

A Journey into the Human Experience of Incurable Disease

A Journey into the Human Experience of Incurable Disease:

From Hope to Healing

By

Malcolm de Roubaix

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I dedicate this book to Marie, Jeanne and Emile who have supported me with love and respect; my teachers and colleagues who helped shape my thoughts and from whom I have learnt so much, and especially to every person who continues life's journey with serious illness as a daily companion. May you continue to hope, may you experience healing and achieve harmony.

A writer should have the precision of a poet and the imagination of a scientist.

—Vladimir Nabokov

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ABSTRACT

Disease is a natural phenomenon, potentially serious, but inherent to the human condition. Against this backdrop, this book critically investigates the history and nature of disease, and how we as humans each uniquely experience and respond to illness. The focus is on the South African situation, though the issues discussed are universal. Illness and treatment as a personal experience affect our bodies and minds, our humanity, and the very core of our existence and identity. So, too, the multitude of tests and investigations patients are subjected to – each adding to the apprehension and uncertainty characteristic of the journey with incurable illness. The aim of medicine is to influence human lives positively – in the words of Hippocrates, sometimes to cure, often to treat, always to comfort – but the positive may not be unqualified: we are often excessively scientific and ignore the suffering patient.

The prologue is an analysis of the nature, meaning and significance of hope in the context of disease. Amongst others, the book analyses the language of illness and medicine, the role of emotions, ideology, and politics in disease, the protection of patients against the hazards of treatment and medical research and reaches a climax – the epilogue: a discussion of healing, quite distinct from physical cure. Without hope the future is bleak; without healing there can be no holistic recovery. The final chapters are devoted to end-of-life decisions – the journey with incurable disease continues.

COVID-19 is a frightening new experience for all of us and emphasises human vulnerability. This book is a timely publication which addresses the unique demands of our time in a novel, systematic framework. The text and style are accessible with ample literature references and citations. The reader is challenged to think anew about the experience of illness.

The original Afrikaans version was published in August 2020 under the title: *Hoop, Heling & Harmonie: Dink nuut oor siekte en genesing* by Penguin Random House SA; winner of the 2021 Andrew Murray Book Prize. It has also received favourable reviews in the media. *From Hope to Healing* has been extensively reconceptualised and revised, with the addition of new chapters on human enhancement and pandemic disease.

INTRODUCTION

Serious, incurable disease precipitates a profound existential crisis affecting every aspect of life. Contemporary medical practice rightfully takes pride in well-nigh unimaginable achievements in managing the biological aspects and consequences of disease. However, appreciation of the psychosocial associations and implications of illness lags in the minds, words and day-to-day practices of health care practitioners tasked with treatment and management of these conditions. In the words of George Engel:

Medicine's crisis stems from the logical inference that since 'disease' is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues which lie outside medicine's responsibility and authority ...¹

This book addresses Engel's 'crisis' by systematically investigating the human experience of illness. This goes beyond charting the physical aspects of illness, important as they are and fundamental as they are in the experience of illness and treatment of disease. Moreover, the duality of mind and body imply a close association in how illness affects the body and how the mind perceives and responds to somatic dysfunction. Because the human experience entails an almost infinite scope, the investigation thereof will be equally wide ranging.

A central objective is to re-examine the accepted or standard views (paradigms) about disease – particularly serious disease such as cancer. The most meaningful assessment of disease is to see it as a natural event without meaning – serious, yes, but simply part of being human; for that matter, of being alive. Against that background, I do an extensive investigation into divergent aspects of illness and disease as part of the human condition and experienced by humans.

The aim of and justification of medicine is to influence human life positively in diverse ways – in the words of Hippocrates: sometimes to heal, often to treat and always to comfort. As with many things in life, the positives are not necessarily unconditional. Probing history provides perspective to the present; analyses of the language of disease informs on how we think and communicate; understanding the nature of disease and treatment provides

insight; and knowing what can go wrong warns us of the limitations of the practice of medicine. Medicine may at times be able to cure but should always aid the healing process. Without hope the future is bleak; without healing the ill remain broken and unable to live in harmony with the divergent demands that characterise serious illness.

This investigation takes place against the backdrop of a fundamental assumption: although medical science continues to make phenomenal progress and discoveries, our insight into and knowledge of disease remains limited – an understanding that holds true for all forms of knowledge. Voltaire (François-Marie Arouet; 1694–1778) declared: “Doctors are men (*sic*) who prescribe medicines they know little about to cure diseases they know less about in human beings of whom they know nothing.”

