Don’t read the label

PERSONAL VIEW Anonymous

My brother was a heartsink patient, I am sure: addicted to alcohol, unemployed, moving often, depressed, and vulnerable. At times of binges he could be utterly unreasonable and downright abusive. And yet, when he was able to control his drinking (most of the time), the real man emerged. Quietly spoken, respectful, intelligent, and insightful, he was honest about his “demons” and quick to apologise. Of these two polarised characters, he was firmly labelled with just one.

The words “hopeless,” “self induced,” and “time waster” were never used directly, but they didn’t have to be. A rushed, curt, and dismissive consultation spoke volumes, and he was on the receiving end of many of these. He was well aware of his label; and although accepting his responsibility for it, he was dismayed by the lack of willingness of some doctors to listen to him in a non-judgmental, open minded way, and this compounded his own sense of hopelessness. His mood was transformed and this compounded his own sense of non-judgmental, open minded way,

Sadly, his label would not leave him alone. His attempts to break out of the cycle of unemployment, limited access to housing, and low income were genuine, but he met with insurmountable hurdles, all serving to keep his self esteem at rock bottom. The penalty for failing to live on £75 (€95; $150) a week was excessive bank charges and the ever increasing spectre of debt. Alcohol provided transient comfort. I recognise now just how difficult it is for people like him to break free from a downward spiral. I have no doubt that our society does oppress so many, and I question how we can allow this to happen. Perhaps we would feel more passionately if we, too, were charged two days’ income for offending the bank. Perhaps our judgmental labels allow us to sleep easy. After all, people get what they deserve, don’t they?

Alcohol was his downfall, but it was also his means of escape from a world he couldn’t fit. That is not to justify self destructive behaviour, and he believed he got what he deserved when he was stricken with days of exhausting withdrawal symptoms, mostly managed alone. He was aware that alcoholism was a disease, probably terminal, and did everything humanly possible to manage it. To his credit, he had long periods of abstinence but would relapse when his label came back to haunt him, knocking his self esteem back into touch.

He died as he had been living: alone, struggling to break free from the destructive power of drink. He said that no one understood the purpose and value of his life; and, true to form, no one understood the reason for his death. Various alcohol related services were mobilised to try to support him in the later months, but even they could not accept that the unpleasant side of him was an expression of illness and despair and would offer help only when he was “well.” It would be laughable to offer the same approach for other medical conditions.

Clearly we will not like everyone we meet, nor approve of their values or way of life. But as a profession, and as human beings, we have a responsibility to offer respect and acceptance to others. My brother apologised many times for unacceptable behaviour, but not once did he receive an apology for abrupt, dismissive treatment or for excessive delays in getting a consultation with a specialist. We doctors are in a position of power, able to influence people’s views of themselves—and this is especially true of vulnerable patients. What gives us the right to look down on others or to justify lesser care because they are not caring for themselves? Do we have all the answers, or are we in danger of hypocrisy? What is the cost of kindness and respect? I believe that our creator looks on each of us as equals. Just as well, really.

We will all meet patients who make our hearts sink. We will all meet patients who challenge our personal values and beliefs. We will all meet patients who will fill us with a sense of disapproval. Next time you meet one, use your influence and status with care. Remember the power and value of open mindedness, acceptance, and kindness. Offering these does not imply that you are condoning their behaviour or views, but it makes room for self esteem and could help shake off the grip of a label.

The tables have turned, and my brother can look down on us. But not like that, of course.

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Why doctors need to embrace death

A new book finds much fault with how doctors handle patients at the end of life, says Margaret McCartney

“Sooner or later there comes a point... when the physician realises that he can do no more than ease the terminal stages of life... Unnecessary investigations or surgical interference should be eschewed, and the doctor ought to concentrate on alleviation of distress rather than systematic treatment.” So wrote Trevor Howell, deputy physician and surgeon, of the Royal Hospital, Chelsea, in 1944 in Old Age: Some Practical Points in Geriatrics. I am in the habit of reading old medical textbooks, because sometimes they help to explain how we came to end up where we are. What they do not always explain is why.

