

SOUNDING BOARD

COPING WITH BLINDNESS

APPROXIMATELY 15 years ago, I was first told that I had macular degeneration. The diagnosis was made by an experienced ophthalmologist in the small city in which I resided at that time. It was subsequently confirmed by a senior academic ophthalmologist in New York City. When, in 1970, I moved to the National Institutes of Health (NIH) in Bethesda, Maryland, I learned that my disease was a subject of research in the National Eye Institute, and I therefore availed myself of the services of the several skilled physicians in that institute. Early during my stay in Bethesda I was seen in consultation by the senior staff of a major academic ophthalmologic institution in the neighborhood. In all, no less than seven distinguished and highly qualified ophthalmologists have considered and reviewed the condition of my retinas.

It is not my intention at this time to discuss the diagnoses that have been made or the treatments that have been provided. Suffice it to say that my loss of vision has been progressive. I stopped driving a car about eight years ago, was pronounced legally blind four years ago, and for the past year or more I have been unable to read. My activities have become severely restricted as my world has shrunk to a sphere with a radius of about an arm's length. Simple chores such as finding the cap of the toothpaste tube when it falls on the floor or carving a piece of chicken at dinner have become formidable, and crossing the road unassisted is a frightening experience.

Through all of these years, and despite many contacts with skilled and experienced professionals, no ophthalmologist has at any time suggested any devices that might be of assistance to me. No ophthalmologist has mentioned any of the many ways in which I could stem the deterioration in the quality of my life. Fortunately, I have discovered a number of means whereby I have helped myself, and the purpose of this essay is to call the attention of the ophthalmological world to some of these devices and, courteously but firmly, to complain of what appears to be the ophthalmologists' attitude: "We are interested in vision but have little interest in blindness."

From a chance acquaintance, a biophysicist whose visual defect was comparable to my own, I first learned of Visualtek (1610 26th St., Santa Monica, CA 90404) and of the Talking Books Program of the Library of Congress. I promptly made contact with both these agencies and gained access to a Visualtek machine — a combination of a small television camera equipped with a Zoomar lens and an inexpensive television monitor. This compact unit permits enormous magnification of printed or written material, and for several years I found it to be a useful accessory in my office. Its presence postponed the time when I would be totally unable to read, regardless of magnification. Although it is costly when compared with simple optical magnifiers (the price is about

\$1400 for the basic microviewer and \$2500 for the RS 10 model) this device clearly has many uses, and I hope that ophthalmologists will familiarize themselves with this instrument.

Far more important to me, and of enduring value, is the Talking Books Program. The local community library, approximately 5 miles away, acts as an agent for the Library of Congress. It provides at no cost a simple tape player and a special record player, both designed to operate at very slow speeds. It also provides a selection from a large variety of books that have been read and recorded onto cassettes or phonograph records. The titles are all cataloged and the catalog is readily available. Once enrolled, I started to receive bimonthly supplemental catalogs showing new additions to the list of available readings. Incidentally, the reading that I have heard is of a highly professional quality, with excellent diction, interesting intonation, and often a dramatic flavor. I go through many Talking Books each month, taking advantage of one of the charming features of the program: the cassettes or records are mailed to and from the distributing point at no postal charge. The program operates at no cost to the beneficiary.

In addition to procuring books on tapes from the Library of Congress program, I also subscribe to several journals through Recorded Periodicals (919 Walnut St., 8th Floor, Philadelphia, PA 19107). The journals arrive regularly and permit me to keep abreast of at least some of the major developments in my fields of interest. *Newsweek* magazine, on disposable phonograph records, arrives with reasonable promptness each week from P.O. Box 6435, 1839 Frankfort Ave., Louisville, KY 40206. A portable cassette tape recorder, specially built for the blind by the General Electric Company, can be purchased through the American Printing House for the Blind, Inc. (General Office, P.O. Box 6085, Louisville, KY 40206), and a wide variety of aids and materials for the visually impaired can be ordered by mail from the catalog of SFB Products, Box 385, Wayne, PA 19087.

Another program, which may or may not be peculiar to the area in which I reside, is the Washington Ear. This organization distributes, at no cost, small radio receivers pretuned to a single station. Every morning, starting at 7:00 a.m., volunteers at that station read essentially the entire text of the daily newspaper. They repeat this reading later in the day, and between these times they read other current material that may be of interest to the audience. Partly because my wife reads selected topics from the newspaper to me at breakfast each morning and partly because the proper use of the Washington Ear requires large blocks of time, which are not usually available to me, I have found this accessory generally less useful. It is, however, a service that is freely available in the Washington, D.C., area and possibly in other parts of the country.

