



SEE BAD
FEEL GOOD

Krister Inde

Krister Inde

SEE BAD FEEL GOOD

About the author

Krister Inde, a BA graduate in education, became visually impaired in his early twenties. He has collaborated with Certec at Lund University and was a lecturer at the Institute of Optometry and Vision Science in Linnaeus University and at the German Jordanian University in Amman (Jordan). In 2015 he was awarded an honorary doctorate by Linnaeus University, and in 2017, he received the ISLRR Award for long life achievements. In recent years, he has been leading a project to make people with visual field restrictions eligible to obtaining a driving license in Sweden.

Krister Inde has published a large number of books and other materials on vision, vision training and vision rehabilitation for children, adults and elderly persons and is a popular lecturer. Today, his methods are practiced in many countries around the world.

Copyrights

See bad Feel good

Author: Krister Inde

Illustrations: Sara Berner

Editing and proofreading (Swedish version): Maria Holmerin Nord

English translation: Eileen Deaner

Copyright © Krister Inde 2003, 2013 for the English version

PDF versions of this book in different languages are available on www.indenova.se

Table of content

About the author.....	1
Copyrights.....	1
Table of content.....	2
Preface.....	3
Introduction: Your vision is only one part of you	4
PART I: DEALING WITH THE GRIEF.....	4
More than 35 years ago	4
A patch of blue sky.....	8
First visit to the Low Vision Centre	11
Someone who believed in me	14
Self-esteem, self-confidence and self-trust.....	17
Checklist for relationships.....	22
Alcohol – friend or foe?	26
Driver's license and your sense of self	32
PART II: MANAGING THE CHALLENGES.....	34
Rehabilitation – recreating your future.....	34
Different ways of seeing	38
An optometrist's point of view	39
The other senses	43
Managing daily life	43
PART III: MOVING ON.....	48
Relapse	48
Your mental map; your view of the world.....	49
Conclusion	55
Postface 1	56
Postface 2	57
Acknowledgements	58

Preface

In May 2003, we held a small book release party at the Cornelis Vreeswijk Museum in *Gamla Stan* in Stockholm. I was surrounded by people who meant a lot to me then and many of them are still part of my life today. It is through them, through the eyes of others, that I view myself. Ten years have passed since the first version of this book was published in Swedish. It has since then been translated to English, Arabic, Hungarian, Icelandic, Lithuanian, Italian and German, allowing me to listen to many people's thoughts on my writings.

Of course, there are people who are not in agreement with me. In the book *Syntråning med optic* (Vision Training with Optics), published in 1975, my friend and co-author Örjan Bäckman and I stated that there are people with low vision who are blind and people with low vision who are sighted. Those who seek various types of financial compensation naturally want to be as blind as possible, and have expressed that my way of using my vision to the maximum is not their thing. Regardless, since then, more technics have been developed to help people with low vision make an optimal use of their remaining sight, which allows me to ride my bike knowing exactly where retina functions at its best – 12 degrees to the left, vertically.

However, the technical aspects are not the most important ones. The essential thing is to “come out”, to be who we are in any given moment. Anytime. Anywhere. Anyhow. Your visual impairment is not the only aspect of your personality, nor is it the most important one! Do not make your visual impairment any worse than it has to be, and do not pretend to have better vision than you do.

I have learned to always use assistance in big airports, but I can find my way around places where I have been before. You may have to put up with some assistants treating you as if you are less of a person because of your low vision, but it is preferable to having to worry about getting lost.

Of course, it feels sad not to be able to enjoy a person's physical beauty, a sunset or other interesting and beautiful things in life that others can, or not to be able to read signs. But, if I no longer curse my fate, I do allow myself a certain amount of grief. A touch of melancholy when I, for example, meet old classmates at an anniversary. But at the same time, it is important to make an appearance at such events because those people know me from before. It helps to show that I have lived and am living a good life given the situation, just like them.

Now all that remains is the rest of my life, and I look forward to keeping busy, spending time with my loved ones and planning for new projects. Three things said to constitute a happy life, and which I wish others to have as well. No one should have to be a victim. That, and all the rest that this book deals with, still apply.

Please feel free to write me at: kristen@inde.nu. It would be exciting to find out if my experiences and the advice I have to offer are of any value or if you have something to add.

Introduction: Your vision is only one part of you

When your vision fails, it is easy to lose your footing. Your sense of being whole as a person can cease to exist for a while. But it does not mean that you have lost that feeling forever.

You have the right to be different and still remain whole and happy as a person, with all the problems and joys that life brings, despite your low vision. This book is about that journey.

These reflections are for those of you who want to become a more complete person and who feel that their bad vision is an obstacle on the road to a fulfilling, real, prosperous and good life.

Those of you who are the relatives of a person with visual impairment can also read this book in order to understand and be able to support and appropriately deal with the person who sees bad and wants to feel better.

In the last chapter Bodil Jönsson advises you to write your own book. But read this one first; see if it can be a source of inspiration for you in telling your own tale.

PART I: DEALING WITH THE GRIEF

More than 35 years ago

It was more than 35 years ago that I began learning what it meant to live as a person with a significant visual impairment. After all these years, you would think that I had adjusted to every situation and am able to manage it all without any problems. But that is not the case. Almost every day I gain new experiences, both positive and negative.

This book is based on the motto: See bad and feel good. That does not mean that the one automatically follows the other, but rather that they are not contradictory. I can assure you of that!

There is something else to discover when you have learned the art of living the life of a person with a visual disability, a life in which your visual impairment is a part of your personality, but where not everything lies before your eyes. Because it is when the bigger picture becomes more important than the visual loss that life has direction, meaning, tempo and joy again. This happens when we can count on the people around us to like us as we are and believe in our capabilities and potential.

It is possible for us to participate in our communities and society on the same terms as anybody else, and that includes the right to be different.

In the following pages, I will be asking you a lot of difficult questions that, when you put the book down, will make you reflect on how things really are. You will just have to work through it because when people are as different as we are – you and I – it means we have to contemplate and decide how things are and how we want them to be. Perhaps even more so than a person who lives a boring, normal life where nothing happens.

The person who learns to live a normal life in which he or she solves problems all the time and moves on, that person will undeniably have greater experience and knowledge than if he or she chooses to avoid and suppress the trials and tribulations that arise through the years. It takes a unique kind of strength that we will shed light on here.

*

Reacting to change

It has been said that humans are constantly striving for harmony, balance and stability. It is with the help of this security we seek adventure.

The changes that we encounter in life as natural phases in our development – growth in childhood, becoming teenagers, getting married and having children, growing older – are referred to as a natural progression of change. Even if they can be difficult enough on their own, they are different in nature from traumatic, entirely unexpected changes.

*

At the eye doctor's

There is nothing worse than getting undesirable news or news that you never in your wildest dreams thought you would receive.

“You have a hereditary eye disorder that we call Leber’s Disease and that is usually characterized by the symptoms that you have. In the middle of the retina there is an area called the macula, and when you have Leber’s Disease, the macula usually disappears, first in one eye and then – unfortunately – in the other. And that is what we have concluded has happened to you.”

“No, I’m sorry to say... There is much research being carried out on this disease but currently there is no therapy or treatment. Glasses won’t help either because there is no problem with your optical system. What you need is magnification, both for distance and close up in order to be able to see what you want to see much better. I am going to give you a referral to the low vision centre and make sure that you are able to get an appointment as soon as possible.”

“Yes, I can write in the referral that you are to be given priority because you still have so much of your life to live. In all other respects, you are completely healthy.”

“There are a lot of aids and devices that I’m sure you can make great use of. But as I said, there is, unfortunately, no medical treatment that we can offer you at this time.”

Period. Nowhere to run. It’s a fact. You are locked in a room and there is no key to the non-existent door.

*

The shock

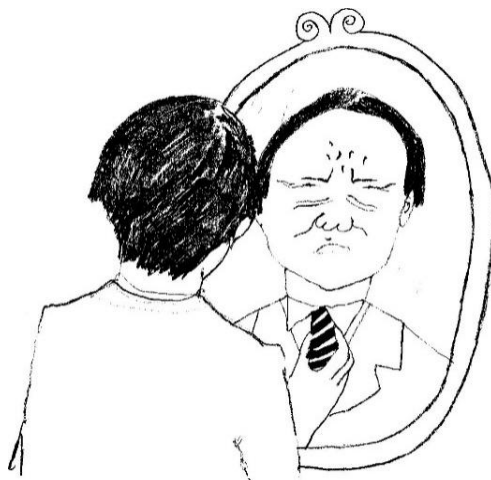
It comes as a shock: you are losing your sight and it is hell. A hell you have not chosen, for which you are not responsible, and that you hate so much that you avoid believing it’s true, avoid thinking about it and you suppress it entirely. It simply hasn’t happened!

Shock is a great fear that occurs when you are confronted with something you don’t know how to handle in the right way.

A first reaction to shock is often a stunned state. You come to a standstill, are immobilized and want to scream but can’t. Or else you scream or react in some other manner, sometimes in a very violent one. There are many reactions to shock and we see them in the movies, expressed in a variety of dramatic ways. What they all have in common is that they are based on fear of something new, horrible and unwanted.

It is impossible for you to control your reactions, be they of a paralyzing nature or something stronger, even if you try. You are so frightened that you cannot, will not or do not have the strength to defend yourself. The usual defence mechanisms don’t work; the shock has to pass before you understand why and what the situation is for you and your eyes.

How long the shock phase lasts can vary from person to person, from a few minutes to an entire lifetime. But it is just as awful – the entire time.



Help! I don't recognize myself anymore!

*

Crisis

Traumatic changes or crises occur when something dramatic, entirely unexpected happens; when someone close suddenly dies; when something terrible happens to you against your will; or when your eyes are afflicted with an injury or disease that cannot be changed, treated or cured. It is definitive.

If you read the book “The Psychic Trauma” by Johan Culberg, you will understand. It is the same thing every time: the same shock, the same reactions, and the same difficult road back to the future; even though people react, respond, hide or display their pain, their tears, their anxiety individually and differently. In each individual there is a spectrum of expressions that he or she uses when something unexpected and catastrophic occurs. The open wound remains for a while – a year, a decade, a lifetime.

*

Grief and tears

Gradually, you let go of the shock. It is as though you have fallen into a pool of water and everything washes over you. You understand how it is. This is the way things are. Poor me. What sorrow. Your eyes are dead. You cry and grieve for what you have lost.

No cure. No improvement. No hope. No nothing. Only some kind of dead-end street into a low vision clinic. What are they going to say at work? What will the neighbours say? I can't go around like this, not being able to recognize people. This is never going to work. Who is going to help me to live? Questions. Questions. Questions.

An adult who cries does so because he or she needs to. Crying is like a valve that the soul opens up to get rid of feelings that aren't needed. You only need someone's shoulder to cry on, someone who understands the value of tears and who neither exaggerates it or is afraid of sorrow.

Tears do not require comfort. They only need another compassionate person's presence and silence. Not being left to cry alone is a comfort in and of itself. Sooner or later the tears will stop. The empathetic parent who lets her child finish crying knows this. So does the person who encounters someone who is overwhelmed by a recent vision loss.

Sooner or later the tears are exchanged for reflections and questions; that is when you need to find someone, a professional who has the answers.

*

Offering comfort

It is very comforting at this point when you are so low to find someone you can rely on. It doesn't need to be a close relative; it can be anyone who knows what a grieving person needs.

If you are the one sitting next to or across from a sorrowing friend, your only job is to be there, silently comforting. And that doesn't mean falling back on old clichés such as...

"This will soon pass; things will get better... So much research is being carried out nowadays and this will certainly work out..."

But that is exactly what will *not* happen. It will *not* be all right.

What the person needs to hear instead at this moment is someone saying:
Nothing.

They just sit there by your side. Hug you. Share your sorrow, and tell you to go ahead and cry; that it's terrible; that it's hard to be human and that it's OK to grieve and tell the world to go to hell. Somewhere there amongst all your tears you may be finally ready to hear:

"You're going to make it through this. You're strong. You're a fighter and when you're finished crying, we can start talking about it. I'll be here when you need me. Even though it's really tough right now, we'll sort this out in a while when we know more."

*

A patch of blue sky

After a while. After two, three days. After a week or three, four weeks or sometimes after several months, the grieving and tears stop. The fog in front of your eyes hasn't disappeared, but suddenly you recognize your thoughts, your feelings and your own way of being. It's like getting back into an old car that you haven't driven for a long time. You remember how it reacts, how it works and how to handle it. You remember what you did. (How you drove a car... but, of course, you can no longer drive. It is only one of many losses.)

But still, the new feeling is like suddenly seeing the sun again after a month of clouds, a patch of blue sky. Then it clouds over once more. Sullen grey.

And then a few days later, the weather is fine again. You realize that there are an infinite number of questions. How do you solve this problem? You really don't know anything more than that the "weather" is a little bit better in your heart, and that's enough to set you in motion.

