

Going blind

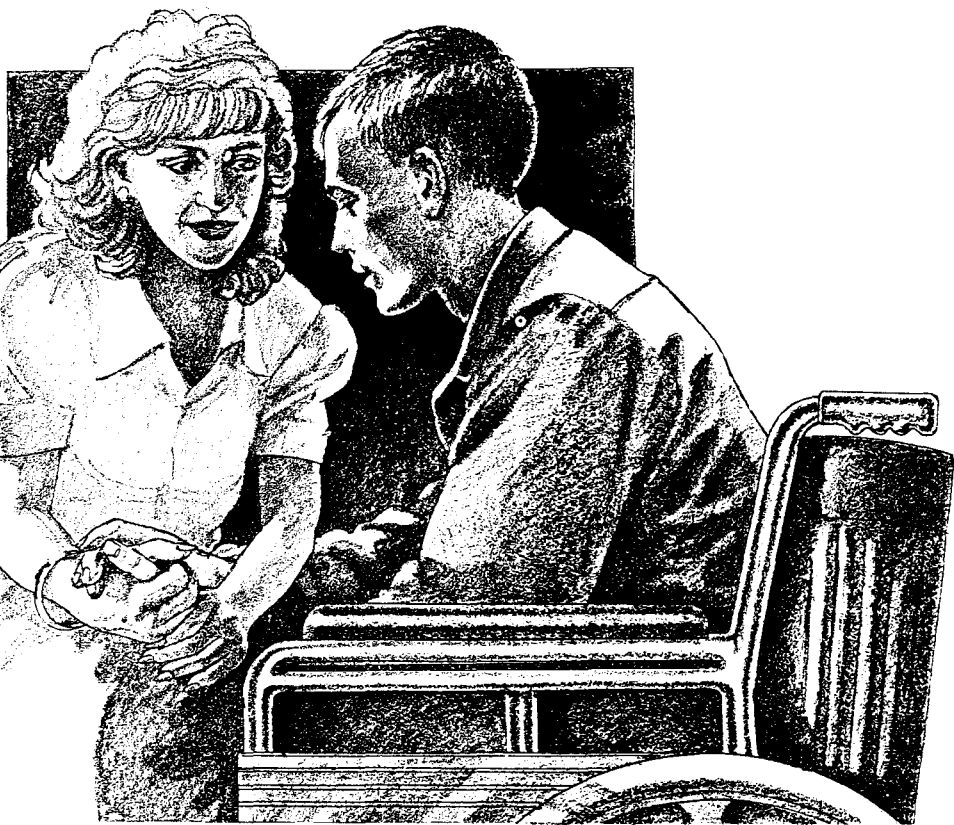
Michael Seyfrit

(Ed note: The following article was prepared from four drafts written by Michael Seyfrit as he went through the process of becoming totally blind due to CMV retinitis. The condition was brought on by AIDS with which he had been diagnosed in January of 1991. The CMV retinitis had begun in January of 1993, and had left him completely blind by April of 1994.

Mike died on May 29, 1994. One week before his death, he had asked his father to get him dressed and to take him to the piano. He played for the last time on Monday, May 23 for only a minute or two.)

For the past two years, I have been dealing with the problems of going blind due to CMV Retinitis, one of several complications brought on by AIDS. Friends have convinced me that I should set down some of the problems and solutions I have found along the way. Since this disease is quite likely to affect a fairly large number of people with AIDS in the future, it seems worthwhile to describe at least a part of my experience.

Going blind is not fun. Visual signals and needs are paramount in our lives. Replacing all the functions our vision performs with suitable alter-



natives (or deciding that certain of them are unnecessary) takes some time. Once you have convinced yourself that it is possible to live with AIDS as a chronic illness (no

