Fighting Glaucoma
An Action Handbook
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Fighting Glaucoma
An Action Handbook

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Authors dedicate this book to all their relatives, friends and the professionals, who do care; and who were kind enough to help, when we inevitably required compassion and help.
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Acknowledgments

In this book, we draw on the academic knowledge and practical experience of many glaucoma researchers and medical practitioners, to whom we are especially indebted.

We are also thankful to those publishers and authors who gave us permission to quote their publications.

Most importantly, I, Ivan Goldberg, am indebted to Vera and our children and grandchildren for inspiring and continuously grounding me, along with my many patients who continue to teach me daily.

Nahum Goldmann is happy to acknowledge Natalya, Alice, Naomi-Roni, Mirele-Bella and Marat for their constant inspiration, support, encouragement and love.
Foreword

Glaucoma affects over 60 million people worldwide and is the leading cause of irreversible blindness. At least half of those affected do not know that they have it. Those who do, are often frustrated in their search for valid and trustworthy information about their disease (there are many different forms of glaucoma) and what they should understand about its nature and treatment in order to obtain the best outcome.

For best results from treatment for glaucoma, patients need to be actively involved in the planning and carrying out of their own care. To be able to do this, they need to understand what is at stake, what needs to be done to save their sight, to know what to do and how to do it. While most of this knowledge comes from a strong relationship with a caring ophthalmologist, a great deal more could be gained with the help of a reader-friendly book that reinforces that knowledge and understanding.

There is a great deal of information, and also misinformation, on the internet, and many advertisements for treatments which may be not yet tested and proven, such as stem cell treatment. Over the years, there have been several books written for patients about glaucoma. What is needed, however, is a book that is written understandably, honestly, and fully explanatory of the different aspects of the nature, causation, manifestations, and treatment
of glaucoma, plus information to guide the reader in searching for further information and assistance.

The book *Glaucoma: How to Save Your Sight* written by Professors Goldberg and Susanna does just that, and now this companion book by Professors Goldberg and Goldmann augments it effectively. This is a work produced by two extremely well-known, talented and knowledgeable authors and the two manuals should be in the possession of all glaucoma patients, and their ophthalmologists as well.

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Introduction

Most likely, gentle reader, you would rather have not opened a book with such a title, unless you felt driven to do so. Probably, you are reading it because you – or someone close to you – has been diagnosed with glaucoma and is on treatment. You might feel that you or this cherished someone might be on the road to losing sight, whether partially or fully; a scary possibility.

As written in the recent book by Professors I. Goldberg and R. Susanna Jr., which we extensively cite in this handbook:

“Glaucoma is infamous as ‘the sneak thief of sight’: the most common types give no warning. They are slowly, progressively destroying a person’s vision. Because usually the vision at first is affected to the side, patients notice little, if anything. By the time an individual realizes something is wrong, there may have been considerable damage.

... Losing vision from glaucoma is tragic. It should be avoidable for most, but unfortunately not all, patients. When it occurs, as in most air crashes, this disaster may follow a combination of misperceptions and oversights, each contributing differently to the final result. Sometimes the disease is relentless no matter what is done; sometimes it deceives the clinician as much as the patient.”
Glaucoma: At times, it is about hard choices

You might need to make some difficult choices, taking on commitments and responsibilities that are likely to apply for the rest of your life. With this book, we wish to help you to make these choices with as much relevant information as you might need. We want to help you to find the inner strength to fight this disease successfully. In a long journey, support from your family and friends will be invaluable.

Regrettably, glaucoma currently remains incurable. Owing to the injury it causes to the optic nerves in one or both of your eyes, any damage to your vision, which would have been quite unexpected, cannot be reversed. The good news is that most often, glaucoma can be controlled; that is, certain treatments could help to prevent blindness or, at least, to slow down any further decline in your vision.

New medical research results, testing and treatment methods become available daily, although progress towards a glaucoma cure is not as rapid as we would like it to be. Even if today for glaucoma patients fully preserving steady vision is not a certainty, your chances for stability might be quite reasonable – providing you make informed choices and take good care of your eyes by following the treatments prescribed by your caring physicians.

Because you are reading our handbook, we understand and respect that retaining as much vision as possible, for as long as you live, has become a major goal for you.
Introduction

We, the authors

This handbook has been written by an unlikely combination of a physician and a patient. We live on opposite sides of the world, and collaborate through the internet. Our educations, experiences, viewpoints and motivations for writing this book are quite different.

Ivan Goldberg is a world-recognized expert in glaucoma treatment, on which subject he has published hundreds of articles, book chapters and a book and has been honored with numerous international awards. He is Head of the Glaucoma Unit, Sydney Eye Hospital, Director of Eye Associates, Sydney, Australia, and Clinical Professor at the University of Sydney. Dr. Goldberg was also President of the Royal Australian and New Zealand College of Ophthalmologists, President of the World Glaucoma Association, Foundation President of the Asia Pacific Glaucoma Society, Chair of the Australian and New Zealand Glaucoma Society and President of Glaucoma Australia. He has been an executive or honorary member of many Ophthalmology and Glaucoma research societies globally. Ivan Goldberg’s most recent book is Glaucoma: How to save your sight! (co-authored with Prof. R. Susanna Jr., University of Sao Paulo, Brazil). It is an example of his abiding interest in the patient’s perspective in glaucoma management, patient-related outcomes of treatment and a patient’s quality of life.