The palliative care movement sometimes sells itself as something new and original—the idea that comfort can and should sometimes replace cure. Yet old books can also tell of common sense, of kind doctors seeing the person’s whole life in perspective as it draws to a close. In her book Iona Heath writes, “Despite the expensive pretensions of medicine, death remains the inevitable end of life, and is often unpredictable, arbitrary and unjust; yet it is seen more and more as a simple failure of medicine and doctors.” She goes on: “We talk all the time about preventable deaths—as if death could ever be prevented rather than postponed.” When did things go wrong?

All that modern medicine can sometimes offer is a change: from one cause of death to another, or one prognosis over another. Sometimes—often even—this is good. Yet both iatrogenesis and ageism exist; we dread complaints; and litigation as a possibility hovers. In our bruised NHS, general practice is being diluted and dissolved, and our profession is increasingly regulated. Is there much of a space left for the kind of meaning ful, durable relationship with patients that allows for real, personal care towards the end of life?

Evidence based medicine, or at least the appreciation of the need for it, has done much good for health. Evidence based medicine, though, does not tell us how best to apply it compassionately and individually. The favourite form of distributing modern medicine is to apply evidence only once it has been cooked down to a protocol. The very favourite form of cost effective, modern medicine is then for the cheapest person capable of doing the job to apply it, and this is more likely to mean someone with advanced training in only a limited field. Such protocols, writes Heath, “regard patients as standardised units of disease. Such protocols have no way of accommodating the unique story of the individual—the particular values, aspirations and priorities of each different person and the way that these shift over time.”

The question then becomes how to be a doctor to the individual person while using and acknowledging the evidence and uncertainty that science presents to us. Some doctors attempt to accommodate the individual by abandoning evidence when it provides results that do not suit or instead parade pseudoscience as a remedy when it happens to appeal. Heath’s illumination is rooted neither in religion nor in the touchy-feely fluffiness of much of modern training in general practice. Instead she argues, often sharply, as a humanitarian. She argues for the general practitioner’s role in “acting as an interpreter at the boundary between illness and disease, and a witness to suffering.” As we are encouraged by a variety of vested interests to overdiagnose and overprescribe, to label everyone with risk factors, and to allow no one to be normal, no doctor can afford to stop thinking about what their role really should be.

This book is a work of practical and radical philosophy disguised as a medical textbook. Heath examines the function of pain, the worth of the “intensity of life, more than its length,” the need for trust between patients and doctors, the materialism of the market based healthcare system, the futility of much “health” advice, and the goodness possible within the given terms of the finite life. It is gold. Some of her conclusions are challenging, but if they cause the reader to think, that is surely worthwhile. Medicine has had a historical tendency to do first and think later, ignoring the need for humane concern in the rush towards unthinking intervention. Those who, like me, struggle with the political direction that general practice has been sent in will find themselves buoyed by Heath’s robust rigour. But it is those in government who really need to read this book.

Matters of Life and Death
Iona Heath
Radcliffe Publishing, £17.95, pp 126
ISBN: 978 1846190964
Rating: ★★★★★

Heath’s illumination is rooted neither in religion nor in the touchy-feely fluffiness of much of modern training in general practice
AIDS conference: more junket medicine

Ballet dancers, colourful artistic costumes, the pop star Annie Lennox—there’s even a place where celebs can have their hair coiffed under the banner “Hairstylists against AIDS.” No, this isn’t the latest summer arts festival with a conscience, but the two yearly August AIDS junket known this year simply as “Mexico.” And before you say that this is just sour grapes—I’m stuck looking at the photos on screen in BMJ Towers, while I could be enjoying the festivities and hobnobbing with the two Bills—it’s not. I’m just unsure whether it’s what the global community needs to tackle HIV and AIDS.

The conference has clearly come at a great cost—and not just to the climate, with 22 000 delegates winging their way across the world to attend. We criticise the drug industry for charging inflated prices while handing out freebies and holding meetings in luxury hotels. Only last month a 43 year old man, Polo Gomez, staged a protest in Mexico City against the rising prices of antiretrovirals by wearing a crown of needles containing his own HIV infected blood. But isn’t it time that the United Nations and non-governmental organisations turned the spotlight on themselves? What message is Mexico sending to those working every day at the grassroots level? Or those trying to alleviate the burden of AIDS by tackling poverty?

