Older Individuals who are Blind Technical Assistance Center

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ON BLINDNESS & LOW VISION

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Lesson 18: Adjusting to Vision Loss One Day at a Time

Introduction

Vision loss changes a person's life in many ways. Most people who experience vision loss or a diagnosis of a visual condition that is considered permanent will experience emotional distress, including trauma, shock, anxiety, fear, denial, sadness, and even depression. In many regards, an individual who has a vision impairment goes through a grieving process. Some people go through an initial grief process and then reach a point of adjustment; however, new feelings of loss can arise when an experience occurs that reminds them of the implications of their vision loss.

You are encouraged to take charge of every area of your life as a person who is blind or has low vision. As you learn new adaptive skills and methods and how to use a variety of devices, you will gain confidence on the road to living with a visual impairment, one day at a time.

Through the lessons in this series, you have learned techniques for dealing with the effects of your visual impairment on tasks like reading and writing, cooking or preparing food, personal care, housekeeping, home repairs, traveling within your community, and relaxing and having fun. Although your new skills are helping you realize that vision loss isn't as limiting as it once may have seemed, you may still have times when you feel overwhelmed, worried, or depressed. Maybe your self-esteem and self-confidence are shaky. These feelings are a natural part of the coping and adjusting process. Everyone deals with their visual impairment with their unique personality, characteristics, abilities, and coping skills. And everyone works towards personally meaningful goals. The purpose of this lesson is to give you tools and resources to empower you to live every day as an individual who just happens to be visually impaired.

Lesson Goals

- Learn to better cope with the emotions that accompany vision loss.

- Plan ways your support team can help you with the adjustment to vision loss.
- Utilize activities toward healthy emotional growth.
- Select a support group so you can share concerns with others who are losing their vision and those experienced in handling the challenges of vision loss.
- Consider participation in a national consumer advocacy organization.
- Actively meet the challenges faced by visually impaired people on all societal levels.
- Develop communication skills to effectively advocate on your own behalf.

Adjusting to Life with Vision Loss

Each person adjusting to vision loss experiences different emotions, at different intensities, for different lengths of time. In time, most of your fears, disappointments, anger, and depression can be managed as you learn adaptive skills to be more in control of your daily activities and as you learn to live independently and cope with life with a visual impairment. However, some negative feelings may crop up again as new situations arise, and some may never go away. There may be special occasions or traditions you would like to see, like a grandchild on his first birthday. Your family may have enjoyed driving to look at holiday scenery, and now you cannot experience this fully. The sadness you experience with the loss of these visual experiences is normal and will likely lessen in intensity as time goes on, but it might never go away completely. You might find certain things embarrassing, like not recognizing someone you pass on the sidewalk or realizing you are talking to a blank space because the person you were talking to has walked away. Remember, even when you could see, you probably did some embarrassing and inadvertent things too.

The stages of adjustment don't occur and then disappear. They overlap and are often jumbled together. Just when you think you no longer have to deal with anger or depression, they come bursting through your door again. You feel like you can finally smile again, but then tears return. You laugh, but a cloud of depression drifts in once more. Don't beat yourself up. This is normal and necessary. It is part of healing, which can be painful.

Much has been written about adjusting to and coping with vision loss, such as *Self-Esteem, Adjusting with Blindness* (Tuttle & Tuttle, 2004). The authors describe "adjusting [to] blindness as the continuous process of adjusting to the daily demands of life with the added characteristic of vision loss." Low vision or blindness is not an external circumstance you finally "adjust to" at some point in time, like adjusting to a new job or new home. It's the total person with all his or her attributes, including vision loss, who finds ways every day to deal with life's demands.

It is important to note that you have a choice of how you will react to your new challenges. If you work on learning adaptive skills, advocating for yourself, and regaining independence with a positive and proactive attitude, you will find you can cope very well as a person who is blind or visually impaired.

Your Support Team

You need to feel like an important, contributing member of your family and the other groups to which you belong. You need to feel valued by others so you can strengthen your self-esteem and self-confidence. The nucleus of your support team is made up of the people who have your back. They are your cheerleaders, willing to urge you on when you are hesitant or lack confidence. They can be family, friends, or coworkers. They are the people who will give you honest feedback when you need a big push but will give it in a way that lifts your spirits.