It may not be generally recognized by the sighted that as one loses vision one becomes disoriented not

merely in space but also in time. When I found that I could no longer read the time from a conventional wristwatch or from a digital watch, I mentioned this to my ophthalmologist, who indicated that he thought there must be devices that could substitute for traditional timepieces. However, learning nothing further from him, I raised the matter with the gentle lady in the Talking Books section of the library in Rockville, Maryland, and she at once knew the answer. She told me that a store no more than a mile from the NIH (Volunteers for the Visually Handicapped, 4405 East-West Hwy., Bethesda, MD 20814) was devoted exclusively to devices to assist the visually handicapped. I visited this store and found available a variety of Braille timepieces that could be read by touch. I acquired such a wristwatch but found that whereas I could easily read the minute hand, I had more difficulty with the hour hand, which often seemed to be concealed behind the minute hand. I used this device until I learned, quite by chance from a salesman, of the existence of a Talking Clock manufactured by Sharpe Corporation. This I was able to purchase locally and since then I have never been far from my cherished timepiece. Now at any time, day or night, I merely have to push a button to hear the synthetic voice say, for example, "It is 5:45 p.m." The Talking Clock also has a charming alarm (it plays the Boccherini Minuet to wake you) and an interval timer that permits the blind person to boil a three-minute egg. The price when I purchased one last January was about \$75.

From my son, who was taking graduate courses at the Massachusetts Institute of Technology, I first learned of the Kurzweil reading machine (33 Cambridge Pky., Cambridge, MA 02142), and I arranged to attend a demonstration of this fantastic instrument in the Washington area. Whereas the price is high (about \$29,000), I was happy to learn that the NIH was willing to procure such an instrument, which is now in my office. The Kurzweil machine scans the printed or typewritten page and recognizes each letter. Having in its memory a list of rules for English pronunciation, it synthesizes each combination of letters into sounds approximating speech. Given a good typeface, the machine produces a spoken language that could be described as a dialect of English. However, I have found that as with other dialects, the more one listens, the more one understands. There are a variety of hazards that the Kurzweil reading machine has not yet overcome. If in the course of the text there is a table of data, a graph, or a photograph, the machine endeavors to find recognizable letters and words, and its output is likely to be gibberish. If the text contains Roman type or a word in italics, this also seems to confuse the machine and render its output incomprehensible. Although the machine is supposed to be able to handle a multicolumnar format on the printed page, in my experience it does not handle this very well. One soon gets used to its systematic mispronunciations of certain words, and one can often

unscramble an incomprehensible word by instructing the machine to spell it out. This the machine does with great clarity.

These, then, are some of the aids with which I have surrounded myself as my vision has progressively deteriorated. I have been struck by the fact that in not one single instance was the device called to my attention by one of the several ophthalmologists whom I consulted. In each case, my contact was initiated and developed through non-ophthalmologic channels. Currently I am in contact, through a chemist friend, with a camera company that recently devised a sonar focusing device. Correspondence has revealed that this company has already explored the possibility of using its sonar device to assist blind persons in their ambulatory navigation. Indeed, such an instrument, the electronic equivalent of the seeing-eye dog, has been built, although it is apparently not commercially available as yet. I am hoping to have such an instrument assembled on the basis of the inventor's plans, in order to ascertain its usefulness to one who otherwise walks into trees and trips over garbage pails. Whereas my electronically minded friends appear to be interested in such a device, I could elicit little enthusiasm among my ophthalmologist friends.

Quite recently I was visited by a laboratory-research assistant at the NIH, who was referred to me by the scientific director of her institute. This woman is suffering from progressive retinitis pigmentosa and is under the care of an able ophthalmologist. She now has very restricted vision and reads slowly and with difficulty. She told me that no one had ever breathed a word to her about the Talking Books Program, large-print books and journals, a large-print edition of the *New York Times*, or any of the other devices described above. Fortunately I was able to provide her with names, addresses, and telephone numbers and to give her encouragement, which she sorely needed. I reminded her that decreasing visual acuity need not mean total dissociation from the real world; her ophthalmological consultant had apparently failed to do so. This is but the latest of a number of similar conversations that I have had with visually handicapped persons. It is in response to these experiences that I finally decided to write this essay.

I do not mean to imply that there is anything peculiar about the behavior pattern of ophthalmologists. Internists concern themselves with living patients and in my experience have relatively little interest in the cadaver. The autopsy represents a failure of medical science and medical art. Blindness, similarly, represents a failure of ophthalmology. No one likes failure. I am nevertheless troubled by the lack of regard, which is apparently quite general in the profession of ophthalmology, for the quality of life of the person whose vision is seriously impaired. I urge that this should be a concern of the ophthalmologist, who is necessarily in contact with the victims of progressive visual impairment. Typically, the ophthalmologist

confronted with a patient suffering from a disease of the eye performs the diagnostic and therapeutic manipulations, provides the patient with refractive correction, and prescribes eye drops or other medication. If after all this the patient still has a serious visual impairment, the ophthalmologist is missing an extraordinary opportunity if he or she fails to direct the patient's attention to one or more of the aids and agencies designed to improve the quality of life of the visually handicapped person. If ophthalmologists will take the small amount of time necessary for this pur-

pose, they will surely be rewarded by the enhanced gratitude and affection of their patients. The many suggestions that can be made may transform the life of the blind from a living hell to a moderate inferno or, perhaps occasionally, a heaven. The ophthalmologist who succeeds in achieving such a transition will be fulfilling one of the highest goals of the profession.

National Institutes
of Health
Bethesda, MD 20205

DEWITT STETTEN, JR., M.D., PH.D.