Letting go

PERSONAL VIEW Alex Paton

We were having a cup of tea in the afternoon when my wife, Ann Pepys, died last November aged 85. At the exact moment the power pack of an Xbox being operated by our youngest grandson blew up, plunging the house in darkness.

She wanted to die, and we realised she meant it. She had had a wretched summer, with several falls and difficulty getting about; she found it hard to read or embroider because of double vision; a keen plantswoman, she said there was no point living if she could no longer garden. A medical check and attendance at a falls clinic did little to improve morale. Matters came to a head with the sudden onset of heart block and her urgent admission to hospital. That evening she had a cardiac arrest for which she was shocked, in spite of providing the staff with an advanced directive stating that she did not wish to be resuscitated. A pacemaker was inserted but did little to improve matters, and she spent a week in a depressing geriatric ward because of a slight fever.

We had difficulty in persuading the doctors to let us take her home and were required to sign her out against medical advice. During the last fortnight of her life, surrounded by our four children and their families, she was able to talk and laugh and share in the gossip till near the end. Professional support was impeccable: practice doctors came on request, and our own doctor appeared regularly on the doorstep “to see how you’re getting on; relatives need support as well, you know.” District nurses came every day to regulate the morphine and midazolam pump; in spite of a heavy caseload they seemed to have all the time in the world. One small incident marred the smooth transition from life to death. Early on a suggestion was made that we should have a series of blood tests “just to make sure there is nothing treatable.” Our unanimous rejection was somewhat coldly received.

My wife and I began to take an interest in euthanasia 40 years ago, soon after the introduction of cardiopulmonary resuscitation and intensive care gave doctors the power to manipulate life and death. Over what seem endless years the debate about its acceptability has swung back and forth, though with polls indicating that most people want an easy death and legislators in general broadening their view. We have been quietly optimistic that the time is coming when euthanasia is normal practice and society will wonder what all the fuss had been about.

We believed strongly that each individual should have the right to choose a way out, when life becomes intolerable, rather than suffer the interventionist nightmare that is so often the fate prescribed by modern medicine. The decision (preferably in advance) must be left strictly to the individual and must never be influenced by friend or foe.

Attempts to legislate in favour of euthanasia by the House of Lords have so far failed, in spite of extensive safeguards, because of people’s fears about mercy killing. Yet more than half the complaints about hospital treatment concern the last years of life, and we know only too well that patients travel abroad to countries that are less rigid in their attitudes to the ending of life. Euthanasia is illegal under British law, but the fact that no one has been successfully prosecuted is currently the subject of intense debate.

When the time comes we are entitled to die with dignity, and one of the options should be euthanasia. Of course, we appreciate the strength of feeling that separates us euthanasiasts from those who believe that life should be preserved at all costs. We respect their views and hope that they tolerate ours. We are not trying to persuade them to join us: that way lies conflict and the tactics of fanatics like the antiabortionists in America.

Discussion of such an emotive topic also requires that we should be careful with the words we use. Euthanasia means “the bringing about of a gentle and easy death.” To label it “assisted suicide” (how often is true suicide assisted?), when suicide implies taking life because of profound depression and despair, turns a carefully thought through decision to end life into something that is distasteful and continues the myth, exploited as usual by the press, that euthanasia is a nasty business. And to describe it as “doctor assisted” alienates a profession that ought surely to be sympathetic. Doctors unfortunately are taught from the beginning of their training to preserve life: in the words of a medical friend, “no effort should be spared to snatch life back from the jaws of death by death denying hospital staff, no matter what the quality of life and the wishes of the patient.” No wonder that polls of doctors’ organisations record a minority in favour of euthanasia. Call it “assisted dying” if you wish, though it doesn’t necessarily have to be assisted.

In the early days inoperable cancer and intractable pain were the usual reasons for hastening death, not always admitted because of the law. It is a measure of society’s increasing comfort with euthanasia that chronic, incurable conditions such as motor neurone disease, multiple sclerosis, and irrecoverable stroke are beginning to be accepted as grounds for it. I have included dementia in my living will and have completed an enduring power of attorney to that effect, in the hope that such cruel loss of identity will be included in due course. It is good to see that the more humane countries of Europe are promoting “tired of life,” “suffering through living,” and even “a wish to die.”

My wife and I felt that it was time doctors stopped playing God and realised that some people just wanted to let go.

