WHEN YOU CAN'T BELIEVE YOUR EYES

VISION LOSS
& Personal Recovery

Hannah Fairbairn

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Vision Loss and Personal Recovery

By

HANNAH FAIRBAIRN

CHARLES C THOMAS • PUBLISHER, LTD.
Springfield • Illinois • U.S.A.

Published and Distributed Throughout the World by

CHARLES C THOMAS • PUBLISHER, LTD.
2600 South First Street
Springfield, Illinois 62704

ISBN 978-0-398-09282-5 (paper)
ISBN 978-0-398-09283-2 (ebook)

Library of Congress Catalog Card Number: 2019014527 (print)
2019980615 (ebook)

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Printed in the United States of America
MM-C-1

Library of Congress Cataloging-in-Publication Data

Names: Fairbairn, Hannah, author.
Title: When you can't believe your eyes: vision loss and personal recovery / by Hannah Fairbairn.
Description: Springfield, Illinois : Charles C Thomas, Publisher, Ltd., 2019. | Includes bibliographical references.
Identifiers: LCCN 2019014527 (print) | LCCN 2019980615 (ebook) | ISBN 9780398092825 (paperback) | ISBN 9780398092832 (ebook)
Subjects: LCSH: People with visual disabilities--Services for--United States. | Blind--Services for--United States. | People with visual disabilities--Rehabilitation. | Blind--Rehabilitation. | People with visual disabilities--Psychology. | Blind--Psychology. I Oral communication.
Classification: LCC HV1795 .F25 2019 (print) [LCC HV1795 (ebook) | DDC 362.4/180973--dc23
LC record available at https://lccn.loc.gov/2019014527
LC ebook record available at https://lccn.loc.gov/2019980615

PREFACE

This book was first projected in 2004, when I was teaching interpersonal skills at the Carroll Center for the Blind in Newton, Massachusetts. The experiences of my adult students—and my own experience of sight lost—convinced me that everyone losing vision needs access to good information about the process of adjustment and practical ways to use assertive speech. *When You Can't Believe Your Eyes* is intended for anyone going through vision loss, their friends, and families. I hope that professionals will also find it useful.

Rachel Rosenbaum, then president of the Carroll Center, gave the project her full support. But it has taken a focus group of former students, comments on the companion website, the generous assistance of my colleagues at the Carroll Center and many other experts, as well as more than a hundred long interviews with adult students, to establish what was most important for people with sight loss and their friends to know.

When You Can't Believe Your Eyes is concise, with twelve chapters arranged in five parts, which follow the phases of adjustment to vision loss. Each chapter contains many short sections and bullet-point lists, intended to facilitate access to the right information. Parts Three and Four focus on the use of assertive speech. Part Five could be a book in itself. Topics have been limited to frequent concerns during the first years.

The book is intended for adults losing vision, including young adults leaving home and people in midlife whose vision is decreasing either gradually or rapidly. Because vision loss happens mostly in older years, the book is written with seniors particularly in mind.

A short book cannot cover all the ways people lose sight or deal with vision loss combined with other disabilities, and I have stopped short of discussing college courses or job choices. My own expertise is in the areas of personal and household management and interpersonal skills. I have written least about adaptive technology because the field is updating too fast for information to stay relevant, and there are good online resources.

I hope that people losing vision, their friends, and professionals in the field will use the book to understand the process of personal recovery after sight loss and the importance of assertive speech in order to regain adult competence and self-esteem.

H.F.

INTRODUCTION

How do you recognize a friend if you can't see her face? How will you get to the store if you can't drive? How do you know which medication to take if you can't read the label?

When You Can't Believe Your Eyes is a self-help book for people losing good sight. Smart technology now gives people with vision loss access to all kinds of printed material, including this book.

As baby boomers age, more people are dealing with impaired vision. This is the first book written for you, the person losing sight. *When You Can't Believe Your Eyes* tells readers how to get expert professional help, face the trauma of loss, and navigate the world using speech more than sight.

When you can't see faces clearly, read small print, or drive, you lose some personal control. Simple tasks may begin with asking someone else to read a label or drive to an appointment. Encounters at a store, doctor's office, or at a party can become awkward or painful. At first you may disregard what is happening or believe it can't be permanent, but after a while you begin to wonder how you can go on being yourself.

