to glaucoma,” said Paul Sidoti, MD. Patients are often willing to share their experiences with others, especially if they might help another person avoid the same fate.



Tools that simulate vision loss might drive the message home. “People often don’t completely understand what glaucoma is and what happens when IOP is elevated for an extended period of time,” patient Christine Appert noted. “One solution might be to create a game that an individual could play at home or use on a computer in the clinic. The game would be used to teach or show what glaucoma can do.”

And provider Kelly Cerrada suggested, “Have a tool that could simulate or show patients what their vision could become if treatment is not started and maintained,” such as a viewfinder or glasses that could simulate vision loss a different stages. “Show the patient this is what you see now, and if you don’t treat it, this is what your vision could become.”

That’s essentially what provider Cindy L. Blachly has done—to make up “virtual reality glasses with various visual field deficits on them.” She used clear safety glasses and etched defects in them, from mild to advanced changes. “Have the non-compliant patient wear them around the office for an hour or so,” she recommended.

Last but not least, there’s the philosophical perspective. As patient Naga Narayanaswamy put it, “Tell yourself it takes one second to put a drop in and yet you waste so much time on unwanted things in life.”

## Use a team approach

“Develop a glaucoma education team that can be with the patient from initial consult through at least the first year,” provider Carol Anderson suggested, with one team member appointed the point person for patient information and questions.

Alternatively, a patient “buddy system” could be established, said Joshua Stein,

MD. Patients who agreed to participate could be partnered up. “The actual patient and the buddy would receive notification of upcoming scheduled appointments,” he said, with the buddies then reminding one another to go to the appointments. He also suggested that all of the buddies could form a local glaucoma support group.

Provider Amanda L. Lee also noted that family members or neighbors could be enlisted as part of a buddy system. “Stress the importance [of follow-up care] to a family member, with the patient’s permission. Delegate them as the responsible one.”

### Enlist the patient’s input

Do any practical physical concerns present a challenge? Misha F. Syed, MD, recommended, “All patients in a glaucoma clinic, both new and returning, should be given a form to fill out at each appointment stating how they are coming to their visits [bus, family, self, etc.] and any potential difficulties in transportation.”

And Inci Irak-Dersu, MD, suggested that physicians “send patients a questionnaire with the reminder of their next visit and ask them: Do you think your eyesight is the same? What would you like to know on the next visit? What treatment would you rather have instead of drops?”

### Provide educational materials

While physicians can’t rely on printed handouts alone, these items can be used to support patient self-care efforts. William Haynes, MD, recommended, “Give each patient a patient compliance sheet to help them understand their medication and its possible side effects as well as to describe the disease and why it’s important to have regular follow-up appointments.”

## BEYOND THE OFFICE

Building a stronger compliance safety net might require moving beyond the traditional ophthalmic trio of physician-provider-patient, several respondents suggested:

**Work with pharmacists.** Open lines of communication with pharmacists might help boost compliance, provider Fredy Andres Otorola pointed out. “If pharmacists alert doctors’ offices whenever a patient has not refilled his or her prescription for more than one or two months, in the same way that they do to request prescription refills,” that would allow ophthalmic technicians to call the patient and find out why the prescription hasn’t been refilled. Moreover, she noted, that gives the technician a chance to “stress the importance of taking the medication, address a way to help the patient and make sure the patient will continue refilling the prescription as expected.”

**Work with other MDs.** It’s also important to “keep the patient’s primary physician in the loop” with regular communication about the patient’s glaucoma, said Lisa Wohl, MD.

**Work with the community.** General community outreach can raise overall awareness and reinforce each individual physician’s efforts. “Establish primary vision stations in medically underserved areas,” suggested Worldster Lee, MD, and Bradford Lee. “People can attend these stations for screening and eye health concerns, and tele-ophthalmology can be used if they need referrals or opinions from other ophthalmologists.”

