Starting and Maintaining a Vibrant Vision Loss Support Group

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Starting and Maintaining a Vibrant Vision Loss Support Group by Second Sense

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Second Sense is a Chicago-based nonprofit organization that inspires individuals to move beyond vision loss and believe in their abilities.

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FOREWORD

Why This Manual?

• To encourage the development of more community-based support groups.

• To give confidence to the social worker, librarian, nurse, or other professional who sees the need to bring people with vision loss together but who doesn’t herself have any experience or background with the needs of people with vision loss.

• To provide structure when creating a new group, for the inspired person who has personal experience with vision loss but not so much with creating and facilitating support groups.

• To be a source of inspiration and revitalization for experienced vision loss support group leaders.
What Makes a “Good” Support Group?

• Group members listen to each other and share feelings and information for the benefit of all.

• Meetings occur with regular dependability to provide a source of ongoing support.

• People feel the meetings provide an oasis of emotional understanding.

• Individuals learn to change for the better, often increasing their confidence and gaining independence.

• Meaningful (and sometimes lasting) connections are made between group members that extend beyond talk of vision loss.

What Does a Leader Need to Be Able to Do?

• Be able to plan, communicate and find information.

• Have an interest and sensitivity to interacting with people.
You don’t have to be an expert on vision loss issues or to have personal experience with vision loss to run an effective support group.

Leading a vision loss support group is challenging and enriching both personally and professionally. You will discover and learn amazing things. Best of all, you will share in the lives and experiences of people on a journey, which in turn will show you a new way to view the world — as your group members are learning to do.

Thank you to the many vision loss support group leaders in the Chicago area (2005-2015) who have inspired and contributed to the contents of this manual.

Second Sense
Electronic magnifiers (CCTVs) are a versatile low vision tool.
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Chapter 1: Getting Your Support Group off to a Good Start

Questions to Ask Yourself Before Starting a Support Group

1. **Why** do you want to start the group?
   
   • Are you a professional and have you noticed a common trend of vision problems with the people you serve? Do you want to help them be more independent?
   
   • You’ve never thought about it before but now running the vision loss support group falls within the scope of your professional duties. You need information on low vision groups fast!
   
   • Are you someone with vision loss and you can’t find a group near you but want to meet or help other people with vision loss?
2. Do you have time and energy in your life to take on a long-term commitment?

- There are many tasks associated with running each group meeting that can take more time than you expect: finding and scheduling speakers, making reminder calls, shopping for refreshments and other supplies, etc.

- Group members will all want some of your time either to chat or to tell you their troubles. They might contact you outside of meeting time.

- If you are a person with vision loss, are you emotionally ready to help others? If you are looking for support for yourself, you might consider also attending a different group. Being a leader and being simply a member each have their own rewards.

- People take time to start feeling bonds with each other and experiencing the benefits of attending a support group. Can you make a long-term commitment to being a part of this group?
3. **Are you comfortable facilitating a group?**

- Can you stand in front of a group and speak clearly?
- There will be many different personalities in the group. Can you get along with most people?
- The group members will look to you to be in charge of the quality of their meetings. Are you up to the task of gracefully ending long-winded, off-topic comments from members?

If you have answered yes to these three key questions, you are in a position to be a vision loss support group leader.
Now That You Have Decided to Start a Group

Here are some other decisions to make:

1. Where are you going to hold the meetings?
   - Can your intended participants get there? Community locations where your intended group members already go to are a good place to start.
   - Churches, libraries, and senior centers will often let you have meeting space. Also try schools, non-profit agencies, and human services offices.
   - Is the room private? People will be sharing personal experiences.
   - Is the room quiet during your intended meeting time? It’s hard to hear and concentrate on what a person is saying if there is a bingo game going on in the next room.
   - Can the lighting be adjusted? Let the group sit with their backs to the window as much as possible. The windows must have blinds or curtains.
• Are there accessible washrooms? People can have needs in addition to vision loss that you might not expect.

• Is there a public address system if needed for speakers? Are the acoustics good enough for everyone to hear one another?

• Can the tables and chairs be moved around according to the group’s needs? Tables and chairs are good for social interaction but auditorium-style seating could be better for a speaker.

2. **What time of day and day of the week?**

• Consider who your target group members are: Are they likely to be more available during the day, evening, or weekend?

• Will they likely be depending on someone for a ride or are there transportation options?

• Are they likely to be away for long weekends seeing grandchildren? You might want to avoid Mondays, Fridays and weekends.
• Is their ability to see likely to be affected by the darkness of evening hours? Some people see just fine during the day but avoid going out at night when they cannot see.

3. How long should the meetings last?
• Meetings should be long enough that people consider it worth the effort to attend but not so long that it is difficult to fill up the time with meaningful discussion or activities.
• 1.5 hours is average. Formal discussions or a speaker comfortably can hold people’s attention for about an hour. The extra half hour provides time for housekeeping announcements or informal discussions/social time.
• If you work at a residential facility, try to avoid picking a time when the monthly shopping trip or other important or popular events are happening.
4. **Will you be serving refreshments?**

- What are the long-term cost and effort involved? It might seem like a good idea to have coffee and cookies (and cups, plates, napkins, etc.) to make people feel welcome — and it does work — but think about your ability to provide that over the long term.

Consider your snack choices carefully to respect the needs of people with diabetes, nut allergies, etc.

Snacks that are finger-food and not messy to eat are easiest for everyone.

- Are your group members going to serve themselves or do you see a need to have volunteer helpers? Sometimes other group members can fill this role.

- Does your meeting location have facilities to make coffee and wash dishes?

- Are there cleaning supplies for unexpected spills?
5. What content do you wish to have for your meetings?

• Are family and friends welcome to be a part of the meetings?

• Do you want all content to be about vision loss or are you open to anything of interest to the group’s demographics?

• Do you wish your group members to talk and share their feelings and experiences?

• Is education a goal?

• Advocacy?

• Can you envision the group going on outings for fun or for educational activities?

• All of the above?
What are Vision Loss Support Groups All About?

Helping people...

- Feel less depressed about a big change in their life that affects absolutely everything they do or want to do all day long.
- Gain emotional comfort from being in the company of others sharing the same experience.
- Manage the feelings of frustration and anger.
- Stop feeling overwhelmed and helpless.
- Learn what they need to do differently to resume their life.
- Gain knowledge of special tools, resources and services that exist for people with vision loss.
- Make choices for themselves that are positive steps towards regaining their independence and sense of purpose in life.

...adjust to vision loss.
Marketing: Finding Group Members

Now that you’ve got a meeting location and a date set for the first meeting, how to you get people with vision loss to find you?

Generally speaking, people need:

• To hear about it more than once.
• To hear a group name that is easy to remember.
• To have a written reminder they can read.
• To have someone recommend it.

Why don’t people come (when you know they are out there)?

• They hear “support group” and picture depressed people sitting in a circle and crying together.
• They hear “low vision” and remember hearing “nothing can be done” — so why bother going to a group if nothing can make it better?
Marketing Strategies

1. Make a flyer and carry a stack with you everywhere.
   
   • Choose a name for your group that is short, simple, for example “The Visionairies”.
   
   • Design a simple flyer that includes the location, date, and time of the meeting. Include a contact phone number for inquiries. It is helpful to meet on a regular day of the week or month (2nd Tuesday of the month at 2:00 pm to 3:30 pm) so as to avoid having to list a specific date. Your flyer will be good to use any time.
   
   • Use at least 20 pt. in a sans serif font such as Arial. The larger your text, the greater the chance that a person with vision loss will be able to read it independently.

