

The Adjustment Process

Understanding the Problem

"If Mother is blind, why does she seem to be able to see sometimes?" People who are severely visually impaired have widely differing abilities to see. Some people may indeed be totally blind. Others may be able to perceive light, or may be able to distinguish shadows and colors. Some have enough vision to see fairly well in most situations, especially when the lighting is correct. For example, a person with a condition like macular degeneration may not be able to read, but may have excellent travel vision. A person with glaucoma may be gradually suffering a loss of vision to the side, which makes walking difficult, yet still may be able to read. A person with diabetes may have fluctuating vision and so may be able to see better on some days than on others. It is not surprising that a good deal of confusion and misunderstanding often plagues family members as they try to cope with the practical effects of their relative's loss of vision.

Ignorance of the effects of the specific eye condition can lead family members to suspect malingering on the part of the newly visually impaired person, or can cause the family great confusion when the person can see one thing but not another. It's a common reaction of relatives to believe that the visually impaired person is tricking them either by pretending to see more than he can to deny the reality of his loss of vision, or by exaggerating the sight loss to gain their sympathy. Occasionally, a newly blinded person will be acting in one of these ways as part of his adjustment process. More often, though, family members simply don't understand the exact condition of their relative's vision. Some family members may even take the attitude that they don't want to know the details of the visual impairment.

One of the most basic (and unfortunately most neglected) ways a family member can help is by learning as much as possible about the degree of sight loss, the kind of sight loss, and the prognosis for sight improvement or deterioration that their relative is facing. Will the sight loss probably continue to total blindness, or is the sight stable? Will the loss be sudden or gradual? Will surgery be needed?

Relatives should read as much as they can about the specific eye condition and-most importantly-ask the doctor to explain in detail. Too often the person and his family are afraid to ask the doctor for more details, believing the doctor is "too busy to talk to us" or "we shouldn't bother him." The family must remember that the doctor is there to help them and that he is the most immediate source of accurate medical information concerning the specific eye condition. To avert confusion and misunderstanding, the questions must be asked. In fact, it's helpful to write down questions between visits so they are not forgotten during the appointment itself.

Knowledge of the eye condition and its limitations. will also help the family to provide the best possible surroundings-surroundings that will enable the visually impaired person to take advantage of any remaining sight. Will more lights help? Does sunlight streaming through the windows only make matters worse? What colors will be most visible? Chapter 3 provides a detailed discussion of specific eye disorders and their effects.

Learning to Substitute

A newly visually impaired person will have to deal with the emotional trauma that loss of vision will probably bring and at the same time begin to reorganize his life in other ways. He may need to learn a new way to travel by using a cane, a sighted guide, or a dog guide (see Chapter 5). He will certainly need to master new ways to cope with the tasks of daily living, such as cooking, writing, and managing money (see Chapter 4). The most fundamental adjustment to the loss of this major sense, though, is to learn to use- the senses of hearing, touch, taste, and smell more efficiently than before.

SUBSTITUTING USE OF TOUCH: Contrary to the popular myth, the remaining senses don't become sharper, more intense, and more sensitive in a blind person. The sense of touch and the hearing remain as they were before the loss of sight. The only difference is that people who cannot see well practice using abilities that previously were used less because sight was used instead. They notice background sounds, odors, and textures that everyone else could also hear, smell, or touch, but that almost everyone with sight ignores.

Initially the information processed through the other senses will not seem as clear and as complete as the information provided with sight. It's an unfortunate fact that the other senses will never match the full and immediate organizational ability of sight. With practice, though, they can be used fully and effectively.

When a person looks at an object, he can immediately observe both gross and fine details. But using his sense of touch, he can only "see" the object piece by piece and then will need to form an idea of the whole object by mentally combining its parts. Both the newly blinded person and his family should remember that exploring an object by touch takes more time than doing so by sight, and the initial slowness of the process can lead to frustration.

Many newly blinded people will quickly lay a hand on part of an object and conclude angrily "I don't know what it is!" or "How am I supposed to know if this is my best shirt or not?" Perhaps someone in the family will take the blind person's hand, have him lightly and quickly touch an object, and then identify it for him. "See, that is your best shirt" Such well-meaning but ineffectual methods only increase frustration.

A person who can't see can quite easily distinguish a toaster from a blender, for example, but he will need time to get some idea of the length and height of the object, or of the arrangement of the controls, all of which he can learn by touch. The best shirt can be identified by a distinctive collar, sleeves, or buttons. Fruits, vegetables and most other foods have distinctive shapes and different textures. A dirty dish does not feel the same as a clean one.

