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- News: Organ donors could be given priority for transplants (*BMJ* 2012;345:e5219)
- Letter: Living donor registries are needed (*BMJ* 2012;344:e2727)
- Letter: Wills and wishes in organ donation (*BMJ* 2012;344:e1232)

"What we really need is a rallying call, like Kipling's poem *If* —" Des Spence, p 49

PERSONAL VIEW **David Shaw**

Don't let families stop organ donation from their relatives

It has recently been suggested that patients should be kept alive using elective ventilation to facilitate the harvesting of organs for donation.[1] But there is a much simpler way. Veto by the family is the main impediment to an increase in organ donation,[2] with at least 10% of families refusing to donate.[3] However, the family has no legal grounds for over-riding the dead person's wishes if that person clearly wanted to donate—for example, by carrying an organ donor card.[4]

Clinicians who heed the veto are complicit in a family denying its loved one's last chance to affect the world. Families often regret the veto within two days, and the regret of having denied a loved one's last wish can last for decades.[5] But at the time families are in emotional distress, and clinicians must help them make the correct decision. Clinicians may be willing to respect a veto to avoid distressing families further.[2] One solution is a system of so called advance commitment, where donors designate a family member in advance to confirm their decision.[2] However, there is a simpler solution: get doctors to do their jobs properly.

Failure to over-rule the veto and to respect the wishes of the deceased is a classic case of clinicians giving in to psychological pressure from people close in time and space without considering the wider effects on others. The doctor's qualms about causing more distress for the family cause deaths by omission and greater consequent emotional distress to far-off families, whose relatives will die because there were not enough organs available.

Here is an example. A doctor approaches the family of a recently dead woman who carried a donor card. The family refuses to believe that she wanted to donate her organs and asks the doctor to leave them alone. He can either do so, or persist. If he persists, and the patient's kidneys, heart, liver, lungs, pancreas, small bowel, and eyes are donated, as many as seven people could survive who would otherwise have died. (The fact that donation saves several people rather than just one should be part of any educational campaigns aimed at increasing donation rates.[6]) This persistence will cause the family some short term distress, but if they follow the usual pattern, they will see within a week that the doctor was right (and of course they have no legal grounds for complaint).

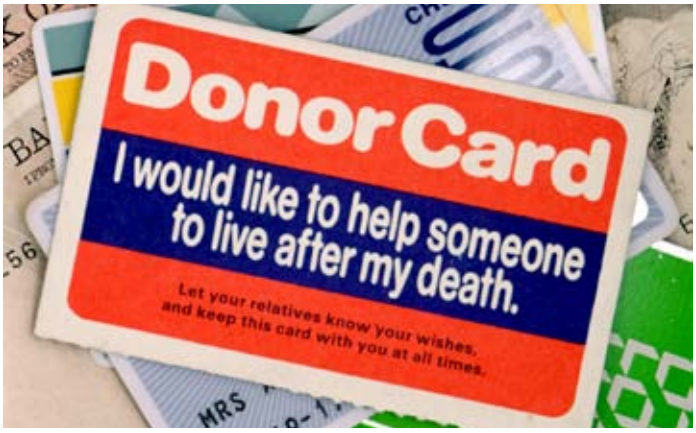
If the doctor does not persist, the family will be (relatively) happy in the short term but will probably soon regret their decision, and may even be annoyed at the doctor for not persisting. Furthermore, the patient's eyes, heart, kidneys, and other organs have gone to waste, and several people have died as a result.

The family cannot be blamed for refusing to allow donation under such stress. But can the same be said of the doctor, facing the stress of going against the wishes of a grieving family? No. Firstly, doctors are professionals with obligations to respect the wishes of the dead patient and to promote the health of the public. Giving in to the family is unprofessional and lets down the patient and potential recipients of the patients' organs elsewhere. A doctor might argue that this family is right here in front of him, but that is simply to admit his error: it is the moral distance from those he will be complicit in bereaving (and to some extent from the dead patient) that makes it tempting to respect the veto. The family's proximity increases the stress on the doctor, but does not change the ethics of the situation. Although we should treat the family compassionately, doctors do not have the same duty to the family as to dying patients or other patients who need organs.

