



I.C. Papachristos, MD

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EXCERPT

The Right To The Truth

For families & friends of patients with cancer

FOREWORD by **Peter Goldstraw**

The Right To The Truth

For families and friends of patients with cancer

By I. C. PAPACHRISTOS, M.D.

English edition edited by George A. Rossetti

With a Foreword by Peter Goldstraw

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*To the memory of my beloved mother **Panagiota** (1930–2004), the Red Cross volunteer nurse who bestowed me with the blessing of Life, and to her father, **Dr. Ioannis A. Princephiles** (1885–1956), and to **all souls** who provided “for the benefit of the sick.”*

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A Foreword

In the last 50 years the investigation and management of cancer has been a major part of my professional life. In the late 1960s many patients were content to be told that the doctor recommended this test or this treatment, often ignoring or pushing away offers of further information as to why such treatment was necessary or what alternatives were available. As a junior doctor working over 100 hours a week such unquestioning faith was flattering and time-saving, but as one gained experience and seniority one came to appreciate the overwhelming responsibility one assumed in such a parent–child–like relationship.

The situation was even more fraught when dealing with patients whose knowledge of English was poor, and one often suspected that the translator did not pass on all of the information one had intended to give to the patient and their relatives.

Fortunately, in most developed countries, the legislative framework and ethical environment have long since changed the doctor-patient relationship, and not just in cancer management. These changes have been largely led by patients and their families, and welcomed by all of the health care professionals involved in the patient's journey. Information and advice is now sought by the patient, their families and advocates from the primary care physician, every member of the hospital specialist team, and latterly the internet. It has become widely recognised that no patient can give "informed consent" for investigation or treatment unless they are fully aware of their diagnosis, the extent and severity of the condition, the impact of pre-existing diagnoses, and the risks and benefit of all options for investigation and treatment.

Imparting "bad news" requires training and takes time. The patient often hears nothing more once the word "cancer" has been spoken and the information provided has to be kept to digestible amounts, often repeated, and tailored to each person's capacity to absorb. How else can a patient make a decision to proceed with treatment, often at great expense, that disrupts their professional and family life, requires hospital time, is associated with unpleasant and painful side effects, and may entail a risk to life, when they have no real appreciation of the possible benefit they may

gain? Providing the patient with all of the information necessary for them to give informed consent often allows appropriate “good news” to be given, providing hope in a dark situation.

Dr. Ioannis Papachristos spent some years of his training in a health care system where a culture of openness was practiced and has since continued his practice within an environment in which the old paternalistic approach of “protecting” the patient from the truth of their condition is still common.

He has seen how the latter approach frequently does not deceive the patient, who is deep down aware that such invasive tests and major treatment could not be justified for the benign and trivial condition from which they are told they are afflicted. If the patient is cured then other sufferers are deprived of the hope provided by such a positive outcome. Sometimes, recurrence of the disease demands further investigation and treatment, and with that more complicated deceptions. Ultimately the deception cannot be continued and the despairing patient loses all trust in their physician and even their own family. At the most taxing time in their lives, sometimes at the very end of their lives, they feel deserted and deprived of the emotional support they so desperately seek!

In this book Dr. Papachristos sets out the arguments for such an open approach, for all conditions not just cancer, and offers real and practical advice as to how such a policy can be implemented in clinical practice. His philosophy and arguments are reinforced by fictional vignettes, amalgams of real experiences in his practice. I am sure that patients, their friends and relatives, and eventually their health care providers, will benefit from the study of this excellent book. Through my own experience I can assure them that they will come to appreciate that such an open approach to the truth benefits not only the patient, but relieves the family, their friends, and most of all their physicians, of the burden of deception.

Peter Goldstraw,

Honorary Consultant in Thoracic Surgery, Royal Brompton Hospital, London.

Emeritus Professor of Thoracic Surgery, Imperial College, London.

