reviews

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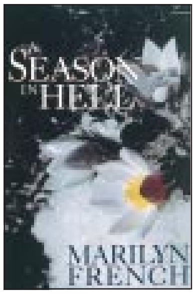
A Season in Hell

Marilyn French



Virago Press, £15.99, pp 288
ISBN 1 86049 447 1

Rating: ★★

This is a remarkable true story. In 1992 Marilyn French, best selling author of *The Women's Room*, was found to have inoperable squamous carcinoma of the intrathoracic oesophagus, presenting with metastatic supraclavicular nodes. She was told that even with localised disease and intensive treatment the chance of surviving five years was less than 1 in 5 and that metastatic disease meant terminal illness. Although espousing truth and assertiveness in her everyday life, she chose to disregard these figures and decided that she would invent a personal chance of 1 in 4. Five years on and in complete remission, she gives her account of treatment with fluorouracil, cisplatin, and radical radiotherapy and its consequences.

I found this a gripping read and enjoyed trying to piece together what really happened and why, and to anticipate the side effects of treatment as the patient began to notice symptoms. There was a "full house" of acute complications—nausea, mouth ulcers, diarrhoea, neutropenic sepsis, paraesthesia—although when they occurred they seemed to take her medical attendants by surprise. Some mysteries I could not solve: why for instance was she in the intensive care unit for two weeks in a coma?

The fragmented nature of transatlantic care is well illustrated: no one provided overall direction and support, each problem was offered to the appropriate specialist and, when she finally reached the end of her tether in clinic and became impatient and angry, the psychiatrist. The patient herself organised her referrals to over 50 doctors for treatment and second opinion, as well as to alternative practitioners for acupuncture and visualisation, and to nurses and physiotherapists. Holistic care depended on advice from her family and friends rather than from the establishment.

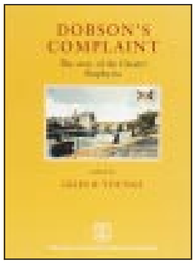
Although they generally did the right thing, most of the medical staff emerge from this account as dogmatic, abrupt, and apparently uncaring. They remained aloof and impersonal, and, because they wished to avoid raising false hopes, were generally gloomy and unwilling even to share her pleasure at the good response to treatment.

Was it all worth it? At present she is a chronic invalid with painful osteoporotic fractures, oesophageal stricture, cerebellar degeneration, diabetes, and kidney stones, spending $1500 a month on drugs and physical treatments, and is by no means an advocate of life at any cost. The final chapter places her experience in context—she feels that response to treatment is a matter of luck and shrugs off the "miracle patient" label. She is eloquent in her description of living for the moment rather than for a delusional and unattainable future ideal. It is a pleasure to read her description of the "plateau of serenity" she has reached, and I hope that this continues.

Irene M Peat, *consultant in clinical oncology, Leicester Royal Infirmary NHS Trust*

Dobson's Complaint: The Story of the Chester Porphyria

Ed Giles R Youngs



Royal College of Physicians, £18.50, pp 200
ISBN 1 86016 047 6

Rating: ★★★

There are many aspects of medical disorders that fascinate doctors: the application of the latest scientific techniques, complex biochemical mechanisms, the detective work involved in teasing out a complex history, the personal strengths that emerge when tragedy strikes, and the thrill of finding a new disorder. This book covers all these features and more about one of the rarer variants of porphyria—Chester porphyria, which results from a combination of the deficits found in the commoner acute intermittent porphyria and variegate porphyria. Although concentrating on this variant, the book also provides an overview of the porphyrias in general.

Giles Youngs, a physician in Chester, tells the story of the painstaking work of himself and his past juniors (who have contributed to many aspects of the research in this book). They traced back members of the 300 strong Cheshire kindred affected by this condition to the marriage of a Dee salmon fisherman in 1888. Youngs is brutally honest about how he was initially shamed by one of the family—who clearly knew more than he did about the nature of the curse responsible for wiping out large swathes of her family—into starting his mammoth task, which clearly became a labour of love as time progressed. He pays due debt to the doctors who preceded him, in particular to Dr Zorka Bekerus, who in 1965 was the first to recognise the uniqueness of this variant of porphyria.