Nahum Goldmann is an experienced high-tech executive, university professor and information scientist, with the considerable background in biophysics, biomedicine and health related subjects, who resides in Canada. Nahum’s
most recent book is *Effective Decision Making: A Primer in Information Retrieval*.

What united us in writing this book is a desire to help people with glaucoma in a practical way. We trust the differences we bring to this venture will enhance the usefulness of this handbook for you.

For a qualified medical practitioner, providing help usually means concentrating on better and clinically proven ways to treat the disease. In contrast, the long-term challenges faced by people with glaucoma are numerous and important. With such a diagnosis, you have to balance many life demands, of which eye treatments are essential but by no means alone.

After all, you are not living to treat glaucoma: you are living a full life into which the treatment of your condition is an intrusion. How could one cope?

Treatment of any chronic and serious medical condition is likely to be affected by many other factors, such as money, the wellbeing of your family, your general health, other calls on your time, fitness and lifestyle, housing, your work commitments, and perhaps supporting family members, to name just a few.

Our experience is complementary; we hope this builds a common and inclusive perspective for your benefit.
About this book... and a couple of others

Several books written for patients describe what glaucoma is, how it is being treated, and the state of glaucoma research. We are unaware of a book on how to live with the glaucomas, covering practical challenges frequently faced by those with glaucoma, who wish to minimize risk of visual disability or even blindness. We hope our book at least partly fills this void.

We try to address specific issues and anxieties that people with glaucoma might face daily, whether large or small. We aim to guide newly diagnosed individuals, their family and friends, on ‘what is best to do’ – and ‘why’. We have seen such ‘what to do’ questions repeatedly on various glaucoma blogs.

This handbook’s focus is on the step-by-step actions that you, as well as supporting relatives and friends, can take to improve your current situation and outlook. We try to guide you where to find additional help to understand better your condition and your prospects. We hope health professionals who help people with glaucoma also find this book useful.

We try to minimize information intake while maximizing personal actions available. We do not explain in much detail various types of glaucoma or cite references to scientific sources, unless it is necessary to validate recommended action. In such cases, we try to present relevant science pragmatically, without specialized medical jargon. With some exceptions, we also minimize formal citations to scientific sources.
You could use this handbook as an everyday reference or as a guide to your glaucoma treatment. We hope you will find it worthwhile to formulate better the reasons for your actions and for your sometimes complicated choices.

To those who would like to learn more about the glaucomas with background science, we recommend a companion book by one of our co-authors, *Glaucoma: How to save your sight!*, by I. Goldberg and R. Susanna Jr. (Kugler Publications, 2015). This book, which we extensively cite below as ‘Goldberg/Susanna’, covers glaucoma research and medical practices in lay terms, with many details and numerous illustrations.

Perhaps you still do not feel that you have enough information to make an informed choice for your treatment, do not know how to get it, or would just like to dig more deeply into specialized medical literature, to identify and track more recent glaucoma research and treatments publications. Then, you might benefit from a book by our other co-author, *Effective Decision Making: A Primer in Information Retrieval*, 3rd Edition, by Nahum Goldmann, ARRAY Development, 2016. That book explains how to conduct effective online searching of scientific and biomedical literature.
Introduction

A digital version of this handbook could be read using computerized gadgets for visually impaired. It could also be computer-translated on the fly to various other languages and without cost, thus reaching the worldwide majority of glaucoma patients who do not read English. See information in the Appendix below on how you can find an appropriate computerized reading device or translate our handbook to the language of your choice.

Request for additional questions

We envision this handbook as an evergreen source of common sense answers to your frequently asked questions. To achieve this, our readers, interested patients and eye health practitioners could submit to us questions about and practical solutions for glaucoma-induced challenges.
Clarifying your diagnosis

Examination by your eye doctor aims to diagnose not only whether or not there is glaucoma present, but if so, what type of glaucoma you have and what damage it has caused up to that point in time. This influences treatment strategies. If at the time of initial diagnosis, glaucoma has caused advanced damage, early or even rarely immediate surgery might be necessary to reduce IOP adequately.

![Diagram of Glaucoma General Diagnosis]

**Fig. 1-1.** A chart to clarify your glaucoma diagnosis. Percentages shown on the chart are approximate total occurrences in the global population, typically experienced by ophthalmologists in their clinical practices. The exact statistics might differ significantly in developed vs. developing countries, within geographic regions and individual countries, and even among ophthalmological clinics in the same city.

For an updated version of this chart see: [https://www.worldgpa.org/patient-resources/helpful-books-and-articles/](https://www.worldgpa.org/patient-resources/helpful-books-and-articles/)
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