

To talk of disease is an Arabian nights experience.

*Doctors must be very careful
When they take the knife.
Underneath their fine incisions
Lies the culprit – life. Emily Dickinson*

Do Not Harm
by Henry Marsh

You are invited to spend some time with Mr. Henry Marsh, an eloquent neurosurgeon who escorts us into his operating theater, his parent's home as his mother lies dying, interminable maddening administrative meetings in his NHS hospital and to accompany him to Ukraine where he has volunteered as a surgeon for over 15 years. You'll share his triumphs and suffer the sadness and humiliation of his mistakes and failures. His war stories are captivating; as are his anecdotes about his family, his education and his jousting with the bureaucracy of the English National Health System (the NHS).

While they were once looked on as gods, surgeons are mortals. Marsh often gets no respect from administration. Although the NHS is vastly different from our system – it is crazy in its own way. While it is not profit driven, it is a bureaucratic nightmare that is dysfunctional in many ways.

Marsh's thoughts about caring for dying brain tumor patients are moving; as are his musings about his failures and screw-ups. His discussions about apology and forgiveness are moving and useful. All physicians are acutely aware of bad outcomes. We fail, we err, we need to be honest with our patients and sometimes we are blessed with their forgiveness.

DNH holds one in thrall. I suspect it will be most important to physicians, trainees and medical students; but the lay reader will find much in it as well. For me, it is a book, like Cushing's Life of Osler, that can be studied as a cherished tome.

Here are some excerpts for those busy souls who wish to have their meals pre-masticated:

Our vulnerability and fear of death when we are patient's knows no national boundaries, and the need for honesty and kindness from doctors – and the difficulties at times in giving these – is equally universal.

Doctors will sometimes admit their mistakes and complications to each other but are reluctant to do so in public, especially in countries that have commercial, competitive healthcare systems.

Chapter 1 Pineocytoma

I often have to cut into the brain and it's something I hate doing. She would be added to the list of my disasters – another headstone in the cemetery which the French surgeon Leriche once said all surgeons carry within themselves.

["Every surgeon carries about him a little cemetery, in which from time to time he goes to pray, a cemetery of bitterness and regret, of which he seeks the reason for certain of his failures."]

La philosophie de la Chirurgie. Part II, chapter I. Translated by Roberta Hurwitz.] This may be the theme of DNH.

Chapter 2 Aneurysm

[At the morning conference...] We sit there, alive and well and happy in our work, and with sardonic amusement and Olympian detachment we examine these abstract images of human suffering and disaster, hoping to find interesting cases on which to operate.

Modern binocular operating microscopes are wonderful things. They cost over 100,000 pounds and although they weigh a quarter of a ton they are perfectly counterbalanced.

It is 100 times more difficult and nerve-racking to train a junior surgeon than it is to operate oneself.

Doctors like to talk of the "art of and science" of medicine. I have always found this rather pretentious, and prefer to see what I do as a practical craft. I had avoided disaster and the patient was well. It was a deep and profound feeling which I suspect few people other than surgeons ever get to experience. Psychological research has shown that the most reliable route to personal happiness is to make others happy. I have made many patients very

happy with successful operations but there have been many terrible failures and most neurosurgeons' lives are punctuated by periods of deep despair.

We have achieved most as surgeons when our patients recover completely and forget us completely. We have been most successful, however, when our patients return to their homes and get on with their lives and never need to see us again. They are grateful, no doubt, but happy to put us and the horror of their illness behind them.

Chapter 3 Hemangioglioblastoma

Informed consent sound so easy in principal. Patients are both terrified and ignorant. How are they to know whether their the surgeon is competent or not?

When I underwent surgery myself, I found that that I was in awe of the colleagues who had to treat me though I knew that they, in turn, were frightened of me as all the usual defenses of professional detachment collapse when treating a colleague. It is not surprising that all surgeons hate operating on surgeons.

My patient did not read the informed consent form – I have yet to find somebody who does.

I admit to myself that soon I will be old and retired and then I will no longer count for much in the world. I might as well start getting used to it.

Chapter 4 Melodrama

Chapter 5 Tic Doloreaux

I carried out brain operations that had not previously been performed in Ukraine. In retrospect, given the poor operating conditions and the implacable hostility of the medical establishment, what I did in those years seems to me now to have been verging on lunacy. (The film the English surgeon Chronicles his time in Ukraine.)

Chapter 6 Angor Animi

I decided that surgery was what I should do for my career. I found its controlled and altruistic violence deeply appealing. It seemed to involve excitement and job security, a combination of manual and mental skills, and power and social status as well.

