

Creating a Vision Loss Support Group

A guide for anyone who would like to
start a support group for individuals
experiencing vision loss



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Older Individuals who are Blind – Technical Assistance Center

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Introduction

Congratulations! You've decided to begin a support group for individuals experiencing vision loss, or maybe you're just considering the option. Either way, this guide can help you through the process. In this manual are tips and ideas for starting and maintaining an effective, successful vision loss support group. The techniques included in this resource are tried and true methods that have worked for other support groups in Northern California.

This manual was produced by Society for the Blind in collaboration with several low vision support groups in Northern California. Lois Brooks with InSight in Roseville, Barbara Smith with Eye Contact in Lincoln, and Lucinda Talkington with OutaSight, Inc. in Woodland are three leaders of established, successful support groups who lent their advice and experience to the creation of this document.

Before we begin, it's important to keep in mind that each support group is as individual as its members, which means that you have the opportunity to shape your fledgling group into whatever fits your community.

This manual will help you navigate the five basic steps of forming a vision loss support group:

1. Finding yourself: Determining your goals, objectives, and mission
2. Getting the word out: Attracting new members

3. Making it happen: Planning and implementing meetings
4. Working it Out: Dealing with possible challenges
5. Keeping it going: Maintaining an established support group

Good luck and enjoy the process of forming a new support group! Please contact Ann Jacobson at Society for the Blind 916-452-8271 with any questions or if you would like a free copy of our Community Resource List.



Step 1: Finding Yourself

Determining your goals, objectives, and mission

It is possible that you have attended support groups that appealed to you, and perhaps some that did not. What was it that made them different? What do you want to emulate, and what would you like to avoid? In order to determine the direction of your support group, you have to begin by asking yourself some key questions. Here are a few useful points to ponder to start the process:

- What is your mission?
- Do you want to serve individuals with one particular eye disease or type of vision loss? If so, which?
- Do you want to serve people of a particular age? Examples: young adults, seniors, etc.
- Where will you hold meetings?

- How often will you meet?
- How many members do you want to have? How is membership defined? How will you recruit new members?
- Do you want to charge dues?
- Are you formal or informal? Do you want to incorporate so you can hold fundraisers?
- What activities will you do? Examples: discussion groups, guest speakers, outings, etc.
- Will you distribute a newsletter? How often? How will it be created? Paid for?
- Will there be officer positions? If so, you may need a constitution to determine:
 - How will officers be elected?
 - How often?
- Who will run the meetings?

Lucinda Talkington of Woodland's Outa Sight! Group, Inc. found it helpful to read articles on the Internet about starting a self-help group. She emphasizes that you don't have to reinvent the wheel in order to have a unique, effective, and successful support group. After you've had a chance to consider these questions, you will have a clearer idea of what kind of structure your support group will have. Both Lucinda Talkington and Lois Brooks of Roseville's InSight support group found it very useful to conduct a survey of members to find out what their ideas were for the group. They

suggest being flexible and understanding that your members may want something out of the group other than what you originally envisioned.

This is a great time to discuss a name for your group. Letting members vote on a name for themselves will help them take ownership of the group and make them feel like a legitimate organization. Some existing support groups are the Outa Sight! Group, Inc. in Woodland, InSight in Roseville, New Outlook in Paradise, the Visionaries in Sacramento, and Misty Eyes in Roseville. Allow your group to be creative and express its personality in the name it chooses.



Step 2: Getting the Word Out

Attracting new members

There is certainly a lot to consider as you prepare to begin a support group, but the brainstorming you do now will be very useful in getting your group off the ground. Once you've decided on the particulars of your support group, you're ready to begin meeting. Meetings can start as a few friends gathering for lunch or as formal seminars for larger groups – or anything in between. After determining a meeting site, there are a variety of ways to begin advertising your meetings and recruiting new members.

- Post or distribute flyers at doctors' offices, senior centers, libraries, community centers, or other places that are popular in your community.
- Submit an article or community calendar posting to local newspapers and community newsletters.
- Try visiting your local consumer organization chapter meetings to let people know that you're starting a group in the area.
- Since individuals often want to attend a group but can't get transportation if the existing ones are out of town, you can contact other support group leaders to find out if there are people in your vicinity who might be looking for a group.
- Call your local Department of Rehabilitation office, social workers, and nearby training centers and ask them to add you to any list of resources they may distribute.
- Always remember the power of word-of-mouth advertising! If you tell two friends and they tell two friends, pretty soon you'll have plenty of potential members for your group.

As you recruit new members, you will be surprised at how many people in your community are in need of a vision loss support group. It may take time to gather as many people as you'd like for your meetings, but more will join as your group gains momentum and starts spreading the word. Enjoy this process of meeting new friends and becoming aware of resources in your area.