The monograph is comprehensive in its coverage of all the aspects of this disorder. Individual chapters stand alone—indeed, several are transcripts of previously published work—and this inevitably leads to a degree of repetition and some contradiction. Nevertheless, the advantage of this arrangement is that the book can easily be browsed and used as a reference for the genetics and biochemistry of this disorder as well as the clinical features. These include neurological and psychiatric disturbances, hyponatraemia, and the hypertension and renal failure that have been responsible for so much of the mortality in the Chester kindred.

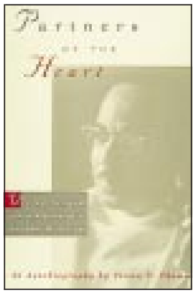
Youngs has traced the death certificates and case notes of long dead members of the families, identifying with the benefit of hindsight the errors made by previous generations of doctors. He avoids, however, any sense of triumphalism and never loses sight of the personal tragedy that obviously still haunts the family.

My only criticism is that no room was found for the family's voice. As with porphyria kindreds elsewhere, morbidity and mortality have been reduced by better diagnostic techniques, avoidance of precipitants (especially barbiturates and other drugs), and treatment of accompanying hypertension. However, family members continue to live with the burden of a rare genetic disorder, one described as the "little imitator" because of the multitude of symptoms, which often led sufferers to be misdiagnosed as "hysterics." With this background, they must have a fascinating perspective, which would have complemented this enthralling book.

Helen Crimlisk, *trainee in child psychiatry, University of Marburg, Germany*

Partners of the Heart

Vivien Thomas



University of Pennsylvania Press, £13.95, pp 245
ISBN 0 8122 1634 2

Rating: ★★★

Multidisciplinary team working is the employment benchmark in the health service this decade. This applies not only in the provision of clinical services, but also in the prosecution of surgical research. However, the concept is not new. Many of the great surgical research laboratories of the past had fruitful collaboration between expert technicians and clinician scientists. In no department was this relationship better illustrated than at the Johns Hopkins Medical School. This autobiography by Vivien Thomas, who ultimately became supervisor at the Surgical Research Laboratory of the renowned Professor Alfred Blalock, essentially concerns this relationship. However, at a different level, the place of a black man's involvement in the, until very recently, white male dominated world of surgery and surgical research is explored.

Vivien Thomas was born in 1910 in Louisville, Kentucky, the fourth of five children. His father was a carpenter, and the young Vivien was brought up in Nashville, Tennessee. He received a good basic education and had ambitions of attending university and possibly medical school. However, the economic depression of 1929 necessitated a job as a carpenter's apprentice, and in 1930 Thomas took what he expected to be a temporary job as a technician in Blalock's laboratory in Vanderbilt University.

During this time, Thomas was involved with large animal experimental work on shock, renal failure, and transplantation. In 1938 he developed with Blalock a subclavian-pulmonary artery anastomosis in an attempt to produce pulmonary hypertension. Although the model was not a complete success, the technique was the answer to the problem of patients with tetralogy of Fallot, when, several years later, it was found that those patients needed an operation that would bring more blood to the lungs.

In 1941 Blalock accepted the position of surgeon in chief and chairman of the Department of Surgery at Johns Hopkins Medical School and invited Thomas to join him as his technician. In the Hunterian laboratory at the medical school new techniques in cardiac surgery were developed to treat coarctation of the aorta, pulmonary A-V fistulae, atrial and ventricular septal defects, and transposition of the great vessels. A number of anecdotes give particular insight to the complex and rather insecure personality of Alfred Blalock. There are illustrations from the techniques of the pioneering experiments that Thomas largely devised.