2. Promote in the beginning and at least once a year to:
   
   • Local or state agencies serving people with vision loss (use the www.afb.org service locator)
• Centers for Independent Living (http://www.virtualcil.net/cils/ for a state-by-state locator)
• Senior service agencies
• Churches
• Libraries
• Community centers
• Hospitals
• Senior centers
• Opticians
• Optometrists
• Residential retirement facilities
• Supermarket community notice boards

A yearly reminder that the group is still meeting and the name of the current contact person helps keep new referrals coming!

Ask to be included in any newsletters, website calendars, or community notice boards.
3. **Never stop promoting.**

- Sometimes you may stop promoting as the group grows, but never miss an opportunity to promote to someplace new. New group members keep the group vital and fresh.

- Keep records or a calendar of who you have contacted.

- Changes to your meeting time or location, or special events such as a guest speaker or group outing, are all excuses to contact everyone you have promoted to in the past.

- Consider using social media to create on-line connections for members interested in this type of interaction.

4. **Involve your group members**

- Give current group members flyers to help spread the word about the group.

- Solicit their ideas for marketing locations.
• Plan fun and/or stimulating events that they will be sure to talk about — “reluctant-to-join” people will soon realize the low vision support group is not what they imagined!

5. **Attend local “health fairs” as a vendor.**

• Having a table gives you the opportunity to meet and speak with interested people and hand out your flyers.

• Don’t forget to visit the other vendors — they work with many people and are a great venue for promotion.
What Do Group Members Need?

1. Facilitated Discussions
   - To understand and explore feelings that occur during all the stages of the grieving process they will experience as a normal part of adjustment to vision loss.
   - To share experiences relating to interactions with family, friends and strangers.
   - To find the humor in their situation and share it with peers who will understand and add a few tales of their own.

2. Informal Discussions/Social Time
   - To build connections and feel a part of the group.
   - To practice social skills that may have become rusty if they have been alone and depressed.

3. Presentations by Experts and Professionals
   - To provide access to information that is correct and accurate.
• To increase knowledge on topics of interest to the group (vision loss-related or otherwise).

• To facilitate an introduction to the Vision Rehabilitation services that assist and instruct individuals with vision loss, teaching them the skills they require for independence.

• To give your meeting agenda some variety and perhaps attract new members who are interested in the speaker's topic.

• To add to your knowledge as the group leader so you can better support current and future members.
Ten Things to Keep in Mind When Interacting with Group Members

Please treat a person with vision loss the same as you would anyone else, but keep these ten points in mind:

1. Ask first if you think someone may need assistance.
2. Offer your elbow to escort your group members to their destination. Never pull someone’s arm or clothing.
3. Let them know about any potential danger in a calm voice. “Please stop. There is a step down here.”
4. Give specific directions such as “to the right” and not “over there.”
5. Use audible cues such as tapping on a chair to show where it is or describing obstacles being passed.
7. Talk to the person, not to their companion.

8. Tell the group when you enter or leave the room.

9. Use words like “look” and “see” just as you would with a sighted person.

10. Ask before you move any personal items.
Chapter 2: Keeping Your Group Active and Vibrant

Nuts and Bolts of Running a Group

1. Check the Room Set-Up

   • Arrive early to the meeting location to make sure that signs to the meeting room are posted, the lights are on, and the coffee is percolating, etc. Be there to make the first to arrive feel welcome.

   • Unless you need auditorium style for a speaker presentation, try to have everyone sitting close (for hearing) and facing each other. This keeps the attention focused on the meeting.

   • Check windows and lights: is the room bright enough? Are people able to sit with their backs to glare-producing light sources/windows?
2. **Refreshments**

- Serving food and drink promotes a social atmosphere. Try to have the table cloth contrast with the dishes. Group members may wish to serve themselves independently on the way in but be prepared to offer some assistance.

3. **Before the Meeting**

- Designate “greeters” to welcome returning members but more importantly to welcome new ones.
  
- Make new members feel welcome — assign a buddy to show them where to sit, show them where the refreshments are, and introduce them to other group members. Be sure to take down their name and contact information to encourage them to come back with a reminder call for the next meeting.

- Keep an attendance list: you will be able to identify active members who are willing to help
out as well as lapsed members who may need some extra support.

4. **Starting the Meeting**

- Start on-time as much as possible. A dependable start time encourages punctual group members.

- Get the group’s attention first. Say “hello” and “welcome” but then wait to continue only after the room is quiet and you are sure you have everyone’s attention. It may take a moment for people to finish their conversation with their partner. Sharing information before you have everyone’s attention means that not everyone will hear it and others will be annoyed that they can’t hear YOU.

- Consider stating agreed upon group communication practices: everyone gets a turn, keep discussion on topic, etc.

5. **Keeping It Moving**

- As a leader, the group expects and permits you to lead, to make the decisions and take the
actions that keep the group running smoothly and pleasantly for everyone.

• Consider reading out an agenda each meeting or having a predictable sequence of events. This especially helps new group members feel secure and able to anticipate what will happen next.

• Give everyone a chance to speak, keep the discussion on topic, and do not let one person dominate:

  “I’m sorry to interrupt but we have to give the next person some time to share their comments.”

  “Perhaps we could continue this discussion after the meeting?”

  “Jean, we haven’t heard from you tonight. Would you like to share anything?”

6. Closing the Meeting

• Give the meeting a definite end so that those people who want to leave can feel able to do so.
• State the date and time of the next meeting with the topic of discussion or speaker to stimulate interest in coming back.

• If your budget allows, consider printing up a large print reminder of the date and time of the next meeting for people to post on their fridge.

• “Thank you for coming today. We’ll see you next month. There are still refreshments for anyone who would like to stay.”

7. Before the Next Meeting

• Confirm your speaker.

• Do reminder calls one week before your next meeting.

• Do any additional marketing.
Meeting Content: Discussions You Can Do!

1. Sharing Ways to Be More Independent Everyday

Encourage everyone in the group to bring (or talk about) something they use that helps them accomplish a task by themselves. Expect to see the following: hand-held magnifiers, black marker for bold printing, talking book machine, bump dots, voice recorder, etc. Check out our handout of the Top Ten Adaptive Products in the Large Print Handout section at the end of this manual to be more fully prepared for this discussion.

To encourage more discussion, consider asking:

• How did they discover it?
• How long they have been using it?
• What does it do for them and could they do the task without it?
• Was it easy to use from the start or did they get help to learn? Who helped them?
• When do they use it?
2. What To Do With Your Time

The purpose of this discussion is to increase awareness of activities that are currently being enjoyed.

Start in the Past: As a child, what was your favorite game to play?

• Encourage sharing of happy times.
• What board games, outdoor games, or other activities were played?
• Who did they play with?

Continue in Adulthood: What pastimes did you engage in as an adult?

• Did you play any sports? What did you do for exercise?
• Did you still play games? Cards? Board games?
• Did you do any hobbies?
• Do you like puzzles, trivia games or Sudoku?
Focus on the Present: What do you still enjoy doing?

- What makes an activity easy or difficult when you have vision loss to deal with?
- What are you using to do some of the activities you like to do? (Better lighting? Magnification? Special item? Descriptions from friends?)
- How do you know who else is participating with you?
- Do you have friends who help you participate? What are they doing?

3. Experiences at the Eye Doctor

Emotions range from high to low during visits to the eye doctor. Experiences can be good, bad, or simply confusing. Encourage sharing of experiences to help people realize they are not alone with these feelings. Try to promote better communication skills between doctor and patient.

- Do you like your eye doctor? Why or Why not?
- How often do you go to the eye doctor?
• Tell us about when you first found out you had something wrong with your eyes?

• Does anyone go with you to the appointments?

• Do you do anything to prepare for your appointments? (Such as make notes of questions to ask?)