The one certainty in life is our mortality. The only uncertainties about mortality are that we do not know the day and date, the manner and circumstance of our meeting with eternity, and the nature of eternity. Our lives may end suddenly due to trauma, stroke, or a heart attack; or we may gradually decline and lose our humanity due to repeated small blood clots (emboli) to the brain until but a heap of living cells without apparent consciousness remains, therefore no longer a person.*

The “benefit” of an instantaneous death is the absence of pain and suffering, and not having to grapple with the fundamental “What now?” question; the “disadvantage” is the unpreparedness, financially and otherwise, and the acute trauma of bereavement. The “advantage” of going “gentle into that good night”† is that there may be time to prepare; for the patient, to get her affairs, will and relationships in order and to express some last wishes, to say goodbye; for the family to show their love and dedication through visits, and to start the grieving process together with their loved one. The “disadvantage” of the chronic is that the person may become mentally and physically enfeebled, painful for loved ones to witness; may experience severe emotional and physical suffering and may at last yearn for release –

* The sudden versus the slow not only refers to older persons. The famous South African writer and poet SJ du Toit – Totius – lost two of his three children weeks apart. On November 7, 1920, his youngest, Francois (1 year), died of meningitis, and on New Year’s Eve of the same year his eldest, Wilhelmina (13 years), after being struck by lightning. He describes the moving sadness of not being able to say goodbye in the poem “Ah, she did not die ...” with the poignant words “Ah, she didn’t die / She was simply dead ...” (my translation)

† Dylan Thomas: Do not go gentle into that good night.

for death. There may be a request for some sort of aid in ending suffering by ending life – physician assisted suicide or even more active euthanasia.* There are tough decisions to be made about treatment; anxieties about finances; concern for the well-being of a spouse who will be left behind. There is fear of an uncertain future, of pain and suffering that awaits, for the big unknown beyond the Styx.

Serious existential questions are involuntarily asked by patients and loved ones: What is the sense of this? For the religious, the question is often: Why? How could a benevolent God allow such suffering, moreover, perhaps cause it? The answers in Christian context seek to explain but fails. From this perspective, suffering can be brought about by lifestyle choices, such as the long-term consequences of alcohol abuse and tobacco smoking, or an unhealthy lifestyle. But this is not generally true. Suffering can be the (divine) response to sin and disobedience, but not all who suffer were necessarily errant (why do bad things happen to good people?). It may be God’s way of purifying us and teaching us that suffering is part of life, but to what purpose? Suffering may eventually be “good” for us, and our response may inspire our fellow human beings, like the history of the mythical Job, but is it necessary? And then there is the ultimate trump of pastoral comfort: “God’s ways are unfathomable and unquestionable; we should resign ourselves to divine will – His grace is sufficient.”†

Viktor Frankl’s motivation in *Man’s Search for Meaning* (1946: Beacon Press) is that even in the worst suffering and hardship – in his case, in the Nazi concentration camps – there is dignity and meaning to human life. Someone – a friend, spouse, someone alive or already dead, or a God – sees our suffering, and would not expect us to let him/her down. This thought is reiterated by another Holocaust victim, Gerda Weissmann Klein in her biography *All but my life* (1995: Farrar, Straus & Giroux).

The only sensible answer that the non-religious (and the more open-minded religious?) person can offer is that there is no supernatural rationale for and meaning to pain and suffering, nor can there be. Suffering is simply part of

* Physician assistance with suicide may be performed in for example the Netherlands, Belgium, and Luxembourg. There are renewed attempts to legalise it in South Africa as a basic individual right.

† I suspect the illness-suffering experience reveals a basic incoherence in our conceptualisation of God. The practicality of our existence indicates that God is and functions in ways different from our general conceptualisations, beliefs, and preaching, particularly as a “micromanaging” being.

the human condition and life, the ultimate way of all flesh. I endorse this view. One of the underlying premises of this book is to perceive, contend and treat disease purely as a biological phenomenon without any metaphysical (supernatural) component.

