Foreword by Professor Edward Byrne AC

SILVER LININGS

TRUE STORIES OF RESILIENCE FROM A GENERAL PRACTICE

DR MRIN NAYAGAM

For my family, past and present, with love and thanks:
Nicholas and Joyce Perera
Prakash, David, Romy and Bryony
Nina and Nicholas

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Foreword

I am very pleased to have the opportunity to write an introduction for Dr Mrin Nayagam's exciting book, *Silver Linings: True Stories of Resilience from a General Practice*. My own training in medicine was as a neurologist but I have long been interested in family medicine. My father was a family doctor and I well remember the dedication that he showed to the care of his patients and the friendships that were formed with families that he looked after for more than one generation.

Mrin Nayagam is an outstanding family doctor who has a great ability to listen to people's stories and understand them. Hippocrates famously said that it was at least as important to understand the whole person as to understand their condition and that applies as much today as it did in ancient Greece. In this book, Dr Nayagam takes us on a series of deeply personal journeys covering periods of stress, pain and fear for patients and their families and showing how ordinary people cope when their health or the health of a close family member is impaired.

Many things in medicine are complex and sometimes difficult to diagnose. Treatment may go on for a long period. It is so crucial on journeys of this type that patients and families have a supportive family physician who understands not only the patient but the family dynamics and is able to provide broad advice and support. Such a doctor is a trusted advisor, a reliable confidante and a pilot who can navigate both the patient and their family through a very complex health system. At the end of the day these stories are inspirational. They describe the triumph of the human spirit and I commend Dr Nayagam for writing this book. We all have much to learn from it.

Professor Edward Byrne AC
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Former Vice Chancellor, Monash University, Australia

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Preface

I have a habit of list-keeping and all patients about whom I've made an interesting diagnosis are listed in a book of *Interesting Patients*. After almost twenty-five years of general practice this list is long and comprehensive.

In the spring of 2006, I started a small appeal aimed at giving the disadvantaged in our neighbouring area a quality meal on Christmas day. I called it the BOXOMETER Appeal, the aim being to fill a minimum of twenty-five cardboard wine boxes with non-perishable foods to share with those in need. At that time, I had a secret wish that this new word would find its way to the Australian dictionaries to mean the number of boxes in a collection. Alas! This was not to be.

Community Support Frankston collected these boxes from my clinic and in turn packed them into food hampers for distribution to disadvantaged people that they assisted.

As the number of boxes donated over the years grew, so too my list of interesting patients continued to expand.

In 2009, the containers were changed to 50-litre plastic tubs and my BOXOMETER Appeal, having failed to make the dictionaries, was renamed the 15 Tubs Full Appeal. With this modest target reached easily in the first year, the bar was set higher for every year following. In December 2016, a total of 102 tubs, the equivalent of 5100 litres of food, were collected. My thanks go to everyone over the years who donated, even a single packet of pretzels. I also thank patients, friends, well-wishers, and my family for their generous support by the donation of one or more 50-litre tubs each year.

The clinic staff has been outstanding over the years and my colleagues have also lent their support over time. I thank them all for their help.

When I showed my book of interesting cases to a student who was sitting with me, she suggested that I could write an actual book! That comment gave birth to the dream of becoming a published writer.

I was not willing to write a book about my patients for personal financial gain, but felt it would be ideal for the purpose of raising funds for charity.

At the same time, I also wanted to ensure the continued success of the 15 Tubs Full Appeal. I knew it needed a dedicated driver, it is time consuming

to check for expiry dates on food items and pack the plastic tubs; to talk to and cajole people into donating food items; and to explain to young people the reason for the collection. I needed to encourage teens to donate of their own accord, in return for a lovely certificate of community service; and to write to colleagues and community leaders for donations. All this takes time, a rare commodity for a busy general practitioner (GP). Realising it would not be fair on my colleagues to expect them to carry this baton into the future, I sought to raise funds for the ongoing support of Community Support Frankston by writing this book.

