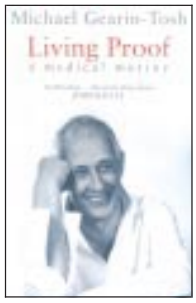
reviews

BOOKS • CD ROMS • ART • WEBSITES • MEDIA • PERSONAL VIEWS • SOUNDINGS

Living Proof: A Medical Mutiny

Michael Gearin-Tosh



Scribner, £14.99, pp 327
ISBN 0 7432 0677 0

Rating: ★★★★

A series of articles about *Living Proof* and its author—an Oxford English tutor "battling" myeloma through diet rather than chemotherapy—appeared recently in the *Times*. Any doctor reading them could be forgiven for prejudging Gearin-Tosh as an academic revealing nothing more than his ignorance of bell-shaped survival curves (which show that it's totally possible to live longer than the average and still not be cured). Yet one message to glean from both the press coverage and this book is that we shouldn't believe everything we read in the papers.

Living Proof is in two sections. Firstly, diary entries cover Gearin-Tosh's initial diagnosis and the turbulent year that followed. At times this sensitive, articulate man's thoughts and his interplay with an accompanying cast of friends rival journalist John Diamond's book *C: Because Cowards Get Cancer Too* (*BMJ* 1998;317:825). *Living Proof* is also a wonderful study in neurosis, and a warning to doctors about the futile cycles our hastily chosen words engender in susceptible people.

After seeking seven different medical opinions Gearin-Tosh discovers, almost by default, that he has rejected orthodoxy. The fact that he remained well throughout months of prevarication clearly influenced him retrospectively to embrace as the sole reason for his survival the "mild" alternative therapies that he had been dabbling with. (He doesn't state this explicitly, however.) Eight years of coffee enemas later he remains triumphantly alive.

In the second section, Gearin-Tosh discusses what exactly he thinks he is "living proof" of. He sidesteps some critics immediately by stating that it is not the diet's effectiveness that has been proven, but rather the "one size fits all" mentality of medicine that has been proven wrong. He argues that patients should be allowed time to try alternatives or to prove themselves "good" outliers on the survival curve before being rushed into chemotherapy.

Although the principle of giving treatment only when it is needed is sound, Gearin-Tosh's arguments are zealously impractical. For acute leukaemias and many solid tumours the sole therapeutic opportunity may be lost in delay. In addition Gearin-Tosh, perhaps not surprisingly given his background, is often wooed more by narrative than by scientific argument. Alternative practitioners are not all repressed seekers of truth and to give them carte blanche is naive.

Despite these faults *Living Proof*'s assertion that we should investigate those who do well and not dismiss them as quirks is undeniable. Perhaps it is the only way to replicate their successes. Setting himself up as the definitive outlier, updating his medical details regularly on a website, Gearin-Tosh's challenging "Explain me" ultimately stands out as laudable, brave, and a little awe inspiring.

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Allowing Dignity in Death

Dave Moor

Privately published
ISBN 0 9540799 0 6
Copies available at £10 each including postage from Michael Irwin, 15 Hovedene, Cromwell Road, Hove, East Sussex BN3 3EH

Rating: ★★★

In 1999, Dr David Moor was tried for murder and acquitted. He was accused of abusing the doctrine of "double effect" (which allows a doctor to administer drugs to relieve pain and suffering, even though the dose used may hasten death). But before you summon up thoughts of another Harold Shipman, think again. Moor was arrested for providing good terminal care for a dying patient. He had done what just about every doctor in the United Kingdom has done at some time or another, and will continue to do. It took nearly two years for the prosecution to bring him to trial and just 69 minutes for the jury to find him not guilty.

Moor and his wife wrote this account from the notes they kept during the two years leading up to and throughout the trial. Although they could probably have found an established publishing house to take it on, this book was published privately. It's a surprisingly good read. Surprising, because most of it is a meticulous blow by blow account of the case as it unfolded in court and I hadn't expected to find it as riveting as I did. I found the early chapters hard work. But later, as he finds his rhythm, Moor becomes a natural storyteller and there are moments of high drama and suspense, particularly as the prosecution's medical evidence is pulled neatly and methodically apart.