Surgery seemed to involve unpleasant, smelly body parts, sphincters and bodily fluids that I found almost as unattractive as some of the surgeons dealing with them, although there were a few surgical teachers in the hospital without whose influence I would never have become a surgeon. It was their kindness to patients, as much as their technical skill, which I found inspiring.

I became hardened in the way that doctors have to become hardened and came to see patients as an entirely separate race from all-important, invulnerable young doctors like myself. Now that I am reaching the end of my career this detachment has started to fade. I am less frightened by failure – I have come to accept it and feel less threatened by it and hopefully have learned from the mistakes I made in the past.

I discussed my career choice, my deep desire to be us neurosurgeon with an older neurosurgeon. His first question was, What does your wife think about it? I think she thanks it's a good idea, sir, I said.

Well, my first wife couldn't stand the idea so I changed her for a different model, he replied. It's a hard life, you know, training in neurosurgery.

Another neurosurgeon told him, the operating is the easy part, you know. By my age you realize that the difficulties are all to do with the decision-making.

Chapter 7 Meningioma

Would you operate if it were your mother? The son asked.

I hesitated before answering because I was not sure of the answer. It is, of course, the question that all patients should ask their doctors, but most are reluctant to ask since the question suggests the doctors might choose differently for themselves compared to what they recommended for their patients.

Today, in the NHS, doctors don't get much respect. A nurse tells him, well there's nothing you can do about it. Anyway you should plan more realistic operating lists.

It has been a good day. I had not lost my temper.

Chapter 8 Choroid Plexus Papilloma

30 years ago British hospitals always had a junior doctors' bar where you could go for a drink at the end of a long day -

At this time in his training his infant son, William developed acute hydrocephalus. His wife and he spent the next few weeks in that strange world one enters when you fear for your child's life – the outside world, the real world, becomes a ghost world, and the people in it remote and ill distinct. The only reality is intense fear, fear driven by helpless, overwhelming love.

Anxious and angry relatives are a burden all doctors must bear, but having been one myself was an important part of my medical education. Doctors, I tell my trainees with a laugh, can't suffer enough.

Chapter 9 Leucotomy

As a practical brain surgeon I have always found the philosophy of the so-called mind brain problems confusing and ultimately a waste of time. It has never seemed a problem to me, only a source of awe, amazement and profound surprise that my very sense of self, the self which feels as free as air, which was trying to read the book but instead was watching the clouds through the high windows, the self which is now writing these words, is in fact the electrochemical chatter of 100 billion nerve cells.

Chapter 10 Trauma

One of the unwritten rules of English medicine is that one never openly criticizes or overrules a colleague of equal seniority, so I remained silent. In this chapter, Marsh talks about the compulsory MAST training which stands for mandatory and statutory training.

How strange it is, I thought as I listened to the instructor talking, that after 30 years of struggling with death, disaster and countless crises and catastrophes, having watched patients bleed to death in my hands, having had furious arguments with colleagues, terrible meetings with relatives, moments of utter despair and profound exhilaration – in short, a typical neurosurgical career – how strange it is that I should now be listening to a young man with a background in catering telling me that I should develop empathy, keep focused and stay calm.

Marsh's comments about neurologists are a bit snide. He says they like strange and obscure diseases, sometimes untreatable, which they find deeply fascinating, and which they collect like rare butterflies and report in their journals.

Chapter 11.

Cancer specialists think it is a big success if the latest expensive experimental new drug keeps a patient alive for an extra few months.

I saw a young mother with two children who had an inoperable brain tumor. I tried to give her some hope but could not pretend that she was going to be cured. With this terrible conversations, especially when the bad news has been broken so suddenly, all doctors know that patients will only take in a small part of what they are told. When I have to break bad news I never know whether I have done it well or not.

Surgeons must always tell the truth but rarely, if ever, deprive patients of all hope. It can be very difficult to find the balance between optimism and realism.

Chapter 12 Glioblastoma

I have little direct contact with death in my work despite its constant presence. Death has become sanitized and remote. Patients wind up in the warehouse space of the ICU after being kept alive for a while by ventilators. Re: my dread of going to talk to my dying patient; I experienced once again my visceral hatred of hospitals in their dull indifferent architecture within the walls of which so much human suffering must be acted out.

When talking to a gravely ill patient HM knelt down on creaking knees. To stand over your dying patient would be as inhuman as the long hospital corridors. I have learned over the years that when breaking bad news, it is probably best to speak as little as possible. These conversations, by their very nature, are slow and painful and I must overcome my urge to talk and talk to fill the sad silence. I wonder if I will be so brave and dignified when my time comes?

Chapter 13 Infarct

I delivered a lecture entitled "All My Worst Mistakes".