This book has twelve chapters divided into short sections, describing how you can manage your sight loss and return to a full belief in yourself. I have consulted doctors, low vision specialists, vision rehab counsellors, and teachers, as well as people who are going through vision loss themselves. The book lays out how to know what is happening to your sight and how to adjust to the loss of good vision so you can take control again.

Most of us who lose crisp, detailed vision can't believe it is happening and disbelieve or deny it at first. It may be your friends, or professionals in vision rehab who read this book first. You may need some help to get set up, but I hope you will read it yourself, and find your way back to full adult status.

I have focused on practical, social, and personal recovery for adults who are losing vision. The book begins where you begin—at the doctor's office or the hospital. Since vision loss takes many forms, there are suggestions for questions you might ask to get a clear diagnosis and the best treatment. Part One also has a description of legal blindness and possible prevention, advice about your job, and tips for life at home. Part Two is about believing in yourself as you deal with the loss, the anger, and the fear before you come up for air and consider training. Parts Three and Four describe using assertive speech and action in all kinds of settings as your independence and confidence increase. Interpersonal skills groups at the Carroll Center for the Blind and a focus group of former students contributed comments and stories to help make your encounters without good sight successful. Part Five gives detailed information about personal concerns, from dating and caring for babies to senior living, volunteering, and retaining your job. You become a whole person again—informed, independent, and in charge.

I have tried to restrict recommendations for resources to well-established organizations, websites, and apps. As this book goes to press the courts are just beginning to insist that companies make their websites accessible under the Americans with Disabilities Act. But the digital world is updating so fast that some things will have changed by the time you read this, and I apologize in advance.

My hope is that in reading and trying out the suggestions, you will recover full confidence in yourself, become a positive, assertive communicator, and lead a satisfying life.

You will find the companion website to the book at www.WhenYouCantBelieveYourEyes.com.

ACKNOWLEDGMENTS

The Carroll Center for the Blind in Newton, Massachusetts, is an internationally recognized vision rehabilitation center for newly blinded adults and people struggling with vision loss. The Carroll Center has long understood the particular importance of spoken communication for people losing vision. Almost every member of staff assisted my efforts with the book.

I am particularly thankful to Jennifer Harnish, director of rehabilitation, who read much of the text and made very many useful suggestions. I am also grateful to Robert McGillivray, director of low vision; Brian Charlson, director of technology; Joe Kolb and Ed Christopher, orientation and mobility instructors; Marianne Gilmore, workforce development specialist; and Ashley Colburn, accessible technology instructor.

At the Massachusetts Commission for the Blind, I would like to thank Joe Buizon, employment services supervisor; Darren Black, vocational counsellor; and Jill Juran, supervising rehab teacher.

Dr. Angela Turalba, ophthalmologist, told me what questions to ask when you are at the hospital. Dr. Lotfi B. Merabet explained how the brain adapts to vision loss. Both are associated with the Massachusetts Eye and Ear Infirmary.

Direct contributions have also come from Spencer Nineberg, psychotherapist; Aaron Rouby and Heather Platt, orientation and mobility instructors; and Kate Crohan, Perkins School teacher.

I am greatly indebted to the focus group: Bill Burns, DeAnn Elliott, Jennifer Harnish, David Kingsbury, Alyce Lanoue, Robert Resnick, and the late Brian Mahoney.

I am also grateful for information and encouragement from Rachel Buchanan, Charles Burlingham, Kim Charlson, Sue Christensen, Margaret Cleary, Roz Cummins, Tina Dearaujo, Audrey Demmitt, Maureen Duffy, Helen Lattanzi, Allan Nineberg, Mary Lou Nye, Jan Pecorari, Doug Rose, Dina Rosenbaum, Maria Rueters, Gina Russo, Paul Saner, Annie Smith, Naomi Tuttle, Kathy Waugh, Alan White, and Karen Wolffe. I hope all these helpful people will forgive me for not including their many achievements.

I am particularly thankful to all the students at the Carroll Center, who suggested and role-played tricky situations in interpersonal skills groups, and to the teens and young adults who brought tough realism and good ideas to People Talk.

No one writes a book without the help of family. My niece Heather Shumaker gave me sound advice about publishing. My son-in-law Robbie Guertin designed and managed the companion website. My cousin Grace Ogilvie and other son-in-law, John Meyers, gave me excellent suggestions and encouragement.

