INTRODUCTION

We have been asked to write a chapter on coping with retinal degeneration (RD) from the point of view of the patient. James Cape, my co-author, has macular degeneration (MD) and I have retinitis pigmentosa ([RP]; dominant inheritance RP13). Because our two different retinal conditions create different experiences and viewpoints, we decided to use a common structure, but to write it from our own perspective. Our viewpoints are different because a picture always looks different if you can only see the middle bits (RP) or only the part around the outside (MD). However, as James and I often jokingly say, together we believe we have 20/20 vision. In this chapter, we will attempt to provide an all-round 20/20 view of the problems of coping with RD. I list here the broad subjects that we have tried to cover. I think you will find that we have not necessarily covered them in sequence, and that both of us sees these subjects from a different view. However, we hope that you will see a common thread running through the chapter.

CHAPTER STRUCTURE

After discussing the most important symptoms of our conditions and how we were first diagnosed, we attempt to deal with the difficult problem of the impact of continuous, slow vision loss. Thereafter, we reveal a number of situations we experienced as young people: with doctors, parents, children, siblings, and our partners. We also divulge our experiences at school, university, and in our careers. We discuss our challenges while participating in sports, social occasions, and travel. Finally, we highlight
how the situation today is different, especially because of the efforts of Retina International and all of our member countries in raising awareness of our condition. Furthermore, given the tremendous advances in technology to aid partially sighted people, and legislative and environmental improvements, we conclude with a view toward the future. We hope you enjoy our contribution.

COPING WITH RETINAL DEGENERATION: JAMES CAPE

Born in 1951, as the youngest of three children, I enjoyed a normal and happy childhood. In 1958, my sister, the eldest of us siblings who was 12 at the time, was diagnosed with MD. As little was known at the time, my brother—13 months older than me—and I were duly examined but were found to have normal vision.

During the ensuing years, I adapted to life with a visually impaired family member, but found it strange that there did not appear to be any magical cure. Throughout my teens and early adult years, I participated in all levels of ball sports, representing my region at the highest level.

At the age of 27 and at the pinnacle of my sporting career and duly making progress in my career as a bank official, I was called up for a military camp as part of the country’s national defence force. Subject to a full medical examination, the military optometrist could not fully understand why I was having problems reading the normal optometrist chart. Consequently, I was simply overlooked on the basis that I was endeavouring to be exempt. Knowing my sister’s condition, I immediately identified my shortcoming and the feeling of dismay remained with me for the duration of my 3-mo call up.

Immediately on my dismissal, I visited my ophthalmologist for a full assessment. After a full diagnosis, he referred me to a colleague for a second opinion. Both concluded that I had MD and were somewhat bewildered by the fact that I had been examined on an annual basis and that the condition had only reared its head at this later stage of my life. At the time, it had only been diagnosed in patients under the age of 25 and after the age of 55 this is known as age-related MD (AMD).

As a young adult enjoying the fruits of life with ambitions and aspirations, the news came as a devastating blow. My immediate reaction was one of anger and bewilderment. I had many questions that needed to be answered by the medical fraternity, my parents, and my faith. This forced me into a state of denial and I almost became an introvert, not sharing or prepared to divulge my inner feelings and hurt. Part of the thought process I experienced was perhaps that there was no light at the end of this tunnel and, therefore, giving up the aspects of living seemed to be the only alternative.

Because my parents had experienced my sister’s condition, they found themselves in an awkward position, as they still did not have what seemed to be the right answers or solutions. Dealing with the emotions and the reality of the situation is not easy to describe as my loss of sight was gradual at the time. But what it did do was start to place an emphasis on the day-to-day aspects with which I was having difficulty. I noticed that I was perhaps not as competitive as I started to focus on the negative aspects of my sporting activities rather than the positive.

At the workplace (I wore spectacles being far sighted in one eye and near sighted in the other for clerical work), I had experienced problems with certain printed material and had merely put it down to an adjustment required to the lenses of my spectacles.