Past President, the International Association for the Study of Lung Cancer, Aurora, Colorado.

Preface

A patient's fundamental, inalienable right to know the true status of his or her condition ought to be carved in stone all over the world. Indeed, the importance of this right is recognized as being so significant that it has at last been codified in legally binding texts such as the UNESCO Universal Declaration on Bioethics and Human Rights (ratified in Paris in 2005) and the Council of Europe's 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine.

Although patients' rights are legally protected worldwide, occasional violations continue to occur. Incidents in which cancer patients are not informed of their diagnosis take place everywhere, from the world's great cities, metropolitan areas, and capitals, to remote rural enclaves in Europe, Asia, Africa, the Americas, Australia and

beyond (e.g. inhabited non-continental island states, wherever medicine is practiced).

Many arguments are offered to justify withholding bad news from patients. One example is that it's just too time consuming. A diagnosis of cancer can be, and frequently is, overwhelming; patients understandably feel shocked, stunned, terrified, perhaps desperate the moment they hear the bad news. Accordingly, during initial disclosure, patients need ample encouragement and psychological support, and that does take a lot of time. They also need answers. When patients are first informed of a cancer diagnosis, they have a lot of questions for the physician. One question leads to another, and the answers can provoke ever-more problematic questions that a physician might not even be able to answer honestly without additional testing, but the patient needs all the answers now. There is no denying that disclosing a cancer diagnosis is an emotionally charged, time-consuming event.

It should come as no surprise, then, that some physicians choose to withhold the diagnosis and not inform their patients that they have a malignant disease. Physicians who willfully choose to mislead their patients like this are obliged to find plausible reasons to justify this unscrupulous policy. Some cynically claim they shield their patients from

the truth out of compassion; it's the right thing to do because patients must be spared from the distress an unpleasant diagnosis might provoke. In fact, some older-generation physicians may genuinely believe it is their duty to withhold bad news from their patients. There was a time when this was considered, not only acceptable behavior, but the compassionate thing to do. They are products of an earlier era; the consensus today, as affirmed by the UNESCO Declaration and the Council of Europe's 1997 Convention, is that physicians are duty-bound to inform their patients of their diagnosis.

Apart from the inordinate amount of time breaking bad news requires (from the physician's perspective), disclosure is abandoned or aborted in the majority of cases because of difficulty and tension experienced by the physicians during previous patient encounters. They are so unnerved and haunted by past experiences with disclosing bad news that they can't face it again and choose instead to avoid entirely this inherently painful responsibility. Or, some physicians say they "decide whether or not to carry through with disclosure" based on their careful assessment of how the patient reacts as he gradually broaches the subject. These physicians will say they "attempted" to disclose, yet "had to abandon" the process as soon as they saw the patient's growing distress. Since it is the rare patient indeed who

reacts with mounting joy while learning he has cancer, these physicians, in effect, never follow through with disclosure, though some (out of embarrassment) might claim they inform "a few."

In more sinister (and one hopes fewer) cases, nondisclosure is systematically and routinely practiced with malevolent ulterior motives in mind, with the aim of deceiving emotionally vulnerable patients and their families by *exploiting false hopes* for profit, as will be exposed below.

Patients' families are often placed in the difficult position of having to decide whether or not to disclose a diagnosis of cancer to their loved ones. It is a dilemma that few are prepared for, and they tend to make decisions based on raw emotions alone rather than reason. These families need to be taught how to think things through calmly and rationally, so they can make reasoned choices about what is best for the well-being of their loved ones, especially when called upon to make decisions that might deeply strain them emotionally.

This book attempts to offer supportive advice for families, for patients, and for all professionals involved in the care of cancer patients. This book offers a wealth of

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arguments in favor of respecting and ensuring patients' right to know the truth. These arguments are framed in the context of clinical case studies that end very badly for patients because a diagnosis was withheld or because the patient was lied to. In addition, this book describes in great detail a structured, systematic method for breaking bad news to patients; attending physicians might find that some of the ideas offered complement their own personal style of providing information. Finally, this book is a clarion call for truth in all aspects of the doctor–patient relationship.