*

Continuing to work through the sorrow

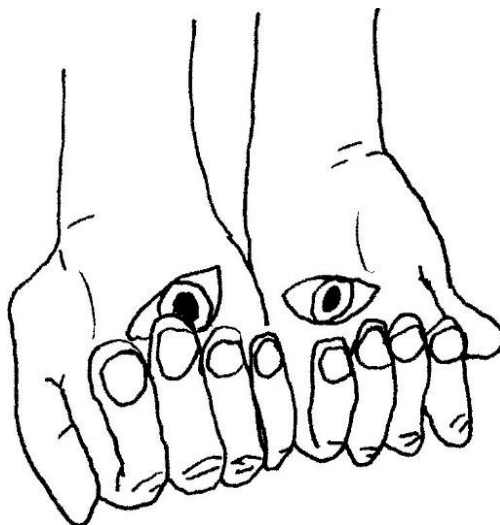
When you talk with people who have experienced the same state of despair, grief, hopelessness and aimless, they can relate a myriad of different ways of behaving, of grieving.

Some turn to someone else who can help them cope; someone they can transfer their problems to; someone who is prepared and has the strength to deal with all the misery. Like a leech, they cling to this person and become very dependent, overprotected and passive. They refuse to go shopping, refuse to decide and refuse to live other than through their proxy.

Others end up in a vacuum. They don't do much more than aimlessly make it through the days with no meaning or purpose. A man in his forties related that he travelled around visiting relatives, but that the best part was the actual journey. The longer it took the better, because it was always easier to be on the road than to arrive. Traveling was the fun part; arriving was the biggest problem.

Another common method is to constantly go around measuring your vision. You find yourself looking about, particularly in familiar places, to check if you can still see things you were able to see the day before: the kitchen clock, the bedroom doorknob and the decorative vase on the bookshelf. Experimentation with and the results of these ongoing "vision tests" are often determined by the mood you are in: If it's a good one, you see better; if you're in a bad mood, you see almost nothing at all.

Now and again the tears return, as though you have to open up the valve and release some of the grief when the pressure becomes too great. You feel such despair because everything is ruined. You grieve over losing the most important thing there is, your vision. Your eyes were two dear friends, two childhood pals who would always be there for you. And then suddenly they died. Maybe not completely, but they've been transformed into two wicked devils that are constantly causing you problems. Problems playing table tennis, reading the newspaper, driving the car,



Two apparent friends, my eyes, suddenly became my biggest problem.

jumping off the cliffs into the sea on the west coast, managing work, recognizing people on the street and going to the movies. Your entire life has changed because your two friends disappeared.

The depression and the misery that has befallen your soul after the initial shock remains for quite some time.

*

Guilt

Whose fault is it?

Since I am the victim, there has to be a perpetrator. Someone who has got it in for me.

It may very well be my own fault. It *is* my fault that I see so poorly or something even worse. Even though it may not really be my fault, I am ashamed that I see so poorly and I am inferior to others who see everything and so can do everything.

Guilt feelings are difficult to get rid of, particularly if they actually are connected to something a person feels guilty about, whether it's true or not.

It's easier to feel ashamed because it's easier to get over being ashamed for seeing poorly than it is to get over feeling guilty for it.

Stop being ashamed! That's where you have to begin and then continue telling yourself that it isn't your fault. You're not to blame for what has happened and you cannot influence it. It's a part of life, but it's hard to just shrug and go on.

It's impossible to understand why it has happened to you or me. It can't be done. There's an element of unforeseen fate in life that you just have to live with. In other words: that's what life is, not knowing and never being able to imagine what is going to happen and how things will be tomorrow.

The father of the well-known Swedish pop singer, Björn Skif, is credited with saying that what's fun about living is being able to see how things turn out. He certainly meant both the happy as well as the unpleasant events. That is what I mean too. Things just happen. It doesn't have to be more complicated than that. If you believe in the supernatural, that there is someone else who controls the world and our destinies, that's OK too. The problem still remains the same: It is impossible to predict how this someone will behave in the future, be it a god, a spirit or whatever the supernatural being is called. What will be, will be. Some of us will be visually impaired, others not.

Some people have the ability to solve difficult problems on their own. Others need help such as reading about it, learning more about visual disorders in general and their own in particular from those who know. By taking the time, admitting the problem and accepting help you will have come a good bit along the way. This is the solution that you will learn more about in the remaining chapters.

*

First visit to the Low Vision Centre

You need to talk to someone. You have to sort this thing out. And you wind up at the Low Vision Centre nevertheless.

You take someone from your family along to the first appointment after receiving the eye doctor's referral. You don't have too much to say to one another. This world is foreign to both of you.

At the Low Vision Centre you will meet people to talk to, cooperate with and learn from. The time has come for you to decide if you are going to rely on these experts – or not, and try on your own to find an alternative or other experts than those the centre has at its disposal.

The centre's low vision therapist, optician, receptionist, social worker, or any one of them can be your lifeline, your lifesaver or simply the one to make sure, in the best case, that everything that has happened to you becomes "an enriching experience", as the author Bo Andersson recalled in his book about the sudden onset of his deafness at the age of 40. Going blind is not only an experience, but also a problem that must be dealt with on many levels.

The Low Vision Centre is a rescue service, a service centre and a security blanket just by being there.

*

For the rest of my life?

Of course, the word "blind" has flashed through your mind just before you fall asleep at night, but then you turn on the lamp again and confirm that you can see everything except the details. You see everything in the room if you look at different angles, but you can't see everything at once. You're constantly explaining to yourself how things are. You're not blind; you just have some difficulties seeing. But how *do* you explain that and why does it have to be this way for you and how long will it last?

Take it in stages! One problem at a time. You need to share the experience you're embarking on with a few chosen people. Talk and tell about what you know and what you don't know. Say exactly what you think and feel, even if you have never done it before. Now is the time because it's necessary for you to find some order in your body, soul and mind.

This is the most decisively important event that you have experienced so far. It usually is for most people anyways, because the visual impairment you now have to deal with will affect your private life, working life, leisure time, love life, interests and a tremendous number of other things for the rest of your life.

The hope that this will pass – what are you going to do about that hope? Are you

going to let it fly out the window or will you hang onto one last ray of hope that doesn't exist?

When are researchers going to find the fix that makes this fog disappear? When is that young, gifted eye surgeon going to turn up? Like a magician he will be able to cure you... or so you think. Dream on! But what if he doesn't come, if he doesn't exist? Then you will be visually impaired for the rest of your life.

Is it possible? Is it a thought that can be translated in to feelings and if so, which ones? Is it possible to reconcile yourself with the idea?

*

Family support and others with low vision

Who is going to call someone they know who has just lost his or her sight and say:

"How are you feeling? How much do you see and what kind of help can you get? Can I do anything for you? Would you like to go for a walk with me or would you like to come over to my place tomorrow because we have no plans for the weekend? It would be fun if you could, for old times' sake."

It's probably just as hard to call your best friend who has lost a child or whose wife has walked out on him for someone else.

It ends up being mostly the family you turn to, those who are closest, your nearest allies who are so important in the initial phase after something awful has happened. Their most important task is to tell you that what has happened, has happened. It can't be undone, but things will look different after a while when you are able to find out more about it and put the whole thing in perspective.

The following message is important above all others: You are just as good now as you were before you became visually impaired – when you could see well. We love you just the way you are, whatever that may be.

For me it has been imperative to keep in touch with people I knew and who knew me when I could see normally. I believe that this is related to the feeling that I am the same person now as then. There is only one characteristic that is different, and that has not changed the fundamental nature of my personality. I can clearly feel it in the air, mostly when I meet those who knew me then and know me now, how they regard me.

"Other people in the same situation" are others with visual impairments. You can find them in the national and local chapters of associations for people with blindness and visually impairment, at courses for this group and occasionally at low vision centres' group activities. But wait to actively get in touch with other people with visual impairment until you no longer feel that they are a threat.

I once participated in a TV program that had the provocative title: "I think blind

people are disgusting". At first, I felt that people with blindness and visual impairment were threatening because I definitely didn't want to be like them. The feeling of disgust wasn't on the personal level, but instead was something that I felt about myself and which I projected onto them.

With time, I got to know many blind people and now when I meet a fellow person with visual impairment in town, it has the opposite effect. I feel as though "here comes someone like me". I'm no longer the ugly duckling; I'm now a swan. When swans meet other swans, a sense of fellowship arises. We all share something in common. We are not alone. I am visually impaired like all of the others, who are proud, strong and do not feel ashamed because they see poorly. But it took time. There was a lot I had to work through before the feeling became a positive one.

*

Second visit to the Low Vision Centre

The second time you visit the Low Vision Centre you will have calmed down. You don't need to comfort anyone other than yourself. You don't need to be ashamed of anyone other than yourself, and you realize that the staff knows what they are talking about. You feel composed for several minutes during the conversation with the low vision therapist and you actually want to meet the optician. Somewhere, far back in the back of your mind are the eye doctor's words about the need for magnification. Maybe it's worth a try?



How much change is it to read this close?

Ugly trial frames are placed on your nose and you attempt to read up close. For the first time in a long time, you are able to see small letters again. Like meeting old friends from the past. Welcome back! But as soon as you relax, you lose focus at that short distance and those small familiar letters disappear into the mist. This is hard; you think and you struggle to restrain that persistent self-pity that you feel creeping back in.

The that's-enough-of-that-hopelessness-feeling takes the upper hand, though, and you listen to the low vision therapist's explanations of what you are to do. You try again to focus up close and look above the letters and move the text slowly in front of the ugly eyeglasses. It's like learning to read all over again. Like starting in first grade.

Now you can see the letters again. You have to hold the text almost up to your nose in order to do so. What is this crap! Don't they have anything better in this primitive place? Can't they give me a pair of real reading glasses to try out? Do they really know what they're doing here?

*

Someone who believed in me

I've taken to heart the advice I've received from many of the people I've met. Just before his appointment at the end of the 1960s, the Swedish secretary of Health, Education and Welfare, a blind man, told me how tough it was to study at the university. "I had had to manage it," he explained, "There was no alternative." He was an inspirational role model. That he didn't say he believed in me, or provoked me into believing in myself was just as inspirational as an ingratiating and phony benevolence would have been.

During my studies at the university in Uppsala, something happened that changed my life. Some of my fellow students from the dormitory came to my room and asked me, a partially blind student from the country who hardly knew who he was, if I would be director for the student theatre. How dare they!

I accepted the challenge and became more and more complete as a person with each passing day. There was someone out there who believed in me. The grief in my heart that was my constant companion lifted as time went by.

My uncertainty and insecurity started to dissipate, primarily when I was going to take the bus to an unfamiliar place or find a lecture hall in room 342, third floor of building B.

I had a goal and was becoming more and more myself – though visually impaired. The people around me took it easy and didn't make a big deal out of my poor vision. I was the one who was most surprised. What was of such great importance for me was actually almost irrelevant for them; it seemed so, anyway.

*

Better and better

“Better and better” is a good expression.

It doesn't mean that you all at once, on a given Wednesday afternoon, switch over from one state to another. It is really a never-ending process.

When I say that this process goes in waves, I don't mean steady, even ones. Their cycles are not fixed. The sea can be calm for a long time, but then one day when something else unpleasant, dramatic and unexpected happens, those other feelings will all come back. The feeling of abandonment, emptiness, panic and anxiety that surface when you lost your vision and that created such chaos have a tendency to reappear, like old unloved acquaintances every time something new, unexpected, disagreeable and traumatic happens. Especially in the initial stages of a severe visual loss.

But that's life. Expected and unexpected crises. Anxiety and joy. Calmness, stability and harmony are continuously changing places with stress and disharmony, unhappiness and, in the worst case, deep anguish.

But the anxiety recedes. Somehow, the bad feelings fade away and the worse discomfort caused by the traumatic events that have occurred grows less with time. If you receive professional help in dealing with all the feelings, it can go faster and be less painful.

It's true: the visual impairment is not necessarily the worst thing that can happen. There are many other even more awful events that may befall you in life. A partially sighted friend of mine said that the worst that happened to him was not losing his sight, but losing his wife. That was more terrible than the impairment; the loss of vision he could deal with, handle and understand that it could happen to him. What he couldn't cope with was his wife leaving him against his will and the deep love he still felt for her. 'That was worse than losing four eyes.' But everything is individual and different here in life. One man's loss may be experienced quite differently by another.

You may think that this entire book is quite unnecessary and that it's just a natural part of life that some people lose their sight. And maybe you can say, “Well, OK, I'm the one.” But I haven't met that person yet...

As time goes by, the emotional roller coaster ride between hope and despair dissipates. It's important to take it easy in the beginning, to think before you act, to reflect over the difference between now and then. You need to work through the feelings you have and allow them to exist, but you also have to allow them to disappear.

It's a good idea to acquire the best tape recorder on the market, the best transport service, the strongest glasses and the best friends. That makes life easier.

Then the waves of hope and despair even out and you no longer need to pretend.