The task of patient selection began. I wrote to fifty patients with the most inspirational and interesting medical histories from my list, and, to my joy, forty-nine agreed to an interview. The only one who did not was because they relocated away from our area. The interviews, carried out at the Village Clinic after normal work hours, took up to two hours and were recorded on my trusty mobile phone. I reached my target of 80,000-plus words after writing twenty-two stories.

I first tested the waters with an abbreviated story in the *Medical Observer* in September 2015. This was well received.

Thus *Silver Linings* was born. The title reflects the beacon of light that people whose lives are devastated by a medical diagnosis or are in an emotional wilderness reach out to. These stories are all true to life and are an inspiration to readers of all ages. I kept the language simple and all technical terms are explained clearly so that the general reader can comprehend and be empowered by the inspirational stories in the following pages.

I hope that my medical colleagues, some of whom have shared the care of these patients; as well as students and registrars in training, will also find these stories an interesting read.

The Silver Linings Charitable Trust, a registered entity that has a zero per cent administration fee, will receive proceeds from book sales.

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For more information about the Silver Linings Charitable Trust, please visit www.silverliningscharitabletrust.com.au.

For more information about the 15 Tubs Full Appeal, please visit www.frankston.net/appeal15tubs.html

A Farewell

Charles Kingsley (1819–1875)

My fairest child, I have no song to give you;
No lark could pipe to skies so dull and gray;
Yet, ere we part, one lesson I can leave you
For every day.

Be good, sweet maid, and let who will be clever;
Do noble things, not dream them, all day long:
And so make life, death, and that vast forever
One grand, sweet song.

Living with progressive blindness: 'I am keen to see the world'

'I cannot change what is to be. If I lost my sight I would still have memories of all that I saw when I was sighted, so I am keen to see the whole world and treasure the memories.'—Clara's optimistic outlook on living with deteriorating vision.

Clara is a keen photographer who hungrily takes photos day-in and day-out, in fine weather or foul, trying to imprint all she sees into her memory. She scans the photos to a wide computer screen where she can see them more clearly. 'These images are stored in my brain's vision centre to sustain me against a day when I am blind', Clara told me. Middle aged, clear skinned, with a long cascade of curly auburn hair, she wears spectacles to suit her complexion. When amused, a beautiful smile lights up her face, and her brown eyes shine behind her thick lenses.

In 1966, when Clara was just eight years old, she learned she had retinitis pigmentosa, an inherited condition that could lead to severe visual impairment—and even total blindness.

This condition, commonly referred to as RP, is an inherited condition that affects the retina, which is a layer of cells at the back of the eye. These cells, called rods and cones due to their shapes, convert rays of light into nerve impulses, which on transmission to the brain, perceives them as images.

In RP, this ability to recognise images fails gradually, as the rods and cones die without explanation. As there are more rods than cones especially at the outer parts of the retina, the first symptoms are loss of night vision and loss of peripheral vision. Later, as the more centrally located cones are affected, there is loss of the colour perception and, finally, reading ability. Eventually, blindness ensues. Sadly, there is no treatment available for RP, and about one in 4000 people are affected worldwide.

The condition ran in the family. Clara's grandmother, mother, three cousins, an uncle and an aunt all suffered from it. Growing up in a small country town in Victoria, when Clara complained of poor vision, the local optician said she had RP just like the rest of her family after conducting nothing but the standard vision tests and prescribed glasses for short-sightedness.

At the time, the diagnosis did not mean anything much to Clara. She went about her day-to-day business as an eight-year-old girl in a small country town. Though she had to wear glasses (her first pair was bright orange) Clara took the matter in her stride. If her grandmother—who was blind and used a white stick—gave any indication of Clara's future, it looked good. 'She was a real character, she managed very well around the house and garden', Clara said. 'I loved her very much, so it did not worry me in the least that I would end up like her.'