Step 3: Making it happen

Planning and implementing meetings

Now that you've attracted members and established the details of your meetings, it's time to set agendas for your gatherings. Lois Brooks of

Roseville's InSight support group reminds us that starting a group does not mean that you have to be the one to talk the entire time. Having guest speakers and activities can be a wonderful way to have great meetings without feeling the pressure to prepare a lecture each time. Plus, members will feel great if everyone speaks up and supports each other. It's very important to keep in mind that, if you are not a trained counselor or social worker, it is not your responsibility to provide counseling for your members. Certainly, members support each other and talk about their triumphs and challenges, but it is not up to you or anyone else in the group to be their personal therapist.

The ideas for activities and guest speakers are limitless. Here are just a few of the countless speakers and activities that your group can incorporate.

- Invite a guest speaker from the Braille and Talking Book Library to come to your meeting or schedule a tour for your group.
- Ask an adaptive technology specialist to come demonstrate all the equipment, programs, and gadgets available to people with vision loss.
- Have a representative from the Society for the Blind come discuss the programs that are available to individuals experiencing vision loss and also give tips and tricks for living independently with vision loss. They can tailor their talk to suit the specific needs and interests of your group.
- Tour the Guide Dogs for the Blind facility in San Rafael.

- Wrap presents together around the holidays and use this time to discuss techniques for shopping, sorting money, and wrapping the gifts.
- If your group deals with a specific eye condition, you can invite an ophthalmologist or other specialist to discuss eye health or diseases.
- Invite a representative of your local public transportation system to talk about transportation options for people with vision loss. If your group is mostly older adults, ask about services that are available for seniors.
- Go shopping, to the movies or a play, to a restaurant, golfing, bowling, etc. as a group and invite someone from Society for the Blind or another organization to discuss techniques for these activities.
- Invite someone from California Telephone Access Program to come discuss the free phones that are available to people with a variety of disabilities.
- Ask a representative of Hadley School for the Blind to inform your group about the free correspondence classes that are available to people with vision loss and their families.
- Ask someone who is blind and knits, sews, crochets, paints, plays sports, or works with tools to come share techniques that allow them to maintain their hobbies despite their vision loss.
- If your group consists of many people who are diabetic, invite someone from a diabetes advocacy group to talk about techniques for managing diabetic testing supplies and insulin without vision.

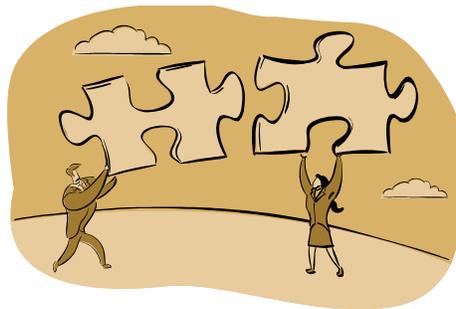
- Invite members of your local consumer organizations for the blind to talk about their groups and help people expand their network of resources, mentors, and friends with vision loss.

Another challenge for some group leaders is keeping the meetings fresh with new discussion topics. Some groups ask a different member to bring a topic each week, while others have one person who consistently brings a theme for each meeting. Of course, members will express a range of emotions during support groups, but it is a good idea to keep a positive attitude at your meetings and help members find a way to grow instead of remaining afraid, angry, or depressed. Your discussion topics are a great way to express your positive attitude and get people talking about solutions instead of problems. A few of the possibilities for discussion topics are listed here, but don't feel limited by these ideas. You are free to create your own!

- How do you manage your wardrobe and match your clothes?
- How do you organize your home and label things like medicine, spices, cleaning supplies, etc.?
- What do you gain when you lose vision?
- How do you keep track of your money?
- What techniques do you use for cooking?
- How do you manage your mail and bills?

- How do you apply makeup, style your hair, shave, etc. without using a mirror?
- What techniques do you use for cleaning?
- What do you do to turn your attitude around when you feel afraid, angry, frustrated, or depressed?
- When did you know it was time to give up driving? This is a good time to talk about public transportation and safe cane travel techniques.
- How do you deal with friends, neighbors, or family members who don't understand your vision loss?
- What techniques do you use for shopping?

Once your group gets talking, more ideas for topics will surface. Just remember to keep the tone positive and focused on finding solutions. Making people feel optimistic about life after vision loss is one of the best ways to make a difference and will also keep your members coming back for more.



Step 4: Working it Out

Dealing with possible challenges

Like the old adage says, the best laid plans are sometimes met with difficulties. No matter how well you have planned and prepared for your support group, some challenges may still arise. This is not a sign of defeat, but an opportunity to problem-solve and make your support group even better. Remember: any obstacle met with creativity, patience, and a little elbow grease can be overcome. Listed here are some common challenges and possible solutions.