Most surgeons – there are always a few exceptions – feel a deep sense of shame when their patients suffer or die as a result of their efforts, A sense of shame which is made all the worse if litigation follows. Surgeons find it difficult to admit making mistakes, to themselves as well as to others, and there are all manner of ways in which they disguise their errors and try to put the blame elsewhere.

(HM was) inspired by Khanaman's book and I set out to remember all my worst mistakes. When I delivered my lecture to my American colleagues, it was met by a stunned silence and no questions were asked.

Surgeons are supposed to talk about their mistakes at regular meetings, where avoidable mistakes are discussed and lessons learned, but the ones I have attended, both in America and in my own department are usually rather tame affairs, with the doctors present reluctant to criticize each other in public.

I invariably become very anxious when I receive letters of complaint. Every day I will make several dozen decisions that, if they are wrong, can have terrible consequences. My patients desperately need to believe in me, and I need to believe in myself as well.

I may appear to others to be brave and outspoken but I have a deep fear of authority, even of NHS managers, despite the fact that I have no respect for them.

Chapter 14 Neurotmesis

I went off to write an operating note. It is quite easy to lie if things go wrong with an operation. It would be impossible for anybody to know after the operation in what way it had gone wrong. You can invent plausible excuses – besides, patients are always warned that nerve damage can happen with this operation even though I have scarcely ever seen it happen. [He then vents his other frustration at the bureaucracy] that promotes poor training and limits the time with patients in favor of endless, stupid paperwork.

Chapter 15 Medulloblastoma

I had dragged myself up to the children's ward, where the mother was waiting to see me. She would not have been expecting to hear this catastrophic news. I have found it very difficult to talk, but I managed to convey what happened. I had no idea how she might react, but she reached out to me and held me in her arms and consoled me for my failure, even though it was she who had lost her daughter.

Doctors need to be held accountable, since power corrupts. There must be complaints procedures and litigation, commissions of enquiry, punishment and compensation at the same time if you do not hide or deny any mistakes when things go wrong, and if your patients and their families know that you are distressed by whatever happened, you might, if you were lucky, receive the precious gift of forgiveness.

Chapter 16 Pituitary Adenoma

Chapter 17 Empyema

[A bad mistake leads to a patient's death and he had an awful feeling of guilt.] I felt as though I was attending my own funeral. He was being sued. The QC said I think this will be difficult to defend. I entirely agree, I interrupted.

I remembered once having to wait outside the office of my school headmaster 50 years ago, sick with anxiety to be punished by the kind old man for some misdemeanor. I knew the barrister was going to be professional and matter of fact but I nevertheless felt overcome with dread and shame.

It's the professional shame that hurts the most, I told my friend. Vanity really. As a neurosurgeon you have to come to terms with ruining peoples lives and making mistakes, but one still feels terrible about it and how much it will cost.

I know one has to except these things, I went on lamely, but nobody nobody other then neurosurgeon's understand what it is like to have to drag yourself up to the ward and see, every day – sometimes for months on end – somebody one has destroyed and face the anxious and angry family at the bedside who have lost all confidence in you. You can't stay pleased with yourself long in neurosurgery, my colleague said. There's always another disaster waiting around the corner.

I had not dared to ask how many millions of pounds the case would probably be settled for. The final bill, I learned two years later, was 6 million.

Chapter 18 Carcinoma

I went to see my mother in hospital on Saturday. She had been admitted for metastatic breast cancer and was doing poorly. My mother was one of the greatest and most philosophical people I have ever known but neither of us could bring ourselves to refer to death by name.

My family were playing out an age-old scene that I suppose is really seen in the modern world, where we die in impersonal hospitals or hospices, cared for by caring professionals, who's caring expression (just like mine at work) will disappear off their faces as soon as they turn away, like the smile of hotel receptionist.

I felt no need to pay her body my final respects – as far as I was concerned her body has become a meaningless shell. In neuroscience it is called the binding problem – the extraordinary fact, which nobody can even begin to explain, that mere brain matter can give rise to consciousness and sensation.

I had such a strong sensation, as she lay dying, that some deeper, real person was still there behind the desk mask.

What makes for a good death? See page 198 – 199.

I must hope that I live my life now in such a way that, like my mother, I will be able to die without regret.

Chapter 19 Akinetic Mutism

Great surgeons tend to have bad memories.

Chapter 20 Hubris

It is one of the painful truth about neurosurgery that you only get good at doing the really difficult cases if you get lots of practice, but that means making lots of mistakes at first and leaving a trail of injured patients behind you. I suspect that you've got to be a bit of a psychopath to carry-on, or at least have a pretty thick skin. My old boss, who was really nice used to say "if the patients are going to be damaged I'd rather let God do the damage than do it myself."