Two related objections can be argued against this view; that it is both fatalistic and defeatist. The intention is neither of the two. On the contrary, this view has certain advantages: If illness is considered a natural process, any form of guilt in the afflicted – that she is responsible for the illness or must have done something wrong and therefore deserves divine punishment – can be more easily discharged as a misconception. Stigmatisation of persons living with HIV or AIDS, for example, is a second disease and this view can also counteract it. Nor do I contend that one should resign oneself to the inevitable when an unfavourable diagnosis is made. The intention is the opposite: to empower the ill to use their energy positively.

In all European Union countries fertility rates have dropped – in Malta to as low as 1.14 per woman and in France, to 1.86 (currently the highest EU figure). Italy is the latest and one of the lowest – at 1.27, versus 2.1 needed to maintain existing population numbers. The result is an ageing population with concomitant disease patterns – more serious diseases such as mental degeneration, other degenerative diseases, and cancer – and serious socio-economic consequences for example highlighted during the COVID-19 pandemic.

The “developed world” component of the South African population follows the European demographic pattern (accrual below the replacement rate). The “developing world” component, on the other hand, follows a different pattern with much higher accrual rates (3.49 births per woman in 1996; down to 3.04 in 2001 and 2.82 in 2011; currently around 2.4). Birth rates decrease parallel to socioeconomic advancement, but from a high base. In 2018, approximately 46% of the South African population was 24 years and younger.

Parallel to the large pool of youth with unique disease patterns, the increasing over-sixties demography in South Africa has a similar spread of disease as their European counterparts: increased incidence of chronic (mostly lifestyle) diseases and especially cancer.* In 2017, approximately 6% of the South African population, that is, more than 3 million persons

* About 100 000 new cancer diagnoses were made in South Africa in the most recent year of report.

(significantly more women than men), were aged 65 years and older.* Nevertheless, due to the large percentage of youth, the median age in South Africa is only 27.3 years.†

Questions that come to mind include:‡

- What was humanity’s historical understanding of disease, particularly chronic, incurable disease, unique to the human condition?
- How are the same conditions viewed now?
- How *should* we perceive these conditions?

This analysis is timely precisely because of the world’s demographic changes. Disease patterns in an older population are also changing. The prevalence of chronic and especially lifestyle diseases such as diabetes, dementia, heart disease and cancer is increasing parallel to ageing; so, too, associated insecurities, pain, and suffering. Avoiding or postponing reflection on these topics until the “big Junk Man” knocks on the door is counterproductive.§ One result of the view of disease as part of the human condition is that we can talk and think about it in a unique way. It is important that we gain as much knowledge as possible about our illnesses and communicate openly and confidently about them.

I approach these and other questions posed in this book from an ethical point of view, dealing with the right-and-wrong, good-and-bad, how-must-I-live questions of life, within the context of the topic. Answers to these questions are not necessarily obvious.

* In the US, life expectancy increased by 50% from the beginning of the previous century. Main causes include the discovery of antibiotics and the resulting effective treatment of infectious diseases, improved nutrition, vaccinations, socio-economic advances, and healthy lifestyle choices. Not only do people get older, but they are also healthier – although the prevalence of diseases such as cancer and dementia has increased.

† The median age of the world population was 31.1 according to 2017 data; for some African countries, it was under twenty, for most under thirty. In the US it was 39.4, for Britain 41.7. The median for the EU was 44.2; the oldest population was Monaco (54.5!), followed by Japan (48.7) and Germany (48.2). There are equal numbers of individuals above and below the median.

‡ I do not primarily write about cancer. Yet a diagnosis of cancer and the word as generic term holds much fear. It is the metaphorical “elephant in the room”.

§ Carl Sandburg’s poem “The Junk Man” pertains to this. Google it.

Where applicable the focus is on the South African situation, though, of course, the underlying problems are universal.

I endorse the argument that illness should not be considered a divine punishment, a demonic visitation, or a metaphysical manifestation, but is simply part of the human condition. Illness simply is something that happens ... nothing else.

About the Contents of the Book

The book is divided into six thematic parts.

Part 1 is a prologue to set the stage for what follows. I introduce, define, and discuss the concept of Hope and the importance of Hope as a central driver and motivation in adversity. **Part 5** is the **Epilogue** to this **Prologue**. These two sections form, as it were, the bookends of the contents in-between.