It was much later that she discovered the severity of the diagnosis. The commonest form of RP passes from a parent—irrespective of their sex—to their children. For each pregnancy there is a fifty-fifity chance the baby is affected, a type of genetic inheritance the doctors refer to as autosomal dominant. Clara discovered that her uncle elected not to have children so that he would not pass on the condition to any of his offspring—a choice she would eventually face as well.

Although Clara was the only one of her siblings affected, she never considered it an unfair twist of fate.

When she was about fifteen, Clara's mother took her to the local hospital to confirm the diagnosis. After some cursory tests, the

doctors informed Clara that she did indeed have RP. Nonetheless, the bespectacled teenager had no explanations, advice or follow-up appointments. Even though her mother was disappointed, Clara accepted this news with the tenacity of youth.

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At nineteen, Clara started dating Rob, whom she described as tall, handsome and kind. Clara decided she needed to know more details about her condition, as it could impact their relationship. As she wished to have children, Clara wanted to know the potential risks. Therefore, of her own volition, she decided to cross the final frontier to have a second opinion and definitive tests to confirm or refute the diagnosis.

Clara underwent a battery of tests at the hospital. Presently, this test, called an electroretinogram (ERG), is far more refined than what Clara experienced decades ago, and patients receive pre-investigation counselling so they know what to expect.

'I was informed in a letter that I had RP, and the diagnosis was irrefutable. They informed me that there was no cure.' The confirmation of the diagnosis deeply upset Clara. Having read up on the subject, she was disheartened. Grateful for Rob's company, Clara shared her fears with him, saying, 'Something is wrong with me. I am defective.' Her brown eyes filled with tears and overflowed.

'Rob held me close and just hugged me', Clara said. She recalled him drying her tear-streaked face with a spotless white handkerchief, while responding, 'No, to me you are amazing and very special.' From that day to this, Rob has never showed any emotions about her disability. The permanency of the diagnosis and its implications never once affected him. If it did, he never gave her an inkling of what was in his mind. She added, 'He just took it in his stride and a future apart was not even considered.' Rob told Clara they would deal with her condition together.

Their relationship grew stronger. Rob reassured her that the diagnosis was not an impediment and the two were married when she was thirty years of age.

Today, Clara describes Rob as her rock. He has never once wavered in his support over the years. They celebrated their twenty-fifth wedding anniversary in 2013.

Clara did not want to risk a pregnancy as she had seen so many of her family members struck down by RP and visual impairment. They were blind or the younger ones were only partially sighted. She therefore decided to follow her uncle's example and not have any natural children of her own. Clara was nervous about falling pregnant lest she unwittingly passed the condition to her own child.

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In her early thirties, Clara continued to live a full and active life, playing squash—she jokes about missing a few—and pursuing her professional career in information technology. She did well and formed her own company, teaching computer skills to the elderly in their own homes, winning awards for her endeavours.

Unfortunately, Clara felt her vision was failing, particularly after dark. Driving at night became frightening. Coming home from the city in the evenings, feelings of terror overpowered her. Once she almost bumped the car in front of her and another time she barely missed hitting an oncoming vehicle.

'Because my confidence was low, I was always unsure about my night vision. I did not want to put someone else at risk. I had a few near misses and therefore I decided to stop night driving. Rob, ever supportive, said, "Just let me know, and I will come and get you".' He was her rock as well as her night-time chauffer.

Despondent and tearful, Clara confided to Rob that she felt 'helpless and hopeless'. He always reassured her, and shortly after each such tearful episode, she found a card or a bunch of beautiful

flowers from him informing her that she, the love of his life, was amazing.

'I was never depressed', said Clara. 'This was due to a variety of reasons, partly because I had a great relationship with Rob. I never had financial worries; both of us had really challenging and rewarding jobs. We were also building our home, so there was no time for depression to creep in.' Together, Clara and Rob even designed and assembled the parquet flooring, which required more than 30,000 pieces of the boards that they cut and put together.

Rob and Clara had an idyllic marriage, yet they felt a persistent void. They both yearned to have children of their own.