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See ANALYSIS, p 1230
REVIEW OF THE WEEK

The new black death

Black men are more likely than white men to develop prostate cancer, but a new film fails dismally to investigate the problem, writes Ike iheanacho

True Stories: What’s Killing Darcus Howe?
More4, 24 November, 10 pm
Rating: ★★★★★

Frankly, it has an image problem. Unlike breast cancer, with which it’s often compared unfavourably, cancer of the prostate gland has little in the way of an “enemy” persona. By and large, it has had to do without the symbolic ribbons, T-shirt campaigns, and masses of celebrity activists— influences that help to keep the “battle against breast cancer” high in popular consciousness.

These aren’t the only reasons for the relatively low profile of prostate cancer. There’s also the fact that the gland itself can be a bit of a mystery. While it would be nonsensical to assume that a patient knows nothing about the location, form, or function of the breast, this could be an entirely reasonable start in discussions about the prostate. And then there’s the worry that common knowledge about prostate cancer might be limited to ill defined links with ageing, urinary problems, and sexual dysfunction—topics way beyond usual polite conversation.

Also, prostate cancer is sometimes trivialised as not quite a disease, or at least not one worth bothering much about. Clever scientists inadvertently encourage this by saying that nearly all men would develop evidence of prostate cancer if they lived for 150 years (a peculiarly silly abuse of the word “if”). More tangible is the knowledge that many men die with, rather from, prostate cancer. But even this point is easily misinterpreted as meaning that prostate cancer is really not that big a deal.

This unpromising background challenges those seeking to raise awareness of prostate cancer. One of these is the eponymous subject of Krishnendu Majumdar’s film What’s Killing Darcus Howe?

For kicking up a fuss about an issue, you could do worse than involve Howe. A long time racial equality campaigner, journalist, and broadcaster, he’s not easily ignored and doesn’t back away from a fight (of which more later). And the phrase “the personal is political” could have been invented for him, as the documentary showed in following the fallout from his diagnosis of and treatment for prostate cancer.

The focus, perhaps inevitably, was on the experience of black men. So we heard that a quarter of men in this group develop prostate cancer and that black men are three times more likely than white men “to be affected,” with these figures providing the background to the personal histories of Howe and some of his friends. Any of these could have been interesting topics for exploration.

But instead Majumdar fixed on Howe’s firm belief that the “authorities” largely ignored the problem of prostate cancer in black men, such that many died needlessly. This accusation really needed proper scrutiny, both with regard to Howe’s basis for arguing the case and to the evidence and what other commentators might have to say on the matter. Unfortunately there was none of this. And it’s not like there weren’t opportunities to seek a broader perspective.

For example, the surgeon who performed Howe’s prostatectomy appeared in the film, shown operating and then chatting with his famous patient. But why wasn’t he asked about the possibility of systemic neglect of prostate cancer in black men? Surely he would have had a view worth hearing?

There was another problem too. The programme gave the impression that to reduce the death toll from prostate cancer, all black men needed to be investigated regularly, through the use of prostatic specific antigen (PSA) testing, followed if necessary by rectal examination. This was a notion that the film maker seemed to accept without question. There was no qualification of this proposed approach, nor any real suggestion that “routine” screening of this type can bring its own problems.

Howe eventually persuaded the son of a friend who had died from prostate cancer to have a PSA test, despite initially fierce resistance. This was presented as a success, and the test result was apparently “normal.” But this man (who was aged under 40) seemed to have committed himself to having the test repeated every six months thereafter; there was, at best, something alarmingly simplistic about the implied take home message about such investigation.

Ultimately, the film failed dismally in its depiction of prostate cancer and didn’t do anything to dispel mysteries about the condition. But one redeeming feature was its uneven but compelling pen portrait of a remarkable man: a charismatic intellectual, with the poetic delivery of a Shakespearean actor and a capacity for blinding rage—a genuine one-off. And brave too, as when he stood up for the film crew when they (and he) were threatened with physical violence in the street at night.

If anything’s killing Darcus Howe, it’s got its work cut out.

