



**Black as a bile pigment stone: novelist Will Self gets liverish, p 1300**

## VIEWS & REVIEWS

### Life is for living

PERSONAL VIEW **Anonymous**

**F**ive years ago I “lost” my husband when he had a brain haemorrhage, but as a result of medical intervention I can still visit him in his caring nursing home. With treatment for his various problems he is usually not distressed or in pain. He is no longer angry at his plight, but in place of a lucid analytical mind he is “sans everything”—with a familiar voice. Fortunately, he no longer has insight into his condition and rarely worries about his future. However, when I consider his situation and then hear about other types of patient who are denied drugs that may improve the quality of their life but that the NHS is not prepared to fund, I question the balance of its and our values and priorities.

I wrote about Michael (not his real name) in the *BMJ* in June 2004 (2004;328:1445) a year after a percutaneous endoscopic gastrostomy (PEG) tube had been placed in him without my consent, against his family’s wishes, and despite the guidelines published in the *Lancet* in February 1997 (*Lancet* 1997;349:496-8). At the time we said, wryly, that it would affect the hospital’s target figures were he allowed to die. Since then we have witnessed his distress, while watching his vascular dementia (a result of his brain haemorrhage, his consultant says) follow its inevitable course.

He is now immobile, despite skilled input from a highly specialised stroke physiotherapist under whose guidance his mobility improved dramatically. He also has intermittent seizures, which his consultant considered are probably drug induced. He had already endured total blindness almost all his life. Five years on I wonder what clinical audits have been done on this decision making process and on the quality of life of patients who are “saved from death” when they are admitted to hospital unconscious and the medical team decides a PEG tube is

needed if they are to survive. Patients with cancer and many other illnesses may be able to express their views. But patients admitted unconscious after a stroke often have only a distraught family whose views may or may not correspond with their own (assuming that the patient has not made a living will or advance directive).

I have seen medical students, like a school party, visiting the nursing home, but this fleeting snapshot does not give them a true picture of these patients’ lives. Many of the students are likely to have little or no knowledge of elderly people beyond their own grandparents, who may have died when they were children. Working for some time in a nursing home would be of practical use to these future medical practitioners, who need to be as fully informed as possible before they, in their turn, make these difficult life and death decisions. They could then observe patients’ anxiety, depression, frustration, and confusion, conditions which, like their physical problems, may not respond to medical intervention.

When I approached Michael’s general practitioner at the time of the decision to place a PEG tube, requesting that he be involved in the decision making process, I was told it was not etiquette. Why? Etiquette and deference to a consultant should be irrelevant. Experienced general practitioners, unlike hospital consultants, may have known a particular patient and their family for many years. They also know the availability of support services. I consider that family doctors should be an integral part of this decision making process when patients are unable to communicate their wishes. With their holistic knowledge of the patient, they should be far more influential than any

nurse or allied healthcare professional at team meetings that consider the future of the unknown unconscious patient.

Some professionals have a religious view that life must be preserved for as long as possible regardless of its quality,

which may not be the views of the patient or, arguably, in the patient’s best interest. Others involved in the decision making process may be comparatively young and fit and have little understanding of an older

generation’s attitude to mortality. Should the religious views of the medical team or fear of litigation be a factor in making the decision to place a PEG tube in an unknown patient? I am aware that in some hospitals the “life saving” PEG is used routinely in such patients.

Of course, spouses and children do not want their loved ones to die, but equally they do not want them to suffer. This whole subject of preserving life needs to be openly discussed in the widest public forum—and not just by those involved in medical care. Encouragement to make an advanced directive or living will may also help to ensure that a patient’s wishes are respected.

Death must cease to be a taboo subject. More research needs to be done so that the clinical decision to place a PEG tube is fully audited and the consequences of this vital decision are better understood, although measuring quality of life, particularly when it is little more than existence, is difficult. Any individual decision is likely to be forgotten by members of the medical team three or five years later. The patient, however, lives with the consequences for the rest of his or her life.

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See also **NEWS**, p 1253

**With their holistic knowledge of the patient, general practitioners should be far more influential than any nurse or allied healthcare professional at team meetings that consider the future of the unknown unconscious patient**

# Our people

FROM THE  
FRONTLINE  
Des Spence



We rushed from the classroom just as Concorde flew over. We watched its beautiful form slip into the horizon. He leant against me, and I put my arm around his shoulder. He was my friend. This was the inner city in the early 1970s. He would always laugh at my freckles and straight blond hair. I asked my mum why we looked different—she just said, “That’s the way we’re made.” He had to return to Jamaica, and six months later a choked headmaster announced that he had died from kidney failure in Kingston. I had my first thought of becoming a doctor.