Look at the PR photos on the official site (www.aids2008.org). All these important people coming together under the goodwill banner of AIDS hiding the fragmented, self interested parties involved. No mention of the thousands of organisations and experts with different agendas competing for money, kudos, and air space. Photographic protests outside highlight the divisions. There’s the Mexican pro-life committee burning government pro-condom information; cross dressers marching against homophobia; and human rights activists campaigning against US detention centres for Mexican immigrants, to name but a few.

I’m willing to admit I’m wrong—I’m not there. I’m only a bemused editor watching the charade on my computer screen. PR shots; tepid press statements; and joint statements from previously antagonistic organisations—not to mention the obligatory calls for more money. What’s new this time? I’m bored with it already.

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Searching for Dr Condom

Although it is one of medicine’s most effective advances, we know tantalisingly little about the origins of the condom. The likes of Bartolomeo Eustachio, James Parkinson, and Thomas Hodgkin have fallen over each other in the scramble to attach their names to parts of our anatomy or our ailments. Yet the identity of Dr Condom—if indeed such a medic ever existed—has remained, appropriately, sheathed in mystery.

Suggested references to early condoms in prehistoric cave paintings and ancient Egyptian tomb art probably owe more to researchers’ overly fertile imaginations than to hard evidence. Historians are on firmer ground with records from Asia that document condom use before the 15th century. Fashioned from oiled paper or animal membrane in China, and from tortoise shell or animal horn in Japan, these were minimalist devices that dealt only with the tip of the problem.

The appearance of syphilis in Europe at the end of the 15th century spurred Westerners to follow suit. The Italian anatomist Gabriele Falloppia advocated a prophylactic made of linen as a barrier against the disease and in 1564 said: “I tried the experiment on eleven hundred men, and I call immortal God to witness that not one of them was infected.” Because the eponymous Fallopian tubes had already been named, his invention remained nameless.

The earliest surviving examples of condoms, made from mammal and fish intestines and dating back to 1646, were recently discovered in a latrine at Dudley Castle, England, where they had probably been flung by Royalist troops making a hasty exit. But the first reference in print to the name that has endured was penned by the irrepressible libertine John Wilmot, Earl of Rochester, in a poem written in 1665 entitled A Panegyrick upon Condom. Plainly his enthusiasm was in vain, for Rochester died in his prime of venereal disease. It may have been his ode that spawned the belief that condoms were invented by a physician to Charles II named Dr Condom or Condom. But it seems that Dr Condom never existed.

Nevertheless, by the 18th century condoms were widely available, though not universally enjoyed. James Boswell donned “armour” for one of his numerous encounters but grumbled that it was “a dull satisfaction.” This was scarcely surprising, as condoms were generally made from sheep’s or pig’s gut, secured with a silk ribbon.

Condoms acquired a certain foreign allure. Casanova described his experience in an “English overcoat.” But although an early 18th century poem praised “matchless Condom” whose fame would last “as long as Condom is a Name,” the identity of the inventor of one of the world’s favourite contraceptives remains hidden.

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Dead wrong

The most famous writer of the name Neruda is undoubtedly Pablo, the Chilean poet who won the Nobel prize for literature. He took his name, however, from Jan Neruda, the Czech writer of the second half of the 19th century whom he admired. Perhaps the reasons for the choice of an author’s pseudonym would make an interesting, if pointless, study in itself.

Jan Neruda is remembered mainly for his tales of Prague life, especially in a district known as the Little Quarter. This was a self contained community, full of interesting characters such as the army doctor regarded locally as a hero because he told a visiting dignitary to the hospitals of Prague that he didn’t know what he was talking about.

Because he was living in a nasty, intolerant autocracy, the Habsburg empire, the doctor was hurried on to retirement. In freedom loving, democratic Britain, by comparison, he would probably have been suspended and referred to the General Medical Council, to be cleared 15 years later at a cost to the taxpayer of several million pounds. You can’t stop progress.