It means that you feel more and more worthwhile. The life you are now living becomes increasingly meaningful and you relate to the new dimension of your personality that involves not seeing well. You can relate to its origins and that it isn't your fault; that it's something you can't influence. You start seeing it as natural that you now make up part of the two percent of the world's population that sees poorly; that you have the right to be different while at the same time having the duty to yourself and those around you to actively participate in your community – on your own terms.

One more thing to learn: other strange and undesirable things that happen to you are not the fault of your eyes. Even the world of sighted people can fall apart – although they see well. Exactly as yours did when you lost your vision.

*

Your relatives' grief

When you have finished crying, your relatives are permitted to express their sorrow.

They also grieve at times over the things you were going to do together. They do not know what it's like to see as badly as you do. And you are unable to explain it to the people you love. It is psychologically too difficult, or visually too difficult to really explain to someone else who does not understand.

Almost every time my wife tells someone that her husband is visually impaired, the same thing happens. They ask, "Was that the case when you met him?" They wonder if she voluntarily got involved in a relationship with a man who couldn't really see, or if it was a fate that befell me a few years into the marriage. Is there any difference between these two situations? Of course there is.

In the first case, you understand more of what it is all about. You know each other and, above all fully understand what the "bad vision" dimension signifies. In the second case the two people have to go through the experience together. The seeing partner needs to adjust too.

It involves a lot of practical things, but also alters the roles in the relationship, including the traditional ones defined by gender. If the man usually drives (which, oddly enough, is more common in our so-called land of equality), the woman has to take and be allowed to take that responsibility. If the man's domain includes the drill, the furnace, the chainsaw, the tractor and the lawn mower – then the woman has to take over or somehow make it possible for the man to manage the tools and equipment now and in the future.

Often it is good for the partner and for the relationship that the man or the woman goes and talks to a third party about how and what they feel. The need may not arise right away but after a while, when both partners have made it through the initial grief and horror and have started to speak about terms for the future. It helps tremendously to have someone to talk to about the traumatic infringement on a

relationship that arises when one of the partners loses his vision.

The third party I am speaking of is not a family counsellor, but rather rehabilitation personnel, mentors, close friends, parents or just some wise person with common sense whom you trust and who is prepared to listen.

There is something called substitute suffering, sometimes referred to as compassion. It's quite natural in a married relationship that your partner suffers with you. But when you are ready to move on, you don't need to be overprotected. At this point, it's important that genuine compassion exists so that the person who has recently lost his vision receives help in a natural manner and that he, as a person with visual impairment, is able to manage on his own in most situations. That is when you can call upon and make use of that genuine, well-established respect you share that is so important for two independent people who love each other.

*

Self-esteem, self-confidence and self-trust

A message for those who have acquired a severe vision loss: you are just as good now as you were then – when you could see well. You are fine just the way you are, however you are.

Just imagine if someone said that to you every day – and to me. It would be much easier to live like that, if you never doubted yourself and your own ego or “being”; if your self-esteem was never negatively affected.

Unfortunately, that's not the way it is. Self-esteem *is* affected.

People with strong self-esteem have learned early on to be needed, to be liked and quite simply, to be seen, loved and wanted. Strong self-esteem is reflected or moulded early in life. It may very well be the most important thing we learn as children: to develop at an early point in our existence a feeling of being wanted and being certain of ourselves. A good sense of self-esteem.

Self-confidence is also important, above all in your relationship to other people and at work. It is vital that you feel that you measure up, that you do good things and that you get the job done.

It can range from doing the dishes to calculating the speed of an object traveling through a vacuum. Good self-esteem and self-confidence make it easier for you to utilize your knowledge and experience.

When your identity has taken a blow, and when you suddenly are forced to re-evaluate yourself in relation to an acquired visual impairment, it is infinitely important to quickly re-establish your lost sense of self-esteem. It's a matter of finding an identity in which you are a person with the same name and nature as before, but in which you also are going to learn to live with a characteristic that in many cases is considered to be negative. For there are few situations in which it is positive to have

bad eyesight, that we can pretty much all agree on.

The new characteristic is, for obvious reasons, not something you accept easily, just verifying its existence and then moving on. Almost everyone reflects over what has occurred in one way or another; the majority grieve and by different means try to keep it at bay and may even refuse to accept what has happened to their vision.

Souls that have been torn apart up by external events lose their trust and credibility, and if you lack trust and credibility in your soul, it is difficult to get other people to trust you and experience you as being credible. Others will not take you as seriously, which means you lose self-esteem which results in.... and so on.

You have to stop this vicious cycle! Make sure that your soul, your thoughts and yourself feel good, even though your eyes are bad. I'll say it again: you are not your eyes! Remember that every time you doubt your ability and your worth. You are not bad just because your eyes and vision have their deficiencies. You are good just the way you are. You are entitled to live a normal life, even though you are different.

Your eyes are bad, but you are good. You are, quite simply, not your eyes. You are everything at once, the entire you, and your eyes and your bad vision are only a part of a functional whole. The visual impairment is only one aspect of a person who is not going to let the fog be the only thing that exists in front of his eyes.

There is an awful lot of normal and fully sighted people who go around and are unhappy, which means that all unhappiness in the world is not the result of seeing bad.

One of the most important factors in compensating for poor vision is a good sense of humour. An example of this can be found in the man who wrote the foreword to this book, Täppas Fogelberg. His great sense of humour, his appetite for life and comfortable approach to things large and small is only one example of how little it means to have bad eyes if you have decided to live and have a good time doing so, in spite of it all. Why not decide that for yourself too?

*

More about your fellow human beings

What does it mean to be a true fellow human being?

That's not so easy to answer because solidarity does not mean being a nice, self-sacrificing person who does everything you want exactly when you want it. Rather, it means being a person with a natural ability for empathy who can translate these feelings into genuine actions.

Empathy means being prepared to vicariously experience another person's difficulties, something that is called a genuine sympathetic consciousness. This can explicitly or inexplicitly signify that, "You and I understand one another and both of us know how things are and we accept each other in spite of our differences."

This genuine compassion means that you suffer with a person that you like, love and feel strongly for.

However, compassion can take on an erroneous and false pretence, embodied in a charitable but skewed way of thinking: that of the do-gooder who does things for others in order to feel good and decent about himself.

You know right away if the person you are talking to is genuinely empathetic and has a truly sympathetic consciousness, or if the compassion they show is superficial and egoistic.

In the acute phase, empathy from others is crucial, but can also be later in life. After living with bad vision, you are often able to sort out the empathetic people from the ones who really don't care or don't understand your condition. Have you considered that this might be a new ability that you are learning?

*

A good example of genuine empathy

My neighbour and I took a trip to the West Coast of Sweden by car (for safety's sake, he drove...). When we passed through towns, he read what was on the signs, which surprised me.

"Why are you telling me where we are all the time?" I asked.

"You can't see the signs," he answered as if it was the most natural thing in the world.

But it's not natural. Those who don't know, ask me what I want; and those who can't or don't want to understand, won't read the signs even after ten years of active reminders that it would be nice to know where we were.

But of course, when you have been married for more than 30 years, it isn't much fun every time we take a trip to the West Coast to always have to say where we are and why. (So, Marianne, you don't need to continue reading all the signs either... but when we are in Beijing or any other city where it's hard to read the signs, we can help one another find the way back to the hotel.)

It's important to utilize your other senses as well, and join in with others who happen to have good eyes. One can look while the other one analyses, confirms or generally helps out. Even if you have impaired vision, you are like everybody else: a companion, one in the gang, a source of knowledge, full of experiences and a friend who also means an awful lot to others.

*

Natural and professional empathy

There are two types of empathy: natural and professional.

My neighbour, the tyre salesman, has natural empathy.

You encounter professional empathy when you meet people in health care and rehabilitation who you can get close to, who can help you learn to master your situation without intruding into your private life or infringing on your integrity.

In both cases it involves a special talent that to a certain extent a person already possesses, but which can also be acquired, practiced and which can become an approach to treatment used by qualified rehabilitation professionals. Certain people are only interested in themselves, and they are sometimes referred to as egoists. But even among the biggest egoists there are people with good empathetic skills and also the opposite.

Those who only care about others and do not devote any energy and love to themselves, can sometimes end up on the wrong track in life, becoming subservient and irritating. Often, subservience demands something indefinable in return. How can two vulnerable people help one another in a difficult situation?

The subservient “soul mourners” with their heads on crooked, who always accentuate their own vulnerability and give voice to everyone else’s hardships can have a negative effect even on those they represent in their suffering – by proxy.

The competent rehabilitation professional is also smart enough to know not to take on the parent role. It is one that some adults adopt, even if they aren’t actually parents. They admonish and tell you what you should do, how you should act and what is expected in a variety of situations.

It’s like coming home to mom and that nice, affectionate person tells you that you should put on your cap because it’s cold outside. You may be able to take it from your mother because it is the business of mothers to have that kind of perpetual benevolence. But when other men and women try to parent us, many of us react negatively; I am one of them.

It is particularly aggravating when this admonishing or know-it-all attitude is used on someone who is at a disadvantage, such as a person who has just lost most of his vision.

The rehabilitation professionals who adopt the role of the guardian are, frankly, unsuitable for the job. They reinforce helplessness instead of strengthening and building up self-esteem again.

But this is the exception in most rehabilitation services. What I mean to say is this: Make your demands heard and let them know how you want things to be done and what your needs are!

USA 1969

All people with visual impairment who work with the problems of others in the same situation do so to solve their own in the process. That is the case for me too.

During my travels in the USA in 1969, I discovered two things: the person who wrote what at the time was the foremost book on the subject, entitled "Blindness", was a Catholic priest, and the person who had the best rehabilitation course in the country was, unfortunately, a blind despot by the name of Kenneth Jernigan.

The Catholic priest, Fr. Thomas S. Carroll, claimed in his book that you sustain exactly twenty losses when you become visually impaired and that the sport of fencing is an important part of rehabilitation. The blind Kenneth Jernigan claimed that those who could see a little should bandage their eyes so that they would learn to be blind because then everything would be much easier.

Enthusiasts are needed to give impetus to low vision rehabilitation, but they still need to be people anchored in reality with a certain amount of common sense and state-of-the-art knowledge.

There is, of course, the Lighthouse in New York City. Here they pioneered services for people with partial vision loss through the establishment in 1953 of the world's first Low Vision Centre by an optometrist by the name of Gerald Fonda. Eleanor Fay, an optometrist with her Norwegian roots, succeeded him, and then the optician Bruce Rosensenthal. In Detroit and Ypsilanti, courses were offered for partially sighted people who wanted to study at university while in Des Moines, Iowa, they were given the opportunity to learn how to use a cane.

Americans were not very popular then because of the Vietnam War, but in the area of low vision rehabilitation we learned a lot from them. Ironically, this was largely because the Veteran's Administration Hospitals had considerable resources for the rehabilitation of war veterans and others who have served in other capacities in the military, thus qualifying for the free services the Veteran's Administration offers.

Visual impairments are a large part of the misery that results from war.

When I came home in the autumn of 1969 and had seen, among other things, a man walking on the moon, I took a look around. What were we doing in Sweden and why were they so far ahead of us in the USA and as I later came to understand, in Denmark as well?

There was much to be done. I had found a new goal. Now it was clear: poor vision can be a good, in fact, an excellent source of inspiration. But it can be the work of a lifetime, for good and bad. One way is to make sure that you adopt the "visually impaired" identity. The other is a lifelong job of developing a patient centred approach, with particular emphasis on vision.

What do you think? Is it enough to live in the world of the visually impaired? Or do you want to find your own place among everyone else, even though you see poorly?

*

Checklist for relationships

In addition to all the assistive devices and economic support you can receive for being visually impaired, your fellow human beings are your most important resource or aid. That is why I have attempted to construct a checklist of what these people should be like. Or, in all honesty, how you should be with other people, which practically speaking makes this a checklist for good relationships.

Here are my suggestions. Do they match your own views?

- Make sure that you meet people who consider your visual loss as an interesting and natural difference and who allow you the right to be different in a natural manner. As a consequence, they help you with the variety of practical difficulties you have, but not to the point that you feel vulnerable, stupid or excluded.
- Make sure that you meet people with a genuine interest in the professional rehabilitation world. They can improvise and be naturally and personally considerate to your level of need and acceptance. Those who work according to set plans and routines should be employed in quality assurance in manufacturing, not with people.
- You also want to meet those who are the best in the business of testing and getting a hold of assistive devices and who you can learn from so that it's possible to live an ordinary life again – in spite of your limited acuity, reduced field of vision or whatever the problem may be.
- You want to meet someone else like you who can tell you what happened to them, what they did, and where a cure, treatment and other assistance can be found. You need to meet other people with visual impairment. If you don't know anyone who is, how are you going to know what it's like to live as one? You will soon discover that you speak the same language in many respects or, more precisely, you speak about the same thing from the same point of view compared to people who see well and represent people with visual impairment.
- A truly good rehabilitation program has a member of its team who is a person with visual impairment; a person secure in who he or she is. It's a prerequisite, though, contingent on certain conditions: It's not good if the people with visual impairment believes that everyone is like him or her, making that the norm. It's not a matter of becoming an entirely different person just because you have acquired an unusual characteristic. It's a matter of learning for yourself, based on the new situation, and to try and

continue from where you left off.