Society now embraces diversity as a matter of absolute political dogma—seemingly being different is in. It is surprising, therefore, how conformist society is, with everybody aspiring to the same things: the best cars, best clothes, best schools, best houses, and best jobs. We have been left haunted by the chimera of utopian perfection. But we all know in truth that perfection is a tyranny and that true friendship is bound by shared weakness and imperfection.

Yet some people are just born different, unable to choose the banal safety of conformity. Take Down’s syndrome. Screening is currently offered to mothers, who are given the ultimate option of termination, yet this week it was reported that more babies with Down’s syndrome are

being born than before antenatal screening became widely available (<http://news.bbc.co.uk/1/hi/health/7741411.stm>). In our first pregnancy we agreed to screening for Down’s syndrome, giving it little thought, desperate for that perfect baby. But in the light of time—given our own imperfect parenting, the unconditional nature of parental love, and the lack of guarantee of the ongoing physical and mental wellbeing of our normal perfect offspring—we vowed that we would decline screening for Down’s in later pregnancies. It is no mean feat to escape from the antenatal screening machine, and we were often given professional blank looks of consternation.

Is it right that medicine continues to screen fetuses for Down’s syndrome? Advances in medical care, better social support, and access to mainstream education have transformed the lives and expectations of those with Down’s syndrome, enabling many people to live full, independent, and active lives. If we are truly committed to diversity, perhaps it is time to rethink our antenatal screening programmes and to revisit some of the imperfect attitudes and assumptions that underpin current care. Different is just the way we are made.

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LIVE FROM  
LONDON  
Deborah Cohen



# Who’d advise anyone to become a doctor?

“This is my granddaughter—she’s a doctor,” my grandfather told his mates in the pub. I didn’t have the heart to correct him and tell them that I was no longer a real doctor working on the frontline and making crucial decisions. He still refuses to admit that as a journalist I’ve slipped from near godliness to somewhere beneath estate agents (with whom he has newfound sympathy), lawyers, and now bankers on the social scale. Needless to say, he’s not a doctor, and to him medicine is still the ultimate profession.

The next week—again in the pub—a group of doctor friends spent half the evening trying to dissuade a banker from quitting his unstable job and going to medical school to ensure a far brighter future. “I want to give something back,” he wailed, a mission statement that probably won’t wash with many interview panels any longer. Apart from derisive guffaws, his announcement was met with “Stick with the

money,” “It’ll be the end of your life as you know it,” and “You’ve no idea what being a doctor is really like.”

It was the banker’s turn to guffaw. “And you’ve no idea what any other job is like,” he retorted. He quite comfortably batted off the doctors’ complaints about job pressure and security, working hours, competitiveness, and government interference. What doctors lacked in remuneration—a concept I’m sure many outside this elite circle would repudiate—they made up in job satisfaction and respect, he said. Also, it’s a job that opens up international borders.

But the banker had a point: most doctors haven’t had any other type of fulltime job before. They have no yardstick by which to measure their career woes. When I hear doctors say there’s no way that they’d advise any child of theirs to go into medicine, that it’s an awful job with little reward or respect, I wonder

what else they think their children should do. Teaching? Or perhaps social work? Who else has to work unsociable hours while putting up with the overblown expectations of the general public and the ire of the media?

Despite the trend to welcome students from “non-traditional” families into the medical fraternity, I always believed that the sons and daughters of doctors held a distinct advantage—and I’m not talking nepotism or a bit of extra help at exam time. They had a realistic expectation of the job rather than a fanciful idea that it would lead to Zen-like fulfilment. But as corporate escapees from the financial crisis turn to the public sector as bastions of stability and job satisfaction—as reports suggest—the question remains: would you advise anyone to become a doctor?

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# The death of the author

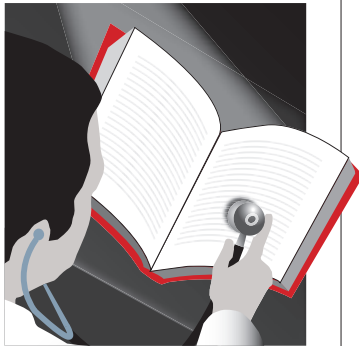
It takes skill to change a person's attitude, even slightly, especially when that person is, like me, obdurate by nature and past middle age in the life cycle. But Professor David Ellis, author of the lucid and moving *Death and the Author: How D H Lawrence Died, and Was Remembered* (Oxford University Press, 2008), has caused me to revise upwards my opinion of Lawrence, at least as a man if not as a writer.

Lawrence died from tuberculosis, of course, as did many other writers. So many of them, in fact, died from the disease that one is inclined to suppose that it was an occupational hazard of a devotion to literature: proof, no doubt, of the danger of drawing conclusions from a numerator without knowing the denominator or the relative risk among authors in comparison with that among, say, pork butchers or organ grinders.

