

How to Have a Happy Life: As a Senior Losing or Without Vision

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1. Foreword

Everyone needs hope and a little help in troubled times. In public opinion surveys, one of the greatest fears expressed is that of losing one's eyesight. Such fear can be remedied by accurate information, effective help, and realistic hope. If you were to see people actually struggling with vision loss and you were in a position to help them, why wouldn't you?

The Seniors with Vision Loss Committee of the California Council of the Blind (CCB) believe we are in an excellent position to offer assistance. Since at least 1993, this committee has existed to promote the capabilities and address concerns of this increasing population. We provide educational and enrichment programs at CCB's annual statewide Conference and Convention. Our members develop a working knowledge of relevant community resources and how to navigate them.

As people successfully living with differing degrees of vision loss, we often become magnets for those seeking information and support. We regularly receive queries

from family or friends of a person facing recent vision loss.

In addition the committee reaches out to educate the general public and to empower seniors who can benefit from our positive message. We find that these awareness-raising activities help all of us. When the public's understanding and acceptance of us and our issues increases, so does our ability to attain a fuller integration into the life of the community.

Creating and distributing literature for seniors with vision loss and those who care about them has been one effective way to get the word out. In 2003, we published a booklet called "Failing Sight and the Family Plight". This piece communicates what many visually-impaired seniors would like their friends and families to know. "Failing Sight and the Family Plight" can be accessed at the CCB website www.ccbnet.org and clicking on the Resources link. This booklet can be printed from the website in English, Spanish, or written Chinese.

The book you are about to read takes a different, more detailed approach. An engaging, mature woman walks us through her vision loss journey, mirroring many

emotional and practical hurdles commonly faced by those in a similar situation. Fortunately she has numerous friends coping with their legal blindness in a wide variety of ways. The diverse coping styles of her friends highlight how much an individual's attitudes and goals can influence his or her adjustment and outcome.

Prior to writing this piece, we conducted an informal nonscientific needs assessment, not wishing to duplicate the work of others. We chose to focus on common barriers to making the best use of available rehabilitation and related adjustment services. As we clearly state, we speak strictly from the perspective of a peer, not a professional.

There are many quality programs and services seniors with vision loss can access. Our goal is to hone in on some of the attitudes (positive and negative), misconceptions, strengths, and a great variety of responses we see our peers display during their accommodation process.

By telling a story featuring people readers can relate to, and perhaps see themselves in, we hope to make a positive impact on their attitudes as well as fostering hope. This work was primarily designed to be read by

persons with vision loss, their families and friends, and to spark some discussion. It might also be useful in vision loss support groups, senior centers, and other centers serving older people with visual impairments. We hope that you find encouragement and helpful information in these pages.

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You can!

2. The Highway of Heartache Leads to the Road to Happiness

The Highway to Heartache

Maybe I'm a lot like you. I was living a pretty good life. I worked hard, took care of my family, enjoyed hobbies and recreational activities. As retirement approached, I looked forward to doing a bit of traveling and spending more time with my ever-so-smart and charming

grandchildren. There were so many things I was postponing until I had the time for them.

Then Boom! Everything changed! I'll never forget that terrible day at the eye doctor's office. He said I couldn't drive any more, actually shouldn't have been driving this long. He told me I was now legally blind. There was nothing more he could do for me. He said he was sorry, but I never heard those words as he doomed me to living death.

Legally Blind. Not me! I couldn't bear to hear the phrase with that scary word "blind" in it applied to me. True, there were those close calls with the car. I could almost read standard print. But it was so exhausting and time-consuming that I rarely bothered with it. Anyway, I could still see quite a bit. I didn't hear the rest of what the doctor said that day because I was too much in shock.

The Road to Happiness

That was a long time ago; I'm now quite comfortable talking about my blindness. The process of changing my attitudes and learning new skills was uneven at

best; sometimes I felt like I was taking two steps forward and one back. But I learned to change course in handling my vision loss. In the beginning, I was headed down the Highway of Heartache.

But now, I'm on the road of Happiness and Hope. Just like you can be, too.

Tea and Sympathy



Caption: photo of tea filled china tea cup and saucer

I have lots of things to share with you. I'd like you to imagine we're sitting in a cozy kitchen sharing a pot of tea. Tea helps with most things after all. So pull up a chair, I'll pour you a hot, fragrant cup of tea and tell you more.

There's Hope

Early on, you may feel like it's the end of the world. But take it from me and so many of my visually impaired friends; it doesn't have to be! Giving yourself time, not

giving up, finding the proper training, discovering the right help and support; these are all keys to success.

So Many Questions

If you haven't known any capable blind or visually impaired people before, you may be struggling with many questions.

- **How can I ever do those things I've been relying on my eyesight for? Things like cooking, managing the house and my money, carpentry, knitting, traveling?**
- **What will I do, now that I can no longer drive?**
- **How do people who can't see well read, use a computer, identify their money, quickly use their phone?**
- **Can I still enjoy going to the movies?**
- **How can I remain physically active? Or feel adequate in social situations?**

Great News!

The great news! You need not be afraid to ask these and so many other questions. All of the above tasks and more are routinely done by people who have low vision or who are blind. I know it may be hard at first to imagine yourself doing certain things without the benefit of good vision. But knowing how possible and common such achievements are may just get you to take those important first steps toward independence and a better life.

3. Hurling into That Horrible Hole That Is Vision Loss

Let's Be Real

Caption: photo of attractive senior woman looking concerned



Let's be real. Sure, some souls seem to sail through life's problems, seeing their vision

loss as just one more challenge to be conquered. But for most of us, dealing with our vision loss wasn't that easy. A period of time was like tumbling into a big, horrible hole; and getting temporarily stuck there. Whereas some find diminished vision a small, annoying pothole, for others, it's a deep, dark, dismal pit. Its walls are tastelessly decorated with words as unclear as their vision. "Low vision, blindness, legal blindness, visual impairment." Such words may mean something to professionals, but to you, these terms probably just stir up anxiety or frustration. Also crowding around in that hole may be the numerous fears and doubts, ebbing and flowing feelings of anger and sadness, resentment and regret over what you've lost.