- You are going to meet people who like you and understand you, if you – after the acute crisis, grief and feeling of incapacity – also understand them and their problems. People who haven't had any problems that they have gained new insights from are not very interesting. Just like you can be, if you continue with your nagging complaints about how badly you see and how awful you feel.

There are two things that have proven to be beneficial when you want to rediscover yourself and adapt to a new situation according to the psychologist Sara Henrysson in an article about how adults with visual impairment adjust to their new situation. One is to receive strong support from your family and the other is to meet other people in the same situation.

*

“Come out” and show the world who you are

Sooner or later life enters into the normal phase of an abnormal situation.

It has to do with “coming out”. It's a matter of being able to see poorly and feel good everywhere. It's being able to say to yourself that you are not your eyes. You are you, and “bad vision” is a part of your personality. Otherwise, nothing has happened, even if it really has.

You can tell anyone that you see poorly, or that you don't see, or that you have lost your vision. Since you don't have to lie, don't have to hide your vision problems, don't have to pretend to see things you can't, a lot of energy is set free and you needn't worry or feel nervous and anxious.

You can become a whole person again. A common person with an uncommon dimension added to your personality that you will learn to control, overcome, exploit and compensate for. A lot is required of you, including, being straight and honest with yourself and many others.

You can say something like this:

“I can't see so could you tell me what's on the menu, please?”

“I have seat number 39 in row 1. Can you show me the way? I'm visually impaired and it's hard for me to see the numbers.”

“Oh, excuse me. I didn't see; my vision is very bad.”

“If you see me in town, tell me who you are; you know that I don't recognize people because of my vision loss.”

When you have learned how to do this, congratulate yourself. Now you can start living a whole life again. You don't see any better, but you count as a person just the

way you are and you are no longer ashamed because your vision is bad.

That's when the inner fog usually lifts and it is a favour to quietly pray for. Believe me.

All of this is not easy. You have to work at it. Tell yourself, "I accept that which I cannot influence or change and which is not my fault." You have to go on and be who you are, even though you are visually impaired.

Welcome back, back to yourself. To a true and healthy life. Welcome to a positive future.

I would like to take the opportunity to make a suggestion to sanctimonious occupational therapists and theoretical disability experts: the concept "rehabilitation" is clearly out of date. It is, indeed, old fashioned, if you consider the person who is going through a process like the one I've been writing about here. I suggest that we call it "future work"; this is a concept I can buy, because "rehabilitation" sounds so tiresome and tedious.

*

Finding your limits

It can be good to avoid doing things you are not sure you can manage so as not to be disappointed. No need to cause yourself unnecessary pain; it's better to take it easy for a while and slowly find your way back to that which works well and that we call life. This advice is valid particularly in the beginning, with a recently acquired vision loss. Later on, when you have accepted what you cannot change, you are free to try everything.

It all has to do with finding your limits: what you can manage on your own and what you need help with. Can I find my way in the middle of the night from the restaurant on 39th street in New York to my hotel near Madison Square Garden? I thought I could, but I couldn't. It all worked out in the end, but I won't do it again because it was an unpleasant experience I could have avoided if I had taken a taxi. As a result, I have learned my limits.

It's possible to find out which things you can improve with training and which ones you need help with – or find some kind of aid or device that can do it for you.

Of course, I could have learned to find my way to Madison Square Garden if I lived in New York, just as I have learned to find my way from the train station in Lund to the Institute of Technology on the University campus. It's a matter of finding landmarks: buildings, churches and directions and then walking the route a couple of times with someone who knows how you handle things. Then you go once on your own and after that, it becomes routine.

You still know and can do a lot. Concentrate on the things you can do and push the limits. Just do it. Starting now.

See how it goes to play table tennis, badminton, run in the woods, bike, go to the movies, eat at your favourite restaurant, be in the audience when your favourite

hockey team is playing or when your favourite entertainer is performing in a big concert arena. Don't give up everything because you will miss seeing part of it.

There are countless examples of the exaggerated importance that good eyesight has for experiencing and appreciating different pleasures in life.

If you have been part of a group of friends who make Christmas cookies every year, continue doing so. Go there, even if it feels uncomfortable not being like all the others, because you would have wanted it that way if someone else in the group had lost another ability, wouldn't you?

Try to avoid, as much as possible, blaming other problems you have in life on the fact that your vision is bad.

It is more often your relationship to your bad eyesight that enters into the picture than the bad eyesight itself. You have to be the one who decides – not your eyes. If the opposite is the case, it's time for you to regain control as far as you are able to.

It's true, life is full of limitations and one of your limitations is your reduced vision. At the same time, you can manage more than you think if you only believe in yourself. Every day you can test to see where your limits lie for your ability to carry out projects, perform at work, love your fellow human beings and feel happiness and well-being.

One of the greatest joys in life is the feeling of being a natural part of a group, and one of the hardest things is being alone in an isolation you have not chosen. That's what the bishop of Värmland said recently on the radio, and I thought it a good idea to add those lines to this book. If you agree with what he has to say – as I do – it's a matter of working towards finding that genuine fellowship, which is more valuable than almost everything else in the world.

It also reminds me of the story of the sports editor of a large daily newspaper who called one of his co-workers at home early in the morning, even though the journalist had only been sleeping a few hours. His wife asked, "Is it important?" The sports editor replied, "Sports are never important – but I have to talk to him anyway." Why do we participate in sports then? The answer: a sense of fellowship in being part of a group.

So, a sense of fellowship is more important than loneliness, and perhaps participating in sports is more of a way to gain friends than to become physically fit, strong and successful.

*

The problem and the process: one more time

- Your eyes are no longer able to send really good images to your brain and it is difficult to interpret the ones they do send. It is hard to recognize people, read, drive a car or motorboat and much more.

- The vision loss affects you very much as a person. A new dimension has been added to your personality, to your sense of self, to your identity.
- You learn the cause, effect and ways of overcoming your visual impairment, even if you see just as badly as when it first happened.
- You adjust to the new dimension and start feeling that you still count as the person you are. There are many things that you can still do and control.
- You allow yourself to be different with others and realize that everyone has a skeleton in the closet, which means that everyone has some weakness that they would rather not reveal. Just like you.
- You are the same person as before, but not quite. A new dimension has been added to your personality.
- You have regained your sense of self, and you can now, in an entirely different way, place demands on the people you meet in rehabilitation. You can say to yourself without a second thought, "I am not my eyes." "My eyes are bad but I am good, or not any worse than many others, in any case." In other words, you have mastered the art of "seeing bad and feeling good".
- Congratulations!

*

Alcohol – friend or foe?

There are few things that can alleviate anxiety as well as alcohol does. Nervousness disappears, the pressure is lifted and it puts you in a good mood. It is, quite simply, easier to lie to yourself with alcohol in your body.

But it is also impossible to constructively work through your innermost feelings and think clearly with alcohol rushing through your head.

After drinking more – especially hard liquor – your weaknesses become even weaker, or your aggression increases in intensity and you're unable to judge your strengths, your vulnerabilities, or what you say to others.

My general advice is: don't drink when you have problems or when you're feeling down.

Refrain from drinking. Put up with the anxiety, anguish and deal with these feelings in another way. Talk to someone you like and who can help you get in touch with your new feelings, situation and future plans.

Are there people who are more vulnerable than others to becoming dependent on alcohol? It may be so that those who have jobs that are very demanding for many hours every day are more vulnerable. An actor who performs every evening and finds it difficult to relax afterwards, or who has stage fright before the performance

can be tempted to have a shot of whiskey to reduce all the fears and bolster his confidence.

The only problem is that more and more alcohol is needed to achieve the same effect and you finally end up dependent, with disaster just around the corner.

People who are visually impaired or others who are having difficulties mastering a new role and situation in life can also behave in a similar manner. They start with a little something to calm their nerves and it gradually increases without them knowing or wanting to know what is going on.

Those around you, though, are observant of when and if you're drinking too much.

Alcohol is, in many cases, directly or indirectly responsible for a person losing his or her vision. This includes everything from "alcohol and tobacco amblyopia" to the syndromes in which alcohol is suspected to be the triggering factor. The most extreme instance in this context is wood alcohol or methanol which damages the nervous system so that parts of or the entire brain is incapacitated, in particular, the visual system.

There are examples of people who have used alcohol as an anxiety reducer and escape mechanism in difficult situations and have managed to cope, just as there are those who are able to stop drinking and continue their careers and lives in sobriety. There are also people who follow the ironic saying which claims that "alcohol saved me from sports." They have allowed alcohol to control what they do and whom they associate with. Whether it be on the park bench outside the liquor store or at fancy dinner parties with plenty of wine in "better" company.

There are those who instead of solving their problems when faced with a recently acquired vision lost, choose to alleviate their anxiety with alcohol and end up alcoholics. It happens easily.

If you find life hard to live, refrain from drinking alcohol entirely during the time you're unhappy and miserable. If you're planning to drink wine or beer anyway, decide in advance how much you're going to consume during the evening. If you drink too much and start bursting out in feelings you wouldn't express otherwise, take it as a warning signal and do something about it.

To express it more dramatically, the distance between living a life with those who are near and dear as opposed to one on the park bench is shorter than you think. Alcohol reduces anxiety and distress, which can feel good, but those who find that it is only alcohol that has that effect should be careful.

In regards to drugs, the situation is even more sensitive. Narcotics do not anesthetize the emotions like alcohol does, but can instead stimulate and exaggerate the feelings that you really want to control.

Tranquilizers or sedatives can also cause problems. They lay a treacherous glaze over anxiety, fear and apprehension. You may be spared the physical discomfort, but

at the same time, it will be considerably more difficult to work through your feelings when they are shrouded in a fog.

While tranquilizers can be a comfort to have on hand when you need something to calm you down, they can also be a scourge that prevents a natural reaction, a natural emotional life and a process like the one I have written about here. Take only the medications that you determine are beneficial when things are extra troublesome. The rest of the time, you have to try to put up with or divert the bad thoughts and feelings in some other way, for example, with the help of those close to you, sympathetic and honest therapists and many long walks with thoughts and feelings spinning around in your head.

*

Are you ready for some harsh realities?

Here are some statements that I have put in someone's mouth. It may be you – it may be me who says:

- I am visually impaired.
- I can't change it.
- There is nothing I can do about it.
- It's not my fault.
- I will always be visually impaired. I will never see better than this.
- I have to learn to live like this.
- I am going to have the best assistive devices in the world.
- I am going to find the best professionals there are who can help me improve the vision and other abilities I have left.
- I am going to live like this.
- I am going to cope with this too.
- I am like I was before, although visually impaired.
- I haven't done anything wrong and don't need to see this as some kind of punishment, trial or something that someone else has done to me.
- I am not a victim.
- Every day I will see just as badly for the rest of my life.
- Every morning, I am going to wake up and see as I do now, yet still think that life is worth living.
- Every morning, every day and every evening I am going to see as I do now. But I still count.

When you have reached this far and all of the statements are close to what you really think and feel, then you've truly accomplished something. That's good, especially for you.

Some bad examples

I'm going to tell you about some people I've meet who appear to have managed well on the surface, but who have done so at the price of an inner anxiety and a great separation of body and soul.

Once I meet a well-educated woman with a considerable reduction in vision. She read with the help of a CCTV magnification system and wrote by hand under a camera. She kept a number of loyal assistants working and as a consultant, she lied to herself everyday by asking her customers if she could read through their hand written orders later in the day (that is to say when she was by herself with the CCTV so that no one could see what she was doing).

She was very successful and believed, or so she said, that if she revealed her secret, customers would stop calling her and she would be singled out and bullied.

Just think if she could learn to use a computer with a magnification program for writing. With synthetic speech she wouldn't have to sit uncomfortably and write by hand under a video camera in a magnification system.

If she learned to use spectacle-mounted microscopic lenses with a reading distance of an inch or so (3 cm), she could see menus, customer order specifications and even read the newspaper on the train.

If she could accept what had happened and what she cannot change, she could adopt the existing methods and technologies. At the same time, she could do many things that other people can but in a different way.

By accepting her weaknesses in other words, she would become more normal in her way of functioning and it's hard to imagine that she would lose customers because of that. She would still have her expertise and her credibility intact – both on the



*Do you dare showing who and what
you are? To anyone?*

intellectual level and on the human one.

Another person drives his car without a thought, even though he has poor acuity and limited stereovision – at a risk for his own life and that of others.

These are two examples of talented people who are unable to deal with the truth and to live normally. Instead, they go to even greater efforts to hide their visual limitations. Discovery would mean disaster from their way of thinking.

A third example is a man who decided to be the country's first person with visual impairment who was not visually impaired. He even convinced himself that he could trick everyone in his surroundings so that they would not think, in their wildest dreams, that he had bad vision.

One day when a co-worker came into his office with a telephone number for him to dial, he asked her accusingly why she had written it in such large characters.

"But you see so poorly so I thought you would like it that way."