Part 2 reflects on disease as a human experience, as part of the human condition. The first chapter deals with the nature and essence of disease, and how the subjective experience of illness affects our humanity. Then follows a discussion of the role of human thinking and emotions on the origin and management of disease. Next, I discuss mainstream religious perceptions of disease. Ancient Egyptian and Greek civilizations fed Western thinking on life in general, and on the origins and implications of disease. I discuss these historical views of disease in order to put present-day perceptions into perspective. However, we are Africans living in Africa, which motivates scrutiny of traditional African views. We are able to distinguish and treat individual diseases – *diseases* with different pathologies and courses instead of *disease* as a single entity – because of a scientific approach based on empirical investigation. Unfortunately, at times we have gone overboard with science. I discuss the accepted, present-day biomedical view of disease; diseases ironically caused by treatment; the issue of preventable (mostly lifestyle) diseases; human enhancement and finally, the inevitable role that ideology and politics play in disease and its management and treatment.

Part 3 deals with protection of the patient during treatment and research. The fundamental ethical guideline in treatment dates from the Hippocratic era and dictates that firstly, no harm should be done (*Primum non Nocere*). It remains a fundamental guideline, supported by contemporary principles such as respect for autonomy, justice, and fairness in the access to medical

services, beneficence, and non-maleficence (respectively, doing good and not doing harm), but also by all guidelines and statements prescribing and promoting ethical treatment. This also applies in research where patients (in research referred to as “research participants”), especially when suffering from serious, life-threatening diseases, do not always understand the distinction between treatment and research and may mistakenly assume that they will necessarily be advantaged by the “treatment” during research. They may even think that treatment during research will be adjusted to their specific needs, as is normally but in research is never the case.*

In addition to these perplexities that should be corrected, researchers are human and may be guilty of unethical, even negligent, and criminal conduct. So-called ethical companies – companies that manufacture drugs and implantable products – sometimes act unethically in conducting, interpreting, and disclosing research that can harm patients.

The first and third chapters in this section deal with informed consent and the rights of patients; the second examines the notion of medicine as a noble cause and how unnecessary surgeries undermines this idea; the fourth explains how things can go wrong due to the deliberate manipulation of information by the pharmaceutical industry; and the last highlights horrific research outrages that have indeed taken place in Nigeria.

Part 4 deals with the language of disease. In this section the language of disease and medicine is critically analysed, especially in respect of the metaphors used in medical communication. Metaphors are inevitable language phenomena, unavoidably also in medical communication. Metaphors denoting aggression and military combat are commonly used in cancer and acquired immune deficiency syndrome (AIDS), but also with other diseases. A thorough analyses of the history, positive and predictable negative effects of these uses is made. I cite patient narratives to highlight the actual real-life employment of metaphors by patients. Next, I explore traditional Chinese and African insights on disease to determine whether these views may assist in deconstructing harmful metaphors and reconstructing them into less adverse images. There is a chapter on children’s views on the metaphors they as cancer patients use. Several alternative passive (pacifist) metaphors are discussed, but the underlying message is that the health care team should be sensitive to the metaphors the patient prefers to use.

* This is known as the therapeutic misconception.

In **Part 5, Epilogue**, the ideas expressed earlier are brought together and applied to discover the meaning and importance of Healing – distinguishable from physical health.

In **Part 6**, I first deal with end-of-life options and choices to explain the current South African regulatory situation. Gaps in current legislation and the importance of a proper living will and/or enduring health care power of attorney/proxy are discussed.

In the last chapter I discuss several coping options and strategies that can be investigated to direct the further course of the sometimes-difficult road with illness. The journey continues ... and the journey in its totality describes the human experience of illness.

The book ends with an explanatory list of technical terms used, followed by a list of abbreviations, and a short postscript.

* * *

Finally, something about my approach. The basis of the book is personal observations and experiences over more than 50 years of involvement in medicine, supplemented, tinted, and interpreted following my formal study of ethics, more specifically bioethics, and appropriate reflection. In parallel, there is also a study of relevant scientific medical as well as socio-scientific publications. However, no literature study can be complete – approximately one million new academic medical articles are published annually! Although search engines track the most relevant articles, due to the volume of publications, there is inevitably some subjectivity in the selection of materials to eventually discuss and include. I have consistently tried to include the most convincing and relevant material, including at times intentionally, also more controversial data. I constantly take on distinct roles: sometimes that of an expert, sometimes an observer; at times critic or commentator; sometimes a cynic; often reflective; sometimes simply an expert medical journalist.