• Does the doctor ever tell you things you don’t understand? What do you do about that?

To prepare for this discussion, read What is a Low Vision Exam? and Vision Rehabilitation Professionals sections in Chapter 3.

4. Successfully Social

It can become difficult to feel comfortable in social situations when a person has vision loss. It can be difficult to see who is in the room if you can’t see faces. What if they think you are unfriendly when you don’t return a friendly wave or smile that you didn’t see?

It can be difficult to mingle if you can’t see your way around and you might miss the refreshments or feel
awkward about participating in the festivities. What if your white cane is making others feel uncomfortable about how to approach you?

• Do you let people you meet know that you can’t see them and will need them to identify themselves the next time you meet?

• What do you do to find out who else is in the room?

• What tricks do you use for getting around a social gathering without bumping into people?

• How do you manage eating in public?

• What do you do when you meet someone new but can’t see to write down their contact information?

Read our Tips for Dining with Confidence for some suggestions on this popular topic in the Large Print Handouts Section at the end of the manual.
5. Changes in Your Home

The familiar can suddenly seem unfamiliar with vision loss. What changes have you made in your home to make it more functional to you? What have you learned to do differently in order to see things better in your home?

- Did you change the arrangement of any furniture to make easier paths to walk along?
- What have you noticed about the lighting in your home?
- What do you do when you want to watch TV?
- Can you use the phone in your home?
- How do you use the microwave?
- What safety concerns have you had and what have you done to address them?

6. Friends and Family

For many people, the safe environment of the vision loss support group is the only place they feel comfortable talking about the fears and frustrations vision loss has caused. Sometimes, it is the people closest to them that they find most difficult to share with. Often frustrations occur when friends and family don’t understand how to support and help their loved one.

- Do you get help from friends or family that you rely on due to your vision loss? What do they do for you?
- Do you feel they understand your vision loss?
- Do you get the right kind of help?
- Do you talk to your friends or family about your vision loss?

Use the Six Tips for Positive Communication with Family Members Large Print Handout to help set the right tone. It is included in the last section of this manual.
You can also check out two additional resources at www.VisionAware.org:

Help Others Understand Your Vision Problems

A Guide to Vision Loss for Family and Friends

Lighting is essential for reading with low vision.
Tips on Using Speakers

• Book far in advance. You are more likely to get the date you want and you will have more time to promote the event and attract a good crowd.

• Provide direction: Professionals are often pleased to share their knowledge with your group but appreciate some direction from the group leader on what information to prepare for the presentation.

• Provide information about your group: Speakers can prepare more effectively if they know an estimate of how many people will attend and what the demographics are. Don’t forget to mention the communication needs of your group and perhaps gently remind the speaker that regular-sized print literature and PowerPoint presentations will not be accessible!

• Respect your speaker’s time: Keep group business to a bare minimum or wait until after the presentation.
• Do a sound check: Make sure everyone can hear the speaker. Encourage the use of a microphone for large groups. It also helps everyone focus their attention on what’s being said.

• Introduce and thank the speaker: it’s the right thing to do and it also cues the group when they should stop talking with their neighbor at the start and when the presentation is finished and they are free to socialize.

• Keep records of whom you invite and when: Most groups will want to hear the information again in a year or two. You can save yourself a lot of planning by simply creating a rotating schedule of topics to have handy when looking for inspiration.
20 Speakers to Invite to a Support Group and Suggested Topics

Vision Loss Related:

1. Optometrist
   - General anatomy of the eye (parts and functions as they relate to vision).
   - Explanation of which parts of the eye are affected by different eye diseases and how this relates to how the patient sees the world.
   - Difference between an ophthalmologist and optometrist.
   - Meaning of 20/20, 20/200 (legally blind), and other lines on the Snellen eye chart.
   - Parts of an eye exam and purpose of common diagnostic tests.
   - Tips to maintain eye health.
   - Charles Bonnet Syndrome (read a complete description of this syndrome that can accompany vision loss at VisionAware:  

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2. Ophthalmologist

• Discussion of a particular eye disease (Macular Degeneration, Glaucoma, Cataracts, Diabetic Retinopathy).

• Which parts of the eye are affected and how disease of these parts affects what and how a person sees.

• Progression of a specific eye disease and the common treatments.

• Tips to maintain eye health.

• Charles Bonnet Syndrome.

• Information on current research seeking a cure (group members may be interested in how they can get involved as a test subject or receive information on the latest studies).
3. **Representative from National Library Service Talking Book Program**

- Demonstration of how to work a talking book machine.
- Explanation of how the program works and what is provided.
- Explanation of descriptive video library (request demonstration).
- Explanation of how to sign-up for the service.

4. **Representative from Local Public Library**

- Description and demonstration of library materials and services of interest to patrons with vision loss: books on CD/tape, Playaways, large print books, outreach services/bookmobile etc. (Many public libraries also have video magnifiers and computers with screen magnification for on-site public use.)
- Information about library events (book clubs, speakers, etc.) that are accessible for people with vision loss.
5. **Representative from State Services for People with Vision Loss**

- Connecting your group members with their local rehabilitation services for people with vision loss is essential! Your group provides the emotional support and much helpful information, but only vision rehabilitation service providers can give each individual the training needed to live safely and independently!

- Explain eligibility criteria for services and process for entering into services.

- Describe scope and length of services and the professionals involved.

6. **Orientation and Mobility Specialist**

- What is Orientation and Mobility training?

- Who benefits from receiving the training?

- What is the scope and duration of the training?

- Tips for traveling safely when out in the community.
• General FAQs concerning use of the white cane.
• General FAQs on guide dogs.
• Human guide training.
• How to receive individual training from an Orientation and Mobility Specialist.

7. Vision Rehabilitation Therapist
• What is Vision Rehabilitation Therapy?
• Who benefits from receiving it?
• What is the scope and duration of training?
• Information/instruction on how to live independently with vision loss in all areas of life.
• Accessible technology (cell phones, computers) to increase independence.

8. Representative Who Sells Products for People with Vision Loss
• Hands-on demonstration of magnifiers, talking products, large print items, and many other
helpful gadgets to make living independently easier with vision loss.

9. Representative Who Sells Video Magnification Equipment

• Hands-on demonstration of desktop and portable video magnifiers for reading, writing, and many other activities.

10. Representative from a Guide Dog School

• Many guide dog schools have local ambassadors or representative who can come talk to your group about guide dogs.

• FAQs about guide dogs.

• What is it like to live and travel with a guide dog?

• Why a guide dog and not a white cane?

11. Hadley School for the Blind

• Listen to a live or archived Webinars@Hadley.

• Hadley’s Low Vision Focus: Instructional audio CDs.
• How to enroll and program information.

• Courses for family members and caregivers.

12. Representative from Para-Transit Services

• Description of services, eligibility criteria, and application process.

13. Representative from Local Chapter of the American Council of the Blind (ACB) and/or National Federation of the Blind (NFB)

• Description of consumer group purpose and activities (benefits of membership).

• Advocacy for people with vision loss in your community.

Non-Vision Related

14. Police Officer

• Recommendations for personal safety “street smarts.”

• Identity theft.
Keeping Your Group Active and Vibrant

- Community Services provided by local police station.
- Emergency preparedness.

15. Firefighter
- Home fire prevention.
- Emergency preparedness.

16. Representative from Community Senior Services Agency
- Description of services and eligibility.
- Transportation options for seniors.
- Social activity programs for seniors.
- Description of services in the home (housekeeping assistance, meals on wheels, etc.).