"That's not needed," he said to his own astonishment, quite aware that this kind of large print could be of great help. Then he wouldn't have to fiddle around with his pocket magnification device when he thought no one was looking.

To him and everyone else who is busy trying to pretend to live a normal life, I'd like to say: Stop lying to yourselves! Tell it like it is for those you believe in it and have confidence in it. If you don't do it the first time, make sure you tell them sooner or later. It's just like dancing: If you don't start talking right away, it will be hard to get something said the whole evening.

If everyone who had low vision stopped lying and hiding their secret, there would be many more of us who read with their noses on buses and trains. Then the unusual would become common and ordinary.

*

What do you gain from being a VIP (Visually Impaired Person)?

There are many gains to be made from seeing bad. They are sometimes referred to as secondary gains and can, for example, involve getting a lot of extra attention, a lot of consideration, a lot of training, a lot of optical and other kinds of devices or disability payments from your insurance company. In a country like Sweden, you may be able to get financial support on the job to employ an assistant and reimbursement for job-related technical aids. At home you can have special lighting installed in the kitchen and bathroom. You can be given a TV magnification system and computer that has synthetic speech and can enlarge the letters to a size you can read.

The secondary gains will be even more beneficial if you have accepted that which you are unable to change. Then you will be able to call the theatre and order tickets saying:

“Now it just happens to be the case that I (or my husband) am visually impaired so it would be really great if I (we) could have front row centre seats if possible.”

Or when you reserve a table at a restaurant. Or when you are going to a hockey game or horse show. It would be nice to have the most attractive seats where you (and anyone else for that matter) see better than everyone else.

My stance is that you should exploit the situation if possible. The disadvantages of having bad vision are many and so it would be good to utilize the few advantages you have nonetheless.

It is also tempting and quite in order that others think you are particularly clever when you are able to manage to study, work, jog and be active in different ways – even though your vision is so bad. When you have worked and practiced hard to do all these things, you should eat up all the praise you can get.

There are actually people who describe a vision loss as something positive in their lives. A low vision counsellor in Sweden claimed that he lost his vision on the job as a metal worker for Volvo. No one paid much attention to him before that. But then there was a flurry of activity: he received rehabilitation, re-education and became a counsellor for others in the same situation. This meant that he was able to meet interesting people, to do something for others, to travel and experience a great deal more variety in life. “IF I hadn’t lost my vision, I would still be at Volvo working at the lathe and nothing would have happened,” he explained.

You can also be interesting as a person because you have a characteristic that is both unusual and which is a disability of a nobler sort. There are – unfortunately – nobler and less noble disabilities here in life. Visual impairment has always occupied a special position when it comes to charity and status. The reasons why are something to consider. But even more importantly is to accept all the opportunities that the welfare system has to offer: personal assistants, escorts service from the county, disability reimbursement from the insurance company, aids and devices from county vision centres and talking books from the library make up a new world of attention and service.

To receive care, warmth and attention from the empathetic people are fine gifts that can be part of the good fruit you harvest, as long as you make sure that you play down the visual impairment, are honest with yourself and others while allowing yourself to utilize the bittersweet taste of seeing bad. That can help you to feel good in the midst of all the difficulties and extra work that being partially sighted entails.

*

Driver's license and your sense of self

A difficult aspect in the art of learning to live with a visual impairment is the loss of your driver's license – sending it in to the state department of public safety before the police come and take it away.

Most of those in this situation (particularly men for some reason) say that the issue of the driver's license is the hardest and most critical one there is. This is when you feel cheated, deceived and offended all over again, and that there is no help to be had.

You don't start grieving until you have something to grieve for, something you've lost, something tangible that you will never be able to do again. There is an enormous freedom in getting into a car, placing the key in the ignition, putting it into gear and driving off all by yourself or with the whole family to a place of your own choice without having to ask anyone when the train leaves.

There are mature adults (still mostly men) who in all seriousness say that a car is their companion. A car is an obvious aid, an instrument of power, a beautiful experience, the fascination of speed and a status symbol. "You are what you drive," according to Mercedes. "You are worth a Volvo." "You can only drive one Lamborghini at a time", the former Swedish soccer pro, Tomas Brodin, is credited with saying.

The hype, the feeling of freedom; all of this disappears the instant you turn in your license, keys and the ability to drive a car.

Do this instead:

- Keep the keys and make sure you can get into the passenger's seat without having to ask. It still feels as though you own the car. Make sure that there is someone in your family or among your friends who can drive the car. Then at least someone in the family is driving it and you will still feel as though you own it, which is as much of the pleasure in having a car as driving it is. You have something to hold on to in any case and to limit the loss. You could also pay someone to drive you places.
- Make sure that you register for the transport services for the disabled and learn how to travel by bus, train, plane as well as those who see.
- Use all the money you save by not driving your own car on other means of transportation. If the transport service is unreliable – call a taxi and use your disability pay on a cab company you like.

You can survive without a license. If you insist on driving with your poor vision in spite of it all, you may regret it for the rest of your life. You could hit a child, drive into a pole injuring your passenger, perpetrate a crime – and then you will really be a victim.

If you don't use your driver's license, there is really no point in having it in your wallet. Turn it in if your vision is lower than the legal limit for driving. It's foolish, cowardly and dishonest to have a license if you don't meet the vision requirements. You are only deceiving yourself and spending a lot of time and energy avoiding the truth.

It's difficult. But it can be done. Just the other day I saw a county governor who wasn't driving himself but sat in the backseat and let someone else do the driving. He thought it was quite all right. You can adopt that attitude too.

*

Your inner resources

No one else can achieve what you want to more than yourself.

Knowledge – both practical and theoretical – is always acquired through your own effort and that goes for the ability to learn about new technology, new environments and new people. You haven't lost that ability just because you've lost a good portion of your vision, but it's not as easy as before, especially not when you're feeling depressed and doubt that you will ever regain your old strength and will power.

Changing this ability is an active process, one that you've chosen and a demanding one. It is something that you influence to a great extent. Think about it for a while. Plan for a while.

Decide when you are going to decide.

Then make up your mind to do it, to do it on your own. No one else.

Choose the path that leads to the goal you have set for yourself and by doing that, you avoid a great peril, namely, that of becoming a victim.

There is much in the brain that doesn't require vision. There are abilities such as different kinds of expertise, imagination and creativity. Everything you have learned in life can help you in compensating for bad vision. Your physical strength and perseverance are also important. Being in good physical shape increases inner well-being and mental energy. Make sure you have it – or acquire it.

When it comes to knowledge, it's not just the theoretical kind that counts. It also includes social competence, the ability to interact with people and animals, fix a good dinner, build things, do the laundry or change the tires on the car. It is possible to do all these things, to a greater or lesser extent, even if you don't see very well. It just involves trying to do it in a new way, in a different way or with someone else who can do the things you can't. It can work out just as well, but it often takes a little more time. We've got lots of time, though. And more of it keeps coming – all the time.

Some people say that everything takes five times longer when you are visually impaired, but I don't believe that. It may be the case when it comes to sewing on

buttons, hanging up curtains or pictures and other practical tasks. But it certainly isn't the case when playing the piano, typing letters on a keyboard or figuring out what you are going to have for dinner.

In the beginning, the actual meal preparation will certainly take at least five times as long as before. But practice makes perfect. Above all, you develop orderliness and organization, sorting things in different containers, drawers and cupboards and thus not having to work yourself to the bone looking for everything.

Don't discard the old knowledge and abilities you still have before you are really certain that you don't need them. Make a point of gaining new knowledge, such as a better and practically adapted sense of order.

Unfortunately, there are rehabilitation professionals and even relatives who will tell you how little you are able to do and everything that you have lost; these kinds of comments can be very hard on your self-esteem. So don't listen to the prophets of woe, but instead trust in your own ability to cope – both on your own and with the help of all the great people you will meet and can benefit from in the future.

PART II: MANAGING THE CHALLENGES

Rehabilitation – recreating your future

Make sure that you regain your self-confidence by training intensively so that you are able to do what you have failed at. You will increase your self-esteem and self-reliance by working with others who understand your situation but who also place demands on you.

It's the same in the world of sports. Athletes with coaches who sets up rigorous training programs go further, as they will readily attest to (even those who arrange their own training programs).

The training program for someone with a recently acquired visual disability has a rather uninspiring name: rehabilitation.

There are many who have tried to explain what the word "rehabilitation" means. My definition is: Getting as close as possible to being the person you were before – given the new situation you find yourself in.

Think of it instead as recreating yourself and being yourself again with all the new dimensions that a visual impairment entails.

The only question is, when are you yourself?

The goal of rehabilitation is for you to win back your identity, your self-esteem and self-

reliance. You are going to work with the following goals and methods:

1. Gaining insight into your situation. This means that you understand both intellectually and emotionally how things are, the causes and the consequences of what has happened.
2. One important and crucial factor in this regard is to learn all you can about your vision loss. In that way, through knowledge, the “enemy” becomes your friend.
3. Motivation. It is also important that you are persistent, involved and determined in utilizing the vision you have left. You will find this extremely useful, especially if you know your limits, when you are able to see what you want to and also when you can't.
4. Even if you receive advice from others, you have to map out your own territory and determine what you can manage. Take advantage of all the possibilities that exist for you to overcome or get around the problems and difficulties that arise due to your disability. Motivation is the same as will power.
5. Assistive technology. The third aspect of rehabilitation is finding the right technological solutions. There are many assistive devices and aids to be had, and some are available at no cost. It's a matter of asking the experts to show you what's available and how it works.
6. Training. What you have learned through training, no one can take away from you. It is also a nice feeling to be able to manage as much as you can on your own. In that way you become independent – as far as possible. You reduce your dependency on others for help.
7. Time. I have said it before and I will say it again: Don't be in a hurry – things take time, especially this process.
8. Determination. Don't let your low vision be an obstacle to seeing the world, if that is your goal. Don't let bad vision stop you from fishing in Norway. Don't let it keep you from acting in community theatre. Decide what you want to do and then ask HOW. You are not just someone that others should be nice to. You have something to give in return.
9. Fellowship. All of these goals and interests can be realized with bad vision, if you see to it that you have the friends you deserve with similar interests in a life filled with peace of mind and assurance.
10. Guidance. When you are ready to progress to move forward, you need the advice of experienced people in all of these areas. You take that next step with the help of good advice, the confidence of others and your own capability.

The question of whether someone wants to spend time with you is a question you

have to answer yourself, by not being ashamed of what you cannot influence. Rehabilitation that involves time, insight, motivation, assistive technology, training, determination, fellowship and guidance provides you with the tools, but you also need to be yourself again and have something to give others in your social interactions.

*

Self-pity

Self-pity is a self-indulgent dwelling on one's own sorrows or misfortunes. It is easy and human to think that what has happened to you is depressing and awful, but you need to get through the sorrow and see the things that you are still capable of, not just what you have lost. Feeling sorrow for yourself the rest of your life will only turn you into a victim.

The art of being or not being a victim is something you have to deal with. You can do it based on the different roles you play, for yourself and for others.

A victim can also be thought of as a loser. Life is not a matter of winning something or of always beating the competition, but it is a matter of surmounting difficulties and solving problems. As an adult, you should be able to do this. Even though you may at times require the help of someone who has more experience, knowledge and determination, you still have to do most of the work yourself.

Take this advice: Don't be a victim. Work hard to get away from this kind of thinking. Because when you come to think of it, who is responsible, who has done you wrong and made a mess of thing? Nobody. It's just your lot in life. Loss of vision is a fact of life. Someone has to bear the burden. It just turns out to be you and me and several others. You *will* be able to manage without feeling sorry for yourself.



*Don't feel sorry for yourself. Instead,
choose from life's good menu.*

As a victim, you end up with two problems instead of one. You see poorly and feel sorry for yourself. This is a natural combination in a transition period, but not in the long run.

You have one life. It contains a multitude of different ingredients. In your case, it also contains the enormous challenge of learning to live with low vision. It's a challenge that many have met and overcome before you. And you will meet and overcome it too.

Make use of your new insight and take your time. Get a hold of good assistive technology, work hard and be persistent in your training. Accept the guidance of professionals and relatives who like you just the way you are.

In the company of others, you will be able to reclaim your future and that's when you will have reestablished a good existence.

*

Taking time to readjust

Time heals all wounds. But not in the way that you always want it to. If you want the life you deserve, you have to utilize time. And when you can't be as vigorous as it's been talked about here and there in this book, let it go and let things develop a little by themselves.

Sometimes it is better to kick back and let life go by. Let it take the time it takes.

Bodil Jönsson, professor and author from Lund (Sweden) who also heads the Low Vision Enabling Laboratory there, agrees with and expands on the Danish philosopher and poet, Piet Hein idea: Things Take Time.

One thing that takes a lot of time is learning what life is all about. It takes, in fact, your entire life and what is the most fun of all is gaining new knowledge and experience. You acquire that over time and with time comes distance from what has happened. With that also comes the feeling that it was a long time ago and thanks to the time that has lapsed, I am now more relaxed than when I was caught up in the middle of it all.