It Helps to Acknowledge the Loss

Now, please don't run away from such talk. True, no one likes to be in that hole of loss. However, you and I have lived long enough to know that we start having to deal with all sorts of losses and grieves from the time we're little onward. And most of us have learned that facing these losses works better than hiding from them; saying a sad goodbye to a family pet, a close friend at school, later, to friends and loved ones. You remember

how hurt and lonely you felt, even though you had many good things going for you then. You've probably already weathered many such losses, perhaps learning you were stronger than you knew.

When you are losing something as valuable as part or all of your sight, well, that loss is a very big deal indeed. You're bound to have feelings about it, lots of feelings.

Your Loss And Your Story Are Unique

Caption: photo of a senior man and woman in comfortable chairs in a living room looking very interested in what each is saying



Look, I'm no mental health professional. I'm your peer, a person with vision loss like you. Through my association with my many friends with vision loss and the support groups I've attended at my local blindness center, I've seen a whole lot of people and a whole lot of emotions. It's like my support group facilitator said,

“Everyone has a story and experience of vision loss unique to him or her.” We each bring our own individual personality and background to this stressful experience. Put five recently visually impaired people together in a room, and you'll find that each expresses feelings of anger, fear, or sadness, in a different way from the others. One will be vocal about his anger or sadness; another gets these feelings out of her system and moves on with her rehabilitation.

Grieving Is Normal

My facilitator said there's not a right way and a wrong way to get through the grieving process. But it's crucial for the person and their family to understand and expect some grieving. Sometimes the only way around something is through it.



Caption: photo of senior woman just beginning a smile

Despite each person's unique experience, some things are predictable about all types of loss. The normal process begins with grieving, moves

to anger and defiance and finally ends in acceptance. The passage through this process takes a different amount of time for each person, and some people unfortunately get stuck, but for most, acceptance finally arrives. If you and your family understand this journey, you won't be surprised by it, and hopefully you won't try to run away from it either. She said if everyone hangs in there, accepting the reality and the effective help that's available, there is light, so to speak, at the end of the tunnel. If you do find yourself stuck in that deep, dark hole, take heart! You can get out! And there is help.

4. Hauling Yourself Out of the Hole

I'm happy to say, you can make it out of that horrible hole in one piece. Just like a car mired in the mud, you may need some help to get untrapped. That is the nature of holes. There's no shame in that! By actively reaching out for and accepting that assistance, you are helping yourself. In my case, always priding myself on my self-reliance, asking for help at first was so hard. Some examples of the kinds of help I'm talking about appear in the resource section at the end of this booklet.

The Right Attitude Is Crucial

I'm making a big deal out of this for a reason. Do you know what the most frequent cause is of older people not adjusting well to vision loss or achieving their goals? Is it because legally blind folks can't learn to cook, or golf, or fit in with social situations? No, the biggest barriers are often attitudes!

Our fears, stereotypes, and misconceptions (beliefs that we may be hardly aware of) can unnecessarily limit us. Initially, we may not have much control over outside barriers, like print we cannot read. But we can do something about our attitudes.

Caption: senior couple working together to do the bills in a laptop

If you're wondering why I'm taking the time to say all of this; well, my friend, there are two reasons. I hate to see needless suffering. Yes, you and I may suffer sometimes because of our



vision loss. Yet some of the things that cause our suffering the most can be avoided.

My second reason? I wish that someone had come along and told me what I'm telling you, back when I was struggling so!

Ask For Help

Remember, when you accept help out of the hole, no one will be telling you what to do or what you want to achieve. Instead, folks who understand what you're experiencing will ask you what you want to learn. Your individual hopes and goals are what is important. It's okay if you aren't sure how to find an agency or center that specializes in vision loss skills and other help. You probably have family members or friends who would be only too glad to search on the Internet, in the local phone book, or call Directory Assistance for you. Making that contact is one giant step on that climb out of that scary hole.

Hang Out With Blind and Visually-Impaired People



Caption: photo of 2 seniors holding on the handle, sharing the load of carrying a hand basket in a grocery store

If your only experience of blind people is the man standing in bewilderment at a street corner, or being led to the front of the line at the airport, or spilling food at a restaurant, then of course, you might fear the worst.

That's why choosing to hang out with lots of other people with vision loss is a smart move. Getting training in the skills for living as a visually impaired person is vital to your independence. But you probably won't make the best of those skills if you don't have that needed ingredient of learning directly from your peers, others who are legally blind. I have gained so much useful knowledge from them. Some folks I met while attending support groups and classes at my local center for the blind and visually impaired. But my best source for meeting these peers has been joining the California Council of the Blind and going to its local chapter meetings and statewide conventions. See the

resource section for more information on the Council and what it can offer you.

The people there have been at this vision loss thing longer than I. So they have a lot of tips of the trade to share. Many have developed the self-confidence that makes this knowledge work well for them. Their self-confidence and positive attitudes can be contagious.

Let Your Peers Be Mentors

Caption: 2 senior men talking over a sports drink cooler at a sporting event



It's amazing what you can find out from your peers; ways to make the most of the Talking Book Library, learning what different services there are out there for people with disabilities. They've learned to use self advocacy skills, going to bat for yourself when you need to. Especially helpful to me was their input in how to understand and deal with my local paratransit service, mentioned in the resource section. Only

someone else who rides on paratransit can really know the ins and outs involved. That includes ways you can make good use of your time as you wait for your ride. That way, you don't feel you have wasted that time and are less likely to resent the fact that you can no longer drive.

I can't list all of the areas in which my Council friends have benefitted me. And I think that I have benefitted them too. Perhaps I appreciate most their leading me to laughter and fun. Sometimes you can take yourself (and life) too seriously.

This community has helped me enjoy things which used to give me pleasure in new, different ways. I thought my cross-country skiing days were over until I met avid blind cross-country skiers. I have replaced those few things I can no longer do with other worthwhile, satisfying activities. I no longer embroider but have learned to crochet. The whole spectrum of activities and relationships built up by associating with numerous, varied people with visual impairments have all been part of adjusting to my vision loss and of aiding me in extracting myself out of that old hole, onto solid ground.

Freeing Yourself From the Hole

There isn't enough space here to list all of the ways to free yourself from that hole, the hole that is really the grief over your vision loss. As many options exist as the number of people who need them; so there are bound to be things that will work for you. Whether you are a loner or a social butterfly, an introvert or extrovert, this vision loss thing is one thing that's much tougher going it alone. It's a funny thing. By facing the reality of your legal blindness head-on and accepting some help sooner rather than later, it's more likely that you'll become the person you want to be.