But there is something unnerving about Moor's telling of his story, and that is his complete lack of negative emotion. This is a man who seems unable to express fear, anger, or hate. At most he describes mild irritation. Here is a doctor who when hounded by the press on what was essentially a trumped up murder charge can only describe the people around him—and the circumstances in which he finds himself—in warm terms. Everybody is just "doing their job." The narrative may be clear and Moor's eye for detail accurate, but his range of emotional expression seems alarmingly narrow. The last line in the book is "I would be the first to admit that it was Hell." But as a reader, this was the first time I had any inkling that his calm exterior had really been pierced at all during the ordeal.

Dr Moor died prematurely in October 2000, just 18 months after being acquitted. I can't help wondering if the emotional stress of his Hell—so conspicuous by its absence in this book—finally caught up with him.

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Items reviewed are rated on a 4 star scale (4=excellent)

BOOKCASE

● Amid the ongoing debate over the increasing use of recreational drugs and whether or not to decriminalise cannabis comes a new edition of **Drug Notes**, a set of booklets providing information on a drug's history, its health effects, legal status, prevalence, and supply (Drug Scope, £1.50 per pamphlet, tel: 01235 465500). Titles include heroin, cannabis, cocaine and crack, ecstasy, ketamine, and GHB (gammahydroxybutyrate). The booklets adopt an informal style (although without too much "street" language) and would be useful for anyone coming into contact with people who may use recreational drugs. They are well written and include short narratives from users that offer an insight into the often very powerful effects of the various substances.

● Despite affecting more than 520 million people worldwide, hepatitis B and C are often poorly understood. **Hepatitis B and C: Management and Treatment** (T Poynard, Martin Dunitz, £19.95, pp 148, ISBN 1 84184 077 7) has very short chapters—often only a few pages long—with frequent subheadings and excellent illustrations, all of which go to make this near pocket sized book easy to read. Particularly useful are the chapters on immunomodulating drugs and comparisons between them, which are not such heavy reading as they may sound. This book will appeal to specialists, but the simple uncomplicated approach makes it appropriate for a wider audience.

● **Elderly Medicine: A Training Guide** (G Rai, G Mulley, eds, Martin Dunitz, £45, pp 430, ISBN 90 5823 234 4) is an evidence based volume covering the whole field from social gerontology and management of Parkinson's disease to how to be a successful consultant. The authors use questions as subheadings on which to hang facts and this gives the book a lively feel to make up for its lack of colour and illustration. End of chapter key points and self assessment questions mean that the book works well as a revision aid.

● **Gynaecology: Integrating Conventional, Complementary, and Natural Alternative Therapy** (A Ostrzenski, Lippincott Williams & Wilkins, $69.95/£53, ISBN 0 7817 2761 8) provides a novel approach. It is an evidence based reference book that details both conventional and alternative treatments to all the gynaecological disorders and diseases. Conventional therapy is, however, very much in the driving seat and often no specific alternative treatment is recommended. Where there are alternative recommendations—for example, for urinary tract infection or prevention of cancer—they are all evidence based and provide interesting reading as a companion to the rather densely presented conventional material.

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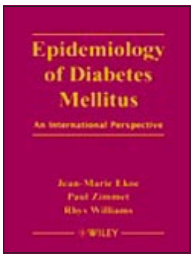
The Epidemiology of Diabetes Mellitus: An International Perspective

Ed Jean-Marie Ekoé



John Wiley and Sons, £120, pp 454
ISBN 0 471 97448 X

Rating: ★★★★

In 1978, Dr Kelly West published his monograph on the epidemiology of diabetes and its vascular complications, earning himself the name of "father of diabetes epidemiology." Almost a quarter of a century later we have a worthy successor to this text. And, if ever there was a need for a compendium of current epidemiology of diabetes and its complications, it is now. Diabetes mellitus, as readers will quickly discover if they didn't already know, is a worldwide pandemic straining medical resources and capacity.

