e-records: reasons to be cheerful

PERSONAL VIEW **Jonathan Gornall**

Like many people, I use the internet for banking, email, shopping, and the transfer of sensitive personal documents, including tax returns. I take sensible precautions—such as declining to give my bank details to phishing fraudsters—and I trust it.

Likewise, I'm relaxed about the prospect of my medical records being available digitally throughout the National Health Service. In fact, as the NHS Summary Care Record pilot scheme approaches its first birthday and enters its evaluation phase, in anticipation of national roll-out, I'm positively excited.

I find it reassuring to think that should I ever find myself in an emergency department, the complete strangers fighting to save my life will have access to any vital personal information that could govern how they treat me. Also, I find it inspiring to think that the information harvested each year from millions of such encounters will be aggregated and analysed to ensure that the NHS is being managed as safely and as efficiently as possible for the benefit of all.

Helen Wilkinson, a former general practice manager from Hampshire, disagrees. A few years ago, when she first got a whiff of NHS plans to centralise patient records, she took a look at her own file and discovered that a surgical procedure she had had in 1998 had been wrongly coded into her record as treatment for alcoholism. "I went ballistic," she told the *Guardian*. "To be labelled an alcoholic—who had seen it?" (www.guardian.co.uk, 2 Nov 2006, "The woman falsely labelled alcoholic by the NHS").

The "computer error," as the *Guardian* put it, drove Ms Wilkinson to embark on a successful battle to have all her records expunged from the NHS and to set up NHS Confidentiality, a campaign opposing the NHS care records system.

Personally, I'm with Gillian Braunold, GP and clinical director of the Summary Care Record and NHS HealthSpace, an online personal health organiser. She thinks that "information is as important as antibiotics for this generation."

RENE DROUYER/FOTOLIA

Let's face it. Big Brother will not be watching you. He probably has better things to do than snigger about your piles

However, a recent survey of GPs carried out for the *Times* by Doctors.net found that four fifths of 640 respondents were concerned that centralised electronic records system would not be secure, and the BMA's 2007 annual representative meeting resolved that members should not cooperate "due to concerns about security and confidentiality."

Some have gone even further. The five GPs at the Oaklands practice in Yateley, Hampshire, for instance, are urging their patients on their website to "opt out of the NHS database without delay" (www.ymcentre.freeserve.co.uk).

Why? Well, the gist of it seems to be that the government can't be trusted not to lose stuff, which to a certain extent is fair comment. But does it really reinforce the refusenik case to suggest that "the unbelievable data protection breaches that were realised towards the end of 2007, including the loss of 25 million child benefit records and 15 000 pension policy records by Revenue and Customs . . . illustrate the very real dangers of choosing to upload personal data to huge centralised government databases?"

No, it doesn't, because of course these examples show no such thing. In fact, they are a good argument for the NHS Spine.

Moving sensitive data around in physical form is asking for trouble—cue endless stories about benefit disks lost in the post, security services laptops stolen from cars, and paper NHS patient records scattered off the backs of dustcarts. Transferring information through a secure digital network is always going to be a much safer bet.

Part of the problem, undoubtedly, is an easily exploited fear of information technology combined with a wearyingly persistent tendency for Orwellian alarmism at the mere mention of computers.

But let's face it. Big Brother will not be watching you. He probably has better things to do than snigger about your piles.

Nevertheless, according to the *Daily Mail*, Ms Wilkinson's much publicised website, The Big Opt Out (www.nhsconfidentiality.org), has now been visited by 200 000 people who have downloaded a pro forma opt-out letter designed to be sent by patients to their GPs. Presumably, they, like Ms Wilkinson, think that they have an absolute right, bought and paid for by their taxes, to have no part of their medical records, however anonymised, available to anyone other than the doctor who is treating them.

But do they really have such a right? What about responsibilities and that unfashionable concept "the greater good?" Of course, patient confidentiality must be taken seriously, but surely it has to be balanced sensibly with the obvious advantages of sharing information.