My two daughters, Madeleine Fairbairn and Catharine Fairbairn, have been constantly encouraging.

Last and most, I am grateful to my long-suffering editor husband Neil Fairbairn, who read the text a shocking number of times and made this book considerably more readable. We are still married!

FIVE WAYS TO USE THIS BOOK

- Use the References and Resources section at the end of the book to find useful organizations, services, and websites.
- Read the very last section of Chapter 12, "Here You Are Again," to know where the book is heading.
- Read the brief introductions to the five parts of the book in the Table of Contents to understand how many people adjust to vision loss.
- Pick out chapters and sections to read as you need them.
- Or just read the book! It's quite short!

The companion website www.WhenYouCantBelieveYourEyes.com has updated and expanded information on even more topics.

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WHEN YOU CAN’T BELIEVE YOUR EYES

Part One

BELIEVING THE UNBELIEVABLE: FACING TRAUMA AT THE HOSPITAL AND BACK HOME

Most people who lose vision or have a diagnosis of future significant vision loss have a problem believing it. (You may feel the same, but then you wouldn't be reading this book!) They know perfectly well that their vision is blurred, becoming contracted, or obscured, but just can't make it fit with their experience of life.

Chapter 1

THE SHOCK AND THE DOCS

TRAUMA AND DISBELIEF

When I lost the sight in my good eye overnight, I went to work the next morning. I was a chef in London and, with help from extra staff, prepared a grand dinner to honor the Archbishop of Westminster. This didn't seem crazy at the time because I couldn't believe anything serious had happened.

Disbelief and denial are common responses to any trauma, and vision loss—even gradual vision loss—is always traumatic. Trauma can mean mental and emotional distress and fear for the future, as well as immediate injury or loss.

Sudden sight loss can be due to accident, violence, infection, bleeding, or spontaneous retinal injury (as mine was), among many other causes. Anyone who rapidly becomes blind, or nearly blind, feels shocked and numb. The loss of clear vision can also mean temporary loss of adult competence and privacy.

Almost everyone uses sight as their major way to understand the world. The brain and memory are set up that way. Most people, including me, want to deny the misty or grey world they now inhabit. And when the loss is slow—a barely noticeable reduction of wide-angled, crisp, three-dimensional vision over years—it's easy to reject acceptance of a serious eye condition. If you are retired, you might think, "This is just another health issue. I don't have to do much." It's hard to face the future squarely, but the hardest part can be just making a start, which usually means finding a good ophthalmologist.

It was three days before I went to the emergency room at London's Eye Hospital. The duty ophthalmologist immediately found retinal detachment. Changes in vision are not always an emergency, but you won't know until you get expert advice.

There are dozens of causes of vision loss. If adult-onset cataracts are diagnosed, visual impairment is probably temporary. Nearly all cataract surgeries are successful. Glaucoma, if detected early, can often be treated with daily eye drops and disease progression slowed. Corneal transplants can preserve useful eyesight, and the Scharioth macular lens helps some patients with adult macular degeneration (AMD). Diet and exercise can prevent type 2 diabetes, with its risk of blindness. There are some creeping forms of sight loss, such as retinitis pigmentosa (RP), that have serious consequences. Find out what's wrong with your eyesight as soon as possible. It's good to know the facts, and any urgent treatment can be taken care of immediately.

The trauma is usually made worse by the lack of knowledge about vision loss among friends. It's rare to have someone you can turn to who has been through the same experience. It's like ending up in Uzbekistan without a guide. This book is here to fill that gap.

QUESTIONS, QUESTIONS, QUESTIONS

"This is very serious. You will have to come in!" said the consultant from the doorway. He then left the ER. It was a week before I met an eye surgeon who explained what had happened in a straightforward kindly way. People skills among eye doctors have improved since then, but not every patient can think clearly or ask the right questions after a shock. It's good to think through questions beforehand. Then you can dictate them onto a smartphone or write them in bold print. (More about this in Chapter 5: "Reading and Writing.") Just a word or two for each question will jog your memory. Keep the questions specific and try to ask for explanations of new words or term. It will be useful to record the visit, (ask if it's okay) or have someone take notes. Here are some possible questions:

- What is the cause of my vision loss?
- What is the diagnosis?
- Which treatment do you recommend, and what are the best and worst outcomes?
- How often is this treatment successful in my situation?