Truth in medicine, of course, extends far beyond disclosing a diagnosis. Patients are entitled to know the nature and characteristics of their disease, the factors involved in staging, and the risks and benefits associated with available, indicated treatments. Above all, they must understand the prognosis associated with treatment “A” versus treatment “B” versus no treatment at all. A patient's signed consent to proceed with a given treatment is valid only when he or she understands fully the pros and cons of all available choices. Unfortunately, too many patients agree to undergo therapies they do not fully understand, because they were not adequately informed or, all too often, intentionally deceived or coerced to sign a consent form.

A CNN article* published in June 2017 shows that, even in the United States, patients are far too often unaware of the true nature—curative, palliative, even experimental—of treatments they undergo for cancer or are left unaware of key elements of their condition. The reasons for this are many and complex; physicians overestimate their patients' knowledge about their condition, patients and physicians don't always communicate effectively, and so on. But there are cases where physicians simply withhold information patients need to plan ahead, or they intentionally provide patients with exaggerated survival times. The latter robs patients of the ability to plan realistically for the future.

Patients are also at risk of being deceived and manipulated for profit. In wealthy, developed countries, such as the US, with a predominantly private health-care system, as well as in countries with a substantial private sector that coexists with a "national" or state-owned health service, the questionable motives, tempting opportunities, and financial incentives of the many stakeholders involved in cancer care (from individual practitioners to industry giants)

* "Despite options, many cancer patients are left in the dark," on June 15, 2017:
<http://edition.cnn.com/2017/06/15/health/cancer-patients-answers-partner/>

are all cause for great concern. Thus, patients need to be protected from exploitation or abuse by being fully informed.

I strongly believe that every facet of the wide array of issues relevant to cancer patients and their families should be disclosed and thoroughly explained to protect them from those who would take advantage of the vulnerable for profit. Toward this end, patient aptitude must be taken into consideration. Facts and findings should be described clearly in *terms a given patient can understand*; they must be able to comprehend what they hear. An ignorant patient is a vulnerable patient; and predatory physicians do, sadly, exist.

Unfortunately, bad things do happen where you might least expect it. In Britain, for example, a 59-year-old surgeon* was sentenced to prison after being convicted of “wounding with intent” nine women and one man. According to an article that appeared in *The Mirror*, he

* “Sick surgeon who butchered breast cancer patients and performed unnecessary ops is struck off” on *The Mirror*, July 25, 2017:
http://www.mirror.co.uk/news/uk-news/sick-surgeon-who-butchered-breast-10870306#ICID=sharebar_facebook

“butchered” cancer patients, performed unnecessary operations, and he exploited vulnerable patients for his own gain by charging for these surgical procedures. These things do happen, albeit rarely. Still, some of my colleagues in the greater medical community routinely make bad choices; sometimes for the sake of convenience and sometimes out of personal greed. Whatever the reason, it is the patient who suffers in the end.

In this book, readers will find stories, at once interesting and appalling, of patients who suffered terribly, and unnecessarily, because they were deliberately deceived by their physicians. Case studies are provided of actual incidents that I have witnessed or otherwise have personal knowledge of. These stories, which appear at the beginning of each chapter, are called “*Clinical Counterexamples*.” The stories are inspired by—or based on—true events, but the names have been changed to protect the privacy of all persons involved. It is hoped that the lessons learned from these Counterexamples will serve to raise awareness among patients and health-care professionals alike, and that steps will be taken to ensure that patients no longer suffer the consequences of being denied the truth. My sole purpose for writing “The Right to The Truth” is to promote the protection of, and respect for, patients’ rights; it is in no way

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intended to raise pointless accusations against any person or provoke senseless scandals.