Fortunately, there are signs that most people will embrace electronic patient records pragmatically.

So far, the trials have seen more than 150 000 summary care records loaded on to the Spine, with opt-out rates running at less than 1%—even in Bolton, where some GPs have been actively campaigning against the system.

Will there be cock-ups? Of course there will. Will the sky fall in? Of course it won't.

Remember the "millennium bug?" Quite.

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Medicine's guiding star, p 393

REVIEW OF THE WEEK

What becomes of the broken hearted?

Is writing about unhappiness some way to diminish it? **John Quin** is moved by a doctor's tale of bereavement

It was the Vichy collaborationist Henry de Montherlant who wrote "happiness writes white," but what did he know, the old sourpuss? We should understand that he wasn't exactly the cheeriest of souls, given his overdetermined suicide by simultaneously taking cyanide and shooting himself. Doctor and author Dannie Abse, one suspects, would take issue with the cynical Frenchman's maxim. The Welshman's uxorious poems on life with Joan, his beloved wife of 50 years, are a testament to the fact that one can write, and write well about joy. Abse's works detail his obvious sublime happiness in marriage, where even after some forgotten row there was still "the sweet armistice of the double bed." In June of 2005, however, Joan was killed in a car crash; *The Presence* is Abse's response to this appalling trauma.

The book takes the form of a journal interrupted by reminiscence and poems by Abse and others germane to the flow of the narrative. The writing is his antidote to his grief, an attempt to find some peace of mind. Abse's hope is that writing about unhappiness is in some way to diminish it—that somehow one might, contra de Montherlant, fight "death's blank ink."

As a retired doctor, Abse is well aware of the patterns of grief and bereavement, the risks of depression and somatisation, the pitfalls of self pity. He admits candidly to being lachrymose, acknowledging that in Britain we are brought up to believe that big boys don't cry. He has limited use for counselling and psychiatry, preferring to think, "For Chrissake, pull yourself together." A friend gives him a copy of Joan Didion's *The Year of Magical Thinking* (*BMJ* 2005;331:1208), her own account of loss, hoping it might help. Abse leaves it unopened, he has little to learn from it—his experience mirrors hers. In tone, though, the writers differ significantly. Didion is frail, questioning, at times understandably near hysterical—archetypically American, one might argue, in her precise and persistent demands for an answer. Abse in contrast is more phlegmatic, aware of the "dignity of saying nothing," being British and Welsh and thus reserved and stoical.

Solitude and loneliness are now his unbidden new subjects. The poet hopes that others "by seeing another's barely disguised despair may feel a momentary consolation, feel a little less alone." It would be wrong though to think that the book is dispiriting. Abse's digressive approach can be as amusing as his fellow north London diarist Simon Gray. He is particularly good on boredom, the endless round of quotidian tasks with which he marks out a dull day. He tries to cheer himself up by going to a Cardiff City soccer game that ends in a disappointing 0-0 draw. *The Presence* is not a maudlin read—it is beautifully paced with some very funny passages, including a laugh out loud story about Celtic manager Gordon Strachan.

The sense of his being well rounded, of being grounded, is in keeping with what cultural critic Fredric Jameson has identified with regard to writer doctors such as Abse. By developing "plausible narrative intersections among people from widely different walks of life" the isolated physician who works with the rich and the poor can "offer a vehicle for the cognitive mapping of society." In fiction this has been achieved by Chekhov, in poetry by William Carlos Williams, and now too by Dannie Abse.