- Transportation can be a huge difficulty for many people who are experiencing vision loss, especially those who have recently given up the freedom of driving their own vehicle. Some support groups help members set up carpools using spouses, friends, and volunteers as drivers. Volunteers can often be found through local clubs and organizations, religious institutions, and colleges and universities. Others purchase taxi coupons that can be given out to those who need transportation. Many groups help connect their members with public transportation, especially door-to-door services for seniors and individuals with disabilities. These services go by different names in different areas, but can typically be found by contacting your local Department of Transportation.

- Dwindling attendance is a problem for some groups, especially in bad weather or during busy times of the year. Barbara Smith, the leader of a support group in Roseville, suggests having a reliable core group of individuals who will attend regularly. Lois Brooks, Barbara Smith, and Lucinda Talkington send out newsletters and reminders to their members, and Lois Brooks uses a phone tree to remind members of upcoming meetings. They all emphasized the importance of keeping in touch personally with members to make them feel welcomed and valued at the meetings.
- Getting people in the door can be a challenge, says Barbara Smith of Roseville. She has found that it takes people time to arrive at the point where they're ready to attend a support group because they won't admit that their vision is changing. She insists that if you get them there, they'll keep coming, so it's important to have good word of mouth advertising. If you ask members to bring someone as a guest, they're likely to realize they need the support and come for future meetings. It's also important to keep advertising your group after it's established to let more people know about it. You can submit articles to your local newsletter or newspaper a few times a year to keep spreading the word about your group.
- Feeling overworked can sometimes cause a support group leader to feel exhausted and overwhelmed. Lois Brooks suggests having as many people around you who can help with the group as possible. Whether they're part of a phone tree, bringing snacks, or helping to send out mailings, having people to help you can serve two important

purposes. First, it helps you as a leader feel less overburdened. Second, it allows more people to be involved in the inner workings of the group, which means they'll be dedicated, excited, and feel ownership of the group; they'll do their part to help the group thrive. These are people who can lead the discussion in your absence, recruit new members, and help with many tasks. Barbara Smith realistically states that starting a support group is hard work and it requires a lot of time and effort, but it's also very rewarding. She says that it's extremely important not to give up if things don't happen overnight. Every support group leader who added ideas to this manual stressed that ***patience*** and ***flexibility*** are the two virtues you will need to exercise most frequently in order to have a successful support group.

- Not having all the answers makes some potential support group leaders feel intimidated. Chances are you are not an eye doctor, trained therapist, or specialist in blindness issues. It's alright to ask questions and get advice from the experts when you feel lost or overwhelmed. You can also take classes or read books and articles about these issues, or about how to run self-help support groups. If you plan to create a group, especially if you want it to be ongoing, it will be well worth your time to get some training in running meetings and issues that will likely be discussed in your group. If you get all the resources, information, and training you can, you'll be a better resource for your members.



Step 5: Keeping it going

Maintaining an established support group

Now that you've found your group's unique personality, planned meetings, and faced some challenges, you should be very proud of the progress you've made and the lives you're helping to improve. As important as it was to do all the things to make your group successful, it's also important to find ways to keep your group moving in the right direction after the initial "honeymoon phase" has worn off. Some seasoned support group leaders give the following advice to keep your group interesting and exciting.

- Ask for ongoing feedback through surveys, a suggestion box, or debriefing meetings with your group's leaders and members. If you keep the flexibility you practiced when starting your group, you will find it easy to go with the flow and allow the group to evolve as time goes by.
- Find new ways to support each other. Go to lunch together, create "buddy" partnerships to foster one-on-one support, or send encouraging notes (on cassette, in Braille, or in large print) to your members. Make sure your members feel that they're part of the

process and are given the opportunity to support each other. That way, they'll feel involved and you won't be pressured to be the only support-giver in the group.

- Keep learning! Get continuing training, keep reading books and articles, and attend classes to help you be a great facilitator and to keep current on issues surrounding vision loss.
- Don't be afraid to repeat what works. If your group loved touring a museum a year ago, take an encore trip. If you really got people talking with a certain topic, bring it up again and let the discussion continue.
- Keep spreading the word and advertising your group through formal methods like the newspaper, newsletters, and flyers, and informal methods like word of mouth. Welcome new members to your group and be open to change.

Congratulations again on your decision to begin a vision loss support group that can enrich the lives of its members and educate the community about vision loss. We hope that the information in this manual made the process easier for you. If you ever have questions or concerns, or would like a free copy of our Community Resource List, please feel free to contact Ann Jacobson at Society for the Blind at 916-452-8271. We wish you the best of luck and success with your budding support group!





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