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## The patient's journey: glaucoma

Christine W Hartmann, Douglas J Rhee

### My good news and bad news

"You have glaucoma," an ophthalmologist informed me when I was 36 (the mean age of onset is 65). Given the uncanny ability of the human brain to compensate for missing visual information, I don't know when I would have noticed my blindness had I not had some unexplained pain in my right eye one morning. As I lay in bed with my hand over my right eye, I looked around the room using only my left eye. I noticed that when I gazed straight ahead at the dresser, I couldn't see part of the closet door. And when I moved my gaze to the closet door, part of the room door disappeared. For the first day, I tried to put it out of my mind, but when the symptoms persisted, I began to get very nervous.

A week later, I sat in the dark examining room, stunned. Tears came to my eyes despite my desperate attempt to appear in control. "You're young to have this," explained the doctor. "But the good news is that there are lots of medications to treat it." Without looking at me he added, "It's not something to be too concerned about." He glanced instead pointedly at his watch. Was I going to become emotional and make it difficult for him to leave the room? Ignoring his impatience, I persisted and asked whether there was anything else that might be causing my vision loss, anything we might want to rule out. He shrugged, "Well, it could be a brain tumour. We could do an MRI, but . . ." His entire body language finished the sentence: "why bother?"

Why bother indeed? They were not his eyes, and he was sure of himself and the diagnosis. A week later I sat before the ophthalmologist whose specialty was vision loss from brain tumours. He told me, "Well, we're going to do an MRI, but I'm sure you have a brain tumour. All your symptoms suggest that." Magnetic resonance imaging was duly carried out and two weeks later was pronounced to show no abnormality. I happily returned to being a patient with glaucoma. It sounded good after the words "brain tumour." What a relief. It's just glaucoma. Lots of drugs exist to treat it.

Since then I have been lucky to find an ophthalmologist, Doug, who is able to look into my eyes and still see the human being, not just the diagnosis. In the beginning we both approached my situation with optimism. There were a lot of drugs to try. When the first one had no effect on lowering my intraocular pressures, we moved on, unconcerned. I came in for frequent appointments. We tried more and more drugs, but with no effect and with an increasing sense of desperation on both our parts.

Four years later we still haven't come up with an effective treatment for my condition. The disease is affecting both eyes, although my left eye is much worse than the right. I don't take any drugs, because none of them work. I have undergone laser trabeculoplasty in my left eye, with no effect. I have my eyes examined every three months. At this point we're just gathering data points to discover what the slope of the line of deterioration might be. I have had several optic nerve haemorrhages, which are highly correlated with progression, but we're not sure how rapidly the disease is going to progress or how much sight loss I will tolerate before I avail myself of surgical options.

### How I travel alone towards an uncertain future and sometimes lose the path

When I try to explain what it's like not to see with glaucoma, I tell people to imagine a digital TV screen with pixels, and to imagine that some of the pixels in an area have ceased to function. The entire picture still exists and moves, but there are areas that simply disappear from the screen. There is no shadow, no light, no colour—just nothing. Unusually and unfortunately, in my case the malfunctioning pixels are near the middle of the screen.

When I try to explain what it's like to live with glaucoma, I don't have such a simple analogy. Part of learning to live with any chronic, debilitating, progressive condition has to be about learning to live with fear of the unknown. In the case of glaucoma, deterioration takes time, and even if my journey results in complete blindness, it will be years down the road. And yet neither the loss I have now nor the possible loss in the future is ever completely out of my thoughts.

And because my own future is uncertain, so is that of my closest relatives and friends. Who will take care of me if I become unable to live without help? I told my fiancé on our second date about my condition, not because I was so certain at that point that our relationship would be lifelong, but because I could not ethically justify to myself revealing such a potential impediment at any later point. Would he walk away? Would he accept me regardless? I had to give him the choice, although I have none.

At the moment I can't see the top of the steering wheel when I am driving. When I bought a new house

Department of Health Policy, Jefferson Medical College, Philadelphia, PA 19107, USA  
Christine W Hartmann  
*assistant professor*

Harvard Medical School, Massachusetts Eye and Ear Infirmary, Boston, USA  
Douglas J Rhee  
*assistant professor*

Correspondence to: C W Hartmann  
cwhrtmm@aol.com

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last year, I picked one near a train station and in a town where we can walk to everything, because one of the first things I will do if my vision loss progresses much further is to take myself off the road. I can't see my own feet when I walk, so I always hold on to a railing or someone else when I descend. I can't see people's mouths move when I stand a comfortable distance away from them during a conversation, so I sometimes have trouble hearing. I often can't see gestures people make with their hands. I can't see my fingers as I type this. But what's most distressing is that I will never again be able to see, up close, the entirety of someone's face.