Abse has long been a master of medical metaphor, appropriating the language to aid better description of the well world outside the wards and the surgery. We read of "an adrenal moment," of his feeling "depleted, untranquil, and for a while physically exhausted like one experiencing hypoglycaemia." Here is an extract of him musing on the different types of silence: "There is the silence I've heard through my stethoscope: the silence between two heartbeats and the commanding silence when there is no heartbeat at all." In *The Presence* he sounds his own sick heart with a skill no cardiologist could match. He knows his good fortune when, more than 50 years ago, "she looked to the right luckily. I looked to the left luckily." He goes on to reveal, "There is also the agreeable, comfortable silence of two people together, two people who love each other and who have lived together for years. I knew that silence."

Abse tells us that "but" is a word authors do not wish to hear: "When 'but' is uttered you know you have failed." There are no buts to report here, and of course no happy ending. Like the Italian writer Cesare Pavese quoted in his epigraph, Abse knows "what really belongs to a man, in life, except what he has already lived?" This is perhaps not a book for the recently bereaved; no, Abse is alert to the "cool stranger," that is to say the rest of us—those who soon enough will be.

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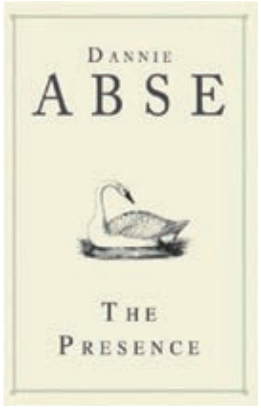

The Presence
Dannie Abse
Hutchinson, £15.99, pp 271
ISBN 978 0 091 79633 4
Rating: ★★★☆

"There is the silence I've heard through my stethoscope: the silence between two heartbeats and the commanding silence when there is no heartbeat at all"

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Zero tolerance

FROM THE FRONTLINE
Des Spence

When I was young we often ran out of shampoo. Then I squeezed washing up liquid into my hand to wash my hair. It gave a fantastic lather, but it was like CS gas on the eyes. Anything was better than a bar of Lifebuoy soap though. Our other male grooming product was Brut, an aftershave designed to cover the fact we bathed only once a week. In the 1970s, advertising was primitive—some catchy jingles to sell pies and boiled sweets. Today I am bombarded by advertising, from face creams to razors that make me a "real man." I consider myself lucky though, for it is mostly women who are in the telescopic sights of the advertisers.

Are women likewise targeted in health advertising? Flick through any medical journal or lifestyle magazine and it is images of women that dominate—from the drinks full of friendly bacteria that transform life, to a mother mouthing the word Tamiflu while clutching her daughter. Like most advertising it plays to base instincts—generally crude fear. Why single out women? Women are more health conscious, they have more contact with doctors, and spend more on health care. Perhaps women should be flattered that they are so pivotal in health care, while we mindless male Neanderthals plough on, impervious to all health messages.

Does this targeting matter? Perhaps it is long overdue post-feminist liberation. But I fear it is much darker. This marketing is a sophisticated attempt to play on women's reflectiveness, sensitivities, and to stir up health anxiety. From the menopause, osteoporosis, depression, premenstrual tension, polycystic ovary syndrome, and restless legs syndrome, women are being pursued. Some might argue that women have benefited from this health focus, but I would say that they have the side effects of medical marketing—medicalisation. Women increasingly get "non-diseases" that seek to redraw the boundaries of normality, thus turning women into patients and then health consumers. The wellbeing of women is being manipulated for profit.

Medical publications could and should exert more editorial control over medical advertising. Likewise the medical profession, stuck in a naive 1970s timewarp, needs to wake up to cynical medical advertising and its ugly brother "disease awareness campaigns," especially those directed at women.

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The mother ship has come in

THE BEST MEDICINE
Liam Farrell

I read that the Conservative party is proposing an innovative support system for new mothers and their babies. Apparently a "health worker" will attend for six hours each day in the first week after discharge, hang out around the house, and be generally helpful—for example, showing the mother how to breastfeed and bathe their baby, looking after older children, and performing housekeeping duties.