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mean feat for many) and have managed to figure out some sort of more or less stable mode of living, the choice is just how to live during the vision loss. I don't know about many others, but I've been through several alternatives, and found most lacking. For example, would it be a good

idea to learn Braille? This is certainly one of the most constructive skills a blind person can have, but at the outset, no one really believes he will go completely or functionally blind. As the awful truth begins to descend, it may already be too late. In my case, I was so afraid of losing my mode of personal expression (composing music) that I started Braille lessons early so I could use the Braille notation for writing music, and would thus not be limited in my work by the loss of sight. Unfortunately, I have found that I have a lack of fine sensitivity in the fingers on one hand, and can only read with one hand, and that quite haltingly. It is quite a challenge to keep at it, and finish the correspondence course, now that I know that I can never learn to use Braille with facility. So now come the options. I can use Braille for labels, for example to la-

bel my medicine bottles, and this is of great use. But, how can I compose? Some blind composers, I'm told, rely mostly on the use of a micro-cassette recorder, both for dictation and to take notes of telephone calls etc. This has its drawbacks, though, because tape is linear, and not easily indexed. Then there are the other electronic aids such as Braille lap-top computers, or regular ones for those of us who still type better than we Braille, reading machines (to speak written text), laser

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and sonar devices for mobility, etc. At some point you have to ask just how much stuff will be of use in however much time you survive.

If I become totally independent with all my new skills, and die the next week, have I used my time the way I'd like? On the other hand, if I assume I'll die next month, and don't learn these skills, either I'll die, or spend the rest of my life without any of these skills. Hmmm. A quandary!

I've taken a sort of middle-of-the-road approach. I've learned grade one Braille poorly, but enough to identify pills, talking book tapes,

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etc., and rely on a secretary for musical dictation and general office functions. I've decided that I'll live however long is allotted to me, and to pursue the things that are most important to me as best I can. I'm also convinced that the general orderliness of my character and my curiosity will keep me alive longer than I may be really prepared for, so I just keep going, and it seems to be working out fine.

Undoubtedly, many of these aids will become more useful to me in the future, but for now I have settled, for the most part, on using the computer equipped with a speech output, and provisions for cursor movement control. There are several such programs for both MACs and PCs. I'm hoping to get a lap-top so equipped on which to keep schedules and other such information.

In the course of loss of vision, there are several other things that can become useful. Local service agencies provide mobility and orientation training, and you can begin this while there is some sight left. Using tape recorders to take notes is very helpful, and memorizing the telephone dial or pad will be a great aid.

Early in my experience with CMV Retinitis, friends asked me what it "looks" like to be going blind. This was a difficult question to answer for two reasons. First, my two eyes experienced different phenomenon, and secondly, at the time I was not completely through with the process. In my case, one eye

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began to be affected first. A gradually descending blackness like a dark horizon fell through my field of vision over a period of about four months. It's progress was so slow, that I thought I'd be spared total loss of vision in that eye (at that time, the least myopic). For some period of time, I had a tiny sliver, like a thumbnail clipping, of peripheral vision at the bottom of the eye. Unfortunately, this portion of the eye was incapable of seeing color, and responded mostly to motion. Thus the remaining vision was of little use. The other eye went through a much more var-

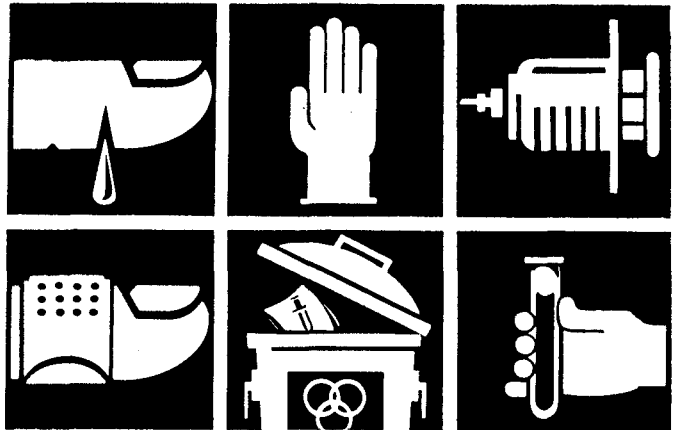
ied process. At first, the field diminished a bit as had the other eye, but then one day, I saw a batch of horizontal parallel bars that were simply black. When viewing television or other well known objects, the bars would slowly dissolve with each new picture, due I believe, to the brain's interposing what "should" have been in the view. Later, that group of bars collapsed into a central clump that resembled a seahorse. I remember that each day I'd wake and look up at the ceiling to see what new shapes were present. The central "seahorse" grew globs that resembled a fictional sea dragon, and then to changing, but unidentifiable

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shapes. No longer was the brain able to "fix" the images it saw. Next, a darker bar bisected the field from side to side, and another shorter bar developed below the first one. Along the way, the distortion of the retina was such that for a time I saw "El Grecco" images, and later, images above the upper bar that were shifted several degrees to the left.