17. Representative from Local Public Transit Authority, as well as the local Township services for seniors, para-transit etc.
- Description of accessibility features of local transit system for people with vision loss.
• Information on local door-to-door options for seniors (dial-a-ride, taxi vouchers, etc.).

18. Representatives from Other Organizations and Services of Interest to Older Adults

• American Diabetic Association (Diabetes being a leading cause of vision loss)

• AARP

• Alzheimer’s Association

• An audiologist (can locate through American Speech-Language-Hearing Association). Vision loss is frequently accompanied by hearing loss as adults age.

• Registered Dietician

• Local Mental Health provider — great for winter months as they can touch on seasonal affect, depression, anxiety and provide resources for feeling better and where to get help.
19. Representatives from local theatres, museums, art galleries and tourist attractions

- Description of accessibility features that make a visit more enjoyable for people with vision loss.
- Description of programs and/or events.
- Plan a trip with your group, taking advantage of the accessibility features.

20. Representative from the Local Assessor’s Office to Speak about Taxes

- Information about property taxes.
- How to understand the tax bill.
- Various taxing bodies and the services they are providing to the property owner.
- Senior exemptions, disability exemptions.
- When and how to file an appeal.
Safety Considerations for Group Members at Your Meeting Location

• Keep the arrangement of the chairs, tables, and location of the refreshments consistent. This will encourage people to move about independently — it’s easy when you know what to expect!

• Keep the lighting as glare-free as possible. Turn on the lights and close the window shades. Put a tablecloth over a shiny or glass tabletop.

• Beware of trip hazards! Sometimes they are not avoidable. For example there might be an extension cord in use that is not normally around. Post a “guard” or use only after everyone is seated.

• Most importantly, encourage communication between group members at all times but especially when moving about the room. Accidents can be avoided.

Example: “Betty! I’m walking your way with a hot coffee in my hand!”
Off-Site Trips

• Use a “buddy” system to help people feel more comfortable and encourage people to communicate if they are leaving the group for a moment.

• Consider bringing along more sighted volunteers for extra assistance. Training these volunteers to use the Human Guide technique will make the experience more enjoyable for both the guide and the guided. (VisionAware offers a great description of this technique: http://www.visionaware.org/info/everyday-living/essential-skills/an-introduction-to-orientation-and-mobility-skills/how-to-walk-with-a-guide/1235.)

• Human guides should not leave a person with vision loss standing in space without contact with a solid object such as a chair, wall, or a bench. This will reduce the anxiety of the person with vision loss if they are waiting or resting alone.
• Advance knowledge of what pedestrians will encounter in the area is very helpful.

• Alert the group of any changes in surfaces such as ramps, steps, or even sidewalk pavement to anything else such as a gravel path or cobblestones.

• Encourage people to come prepared with sunglasses, magnifiers, and any other devices they use to control glare and stay independent when out and about.

• Stop or slow down when changing from outdoors to indoors to allow people’s eyes time to adjust to the new lighting situation.

• Do not rush or push people to move faster. People with vision loss often need to take their time and pay attention to walking so as not to trip or fall.
Planning for Leadership Transitions

The day will come when your involvement with the group will end.

Yes. It will.

The loss of a leader places the group in a precarious position. If the leader has always done everything there is no one to pick up the leadership role and the group may simply dissolve. If you feel the existence of the group is more important than any one person, plan for the day you will leave from the very beginning.

• Keep a written record of the group’s activities. Record the date, what was discussed or who the speaker was (include contact information), number of attendees, and any other information you consider important. This leaves a historical record of the group’s activities that will inform the future.

• Plan group activities and meeting content at least 4-6 months ahead. If you must stop leading
the group unexpectedly, it will be able to carry on and hopefully a new leader will emerge during that time.

- Consider assembling a Planning Committee so that you won’t be the only one who knows what the future meeting content will be.

- Target and engage as soon as possible any group members who seem likely candidates to assist you with different aspects of running the meetings.

- Intentionally give other people responsibility for running different parts of the meetings. Rotate this responsibility so that many different members acquire experience acting in a leadership role if only for a portion of the overall meeting. Someday they may feel comfortable enough to run the entire meeting.

- Step back. If you know you will be leaving, arrange to be absent in advance of announcing your departure and set the group up to succeed for one meeting without you. See how it went
without you. You will have time to work out any kinks before you must leave for good.
Jobs You Can Delegate: Engaging Group Members

You have taken on a lot of responsibility by becoming the support group leader. But, this doesn’t mean you have to (or even should) do everything yourself.

Encouraging your group members to take on some of these roles can give you more time to focus on the meeting and can increase your members' engagement.

1. Several volunteers to make reminder calls.

2. A “Greeter” to welcome people and assist with refreshments (even if it is just letting them know what’s available).

3. A “Buddy” for new members who is available to give extra attention to anyone new, and:
   • Take their name and phone number.
   • Show them where to sit.
   • Show them where the washroom is.
• Introduce them to other group members but also stay near them during their first meeting in case they have questions.

• Alert the group leader that someone new has joined for that meeting.

4. Someone to serve refreshments to people whose mobility makes it too difficult to carry food/drink or maneuver safely without help

5. Someone to help with set-up and/or clean-up

6. A committee to plan speakers or discussion topics for the future
Vision Rehabilitation Therapists can teach alternative techniques for many daily activities.
Chapter 3: What You Need to Know

What Is Vision Rehabilitation and Who Are the Professionals?

After or in conjunction with treatment by the optometrist or ophthalmologist, there is more help available that is of the most practical kind.

Vision Rehabilitation refers to the services that restore independence after vision loss. It does not mean that the vision itself is rehabilitated, but rather the person with vision loss receives the services and training that bring independence and maintain quality of life. People who are blind receive these services as well as those who have some usable vision — which most people do.

Vision Rehabilitation services are provided by several different specialized professionals. It takes a team of professionals with their specialized knowledge and the support of family and peers to help most people
with vision loss regain their sense of self and the skills needed to live independently.

Who Are The Vision Rehabilitation Professionals?

A more accurate description of these professionals would be to say they are experts on **blindness**. They know what the appropriate response should be when vision loss occurs.

These professionals have post-graduate degrees in vision rehabilitation and must complete an intensive internship. National certification is available but not all choose to go through the certification process.

- **Vision Rehabilitation Therapist (VRT)**
  
  Certified Vision Rehabilitation Therapist (CVRT)

- **Low Vision Therapist (LVT)**
  
  Certified Low Vision Therapist (CLVT)

- **Orientation and Mobility Specialist (OMS)**
  
  Certified Orientation and Mobility Specialist (COMS)
The Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP) offers certification (www.acvrep.org).

All three professions have knowledge of:

1. **Medical Aspects of Vision Loss**
   - Basic anatomy of the eye.
   - Functional implications caused by different eye diseases and disorders.
   - Medical, surgical, and optical treatments.
   - Assessment of whether visual, non-visual or a combination of strategies is needed to achieve the goals for independence.

2. **Psychosocial Implications of Vision Loss**
   - Stages of adjustment to vision loss and strategies needed to assist people with vision loss (either from birth or later in life) and their families.
   - Positive self-advocacy techniques.
3. **Teaching and Learning Strategies**

- How to perform a functional assessment and design and implement a sequential training program appropriate to the age, abilities, and goals of the person with vision loss.

- Ways to adapt the instructional process when the person has additional physical or health issues such as hearing loss, deaf-blindness, cognitive impairment, age-related issues, etc.

- When to use interdisciplinary teamwork and case management practices: the vision rehabilitation professionals will refer to other health professionals as needed to ensure holistic treatment for their client.

For a complete description of each please refer to ACVREP (www.acvrep.org).

**Low Vision Therapist**

A Low Vision Therapist performs a functional vision assessment to assess acuity, visual fields, contrast
sensitivity, and visual perceptual and visual motor functioning.