Lawrence bore his illness with dignity, fortitude, and courage. Of the many interesting facts in this book, two in particular startled me. When Lawrence tried to enter the United States, which would not allow entry to people with tuberculosis, he put rouge on his face to disguise his pallor (it was successful). And when, mortally ill, he went to stay in the town of Vence in the south of France he was asked to leave the first hotel in which he stayed, not only because his coughing at night disturbed the other guests but because the hotel did not want to get a reputation as a sanatorium. Chekhov had had exactly the same experience.

Lawrence didn't really have much time for doctors. You could understand this, in a way. In his era they could diagnose tuberculosis all right but do very little to halt its progress. Many of their treatments were no better founded than those of the veriest quacks. They took control of people's lives without any evi-

## BETWEEN THE LINES Theodore Dalrymple



**"My one regret is that I have used too many commas. On the question of semi-colons, I have nothing to reproach myself"**

dence that it did any good.

Lawrence denied for a long time that he had the disease, insisting that it was only his "bronchials." He didn't believe in modern theories of disease of the kind that soulless doctors propounded, which in his view reduced man to a mechanism. Indeed, in his poem *Healing*, he wrote: "I am not a mechanism, an assembly/of various sections./And it is not because the mechanism/Is working wrongly, that I am ill./I am ill because of wounds

to the/Soul, to the deep emotional self."

It isn't surprising, then, that he told another literary sufferer of tuberculosis, his friend Katherine Mansfield, "Katherine, *on ne meurt pas*. Be damned and be blasted everything, and let the bloody world come to its end. But one does not die. *Jamais*."

He applied the theory of self inflicted illness to his mother, who died relatively young of cancer. In his opinion her tumour derived from her character. It was the result of a combination of her tendency to anxiety and her repression of her natural feelings.

This view of things, simultaneously overoptimistic and cruel, has triumphed. Speak to any young drunk or spectator screaming obscenities at a football match, and he will tell you that he has to let his feelings out—or, presumably, he will end up like Mrs Lawrence.

Incidentally, Professor Ellis's book quotes what have become my favourite last words, those of the journalist Hugh Kingsmill: "My one regret is that I have used too many commas. On the question of semi-colons, I have nothing to reproach myself." Ah, if only I could say the same, especially about colons.

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## MEDICAL CLASSICS

**L'Assommoir** By Émile Zola

First published in 1877

Deliberately apolitical, *L'Assommoir* is set in the dirt and filth of working class Paris, where life was hard and lives depressingly short. Zola researched in great detail the impoverished quarter of which he wrote, so that the work is an ethnographic novel and probably the first of its kind. Zola lays bare the human spirit, exploring the theme of social mobility and its fragmentary effects on the physical and mental health of a community. Zola broke new ground by using the language of the street, a shocking deviation from accepted literary practice that established him in the vanguard of modern literature. He does not judge; rather, he describes, and it is his descriptions of poverty, infidelity, prostitution, and sexual and emotional abuse that mark out this novel as a timeless piece with special relevance to those in the healthcare professions.

Gervaise Macquart, the heroine, a mother at 14, arrives in Paris with her two children and common-law husband, Lantier. She has broken away from a loveless and unhappy home, so finding a room in an area where "not even impoverished artists set up home" presents no difficulty. It is not long before she is abandoned; but, rather than crumble, Gervaise, a determined woman, slowly secures a life for her family. While working in a laundry she meets Coupeau, a local roofer. He is persistent with his affection, and it is not long before they marry. Gervaise establishes a laundry business that quickly flourishes, but Coupeau likes to drink and one day falls from a roof, sustaining serious injury. He becomes depressed, then indolent and dependent on his wife for support. He begins to drink heavily and becomes dependent on alcohol. The inevitable decline of their family is documented in graphic detail.

Much of the action takes place at Père Colombe's bar, the generically named Assommoir (derived from the verb "assomer," to stun or bludgeon). Here, "the real attraction of the place . . . was the still . . . in front of which boozing workmen

would hang about and day dream." Coupeau increasingly spends his days and evenings there, rolling home to behave abominably, while Gervaise desperately tries to keep him home.

Eventually, inevitably, with the business in tatters and her resolve broken, she is enticed into the welcoming arms of the Assommoir. Zola's descriptions of Coupeau's hospitalisation with pneumonia, where he lay in a line "of white beds like rows of graves," and thence his transfer to the Bicêtre asylum, south west of Paris, as he went "round the bend" with delirium tremens, are accurate and moving. His writing is direct and uncomplicated, his set pieces beautifully but simply crafted. The language used is always colloquial and often coarse, so that we hear the unscripted and often painfully moving voices with which we are familiar in modern medical practice.