Danger Signals



Caption: photo of a woman respectfully smiling at, and appearing to listen to, a senior woman looking sad

According to my support group facilitator, there are certain alarm bells of being stuck you should not ignore; my best advice when such signs appear is to

seek prompt professional help, to get unstuck from that horrible hole of loss. These signs not to ignore include:

- Your anger or sadness are affecting your daily life and activities, or in very rare cases, you feel life is not worth living anymore.
- Your response to your loss is hurting your relationships; those close to you either tell you or show you that your anger, sadness, or other reactions is harming them.

The staff at your nearby blindness center or a mental health professional are good places to turn for help. By combining their specialties to understand both your emotions and your vision loss, they can deal with all the complexities to support you in coping with your situation. There are books, classes, and support groups to help you and your family understand and cope with grief, after the crisis is under control. Your primary care physician and house of worship can also offer their guidance.

Remember, hope is your path out of the hole.

5. What Happens to You Happens to Your Circle

Caption: a 3-generation smiling family group photo in the park with their dog



Yes, it's your vision loss. But like any other big event in life, what hits you also lands on your

family and friends: on anyone you have frequent contact with. Even though they don't live in your skin and can't know exactly what it's like for you, your loved ones often experience similar emotions to yours.

They, too, may feel fear, anger, and or sadness. They may try to tell themselves that your eye problem isn't what the doctor and the evidence says it is. If you and they are like most people, this experience is something new and scary. They don't know what to do or say. It can be a difficult time for everyone.

You and Your Partner: The Impact On Couples

For those of us who are part of a couple, vision loss most probably becomes a big deal. "Spouses," "partners," "couples," whatever your situation, this most intimate of relationships may bring extra stress. Severe vision loss is just one of those life-changing events we may have to experience, and it's a sensitive subject. So please hang in there with me as we talk about it.

Roles and Role Reversal



Caption: senior couple on couch, his arms lovingly around her, both smiling, her head resting on his shoulder

Take me and my husband. We've been married for many years and had already gone through some other family and health crises by the time my vision loss hit Big-Time. That practice in coping with major changes and challenges definitely helped us in some ways to cope

with this one. Yet as you'll see, we didn't exactly handle everything well either.

In our relationship I was the errand runner, activity organizer and chauffeur. When I lost my driver's license all that changed. My husband had to take on the bill paying and much of the cooking; we had to ask favors of people to drive the grandkids to their social activities. Willing neighbors drove me to the doctor's.

A Partner May Become Resentful Or Angry

At first the burden of doing most of what I used to do fell on my husband. He couldn't help it I guess; he began to resent his heavier load.

Getting You Both From Where You Are Now Closer to Where You Want to Be

When your eyes just don't work like they used to, so many changes and adjustments must be made; so many emotions come in to play. Who wouldn't have some difficulties and strong emotions to deal with? The tricky thing is, there are the two of you involved in this

loss. Even though you may be very close, you may have differing emotions, needs, and literally "see things" quite differently.

Take Care Of Yourself First



Caption: photo of group of seniors enjoying lifting hand weights

My husband used to be a heavy smoker; I

desperately wanted him to quit. I nagged; I coerced; I threatened. Nothing changed. In fact, he became even more resistant. In the end he did stop smoking. What began the change? On the advice of a friend, I joined a support group for partners of people with addictions where I was able to deal with my own emotions and attitudes. A similar path is available to you. The most important first step you can take in coping as a couple, family and in your circle of friends, is for you to take care of yourself first!

Yes, many of us have found that a good first step is to be brave, take a step back, and honestly look at how

vision loss has affected your particular life and relationship. Do this alone if you must, but remember, working in a supportive group may move the process along. If you can, look inside yourself and notice how your vision loss has influenced how you see yourself. Professionals call this your self-image, your sense of worth as a person. For instance, do you think you are less attractive now that you can't see? Do you believe you are a less productive contributor to the family or community? Find a safe place and scream, or throw a pillow! But let your emotions and feelings surface! As I said, this is a whole lot easier in a safe group environment.

Assist Your Partner In Dealing With Concerns

Now, keep that courageous hat on, and stop to think about how your sight loss may be affecting your partner. Is she feeling overwhelmed? Does he wonder if you're ever going to contribute to the family again?

Support Groups For One, Or Better Yet, Both Of You

We can't delve into all of the possible responses to your vision loss here, but let's say that these issues and differences are frequent subjects of discussions in support groups. Since self examination can be uncomfortable, what's the payoff? By making the effort to honestly look at your situation, you do an important thing. You give yourself the opportunity and the power to take charge of your life and not be a passive victim of your loss. This is Huge! Perhaps your thoughts and energy are taken up with trying to deal with blindness or the accompanying emotions.

On the other hand, your partner, even if a loving and empathetic one, cannot know what it feels like to be you. But at the same time, your other half has his/her own track to cope with, own set of fears, uncertainties, even anger because of what the loss has brought. A support group, perhaps different from the one you're in, might be just the solution.

Don't Waste Time Waiting For The Cure

Let's get back to what happens when you take that first big step and look within yourself. Here's an example. I

know some folks who haven't really acknowledged their vision loss as something they need to adjust to.

Instead, they're so preoccupied waiting for The Cure, they just wait to be saved by Science. Now, many of us hope that we, or future people, will see remedies for conditions that now cause life-altering vision loss.

There's nothing wrong with holding out hope—we all need hope in our lives. But until The Cure comes to you or me, why waste valuable time? Why not learn those new living skills and decide it's okay to not see so well: for now anyway! Your partner, who may not be in such denial, may be very glad you adjusted to this change. If The Cure comes, you can all celebrate together!

Role Reversal Revisited

Of course, it can work the other way. Prior to my serious vision loss, my husband depended on me to do all the cooking, run the errands and to handle our checkbook. When my sight failed and I initially couldn't do those things, he didn't know what to do. So he did nothing. I was having enough trouble coping with my own feelings about this, let alone the practicalities. You can just guess the kinds of problems we faced getting those bills paid, etc. We both had to make changes and

learn new skills in order to get these jobs done. Our electricity's still on, and we still have toothpaste in the house, so I guess we survived!

