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Lighthouse International is a leading resource worldwide on vision impairment and vision rehabilitation. Through its pioneering work in vision rehabilitation services, education, research, prevention and advocacy, Lighthouse International enables people of all ages who are blind or partially sighted to lead independent and productive lives. Founded in 1905 and headquartered in New York, Lighthouse International is a not-for-profit organization, and depends on the support and generosity of individuals, foundations and corporations.

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When Your Partner Becomes Visually Impaired ...

Helpful Insights and Coping Strategies

by Carol J. Sussman-Skalka, CSW, MBA

Firsthand feedback about the value of support groups:

“The group is a life saver. What we discuss really helps. Coming up with some of the solutions to some of the problems.”

“Being in this group makes you think about what you’re doing and where you’re going. We can help and learn from each other.”

“Hearing the concerns of others, talking about the guilt — just knowing that other people have the same concerns, same anxieties, and knowing you are not alone is helpful.”

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First Steps

When your spouse or partner becomes visually impaired, both of you are likely to feel overwhelmed. You also may experience a range of feelings, from sadness to guilt, and there are many day-to-day adjustments to make. It's hard to know where to begin — or how to access information about vision conditions, treatment options, help and resources.



Vision rehabilitation services — which include techniques for accomplishing daily tasks and resuming leisure activities, as well as emotional support — can make an important difference in the lives of people with vision loss, particularly in their ability to regain independence. Encouragement from family and friends also can be vital in supporting their participation in these training programs.

While you can play a key role during the rehabilitation process, you undoubtedly have many adjustments and concerns of your own. You may find yourself putting aside your feelings and needs to focus on helping your partner cope. Yet, in many cases, you may feel alone and at a loss about what to do or how to help. As one couple shared, “Vision loss happened to us.” You also can benefit from programs to better understand your situation, get support for your own emotional needs, and learn about relevant resources and services. Although your specific concerns may differ based on the extent of your partner’s vision loss — and how long you’ve been dealing with it — you have many common issues with other sighted partners.

Some of the most frequently expressed concerns and feelings are discussed on the following pages. They include: understanding what your partner can see and do, communicating successfully, relating to family and friends, dealing with independence and dependence issues, appreciating the benefits of vision rehabilitation and handling stress. We hope that this resource will provide support and information to help you cope better, and will, in turn, create a more positive quality of life for both you and your partner.

Share Your Feelings: You're Not Alone

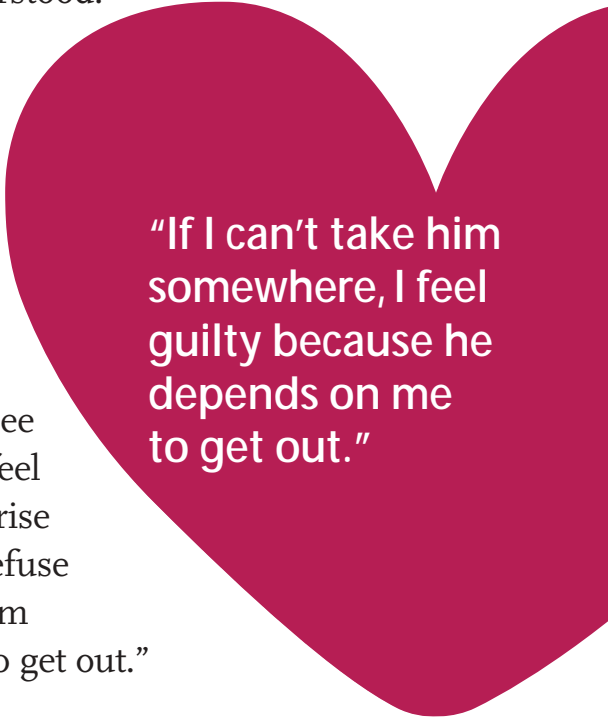
When your partner becomes visually impaired, you may experience many different emotions, including fear, guilt, anger and frustration. These feelings can be hard to admit or accept, because they are commonly perceived as negative. It may help to keep in mind that feelings are neither right nor wrong. However, feelings can get in the way of your relationship with your partner if they are not recognized or understood.

Guilt

One of the most commonly expressed emotions, guilt can appear in many forms. It may drive you to take on unwanted responsibilities. As one partner reluctantly admitted, “I don’t like reading financial statements, but I do it because I feel guilty.” Others experience guilt when they forget that their partners can’t see things or expect that they should be able to see something because they saw it before. You also may feel guilty about taking time for yourself. And guilt may arise when you can’t meet an immediate need or have to refuse a request. One wife said poignantly, “If I can’t take him somewhere, I feel guilty because he depends on me to get out.”