It is as if time itself has healing powers and – by waiting and being patient – you permit time to be the power providing the natural healing that is so important, whether it has to do with physical or emotional illnesses.

So, allow the process to take time and don't hurry it along. You needn't do everything as quickly as before, and if it takes five times as long in comparison, let that be the case in the beginning. Relax. Let time pass. When the time is ripe you will rise up and use the power that time has given you and start the trip back, the actual recreation of the person you were before and the person you want to become now and later. Recreation of belief in the future, to put it quite simply.

Bodil Jönsson calls the time it takes to change from one activity to another "setup time."

Different ways of seeing

In low vision rehabilitation today, it is an accepted practice to divide visual impairments according to how people see (after their refractive error is corrected) and not according to the kind of eye disease they have. There are, of course, organizations for people with RP (retinitis pigmentosa) and glaucoma, but before beginning training, people with low vision are usually divided into five categories. Which one do you belong to?

1. **People with central visual field loss.** Many have this symptom for a number of different reasons and diseases. To be a true member of this category with central field loss or scotoma when gazing directly forward, you have to have a visual acuity under 20/200 (6/60, or 0.1), which means that you are unable to read the top row on the eye chart at the ophthalmologist. Your eye movements are normal and the retina outside of the scotoma also functions normally.

For this category, it is difficult to recognize people on the other side of the street or even a few feet away, unless you are able to observe some particular attribute. It is difficult to read normally, drive and to see details on the whole.

2. **People with nystagmus.** This category consists of most of the people who were born with low vision but who have some functional remaining vision. They have, for different reasons, not learned to fixate and control their eye movements. It is difficult for them to focus on an object and in most cases hard to see with both eyes simultaneously and achieve normal stereovision. People in this category most often have to read in a different manner than those with normal vision.

3. **People with peripheral visual field loss.** People in this category have difficulties seeing out of the sides of their eyes and see better straight ahead. In this symptom category you will find people with retinitis pigmentosa (RP), glaucoma and other eye diseases. Because they don't see 'the big picture', they have problems orienting themselves visually in daylight in unfamiliar places.

One consequence of this condition is night blindness, which means that you cannot see at dusk and in the dark. This is due to a lack of rods in the periphery of the retina. The rods send visual impulses to the brain when illumination is poor. People with reduced peripheral vision are those who primarily have night blindness or reduced vision in the dark.

Night vision can also be reduced for other reasons in other optical parts of the eye such as having cloudy lenses or as the result of laser treatment to the retina, which is a good method for preventing bleeding in the retina due to diabetes, for example. You can say that reduced night vision is a negative side effect of the otherwise positive effects of laser treatment.

4. **People with reduced acuity, normal peripheral vision and normal eye movements.** Most people with low vision have acuity that is greater than 20/200

(6/60 or 0,1) and since most of them can see straight ahead with magnification aids, the majority of all those with low vision are to be found in this category. When reading, the text has to be held close to the eye to achieve magnification on the retina. For distance viewing, different types of small telescopes and telescope systems are used.

- 5. People with visual field defects.** Like hemianopia or quadrantanopia, this vision loss is mostly caused by a stroke where half of the visual field to the right or to the left is gone on both eyes. Sometimes only a quadrant i.e. from 12 to 3 o'clock on a watch is gone as a result of brain damages caused by a stroke or a bleeding in the visual cortex.

It is quite worthwhile to find out which category you belong to in order to learn the methods and strategies you can use to see as well as possible, in other words, how to utilize your remaining sight to the max.

It is, of course, possible to divide people with low vision into these four categories, but it is also the case that life is not always so clear-cut. There are people who see in different ways, for instance, who have nystagmus and central visual field loss and so belong to two of the categories. Sometimes it is good to simplify reality so that you are able to understand just how complicated it really is.

Ask at your low vision clinic to find out more!

*

An optometrist's point of view

By Jörgen Gustafsson, doctor of optometry and researcher, Lund University, Sweden.

It is important that you are mentally ready when you start using your remaining sight with optical devices. It requires that you have worked through most of the initial grief that many people experience. For others, their visual abilities have declined over a long period of time and the adjustment has not been as drastic.

Throughout the many years I have worked with the adaptation and adjustment of optical devices for people with low vision, I have clearly seen that the person's attitude is crucial in determining what he or she is able to utilize in the form of advanced specialized optical solutions. Far too often, failure in using magnifying optical devices has been because the person is not ready to use the vision he or she has left in the best manner. Sometimes this is because they are ashamed to reveal how bad their vision really is.

There are many options. When you have lost much of your vision, the first thing you have to do (after receiving the diagnostic and treatment from the ophthalmologist) is make sure you have tried out the best possible refractive correction with glasses. Surprisingly enough, this aspect often is neglected because the focus is concentrated on the medical defect.

When the eyeglass trials are completed, you can start exploiting your remaining

vision through the utilization of magnification equipment.

Here are some examples:

- Hand or stand magnifiers
- Spectacle-mounted microscopic lenses
- Spectacle-mounted telescopes
- Closed-circuit television magnifier (CCTV)
- Handheld telescopes
- Tinted and filtered lenses

When regular glasses are not sufficient, the first devices a person usually tries are magnifiers. Many people can manage well with one of these, and for some it is useful for reading labels and instruction and shorter texts.

Unfortunately, reading this way can be tiring and a magnifier can be difficult to handle. Magnifiers on a stand are an alternative.

Spectacle-mounted microscopic lenses are often a better choice. The creation of a bigger image on the retina gives without a doubt the largest usable surface or visual field, enabling you to read as well as possible. The disadvantage is that the reading distance is much shorter, often under 8 inches (20 cm).

Those who can accept the short reading distance, as little as an inch for some (3 cm), can in many instances significantly improve their reading ability with training. An alternative for reading is spectacle-mounted telescopes, also called telemicroscopes that allow for greater reading distances. Unfortunately, all types of telescopes limit the visual field and because of that are often more difficult to use. If you are unable to achieve adequate reading ability with strong optic magnification, a CCTV is a very good device. The system consists of a TV camera with a zoom lens mounted on a stand and uses a monitor screen for viewing.

CCTV is sometimes the best device for reading and seeing pictures. Magnification devices mounted in the frames of the eyeglasses can be a complement when you do not have access to the CCTV.

Recently, I met a man who studied and worked in a senior position within a university for 20 years. His only optical device was his CCTV. With his poor vision, I was very impressed that with strongly magnified spectacle-mounted microscopic lenses at a half-inch (1.5 cm) reading distance he was able to read normal sized text after training. This meant that while traveling he could, for example, read his lectures and the seat number on his ticket. It significantly increased his independence.

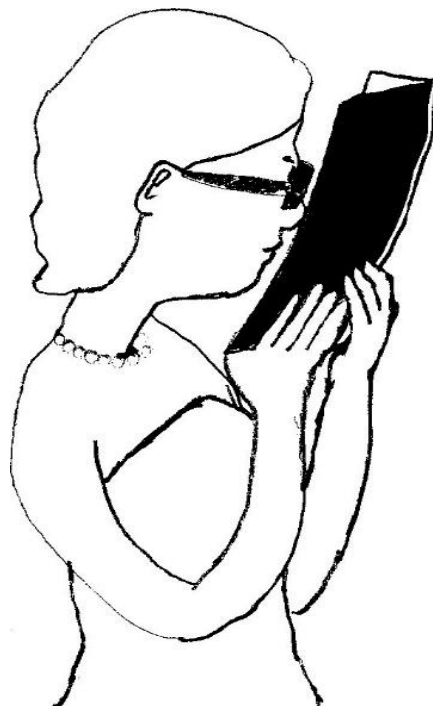
Telescopes are excellent devices for longer distances. Friends of mine with visual impairment have described the small telescope as peep hole to the world around them. If you are unable to see the TV screen from a distance of 3 to 6 feet (1 to 3 m), there are spectacle-mounted telescopes that can improve the picture. Sitting up close to the TV

does not damage vision and is the preferred means of achieving magnification to start with.

The greatest added advantage in using a telescope is that you can see signs, numbers and objects that are too far away to make out with the limited vision you have. Small, stylish and easy-to-use telescopes can move the image three to eight times closer and enable you to function much more independently.

To see better on the computer screen, the modern magnification programs are very useful in conjunction with a large screen. In this context, and if you use a computer a lot, it is important to remember that eyeglasses specially adapted for the distance from your eyes to the screen can facilitate your work considerably. In some cases, eyeglasses well adjusted for computer workplace let the user reduce the screen magnification, so that he or she gains a better overview and better ergonomics. Even if that is not the case, computer glasses offer the reader greater comfort, allowing them to work for longer periods. It is also possible to combine the need for magnification while reading with an optical correction for the computer screen in the same pair of glasses.

Many people with low vision are sensitive to light or have poor contrast vision. For those who are light sensitive, coloured lenses can reduce the problem. For many with a damaged retina, filtered glasses with yellow or orange tinted lenses are a better choice than regular sunglasses. Combinations of different, individually adapted colours and filters have proven to work well and can even result in better contrast vision. If you have reduced macular function, these specially filtered lenses enable you in many cases to better utilize your remaining vision. But it is important that they be tested and adjusted on an individual basis.



*When you are who you are, then you are good enough
even if you have to look this closely.*

Using your remaining vision does not cause further damage to your eyes. The opposite is often the case: through conscious usage of your poor sight, you can manage several functions even though you may find it tiring.

During the 20 years since I started working with people with visual impairment, I have often been surprised at how good some of them are at utilizing their very little remaining vision. To be able to do this as well as possible requires well-tested and adjusted optical devices. But in addition, it demands that you are willing to use your different way of seeing and your unusual visual devices in public. Using a telescope to see your friend's face from the distance of a few yards and still not being able to see as well as he does is nothing to be ashamed of.

*

It's not dangerous to use your eyes

"It is a common misunderstanding that there is a connection between holding things too close to your eyes and ruining your vision. In reality, it is necessary to hold a text close in order to be able to see when you are partially sighted."

That is how Bo Bengtsson, doctor of optometry, formulated it in 1975 in the preface to the book "Low Vision Training."

It is extremely rare that a person with remaining, usable vision is advised by an eye doctor to rest or be careful about using his eyes when it comes to seeing or training his vision. Swedish vision rehabilitation is based on close cooperation between the eye doctor, optometrist and low vision therapist. It is in collaboration with and through a referral from the eye doctor that rehabilitation begins. That also guarantees that there are no other acute conditions such as high blood pressure, bleeding or anything else that can prevent or impede the maximum use of the remaining vision.

It is not dangerous to move the six eye muscles and allow light into the eye. Strong sunlight is an exception, for everyone but especially for people who have a predisposition to age-related macular degeneration (ARMD). For this particular group, it is recommended to use filters that block the blue light, which is involved in ARMD. The eye should also be protected from welding flames and strong sunlight reflected off snow or the glittering surface of the sea because this can cause small sores on the cornea (snow blindness).

Reading with spectacle-mounted microscopic lenses for several hours under a regular light bulb or a fluorescent one is not at all dangerous. On the contrary, it stimulates vision and gets you to use your eyes and remaining vision so that you manage life better.

Each category of symptoms has a training program and each retina and each individual has to be offered a program adapted to his or her abilities, after having received a magnification device that projects a good image in the right location on the retina.

*

The other senses

It has been said the people with visual impairment hear better than others, but that is not the case. Instead, another way of explaining it is to say that hearing has to take its own responsibility since it can no longer rely on vision as a big brother. It gradually becomes easier for a person with low vision to recognize voices, sounds and tones without always checking with his sight. In this way, “well-trained hearing with its own responsibility” in an experienced person with visual impairment can appear to be more developed than the corresponding ability in someone who sees but doesn’t trust his ears without checking with his eyes first.

It is the same with touch, smell and taste and their own responsibilities with the person who has grown accustomed to looking at what he feels, smells or tastes. Besides, it can actually be easier to feel without seeing a piece of material, for example, if you want to identify what kind it is – even for a seeing person. Many close their eyes when they taste a sauce, evaluate the quality of a textile or listen to music. Have you ever thought about that?

It just may be easier for many people to concentrate on beautiful sounds without the interference of visual impressions. You can just close your eyes and enjoy.

*

Managing daily life

Dropping and searching

When someone drops something on the floor, you are no longer able to help find it. You are no longer able to find needles, slivers of glass or other things that are dropped. If there is a seeing person nearby, let them look and use their eyes so that you don’t have to feel stupid.

There is a “look-for-things-you-have-dropped technique” that works quite well when there are no sighted people close by. Search without using your eyes by bending your knees so that you are close to the floor (don’t lean forward because you can hit your head). Search with your hand by starting in the middle of an imaginary arc and then making bigger and bigger half- circles out from the centre.

This is a way of searching through one area at a time. Start in the place you think you heard the object fall, of course. It takes a while, but you’ll find it sooner or later.