Doing Nothing Is Not An Option

I can't emphasize this enough; we don't have to like change, but we do have to respond to it when it happens. What if you had a pot of water on the stove about to boil over? Or your dog was about to launch into your freshly baked pie? Would you just stand by and watch? I doubt it! If these things are too scary for you to handle alone, there are good places to turn for help and a hand up. Some of them are found in the Resources section. Your local agency or center for the blind or visually impaired and a vision loss support group are two such places. Remember, there is no shame in reaching out for a little help. Doing so will save you a lot of needless aggravation.

Communication Is the Key

On TV and everywhere we turn, we are constantly reminded how important effective communication is for

couples. We kind of know that, yet we're busy just living our lives and getting through the day. Because we all know a lot of people, we know that some couples seem happy and some, not, and we don't know whether or not they communicate well in private. There are as many different patterns and ways that couples interact with each other as there are couples.

We cannot overemphasize the fundamental point that effective communication among loved ones takes on even more importance than ever before when a major event like loss of eyesight occurs. Whether we find such discussion easy or hard, more things now have to be expressed, listened to and resolved.

Communication Communication Communication

You know the old adage about successful real estate: Location Location Location. Success in dealing with your vision loss deserves the triple use of the word "Communication." Let's say you feel your fully sighted partner remains overprotective of you, discouraging you from practicing the new skills of daily living you've

worked so intensively to acquire. Perhaps you're both feeling fear and frustration, but what do you do now?



Caption: photo of senior man and woman figuring out operation of a cell phone

Sometimes the opposite is true. Maybe the anxiety or doubt of the one with the

vision loss keeps him/her from using or even learning alternative techniques of daily living. Taking care of one's personal grooming needs, going out and enjoying a movie as a couple— become stressors for both partners. Admittedly, you both need more than just good communication to get past these kinds of concerns, and we'll talk more about that in a bit.

But doesn't success begin with effective communication? Talking, and really listening to our partner, to explain or learn why each of us does or does not do something: that allows us to begin to work out a solution. It clears the air at least, lets us know we've been heard, and helps us feel closer.

At times, the needs of the person with vision loss conflict or clash with the needs of the other partner. In our case, my husband liked to go on weekend fishing trips with his buddies, and both of us were concerned about leaving me alone at home before I learned how to take care of things as a nearly blind person. Or we had always enjoyed taking day hikes together and going bowling. At first, I felt there was no way I could still do those things and could certainly no longer enjoy them in any event.

You can see why some open discussion was necessary in order to understand, and then figure out how to handle the situation. By the way, I still like to cheer my husband on as he participates in his bowling league, and who knows, one day I may get involved in a blind bowling league. My orientation and mobility instructor gave me some useful pointers that have made it comfortable to again share wonderful moments with my husband on our resumed day hikes.

Find Your Communication Comfort Zone

Facing up to your own feelings and questions about vision loss may not be easy but certainly is worth the

effort. Doing that lets you move on to the next step of communicating with your partner. My definition of effective communication is finding ways that work for both of you, most of the time. Some couples I know just seem to do their sharing without any help from anyone, finding a comfortable place to talk and listen, at a time when they're not too upset or distracted. Some of us though, can use a little assistance. As was said earlier, there should be no shame in reaching out for support. A recommended counselor, an agency or support group specializing in the experience and issues of people with vision loss are all good places to start.

Getting Good Information on Living Well After Vision Loss

You've heard that knowledge is power! Never was that more true than with the process of learning to cope with later life vision loss. Gaining useful information is like receiving a great set of power tools to build a nice addition on your house. Or like a shiny new car of your choice to transport you where you want to go.

Information, for example, can free you both from the common misconceptions about people who are blind or visually impaired. It helps to be able to separate fact from fiction: what living with vision loss actually means, not what you're afraid it will mean. These misconceptions can really get in our way! Occasionally we can be turned off because of an unfortunate past experience, encountering someone who handled their visual impairment with a poor attitude or with poor daily living skills. Such an experience can lead you to think that everyone with "eye trouble" automatically has these difficulties. But more often, we just imagine something negative, like briefly picturing how awful it must be not to see well.

Now imagine the relief you feel to discover that most people with severe vision loss lead the active, meaningful lives they want to. As we said elsewhere, with time, training, positive role models, and encouragement, they do! You and your partner can, too!

New Attitudes, New Techniques and Changing Roles

True, working in the kitchen may be done differently than it used to be. The blind cook who used to do everything in the kitchen may ask her partner to dish up. She may sort the laundry while the blind husband does laundry. And once he has a color identifier and knows all the family clothing by touch, he can once again become the Laundry God. New techniques must be learned for just about everything from styling one's hair, to handling the checkbook, to getting around town. All these tasks are now accomplished with what's called alternative living skills. That means in a new way that works for someone with poor vision. But people will not get to the point where these successes occur without the belief that those things can be done by a person not depending on sight. And the more capable you become as a person with vision loss, the more you may change roles and tasks yet again.

Some Problems Were There Before the Vision Loss

Sometimes my friends have to laugh. Well, we can laugh about it now! Vision loss gets blamed for so many things that are really unrelated. The loss wasn't the cause. Something else was: such as the person's

personality and how they responded to past hardships in life. Take my friend who wants to stay dependent on her family for just about everything. It's part of her personality to look to others rather than herself for strength and solving problems. She says she's always really needed people to pay attention to her. Now that she can't see, she figures they have to!

When you look at the situation my emotionally needy friend and her family are in, you can see how important our first two points for couples are. Getting accurate information about the capabilities and help available to those with vision loss in later life may not reach a couple if one or both have not addressed the self reflection and the communication issues.

Acknowledge Feelings, Communicate, Get Information

All three things are needed: awareness of how this loss is affecting you both, open and honest communication, and reliable information. They will go a long way toward moving you in a positive direction.

As I've said, I've been greatly helped by and gained a lot of wisdom from the positive role models I met in the California Council of the Blind. I found additional guidance at my local center for the visually impaired and from a support group they run. It was hard to make that first call and attend my first meeting. But now I'm so glad I did. Sometimes I don't know what I would do without them all.

Become an Advocate

Regardless of where you live in California, these resources are likely to be available to you, especially in most metropolitan areas. If you have difficulty (for example in finding a support group in your local area) I have a thought. Self advocacy, the skill of being polite but persistent, speaking up and going to bat for yourself and your needs, is a skill you will now need to get good at. Why not start to advocate for a support group, through your local center for those with vision loss or an independent living center in your area, through your local Senior Center or your church. See our Resources section.