Within the covers of this book are insights from the studies of diabetes in different populations. For example, the incidence of type 1 diabetes in children is over 35 in 100 000 in Sardinia and Finland but less than 10/100 000 in Italy and France. There are differences in sex ratios in childhood type 1 diabetes—a large excess in girls in Slovenia and an equal but opposite excess in boys in Portugal. Diabetic nephropathy is rapidly declining in some countries (in Sweden, it is virtually disappearing). There are also two populations of African-Americans with type 2 diabetes—one with and one without insulin resistance.

There are pithy, readable sections focusing on the major diabetic complications (for example, nephropathy and neuropathy). Special praise is due to Karvonen et al for a superb perspective on the global epidemiology of diabetes; to Banerji and Lebovitz for insights into type 2 diabetes in African-Americans; and to Ekoé and Shipp for a fascinating compilation regarding the enigma of malnutrition-related diabetes.

Since each review stands on its own, one can dip into this volume at any point to satisfy a particular curiosity. All of the chapters are as up to date as they can be in a multi-authored text and provide guides to the ferment and richness of current studies in this rapidly changing clinical arena.

One hopes that this is just the first edition of what will become the definitive textbook in the field.

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WEBSITE OF THE WEEK

Assisted suicide In the past 20 years, we've seen the rise of a genre of writing in which patients recount their personal battles against illness. Jeff Aronson calls these stories "autopathographies," and is compiling the definitive list of such tales (http://bmj.com/cgi/content/full/321/7276/1599).

If Aronson included patients' internet diaries, his list would grow exponentially. How would he begin his search? One place would be the Personal Documentary Center (http://home.earthlink.net/~hevern/diaries.html), which chronicles personal testimonies on the internet.

Why do patients want to tell all? For many, it is a cathartic release of emotions that patients fear might be toxic if repressed. But for Nancy Crick, a 70 year old Australian woman with bowel cancer, self expression has become a political tool in a campaign for the right to die.

Crick says she can no longer tolerate the chronic pain and diarrhoea that are a constant part of her life. For a brief time in Australian history, she could have requested physician assisted suicide in Australia's Northern Territory. An act permitting such assistance, The Rights of the Terminally Ill Act, took effect on 1 July 1996, but it was overturned by the federal parliament in March 1997. And now, at the time of the fifth anniversary of the act being repealed, Crick is planning to end her life by taking an overdose, surrounded by her loved ones.

Crick wants the act reinstated, and to argue her case she is keeping a diary of her suffering in the run up to her suicide (www.protection.net.au/nancycrick/). Her diary entries are intended to make us feel uncomfortable, so that we might get a glimpse of her agony. On 16 February, she wrote, "Today I rose at 4am to visit the toilet, stayed there till 10am." Under a photo of the toilet, she writes, "Welcome to my world."

Crick would have been heartened by a recent *BMJ* editorial (http://bmj.com/cgi/content/full/323/7321/1079) arguing that physician assisted suicide should be legalised. Others, however, were horrified (see p 846). But whatever our views, a series of high profile cases around the world is forcing us to acknowledge that patients want a greater say in decisions at the end of their lives.

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PERSONAL VIEW

The role of role avoidance

I've only recently heard of the term "role avoidance." Looking back I realise that it's a strategy I've been using for a long time but one which has remained nameless until now. Perhaps I should explain. I am a doctor who stammers and have just embarked on a course at the City Literary Institute in London in what is called "block modification." Those of you who are familiar with stammering therapy will know what this entails. For those of you who aren't, it is based on the work of a number of American speech pathologists, including Charles Van Riper and Joseph Sheehan, and basically comprises three stages—identification, desensitisation, and modification.