*

Meetings and greetings

People who say hello. When someone says “hello” to you on the street, the person you are walking with usually tells you who it is. There are two reasons why you don’t make contact when

you are on your own: The person you meet does not know that your vision is so bad or you have not explained to them how you want to handle the situation. The best way, of course, would be to hear the person identify him or herself saying:

“Hi, Krister, it’s Kicki.” Then you can answer: “Hi, Kicki.” You can add: “It’s Krister (I usually do that when I’m in a good mood!).”

People who don’t say hello. “I saw you in town yesterday,” some of my acquaintances say, “but you didn’t see me.”

The reason is that many of them don’t know “my secret”. They don’t know that I see poorly because I haven’t told them.

Many times, you (and I) haven’t told them because there hasn’t been any really good reason to say: “Don’t be surprised if I don’t say ‘hello’ to you in town because I don’t see very well.” Look at the chapter entitled “Coming out” and show the world who you are.

Ask your friends to greet you by saying your name – and then theirs. It creates a feeling of familiarity.

*

The movies and theatre

At the movies and the theatre, it is a matter of sitting as forward as you can so that a bigger image is projected on to your retina than if you sit further back. The movies are good for many people with low vision who can obtain a visual acuity of 20/500 (6/160), or are able to count fingers at three to four feet.

For people whose acuity is worse, there are movies or plays where someone tells you what is happening through earphones. There are also visually interpreted videos, even though the selection is still limited. With the new CD technology there are technical possibilities to add a channel where scenes and environments can be described and subtitles read aloud for those who don’t speak Spanish or Russian, for example.

Of course, partially sighted people utilize different types of spectacle-mounted telescopes when they go to concerts or the theatre. It’s good to have an optical device that you can wear on your head so that you don’t have to bother with a telescope that has to be adjusted every time you use it as well as the static fatigue that comes from sitting and holding it for a long time.

But most of all, don’t stop going to the movies and the theatre. It is socially stimulating to be with others. I think the best help optical devices can offer you is a good experience, almost all the time.

*

Exercising and sports

When you are going to go skiing, it is important to have a good track to follow, which makes it similar to riding a streetcar. It's even easier if you ski with someone in front of you, someone who knows how you function – at least the first time – so that you can learn the track and when and where the curves and bumps come.

The third and fourth time you can ski on your own because you have memorized it. This is how professional downhill skiers do it. They travel at such high speeds that it is impossible to see everything they pass. They have to have the track programmed in their bodies using what is called muscle memory.

The most comfortable is to always have someone else – an escort or guide – with you when you go skiing. But the difference in going on your own is that feeling of independence: I can do it myself. That is why so many people with visual impairment become so conservative in the way they live. They prefer to do what they know they can manage, which is why they go cross-country ski in the same track every time, for example.

The only difference when the ground is bare is that running is a lot slower than skiing.

Bicycling and inline skating work well for most people who have some peripheral vision, but a limited visual field makes it more difficult. As an acquaintance with visual impairment once said to me, "It's so nice to be able to go out and ride a bike all on your own, since you can no longer drive a car. You have control over a new kind of vehicle."

It works out particularly well on familiar stretches but you have to know how to avoid obstacles on the ground. If you can't see straight ahead, you have to look sideways and if you can't see from the sides, you have to keep turning your head to see what's coming and adapt your speed to your visual capacity.

*

Meeting a partner

How do you do that? Is there anyone who can explain clearly and concisely how you go about accomplishing that? Hardly. But a few friendly words of advice and experience can help along the way.

Somewhere there in the fog you find a person who sounds nice. Your first task is to transform him or her from radio to TV. You have to put a face to the voice.

You need to cautiously approach the person and at the right moment, sit down beside her and continue the conversation as if nothing had happened. At the same time, when you are close enough to see, you need to register and store the picture of this person in your visual memory.

When you then speak with the person at a greater distance – and that goes not only

for future partners – you can't see her face, but you can sense what she looks like. This process can then continue for more than 30 years and be a natural and positive way of living together with your husband or wife.

Look straight at the person you are talking to. Even if you don't see his or her facial expressions, fix your gaze somewhere where you expect the nose would be and hold your eyes steady there. Your partner in conversation will then feel as though she has made eye contact with you.

If you look up in the air or down on the ground, you will appear odd in more ways than one: You not only see poorly, you act strange. *One* handicap is enough, isn't it?

This is all the advice you need as a person with a visual impairment – the rest is the language of love.

For the relationship to continue and grow, you have to be in agreement in many other areas. To achieve that, the terms have to be clear: you cannot lie. For if you do that, the person you love won't be the person you are the closest to, and love is based on being very close to someone, so close that you see and understand all kinds of things together. Love is the state where everything is possible. Sometimes people even say that "love is blind."

*

Disability pension or blind trade?

The social insurance office in my hometown suggested that I take a full disability pension. Now you have to remember this was in the good old days when Swedish social services could afford the gigantic loss of revenue it meant to allow a person to be supported by the state from the age of 19 until death.

At that time, many partially sighted people were given full disability pensions when they completed compulsory school, if they weren't offered the opportunity of getting into a "blind trade".

Many of the blind trades added to my panic: Not being able to support myself, not being able to live like a real person with normal habits (well, my own anyway), meeting real people. Being forced to live on the margins of society as a disability pensioner. No, it simply was not an alternative, but the idea made my head spin.

Today, blind trades are almost extinct. Even if there are a number of brush makers left in the country, it's not a full-time job for very many, compared to how it was well into the 1960's and 70's. Piano tuner, X-ray technician, medical secretary, switchboard operator and programmer are more modern professions accessible to people with visual impairment, but even these jobs have more or less been replaced by other technicians.

What jobs are people with visual impairment supposed to have? Well, ordinary jobs

that require all of the qualifications that you have but that do not necessarily require good vision. In any case, a disability pension is *not* to be seen as an alternative to a real career with workplace camaraderie, new skills and meaningfulness.

Do what you want to and can do, without taking too much consideration to how much you see.

*

Work

At work, you have to be a team. Even for seeing people who drive buses or trains, perform operations or teach; most of them have someone else they work with.

If you can find your place on the team, you have found your place in working life. How you go about doing that? It is not easy to answer, but one method is to try and find a special area based on your knowledge, education, experiences and qualities; something you are really good at, even though you don't see well.

If you have work assignments that require using your eyes to carry out inspections, work with a microscope or drive a car, you with your employer, your co-workers, the union and the employment office have to find another position where you are able to utilize your knowledge, experiences and strengths in a new function.

It *is* possible. Many others have demonstrated this before you, and you don't need to take the jobs that blind or partially sighted people have worked with traditionally. Brush making is not particularly suitable for people with visual impairment and it is quite monotonous. X-ray technicians, as already mentioned, are no longer needed and not everyone can be a piano tuner.

Assume that most problems can be solved with technology, ergonomics and new knowledge and information.

But first you have to decide that this is the way it is. The next question you ask is: What do I do now? Do I need technical aids in the workplace, an assistant on the job and everything else that's available? What information does my old or new co-workers need in order to understand?

A visual impairment can occur any time in your life, when you are driving or drawing blueprints for a new house or some other activity involving good vision. Then you have to re-train for something entirely different, or utilize your previous knowledge and training but in another position on the team and from another perspective.

What can an architect do if he or she can no longer see straight ahead and so misses all the details? How about working as a project manager for a group of architects, keeping track of the schedule, budget and coordinating with management. It's a matter of quickly making sure that charts, computer screens and other materials can be enlarged to the right degree and that the experienced architect learns to handle the assistive technology.

What can a truck driver do if his vision is no longer to keep his license?

An experienced driver can sit at a coordination centre and from there guide, direct and improve the organization economically and logistically.

These possibilities are important to point out instead of what was done in the past – start discussing the types of blind trades available or the size of your disability pension. All of a person's skills, knowledge, training and experience should be determining factors, not just the eye deficits.

PART III: MOVING ON

Relapse

Now you are no longer sad. Psychologists would say that you had made it through the grieving period that comes after the shock that arises when something unexpected and negative happens. You are on the road into the future again.

But sorrow doesn't disappear from one day to the next. Life isn't so easy and simple and orderly. That feeling of paralysis, powerlessness and grief can come back without you being able to or even wanting to defend yourself.

The advice to people who believe their sorrow, sadness and longing have passed is: let the awful pain return. Let it come with the assurance that it will never be as long in the relapse as it was during the initial shock. And no one cries or is depressed forever just because they have suffered a visual impairment.

If that turns out to be the case, it is due to other reasons that have to be dealt with on their own terms. These can be previously unsolved problems that are often amplified when a new wound is inflicted upon your soul and a new difficult period after a mental trauma. Sometimes it's called psychological accumulation, which is the piling up of one problem on top of another.

That is why it is so important to take a stance on and work through one problem at a time.

So go ahead and cry a little while longer; grieve a little more in the same way as you grieve for someone or something else that you have lost and that you miss more than your good eyesight.

Sometimes it feels good to cry over your weaknesses as a way of admitting them.

Look at it positively and feel that you are a whole person who can show both joy and pain and that it's a part of life. You will make progress but you will also make a fool of

yourself at times.

But the most important thing in life is happiness, isn't it? That's true, but how can you know what happiness is if you don't have the ability to feel the opposite: sorrow?

*

Your mental map; your view of the world

Inside your head, you have a mental map that acts as your orientation tool, your signpost in life. It supplies you with impulses and impressions when you do things. Your mental map is - freely translated - your self-understanding.

We do things based on these concepts, not based on what a situation really is like or how things are objectively. You and I are subjective people, controlled by concepts we have or have learned.

One of these concepts is our sense of self – who you think you are. Another is how others see you. A third is how you see the rest of the world, the society and your community.

A fourth is your understanding of inanimate things, the technological world and your relationship to objects and their value. How important, for example, is it to have a fancy car and what does that mean for your self-image?

A fifth dimension in your mental map consists of your concept of time. How important is time for you? Do you let it pass naturally or do you try to use every second?

As an adult, our mental maps are often relatively complete. But then one day something radical happens, such as losing your sight, partially or totally. A lot or a little. It really doesn't matter, even though there is a huge difference between being able to see the top



*Sometime you make a fool of yourself
and say hello to people you don't know!*

row of letters on the eye chart and hardly being able to differentiate between light and dark.

I would like to give you these tools to use as the basis for a discussion with yourself, or someone else who is also interested in philosophical questions. Compare your concept of time, your attitude to objects and who you think you are with the other person. It is very liberating to find this out from someone who can and wants to express it in an amiable and sincere way. Or with a professional psychotherapist as I did for a while.

*

Strengths and weaknesses

Strengths and prospects are on the positive side of the scale. Weaknesses, difficulties and problems are on the negative side. That's the way it is for everybody. How is it for you? What possibilities do you have; what threats can you see? What do you do to let the strengths outweigh the weaknesses, and the possibilities outweigh the threats?

Let your point of departure be that your eyes are bad, but as a person, you are still just as good as before. All the strengths and prospects that you had before you became visually impaired can't have disappeared into thin air.

Take the time to answer the following questions. Spend a few minutes on each question every day until you know where you stand in terms of strengths and weaknesses, threats and prospects.

- What strengths remain? What new strengths can your poor vision offer you?
- What weaknesses remain and what new ones have you acquired?
- What prospects do you have now?
- What threats are you expecting to have to face in the future?

If you are not sure about the answers to these questions yourself, ask those that are the closest to you, or talk to

a professional. Ask them to listen to your answers too. It is important to confirm whether they correspond to reality or not.

*

Someone to talk to

There are obvious difficulties/dangers with trying to deal with all these new feelings and needs entirely on your own. It is just as difficult as trying to manage a top executive position in a company or a government completely on your own. You need someone to discuss with, vent your feelings with, bounce ideas off of, compare your own opinions with. Someone who is not too close and not too far away.

Your partner in marriage is often already entirely too involved. Sometimes she or he is placed in the position of “deputy sufferer”, grieving almost more than the partner who has been disabled.

Another position a partner can take is to withdraw and wonder how things will turn out. For this reason, the relative involved can also need someone to talk to.

That warm and understanding person in your circle of friends is perhaps the guide or mentor you need. Or a person with visual impairment who lives an ordinary life – in spite of it all.

Another alternative is to talk to a professional psychotherapist who can help you sort out all your different thoughts and feelings so that you don’t become too disturbed by all the unpleasantness that has suddenly befallen you; so that you can ventilate your positive and above all your negative feelings, or hear other answers than the ones you have come up with.

It’s not dangerous. You don’t need to be nervous, nuts or strange in any other way in order to call a psychologist or psychotherapist and say,

“I need to come to you and talk through some thoughts and feelings I have and that I don’t really understand. I also get very depressed sometimes without really knowing why.”

These discussions – they don’t need to continue indefinitely – are very good; actually quite comforting, even if it can be difficult to work through the feelings you have towards yourself and others.

Some good advice is to talk with your eye doctor or your regular doctor/health care provider and ask for a referral to a therapist so that the cost will be covered by your insurance. You can go to a private therapist as well and pay for it yourself. The most important thing is that you take care of yourself and know that you have the right to use all the services available in order to “see bad and feel good.”