With Lemons, Make Lemonade

Good for you, if you've been courageous enough to read and think about these delicate matters relating to couples. Instead of just seeing the negatives involving the vision loss, my friends and I hope you'll "see" the opportunity. An unasked for opportunity, true; but not a catastrophe. Certainly an opportunity to grow closer as a couple, to make your relationship richer, deeper, and stronger. And remember, you're not alone. Blessings!

Widening the Circle to Your Family

Much of what we said about dealing with your vision loss as a couple applies to the larger circle of your family; only things get even more complicated. My experience with a support group and the Council gave me some valuable perspective on what was going on with me and my family. Now I know that some families take everything in stride. Their members are ready, willing and able to give whatever help is needed for as long as necessary, and may even count it a privilege. But for me and many of my friends, it wasn't that easy.

Family Members Need to Adjust to Your Vision Loss

Caption: photo of 3 generations of a family



My family had always looked to me as the chief doer and party organizer. I did most of the cooking and decorating and oversaw everything. Yet that was nothing when compared to my role as family chauffeur. I was the driver they could depend on for ferrying members to medical appointments and social functions. When my vision loss became apparent, I know that they, too, felt cheated because I couldn't perform my predictable tasks. We as a family were not used to making the time and the effort to think about our concerns and then communicate openly about them. So we endured some needless hard times early on.

I learned that there can be many different circumstances that can affect how a family reacts to an older member's losing sight. Here are some examples which depend on the type of vision loss.

- **Whether the vision loss was gradual or sudden and dramatic.**
- **Whether it was partial, total blindness, or might-as-well-be total.**
- **Whether the loss was considered a stable situation or likely to keep getting worse.**

Other considerations concern how the family has approached its problems in the past.

- **Whether it was a close family before, or had strained relationships.**
- **Whether family members had clearly-defined or fixed roles.**

Every family does things in its own unique way.

Cultural Attitudes Toward Blindness

I have friends who come from a variety of different cultures and family backgrounds. They've taught me that different cultures or family traditions can have

differing expectations on their members than what I'm used to in my family. Some cultures treat elders with respect, no matter what their condition. In other cultures, disability is viewed with shame, perhaps even the fault of the disabled person; other cultures require the disabled person to be hidden away. Think how boring life would be if we humans all did everything just the same!

Doing Nothing Is Not An Option

You've come across this subheading earlier. As with couples, so, too, with families. I bring these family issues up because no matter how our families handle life's tough stuff, this is surely not a time to do nothing! It's to everyone's advantage if we and our families educate ourselves as much as we can about our vision loss and options. And it's a good idea to see if we and they are on the same page regarding getting our needs and their needs met.

Let me tell you about my daughter and me. For a while after I lost my driver's license, I was too busy attending my own pity party to think about anyone else's needs. My pride just wouldn't let me arrange for paratransit

service. Who wants to share a ride with strangers on a "special" bus, I reasoned. So whenever I had to go somewhere, who did I constantly call? The person closest to me, my daughter. She came to resent my depending on her, but she felt guilty about saying anything to me. After all, at least she could still see! Right? When she learned that paratransit would take me door to door for about the cost of a bus ride, she said, "Come on, Mom. We're signing you up." If my daughter and I had communicated openly and earlier, it would have saved a strain in our relationship.

The Wider Circle Of Friends

What Do You Say to a Blind Person?

Your friends and acquaintances will struggle with the same worries and fears which your family deals with. They may literally wonder what to say to you. They may ask questions or have thoughts like these:

- **What word should I use because "blind" is so harsh?**

- Is it dark for her?
- Should I avoid the word "see" or "look"?
- Should I avoid touching him so he won't get startled?
- How will I let her know I'm here?

The Widest Circle: Strangers

Most people have never ever talked to or had any dealings with a person with vision loss. Just remember how you used to view people with vision loss before you learned better. They usually don't know what to do, and often what they do is wrong, misguided, or downright insulting. Any of the following could and often does occur.

- People speak to you in a loud voice and generally treat you like a 5-year-old. (They may call you "Sweetie" or "Dear".)
- They will speak to others as if you are deaf or don't speak the language. (The waiter may say, "Does

she take sugar in her coffee?")

- A person may (thinking blindness means total darkness and fearing they themselves would not be able to judge) grab you: certain that you do not know a step is ahead.

Your Secret Weapon: Take the Initiative

Take control whenever and where ever you can. Put your friend at ease by asking her to call you by name so you know she's there. Show her how to let you take her arm when you walk together. Mention that you still enjoy "watching" television and it's just fine to say, "I see what you mean."

I fear all too often since becoming blind I have forgotten how to be kind to strangers. I have yelled; told people to get away and that I don't need their unasked-for help thank you very much! All of which of course got me nowhere but feeling angry and guilt-ridden.

People Mean Well: They Just Don't Know What to Do

Remember the person who grabs you is fearful for your safety, however misguided their action. The restaurant waiter doesn't know your name so truly isn't sure without eye contact how to engage you. Here's where the Golden Rule really comes into its own. Be kind to strangers and kinder to your friends and acquaintances. You are all on the journey of discovering how to deal with your vision loss together.

6. Our Attitudes: They Can Help or Hurt

Caption: group of senior men and women with coffee mugs at table all smiling and appearing to enjoy each other's company



We know them when we see them. Their results are easy to see. Attitudes matter! How we think and continue to feel about what happens to us: attitudes influence our actions.

Why talk about attitudes, positive and negative ones? Because in living well with vision loss, they're a huge

deal! As my friends and I have discovered along the way, our negative attitudes can:

- keep us angry or sad and withdrawn;
- make us more fearful than need be, missing out on life.

I realize that other people's attitudes toward our vision loss can be our biggest barriers. But we have only so much control over other people's beliefs. We have much more control over our own. Here are some examples.

Attitudes That Hurt

- You can't teach an old dog new tricks.
- A person who is blind or has low vision is less capable than a person who is fully sighted.
- If I can't do something the way I used to as a fully sighted person, then I just won't bother doing it. (I don't want to do things like a blind person.)

