



“I pale at the potential consequences of the current sun policy on the long term health of our children.” Des Spence on bad medicine and melanoma, p 484

VIEWS & REVIEWS

Social care homes: what the media forget to tell us

PERSONAL VIEW **Graham Mulley**

“It’s the BBC: they want help with an exposé of nursing homes.” My secretary transferred the call. The programme producer told me that a care home employee had reported that a culture of poor quality care was going unchecked. The plan was for a journalist to apply for work experience and surreptitiously film examples of inadequate care. Would I consider being a consultant adviser, providing guidance on what constituted good practice?

I had just returned from doing a teaching round in an excellent care home, where nurses and care assistants provided first rate care—despite low wages and at times inadequate staffing levels. I knew how the staff were buffeted by relentless negative media stories, and how another undercover report might demoralise diligent workers. I declined to help, and disingenuously asked why they did not consider making a truly original programme, one which celebrated all the excellent work that is taking place in many care homes. There was a long silence.

Media coverage of care homes is rarely positive. Newspaper stories that make the front page are usually about financial aspects—

for example, homes going into administration, or fees for care. Inside, stories focus on neglect, dangerous practices, loss of dignity, dehydration, and subnutrition. Heartbreaking stories feature in broadsheets as well as tabloids.

When the Irish businessman Gerry Robinson made television documentaries about dementia care homes, he described a broken system that was in the dark ages, where residents were consigned to a stagnant life, sitting and doing nothing, with loss of dignity and delayed responses to cries of anguish. Unlike most accounts in the media, he probed the factors that contributed to inhumane and inadequate care: the staff, many from abroad, worked long hours for minimum wage and had few perks (some received no meals). They felt ignored and received little specialist training. Matrons were sometimes out of their depth and spent excessive time on documentation. There was constant criticism from inspectors.

This negative reporting can upset relatives and dismay staff. This must add to the guilt felt when a loved one eventually goes into a home. Angela Rippon, a former television

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newscaster, described her family’s experience of Alzheimer’s disease in the *Daily Mail*. When her mother had to go into care, Rippon said she “was amazed at how good [the homes] were. Like everyone else, I had heard all the horror stories, but these were happy, clean, warm places with staff who knew how to deal with dementia and who cared deeply for the dignity of residents” (2008 Dec 9, www.dailymail.co.uk).

To his credit, Robinson also illustrated exemplary care, where residents’ meals were highlights, not merely refuelling sessions; where engagement between staff and residents was meaningful; where old people’s personal histories were explored; and where imaginative ways were found to fill the spaces in people’s lives.

Sir Michael Parkinson, recently the national ambassador for the Dignity in Care campaign, described excellent care given by inspirational people, but heard about lack of privacy, food, and fluids. His mother received both wonderful nursing and undignified care.

The facts about quality in elderly care homes are comprehensively covered in a recent report of the British Geriatrics Society, *Quest for Quality* (<http://bit.ly/jGr3HP>): the United Kingdom has 13 000 care homes, with 507 000 staff managing more than 450 000 old people, of which almost half have dementia, three quarters are disabled, and more than 70% are incontinent. It concludes that there are many examples of good practice in care homes that improves the quality of life and end of life care for residents.

The Care Quality Commission is the independent regulator of social care in England. Though its tools of inspection have been criticised, the commission has found a year on year improvement in standards of care in the past seven years. Its latest report states that 86% of homes that admit residents supported by local councils are “good” or “excellent,” with only 1% “poor”—a remarkable situation that received little media attention.

Care homes are responsible for the care of frail, vulnerable, old people with complex needs. Nurses and other staff do a special job, often to high standards. Where care is unsafe, lacking in skill, humanity, or empathy, this must be identified and rectified. The media have a role in rooting out poor care, and of course scandal sells. But in addition to reporting poor standards, the media and high profile individuals should celebrate the many unsung examples of extraordinary long term care. Perhaps all of us who witness such excellence—relatives, professionals, and other visitors—should write or tweet positive messages to balance the prevailing nihilism.

Competing interests: See bmj.com.