Now you might be saying, as many others have, that all this about seeing a psychologist can wait. Things aren’t that bad. I’ll finish crying soon and won’t always feel so uncertain.

It doesn’t really make a difference who you talk to, and there are psychotherapists who you may not like, just as there are bike retailers who are unsympathetic and who you don’t want to buy a bike from. Shop around and choose a person you have confidence in, with whom you can talk to with and sort out your feelings with.

Right up until the time you start asking yourself why you need to go there. “I’m not getting anything out of it anymore,” you think, and then it’s time to say to your psychotherapist, “Thanks. Now I can manage on my own.”

*

Everything I am able to do

Some days all you can think about is all the things you can't do. But if you instead ask yourself the question, "What am I capable of in spite of my visual loss? There is actually a lot. Here are some examples:

- You can listen to what you write on a computer with synthetic speech.
- You can listen to music and decide if it's good or bad.
- You can listen to theatre, particularly radio theatre or visually interpreted theatre and enjoy it tremendously or think it's a real flop.
- You can feel, perceive and experience.
- You can taste and smell (often you do them both at the same time).
- You can have an opinion.
- You can create and use your imagination.
- You can write (especially if you learn to touch type when using a word processor or Braille keyboard with only six keys).
- You can do math with a calculator (under the assumption that you learn where the keys are).
- You can figure things out.
- You can give advice.
- You can supervise other people in recreational activities or on the job.
- You can plan.
- You can see a little – if you haven't lost all your vision, of course.

Even if your loss of sight is quite handicapping in certain situations – there is no denying that – you have a good number of abilities left. You can, above all, practice – consciously and unconsciously – letting your other senses take over some of the control functions your visually ability has had over them in the past.

You can practice using your sight.

You can practice doing what you have been putting off doing for a long time.

You can exercise more so that your body feels better.

You can practice thinking positively.

Just imagine all the things you can do!

*

Make an inventory of your abilities

You can do something as concrete as sitting down and making a list with the following five headings:

1. This is what I can do.
2. This has become more difficult.
3. This is what I can't do at all.
4. This is how I solve it.
5. This is what I need help with.

The easiest way is to make different lists. One can be about your job or education. Another "can-do/can't-do-very-well" list can be about everyday activities and a third about your favourite hobbies.

Even if you don't make a list or get help in doing it, you can still try to use a little time now and then to practice your powers of positive thinking. You will then notice that there always are more items under the "can-do" heading than under the "can't-do-very-well" one. Especially when you have gotten over the shock, crisis and grief and are on your way forward again.

That's the way it is.

*

Stand your ground and take advantage of everything you can

There is, of course, a lot of advice I can offer you about activities of daily living like how to pour milk in a glass, how to sign your name using a frame and a thousand other small details in life. But this is not meant to be a practical, how-to-do handbook.

This is a handbook for those of you who want to be inspired to do what you had planned to do anyways. You certainly hadn't thought about jumping off a bridge or letting life continue without you just because you see poorly, had you? You may not have thought about giving up, but now you have received some personal advice showing you why you shouldn't. If you have been inspired in that direction, then I'm happy about it.

This small book will also help you to stand tall and make sure that you get the respect you deserve from those in your surroundings; that you go for all the opportunities you have a right to and are able to receive. Plus a few more that are described in the chapter on the secondary gains to be made from being a VIP. Go for all of it!

The pessimist's slogan is that it is never too late to give up. Throw that one out because you only have one life to live and it's offering you a challenge that you are going to meet. By standing your ground and acquiring lots of knowledge and insight, your life will be richer and you will meet many people you never imagined existed.

You will encounter professionals in rehabilitation, you will make friends who are visually impaired and you will be able to keep all the true friends you have in your life. You will become an inspiration for others.

If you incorporate what has happened, convey it to yourself and others, stand your ground and go for all that life has to offer, both the good and the bad – everything will be as it was again, yet in a different way.

*

Be yourself – live the way you want to live

There is a lot of advice in the book. Much of it is obvious, but it is still there because sometimes you want to hear that the obvious is important too. Besides, what is obvious for one person may not be so for another.

This book is really a contradiction in itself. I claim in a number of places that the way a person reacts is individual and variable, and yet the entire time I describe people with visual impairment as a group that reacts in quite a similar manner. That's not the way it is, of course, and to round it all off I would like to encourage the reader to see him or herself in this context. If you think what I have written is wrong, then it's wrong, because you know better than I do, at least when it comes to your situation.

The greatest expert in all treatment that requires dialogue is always the person for whom the treatment is intended. An optician may know more about optics than you do, but you are the only one who knows what you really want. Assert yourself when you receive advice, when you meet people in rehabilitation and when you are going to initiate and participate in this process. See to it that you are involved and that your needs are met the entire time. Make sure that nobody makes decisions without your consent. Make sure that you see as well as you possibly can and become an expert on your vision and situation.

Then, it's like driving a car; you don't have to think about the fact that you are living all the time. You just are. When I drove a car, I remember the feeling of driving mile after mile and suddenly arriving without having any idea how it happened. That's how it is with life too when you have learned the art of living. You just live, no matter how much or little you are able to see.

Good luck in a life that runs along on its own – in due time.

Conclusion

by Professor Bodil Jönsson, Certec, Institute of Technology, Lund University, Sweden

When I read the manuscript to this book, I had the intense feeling that this is something the Krister will never really be finished with. Because there is more and more and more to say all the time – Krister has more or less written a book about life, even if he has tried to concentrate on vision and vision loss.

Well, I will in any case try to help in bringing it to a conclusion. It is probably easier for me because I am not visually impaired. And exactly because of that, I am not able to add very much to this book – I am unable to write anything about what it *is* like to have very limited vision and I absolutely don't want to write anything about how it *may be*. Because I haven't been there (yet). What is so wonderful about this book is that it is absolutely free from sermonizing and lecturing.

The perspective of the person who is going through an experience is the most relevant one of all, while at the same time the least utilized. Articulate expert patients such as Krister are needed who can tell about their road to recovery (and in other cases, pain patients who have become masters over their pain, breast cancer patients after surgery who have reclaimed their full identities, etc.). More and better methods are also needed for eliciting responses from the *person directly affected*. She is the only one who really knows how her reduced vision affects her in particular. Others with exactly the same visual reduction can have entirely different experiences.

But there is one thing we all have in common, whether we are visually impaired or see normally: that we can arrive at a more accurate idea of what vision is if we also see the eye as an actively searching organ, not just a passively receiving one. The entire visual system, of which the eye is only a small part, is continuously on the lookout, seeing and interpreting – I was almost moved to tears when I read Krister's description of how it felt when he reestablished his acquaintance with those squiggles, we call letters. The fact that seeing is both a matter of searching and receiving can help in the analysis of the great differences that exist between different people with one and the same visual impairment.

I hope that many others will be inspired by Krister's story to tell their own – it is the only way that the patterns of variation will become visible and clear. The Low Vision Enabling Program and Lab at Certec in Lund will also contribute through better documentation of individual differences in the utilization of reduced visual abilities.

Krister writes that you have to let time pass. That's good, because it's as if *time thinks* as it moves along. Time thinks – but it doesn't act. We have to do that ourselves. And that is exactly what you have done, Krister, because you have written a BOOK. And now it's finished!

Postface 1

Although like Krister Inde I have low vision, I have never lost vision. I have never worried about losing more vision or worried that my friends of many years would think of me differently than they thought of me yesterday. My low vision is the result of a condition that was present at birth. So, I've never experienced the emotions or the concerns that Krister Inde writes about as he describes his own voyage from seeing well to seeing poorly – and from seeing poorly to feeling good. Although Krister and I have had to come to a realization that we could each See Bad and Feel Good, our journeys have been very different.

When people *See Bad* from the onset of a visual impairment, they not only have to adapt to a change in what the world looks like to them, they also go through a change in how they think of themselves. They worry about what will happen to them and they re-assess who they are and how they will cope with life's challenges. Krister has written a book that Americans might say is "in your face."

He presents his personal reactions to the reader as if the reader is someone with whom he is able to share an intimate friendship. Nothing is hidden. Everything can be spoken. He speaks what he feels a reader needs to hear.

If you are reading this book because you are losing vision or have an acquired visual impairment that is stable, I know this book will help you on your journey to feeling good once again. If you are a loved one of a person experiencing a visual loss, or a friend, or even an employer of someone who is experiencing this transition from seeing well to seeing poorly, I know this book will help you to understand what they are going through.

In my personal and professional life I have known people of different ages who have lost some or all of their vision. When an adult speaks of worries about becoming dependent because she must give up her driver's license or when a teenage girl tells me she worries that boys won't think of her for a date if she uses her optical device, I am able to listen and offer some words of comfort and some strategies to use. Now, having read *See Bad, Feel Good*, I better understand what they may be feeling, especially with a visual impairment that comes after having had good vision. Having read *See Bad, Feel Good*, I also feel more confident that while they may not believe it in the moment, there will come a time when they will Feel Good.

Even those of us with congenital low vision need to read and be reminded that the point of *Seeing Bad and Feeling Good* comes to different people in different kinds of journeys. Thank you Krister.

*Dr. Anne L. Corn, Professor of Special Education, Ophthalmology and Visual Sciences
Vanderbilt University, USA*

Postface 2

Being visually impaired feels at times, and literally is, like groping in the dark. This can be a very isolating experience. Who am I? And where am I going? These aren't easy questions to answer, even for those who see well. What mirror can reflect the way I feel in the state I'm in, and where I stand all alone?

Becoming a person is a big project and those who are partially sighted can experience their situation as a never-ending affront or, oddly enough, poor vision can also be comforting: I am sick – therefore I am!

But why should I be satisfied with less? And just because I'm blind, I don't want to experience any of these pitfalls myself.

My eyes don't function anymore and since there is nothing that can be done about it, it's just as well to accept it for what it is. Or as Krister once said to me on the phone when I was on the verge of drowning myself but wanted to make one last call:

"You ARE not your eyes," he told me in a friendly, factual manner and the knot in my stomach loosened. It was during the time when I didn't want to admit to myself that I was visually impaired. But if you have a problem and deny it, you REALLY do have a problem. To be left sitting on the fence is no fun, but when you get around to accepting your situation, you can accomplish almost anything – just like anybody else.

Luckily, Krister Inde has a screw loose, which means that he can "see" a causal connection from several different angles simultaneously. Spending time with him in our unofficial and unorthodox society of the blind and partially sighted has strengthened my opinion that a human being is first and foremost just a human being. If you are also partially sighted, you can do something about whatever it is that can be changed. Then it's basically just as it is for everybody else. You can live your life as richly as possible. I am thoroughly convinced that this book can cut through the fog, even for the person who can no longer discern with his own eyes the landmarks along life's winding road.

Täppas Fogelberg, Swedish radio personality

Acknowledgements

Thanks to the following people, you are now able to read or listen to this book in English.

When I worked at Lund University, at Certec, I had a very nice neighbour. Next door to me and Dr Jörgen Gustafsson, Mrs. Eileen Deaner had her office – an American woman who has been destined to live her life in the cold country of Sweden. She is well-known for two reasons – one of which is her wonderful laughter. I asked her if she wanted to translate my book *Se dåligt Må bra* (See Bad Feel Good) into English. She did a great job and now, ten years after the book was published online, I would like to thank her once again.

It was released in Swedish in 2003 and as of today it has been translated into seven languages: Icelandic, Lithuanian, Hungarian, German, Italian, Arabic and English. All of the foreign versions are based on the English translation – so without all these people – none of this would have been possible. Aries Ardití read the manuscript and provided me and Eileen Deaner with a lot of helpful advice on how to improve the English version, making the text as lucid as possible.

In this edition, the guest writers also share some of their previous themes. Dr Jörgen Gustafsson, my dearest friend, shares his writings on optics, and professor emerita, Bodil Jönsson, contributes with a wonderful final chapter. Another guest writer is an old friend of mine, and one of the few people with visual impairment I know, Mr Tåppas Fogelberg. He is the smartest person I know when it comes to dialogue and making witty comments, which is also the reason why many Swedes listen to him on the Swedish Radio where he hosts the morning program *Call P1*. Some people love to hate him and I always ask them: Why do you listen then?

Finally, my gratitude goes to Dr Anne Corn. She is my low vision sister and she retired some years ago, which – for my own egoistic reasons - I am not that fond of. But I understand you, Anne. Sometimes low vision gets to be too much and universities do not always support the good ones, the thinkers. Anne belongs to them – and to my close circle of friends. Thank you for your kind words dedicated to me and the readers in the English preface.

So, if you feel I have not thanked you enough during the past five years, you are probably right. But now, finally, I am declaring my gratitude and I have managed to complete this book thanks to the comments made by my Cameroon friends Joseph and Jonson, my students in Amman, Jordan, in November 2010. They made me do a table of contents, and Aries Ardití told me what he thought of people with bad manners in Valladolid, Spain, in October.

People with visual impairments can be found everywhere and having low vision means that you are always going to be faced with challenges. One of my sayings is that even heterosexual people with visual impairment have to “come out” now and then in order to cope with these challenges in a better way.