Remember that you’re not alone. Your partner probably feels guilt as well — most likely about the additional burdens and responsibilities being placed on you.

It is interesting to note that guilt is defined as remorse for doing something wrong. Therefore, people may say they feel guilty, when actually they are experiencing regret, wishing that the situation in which they find themselves was different (Schmall et al., 2000). Talking with your partner about “guilt” may bring some relief. By learning that you both have similar emotions, you can each develop a better appreciation for the other’s position.



“If I can’t take him somewhere, I feel guilty because he depends on me to get out.”

Fear

Fear, another frequently expressed feeling, often stems from wondering whether vision loss will get worse: “Will my partner become totally blind?” You also may fear for your companion’s safety while performing tasks such as cooking, or getting around at home or in the community: “Can my wife be left alone?” Inevitably, there are questions about the future: “What happens if I become disabled or die? How will my spouse manage?” This issue is particularly difficult when your partner has other conditions aside from vision impairment, such as physical limitations or memory problems. While there are no easy answers, encouraging as much independence as possible, and talking about alternatives for future living arrangements, can be good first steps.

“I know if she could see to do it, she would do it herself.”

Frustration

Frustration is common, particularly when you’re trying to figure out when to offer help — and how much. It’s hard to encourage someone to exercise his/her independence if there is reluctance to try new techniques. You may do more for your partner than you think you should due to safety concerns. Others admit that they sometimes find it faster and easier “to get the job done,” rather than let partners do it themselves. But keep in mind that taking over can affect your partner’s progress toward independence, causing feelings of uselessness and loss of control. Further, if you “take over,” you may feel even more frustrated and angry, as you’re now managing even more responsibilities that may not be necessary.

Anger

Many people reluctantly admit feeling angry about the whole situation. Like you, they struggle with their own loss of independence, as they take their partners everywhere or adjust their schedules to meet their needs. You may feel irritated by having to stop what you’re doing to meet a request, and then feel badly about your reaction. One man stated, “I know if she could see to do it, she would do it herself.” Resentment also arises when you feel that your partner could be more active and independent, or if you’re not getting much-needed time for yourself. As one partner shared, “I have a life, but it’s not my own.”

Sadness

Feeling sad — even depressed — especially at the beginning, is common for both people in the relationship. While counseling often is available for the person experiencing vision loss, you, too, can benefit from the same kind of support. As one sighted partner reported, “There’s a tremendous, overwhelming sadness. It’s a loss of plans and a loss of what you thought [retirement] would be.” Another shared, “I was so worried about his being depressed, that I couldn’t [let myself] get depressed, but I felt I needed therapy.” Sighted partners who sought professional counseling found it very helpful to acknowledge, and validate, their feelings.

It may not be easy for you to talk about emotional issues with your partner. As one spouse shared, “I keep everything inside and that is not good for me.” As your partner struggles with the adjustment to life with impaired vision, he/she may not always recognize the impact it has on you. At the same time, you may not want to add to that burden by sharing your own feelings. However, those who attended partner support groups found this outlet to be incredibly helpful. “Sometimes, you think you’re alone, but being in this group, you find that many people have the same problems and feelings you do.” Sharing with others who are in the same situation can ease some of the negative feelings and allow couples to more fully enjoy their life together. As one man explained, “Being able to define my feelings better has made it easier for me to talk to my wife about them.” To locate a support group in your area, call Lighthouse International’s toll-free Information & Resource Service: **(800) 829-0500**, or E-mail: **info@lighthouse.org**.

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Understanding What Your Partner Can See and Do



If your partner's vision impairment developed recently or is progressive, it's hard to get a handle on what he/she can and cannot see, and how vision loss affects what can and cannot be done. When in doubt, ask! All people with vision loss do not see the same. Different eye conditions cause different types of vision impairment, and there are varying day-to-day consequences of each condition. For example, a person with macular degeneration may be able to move around comfortably using peripheral (side) vision, but may have difficulty recognizing faces or reading. A lack of information can create confusion and misunderstanding for family members and friends when your partner can do some things but not others. As one woman said, "I didn't realize how little he could see. I'd get annoyed if he couldn't find something because he was functioning so well in other ways."