Despite her earlier misgivings, when she reached thirty-five years of age, Clara and Rob discussed an assisted pregnancy using a donor's eggs. Fortuitously, Clara met a colleague who agreed to be an egg donor so she could have an in vitro fertilisation (IVF) baby.

Sadly, the first attempt failed. Despite the exorbitant costs, they attempted the IVF process twice more, both without success. Having a deep sense of spirituality, Clara felt this was a sign that she should not worry about donor eggs and try to have a baby of her own.

When Clara was thirty-eight, she and Rob tried for a pregnancy and were overjoyed when she became pregnant. Unfortunately and painfully, she miscarried at sixteen weeks. This was a traumatic and heartbreaking time for them both. Shortly afterwards Clara fell pregnant naturally a second time only to lose the pregnancy to a miscarriage again.

Clara, desperate and nearly forty, and Rob decided to try IVF again, this time using their own eggs and sperm. A beautiful baby boy rewarded their perseverance. I can still recall her thrill at being a mother, and the infinite joys of parenthood as Clara shared this news with me.

Never a clucky, motherly person and never envious, Clara carried her friends' babies, enjoyed them for a few minutes and handed them back without a qualm. However, she described the light in her life and her heart's jump for joy the moment she held her firstborn son

in her arms, 'It is an indescribable feeling to know that this life was created by my husband and me. It has to be experienced to know what motherhood is all about. All I wanted to do was to protect and shield him against all harm forever.'

Her heart exploded with boundless love.

The new parents decided to have another try at IVF as before. Almost like restitution for previous disappointments, Clara conceived easily. Their second son was born four years later.

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As the children grew, Clara noticed that it was increasingly difficult for her to see clearly when driving during the day. At times, she felt that she narrowly missed having an accident.

'I was fine till my fortieth birthday when I still had single vision glasses. But, I realised my vision was patchy and found difficulty in seeing cars rushing towards me, especially on a grey cloudy day', Clara explained to me. There appeared to be small gaps in the picture her eyes framed for her. She saw a specialist who recommended regular annual reviews.

Each of Clara's eyes failed when tested alone. However, when tested together, she saw enough to pass. Vic Roads, the state authority, ruled she restrict her driving to the local area and mandated regular assessments of Clara's fitness to drive. Sadly, Clara decided she would have to give up her thriving business, as she was unable to get to the homes of her clients who lived beyond her locality.

Soon afterwards, Rob and Clara noted that their older son, Andy, was walking tentatively when out at night. When Clara questioned him about this, he simply said, 'It's because I can't see.' Fear clutched at her heart as her worst nightmares became a reality.

The family had him tested, but at the age of eight, it was too early to make a firm diagnosis of RP. They decided to have him assessed annually. Around the age of fifteen, Andy learned that his vision was

impaired and deteriorating much faster than his mother's sight when she was his age.

Andy had always wanted to be an airline pilot. Clara was surprised at her son's inner strength as he accepted the heartbreaking verdict. She hugged him and said, 'There is a purpose for you to be present in this world. You may not know why right now, but you will do special things as you are intelligent and talented.'

A typical teenager, Andy replied nonchalantly, 'It's all good, Mum', and hugged her back.

To Clara's knowledge, her son never showed emotion about this diagnosis even though it troubled him. Always a quiet teenager, Andy was close to Clara. Torn with grief and guilt she gathered him close and said to him, 'When I decided to have you, I was aware of the possibility that you could get RP, but hoped you would be spared. I wish, as you do, that you did not have RP. However, I want you to know that I will always look after you and support you. I love you and I cannot ever imagine a world without you, so I will never regret having you. I will support you every step of your way. Your father and I will be your rock just as your father has always been mine.'

Once again, all he said in response was, 'It's all good, Mum.'

Around this same time, Clara's vision deteriorated further. She described her eyesight as similar to seeing a picture with holes cut out. If she were to scan the image again by moving her head, the missing bits would appear. There would be a fractional delay in the perception and recognition of the image. She said this was critical in her decision to give up driving.