When the vision was nearly gone, and for some time after it was totally gone, I "saw" things that were not actually there. With my eyes closed or open, I "saw" moving black blobs on a dark purple field, which gradually became less and less distinct. There were also three "shining spots" that looked like light bulbs.

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They were not always present, but came and went frequently. There are still sudden "lights and lightning-like patterns" (these in red and green) that occur much less frequently. Also, the whole field sometimes appears so bright that for a second, it seems as if a search light is shining directly into my eyes. I'm told that all of these things will eventually diminish, and leave me with a less interesting, though less startling, dimness.

Later, I reached another point in the progress of the CMV Retinitis. Many objects reflect light, and since I can now only see light, I cannot always decide what the patch of light represents. Just a few minutes ago I came into my office to type these few paragraphs, and thought the light coming in through the window was the computer screen. I nearly missed the chair at the computer since the computer screen is about a foot to the right of the window. Because of the light reflections, and my not thinking, I have, several times missed a door where I intended to go, and found myself at the next doorway in another room. It's the

little things like this, (and the bruises that result) that are taxing.

For some time, I've thought that the experience of going blind from AIDS-related CMV and other causes are materially different. I suppose that the closest other cause might be diabetes. Usually occur-

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ring later in life, diabetic blindness is usually a slow degeneration of the most sensitive portion of the retina, that is, the portion where the most exacting work is done—reading, sewing, etc. In diabetes-caused loss of vision, the process usually occurs over several years, and is by some accounts barely noticeable so that accommodation to its changes are nearly imperceptible. CMV retinitis also has this in common with dia-

betic blindness: Blindness is not the only thing happening to your health.

The moderate pace of the process, taking from several weeks to a year or so, means that there is a continual adjustment to be made to accommodate the loss of vision. I keep thinking that it might be better to get the process over with, and be totally blind so that I could get on with other concerns. There are so many skills I'd like to learn that might be helpful. Because of our statistically short life-span, it is hard to decide which skills would be most useful—Braille, cane mobility, guide dogs, computer terminals, etc.—there are a number of possibilities. For example, as I mentioned earlier in this discussion, I had thought I would learn Braille, and be able to read it well by the time I could no longer read print. Unfortunately, various complications from AIDS kept me from devoting the necessary

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time to that effort. Also, my finger sensitivity on the right hand has gotten worse, so I have relied on tape recording and secretarial help in my music composition.

Vision is really the principal sense for relating to the world around us. It allows us to scan our environment, to search through a book for the place we left off, to avoid the furniture, to spread peanut butter on a slice of bread, to manipulate the dials or buttons on our radios, microwaves, televisions, and a host of other pieces of equipment. It allows us to be "in" everything we

view. Blindness, as it progresses, shrinks our view to a very small space.

I have a catheter installed to aid in giving myself the daily intravenous medications that have been prescribed. Finding the proper place to insert the needle to draw up the flush solution from its container is a real chore. Finding the proper ingredients, measuring them, and properly mixing them to bake a cake presents a number of challenges. Remembering exactly where everything in the refrigerator and cupboard is located is likewise a very real problem. Remembering to put everything back in its proper place (and even more difficult, getting other members of the household to remember) is also difficult.

Routine information flow has become harder, too. I can still retrieve the mail from the mailbox, but I must wait for someone else to read it to me. Current information about local, national, or world events must be received second hand or from radio or television. Recently published books such as those on the best seller lists are generally not available without a significant delay. Written communication has been drastically cut back for me. I am forced to live in a partial information vacuum, and to live a life that is much more internal than before.