It's hardly a secret that we live in an imperfect world. Bad things happen to good people. It's bad enough that some of them get cancer; what's even worse is that the very people they look to for treatment, support, and hope would lie to them, withhold information they need, or even exploit them for profit. We must, all of us, appeal to the "better angels of our nature" and try to make it a better world for cancer patients by simply telling them the truth and showing sincere compassion and empathy. Let us stand by them as trusted allies, offering all the support they so badly need as they fight their disease.

1.

In the Limelight of Imperial Capitals And Out of It

Historic Fact

The guards and everyone else in Buckingham Palace were puzzled by the presence of a peculiar scent—that of iodine and other antiseptic agents—permeating the air of the first floor in September of 1951. The strange odors wafted from freshly opened containers in the Buhl room, which had been converted into an operating theatre. In that room on September 23, His Majesty King George VI underwent major surgery wherein his left lung was removed because of cancer. The left recurrent laryngeal nerve also had to be removed during the procedure, which subsequently caused the King to speak with a hoarse voice.

His Majesty was completely unaware that he had cancer, despite his thoracic surgeon's intention to be frank. The surgeon, Sir Clement Price Thomas, was

overruled by higher authorities. Thus, the unfortunate sovereign was deprived of the same patients' rights already enjoyed by all his subjects during that era. The diagnosis was withheld from the noblest patient in the realm to benefit the interests of the mighty Empire that was soon to be reduced to a Kingdom. A few months after surgery, King George was finally informed of the truth about his cancer, when disease recurrence made further deception impossible.

Continuation of Chapter 1

Unfortunately, occasional violations of a patient's basic right to know the true status of their own condition do take place throughout the world. Of course, "the greater good" is invariably held forth in defense of such inhumane violations of trust; sometimes for the ostensible benefit of the patient or, as is more often the case, for the benefit of others surrounding the patient. In some cultures, nondisclosure by physicians is almost customary and justified as a courtesy to the patient, as in Japan for instance, where informing patients they have cancer might be regarded as a cruel or unkind act!

In far distant places and countries around the globe inhabited by people known for their passionate or highly emotional natures (e.g., Mediterranean countries), a family member may well demand withholding a difficult-to-reveal diagnosis from a loved one. In Portugal, Turkey, Latin America and elsewhere some relatives are tormented as they weigh the pros and the cons of letting their loved one know they have a frightening diagnosis.

One may think that it is only in rural places and among the peasantry as well as in deserts of the Arabian Peninsula and in remote areas of countries such as Iran, Qatar,

Egypt, etc. where patients are kept uninformed by illiterate relatives. Nondisclosure, however, routinely takes place even in urbane, civilized cities and capitals in Europe and elsewhere. Even inside imperial palaces, as we know. Excessive, but ultimately unwise, concerns about a patient's emotional state may lead to the extreme of withholding the diagnosis altogether, as happens in some cases in France or Italy.

From the physician's perspective, breaking bad news to patients is often difficult and unpleasant. Many physicians the world over are discomfited by the emotional burden of having to reveal unpleasant truths to their patients. Hence, some young or inexperienced physicians may opt for the gambit of delaying disclosure, thus buying time—they hope—for information to be provided to the patient by some relative or by any other person willing to do so. The problem with this, of course, is that untrained nonprofessionals are likely unqualified for the task at hand and might resort to amateurish improvisations, which won't benefit the patient at all. Perpetual delaying of disclosure may lead to complete unawareness wholesale!

Patients intentionally left in the dark about their own cancer diagnosis are found all over the world. Yet no other country on Earth is as unique in this context as Greece, where

patient unawareness is rampant. In Greece, the great majority of physicians refrain from informing their patients of their true diagnosis in order, ostensibly, to “spare them any distress.” It is estimated that as many as approximately 79% of Greek physicians have never told even one patient about his / her cancer diagnosis during the entirety of their professional lives! Even if the actual percentage of those who do so is somehow lower, the clinical practice of withholding cancer diagnoses is exceedingly widespread in Greece.