Recognition came very belatedly: shortly before his retirement in 1976, he was awarded an honorary degree by Johns Hopkins and given faculty status. Tellingly, he received his first coauthorship only after nearly 20 years as a technician, despite his seminal contribution to many important early surgical studies, including pioneering work on paediatric cardiac surgery. How much this reflected Thomas's status as a black non-graduate technician and how much it was due to the then practice of citing one or two authors on a paper is unclear, but it makes an interesting contrast to the now opposite problem of adhering to the Vancouver criteria.

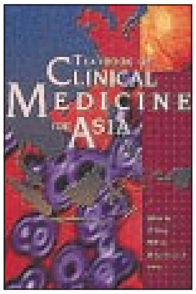
Disappointingly, Thomas somewhat misses the opportunity to give a sociopolitical and cultural account of the changing role and position of black Americans in professional and academic roles between 1930 and 1977. This was a time of change and upheaval, and it may be that the author was too engrossed in his research and family life to feel able to make comment.

None the less, both clinical and academic surgeons and medical historians will find this a worthwhile read. This is reflected in the fact that the text has been used as the basis of a television documentary.

Anjan K Banerjee, *consultant surgeon, Royal Halifax Infirmary*

Textbook of Clinical Medicine for Asia

Eds J Y Sung, P K T Li, J E Sanderson, J Woo



Chinese University Press, $60, pp 848
ISBN 962 201 773 8

Rating: ★

This book reminds me just how advantaged we Western Europeans are in medical education. As students, we can read textbooks of medicine that are predicated on diseases common and relevant in our environment, with epidemiology, clinical features, and treatment based on information gathered from industrialised societies. Such advantages are even greater for those that have English as their first language because most medical literature uses this medium, and clinical medicine is often brought to life by colourful descriptive and vernacular phrases.

In Latin America, most of the leading US textbooks have been translated into Spanish and Portuguese, and there is a growing market in specialist texts written by "local" authors. Having contributed to one textbook on infectious diseases in Brazil, I can testify to how successful such ventures can be in harnessing regional expertise to produce a valuable national resource. In Africa one postgraduate text stands out—Parry's superb *Principles of Medicine in Africa*—and is the benchmark for any attempts to capture the intricacies, subtleties, and fascination of medicine in that continent.

Those textbooks that succeed usually take as their standpoint the practice of medicine in that locality first and foremost, and then contrast this with Western (north American and European) experience where this is relevant. The reader should end up with a relevant and appropriate overview and feel for what he or she will be faced with, and which, with further experience, can be contrasted with disease patterns and management issues far away. A physician from outside the region should come away with the sense that either his or her specialist area is surprisingly similar or has intriguing and important differences.

Against these benchmarks, how does *Textbook of Clinical Medicine for Asia* fare? It originates from Hong Kong but rather ambitiously aims to cover Asia. The authors are a mix of expatriate and local consultants. None of the expatriates has the feel, passion, and breadth of vision that, for example, Eldryd Parry had for Africa, and this shows. The local authors are anglocentric, approaching their chapters from a Western standpoint and then trying to contrast this with smatterings of local data and anecdote. No references from Chinese sources are cited, and I get little feel for medicine in Hong Kong, let alone South East Asia. Students may find it useful to pass exams set by their professors, but I fear it will inspire relatively few. Production of such a book is timely and would fill a gap in the literature, but this text is, sadly, quite a disappointment. I hope others will try to improve on this first effort, and learn from its shortcomings.

Charles F Gilks, *senior lecturer in tropical medicine, Liverpool School of Tropical Medicine*

Reviews are rated on a 4 star scale (4=excellent)

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Viagra, rationed

On 21 January, the health secretary Frank Dobson's announcement on prescribing Viagra (see p 273 and p 279) was denounced by the BMA as "cruel and unethical." But doctors found few allies in the press. As Jennifer Trueland wrote in the *Scotsman* (22 January), the Viagra debate "shows that the NHS has finite resources and that it cannot meet every demand." The *Evening Standard*, however, was first into the fray (21 January): "Doctors do not run the National Health Service: taxpayers do. But try telling that to the British Medical Association. It was in the interests of the taxpayers, and of common sense, that the Health Secretary, Frank Dobson, announced his new, binding guidelines.... The BMA needs to be slapped down hard on this."