It is an experience unique to neurosurgeons, and one with which all neurosurgeons are familiar. With other surgical specialties, on the whole, patients either die or recover, and do not linger on the wards for months. It is not something we discussed among ourselves, other than perhaps to sigh and nod your head when you hear of such a case, but at least you know that somebody understands what you feel. A few seem to be able to shrug it off, but they are a minority. Perhaps they are the ones who will become great neurosurgeons.

There were two other lessons that I learned that day. One was not to do an operation that a more experienced neurosurgeon than me did not want to do; the other was to treat some of the keynote lectures at conferences with a degree of skepticism.

Chapter 21. Photopsia

You are suddenly exposed to a terrifying new world of illness and death, and you learn how terrible illness often starts with trivial symptoms – blood on the toothbrush might mean leukemia etc.

It would be impossible to do the work if you felt the patients fear and suffering yourself. Besides, the increasing responsibility that comes as you climb the career ladder brings greater anxiety that you will make a mistake and that patients will suffer.

(HM had a retinal detachment) I knew my retinal surgeon would dislike having to treat a fellow surgeon – it is both a complement and a curse for your colleague asked you to treat him .

I realized how lucky I was compared to my own patients – what could be worse than having a brain tumor? What right did I have to complain when others must suffer so much more? Perhaps it was also because I was using my private health insurance and so avoided the loss of privacy and dignity to which most NHS patients are subjected.

After my eye surgery, I felt a little embarrassed that my patients could see that I was not in perfect health.

It was shortly after his retinal detachment that he broke his leg. When they took me to the accident and emergency at my own hospital I was facing one of the receptionists. Name? She asked.

Henry Marsh.

Date of birth?

Five 3 50. Actually I am a senior consultant neurosurgeon at this hospital.

Religion? She asked in reply without batting an eye lid. As a neurosurgeon, I rarely touch my patients. Other than when operating on them, of course. It's all just the history and the brain scan and long depressing conversations. Not at all like the orthopedic surgeon surgery I had. This is rather nice.

Chapter 22 Astrocytoma

The urge to help, the planning of difficult and dangerous operations, of taking carefully calculated risks, of saving lives, is irresistible and even more so if you are doing it in the face of opposition from a self-important professor.

Few people outside medicine realize that what tortures doctors most is uncertainty, rather than the fact that they often deal with people who are suffering or who are about to die.

Chapter 23 Tyrosine Kinase

This chapter describes the workings of NICE (The National Institute of Clinical Excellence) and how they approve drugs for use in the UK. There are many droll anecdotes and harsh pokes of fun at his committee members.

Chapter 24. Oligodendroglioma

Doctors treat each other with a certain grim sympathy. The usual rules of professional detachment and superiority have broken down and painful truth cannot be disguised. When doctors become patients they know the colleagues treating them are fallible and they can have no illusions – if the disease is a deadly one – about what awaits them. They know that bad things happen and that miracles never occur.

I build a roof garden in the attic of my house. I like to sit there in the summer evenings when I get home from work. So I sat there after returning from the hospital, with a gin and tonic, and a typical self London Vista of chimney pots and slate roofs and a few treetops stretching away from me into the distance. I thought of my parents. I thought of my colleagues, and of the man to whom I had just read out a death sentence. I thought of how he had immediately understood that he would never get home, that his strange family would never visit him, and that he would die in the care of strangers in some impersonal place. I thought of how I had walked away – but what else could I have done?

Chapter 25 anesthesia Dolorosa

The new executive chief from the trust, the seventh since I had become a consultant, was especially came on the 22 page trust dress code and my colleagues and I have been recently threatened with disciplinary action for wearing ties and wristwatches. There is no evidence that consultants wearing ties and wristwatches contribute to hospital infections, but the chief executive review this matter so seriously that he had taken to dressing as a nurse and following us on our ward rounds, refusing to talk to us and instead making copious notes. He did however wear his chief executive badge – I suppose just in case somebody ask him to empty a bedpan.

In his hospital the outpatient wards had all the charm of an unemployment benefits office although with the added detail of a magazine rack holding leaflets on how to live with Parkinson's disease,, Prostatism, irritable bowel syndrome, myasthenia gravis, colostomy bags and other unpleasant conditions.

My outpatient clinic is an odd combination of the trivial in the deadly serious. The patients here are not yet in – patients who have to submit to the D personalizing rituals of being admitted to the hospital, to be tagged like captive birds or criminals and to be put into bed like children in hospital gowns.

Some of the conversations I have in the clinic are joyful and some absurd and others can be heartbreaking they are never boring.

she was then and had the haunted expression of somebody in constant pain and deep despair. I learned a long time ago in the outpatient clinics to make no distinction – as some condescending doctor still do – between "real" or "psychological" pain. All pain is produced in the brain, and the only way pain can vary, other than in intensity, is how it is best treated.