- If I'm learning something too slowly for my taste, I might as well give up trying.
- I don't like to be around anything or anyone who reminds me of my vision loss. (So I prefer not to be around "blind" people. I won't use words like "blind," "low vision," "visually impaired." I avoid words such as "I watched TV." If it comes to it, I'll just keep to myself.)

Attitudes That Help

- There's usually more than one good way to get a task accomplished. (It doesn't matter how something gets done, only that it gets done.)
- Accepting some help when I need it shows my strength and maturity, rather than my weakness.
- I still have just as much to offer my family, friends and community as I did when I was fully sighted. (People still need me, and I'm glad I need them.)
- I may no longer be able to recognize people's faces or see other social cues, but their tone of voice tells

me a heck of a lot. (I refuse to let that stop me from attending those gatherings I've enjoyed.)

- **My vision loss is no crime, no disgrace, certainly no reason to hide! (If I get embarrassed sometimes, so what!? Good grief! I embarrassed myself plenty of times, back when I was fully sighted, too.)**
- **I'm glad for my involvement in regular community activities of interest to me. I'm also happy to be connected to my visually impaired friends and acquaintances. (I value the support, knowledge, and fun we share.)**
- **Sure, I miss many things I can't see anymore. But I have filled my life with so many other things, I seldom feel bad about what I don't have.**

Learn, Laugh, Share

Play, Create, Give!

We're not too old!

Caption: photo of group of seniors with huge smiles on faces and thumbs up



Attitudes can be our strengths or our stumbling-blocks. Since they can make such a difference in our quality of life, wouldn't it be worthwhile to work on them?

7. Hard Choices

No, I never said dealing with vision loss was easy; just doable and worth the effort. In living with diminishing sight, there are a number of things we have little to no control over. Yet, there are many areas where we can and must make choices and decisions about what we will do. My friends and I in the Council often find these things coming up in conversation when we gather.

In That Horrible Hole or Out?

Maybe the earliest choice the person facing vision loss must face is along these lines. "Will I hasten my hike

out of that horrible hole that is allowing my changed condition to keep me stuck? Or will I take full advantage of the help toward greater independence that's available? Will I ignore and pretend? Or is my independence not so important to me."

Some Other Questions And Choices

- **Will I learn to use a blind person's cane? Can I learn to overcome my discomfort in being seen with a cane and use the cane properly to stay safe and to get around? Might I look into getting trained with a guide dog eventually?**
- **How about lessons in using a computer as a visually impaired person? Or will I tell myself I don't need to: that that's what I have kids and grandkids for!**
- **Is there any benefit for me in learning braille? Even though I still have some vision, I'm hoping to use Braille to quickly write down phone numbers and to label food items, files, and other things at home. After all, I can't even read my own handwriting anymore!**

You get the idea. There are actually so many possibilities and issues over which to make active choices; everything from compensating for not being able to drive or read standard-sized print anymore to how you're going to handle social opportunities to meet new people.

Similarities Between Blindness and Aging

There's another interesting choice that doesn't always get talked about, but my friends and I discuss it often. At this stage in our lives, having lived most of life as a person with normal eyesight, how will we and our family work out accepting our need for independence versus our increased need for their help? And importantly, how will our needs affect whatever needs they have? We've already talked about how much smoother things go when we and our family communicate well. I bring this up again because I was surprised at how frequently the issue came up with us senior folks. I suppose it's partly because we may have increasing health problems other than our vision loss as we age. But even if not, this subject of the degree to which we wish to remain independent is one hot topic!

Caption: photo of one showing another a daily pill organizer with large print and tactile markings



One friend says he could probably live alone if he wanted. But as far as he's concerned, he has worked hard all his life and sacrificed for his family. Now by golly he says it's their turn to take care of him! I have two other friends who strongly value their independence in the home, and want their families to see them as independent and capable. One says he declined an offer from his daughter to move to another city and live near or with her family. He likes his freedom and is reluctant to give up his blind golfing and bowling groups here. Cooking, travel, and home management techniques he learned at the center have over time helped him achieve confidence about his ability to manage well. Though separated by the miles, he and his family continue a close, positive relationship.

Another friend doesn't apologize for the fact that she has enough money to pay for all the assistance she needs. Still another friend, who doesn't see at all now, also wants to stay independent in her own home and

interdependent with her family and friends. Having become accomplished at the skills of daily living as a totally blind person, she remains in her home, active in the choir and other activities at her house of worship. Further, she feels it's a sort of a calling or legacy to her grandchildren who live nearby. By coping well with her disability and enjoying herself in the process, she believes she is showing them, by her example, how to handle life when the tough stuff happens.

Yet another pal continues to find this vision loss thing to be really troublesome for her. She is still afraid to be on her own: constantly asking her children and grandchildren to spend time to help her with tasks and errands. She knows they are already busy: in fact so busy she fears they might just find it easy to forget to visit her. That is, if she didn't need their help so much.

Good Advice Without Judgment

When we spend time around the table, talking about these and other things, we get out our frustrations. But I assure you, there is also a lot of laughter too. It feels good to be able to relate to others who understand. And sometimes, they give you useful tips. Of course, we

have to be the one to decide how we are going to approach our situation. I admit sometimes I've learned from my peers what not to do! But even that can help. Best of all is the feeling that it's okay to be who I am, and that I'm not alone.

Staying In the Driver's Seat

In telling you about myself and my friends, I'm not making any value judgments here. Only you can know what you want out of life, what you need, what you have to give. I'm just suggesting one way for you to save yourself a whole lot of wasted time spinning your wheels. By doing the hard work of thinking over what your most prized values and priorities are, you stay in the driver's seat so to speak! On the other hand, by just letting life after vision loss happen to you, you are letting your circumstances decide, not you.

I assure you, dealing with vision loss is a process, not a one-time deal. Remember there are people to help you if you want it. For example, is your independence in your home and in the community so important to you that you will do what it takes to keep it? Or, if you were honest with yourself, is your independence not so high

on your list? And in fact, all this talk of independence just makes you feel uncomfortable. Either way, it's okay. Knowing what you want will make a big difference in the kinds of help you seek, and importantly, in how satisfied you are with the results of that assistance. I'm so certain about that because of what I've seen in myself and many of my peers.

No, you didn't choose this vision loss journey. I can only wish you the very best on the journey you now choose.