The *Independent* (23 January) argued that "rationing by queueing" was as old as the NHS, and that, while the 1990s was "the Happy Decade" (thank you Prozac and Viagra), it would "also be remembered as the decade in which the rationing of healthcare started in Britain." The BMA, it claimed, was more concerned about doctors' priorities than those of the NHS—"as selfish and irresponsible a vested interest as the worst of the flying pickets in the 1970s." Doctors had become rebels, and their leaders rabble rousing trade unionists: "For the BMA to instruct its members to defy the Government by prescribing as much Viagra as they think is justified by 'clinical need' until the guidelines take effect is the kind of gesture politics which got Arthur Scargill where he is today."

"Dobson's choice," as the media dubbed it, centred around the health minister's belief that impotence isn't life threatening and doesn't cause physical pain. "We have to find a sensible balance between treating men with a distressing condition and protecting the resources of the NHS to deal with other conditions, for example," chose Mr Dobson, "cancer, heart disease, and mental health problems." Apparently not the mental anguish of impotent men, though.

STEVE BELL

General practitioner David Devlin told the *Daily Telegraph* (22 January): "I think this is quite unfair. I have more than 100 patients on Viagra and all are suffering from impotence caused by psychological or physical disorders. A lot of people consider Viagra users to be promiscuous men. This is not true."

Andrew Marr of the *Observer* offered an explanation (24 January): "We had reason to think that his [Dobson's] contribution to the drugs debate would be to manufacture the filthiest Viagra joke on the planet. Instead he has changed the National Health Service forever. This is about values: and unlike his jokes, Dobson's are decent to the core. A nation which spends taxpayers' money on better erections, while leaving old ladies to soil themselves and starve in under-staffed wards, is sick indeed." Marr is convinced that Dobson's choice is the "clearest act of national drugs rationing yet." Who could disagree?

Mr Dobson was firm, doctors were defiant, and Pfizer—manufacturer of Viagra—was furious but exploring "all its options." For three days the controversy raged: "Impotence is not a joke, say doctors" (*Independent* 22 January), while "Impotence is not really such a serious problem, claims Dobson" (*Express* 22 January). The *Express* applauded as "Dobson strikes right balance on Viagra" (22 January), but added a new twist: "And today The Express reveals that because the drug is registered in Britain, this country's exchequer makes money from every pill sold across the world—in theory, more than enough to offset the costs of prescribing Viagra."

Confused? The *Sun* seemed to be as well. The "Sun Man's Sex File" confessed: "Dear Mr Dobson, I am a Sun journalist and I am on Viagra—when I can afford it" (22 January). Page 3 not doing the trick then? "How dare you suddenly change the rules of the NHS now, after I have spent the better part of my working life paying into it? Viagra has been a Godsend." Another *Sun* journalist, Richard Littlejohn, was unhappy that the NHS should "legalise and supply a proven killer like Viagra." Instead, he offered his own rationing test: "If you're strong enough to get the cap off the bottle, you can buy it yourself."

Inevitably, the prime minister made one of his regular forays into the tabloid press. "We have to be hard on Viagra," he exclusively told the *Mirror* on 23 January. "I personally believe that the public understands very well that there are certain severe medical conditions in relation to impotence that should be treated on the NHS." Do they? "You have got to make a choice as to priorities."

Rationing is the word the government dare not mention—prioritisation is more acceptable in "Third Way" terminology—but everyone else is dispensing it freely. The first rationing skirmishes have been won in the press by the government, with doctors portrayed as power crazed idealists rather than patients' advocates. Rationing is now clearly with us, though the method of making it work remains elusive. Where will the National Institute of Clinical Excellence fit in? How might doctors' and patients' views be better considered?