This is obviously a brilliant idea, but we have to tread carefully because the healthcare jungle is full of predators; initially we will be under the nursing umbrella, but that's just our fifth column. Slowly but inexorably we'll move to autonomy; first a few weekend courses, then a diploma (by correspondence) in mothering, then a degree course, a mothering tutor here, a mothering lecturer there, until finally, bless the day, our first professor of mothering, with faculties, lustrous peacock robes, academic processions, the whole shebang. A few emeritus chairs sponsored by the baby milk and nappy industries (strictly non-promotional, of course) will keep up the momentum until we have our very own royal college, complete with members and even fellows (for only a small increment on top of the annual levy).

At some stage men will enter the new profession and make the very understandable point that, hey, you can't pay a mortgage and school fees on this wage, and, hey, what about the defence premiums? Forget all that trite rubbish about caring being a vocation, we need to be recognised as the highly trained professionals we are; it's not about the money, of course, it's about being valued. This will be the most strategic time to appoint consultant mothers, able to lecture the ordinary nurses and midwives on mothering and to supervise the flying squads for those time critical laundry emergencies.

Of course, you can't expect consultant mothers to actually be hands on—washing babies, changing nappies, doing dishes, and generally getting down and menial and dirty—and anyway it will be too expensive to provide a consultant mother for every home. A whole new tier of low paid "auxiliary" mothers will have to be established, and these will certainly prove to be attractive jobs for our ever growing immigrant population.

Fathers, grandmothers, and aunties will be advised to keep their distance and be reminded of their limitations; they have absolutely no qualifications, and, anyway, they aren't insured. The obligations of our new evidence based discipline are much too important to be delegated to mere lay people.

What would mothers know about mothering?

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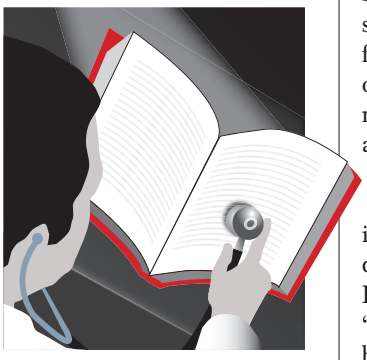
Singing the royal blues

BETWEEN THE LINES
Theodore Dalrymple



Schiller . . . understood that power and wealth were no bar to suffering. Perhaps it was his medical training that gave him the broadmindedness to do so

Friedrich Schiller (1759-1805) was the son of a doctor and a doctor himself, and yet when people compile lists of famous doctor-writers, strangely he is seldom included. I don't really know why this should be. It is true that he was a somewhat reluctant member of our profession, and practised for only a short time as a regimental surgeon in Württemberg; but Somerset Maugham never practised once he had qualified, and he is always included in such lists.

One of Schiller's best-known plays is *Don Carlos*, which combines romanticism with the ideals of the Enlightenment. It is so long that it has never been performed in its original version, concision not being Schiller's virtue at the time. Set in the Spain of the 16th century, it is an appeal for political liberty in the Germany of Schiller's day, and has been staged as such ever since.

According to Schiller, Don Carlos, the son of Philip II of Spain, is a democrat who wishes to oppose his father's oppressive policy in the Netherlands. Domingo, the king's confessor, says that Don Carlos has caught that most terrible and contagious of diseases, humanity.

The Don Carlos of history was slightly different from the hero of Schiller's play. Inbred, he was regarded by almost everyone as retarded and even possibly as mad (as his grandmother, Juana, had been). His head was so large that his enfeebled body had difficulty supporting it, and as a consequence he once fell down, banged it, and survived the subsequent trepanning operation, probably his greatest achievement of his life. It is still not clear, and probably never will be, whether Philip II ordered his murder.