This book is written for people who have the courage to ask questions about the difficult facets of life, who are willing to critically question accepted paradigms. The only requirements are an open mind, logical thinking and an absence of preconceived beliefs and answers. There hopefully is adequate depth for medical students, health care staff, ministers of religion and therapists – in short, anyone who wants to dig a little deeper into this facet of the human condition and seeks an understanding of how illness affects our lives.

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Reference

1. Engel G (1977). *The Need for a New Medical Model: A Challenge for Biomedicine*. *Science* 196.4286 (1977): 129–136.

PART 1

HOPE

***Do I have hope? Without hope it would be hard to wake up in the morning.
I have hope – without hope nothing would be worth anything.***

—Tova Friedman, Holocaust Survivor, in a BBC Hardtalk interview with Stephen Sackur, 29 December 2022

Beware how you take away hope from another human being.

—Oliver Wendell Holmes Snr.

Hope is a positive expectation based on realistic and realisable assumptions. Hope is both a human emotion and a virtue, but more than that – it has a cognitive element and biological explanations. It promotes courage and a sense of cohesion with others. Hope should form the core of the treatment plan for all serious diseases. Hope provides therapeutic value for both mental and physical facets of the course of disease. Hope does not disappear should disease become serious. It merely refocuses; from curing to healing and to personal goals that help the afflicted cope with illness.

CHAPTER 1

HOPE

How do we define hope?

The Afrikaans poets, AG Visser, defined hope in this beautiful verse (my sorry translation!):

Hope
On the wings of the breaking day,
In gold-embroidered cloudy garb,
With glad greetings and happy laughter,

Comes hope, aflutter from the night;
Enthralling in her playful youth,
She spreads light and sweetest joy,
Her face anointed with life's courage,
For all true and clean and good,
With golden hair and bluest eyes,
Appears she, shining, from on high.¹

Visser personifies hope as an attractive young woman, revealing several characteristics of hope. Hope is the response to something negative (the night); hope is always positive with the promise of something good, something cheerful, alluring, but perhaps also with a touch of the seductive. But hope can be false, unfounded, and unrealistic; it offers no guarantee, and it can be foiled. Expectations should therefore be both realistic and achievable, and rational and reasonable.

The American poet Emily Dickinson's description of hope dates from about 150 years ago:

(314) Hope is the thing with feathers*
'Hope' is the thing with feathers –
That perches in the soul –

* None of Dickinson's 1,800 poems have titles, but according to convention, the chronological number of the poem and the first line act as the title.

And sings the tune without the words –
And never stops – at all –

And sweetest – in the Gale – is heard –
And sore must be the storm –
That could abash the little Bird
That kept so many warm –

I've heard it in the chilliest land –
And on the strangest Sea –
Yet – never – in Extremity,
It asked a crumb – of me.²

Dickinson's beautiful metaphor for hope is a gentle, eternally singing, and inspiring little bird that rests lightly on the soul and never demands anything in return – reciprocity. A bird whose wordless song rises above the fiercest storm. Even in the most difficult circumstances, hope is ever-present, does not disappoint.

Both beautiful poems omit important characteristics of hope: that hope always has content; hope that something good will happen, and hope is based on sound reasons. Not so optimism: optimism describes a positive mindset that views life through rosy specs, reality notwithstanding, pessimism the opposite. Hope has content, substance; hope outlines a specific, positive, and realistic expectation, to want or to make something happen, or expect it to be or become true, linked to a sound reason to expect it. Hope is a wish with the expectation or belief in its realisation. Hope is an optimistic state of mind based on the expectation of positive outcome with regards to events and circumstances. To hope is, to expect with confidence, to desire with expectation.

For those familiar with the Christian's hope of resurrection and eternal life in divine presence, there is no better definition of hope.* As the definition above suggests, there is indeed an element of justified optimism in hope. Hope, however, is far more than mere optimism – indeed it is “optimism-plus”.

* In Ephesians 1:5–8 Paul describes the principles of Christian hope: forgiveness of sin and eternal life. Also, Peter (1 Peter 3:15) speaks of hope as alive in the Christian. For the Christian hope is substantive: a firm belief in the realisation of the promises made in the New Testament.