Viagra has crystallised the rationing debate as only a matter of male sexual prowess could. Where now Viagra? Where now rationing? The future is foggy, not least for impotent men.

Kamran Abbasi, *BMJ*

WEBSITE OF THE WEEK

http://www.viagra.com/ Viagra has so thoroughly captured the popular imagination that it is surprising that its official website is not more extensive. Perhaps aware that on the internet all the hype will happen elsewhere (for example, try alt.support.impotence at http://www.dejanews.com), its manufacturer, Pfizer, has supplied a few tasteful graphics—of mature elders gazing lovingly into each other's eyes—and a datasheet for healthcare professionals and left it at that.

It is an interesting question whether supplying the detailed information on a datasheet will dampen public enthusiasm for the drug. Information about serious cardiovascular events associated with the drug is prominent on the site, and, unsurprisingly, most occurred during sexual intercourse.

The mind-body split is informing the actions of the British government, which forbade NHS prescriptions for non-organic indications last week. Patients with an organic cause for their impotence will be allowed one tablet a week by the taxpayer. This is illogical, as the drug treats only the condition of desiring an erection, not the underlying disease. Leaving such philosophical disagreements aside, the thought of so august a body as the Standing Medical Advisory Committee solemnly deciding how often one should have sex is highly amusing.

Those whose desires are greater will find a mountain of links for online ordering—http://kwikmed.com/viagra/101297/ is a typical example. Customers fill out the online questionnaire (including credit card details), pay the consultation and prescription fees, and wait for the postman. It is also an opportunity to see what modern repeat prescribing software might look like, and how easy it will be to lose your patient's attention in a networked world.

Douglas Carnall
http://www.carnall.demon.co.uk

PERSONAL VIEW

The sharp edge of Damocles

Cicero tells of a courtier named Damocles, invited to a banquet hosted by the emperor Dionysius, who requests that Damocles is seated beneath a sword suspended from the ceiling by a single horse hair. Initial delight at being placed in the seat of honour turns sour when Damocles realises the ever present threat of untimely death.

I was fascinated to hear the term "Damocles syndrome" used to describe the psychosocial stresses experienced by survivors of childhood cancer. No story could more accurately describe the legacy of overcoming the original diagnosis.

Sixteen years ago I developed an osteosarcoma of my femur and underwent an above knee amputation and a prolonged course of chemotherapy. I was 16 at the time and hoping to become a doctor. My life was irrevocably changed by this experience—not as you might suppose for the worse. I have experienced an intensity of life that I do not regret, in living each day as if it were my last.

There was no formal psychological support ... where I was treated

The period of initial surgery and chemotherapy was incredibly traumatic. It was a time of pain, fear, and confusion on an overwhelming scale. It was only my family and my faith that enabled me to overcome the despair I felt. There was no formal psychological support provided for patients with cancer and their families at the hospital where I was treated. We muddled through with a combination of self help, close friends, and prayer.

A year after my amputation, I was able to take up a place at Liverpool University to study medicine. This was the point when I decided that I would overcome cancer. Life suddenly became too good to miss out on, and spurred on by my fellow students I realised that the only way out was through.

My initial taste of Damocles was the fear of relapse from metastatic disease. Until this point I believed that my cancer was fatal. "The Big C" mentality of society had already stuck, and despite the months in hospital I do not recall anyone telling me that I could survive. Armed with several orthopaedic textbooks, I became an expert on osteosarcoma. I discovered that I had reasonable "odds." Survival was not guaranteed, but at least it was an option. Instead of worrying about "lumps everywhere" I learnt about the likely sites of relapse, limiting my concerns to my lung and brain. The possibility of metastases loomed in my mind constantly. In order to cope with my anxiety, I set myself small goals to live for—Christmas; the medical ball; exams. Consequently the first and most crucial disease free anniversary came round much more quickly than I had expected.