8. Say Hello to a Happy Life

By now we've shared three, four or more cups of tea together. I wanted to give you a glimpse of the hope ahead for you as you begin to handle your vision loss. I truly believe that if I, with all of my hang-ups, could do it, so can you.

When I first began coping with my diminished vision, I could have never imagined that I would go on to lead such a full, productive life. When my sighted friends and I get together, I can more than keep up my end of the conversation on what we've seen and done. These

friends no longer focus on what I can't see, because I don't. They've mostly stopped feeling sorry for me, and we have fun.

I sometimes attend my grandchildren's ball games and admire their artwork, even though I can no longer see the detail. We watch TV together, and we laugh a lot. They understand that Nana can't see very well. We talk openly about our frustrations over that, as well as some benefits. They're becoming animated describers, and they're learning that people don't fall apart when they struggle in life.



Caption: photo of a hand using a hand-held magnifying glass to enlarge words in a dictionary

I still help out at my house of worship, switching from the decorating committee to jobs that fit with my skills with my adaptive computer and phone

work. And I'm always good for making goodies for social hour. (Of course, I still put my two cents in with the decorating.) As for my spouse and me, dates at the

movies or romantic walks on the beach continue to provide good memories. By the way, I still enjoy sharing a sunset with him, though I experience the sublime moment in a different way now.

I'm not going to say life is perfect. As I recall it was far from perfect back when I was sighted either. There's the occasional bad day when I miss terribly what I can no longer see. Things such as my loved ones' faces, and details of my granddaughter's recent wedding pictures. Though I know where to find it, my crying towel is rarely used. I usually prefer to spend my precious energy and time on the host of things and people I enjoy.

I'm glad I don't let vision loss stop me from having the social life I want, and that many people appreciate what I can contribute to their lives. By seeing me function and using my blindness skills, they are getting the idea that it's okay to have a disability. But even more meaningful to me is how I now feel comfortable in my own skin. Much of the credit for that goes to my friends in the Council, from whom I keep on learning. You're welcome to drop by and visit any time. I always keep a really tasty variety of teas around. I'm sure we'll have a lot to talk about. We can commiserate some if you want. But mostly we'll take courage and laugh. I'll look

forward to hearing about your happy life: yes, colored by vision loss, yet colored with beauty and hope.

9. A Handful of Helpful Resources

Resources are programs or services in the community, designed to assist with specific needs. Many of the resources listed here are free. Some receive government support; most depend on private donations in order to provide their services. Some have eligibility requirements which may include an official statement from your eye doctor as to your specific eye condition and status as a legally blind person. You can learn the necessary particulars as you contact each individual resource. If you are unable to find what you are looking for in the phonebook, Directory Assistance, or if you don't know the website, your favorite computer search engine should lead you to your goal. Hint, if you prefer, grandchildren are really good at finding things on the Internet.

Please note, this section is not intended to be a professional, thorough listing or a description of all of the available resources. Only a few items are mentioned, to get you started. There are other sources

of more complete lists of services and vendors out there. The purpose of this section is to enthuse you and your family about connecting with the resources. The possibilities are numerous and keep growing. That is both exciting and intimidating. But don't let that overwhelm you. Just start with one at a time, or whatever you are comfortable with. The first two listed items may be the best places to begin.

The American Council of the Blind is a grassroots nonprofit organization of blind and visually impaired people, working on the local, state, and national level. The Council "strives to increase the independence, security, equality of opportunity, and to improve the quality of life for all people who are blind or visually impaired." As seen above, the Council also contains numerous affiliate organizations and committees with a special focus. The ACB and many of its affiliates produce informative newsletters for their members and are wonderful sources for networking and peer encouragement. Membership dues are nominal. The Council also includes groups for members who use computers, the Talking Book Library, guide dogs, rehabilitation services, issues of concern to seniors, and many others.

There are many benefits to joining the Council and its special interest affiliates. You will be learning about and helping to support advocacy for such vital issues as improved access to transportation, signage and wayfinding we can use in public places, and much more. Largely due to our advocacy, we now have talking Automatic Teller Machines in many banks. We are working toward increasing the amount of audio description in the movies and on television and being better able to access all of the information that sighted people easily access on their TV and computer screens. We don't begin to have the space to list everything the Council does on behalf of people with vision loss. Serving people of all ages and backgrounds, the Council is there for you, showing by example and by action that you can still achieve your goals.

American Council of the Blind (ACB)

Toll-free phone: 800-424-8666

Website: www.acb.org

California Council of the Blind (CCB),

(an affiliate of the American Council of the Blind)

Toll-free phone: 800-221-6359

Website: www.ccbnet.org

**Council of Citizens with Low Vision International,
(an affiliate of The American Council of the Blind)**

Toll-free phone: 800-733-2258

Agencies and Centers Serving People Who Are Blind and Visually Impaired

These are private, nonprofit centers throughout the state, specializing in equipping people with vision loss to lead the lives they want. They do this by teaching adjustment to blindness and activities of daily living skills such as cane travel, cooking, home management, how to use a computer, and many others skills. These agencies often have low vision clinics, information and referral to other community service agencies, support groups, accessible enrichment classes, and Braille classes.

There is no uniform name by which you can look these centers up. Some have obvious names, "The LightHouse", "Braille Institute", "Center for the Partially Sighted".

Many will contain within their names words such as "Center for the Blind and Visually Impaired" or just

"Blind". If you are still uncomfortable with your vision loss status, please don't let the word "blind" in a center's name put you off. The agencies for the blind of today realize that most people who seek their services are older, are new to vision loss, and frequently still have some usable vision. Most have vision assessment and rehabilitation services to work with you and your eye doctor on how to help you make the best use of your remaining vision. Low vision issues can be quite technical and complicated. So suffice it to say that regardless of how much or little vision a legally blind person has, getting promptly connected with a center is critically important.

Briefly there are other agencies throughout the state called Independent Living Centers. They are not places to live, but they do work with people with a wide variety of disabilities. Especially if your disability status is new, their benefits advocacy and general Information and Referral services may, among other services, be helpful. In addition, some of these centers have some specialized services for visually impaired seniors under the Rehabilitation Services Older Americans Act.

State of California, Department of Rehabilitation (DOR)

Some seniors want to, or feel they need to work. Having vision loss need not necessarily prevent you from being successfully employed. The Department of Rehabilitation, DOR, may be able to assist you with your vocational goals to obtain or maintain your employment. The division within Rehab which can help is called Blind Field Services. Their counselors specialize in the specific needs of those with vision loss, including work and other issues.