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- Review of the Week: So, did Gerry fix it? (*BMJ* 2007;335:1268)
- News: UK public must expect to pay for long term care, says care services minister (*BMJ* 2011;342: d4167)
- Editorial: How to meet the challenge of ageing populations (*BMJ* 2011;342:d3815)



ROB WHITE

REVIEW OF THE WEEK

Primates at the pictures

A blockbuster film incorporates the themes of Alzheimer’s disease and biomedical ethics, says **Desmond O’Neill**

Rise of the Planet of the Apes

Directed by Rupert Wyatt

Rating: ★★☆☆

Project Nim

Directed by James March

Rating: ★★☆☆

Summer blockbuster films usually have large visual impact, a quick surge of gratification, but little by way of lasting fulfilment. Occasionally, however, they provide a bit more. *Rise of the Planet of the Apes*, the latest iteration and prequel to the *Planet of the Apes* saga, is definitely in the latter category. Hugely entertaining and well constructed, it is also layered with contemporary themes that add piquancy for medical viewers. These include Alzheimer’s disease, primate research, pandemics, research ethics, and the distortions created by the medical-industrial complex. Interestingly, this medical flavour parallels the original 1968 film, which starred a very skilled ape surgeon called Galen and in which lobotomy featured as an instrument of both control and punishment.

The plot centres on a cognitive enhancer with untoward side effects. These unravel when the flawed hero, a research neuroscientist, breaks several ethical barriers. He treats his own father in secret and without formal clinical trials having occurred, and he hides a baby chimp destined for destruction as a pet in his home. Corporate greed and ethical blindness amplify the consequences, and the rollercoaster of

action gathers momentum. In a very modern trend, started by the Marvel action hero movies, you need to stay for the credits at the end to get the full story.

It is a telling tribute to the sophistication of computer generated (or enhanced) imagery that the most affecting character in the film is the cognitively enhanced chimpanzee Caesar, “played” by the British actor Andy Serkis with a subtle mixture of quietude and passion. Ironically, the other most memorable character is the scientist’s father (played by John Lithgow), who is affected by Alzheimer’s disease.

The mirrors to contemporary anxieties and public awareness in the film are telling. As a geriatrician, I was struck by how casually the protagonists tossed about the term “cognitive function”: would that colleagues in other disciplines and trainees of all hues showed as much awareness of it in their dealings with older patients. It is a signal marker of how far the awareness of diseases affecting cognitive function has advanced in the public eye.

Although some may quibble at some details of the portrayal of Alzheimer’s disease (dips in cognitive status are matched by wild tonorial disarray and dramatic stubble growth) there is a poignancy to the presentation of the

son’s loving relationship with his father. Our first encounter is off-stage, hearing Lithgow’s character struggle unsuccessfully to launch a Debussy prelude on the piano: the success of the research compound, in a truly novel outcome measure, is signalled by some delightfully articulated Bach.

His declining memory is a dramatic foil to the burgeoning intelligence of Caesar and his fellow apes. Both link us back to fears about the influence of the medical-industrial complex, increasingly seen by some commentators as just as forceful and as undemocratic an influence on society as the military-industrial complex about which Dwight Eisenhower famously

warned at the end of his presidency in 1961.

One of the bulwarks against such overt and covert steering of the healthcare agenda should be a high level of ethical discourse in the training and practice of

scientists, and the film is a reminder that this is not yet the case, even allowing for the artistic licence and oversimplification demanded by such movies.

Although doctors and their regulatory bodies have made enormous strides in the past few decades in developing and implementing ethics courses in undergraduate and postgraduate curriculums, most countries have substantially less provision for ethics courses in the so called basic sciences and engineering, even allowing for advances in biosciences education in the UK (see *Bioscience Education* 2005;5:c1, www.bioscience.heacademy.ac.uk/journal/vol15/beej-5-c1.aspx). Yet the potential fallout from developments in a broad range of sciences, from climate control through nanotechnology to genetics, has as much if not more potential to wreak havoc on a wide scale as anything in medicine.

A neat accompaniment to this blockbuster, and also well worth seeing, is the documentary *Project Nim*. It recounts the true life story of the chimpanzee Nim Chimpsky (a wry homage to the renowned linguist) and a hubristic project to establish communication between man and monkeys. Every bit as fascinating as the life story of the chimpanzee is the unfolding of a saga of the misguided and deeply unprofessional behaviour of the scientists, and the willingness of a wide array of educated people to subscribe to a sentimental, anthropomorphic delusion.

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20TH CENTURY FOX/EVERETT/REX FEATURES

BETWEEN THE LINES Theodore Dalrymple

Peake, Prunesquallor, and Pye

Like many a famous author, Mervyn Peake (1911-1968) had a medical father. Dr Peake was a medical missionary in China who once had to prove his prowess by operating on an official's cataracts in public. Fortunately for him he passed the test; he might otherwise have been done to death and Mervyn would never have seen the light of day.

Dr Peake returned to England to become a general practitioner in Surrey. The young Mervyn showed artistic promise early, and studied at Chelsea Art College, where he met his wife, Maevie Gilmore, whose father was also a doctor.