Clinicians in this position should conduct a thought experiment. As well as the family that is there in front of them, they should also imagine confronting the families of those who will die as a consequence of not receiving the donor's organs. Most doctors are reluctant to add to a family's suffering at having lost a loved one, and families who refuse permission are rarely over-ruled. Mason and Laurie, authors of *Law and Medical Ethics*, state that "while this may be laudable sympathetic medicine, it is paradoxically doubtful medical ethics." In fact, it may not even be sympathetic medicine because the family are not patients, but the people who will die because of the failure to donate are.

To respect a family's veto when the patient was on the organ donor register is a failure of moral imagination that leads to a violation of the dead person's wishes and causes the death of several people (and all the sorrow consequent to this), and many family members who stop donation come to regret their decision. Moving towards elective ventilation might alienate would-be donors and will not be necessary if doctors remember that respecting a veto of organ donation is unethical, unprofessional, and against the spirit of the law.

Doctors should imagine confronting the families of those who will die as a consequence of not receiving the donor's organs



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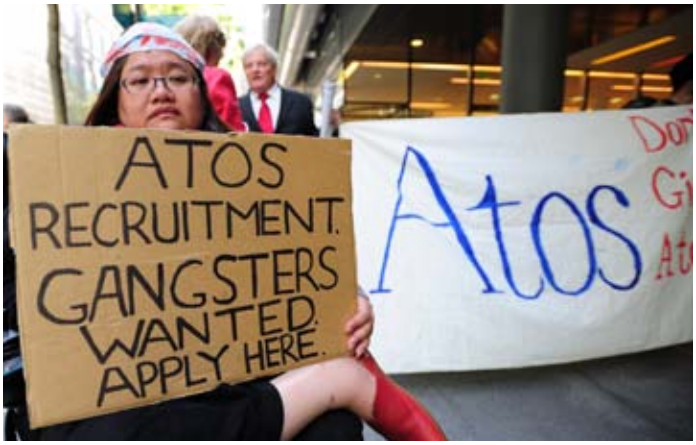

ALEX MILAN TRACY/DEMOTIX/PA

REVIEW OF THE WEEK

The disturbing truth about disability assessments

Two television programmes have shown that the benefits tests by the private firm Atos are unfit for purpose. Why are doctors involved in this farce, asks **Margaret McCartney**

Atos Healthcare carries out disability assessments on behalf of the Department for Work and Pensions. When I tried I failed to find out about the content of assessments, their evidence base, and the training and auditing of assessors.[1 2] I wanted to know basic things. What medical criteria were used in assessments? How could the assessor—having no access to medical notes, test results, clinical opinions, or history—make a valid decision about whether the person was fit, or not, to work? Despite Atos's services costing the taxpayer £100m (€125m; $155m) a year, commercial confidentiality is given as the reason why the veils are persistently and firmly drawn.

The general practitioner Steve Bick thwarted this tangled web by going undercover as a new recruit, filming his training sessions for *Dispatches*. It made for painful viewing. Incapacity benefit is being converted to employment support allowance, with the intention that every claimant would have a medical reassessment—the "work capability assessment." This is a medical examination carried out by a nurse, physiotherapist, or doctor. The tests—peak flow, limb movements, pushing a box around, pressing a button—are clearly unable to distinguish someone who can work from someone who can't. Points can be awarded in several categories and are forwarded to the decision maker, a Department for Work and Pensions assessor, for judgment. The box ticking to achieve enough points to be granted employment support allowance was ludicrous.

The doctor who trained Bick explained the distinctions. Oral chemotherapy or hormone therapy, say for prostate cancer, doesn't get points; intravenous chemo does. When Bick asked why, he was told, "That's the legislation." Disabled claimants were assessed as though they were using a "hypothetical" wheelchair. Having one hand or one leg is not enough to generate points; you must have no use of either of a pair of limbs to get a tick. This was described as "almost unachievable." The assessment bears no resemblance to real life. Why are doctors involved in such a farce? Atos has been allowed to take over the assessment of the most vulnerable people in society without proper scrutiny. The many successful appeals, which cost the taxpayer £50m a year to administer, shows the system's failure, and we do not know how many others do not appeal. Why are we not acting on the human cost of stress and anxiety caused by the assessments?

Citizens Advice, which helps people with appeals, has had its funding cut by an average of 10% from local government and reported last year that it was able to help 7% fewer people.[3] A video recently created by Her Majesty's Courts and Tribunals Service for appellants, which gave tips that might increase the chances of success, has been withdrawn after Chris Grayling, employment minister, complained about the "tone." Grayling went on camera for *Panorama* to deny that there were targets for assessment results, describing the push to get people off benefits as "tough love."