## My ways of coping

I do question why I was not diagnosed earlier. I have myopia and have been to see an ophthalmologist almost yearly since I was 10. During the regular eye examinations I was sometimes even "tested for glaucoma"—that is, tested for elevated intraocular pressures. But I can only remember receiving one dilated eye examination in my life, when I was in my late teens. And no health practitioner ever asked me simply to close one eye, look at a fixed spot in the room, and notice whether anything was missing.

Fortunately, up to now I have been able to live without much aid. I have considered joining a glaucoma support group, but given the age of the typical glaucoma patient, I am hesitant. To calm my own fears, I empower myself by learning as much as possible about the disease's theories, treatments, and outcomes. I work at a medical college, so I have ready access to and read all the literature on glaucoma. I have not been reticent to seek second opinions, for which I have flown to Florida and telephoned an expert in Switzerland. I have sought out complementary and alternative treatments. But there is no way to judge whether unconventional therapies are having any beneficial effect, and there are distinct limits to what I will try. Nevertheless, all of these things I do to remain somewhat in control of a situation that is almost completely out of my control. In the long run I believe the only thing I can do is to remain the expert about my own eyes.

## My journey's end

At any age increasing vision loss is incredibly frightening and debilitating, but facing this prospect so early in

### What I need along the way

I have used the internet to gather basic information about glaucoma. Here are some of the websites I have found most useful:

- [www.nlm.nih.gov/medlineplus/glaucoma.html](http://www.nlm.nih.gov/medlineplus/glaucoma.html)—provides links to many other sites on specific glaucoma related topics
- [www.glaucomafoundation.org/index.php](http://www.glaucomafoundation.org/index.php)—gives an overview of the disease, provides answers to common questions, and provides links to other sites
- [www.nei.nih.gov/health/glaucoma/glaucoma\\_facts.asp](http://www.nei.nih.gov/health/glaucoma/glaucoma_facts.asp)—defines the disease and its causes, symptoms, and treatment and contains links to publications
- [www.glaucoma.org](http://www.glaucoma.org)—provides information about glaucoma, living with the disease, and treatments, as well as an overview of some current research

### My companion on the journey: Douglas Rhee's perspective

I am Christine's ophthalmologist. When I first met her she already had significant damage in both eyes with moderate (by conventional standards) visual field loss. I thought that it was unusual for someone as young as she was to have developed low tension glaucoma (glaucoma with intraocular pressures that are within the statistically average range); however, the diagnosis was clear. I started out quite optimistic, as we have numerous treatments, but became more despondent as each drug we tried and added failed to have any effect in lowering her intraocular pressures.

Studies estimate that about 25% of people with glaucoma receiving state of the art care will still go blind in one eye and 10% will go blind in both eyes (that is, functionally blind) despite all our technology. I choose to specialise in glaucoma in part because of those daunting statistics: I want to help to stop the harm from the disease, or from the treatments themselves. Doctors are, however, susceptible to marginalising patients who "fail" treatments, because there is the potential to view the situation as personal failure. Nevertheless, even after treatments fail or someone goes blind, there is still the potential to offer healing. The patient's life still goes on, and perhaps that is when they need us the most.

I have spent my career trying to convey my genuine compassion and to be a good healer. However, Christine's story made me understand how limited I and other doctors are, in some cases because of the time pressures induced by a managed care system, and in most cases because we often don't fully understand what it is to have glaucoma. Even if we have heard the descriptions of "fog" or "misty" (or worse yet "dark"), we never truly know about the actual impact of these visual deficits. Christine's detailed and emotionally open descriptions made the condition more real for me. I have continually striven to understand from patients the impact of glaucoma, and I even lecture to doctors on what it is that patients "see" and the physiological basis for compensatory mechanisms, yet I did not have a complete picture until I heard Christine's testimony.

Christine and I have walked hand in hand, trying to pursue treatments that make medical sense and that also work with her overall life plan. I am relieved that her rate of decline has been very slow, giving us time to wait for new discoveries rather than forcing our hand towards a surgical method to lower her intraocular pressures. I stand ready to take the next step of conventional glaucoma surgery if we both decide that this has become necessary. Until that day I continue to endeavour in the laboratory to help develop some of those new treatments to some day help Christine and others like her. Although we save the sight of most, we still need to do a better job.

life adds another layer of complexity. Nevertheless, I have hope for the future: hope that understanding of glaucoma will progress to the point that treatments will no longer be shots in the dark, hope that the medical system will increase its flexibility and support of those of us who have to visit clinics frequently for chronic conditions, and hope that education of medical staff will increasingly emphasise a more holistic perspective. The uncertainties of the present I intend to confront with confidence in my own abilities and the help of the companions on my journey. After all, a patient with glaucoma or not, I still have a life to live.

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### After the cure

Every patient is a doctor after his cure.

Irish proverb

Submitted by Prakash Saha, *senior house officer in surgery, St Helier's Hospital*