One of the main characters in Peake's Gormenghast trilogy of novels, *Titus Groan* (1946), *Gormenghast* (1950), and *Titus Alone* (1959), was Dr Alfred Prunesquallor. He is physician to the 76th Earl Sepulchgrave: "The doctor with his hyena laugh and his bizarre and elegant body, his celluloid face. His main defects? The insufferable pitch of his voice; his maddening laugh and his affected gestures. His cardinal virtue? An undamaged brain."

He is actually a good man, this unpromising depiction notwithstanding; but in Peake's other novel, *Mr Pye*, the doctors do not come out well. Mr Pye is an evangelical who has decided to convert the fractious inhabitants of the island of Sark to sweetness and light (Peake visited the island many times, and lived there for several years, both before and after the war). Mr Pye is so unremittingly good that he begins, to his horror, to sprout angelic wings. He goes to Harley Street to consult the most eminent physicians, including Sir Daniel Thrust, as to what he should do to disembarrass himself of them. Not surprisingly, perhaps, and with great pomposity, the doctors are completely stumped. Mr Pye decides that only evil deeds will make the wings wither and disappear.

Peake's own medical history was tragic in the extreme. During the war he had a couple of breakdowns, and did once consult a Harley Street specialist, an experience that might have been the inspiration for the Harley Street episode in *Mr Pye*. In his 40s, Peake began to develop symptoms of

In his 40s, Peake began to develop symptoms of Parkinson's disease, and then dementia. He spent the last few years of his life in institutions, unable to write, draw, or speak



RAYMOND KLEBOE/GETTY

Parkinson's disease, and then dementia. Of great charm and good humour, an accomplished draughtsman and painter, a poet and novelist, he spent the last few years of his life in institutions, unable to write, draw, or speak. (He was subjected to both electroconvulsive therapy and surgery that proved useless or worse.) His wife's memoir, *A World Away*, published in 1970, is almost too painful to read.

The manner in which Peake's doctor at the National Hospital, Queen Square, London, breaks the news of the diagnosis to Mrs Peake is an object lesson in medical insensitivity. Mrs Peake asks to meet him but is told that he is too busy at the moment; perhaps he might be able to see her on his way out if she waits in the entrance hall for him. There, in the middle of the busy hallway, he says to her, "Your husband has premature senility." Peake was 46; she was 39.

She addresses a postscript of her memoir to Peake, describing a visit to him before his death, when he is completely immobilised by the disease: "We sit silently, and then you are restless. You want to move and cannot. You want to speak and cannot, and the silence no longer has peace in it." Then: "When I leave you, I say 'Goodbye,' but goodbye was said many years ago, before we knew we were saying it."

I have made a resolution never to complain again, but I know that I shall not keep it.

Theodore Dalrymple is a writer and retired doctor

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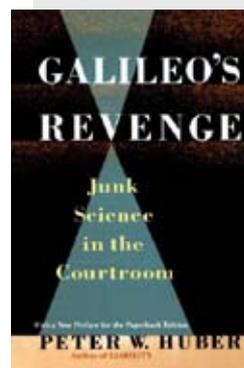
MEDICAL CLASSICS

Galileo's Revenge: Junk Science in the Courtroom

By Peter W Huber, first published 1991

This book is about bad science, particularly bad medical science in the courtroom. It contrasts good science—the science of publication, replication, verification, consensus, and peer review—with so called junk science: identified by lack of rigour, power to stir up fear, bamboozlement, and misguided certitude. The book documents landmark legal cases in which manipulative, charismatic lawyers have trampled on scientific evidence, championed the maverick, and won huge sums of money in compensation despite flawed evidence.

Examples include a successful claim resulting from a chemical spill in Sedalia, Missouri, which was said to have caused anything from constipation to cancer within a 50 mile radius, and the alleged teratogenicity of the drug Bendectin (a combination of pyridoxine and doxylamine) and how greed and unscientific arguments have arguably deprived patients of a useful drug for hyperemesis. A great strength of the book is its observation of the evolution of scientific medicine from the 17th century, when a medical career, "flourished or floundered according to the relationship the doctor managed to strike up at the bedside" to present evidence based practice.



Peter W Huber journeys through Xavier Bichat's descriptions of disease specific pathology; Pierre-Simon Laplace and the power of statistics; John Snow and the story of cholera; and the importance of the centres of medical learning shifting to hospitals, where patients can be studied in large numbers. Huber reminds us of the power of

collegiality and consensus and how science should be defined by the community and not the individual. On the other hand, unorthodoxy can flourish with the never ending call for more research. Some may find it comforting to declare that we need more research but, says Huber, this view is always trite and often wrong. Karl Popper said that real science had "stopping rules." After a fair test of time there should be an end to fruitless, wasteful speculation on, for example, total allergy syndrome, chemical AIDS, and traumatic cancer.