- Instructs how to make the most efficient use of residual vision, based on the results of the function vision assessment.

- Teaches an individual how to use their optical devices, adaptive technology, and other special equipment and how to integrate them into their daily activities.

- Instructs an individual to use techniques for all activities of daily living: reading, cooking, organizing, cleaning and grooming with appropriate adaptations.

- Helps determine the need for modifications in the environment (home, work, or school).

When the person’s visual ability is severely compromised, a Low Vision Therapist will refer to a Vision Rehabilitation Therapist for additional services.
Vision Rehabilitation Therapist

A Vision Rehabilitation Therapist's expertise encompasses that of the Low Vision Therapist with the addition of special skills and knowledge, such as braille to teach adaptive independent living skills to people with no useable vision.

Orientation and Mobility Specialist

Teaches a person with vision loss how to travel independently both indoors and outdoors. Training is one-on-one. It usually, but not always includes instruction on how to use a white cane (called a “mobility cane”).

• Training teaches how to focus on and interpret sensory information in the environment (for example, the slope of a sidewalk, sound of a traffic surge, the smell of a nearby cafeteria) to assist in maintaining orientation as they travel to their destination.

• Any residual vision is incorporated in to safe travel techniques and strategies as well as use of optical devices and a variety of technological
devices designed to facilitate safe and efficient travel.

Mobility Instructors teach techniques for safe travel both indoors and out.
Optometrists, Ophthalmologists and Low Vision Specialists

Optometrist (Doctor of Optometry O.D.)

Optometrists are the first line of detection and defense for eye diseases and disorders. They conduct eye examinations, diagnose eye diseases and disorders, and prescribe corrective lenses. They will often see additional training to become specialists in a specific area such as neuro-optometry or geriatric eye care.

Ophthalmologist (Doctor of Medicine, M.D., or Doctor of Osteopathy, D.O.)

Ophthalmologists are physicians who specialize in the medical and surgical care of the eyes. They can provide the full range of care from prescribing glasses to performing surgery. Often they will specialize in a specific area of eye medicine and become, for example, a retinal specialist.
Low Vision Specialist

Both optometrists and ophthalmologists may choose to specialize in the unique needs of low vision patients. Low Vision Therapists are often found working closely with Low Vision Specialists.
Age-Related Eye Diseases

Information on this page was gathered from the National Eye Institute’s website. All photos are courtesy of National Eye Institute.

Age-Related Macular Degeneration

Age-related macular degeneration (AMD) is a disease that affects the part of the eye that allows you to see fine details (the macula). It blurs the sharp, central vision you use for activities like reading and driving.

People with AMD commonly experience a blurred area near the center of vision. This area may grow larger over time, with the speed of growth varying from one person to the next. In time, you may develop blank spots in your central vision. Objects also may not appear to be as bright as they used to be.
While AMD does not lead to complete blindness, it can significantly interfere with simple everyday tasks. You may not be able to see or recognize faces, drive, read, write, or do household chores.

AMD is the most common cause of vision loss in individuals over 55. An estimated 10 million people in the U.S. either have AMD or are at substantial risk of developing it. For more information, visit the National Eye Institute’s website: https://www.nei.nih.gov/.

**Diabetic Retinopathy**

Diabetic retinopathy is the most common diabetic eye disease and is caused by changes in the blood vessels in the retina. It is a leading cause of blindness in American adults.

At first people with diabetic retinopathy may not notice changes to their vision. But it can get worse and cause vision loss. Diabetic retinopathy usually
affects both eyes. To learn more, visit the National Eye Institute’s website: https://www.nei.nih.gov/.

**Glaucoma**

Glaucoma is the leading cause of preventable blindness in the United States. It is characterized by elevated pressure inside the eye, damaging the retina and causing progressive tunnel vision.

At first, glaucoma has no symptoms and no pain.

Without treatment, people with glaucoma will slowly lose their peripheral (side) vision. Over time, central vision may decrease until no vision remains.

Glaucoma testing is a standard part of an eye exam and should be done at least once a year. It can be treated if detected early. To learn more, visit the National Eye Institute’s website: https://www.nei.nih.gov/.
Cataract is a clouding of the lens in the eye and is usually related to aging. By age 80, more than half of all Americans either have a cataract or have had cataract surgery.

A cataract can occur in either or both eyes. For more information, website: https://www.nei.nih.gov/.
What Does “Legally Blind” Mean?

Measuring Visual Acuity

You are most likely familiar with the term “20/20”. The number to the left of the slash (/) is the testing distance. Most people are tested at 20 feet, resulting in a reading of 20/X. The number to the right of the slash (/) indicates the distance at which a person with normal vision can see the testing object. For example, if a person’s vision was determined to be 20/40, that would indicate that at a testing distance of 20 feet, the patient was able to read what people with normal vision could read at 40 feet.

• Ideal vision, or acuity, is considered to be 20/20. Those with 20/20 vision can see an object 20 feet away as they are intended to see it.

• Low Vision is acuity starting at 20/70; it is the lowest visual acuity acceptable to retain a daytime only restricted driver’s license in the state of Illinois. Prevent Blindness America has state-by-state standards for visual acuity requirements for driving privileges.
Legally Blind is acuity of 20/200 or a visual field of 20 degrees or less in the best corrected eye (even if a person has only one eye). It is a statutory definition created by the Social Security Administration to determine eligibility for disability benefits. It is a legal line that separates people whose vision loss is severe enough to merit special status from everyone else.

The term “Legal Blindness” also encompasses the following levels of vision loss:

**Severe vision loss** is an acuity between 20/200 to 20/400.

**Profound vision loss** is an acuity below 20/400. Generally, a person with this degree of vision loss cannot read a standard Snellen eye chart and low vision testing such as counting fingers is used to measure visual acuity. For example, a notation of CF 3 on an eye report indicates an ability to count
fingers on the examiner’s hand at a distance of three feet.

**Light Projection** (LProj) is the ability to discriminate light from dark and to determine the light source such as a window or lamp.

**Light Perception** (LP) is the ability to distinguish light from dark, but the source of the light cannot be determined.

**No Light Perception** (NLP) is total blindness.

Therefore, if a group member tells you they are “legally blind”, it could mean anything from “I can only see the E at the top of the eye chart” to “I can’t see my hand in front of my face” and every level of vision loss in between.

Asking group members to describe what they can see is often a better approach to understanding their visual needs.

- “Do you read newspaper headlines?”
- “Can you see your watch?”
• "What do you see when you stand on the street corner?"

• “What can you see when you look at my face when standing next to me?”

**Amsler Grid**

1. Hold card approximately 12" from your eye.
2. Test right eye first, by covering the left eye. Then repeat with the left eye.
3. Concentrate on the center dot.
4. If you notice any wavy lines, distortions or blind spots in the lines, inform your eyecare specialist immediately.
What Is a Low Vision Exam?

A low vision exam is different from a normal eye exam given by an optometrist. This exam, usually provided by an optometrist or ophthalmologist who specializes in low vision, is used to determine how the visual impairment affects daily life and prescribes tools to enhance remaining vision. Instead of using a standard eye chart, the low vision specialist will use portable charts and a device called a “trial frame” that is worn like a pair of glasses to measure visual ability.

Questions the specialist may ask relate to how a person sees in certain situations — going from light to dark, traveling at night, ability to see faces, etc.

Questions concerning one’s ability to manage everyday tasks like dressing, cooking, or reading may also be asked to determine level of function so recommendations can be made for specific tools to manage these tasks.
The low vision specialist will also provide training on magnification devices prescribed to ensure proper use and maximize their effectiveness.