In the early stages of adjusting to vision loss, you need support that's balanced and not so helpful that you don't learn how to do things yourself. Help others understand your vision problems by telling them what you can do independently, what you need a little help to do, and what you need someone else to do. When you have gained some confidence, it is time for members of your support team to back off and allow you to apply what you have learned and exercise your independence. However, it is important to remember that there is nothing wrong with asking for and accepting help. Helen Keller said, "Alone we can do so little, together so much." There will be things you can no longer do and things where you could use some help. Figuring out how to balance independence and interdependence will help you feel more in control.

Healthy Emotional Adjustment

You might be a member of a group of newly visually impaired people who tend to memorialize their former sighted selves. It's easy to forget that your sighted self ever burned the toast, wore two different shoes to a business meeting, got on the wrong commuter train, or committed any other mistake or accident. Some people who have been visually impaired since birth wrongly think that sighted people rarely burn toast, never wear two different shoes to a meeting, and always correctly read signs for commuter trains. Too often, these misguided perceptions, along with social stigmas, prevent visually impaired people from recognizing that everyone—young or old, blind or sighted—makes mistakes. Those misperceptions may hinder you from accepting and valuing your visually impaired self.

You may find it difficult to laugh at such situations if you are struggling to find your equilibrium and adjust to the demands of everyday life along with visual impairment. In time, you will realize one of the best therapies for learning to accept and value your visually impaired self is to laugh at your mistakes and to use humor to help sighted people relax if they are uncomfortable with your vision loss.

Another helpful activity might include reading books, especially biographies. These stories can inspire, encourage, teach, comfort, and counsel people about life's challenges. The nature of these books can be quite therapeutic, especially if the book addresses your specific problem or need. Talk to a Talking Book librarian about finding books on coping and adjusting and about people who have successfully navigated the challenges of vision loss.

Support Groups

Connecting with other people who are blind or have low vision can be of tremendous value. Support groups bring together people who share a similar life challenge, such as vision loss. Joining a support group may be one of the most important things you'll ever do. Whether it meets over the phone, online, or in the community, these groups offer opportunities to talk to other people who are losing their vision and people who are experienced in meeting the challenges of vision loss. Support groups can help you find solutions for your vision-related difficulties. You will meet people who can empathize with your frustrations, fears, disappointments, embarrassments, and tears because they have experienced similar feelings. You will hear how others have managed these feelings and found ways to successfully navigate life with a visual impairment. It may also be helpful for your family members or friends to participate in the support group from time to time.

Some groups are led by visually impaired people, and others are led by professionals who are independent living or orientation and mobility instructors, social workers, or nurses. The format of a group may include topical discussions, guest speakers, hands-on workshops, and demonstrations of products for people with vision loss. A support group can also be a great place to socialize and make lasting friendships.

National Consumer Advocacy Organizations

Along with joining a support group, consider joining one of the major visual impairment consumer advocacy organizations in the United States, including the American Council of the Blind (ACB) and the National Federation of the Blind (NFB). These organizations strive to increase the independence, security, equality of opportunity, and quality of life for people of all ages who are blind or have low vision. They are available at the local, state, and national levels. Joining one of these organizations can offer many benefits, such as:

- Meeting and making friends with people who are blind or have low vision who share your profession, hobbies, interests, or goals.
- Finding hope and moving forward after vision loss.
- Accessing local and national networks of people who are blind or have low vision who can provide information and support about living, working, learning, and thriving as a visually impaired person.

- Advocating at local, state, and national levels to change misconceptions about blindness and policies and laws that affect people who are blind, low vision, or losing their vision.

These organizations are guided by the conviction that people who are blind or have low vision are fully capable of representing their own situations and needs. They are governed by people who are blind or have low vision but also encourage membership of sighted people—family members; friends; members of service organizations; and local, state, and national organizations—who will advocate for the organizations' core principles. These organizations have affiliate chapters in most states.

The Blinded Veterans Association is a nonprofit organization of veterans who are blind or have low vision. This organization provides information and referral services, regional groups, advocacy, and more. Call (844) 603-0145 or visit Blind Veterans Association to learn more and get connected.

The National Organization for Albinism and Hypopigmentation provides information and referral services, advocacy, and opportunities to connect with others with albinism. Visit National Organization for Albinism and Hypopigmentation for more information.