Hope in medical context

In his book *The Anatomy of Hope*, Jerome Groopman makes the following important observation:

I understand hope as an emotion made up of two parts: a cognitive part and an effective part. When we hope for something, we employ, to some degree, our cognition, marshalling information and data relevant to the desired future event. If ... you are suffering from a serious illness and you hope for improvement, even for a cure, you have to generate a different vision of your condition in your mind. That picture is painted in part by assimilating information about the disease and its potential treatments. *

Doctors and therapists rarely use the word hope in the context of treatment. And yet hope is, in a manner of speaking, the essential commodity of their trade, armed with which patients approach an uncertain future with serious illness. Physicians use an impressive synonym for hope, namely *prognosis*. Prognosis is the distilled expectation of the course of a disease, and outcome with treatment. It is the refinement of experience, knowledge, statistics, anecdotes, meta-analyses, and research. However, because no individual warranties can be provided, prognosis is based simply on the expectation – the hope – of a particular outcome, based on certain rational assumptions.

I suspect the opposition to using the word *hope* has much to do with the belief that hope implies the denial of scientific data, while this is not the case. The two are truly related. A second plausible reason is that the word hope does not fit into scientific medical discourse. This may be understandable because the word can be used in other contexts. It may be the ordinariness of other uses that deter. Nevertheless, I believe the first reason is the weightiest.

Hope is not part of discourse when the doctor interacts with the patient about serious illness. I believe it should form the core of all physician-patient interaction. When the curious Pandora opened the metaphorical forbidden jar (usually described as a box) and unleashed all kinds of evils, diseases, misery, and mortality on an innocent and spotless world, she also discovered one virtuous spirit at the bottom of the jar, the only one that had not escaped.

* From: Groopman J. *The Anatomy or Hope* (2005; Random House). Dr Groopman is an oncologist specialising in blood cancers, and professor at Harvard. He reflects on his long-standing experience: why some persons remain hopeful in similarly difficult circumstances and others do not. He highlights a positive effect of hope: the secretion of endorphin (see also discussion of PNI in Chapter 3).

This spirit was *Elpis*, or *Hope*.^{*} Hope is therefore the metaphorical force opposing all evil that manifests in the world. Not that illness is an “evil”; but rather, hope counteracts the negatives surrounding illness. Indeed, there is no need for, no talk of hope before some misfortune or crisis disrupts our lives. I cling to hope when the doctor tells me my child is seriously ill, but ought to recover. Hope then perches lightly on my breast and sings its wordless song – provided I have the realistic expectation that my son will recover, based on the doctor’s prognostic opinion.

Hope thus lies at the heart of and is of vital importance to the experience, management, and treatment of every illness. I fully underwrite Catherine DeAngelis’s statement: “No patient should ever leave a visit with a physician without a sense of hope.”³ She adds that hope arises when patients get the impression that “something can be done for their illness; that they will be actively involved in their treatment; or (with) knowledge that hospice care may provide solace for their last days if their illness is terminal”.

What generates hope in patients?

- A human connection is made between professional and patient.
- The personal dimension is developed.
- If the patient can speak freely and the doctor is prepared to listen.
- If the patient perceives the doctor as an expert ally.
- If the doctor notices the obvious gestures of hopelessness and reacts with comfort.³

Besides expertise and knowledge, patients *especially seek hope* from their doctors. Patients’ hopes and expectations of positive outcome are associated with more favourable outcomes. The following strategies can promote this:

- Convincing (note, not guaranteed) treatment plans.
- Anecdotal examples (not guarantees) of good outcome with the proposed treatment plan.
- Promoting the patient’s trust in the physician.
- Promotion of realistic expectations.
- Promoting patient participation in decision making.⁴

^{*} From the classical poet Hesiod’s *Works and days*. Pandora immediately returned the lid. However, Hesiod does not explain why *Elpis* had not also fled.

Unrealistic expectations

Hope is one of our central emotions, but we are often at a loss when asked to define it. Many of us confuse hope with optimism, a prevailing attitude that ‘things turn out for the best’. But hope differs from optimism. Hope does not arise from being told to ‘Think Positively’ or from hearing an overly rosy forecast. Hope, unlike optimism, is rooted in unalloyed reality. Although there is no uniform definition of hope, I found one that seemed to capture what my patients had taught me. *Hope is the elevating feeling we experience when we see – in the mind’s eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion.*

—Jerome Groopman⁵ (my italics)

The expectations on which hope is based must be realistic and achievable, otherwise all hope will be false hope. Hope designates possibility or probability, nevertheless without certainty.