VisionAware, www.visionaware.org, has a detailed description of a low vision exam and questions to prepare ahead of time for the doctor visit.
Adjustment to Vision Loss

Adjustment to vision loss is a process. It is very similar to the stages of grieving experienced with the loss of a loved one. A person may feel as though they are grieving the loss of their sighted self. People will progress through the stages in different amounts of time. Progression is generally sequential as listed — but not always. These feelings may reoccur from time to time even when someone has been living with vision loss for a long time. Additional loss of vision may also trigger the cycle.

Your group members will all be at different stages:

- Shock and disbelief occur when a person is told or realizes that their vision is not coming back and perhaps is going to get worse. They need time to absorb the news.

- People who are in denial may believe a medical miracle or their faith is going to cure them. If a person’s vision is not going to return, it is important that they hear that information from the doctor. Only then can they move past it.
There is nothing wrong in hoping for the future but today and tomorrow are what must be lived.

- Your group may include people who feel very depressed and hopeless about their vision loss. They may be withdrawing from normal social interaction. They will often focus on what they perceive to be their many new limitations.

- The adjustment process often causes a person to spend a great deal of time reflecting on what they still value in life, what is important to them, and normally will come to the conclusion that there are still reasons for living and going on. Many aspects of life that everyone values such as being a good friend, being kind and compassionate, helping others, have nothing to do with vision loss. A “turning point” is reached and a person with vision loss will start to look forwards instead of dwelling on negative feelings.

- Once vision loss brings about changes in life, a person will start to seek proof (more than what their suspicions tell them) that a different life is
possible with vision loss. Support groups fill this need for answers and information that validate a life lived with independence.

- As new skills and knowledge are gained, a person reaches a point of self-acceptance and increased self-esteem. This person will be your valued group member who inspires and shares his or her knowledge with the group members who are feeling overwhelmed, frustrated, and angry.
Everyday Tasks with Low Vision

How can you dial a phone, write yourself a message, or send an email if you have low vision? This section describes some of the common strategies and tools used to accomplish Activities of Daily Living (ADLs) when reading regular print or seeing clearly is not possible. You will learn that HOW a task is performed is not as important as getting the job DONE.

1. Seeing

- Color contrast is important to make objects visible. Like colors cause objects or their features to blend in and become invisible to the low vision eye. Many people will purposefully consider and build color contrast into their environment: black coffee is more easily seen in a white cup.
• Lighting is very important. Task lighting increases visibility on reading material or whatever a person is trying to see close up. Ambient and accent lighting (such as over kitchen counters) increase a person’s ability to function. Many people will use small flashlights or other portable lights to illuminate restaurant menus. Most hand-held magnifiers also include a small LED light for this purpose.

• Glare is the light that bounces off shiny surfaces or general brightness that prevents a person from seeing clearly. Sunglasses or a hat with a brim are excellent protection against glare. So are curtains and blinds—as long as the lights are on in the room.

• Regular glasses may not give a person 20/20, but they will give the best possible corrected acuity.

• Close proximity often helps a person see something better. Most commonly, a person will have to move their chair closer to the screen to watch TV.
2. **Reading and Writing**

- **Bold black pens** are more easily seen than regular blue ball-point pens. Sometimes very thick black markers are the only tool that produces a legible document for someone making notes to themselves.

- **Printing** is more legible than cursive writing. Upper and lower case letters should be used as appropriate for better overall word shape recognition. (Words written in all capitals become all rectangular in shape: “EGGS” vs. “eggs”)

- **Bold line writing paper, plastic writing guides, a crease in a piece of paper or a ruler** can all act as a guide to keep a pen writing in a straight line.
• Hand-held magnifiers, desktop video magnifier, or portable video magnifiers are all ways of enlarging print.

3. Keeping Appointments/Telling Time

• Calendars and watches come in large print sizes that are big and easy to see.

• Talking watches and talking clocks eliminate the need to see the time.

• A small portable voice recorder is a quick solution to recording important information such as doctor’s appointments, phone numbers, and other personal notes without having to worry about reading handwriting for accuracy later.

4. Using the Phone

• Large button phones are easy to see and are good for at home. Many have helpful features like speed dial. Most phones have a bump or other tactile marker on the “5” to help locate all the buttons.
• Odin, Jitterbug, and Doro are all brands of vision loss-friendly phones with features that make them easy to see or hear.

www.dorousa.us

www.odinmobile.com

www.jitterbugdirect.com

• SIRI on iPhones will allow you to dictate who you wish to call from the list of contacts.

5. Using a Computer

• Windows computers have some optional accessibility features that enlarge font, increase color contrast, or make the mouse and cursor easier to see. Look under “Control Panel.”

• Apple computers also have low vision accessibility features built into the operating features. Look under “General.”

• Other “screen magnification” programs can be purchased and added to a PC such as ZoomText®, iZoom® and MAGic®.
There are adaptations for everything a person needs to do (ADLs) and wishes to do. “Making Life More Livable” (revised by Maureen A. Duffy) from AFB press is an excellent resource to have on hand. Visit www.afb.org/store to purchase.

iPhones are accessible to low vision and blind users.
Magnifier Facts

• Drugstores and hobby shops often carry weak-powered magnifiers. Stronger magnifiers are found through agencies serving people with vision loss, low vision clinics, and catalogs.

• It is important that a person have guidance from a vision rehabilitation professional when selecting a magnifier. Otherwise a too-strong or too-weak magnifier will not have the desired results. Instruction is also needed to ensure that the magnifier is held and positioned correctly or a person will not be able to see their best.

• Every magnifier has a certain strength. It is a number written on the handle or the packaging. The higher the number the stronger the level of magnification.

• As magnification power increases, the size of the lens diameter decreases. What you see is bigger but you will see less of the whole at one time.
• As magnification power increases, the distance you hold it from the end of your nose, and the object in view decreases.

• The lens must be parallel to the reading material. The reader must look straight down through the center of the lens to see as well as possible.
Step-by-Step Guides to Help Group Members with Common Problems

Vision Rehabilitation Professionals are always the experts you can refer when questions arise. However, there are some basic tips and troubleshooting you can do to help someone be more independent.

(At any time, if you don’t feel comfortable using the tips provided or start to realize the group members’ questions are beyond what you know, then it is time to refer to the local vision rehabilitation professionals.)

Each of these tip sheets has a corresponding Large Print Handout that you can copy and provide to your group members. These Large Print Handouts are located in the last section of the manual.
What to Do When a Group Member Says the Magnifier Doesn't Work

1. Trouble Shooting with a Hand-Held Magnifier:

- Is the magnifier broken or did they just get a new one and can’t see through it to read successfully? (They may need to contact the point of sale or their eye doctor.)

- Is the magnifier lens clean? Scratched? (Clean for them if necessary.)

- Do the batteries work? (Sometimes people don’t realize the light is weak or not working from dead batteries.)

- Is the switch working? (A switch that doesn’t work usually means the magnifier must be replaced.)

- Do they wear glasses and are the glasses clean?

- Did a doctor or some other professional recommend they use that strength? (They may have picked up a magnifier from somewhere that
is not the correct strength for their vision. Refer to Vision Rehabilitation Services.)

2. **Care and Use of Magnifiers:**
   - Clean lenses regularly and do not store for long periods of time without removing the batteries.
   - Magnifiers need to be held parallel to the reading material.
   - Magnifiers must be at a certain distance from the person’s nose and from the reading material. These distances change with the strength of the magnifier. The stronger the lens, the closer everything is to the reading material. If the person has switched to a stronger magnifier, he might not be aware that it needs to be held closer to the face. Refer the person to a vision rehabilitation professional for instruction.