During support group meetings, many found it helpful to experience what their partners see through the use of vision simulator glasses, which approximate different vision conditions as well as blindness. While wearing simulator glasses, participants tried different tasks like writing a check or reading a newspaper. These experiences allowed them to better appreciate the frustrations of managing everyday activities. Afterward, one person noted, "Now I understand how sometimes he can get a glass of water off the table, and sometimes he can't." For information about vision simulators, call (800) 829-0500.

Sighted partners also had the opportunity to use different optical devices, such as high-powered magnifiers, which gave them a firsthand view of the challenges involved in learning to use them, and an understanding of what these devices can and cannot do. One man admitted, "It's very tedious to use these devices — they're frustrating."

During vision simulation activities, sighted partners experienced a range of emotions — including sadness, frustration, guilt and fear. One participant commented, “It’s scary to look at the world through this perception.” But the experience also provided a starting point for talking with their partners about the impact of vision loss — to learn more details about the effects of their conditions, such as how lighting affects them, which colors improve contrast, or which print size is most accessible. In addition, you also may find it useful to attend a low vision examination with your partner. Use it as an opportunity to ask questions and learn more.

What is a Low Vision Examination?

An eye examination conducted by a specially trained low vision specialist is usually the first step in the vision rehabilitation process. Special charts are used to determine how well individuals can see up close and at a distance, as well as how well they are able to distinguish objects from their background (contrast sensitivity). The specialist also will want to know how vision loss is affecting everyday activities. Optical devices, such as high-powered magnifiers and telescopes, often are prescribed — and instruction in their use is provided — to help people maximize any remaining vision.



Enhancing Communication

Communication can be a challenge for any couple. However, when one partner is visually impaired, there are additional sensitivities that come into play. Many couples admit that talking openly about mutual frustrations, and how vision loss has affected them, is not always easy.

What gets in the way of talking freely? Couples share the following concerns:

- ▶ Difficulty expressing anger and frustration out of fear of hurting the other's feelings
- ▶ Hesitancy to say anything that will be taken as criticism
- ▶ Discomfort with putting one's own needs first
- ▶ Guilt about having, admitting or expressing negative feelings

People in relationships often keep frustrations to themselves because they don't want to make each other feel bad. For example, your partner may accept unwanted assistance to be polite. On the other hand, you may clean up a spill yourself rather than point it out. But these unexpressed feelings can build up over time and get in the way of your relationship. As one person shared, "When I feel worn out, I start getting angry at my wife's requests but I don't want to show that I'm angry. I don't even like to recognize it in myself. It feels selfish. But unless I can feel good about myself, I really can't be caring of her, so I kind of own up to my feelings. It's hard."

Some couples point out the benefits of venting feelings on both sides and moving on. Others find that the best way to ensure that the partner with vision loss does not feel like the object of sympathy is to be open enough to argue. Talking candidly about how vision loss affects your lives also can bring you closer together. One partner commented, "We were very, very close before, but we are probably even closer now." Even if you haven't routinely shared concerns or feelings with one another in the past, there's no reason why you can't start now. One man summed it up well: "The frustrations — it's good to get them out. We talk to each other about it. It doesn't change things, but you do feel better."

"We were very, very close before, but we are probably even closer now."

Tips from Couples Like You

- ▶ Positive communication often requires some preparation. Think about how you feel, what you need or how you'd like things done.
- ▶ Focusing on your own feelings is less likely to put the other person on the defensive. For example, say "I feel upset about ..." or "I would appreciate help with ..." rather than, "You made me feel ..." or "You could have done ..."
- ▶ Being specific about what you want is less likely to cause a negative reaction. Ask your partner to be specific about what kind of help is needed, and you should do the same.
- ▶ Acknowledge what you heard to assure your partner that you're really listening.
- ▶ Give your partner your full attention to prevent missing important points. Conversely, ask the other person to tell you what he/she heard to avoid misunderstandings.
- ▶ Postpone conversations when emotions are high. Wait for a time when both of you are calmer.
- ▶ Taking time to better understand each other's situation is likely to create more empathy. As hard as it may be, try to put yourself in your partner's shoes.

Additional Factors to Keep in Mind

Nonverbal expressions often are so automatic that it's easy to forget that you're even using them. Try to remember that the usual gestures, nods, smiles or frowns no longer may be visible to your partner.

One woman shared a useful tip:

"I call out my husband's name to get his attention. Since he can't see that I'm looking at him, he doesn't know when I'm talking to him."