New chemotherapeutic treatments and approaches hold the risk of a media buzz (hype) causing unrealistic expectations and irrational patient decisions. This has not yet transpired in South Africa due to the structure of health care delivery, the absence of direct marketing to patients and marketing to the professionals involved in treatment. Direct public marketing of new chemotherapy in the USA without any input by oncologists has affected patient decisions. Yet the medical community throughout the world follows the same science and applies the same treatments, and a flutter across the pond is likely to cause local ripples:

- In Houston, Texas, the word “cancer” in the logo of Texas University’s MD Anderson Cancer Centre was crossed out in red in advertising on buses and buildings and replaced with the words “Making cancer history”.
- Patients and relatives are bombarded with positive results cited out of context, with “longer survival” sometimes meaning just weeks or a few months.
- Ads often show smiling actors playing golf or romping with their grandchildren.
- Implied outcomes are better than in reality.
- New cancer drugs are announced with great fanfare.
- Unrealistic expectations are created, prompting patients to undergo untested treatments instead of preparing for possible negative outcomes. Patients may choose treatment options that can involve

- serious financial impact, even financial ruin for the family, with little gain.
- Laboratory breakthroughs are disclosed to the lay public prematurely and out of context – characteristic of the American system – to attract investors.
 - Huge fortunes can be created within these techno companies with multimillion-dollar takeovers. If ultimate results of research do not meet expectations, the cycle and investors' excitement is simply shifted to the next miracle remedy.
 - Financial considerations play a significant role in cancer treatment – in 2014, American health care insurers paid \$88 billion towards treatment, \$4 billion coming directly from patients.
 - Even ex-President Obama announced a “Cancer Moon-shot” with the motto: “Let’s make the U.S. the country that ultimately cures cancer.”⁶

Although authentic, the data cited above is from a publication of the Kaiser Group, the largest health care group in the USA. Sceptics may ask who benefits most from disseminating such data – health care providers and insurers, or Big Pharma? How are patients' interests protected and promoted? Who acts as a patient advocate in such a sick system? Is it but a battle between commercial interests? I do not intend the comments and citations above to be seen as critical of oncologists; especially not locally (in the greater Cape Town area). These actions and data confuse patients at critical junctures in their lives, when they are upset, insecure and vulnerable. Furthermore, it emphasises the importance of the ability to trust in and the integrity of health care providers.

Finding a realistic balance between false hope and false hopelessness for each individual patient is like walking a tightrope. False hopelessness is a risk because informed consent must be comprehensive and extensive, disclosing a possibly overwhelming range of side effects and conceivable complications – if only for fear of litigation.* False hope, on the other hand, poses the risk of disillusionment and excessively aggressive treatments with little gains.⁷ It has been argued that “false hope” does not exist because hope invariably involves one person's subjective evaluation of circumstances. Therefore, it might be better not to focus excessively on future hopes and expectations at the expense of “being able to live well today.”⁸

* See also Chapter 15, Consent in medicine.

We should distinguish between false hope based on insufficient information and false hope that is *accompanied* by ignorance but not *based* on it. The latter is the hope to which patients can cling when there is no realistic and rational hope for a good outcome.⁹

Two outstanding virtues of responsible physicians are integrity and trustworthiness. Integrity, honesty, and strong moral principles go together, predisposing to treatment decisions and advice that can be trusted always to be in patients' best interests. This is what every patient implicitly relies on to find her way through the maze sketched above. Responsible practitioners should ensure that patients carefully consider their treatment choices to ensure that their expectations are realistic, and expected outcomes justify the cost and disruption of treatment for them. Honest, appropriate, and understandable information is indispensable, as is the reliable guidance of a morally principled physician, a person of integrity.