Encourage the newly blinded person to touch everything! The sense of touch is a most valuable tool, but it must be trained and encouraged. Substituting touch for vision does not "come naturally" to most people. But it will come with training and patience.

SUBSTITUTING USE OF HEARING: A sighted person usually uses vision to locate objects in relation to his own position. A person without sight can often use hearing to determine the same thing. Large objects can be recognized by use of reflective sound waves to "hear" where and what they are. For example, with practice, a blind pedestrian can tell whether a parked vehicle is a truck or a car, because the truck will muffle the sound of street traffic to a greater degree and for a longer time as he walks by it. Because of echoes, speaking close to a wall doesn't sound the same as speaking in the center of a large, high-ceilinged room or speaking outdoors. A blind person can use this information to orient himself to his surroundings.

Hearing can also help a blind person know how far away another person is—the loudness of the speaking voice is the clue. A blind person can tell if another person is walking or moving his head around as he speaks, for the voice will move around as well. It's obvious that blind people can learn to recognize voices and other distinctive sounds in order to use that information partially to replace the information that vision once provided. But none of this ability comes easily or quickly. Practice, training, and encouragement are all necessary to use hearing more efficiently and to change the lifetime habit of using sight first and foremost.

This habit of using sight can be a tremendous resource to a person blinded later in life. The years of visual memory provide the security of understanding how the world is organized. A person who has had normal vision has a clear concept of the identity of objects and the inter-relationship of people and objects in motion. He will remember, at least for a time, the faces of people in his life, colors, and the arrangement of his home and community. This memory bank of experiences is a tremendous asset to ease the process of learning "substitutes" for sight. It provides an invaluable background of knowledge and understanding.

Communication

Communication and social interaction may initially be more difficult for a person who has lost vision because he can no longer see the body language, facial cues, or hand motions of others. Because he must rely on voices alone, he may

feel he's missing vital cues about what is really being said and that he is operating in a communication vacuum. Sighted people conversing with a newly blinded person may feel awkward themselves, because the eye contact that they're used to with the person is no longer possible.

One simple method to replace eye contact when talking to a blind person is to use the person's name in the conversation ("John, what do you think?") and to face him while speaking. In this way the speech is literally directed toward him. Touching the person lightly on the arm or the shoulder can also help to make the link that eye contact used to establish so quickly.

Voice recognition will become a useful tool for a seriously visually impaired person, especially in dealing with family members and close friends on a constant basis. But this, too, takes time, and one of the rudest and most condescending tricks to play on a blind person is to approach him and ask "Do you know who this is?" Most people have received a phone call in which the caller failed to identify himself before beginning the conversation. Until the voice can be linked to the proper name, it's very difficult to focus on the discussion and respond appropriately. The same is true for a blind person who is put in the awkward position of not knowing to whom he is speaking. In addition, such "games" remove the freedom that all sighted people enjoy to choose their conversational partners. Sighted people shouldn't assume that voice recognition is instantaneous, especially in newly blinded people, and should identify themselves at the beginning of a conversation with a blind person as needed.

Rebuilding Relationships

As mentioned earlier, it is virtually certain that the newly blinded person will suffer through a period of mourning for his lost eyesight. His personality and emotional character, the suddenness of the loss, and the available support will help determine the length and intensity of this adjustment process. The family must allow the newly blinded person the time and support to work through this emotional phase. This process, moreover, is seldom a straight-line progression from anger to acceptance.

A 42-year-old man had not been diagnosed as being diabetic until his disease had "gone out of control, leaving him totally blind and physically weak. After some lessons from a special instructor, he was becoming an excellent traveler with the proper skills-good posture and cane techniques, with knowledge of environmental cues to maintain his orientation. Because of his general physical condition, though, he sometimes tripped on curbs and his pace was slow. One day he tripped and fell while stepping off a curb. Suddenly, this seemingly well-adjusted man exploded in rage, throwing his cane as far as he could and shouting that he hated stumbling around and moving so slowly. Despite his instructor's assurances that he was indeed a good traveler, this man could only remember that as a hunter he had been able to walk a mile in ten minutes. As a

blind diabetic man, he could go ten blocks in an hour, and he saw himself as less a person than he had been before. Eventually he did indeed realize that he was still a significant person with an active life, but on the day in question, his pain was very real.