Galileo was imprisoned for heresy. The scientific community was forbidden to replicate and verify. So when the judge, select committee, or journalist gives equal weight to both the pseudoscientist and the acknowledged expert, the result is often confusion and lack of progress, and Galileo has his revenge.

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Bad medicine: melanoma

FROM THE
FRONTLINE
Des Spence



Sunlight is relaxing. Our body rewards us for being in the sun, and evolution dictates that everything happens for a reason. Pale skin was positively selected for as our ancestors ventured north, like economic migrants of 100 000 years ago, to aid synthesis of vitamin D in a temperate climate. It is no mere chance that the Celts who live in the perpetual rain of the west of the United Kingdom are porcelain pale. Sunlight is fundamental to human survival. Today, however, pressure groups call for a so called enforceable sun protection policy for children, involving sunscreen, hats, and active avoidance of the sun. But does this police state approach make sense in Britain?

The baton of policy enforcement is the near tripling of melanoma incidence since 1980. But the evidence presented for the campaign has the whiff of propaganda and is riddled with contradictions. Melanoma most commonly occurs in areas that are less sun exposed. It is 50% more common in social class one, despite the fact that manual workers are more likely to work outside and use sun beds. And women have a 20% greater incidence of melanoma yet a 20% lower death rate compared with men.

There is no dose-response gradient. The most conflicting evidence, however, is that despite a reported tripling of incidence, the actual death rate under 65 has remained unchanged. This observation cannot be explained by better treatment, because melanoma remains resistant to chemotherapy.

Nor indeed can it reflect a recent increase in sunlight exposure because melanoma is a disease of the old, so the potential risk from sunlight has a long lag time. Logically this would have been in 1920 onwards, not a period associated with cheap foreign travel. Is there a more rational explanation?

Campaigns against the sun started in the early 80s, fuelling anxiety and referrals, especially in the health conscious middle class. Dermatologists opened public and private so called pigmented lesions clinics. Removal rates took off. But melanoma incidence is directly linked to rates of biopsy.

So, because deaths from melanoma are unchanged, the only logical conclusion is that the rapid and steep rise in melanoma is not real but an artefact of overdiagnosis. Dermatologists are removing lesions that will never progress. Further, there is scant evidence for the beneficial effects of sun block or avoidance of the sun on incidence of melanoma, and no evidence that they reduce mortality.

What we do know is that vitamin D deficiency is increasingly common, and sunscreen blocks the synthesis of vitamin D. Deficiency causes bone diseases and is linked to cardiovascular disease and a range of cancers. I pale at the potential consequences of the current sun policy on the long term health of our children. We should trust evolution: the current policy is counterintuitive, and bad medicine.

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Confessions of a technophile

STARTING OUT
Kinesh Patel



I've got a confession to make: I like *The Archers*. I've been listening for about 20 years. But rather than tune in six days a week, I prefer the Sunday omnibus edition, with all the week's episodes in one broadcast.

This, however, rather interrupts my Sunday morning snooze, so six or seven years ago I used to program the family stereo system to turn itself on and begin to record onto a cassette tape, which I would then play back at a convenient time.

Then, in 2007, came the wonderful advent of home broadband. The BBC put the episodes onto their website, and I downloaded them to a portable digital music player.

Now my MP3 player gathers dust: it has been usurped by my all singing, all dancing smart phone, bought three years ago. *The Archers* is automatically delivered wirelessly to my phone for me to listen to whenever I choose.

Why is this seemingly tedious account of the history of broadcasting relevant to healthcare? Because it reflects how society has changed in its mentality and expectations. We have moved from hissy magnetic cassette tapes a mere five years ago to instant delivery today. And the (mentally) youthful part of the population has kept up with this pace of change with relative alacrity.

Such pace of change is unprecedented. And the likelihood is that it will accelerate. This is, after all, the Twitter generation, the generation of instant gratification, as demonstrated recently in the looting on the high streets of English cities.

What people expect increasingly is that the organisations they interact with exhibit a similar pace of change. I can book a gas engineer online, request a replacement driving licence, or make dinner reservations.

What does the NHS have? "Choose and book," which lets patients choose where and when they are seen for only the first hospital appointment—but not by whom. And that's it. You can't change the time of your ultrasound scan or log in to find out that your scan is normal.

The NHS has been shielded from the technological changes in wider society. Because its users tend to be older, expectations have been moderated. But as the Twitter generation ages and begins to place more demands on the health service, as certainly will happen, our Neolithic systems will be challenged. And that is an ominous prospect because you can be sure that the inevitable competitors to the NHS will be very much more switched on than us.

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