Hope Theory

The original version of this theory was described nearly 40 years ago and suggests that hope is a cognitive expression (based on thinking, reasoning, and remembering), rather than an emotion. It consists of three elements:

- Goals – the ability to identify, anticipate and visualise clear and realistic endpoints.
- Routes or purposeful action (a plan) to achieve goals.
- Agency, or the ability to act positively to achieve the goals, based on patient autonomy (the right to choose).¹⁰

You should therefore be able to identify goals, devise a realistic method or pathway to reach them and be able to motivate yourself to stick to that route, such as undergoing proposed treatment.¹¹ The main purpose of hope therapy is to address obstacles that hamper purposeful action. The second approach is more appropriate in medicine because it focuses on the identification of strategies to deal with disease. The premise is that patients often do not have control over the goals they want to achieve (healing, being free from pain). They do have control over personal disease handling strategies.¹²

To quote more of Jerome Groopman:

Hope can only flourish when you believe that what you do can bring a future different than the present. To have hope is to acquire the belief that you have

some control over your circumstances, that you are no longer entirely at the mercy of forces outside yourself.¹³

Note, the reference is to “some control”, not “absolute control”, else hope would be redundant and replaced by certainty. There are always factors beyond our or even anyone’s control that influence the realisation of hope, which implies a degree of acceptance – that what we hope for may not happen.

Focused versus intrinsic hope

Is it realistic to retain hope if cancer returns or cannot be cured, if the inevitable is to be accepted? When a cure is possible, especially after surgery or with the first course of chemo, hope is focused on that. But it is rare for the prognosis of advanced cancer treated with chemotherapy to remain favourable over time. However, as illness progresses and a cure is no longer possible, hope does not disappear. On the contrary, intrinsic, internally focused hope takes over, and the responsible physician should promote it. Hope which had focused on a cure now directs inwards. Hope now centres on aspects that are important to the individual, such as not being a burden, not experiencing pain, being nursed at home, giving, and receiving love. Two strategies can help patients: purposeful, effective control of pain (pain is the great destroyer of hope) and open, honest conversations about prognosis and realistic expectations.¹⁴ In this way, patients can continue to hope even in challenging times, and continue to experience the positive consequences of hope.

The biology of hope

A subdivision of Groopman’s publication which I have referenced several times, carries this title. It addresses what I shall examine in Chapter 3 – psycho-neuro-immunology (PNI). In short, I argue that in addition to hope being based on rationality and realisability, there are biological underpinnings to hope. Groopman writes:

To have true hope means to have information in order to think logically about your condition, to see all the pitfalls and all the problems that are in front of you. In this way, true hope differs from optimism. Optimism says everything is going to work out all right. Well, the truth is, everything doesn’t always work out all right. Things sometimes work out very badly. Optimism is a character trait. It is almost a given. Hope is an active emotion. Hope requires meticulously surveying everything in front of you—all the

obstacles, all the pitfalls—and finding that path that can bring you to the future. That’s the cognitive part. The second part is the effective part. We talk about wings of hope, being uplifted by hope. There is an energizing feeling that we experience with hope.¹⁵

What is the nature of Groopman’s “energizing feeling”? Musschenga describes it as follows:

Hope is the energy and direction that we can offer, not only making the world into how we want it to be but regulating and developing our capacities to act. Hoping is to offer the motivational force for using and developing our abilities to fulfil our desires. Hoping is using our abilities to be imaginatively and constructively engaged in the world around us, even in the face of our limitations. Hope is inseparably connected to the belief in self-empowerment.¹⁶

There have been various positive findings in patients who remain hopeful despite serious illnesses, especially hope for specific outcomes.* One mechanism is the “placebo effect” (even drugs that have no proven medicinal effects may show positive treatment results). Other specific positive findings include for example the management of asthma, chronic pain and Parkinsonism. The biological explanations are changes in the levels of neurological transmitter substances in the brain.¹⁷ These findings justify emphasis on promoting hope as part of the treatment process.¹⁸ No patient should leave a consultation without hope.

Richard Davidson offers a biological basis for hope from a totally distinct perspective. For 30 years he worked on correlating the emotional functions of the brain with its electrophysiology (as shown, among other things, by fMRI studies[†]). He identified two related parts of the brain and coined the term “neuroplasticity”: throughout life, the brain’s connections and functioning remain subject to change. “Managing” this change may have positive results. An example is negating anxiety – in this context due to fear of an uncertain future – by cultivating programmes that positively influence children’s emotions and behaviours, along with programmes that generate hope. One of the keys to this is meditation. Davidson studied Tibetan monks

* Even if it only leaves patients feeling better from increasing endorphin levels in the brain – one of the “feelgood” hormones.

† Functional MR-imaging (fMRI) shows increased activity in certain areas of the brain during the execution of specific commands. It helps researchers to localise brain function.