You may be eligible for what is called "Homemaker services", a program under which independent living skills are taught in your own home. In some areas of the state, these skills of independence are offered at a center. Perhaps you feel that you would benefit from the more extensive training that a stay in a residential program can provide. The DOR runs such a program: The Orientation Center for the Blind, in Albany, CA in the Bay Area. Rehab also sponsors some other residential skills training programs elsewhere in the state.

There is a process to apply for services under the Department of Rehab. The services you are eligible for depend on many factors. So it is best to contact a staff member of Blind Field Services to discuss the specifics of your situation. The contact information for Rehab below will help you get started.

State of California, Department of Rehabilitation
Numbers listed here are all in Sacramento, thus, long distance charges may apply.

For general information, call:

Phone: 916-324-1313

For Blind Field Services information for residents living in Northern California call:

Phone: 916-322-7085

Blind Field Services information for residents in Southern California call:

Phone: 916-558-5419

Website: www.dor.ca.gov

Senior Center Without Walls

Senior Center Without Walls is a free telephone community for people in California, over age sixty.

Think of it as attending a virtual senior center via phone conference call. Groups are structured and comfortable.

They cover a wide variety of interests: for lovers of music, pets, armchair travel and bird-watching, writing, and many more. Most popular and uplifting are the daily gratitude groups. This is a program not limited to persons with vision loss but is very friendly to them. Usually there are one or more support groups offered addressing vision loss and low vision.

To register, request a catalogue, or learn more, call the toll-free number below or visit the website.

Senior Center Without Walls

Toll-free phone: 877-797-7299

Website: www.seniorcenterwithoutwalls.org

Friendship Line

Friendship Line is a free service for seniors, offering crisis counseling, emotional support, and information and referral to resources in your local community.

Trained supervised volunteers answer calls for a good portion of each day. Consultations by phone for those dealing with grief and bereavement can be requested.

This call-in line is sponsored by the San Francisco-based Institute on Aging.

Friendship Line

Toll-free phone: 800-971-0016

Paratransit

Can't drive anymore? Want your independence back? One solution is to apply for your local Paratransit Program. The listed names of paratransit services and how they work vary widely from place to place and county to county.

Paratransit is a shared ride provided for people whose disabilities prevent them from being able to use the regular fixed route public transportation bus system. Thus many sighted people use this service too. Rides must be scheduled ahead of time, take you curb to curb, or door to door, for a higher fee may be charged. Of course some visually impaired seniors choose to use the regular bus or rail systems. Cane travel or mobility instructors can teach you how. To apply, or to find out if you're eligible for paratransit, contact your local Public Transit Authority. If you don't live in a metropolitan area, your county offices would be a good place to inquire. Using paratransit is not as convenient

as driving, but it can allow you to get around town independently.

The Talking Book Library

This entity has a very long name, "Library of Congress, National Library Service for the Blind and Physically Handicapped", (NLS) for short.

Use the toll-free phone number below to find a location nearest you and how to apply.

Miss having reading materials you can use? You can listen to a wide variety of newspapers, magazines, classic and contemporary books by signing up for the free services of the National Library Service, otherwise known as the NLS or the Talking Book Library. Several regional branches of this library have been set up throughout the state. You borrow and return the books through the mail; mailing and the necessary book player are all free. If you have the necessary computer skills, you can even download your choices. Reading by listening may become more comfortable for you than you think, if you give it a chance. Doing so will open countless doors to you. For users of large print or

magnified text, there are at least two wonderful sources of assistance: the vision rehabilitation professionals in low vision clinics and your peers in the Council of Citizens with Low Vision International mentioned above. Each with its own kind of expertise can help you put the pieces of your reading needs puzzle together.

The Talking Book Library

Toll-free phone: 800-424-9100

Website: loc.gov/nls

California Telephone Access Program (CTAP)

This program, free to qualified consumers, provides adaptive telephones. That means phones that better meet the needs of people who have difficulty seeing, hearing, communicating, moving, or remembering. Phones with larger buttons and numerals make it easier for a person with low vision to use. Also, check with your phone service provider regarding eligibility for free Directory Assistance as a visually impaired person.

California Telephone Access Program (CTAP)

Toll-free phone: 800-806-1191

American Foundation for the Blind, Senior Site

This is a comprehensive source of information regarding adjustment to later life vision loss. There are nationwide listings of community resources, educational and inspirational videos, and more.

American Foundation for the Blind; Senior web site:
Website: www.afb.org/seniorsite

Blindskills Inc.

This small nonprofit publishes Dialogue, a quarterly subscription magazine. This periodical is full of resources and practical living tips. There are many helpful and inspirational stories of and by blind people of all ages, and on a vast variety of pertinent topics. On the website, you can also find a helpful handout to assist hospital staff in better meeting the needs of a visually impaired person who is hospitalized.

Blindskills Inc.

Toll-free phone: 800-860-4224

Website: www.blindskills.com

Vendors Selling Equipment for the Blind or Visually Impaired Person

If you are new to vision loss, you should know that there are a large and ever-growing number of private, for-profit companies that make and or sell everything from cooking aids to computer software, and everything in between. These products are called adaptive because they make it possible, or easier to be used by a blind or visually impaired person. Our purpose is not to recommend any product. Rather, as a person beginning to deal with vision loss, your options are constantly increasing. More than just computer software and magnifiers, adaptive products range from talking microwave ovens and timers, books and board games to be shared by both those with good vision and not. You may be best served by working with your center for people with vision loss on what adaptive equipment best meets your individual needs before too hastily making purchases. Through your training at the center and your many connections with other visually impaired

peers, you will learn much more about the endless variety and uses of low and high tech adaptive devices.

The Office on Aging, or Area Agency on Aging

As time goes by, seniors can develop other issues beside vision loss. If you're not sure where to turn, or what help is available in your area, this is a useful number to call for information and referral for the community resource you need. Listed services available vary tremendously from one area to another. Just some examples of non-vision-related senior services might include: Mental Health, Meals on Wheels, Telephone Reassurance Programs, and social services.

The Office on Aging, or Area Agency on Aging
Phone Toll-Free throughout California: 800-510-2020

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**Bonnie Rennie,
Retired Licensed Clinical Social Worker**