Clara took a taxi to see the local ophthalmologist for her final driving assessment. She made up her mind that whatever the outcome she would not drive again. After a brief assessment, the specialist agreed. Clara said, 'I felt so vulnerable. My pupils dilated, I could not clearly see my way out of that room. I groped my way towards the reception desk. As the digits on my mobile were unclear I could not phone for a taxi and the receptionist helped me.'

Once she got home, Clara wept. Afterwards, during a two-hour walk to clear her mind, a sense of peace engulfed her. She counted her blessings: 'I am healthy, I have a loving husband and the two best sons in the world who love me as dearly as I do them, and we have our own house in the best part of Australia. This is just a little blip, which I need to overcome.' She decided a bicycle would be a far safer option for transport.

Once again, she lost her independence, this time permanently. Once again, Rob rescued her. He promised to take her to the shops every Saturday for the groceries and assist with transport. Even today, they spend quality time together each Saturday after the shopping, when Clara has the choice of deciding how they will spend their afternoon.

He was now her rock as well as her full-time chauffer.

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When I asked about the future, Clara said she is preparing for the day when she may need to rely on her other senses rather than her sight. 'I know my way about my house and know exactly where the steps are and the length of each passage.' She is prepared to have a white cane and even a guide dog—Clara loves dogs—but she hopes she will not need to.

Being an optimist, Clara said to me, 'I hope my vision stays at its present level and does not deteriorate further. My mother's RP is like that. Even though she is much older, she and I are on par as far as eyesight is concerned.' She is also hopeful that the Bionic Vision Australia bionic eye project may help her and particularly her son at a future date.

Reflecting on her life to date, Clara says the greatest joys of her life were meeting her husband and having their children. She feels that the birth of a child is the supreme achievement for a woman, saying there is no parallel to motherhood. She treasures every moment she

spends with her sons, imprinting their faces in her memory. Clara believes the risk of possible blindness should never be a reason for not having children and she has never regretted having hers. Although Andy has RP, as he is compassionate and intelligent, Clara feels he will be a high achiever.

Clara travels the world whenever possible with her husband and sons, particularly Andy, enabling him to gather as many images as possible. Despite not being able to qualify as an airline pilot, Andy loves travelling by air and always sits by the window to view as much as he can of the scenery flashing by. Clara says he loves being amongst the clouds imagining he is at the controls of the aircraft.

Clara remains cautiously optimistic that her younger son does not have RP. Taking him for regular vision tests, Clara tells me that so far the results have been normal.

She is cautiously optimistic that during Andy's lifetime, if not hers, the severe sufferers of RP may have access to bionic vision. She encourages him to develop an interest in photography so that he too can see the world better and have a lasting memory of our planet.

Cancer in infancy: 'Live one day at a time'

'Live one day at a time. One good blood test result or one good urine result at a time will give you strength. One good scan report will keep you going. Try not to think of the bigger picture. Do not doubt yourself. Trust your instinct.'—Brooke's advice to parents whose children face a life-threatening illness.

'The twenty-second of August 2008 is a day that is etched in my memory,' said Brooke, a nurse who works in the Mornington Peninsula. Ever the caring mother, soft-spoken with a gentle personality, her short straight blonde hair framing her face, she presented to the clinic whenever her children were unwell. Always friendly, eager to share news of her children's progress whenever we met, Brooke's understanding of medical issues made our consultations a pleasure.

Brooke brought Kate, her seven-and-a-half-month-old daughter, to the clinic because of a chest infection. Blue-eyed, beautiful baby Kate was not her happy self. During this routine visit, I detected a rapid heart rate and a heart murmur. I explained to Brooke that infants often have a rapid heart rate, especially if they have been crying or had a fever, which can also cause a heart murmur. However, the murmur and the heart rate seemed disproportionate to Kate's condition. Reassuring Brooke that her daughter's infection would settle, I still strongly advised her to see a paediatrician for a second opinion.

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