Witnessing such an outburst can be traumatic for family members or friends who may want to cry themselves or scream in anger. Often others will become so frustrated that they'll try to avoid all such encounters in the future. They will start to find excuses for not visiting their newly blinded relative or friend. A common comment is "It's too depressing to see him this way."

Feeling that a relative's blindness makes him or her less a person and resenting his new dependence are normal reactions to the situation. These emotions aren't "bad," and they should be confronted, not buried. It can be truly threatening to realize that the newly blinded family member will probably fill a less responsible role in the family life at least for a time after his loss of sight. One girl reported that her main reaction to her mother's blindness was anger because she was a teenager who wanted a mother to help her, not a mother who needed help to adjust to a major change in life. A woman whose husband was both chronically ill and losing vision said, *"Why doesn't anyone care about me? All anyone ever asks about is how he is. Don't they know my life has been changed too? I wish someone would tell me I'm doing a good job in a difficult situation."* Family members need to recognize and discuss feelings of disappointment, resentment, or fear with sympathetic and knowledgeable listeners, such as others who have faced the same problems or perhaps with professional counselors or therapists.

Outside help may be needed to aid the family in building new constructive relationships. But most people—especially those who enjoyed strong relationships prior to blindness—simply need to recognize the emotions of those involved, understand the fears and frustrations that must be overcome, and realize that normal roles and personalities previously enjoyed in the family will survive, and that with work and time they probably will be as strong as ever.

Understanding the Rehabilitation Process

There are two crucial elements in the rehabilitation process which the family must understand to be effective in encouraging the newly blinded person to pick up his life and return to self-sufficiency. One element is to judge correctly how much any dependency being displayed is due to the blindness itself, and how much is due to the illness or accident that may have caused the sight loss in the first place.

Many of the diseases that cause visual loss have other effects on the person. For example, a diabetic may experience diabetic neuropathy (a loss of sensation in his hands and/or feet). He may be coping with the loss of vision and the loss of touch simultaneously. The frustrations inherent in his situation are obvious.

Many times the diabetes, the stroke, the brain tumor, or other illnesses will cause problems of movement, endurance, or memory, problems that may be more difficult to overcome than any sight loss. Does Dad not know his way around the house because he can't see where he's going, or because his stroke caused a memory loss? Does mother resist taking a walk because it's frightening for her to walk without vision, or because her feet have lost feeling as a complication of diabetes?

Correctly assessing a person's true condition is not easy, for there are often complicated combinations of factors. Specialists in working with blind and visually impaired people can be very helpful at this time. These professionals can break a task down in order to determine which part the person is really having difficulty with, and why, is it the steps, or having to grasp handles? Is it having to remember where things are, or general frustration and depression? When the difficulty is isolated, specific instruction in new skills can help to overcome it, or modifications can be made to work around it. Perhaps that task may prove to be one that the person can no longer do independently because of medical problems other than blindness.

The other major element-timing-is an equally important consideration in encouraging the newly blinded relative to try to do things for himself. "When will he be ready? All he does is sit there and he won't let us call anyone to help him." As a general rule, six months are needed before a person accepts the permanence of sight loss and decides that something has to be done to enable him to live with the blindness. Most people initially believe that their sight will surely be restored, and do not want to discuss their blindness or to learn new skills because it's "only temporary." Of course, some people accept the situation sooner than six months, and others take even longer.

Forcing rehabilitation before a person is ready to accept help will not work. The blind person may resent family interference and will ignore suggested changes in his current life of dependence. He should be given as much information as possible about what services are available to help. An effective professional or an articulate person who has faced the same adjustment may help to speed up the process, ' but before real progress can be made, the newly blinded person will have to decide for himself that he wants to be helped. The verbal clues will be fairly obvious: "I wonder if I could learn to sew again?" "Do you remember hearing about books recorded for the blind?" "Maybe I should get a cane' " "I'd like to talk to someone else who has lost his sight." From this point, outside help will probably be welcome.

Learning itself can be therapeutic. If the person who has lost his vision will allow someone to teach him one thing, however small, the door will usually open for more and more adjustment. "If I can learn my way around the house, maybe I can learn to go out for a short walk ' "The learning process will begin to snowball.

When the newly blinded person indicates that he wants to learn anything-from shaving himself to making tea to counting money-that is the time to begin the rehabilitation process that may well lead to independence again.