Thus, Greece will serve as a model in this book. Clinical stories involving unaware patients, as the reader will see, reveal how withholding information inevitably led to major catastrophes that ought to be inconceivable in the modern era. These stories herein will be called “*counterexamples*.” Each clinical story—inspired by true events from the author’s medical experience—will stimulate critical thinking and arguments about what is best “for the benefit of the sick,” as Hippocratic ethics demand.

Whenever in Japan, or Lebanon, or even the UK, one even considers hiding the cancer diagnosis from a relative (or from one’s patient), then one might learn valuable lessons by reading about the consequences of other people’s

I.C. PAPACHRISTOS, MD

mistakes caused by depriving patients of their inalienable right to know the truth!

7.

Informed Consent

Clinical Counterexample

Peter had been a truck driver. During his retirement years he enjoyed drinking a little bit more than he did while employed, and he continued smoking as well. Before the Christmas holidays, he caught a cold and became hoarse. The hoarseness, however, persisted for far too long—more than 20 consecutive days since the onset of his cold symptoms. Peter's nephew, who was a year shy of receiving his medical degree, grew quite concerned; he insisted that Peter needed to be examined by a physician at the earliest possible date—before New Year's Day—and undergo laryngoscopy.

Laryngeal cancer was diagnosed without any spread or dissemination of the disease. Peter underwent surgery at a large teaching hospital in

Northern Greece. Peter's laryngectomy was successful. Of course, removal of the larynx, or "voice box," meant that Peter could no longer speak.

Prior to surgery, Peter's surgeon did not inform him that he had been definitively diagnosed with cancer or that he should expect to lose his voice. Hence, he postoperatively felt misled and betrayed.

Peter survived his cancer and lived another 20 years. But the loss of his voice caused profound emotional distress and he took to drowning his sorrow in drink. He couldn't possibly feel happy or even grateful—to God or for his good luck—about the favorable outcome achieved, because he ultimately rejected the initial diagnosis of cancer altogether. For fear of upsetting him, Peter's family did not inform him of the diagnosis until five years after his surgery.

He kept drinking on a daily basis, feeling sad, bitter, and cursing his nephew for talking him into undergoing examination and laryngoscopy. It was unfair to hold his nephew responsible for the ostensibly unnecessary loss of his speech. Peter should have been thanking him, of course, because it was indeed his nephew's prompt action that led to an early diagnosis

and curative treatment! Strangely enough, Peter never expressed any complaints nor muttered any curses against the surgeon who had performed the procedure... without having first obtained his informed consent!

When Peter was eventually told the truth, many years later, he simply didn't believe it. He made that clear to his family in a blistering accusation written in his journal. His message read as follows: "You're lying to make up excuses for my cursed nephew, who wronged me. If I had really had cancer, I would have been dead by now. You either lie or the diagnosis was mistaken."

In Peter's mind a cancer diagnosis was ruled out by the fact that he was still alive. He always thought of cancer as a death sentence, and this perception persisted despite his own reality! He died some twenty years later of an unrelated cause, always complaining and without ever celebrating his victory or having felt any joy for his luck. Not even those in his social sphere ever knew that one of their own had been diagnosed with cancer, was cured of cancer, and survived 20 years in the small town in Thessaly, central Greece.

Peter was cured of cancer he didn't know he had thanks to a surgical resection that permanently deprived him of his speech. He went into surgery, however, without being informed of, and consenting to, the known consequences of laryngectomy!

One can purchase this book—in print or as an ebook—through *links* in its *official webpage*:

<http://www.papachristos.eu/righttothetruth/>

QR code for accessing the book's official webpage:



Direct link for the book's "detail page" (*kindle* edition) on *US Amazon.com store*:

<https://www.amazon.com/dp/B07642W9JM>

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