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Smoking: out for the count

The first campaigner against passive smoking was probably the greatest novelist the world has ever known, Leo Tolstoy. In his essay “Why do Men Stupefy Themselves?”—published in 1890 as an introduction to a book by his medical brother in law, Dr S P Alexeyev, with the title Drunkenness (he was against it)—Tolstoy wrote: “Everyone of average education considers it inadmissible, ill bred, and inhumane to infringe the peace, comfort, and yet more the health of others for his own pleasure. But out of a thousand smokers not one will shrink from producing unwelcome smoke in a room where the air is breathed by non-smoking women and children.”

Bravo for Tolstoy, you might say. And with his usual grasp of psychology he understands that the polite question “Do you mind if I smoke?” is not a genuine request for information on the acceptability of smoking to a non-smoker, any more than the question from a nurse to patient “What would you like to be called?” is neutral as to whether first name or surname is proffered. For “Do you mind if I smoke?” almost invariably calls forth the answer “Not at all,” even when the non-smoker detests smoking and all its works; just as the nurse’s question is answered “Bill” rather than “Professor Smith,” even if this is what he wants to be called.

The problem with the essay is that Tolstoy is mad, in the loose sense of the term. He begins it with a very pertinent title. He begins it with a very pertinent term. He begins it with a very pertinent term. Tolstoy goes on to attribute European militarism to the fact that all Europe’s leaders smoked and were therefore “drunkards who never reach a state of sobriety.”

The answer for Tolstoy is crystal clear, for once he starts thinking about anything, doubt and qualification are removed from his mind (Chekhov once called him an ignoramus). It is that stupification is the means by which they quieten or suppress their conscience.

For Tolstoy there is no such thing as moderation. Nor is there any other possible reason for people to resort to things that stupefy them. And he has it in for smoking particularly, not on health grounds but because it clouds consciousness and makes people do stupid or wicked things they wouldn’t otherwise do. He says that all decisions taken while smoking are like decisions taken by a drunkard.

His prime example is a rather surprising one: “Without any need whatever, a company is formed, capital collected, men labour, make calculations, and draw plans; millions of working days and thousands of tons of iron are spent to build the Eiffel Tower; and millions of people consider it their duty to climb it up, stop awhile on it, and then climb down again.”

And this, all because they smoke! In case the reader should still harbour any doubts about the evils of smoking, Tolstoy goes on to attribute European militarism to the fact that all Europe’s leaders smoked and were therefore “drunkards who never reach a state of sobriety.”

There is really only one possible explanation for how the world’s greatest writer of his time could have come to write such terrible nonsense. He must have been drunk.

Theodore Dalrymple is a writer and retired doctor

BETWEEN THE LINES

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Tolstoy goes on to attribute European militarism to the fact that all Europe’s leaders smoked and were therefore “drunkards who never reach a state of sobriety.”

MEDICAL CLASSICS

George’s Marvellous Medicine

By Roald Dahl First published 1981

This charming children’s book, as old as this reviewer, is based on the pharmaceutical misadventures of George Kranky, an 8 year old boy, which are stimulated by the dislike of his “grousing, grouching, griping, grumbling” grandmother. In the absence of rats, snakes, or fireworks to teach her a lesson he embarks on creating a blockbuster drug from lotions and potions usually found in the bathroom, bedroom, kitchen, and shed.

His grandmother, blunt of affect and sharp of tongue, advocates traditional remedies such as caterpillars, cabbage, and crunchy beetles; but George prefers biomedicine and, being pressed for time, skips animal models and heads straight for phase I trials, with his grandmother as sole, uninformed recipient. He aims to create a “magic medicine, a medicine no doctor in the world has ever made before,” a polypill to cure dental caries, malodour, hoarse voice, and arthritis.

After the first dose causes his grandmother to grow higher than the family farmhouse, George and his father decide to try it on their farmyard animals, creating, among others, a chicken the size of a horse and a horse the size of a bus. The mixture soon runs out, and George can’t remember the quantity, order, or nature of the ingredients in his pretternatural concoction. As a consequence their attempts to formulate a “me too” drug ends not in six foot tall chickens but rather ones with six foot necks or the size of a sixpence.

As strange as some of George’s more fanciful ingredients are—“squiggle from the sea . . . sting of a bumblebee . . . fruit of the ju-jube tree . . . bone of a wombat’s knee”—I have seen similar mythical things written on drug charts and in allergy boxes. George embodies the enthusiasm and vitality often seen in medical students and new doctors, and like Grandma we are often guilty of resenting their youth and quashing their promise with our cynicism. Instead we should cast our minds back to before we were “grizzly old grunions” and harness their energy and inquiring minds.