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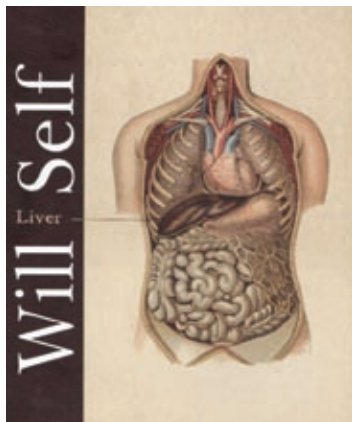
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REVIEW OF THE WEEK

# The livers of London

Will Self's short stories feature the liver in varying states of disease and decay, finds **John Quin**



**Liver: A Fictional Organ with a Surface Anatomy of Four Lobes**

Will Self

Penguin, £18.99, pp 277

ISBN 978-

0670889976

Rating: ★★☆☆

The liver is an unjustly neglected source of literary inspiration. Will Self corrects this, appropriating medical jargon to serve up a gamey pâté of metaphors linking the organ to contemporary London life. Here is another moralist updating Hogarth's gin sodden lanes for our own binge drinking times. Self's people are like "a hepatocyte in a lobule in a lobe in a liverish city. London, a metropolis that had itself been breaking down cultural toxins and processing rich nutrients for two millennia, yet could only do so by manufacturing hectolitres of bile."

Four lobes, hence four stories with a hepatic theme. "Foie Humain" begins the collection, an extension of a gag the broadcaster Jonathan Meades once made about who he would eat were he a cannibal, the answer being a well known corpulent politician. It is a fetid tale centred on the denizens of a Soho drinking club, a rum bunch, who merrily marinade themselves in spirits and trade tired monosyllabic insults. Self describes a world as putrid as fetor hepaticus. Ludicrously, their frolics are disturbed by an alien who removes their livers as they lie in encephalopathic extremis, because his people far away have a taste for these. This seems odd and not quite right—surely cirrhotic livers are too tough and chewy and not a bit like proper foie gras. These aliens miss out on all those obese millions with their non-alcoholic fatty liver diseased organs that one suspects are much smoother with toast and a nub of Sauternes jelly.

The book's beautifully researched main story, "Leberknödel," revolves around a retired NHS chief executive who, on learning that she has liver metastases, takes herself to Zurich to arrange her own death. She likes the Swiss—"finally she was among others who understood the virtues of careful administration as she." Her "respectable working class liver cells had gone berserk, smashing the chemical refinery they laboured in." Here the tone changes and is more serious: "She did find herself caught up—lost even—in the roomy soutane of death, its folds at once heavy and invisible, but there remained no escape from the trivial, the ugly, the banal." There is an excellent example of jargon

to avoid in her discussion with her doctor: "Occult?" What was he talking about? A silver bearded wizard? A voodoo priest?"

After a chance meal of leberknödel (liver dumplings) she starts to feel better, indeed has a miracle cure. Soon, "healthy blush blood jetted from Joyce's hepatic veins" and she regains her libido. "This had been one of the conversations the crab had scuttled her away from: the delirious gabble of arousal." Joyce's recovered body is now "a rambunctious teenager partying in the worn out mind of an elderly woman," and she can't cope. She heads back to the clinic, now accepting depressives for euthanasia.

"Prometheus" features an advertising executive who has his liver eaten regularly by a vulture, another spin on the Greek myth. He sees a Doctor Ben who "isn't a liver specialist but rather a medical generalist with a nice drip of honey for the moneyed," who sensitively tells him, "I'm going to have to put a shunt in—otherwise you'll drown in your own blood." The rapacious parasitical world of advertising is here presented as welcome as an amoebic abscess, as appetising as an anchovy sauce sandwich.

The final tale, "Birdy Num Num," concerns a group of dull, shifty heroin addicts. Intriguingly, cleverly, it is told by a hepatitis virus that knows the addicts are all infected. "True for some I am death's helpmeet, but I'm not a psychopath, only a cytopath." The virus is insightful: "For us human death is a failure; unless, that is, enough of us have blasted off to colonise new worlds." And it is aware that it is at war: "They are mobilising against us. Pegylated interferon alpha, Ribavirin—crass names, brutal enemies." The junkies are a ward round waiting to happen who will have "unwound four feet of crêpe bandage to expose the open cast bacteria mine" or emphysema, rendering them "blued by anoxia." A new arrival will shortly become infected. This turns out to be a writer, and Self tells us this about the fictional author's work: "The received opinion [was] that it was glib, and that he was an egomaniacal pasticheur." Which sounds suspiciously self referential.

*Liver* then is a work of scabrous misanthropy, black as a bile pigment stone; there's not much redemption or hope going on in here. It is original, though, and reads entertainingly; imagine William Burroughs spliced with Dame Sheila Sherlock. Self's often raw language and xanthochromic view might not be everyone's idea of fun but should not come as a shock to those well acquainted with the piecemeal necrotic world that is Friday night in an accident and emergency department.

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