I'm not saying that these difficulties are not surmountable—many blind people live quite successfully by themselves. However, in most cases, they have been educated in schools for the blind where coping with these everyday matters is part of the curriculum. With AIDS induced blindness, we are faced with the dreadful uncertainty about the remaining weeks, months, or years

we will have. How much effort should we devote to learning coping skills, and how much should we depend on others to be our "eyes?" Should we forget the pursuits we have previously enjoyed, or spend

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the time needed to learn to participate, even with our blindness? I have found it quite taxing to learn to move about in my own house, using my hearing and touch more and more. The disease progresses slowly enough that one day seems not so different from the previous one in so far as sight capabilities is concerned, however, things are getting worse. Two weeks ago I could, on bright days, use windows in the house to get my bearings and avoid missing the furniture. Now, I can't.

Lest I be accused of simple laziness or sloth. I have found that I can do more things by myself than I had thought would be possible. There seem to have been many milestones along the way in the approximately one and one-half years since I learned that blindness was to come. Each has marked a particular loss of function or capacity I had taken entirely for granted. In mid-November 1993, I had to quit conducting *The Desert Peach*, for which I had composed the music.

I could no longer keep my place in the more complicated numbers of

the musical. In December, I had to quit driving at dusk or at night, since I didn't feel safe. In January, driving became impossible at anytime. (Luckily, my lover obtained his

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driver's license before I had to completely quit driving.) I began to use screen enlarging programs on my computer, and obtained a larger screen. I could no longer read anything except very large print by February, and by March, could read nothing at all. I bumped into a lot of walls and furniture. (The coffee table has a special fondness for an area just below my kneecaps.)

There are a few observations about personal contacts that I have noted since becoming blind. I am now only moderately interested in what people look like, and my principal recognition skill has become their height (where the voice is coming from) and the quality of the voice. Unfortunately, I have always been weak on remembering names, although I remembered faces very well. That is, of course, totally gone now, and names are all you have to use for communication in a crowded room. At a social or public gathering, I have to try to remember where everyone is sitting, or to say their

name when starting a conversation—something that makes ordinary social conversation quite different. It is funny, and a bit startling to open the front door, expecting a particular person or services, only to have someone rush in, give me a big hug, and start talking a mile a minute, while I try to get a handle on just who they are. Voices with very similar sounds are also difficult and it is dangerous to make assumptions.

The phone takes on a new importance as a method of keeping in contact with friends, and (often distant) friends become a part of your "support group" rather than the people near you but just out of reach. Looking up "unlisted" telephone numbers is difficult without either Braille or a computer rolodex at your disposal.

While I see solutions to most of the difficulties I have encountered, (provided I live long enough to acquire the skills needed) the issue of creative output is more difficult. Shall I start a large concerto, only to be unable to finish it? Can I accept a commission and be able to deliver the work in a reasonable time? I have found dictating music extremely tedious, and also inaccurate. A simple glance at a page would have told me before that I was writing in the wrong measure, but with a computer, and an amanuensis (person with hands and sight to operate the computer) things are forbiddingly slow. Perhaps I should stick to piano music or music for solo instrument.

I had hoped that having AIDS would allow me to use my remaining strength and energy for composing and promoting my works, but it seems that keeping track of health care paperwork, (which, of course, I cannot read for myself) has proven

to be such a large task, and composing so much more difficult and time-consuming, that I am afraid it is often just avoided. At least I was able to finish a few large works, and composed and produced a musical before my sight was totally lost.

Where is all the sci-fi promise of direct connections to the brain?

The disease progresses slowly enough that one day seems not so different from the previous one in so far as sight capabilities is concerned...

Geordi, I could sure use your visor now!

Mike died on May 29, 1994. He had written four articles concerning his struggle with CMV Retinitis, none of which had been published. This is a distillation of those four writings.

In one of the earliest of Mike's writings, he wrote these words:

"I try not to let myself get too rundown even in pursuit of various 'dream' activities I move toward, so I can recover from each infectious setback and renew my activities. I also think that having strong interests, perhaps an abiding passion for something, is essential to longevity. Without this, the lack of information flowing in, and the difficulty of so many routine daily activities would make living too much work."

Mike's passion for music, and his drive to compose, extended his life well beyond what it might have been without these interests.