I discovered three interesting facts about Roald Dahl while reading this book: if he had not been a writer he would have become a doctor; he founded a charity that provides funding for specialist paediatric nurses; and after his son Theo was injured in a car crash he codeveloped, with a hydraulic engineer and a neurosurgeon, the Wade-Till-Dahl valve for use as a cerebral shunt in cases of traumatic hydrocephalus.

Dahl is a master storyteller, yet the influence of the illustrator can’t be ignored. Quentin Blake brings the story to life, from grandma’s sublime “small puckered-up mouth like a dog’s bottom” to the ridiculous “chicken on stilts.” This book captures the sense of adventure and mischief many doctors experienced as knee high clinicians and potting shed musicians. But remember: “Do not try to make George’s Marvellous Medicine at home. It could be dangerous.”

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BETWEEN THE LINES

Theodore Dalrymple

Tolstoy goes on to attribute European militarism to the fact that all Europe’s leaders smoked and were therefore “drunkards who never reach a state of sobriety.”

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Comrades in arms

We weren’t totally convinced that the action was necessary or even that it would work—we cursed this interventionist, US style of attack. The standard issue equipment, the multi-vials and the syringes, were sub-standard and flimsy, and the syringes had too narrow a needle. I had decided to use my own equipment. But just like every practice across the county we obeyed our orders, rounded up suspects, and went on the vaccination offensive.

We called up the reservists, pulled on our work uniforms, and marched in on successive Saturdays. Reception staff tried to keep the peace in the waiting room—we wanted the process to be open, fair, and free, with those most in need being vaccinated first. The doctors instructed our young female healthcare assistants in how to make up the vaccines. Mission accomplished, we were worn out, but a long forgotten feeling came over us: camaraderie.

Ours, however, is a phoney war. In Afghanistan real soldiers are dying. I could lie and say that I never supported this war, but a long time ago I rationalised that force is part of the human psyche and that passivity, despite its intellectual appeal, was phoney too. Indeed intervention had saved thousands of lives in the Balkans, so Afghanistan seemed a just war against the tyranny of extremism. But if I wasn’t wrong, I was certainly naive. As I see yet another coffin borne from the womb of the transport aircraft, the grief of families, and pain of the maimed—I must accept some responsibility.

The troops are doing our bidding, working within a strict professional code, and trying to believe what they do is right. But regrettably our profession has largely overlooked and forgotten our medical and nursing colleagues who are serving. We doctors believe ourselves to be under the constant fire of the media and complain about our working conditions—this is the petty nonsense that now passes as modern medicine. Meanwhile our colleagues at war rush to helicopters, day and night, taking rest when they can, and face threat and uncertainty—these are very real foes. They treat combatants from both sides and civilians with professional care and duty. So to our brothers and sisters working in the forces (and also doctors working for charities and in adversity around the world), we owe you our gratitude but above all our respect—we are always one profession.

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Come dance with me in Ireland

Admit it. You know it. I know it, we all know it: a doctor’s most secret and unholy joy is making another doctor look like a klutz. It can be subtle: the almost imperceptible raising of an eyebrow, the almost inaudible in-drawing of breath. Or it can be a custard pie in the face.

“Perhaps you could take this call,” said my partner, poker-faced. I was young, keen as a puppy, and I bounced beamishly out the door. I didn’t know the call had come from yet another browbeaten home help who just couldn’t take it anymore and who felt it only fair the doctor should share in the invective.

The living room was cluttered and forbidding.

“Who are you?” she demanded.

“I’m Dr Farrell,” I said, “and I just called to see how you . . .”

“Get out, or I’ll set the dogs on you.”

“I know, the dogs,” I said, surmising a fierce territorial instinct centred on the living room and her picture of the Pope slotting a penalty past Stalin. I learnt that day that enduring insult is just another part of a doctor’s shtick, another weave in the great tapestry that is family practice.

Again she followed.

“Arrah, I’m only a poor old woman, lie me under the greenwood tree.”

The dance went on, in and out, like waves on the sea, a medical hokey cokey, until eventually I conducted an ersatz consultation on the porch, in the no-man’s land between unrestrained fury and overwhelming pathos.

And arriving back at the surgery: “Hello, I must be going,” sang my partner.

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