3. **Help You Can Offer Your Members:**
   - Ask if they were ever shown how to use that magnifier. If they received it through a doctor or
low vision clinic, recommend they call back to have a follow-up visit.

• Ask person to demonstrate how they are holding the magnifier. Check for parallel position.

• If using a lamp, make sure it is directing the light at the reading material and not at the person’s face. This will help control glare.

• If the difficulty is finding the beginning of the next line, suggest they track backwards to the beginning of the line just read and then move down to the next line.

• Is the person able to read more easily and more comfortably?

If these quick suggestions do not provide success, then refer to a low vision clinic or vision rehabilitation professional.

Copy (or download from our website: www.second-sense.org/vision-exchange) our "Before Buying Your First Magnifier" in the large print handout section to share with your group.
Helping Your Group Members Use Devices with Button Keypads

Your group members may need assistance using common devices, like phones or television remotes, that have buttons they can no longer see. Here are some tips you can use to help your group members.

Questions for assessment

- Do they know what all the buttons do?
- Can they feel or see the buttons? (Some buttons might need enhancing with bump dots.)
- Can they locate the button they need when they want it? Are they hitting wrong buttons?

Familiarization

Allow the person to explore the device and learn how the buttons are laid out. Describe what each button does as they find it. Use words such as “to the left,” “above,” etc. It may be helpful to give an overall description first, depending on what the person can
see of the buttons and how much they like to explore with their hands.

**Encourage use of touch rather than dependence on sight.**

- Some keypads are “7, 8, 9” across the top row (calculators) and some are “1, 2, 3” across the top row (phones).
- The “5” often has a tiny bump on it already. (Have you noticed?) It is also the center of the keypad.
- With complicated remotes it may be helpful to cover buttons that will not be used with tape to make a “Don’t bother with it” zone.
- Large button devices may be helpful if vision permits however a person should still be able to dial 911 on a regular phone keypad for safety, for themselves or others.

**Help**

- The goal is to be able to “dial” sequences of numbers. Wrong numbers usually happen when eye and hand do not work together so it is
important to emphasize the person’s knowledge of where the numbers are.

- The technique for dialing is to place three fingers on a row of buttons and then slide up or down the rows with all three fingers.

- Start by finding the 5. This is the landmark for the middle finger. The index of the right hand is on the 4 and the ring finger is on the 6. Get the person used to this position by asking them to hit the numbers on that row one at a time and then in short sequences (4, 5, 6 then 4, 4, 6, then 6, 4, 5, etc.) This is “Home Row”.

- Explain that to reach other numbers as you dial, all three fingers slide together up and down the rows as needed. Slide all three fingers up to the top row and repeat.

- Then try sequences of numbers that involve the two rows. Watch for accuracy and confidence.

- Repeat for remaining rows: get familiar with the numbers on that row before adding the other
numbers into the sequences. Channels on a TV remote are short. Phone numbers take longer to build up to.

Check for understanding:

• Observe and watch for hesitation or mistakes which mean you will have to go over the instructions again. Talk about some other topic for a few minutes then try a few number sequences.

• If there are buttons with other features to learn go over those and quiz:

  “Can you show me how you would...?”

  “What are the steps for...?”

  “Where do you find the button that does....?”

You have been successful in helping someone learn the device if they demonstrate ability to operate it correctly with confidence.

Copy (or download from our website) our "Dialing the Phone" large print handout.
Troubleshooting with Writing Guides: Letter, Envelope and Signature

1. Questions for assessment:
   • Can they read large print? (Even with magnification?)
   • Are they writing information down and are unable to read it back later?
   • Are they writing overtop of previously written words?
   • Are they having trouble staying on the line?
   • What kind of pen are they using? Paper?
   • Ask the person to write something for you. Can they read it? If you suspect it is read more by memory, write something yourself and ask if they can read that. Use familiar words such as “happy birthday”.

2. Familiarization:
   • If a person can read large print, then writing larger will often help.
• Printing is more easily read than cursive writing. Use lower case to create recognizable word shapes rather than all capitals which tend to make all words look like rectangles.

• More space between letters, words and lines also increases legibility.

• Bold black ink from gel ink pens or 20/20 pens is often preferred.

• Yellow paper may seem better than white.

• Writing guides might only be used when writing for others if a person’s everyday writing for personal purposes needs to be larger than what the guide allows.

• Writing guides work best attached with clipboard or paper clips to paper. They help keep writing where is needs to be (e.g. contain a signature) and in straight lines. Fingers of free hand should be used to help keep place as writing may be too small for the person to see. If writing is
interrupted, leave a small object on the guide to mark the place where writing ended.

• Creasing the paper can also create a line to follow although it will only be tactual.

• For envelope guides that do not fit the envelope size, simply match the top left corner of the guide and envelope for the return address and the bottom right corners for the mailing address.

A person who cannot read their own handwriting or write with accuracy should consider switching to a voice recorder, such as the Wilson, to gather and retrieve information for personal use (appointments, grocery lists, and other notes to self).

3. Help:

• If during the assessment, the person said large print is legible, print a large sample of a familiar word. Ask if they can read it. If the person can see it, ask them to copy it. Frequently you will notice that people will say they cannot read their
own writing but do not think to alter their writing to a size they can see.

• If necessary, demonstrate how to attach paper to writing guide to prevent slippage.

• When using writing guides, words must be written in the middle of the space provided as otherwise there is no room for “y” and other letters that normally fall below the line. It is also possible simply to write those letters as if they were capitals if it seems easier (ex. “eGG”). Legibility is the goal, not perfect penmanship.

• Encourage use of other hand to place a finger at the start of each line to keep track of line in use.

• Practice writing a grocery list or other everyday writing tasks. Try different pens and colors of paper to determine which seems easiest to see.

4. Check for understanding:

• Ask which pen they liked. Can they tell you why? Usually it will be the one that writes the bolder line.
• If using writing guides, make sure the person is able to demonstrate positioning the paper under the guide with edges matched and attaching guide to paper (or writing without slippage).

• Take a sample of their writing from earlier on and ask them to read it back to you. If they can’t read it then more practice with perhaps larger printing is needed. It is very difficult for some people to accept the need to write differently if they wish to read back the information later but it is rather important for keeping track of phone messages, appointments, etc. to manage life independently.

Refer to vision rehabilitation professional if these quick suggestions do not get results.

Copy (or download from our website: www.second-sense.org/vision-exchange) our "How to Use a Handwriting Guide" large print handout to share with your group.
Beyond Low Vision

What if your group member has experienced significant vision loss?

There are more adaptations they can learn to remain independent. The senses of touch and hearing become more important in order to compensate for the vision that has been lost. Additional training from a Certified Vision Rehabilitation Therapist and a Certified Orientation and Mobility Specialist is highly recommended.

Talking products, such as talking watches and talking calculators become essential when a visual display no longer is accessible. Computer users will switch from using screen magnification to programs that read what is on the screen (touch-typing is the most efficient method for using a computer although voice-input programs such as EVAS Guide Hands-Free and Dragon Naturally Speaking do exist).

Instead of writing information down with a pen, most people switch to using a voice recorder.
Reading print can be accomplished by devices that scan the page and then read it aloud.

Contact Second Sense at 312-236-8569 or info@second-sense.org for more information on adaptations for people with no useable vision.
Large Print Handouts

The following sheets are intended to be given to your group members. Support group leaders may copy these large print handouts, without making any changes to the documents, to hand out to their group members. These are the only pages in this manual that should be copied and provided to group members.

These same handouts are available as downloads from our website at www.second-sense.org/vision-exchange.
TOP TEN ADAPTIVE PRODUCTS

These products can help complete many daily tasks with little or no assistance. Most can be purchased from Second Sense, from online catalogs and through a state’s vision rehabilitation program.