My first anniversary was a black day, as the reality of cancer hit me again. Each subsequent year my fear reduced, and I began to hope that I would qualify as a doctor. I never set myself the goal of a total cure, imagining that this would tempt fate. Instead I planned in anniversaries and special occasions. There were many scares over the years. I became obsessed with checking for lumps and sinister symptoms. There was more than one 3 o'clock in the morning diagnosis of lymphoma or brain secondaries, leading to another round of negative investigations. I had always set myself a special goal of five year survival, and when the anniversary came round I threw a huge party to celebrate with plenty of champagne. The celebration marked a putting away of the fears of metastatic disease.

New anxieties about starting a family followed. Somewhere in the recesses of my mind I have memories of being told about infertility and teratogenicity after chemotherapy. Over the years I had come to accept that I would never have children, so I was delighted when I became pregnant. The pregnancy was beset with worries that my child would be born with serious congenital problems, and I experienced frequent nightmares. My healthy son was born on my 10th anniversary, which I felt was an appropriate time to discharge myself from formal follow up. Two miscarriages followed, which heightened my concerns, but during my fourth pregnancy frequent scans reassured me that my daughter was healthy.

The most recent fear to arise is the possibility of developing a second primary cancer. Memories of the chemotherapy and radiation I have received sometimes haunt me. When these fears occur, rationality and clinical acumen disappear, and I become a cancer patient trying desperately not to panic. My worries have not been brushed aside by my colleagues, who have acknowledged my need to be reassured.

I do not know how far Damocles made it through the banquet, but I think I am on the "coffee and mints" course now. I have glanced at the ceiling more times than I can remember, but I have enjoyed the tastes of survival. I have not got to this point on my own. My faith has helped me through the dark times, and the reassurance of family, friends, doctors, and colleagues has served to place a much needed safety net between me and that sword.

Mary Self, *psychiatric senior house officer, Cardiff*

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SOUNDINGS

Science night

"Science," announced my 9 year old son recently, "is BORING."

In a household where everything from cookery to bicycle maintenance is hypothesis driven, and where the younger sibling invariably has experiments on the go in the compost heap or outside drain, this statement is the ultimate heresy. We book our elder son and six friends in urgently for a night at the Science Museum.

For £20 a head, we get to pitch our sleeping bags under the exhibit of our choice—from a 30ft double helix to an original prototype of the internal combustion engine. Our own personal trainer in a red sweatshirt runs us from one hands on activity to another until just short of midnight, and resumes again at 6 30 am. Four hundred of us make our own slime by adding the three "carefully measured" and very smelly ingredients up to the black line in a tall plastic beaker, placing lids on tight, and shaking on down to Chubby Checker. The kids feel chemistry happen in their hands, and the slime goes into the party bag.

"Does hydrogen burn?" asks an impish demonstrator, as if she genuinely cannot remember. A show of hands suggests we are not sure either. She holds a taper to the balloon, which explodes in a blue flash and a loud bang. Everyone is now paying attention. Another demonstrator holds an air filled balloon in liquid nitrogen and we watch it slowly collapse—"Must be about minus 79 in there now, which means it's snowing pure carbon dioxide"—and re-expand exactly on rewarming. This time, no bang. We discuss the anticlimax.

An astronaut in a space suit and with an authentic American accent tells us what we really wanted to know about flying to the moon—how to get the bubbles out of cherryade, and how to go to the lavatory when there is no "down." Later, we have a midnight feast in the shadow of a real lunar module, and press a button to hear Neil Armstrong's crackling voice, "One small step for a man . . ."

We've seen and heard most of it before, but when you're sliding in your socks along the polished floors hours after official bedtime, and still no one is telling you to stop fiddling with the switches, science is no longer boring. My son is a willing convert to a career in science, which gives me an idea for the various recruitment crises in medicine. Anyone fancy running a sleep over at the Royal College of Psychiatrists?

Trisha Greenhalgh, *general practitioner, London*