One of Neruda’s tales is about Dr Heribert, who studied medicine but never practised it—as far as anyone knows, he had never so much as laid a finger on a patient since his graduation.

One day Dr Heribert was out walking when the funeral procession of Mr Schepelet, a prosperous local bureaucrat, passed him. Prominent among the mourners was Dr Link, the physician of the deceased, who was known to have received a fee of 20 guilders for his unsuccessful ministrations to the man in his last illness.

As luck would have it, the pallbearers dropped the coffin just as they were passing Dr Heribert. The lid came off and, the coffin now being tilted at an angle, the right hand of the deceased emerged.

Dr Heribert, being nearest to it, picked it up to return it to the coffin. “But he held on to it for a moment, his fingers playing uneasily and his eyes peering into the dead man’s face. Then he opened the dead man’s right eye.”

One of the mourners, who stood to inherit 500 guilders from the deceased, demanded to know what Dr Heribert was doing. The doctor cried out, “Wait! This man is not dead!”

Dr Link was not pleased. “That’s ridiculous!” he bellowed. “He’s insane!”

But of course Dr Heribert was right. The body was taken to an inn, where it revived, and Mr Schepelet soon resumed his bureaucratic duties.

For a time thereafter, Dr Heribert’s reputation stood so high that, from far and wide, rich and prominent people offered him a lot of money to be their doctor, but he always refused, retiring to his previous existence as petty rentier. Mr Schepelet remained his one and only patient.

The story does not recount Dr Link’s feelings on Mr Schepelet’s recovery, but it is unlikely that they were unmixed. What doctor has not felt the mortification of having been proved wrong by a colleague—or, for that matter, the joy of having proved a colleague, especially a prominent one, wrong? Always in the interest of the patient, of course.

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What doctor has not felt the mortification of having been proved wrong by a colleague—or, for that matter, the joy of having proved a colleague, especially a prominent one, wrong?

self-portrait with Dr Arrieta

For much of his working life the Spanish painter Francisco de Goya was not fond of the medical profession. In the “Caprichos,” a series of prints painted a few years after a prolonged and debilitating illness that left Goya deaf, a doctor is portrayed as an ass, sitting with a vacant expression at the bedside of a moribund patient, while in the background two dark figures stand menacingly over the bed. The print is cynically titled What Illness Will He Die From?

By contrast, however, is the double portrait that Goya produced many years later of himself with the physician who attended him during another bout of illness, Dr Arrieta. As in the earlier print this painting shows two main figures: the patient in bed and his doctor beside him. The pair are placed prominently in the foreground, light shining mainly on the doctor and the side of Goya’s face next to him. Goya is sitting up in bed, supported by one arm of his doctor, while the doctor holds a cup of medicine or water up to his lips. Behind the two in the dark background are three shadowy figures.

Goya’s face is turned away to the side, his eyes sunken, and his hands clutch at the bedclothes. By contrast the doctor appears alert and occupied in his task, his face a picture of focused determination as he supports Goya. It is not known who the figures at the sides are: whether they represent anxious friends or something more figurative and sinister. Either way, they are bystanders who contrast with the keen engagement of Arrieta and Goya.

Beneath the scene, as a way of explanation, is written: “Goya in gratitude to his friend Arrieta for the skill and great care with which he saved his life in his acute and dangerous illness, suffered at the end of 1819, at the age of 73 years. He painted this in 1820.” So the artist anchors the portrait to a specific time in his life, but the themes expressed in the painting are more enduring. The image Goya uses to convey his gratitude to Arrieta is one that symbolises the ideal of a successful bond between doctor and patient: a doctor engaged in performing a simple act, while holding his patient in an almost comradely embrace.

In addition, Goya portrays what serious illness feels like to a patient, more than any number of words. In the picture he appears tensed as he clutches nervously at the sheets; his face is grey and turned to the side in great pain and distress, almost on the point of giving up. This is the face of every patient who has had “œ [on examination]-looks unwell!” written in their notes.

The painting is in the Minneapolis Institute of the Arts. James Curran, GP locum, Glasgow jdcur@dircon.co.uk

Painted in 1820

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What serious illness feels like to a patient