Hadley is an organization dedicated to providing free educational information and support to individuals who are blind and vision impaired. They run a variety of discussion groups where you can meet others with vision loss. Visit them at https://hadleyhelps.org/ or call them at 800-323-4238 to connect with their services.

Self-Advocacy and Effective Communication

Self-advocacy means speaking and acting on your own behalf. There are federal and state laws that protect your rights, and there are organizations that act on behalf of people who are blind or have low vision fighting against discrimination. Ultimately, living independently is your responsibility, and part of that is learning to advocate for yourself.

Individuals who are newly visually impaired may react passively or emotionally when encountering situations that are uncomfortable. At times, a significant other or family member may be allowed to do something for you that you know you can do yourself or want to do yourself. At other times, you may feel like you have been pushed around and get angry or act aggressively.

It is helpful to understand the differences between assertive, nonassertive, and aggressive behavior. People who are nonassertive allow others to choose for them and, unfortunately, seldom achieve their goals. At the other extreme are people so aggressive that they usually get their way, but at the expense of others.

On the other hand, being assertive means taking responsibility for what happens to you. Assertiveness enables you to make choices for yourself without giving others the power to do so. For example, how often in a doctor's office, restaurant, or store, has a staff person spoken to your sighted companion rather than directly to you? Do you speak up for yourself and communicate your desire to be treated as a competent equal, rather than as a nonperson? Or do you allow your companion to answer for you?

Here are suggestions to help you improve your ability to respond assertively instead of nonassertively or aggressively:

- Roleplay common situations you face with a family member, a person on your support team, or with a trained blindness professional.
- Introduce this topic at a support group meeting. Others in your group may also have difficulty speaking up for themselves. Perhaps you could roleplay with each other or invite a blindness professional to join a meeting and offer suggestions.
- Keep a journal of experiences you encounter that require you to be assertive. Take time to reflect on what you might have done differently or praise and reward yourself when you've been assertive.

- Talk to family members or friends who regularly accompany you to medical appointments, restaurants, and on other outings. Ask them to defer to you if a doctor, waitress, or clerk speaks to them rather than directly to you.

In time you will become more confident and will feel more in control of situations you encounter. Learning and using verbal and nonverbal assertiveness and communication skills will enable you to move more confidently through the tasks of daily life.

Summary

Accepting vision loss is a journey and each person travels at their own pace along that path. To be self-accepting, you do not need to like blindness or low vision; however, you do need to internalize visual impairment as one of your many personal traits, like being male or female, tall or short, artistic or athletic, a teacher or an engineer, and, oh yes, visually impaired or sighted. Self-accepting people are those who have learned to accept all their traits, the strengths along with the limitations. They are at peace with themselves, comfortable with themselves, and they like themselves. They recognize that everyone has limitations, and limitations do not diminish a person's dignity and worth. You are not less because you are now blind or have low vision. This challenge will require you to be a better problem-solver and communicator and a more adaptable person.

Life can be as full and as rich as you choose. If you spend your time on the possibilities and opportunities, life can be full and satisfying. The possibilities of life as a person who is blind or has low vision are as numerous as you make them. Loss of vision presents many challenges, but with a positive and determined attitude, learning adaptive skills, proper support from loved ones and peers, training, and access to resources, you can not only adjust to life with a visual impairment but learn to thrive.

Suggested Activities

What positive and proactive strategies can you implement to learn to live and cope with your visual impairment? Here are some suggestions:

- Join a support group.
- Tell your support team, including family and friends, what you need help with and what you don't.
- Read books written by and about blind people who live meaningful lives despite vision loss.
- Connect to blindness services in your area.
- Learn the adaptive skills necessary to be more independent.

What positive strategies can you use to advocate for yourself? Here are some suggestions:

- Use humor to help sighted people relax when they seem uncomfortable.
- Speak up for yourself in an assertive, yet respectful way.
- Explain your needs calmly without giving away your power.

Resources

- Blinded Veterans Association
- American Council of the Blind
- National Federation of the Blind
- National Organization for Albinism and Hypopigmentation
- Hadley

Reference

Tuttle, D. W., & Tuttle, N. R. (2004). *Self-esteem and adjusting with blindness* (3rd ed.). Charles C. Thomas.