1. Large Face or Talking Watch

A large face watch has good contrast and large numbers for easy readability. A talking watch can announce the time with a touch of a button and offers hourly announcement and alarm.

2. Talking Clock

Talking clocks come in a variety of sizes and shapes and are stable to put on a nightstand or tabletop. Time is announced with the touch
of a button and the clocks are easy to set. Some talking clocks offer hourly and date announcements, large displays, volume controls and different alarm sounds.

3. 20/20 Pen

This is a bold, felt tip pen that makes handwriting stand out. The pen does not bleed through paper and does not leak.

4. Writing Guides: signature, check, envelope or letter

Writing guides come in a variety of sizes and are designed for specific tasks. Sign a receipt, write a check or address an envelope following the guides.
Guides are made from durable plastic, are lightweight and easy to carry.

5. Large Print Calendar or Date Book

Large print wall calendar or spiral bound datebook provide ample space to write down appointments and special days. The days and months are in bold print for easy readability.

6. Large Print Address Book

A large print address book is an easy way to keep track of contacts, with plenty of space to write phone numbers and addresses.

7. Digital Audio Recorder

Digital audio recorders are great for taking down important information such as doctor’s instructions, medication dosages, phone numbers and dates. Recorders range from easy-to-use to
technical with varying amounts of recording time and battery life.

8. Magnifiers

Magnifiers help with reading small print. Available with or without light, magnifiers come in a variety of sizes and strengths and are great for reading price tags, food labels or medication bottles.

9. Bump and Locator Dots

Bump and locator dots come in a variety of sizes and shapes providing a way to differentiate between many surfaces. These tactile reference points are great for labeling flat screens on microwaves, stoves, washers, dryers and computer keyboards.
10. Sunglasses or Sunshields

Sunglasses with UVA and UVB protection are essential for protecting eyes from ultraviolet rays that can damage eyes. Sunshields come in a variety of tints to help with glare control. Sunshields have a comfortable fit and can be worn inside or outside or over an existing pair of eyeglasses.
TIPS FOR DINING WITH CONFIDENCE

Do you worry about knocking over your drink?

Are you frustrated with food ending up everywhere except on your fork?

Can’t read the menu? You are not alone!

1. Trust Your Sense of Touch

• Reach for your drink by sliding your fingers across the table until they touch the glass instead of reaching through the air.

• Start each meal by taking a moment to feel the weight of your empty fork. Your sense of this will alert you during the meal if you have an empty fork instead of a forkful of food.

• The shape of the knife handle often indicates which way the blade is — handles are curved underneath and flat on top. No need to touch the blade with your fingers.
2. Practice New Techniques

• If you can’t see what’s on your plate, probe gently with your fork and discern by texture what is to the left, right, top or bottom of your plate.

• Use a piece of bread or a knife as a “pusher” to get food on your fork (resist the temptation to use your fingers).

• Cut only one bite at a time. Stay close to the edge of the item you are cutting and cut close to the fork to ensure a nice small bite.

3. Prevention: Get in the Habit!

• Lean over the plate when you take a bite. If something falls it will land on the plate and not in your lap.

• Use your knife or side of your fork to sweep food from the edge of the plate towards the
center to prevent morsels from falling onto the table.

• Having some soup? Eat the liquid first to prevent a splash.

4. Dining Out

• Hold onto a friend’s elbow and stay a step behind when moving through an unfamiliar restaurant. Ask your guide to let you know about any steps.

• Request to be seated where the light is adequate.

• Navigate long menus quickly by telling your reader what you are interested in (“I’d like something with chicken and pasta”) rather than listening to them read from start to finish.
5. Adapt When Necessary

• Drink your soup from a mug instead of eating it from a bowl.

• Eat your peas with a spoon to stop them from rolling away.

• Ask your friend or server to tell you what’s on your plate “Potatoes are at 12 o’clock, chicken at 6.”

Remember everyone spills sometimes, so concentrate most on enjoying good food and good company!
SIX TIPS FOR POSITIVE COMMUNICATION WITH FAMILY MEMBERS

Adjusting to life with vision loss is frustrating and stressful for both your group members and those who have close relationships with them.

Often, unclear expectations and negative feelings can lead to misunderstandings and result in a person not receiving the help needed to begin or continue the adjustment process.

When everyone makes a special effort to communicate clearly and positively, it promotes healthy relationships where both parties feel validated. If your group members are having difficulty getting their family or friends to understand their needs or wants, here are some suggestions they can try to promote positive communication:
1. **Set aside a time to talk**

Setting aside time to have an honest and thoughtful conversation can go a long way in relieving anxiety and stress.

2. **Be a good listener**

Listen and acknowledge fears, feelings and concerns for both people.

3. **Ask questions**

Ask for and acknowledge fears and concerns.

4. **Be specific**

Try to get to the heart of the matter citing specific examples. Try to avoid words like “always” and “never.”

5. **Make a plan**

Agree on ways the specific issues can be resolved.
6. Follow Up

After your discussion, check back to make sure things are going more smoothly. Acknowledge positive changes and say “thank you!”
DIALING THE PHONE

1. Rest the index, middle, and ring finger of your dominant hand on one row of the keypad.

2. Slide up or down the rows of buttons, all three fingers staying together, until you feel a difference in the key under the middle finger. It might be a small bump in the middle or a ridge to the side of the button. This will be the number 5.

3. If you are right-handed, your index finger will be resting on the number 4 and your ring finger will be on the number 6.

4. To locate any of the numbers, slide all three fingers up a row for 1-2-3 or down a row for 7-8-9 from the 4-5-6. Keep contact with the keypad at all times. If you get
lost, go back to the row with the number 5. Think of it as “home row”.

5. Practice familiar area codes with the receiver down until you get comfortable using your fingers and sense of touch to dial. Work your way up to a full phone number. Get a friend to watch for confirmation that you are hitting the numbers you want.

Are you thinking about getting an iPhone? Call Second Sense for advice, information and training on this accessible phone or for other large button phone options.
BEFORE BUYING YOUR FIRST MAGNIFIER...

1. Make a list of what you most want to be able to read or see with it.

2. Decide if you want it to carry with you shopping or dining or if you want to only use it at home.

3. Know your physical limitations. Mention if you have a weak grip, arthritis or a hand tremor.

4. Bring something from home that you have been trying to read with you.

5. Ask the seller about return policies — the lighting in the store will not be the same as in your home.
HOW TO USE A HANDWRITING GUIDE

1. Print in lower case with capitals as appropriate.

2. Use a bold black pen.

3. Touch the guide with your finger to find the starting point and to find the next line.

4. Write in the middle of the line space to leave room for tails on “y”, “g” and other letters.

5. OR use capitals for letters that normally hang below the line.
References


Websites

Second Sense
www.second-sense.org

Vision Exchange
www.second-sense.org/vision-exchange

Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP)
www.acvrep.org

American Council of the Blind
www.acb.org

American Foundation for the Blind
www.afb.org

Hadley School for the Blind
www.hadley.edu

National Eye Institute
www.nei.nih.gov

National Federation of the Blind
www.nfb.org

Prevent Blindness America
www.preventblindness.org

Vision Aware
www.visionaware.org
This first edition of Starting and Maintaining a Vibrant Vision Loss Support Group was developed as a resource for leaders of low vision support groups. It is full of resources and practical tips to help you keep your group members actively engaged in adjusting to vision loss and learning the skills that will help them remain independent.

Polly Abbott, CVRT, OMS, has 15 years of experience working with low vision support group leaders. During this time, she has helped start up new groups and revitalize established groups.