The identification stage involves looking at both the overt and covert aspects of stammering, and the "iceberg model" described by Joseph Sheehan is useful for this purpose. Just visible above the waterline are the overt aspects of the stammer—the outward struggle, as it were. However, below the waterline lurks the often much larger covert component—the feelings of anger, resentment, frustration, and poor self image. It is these that result in avoidance strategies to lessen the discomfort associated with speaking situations, and right at the top of the hierarchy of avoidance is role avoidance. Although something of an abstract concept, the essence of role avoidance is the use of tricks or techniques to achieve fluency and thereby avoid taking the role of a stammerer, which as a doctor would be unacceptable.

From the moment I entered medical school and throughout my career it has been apparent to me that medicine favours outwardly "flawless" individuals. The embarrassed looks of the panel as I struggled my way through medical school interviews. The nervous laughs of my colleagues as I did presentations. The "do something about your speech" comment from the surgical senior house officer when all I wanted was an opinion on a patient. And perhaps most galling of all, being turned down for a GP rotation at a hospital at which I had worked previously and from which I had good references, just because I stammered. All these experiences fostered in me the belief that somehow I wasn't a "proper" doctor, that it would be far easier to avoid being a stammerer at all.

To do this I've created a doctor persona—authoritative, knowledgeable, perhaps slightly brusque even, and usually avoiding eye contact for fear of seeing a reaction in my listener. In this role I can be considerably more fluent than I normally am. I can't deny that this strategy has served me well in the short term. It has enabled me to function effectively as a doctor for several years despite having a stammer. So why change it, you may ask?

Well, I believe that block modification therapy is only going to be truly successful if I can disassemble my role avoidance strategy and be more open and honest about the fact that I stammer. This is the difficult part—old habits die hard. Coupled with this is a need to work on some of my beliefs, and I have made some headway already in this respect. Attending a self advocacy course for people who stammer at the City Lit last year and more recently going to the British Stammering Association's annual conference in Liverpool have both had a profound impact. Meeting other stammerers who are both eloquent and intelligent, and listening to their often inspirational stories, has filled me with the sense that I can be an excellent doctor who, by the way, just happens to stammer.

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SOUNDINGS

A painful experience

I was on an Airtours flight from Florida recently when medical assistance was called for. The patient had benign prostatic hyperplasia and was in retention. Since we had another seven hours to fly, holding on was not an option. He needed a catheter, so I was reassured that the plane's inventory of medical equipment included catheters and collecting bags. But I then found that there was no lignocaine gel, no lubricating jelly, and no gloves.

Performing a catheterisation without gloves or anaesthetic was not pleasant, but the lack of lubricating jelly proved a bridge too far, so when the patient started screaming I deputised some antiseptic cream as an ersatz lubricant.

As the catheter was non-retaining, I advised the greatly relieved patient not to drink any fluids for the rest of the flight and to attend accident and emergency on his way home. I then had to remain on alert for the next seven hours. Before disembarking I was asked to sign a form indemnifying Airtours against any claim arising from the procedure and was offered a bottle of wine as a gesture of appreciation.

I had expressed my concerns to the steward, but having heard nothing after a few weeks I contacted Airtours. The company's flight officer explained that Airtours usually received inflight medical advice from an institute in the United States and the airline's medical officer assured me that gloves had been present in the equipment box—I just hadn't found them. He said that he had done hundreds of catheterisations and had never used lignocaine gel. In a subsequent letter, he insisted that the company's equipment was standard to all airlines, and that "the catheters are self lubricating, and being small and atraumatic do not need lubrication or local anaesthetic." Really?

As a doctor, I had no choice but to respond to the patient's needs, and without that choice I was forced to perform a difficult procedure with inadequate equipment. The poverty of the Airtours response was depressing, especially considering how much money I had saved the company; if a doctor hadn't just happened to be on board, the plane would have had to return to Florida. Maybe in future Airtours should take one fewer passenger and a bit more equipment, and maybe omit those magical self lubricating catheters. I won't be travelling with Airtours again—not without taking my own lubricating jelly.

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