Schiller, unusually, portrays Philip with some sympathy, ascribing his cruelty to his extreme isolation as the absolute ruler of the largest empire in the world. But Schiller does not mention another possible reason: Philip suffered from gout for the last 30 years of his life and had neither indomethacin to relieve it nor allopurinol to prevent it. Here is an account of his death, from Henry Kamen's biography: "The agony suffered by the king was so great that the doctors dared not move him. He had to lie on his back in bed. For the fifty-three final days of his illness he could not move from this position. The attendants could not change the bedsheets or the king's clothes. When the doctors opened his sores, the smell that came out was overpowering. The king had to evacuate in his own bed, soiling his sheets, which could not be changed. The fever never left him. The pain was unceasing."

Philip did not complain. In this he was like his father, Charles V, who abandoned the throne and retired to live out his last days in religious contemplation in the monastery of Yuste. There he lived in a kind of austere magnificence, suffering from the gout as severely as his son was to do, and spending much of his time in a special chair, which kept him motionless and which is still to be seen at Yuste. His son also had such a chair made for him.

According to one historian, Charles's gout worsened whenever he received bad news, but was relieved by a diet of fish. There is no doubt that, overall, he suffered horribly.

Schiller disapproved strongly of the Hapsburgs, of course, but yet he understood that power and wealth were no bar to suffering. Perhaps it was his medical training that gave him the broadmindedness to do so.

Theodore Dalrymple is a writer and retired doctor

MEDICAL CLASSICS

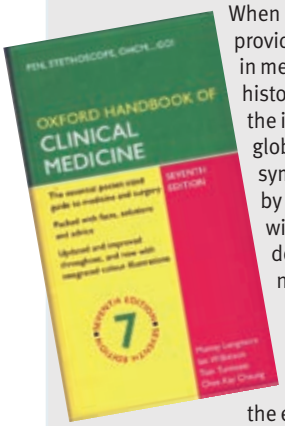
The Oxford Handbook of Clinical Medicine

First edition 1985

What do Inspector Morse, Marcel Proust, and Sengstaken-Blakemore have in common? Did they meet at college? Were their middle names all Kenneth? No. They can all be found in the *Oxford Handbook of Clinical Medicine*. First written by a group of friends as a collection of notes designed to help new doctors, it is now in its seventh edition and approaching its 23rd birthday. It covers everything in medicine and surgery, from advanced life support to zoonoses. Since its conception in the 1980s, the 400 gram tablet has kept up with the times—from monochrome to colour, regular size to mini version, and now paper to digital. There is also a range of more than 40 other handbooks in the series, from wilderness medicine to palliative care, their unique appeal lying in a triumvirate of brevity, clarity, and portability.

A copy has been begged, borrowed, or stolen by nearly every medical student, and only stethoscopes and hand gel match its ubiquity in hospital. As we peripatetic clinicians move from hospital to hospital, it remains, along with the *British National Formulary*, one of the few familiar and friendly faces.

It is not a textbook, nor does it pretend to be, rather it teaches how to be a well rounded doctor—one of culture, patience, reflection, and, above all, humility.



When I was a medical student it provided unforgettable lessons in medicine at the bedside; in history taking, examination, and the interpretation of medicine's global currency, signs and symptoms. Though best learnt by doing, these are purposeless without structure. Now I am a doctor, the handbook is still never far from my side.

My favourite chapter is "Eponymous Syndromes," as nothing is more pleasing to the ear or intriguing to the eye than an eponym, such as Ekbom's or Osler-Weber-Rendu syndrome.

The most important chapter is "Thinking about Medicine," not least because it sets out ideals and standards of practice, which "like stars are hard to reach—but they serve for navigation during the night." It quotes widely from authors such as Jung ("unless both the doctor and patient become a problem to each other, no solution is found"), Shakespeare, and McEwan, serving to empower us, like children, to ask the question "Why?" It warns against the "prejudices and expectations which all good practitioners ignore" and encourages readers to see each patient as a blank canvas, and not as the "chest pain in resus" or the "frequent flyer in bay four."

This book remains a medical classic. It moves with the ever changing landscape of medicine, reminding us why we are all here, what we have learnt, and how much further we have to go. It is, in short, a guiding star.

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