So, how does this work with, say, assessments of people not working because of mental illness? *Panorama* showed a man detained in hospital under the Mental Health Act who was pronounced fit to work. How do the assessors make judgments without recourse to notes or third party information, knowledge of stressors, patterns of illness, chronicity? What evidence does Atos have to show that its assessments are fit for purpose? The variety of backgrounds of the health professionals doing the assessments means that some may have no clinical experience of mental illness. Their only training may be from Atos. Is this enough?

Having professionals on board lends legitimacy to Atos's process. Yet the potential for deprofessionalisation in this environment is overwhelming. Malcolm Harrington has written three independent reviews of the work capability assessment for the government and has asked for substantive changes, including improvements in the assessment of mental illness and to transparency of the process. He told *Panorama* that the assessments needed human medical judgment to work. At the Atos recruitment evening I attended we were told that there were no targets; there were, however, averages, and if you fell beyond these you should expect close auditing. This was confirmed by *Dispatches*, but the derivation of these averages is unknown. So there was no room for medical judgment or nuance. One health professional explained that she felt awful for scoring a man with prostate cancer as fit to work. No wonder Bick's trainer explained that this was a "toxic" job: "That's why I don't do overtime."

The question of how we got ourselves into this mess is one thing. How we get ourselves out is another. Fear of losing their jobs, and the confidentiality agreements, means that few Atos Healthcare staff speak out. Bick was told, by a doctor who assessed a patient he had never met, to alter his examination findings. This should be intolerable. The BMA's conference of local medical committees in March voted that the work capability assessment was unfit for purpose.

The evidence for the processes that Atos uses needs immediate public scrutiny, and the harms of this system must be examined urgently. We should support and protect health professionals who work for Atos and want to speak out. We have allowed medicine to be made responsible for a dreadful process. We need to work together to make it clear that it cannot be.

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References are in the version on bmj.com.

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Disabled or Faking It?

A *Panorama* programme first broadcast on BBC Two on 30 July

www.bbc.co.uk

Rating: ★★★☆

Britain on the Sick

A *Dispatches* programme first broadcast on Channel 4 on 30 July

www.channel4.com

Rating: ★★★☆

BETWEEN THE LINES **Theodore Dalrymple**

His gastronomical practices

"His medical and gastronomical practices were wonderfully combined in so much that his guests could not tell whether what was set before them was a meal or a prescription"

A US magazine once asked me to write an article about doctors who had become political leaders: presidents, prime ministers, that kind of thing. What I discovered was that doctors were better at being dictators than democrats. By "better" I mean more fitted by experience and temperament, not better morally.

Doctors have always been prepared to step outside their professional field, in a wide variety of roles—for example, that of cook. The most famous medical cook was, perhaps, William Kitchiner (1775-1827), whose book, *The Cook's Oracle: Containing Receipts for Plain Cookery on the Most Economical Plan for Private Families, Being the Result of Actual Experiments in the Kitchen of William Kitchiner MD*, went through many editions, was in print for decades after his death, and had sold more than 15 000 copies by 1822. Cookery book bestsellers, it seems, are not a new phenomenon.

Kitchiner claimed to have been a medical graduate of Glasgow University, though the *Dictionary of National Biography* disputes this. However, since he was always regarded as a medical man in his lifetime, let us be charitable. He was also interested in music and optics; his researches in the latter discipline accounted for his election to the Royal Society.

He was a noted eccentric with a large inheritance that allowed him to follow his interests at will. At his dinner parties he would hang a large notice over his fireplace: "COME AT SEVEN, GO AT ELEVEN." I think some enterprising person might nowadays make a small income from printing and selling such notices.

Kitchiner: in the kitchen

Dr Kitchiner's friend, William Jordan, wrote of his dinners that, "His medical and gastronomical practices were wonderfully combined in so much that his guests could not tell whether what was set before them was a meal or a prescription." And, indeed, one of Kitchiner's other works was entitled *Peptic Precepts*. There are many medical allusions in *The Cook's Oracle*. The preface to the third edition begins:

> *Among the multitudes of causes which concur to impair Health and produce Disease, the most general is the improper quality of our Food; this, most frequently, arises from the injudicious manner in which it is prepared:—yet, strange, "passing strange," this is the only one for which a remedy has not been sought;—few persons bestow half so much attention on the preservation of their own Health, as they daily devote to that of their Dogs and Horses.*

Dr Kitchiner's medical interests are evident throughout. Of lobsters he says:

> *Buy these alive—the Lobster Merchants sometimes keep them till they are starved, before they boil them; they are then watery, have not half their flavour, and, like other Persons that die of a Consumption—have lost the Calf of their Legs.*

The book ends with a poem:

> *We now have made, in one design,*
> *The Utile and Dulce join;*
> *And taught the poor, and men of wealth,*
> *To reconcile their tastes to health,*
> *Restrain each forward appetite,*
> *To dine with prudence and delight,*
> *And, careful, all our rules to follow,*
> *To masticate before they swallow.*

Alas, Dr Kitchiner died (it is suspected) from imprudence. Having made it widely known that the next day he was going to cut out his good for nothing son from his will, he dined with him. He died overnight, probably of poisoning.

Theodore Dalrymple is a writer and retired doctor

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MEDICAL CLASSICS

The Idiot

A novel by Fyodor Dostoevsky; first published in Russian in 1869

Many of Fyodor Dostoevsky's characters are haunted by their own internal pandemonium: the great Russian novelist is probably best known for his murderers, suicides, liars, gamblers, drunks, and other figures of the underworld. But in 1868 he set out "to depict a completely beautiful human being." Generally in art, the difficulty with good characters is that goodness just isn't as interesting as wickedness, but this disorderly masterpiece is compelling. What's more, *The Idiot* shows how art can contribute to scientific observation, for Prince Myshkin, the idiot of the title, has epilepsy.

At the beginning of novel, Myshkin is returning by train to Russia after four years in a Swiss sanatorium, where he was treated for "some strange nervous malady—a type of epilepsy, with convulsive spasms." He is, by his own admission, a "complete child." In an adult society obsessed with money, power, and sexual conquest, his relationships—especially with women—turn out badly. Although he is "good," he can't seem to make anyone's life any better. By the end, he has "fallen" (the Russian term for epilepsy was "falling sickness") into a world that doesn't understand him.

Dostoevsky himself had epilepsy, and he endured seizures every three weeks. Although Sigmund Freud wrote in a 1928 article that this "so-called epilepsy" was really psychogenic ("severe hysteria"), most recent studies observe that Dostoevsky's symptoms, such as ecstatic auras, suggest a dominant temporal lobe epilepsy. In Dostoevsky, neurologists have a rich source of information about epilepsy. Some of this is first hand, in descriptions of his seizures and symptoms in his letters. But the disorder had a huge impact on his art: six characters in his 12 novels have been identified as having epilepsy.

The passages in *The Idiot* that describe Myshkin's seizures are considered to be some of the most accurate and intense literary accounts of ecstatic aura. He describes how his "sensation of being alive and his awareness increased tenfold at those moments which flashed by like lightning . . . All his agitation, doubts and worries, seemed composed in a twinkling, culminating in a great calm, full of understanding . . . but these moments, these glimmerings were still but a premonition of that final second . . . with which the seizure itself began. That second was, of course, unbearable."

This portrayal of mystical ecstasy has occasionally been dubbed "Dostoevsky's epilepsy." Although his terminology doesn't feature in the official classifications of seizures, it has secured a place in the literary canon for good. Myshkin's spasm of consciousness is a moment of exposure to the total dimensions of what Wallace Stevens called our "spiritual height and depth." Dostoevsky's creative achievement is to bring inexpressibly intense experiences within the jurisdiction of language.

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FROM THE FRONTLINE **Des Spence**

What is good medicine?

I write about bad medicine; not for the money, nor to be liked. I am not here to spread happiness, or insincere, sycophantic, doe eyed nonsense, but to counter what I see as the unrealistic, ill informed, pompous, overoptimistic ideas and practices that are pervasive in medicine. My remit is to blow some smoky realism into watering medical eyes. But I am no burnt out cynic, and I promised as penance to write about good medicine too. So many things spring to mind: vaccination, joint replacements, palliative care, anaesthesia, HIV drugs, antipsychotics, insulin, anticonvulsants, advocacy of exercise, and banning smoking. However, when I ask what good medicine is, no one mentions these technical advances. Good medicine seems almost solely dependent on the attributes of the doctor, the application of medicine.

And we should avoid medical narcissism because good medicine is entirely dependent on good nurses, allied professions, receptionists, managers, cleaners, and porters. We are all in it together. And on a macro level good medicine requires effective housing and social policy. My observation is that there are good doctors everywhere. Not the great, well known, media doctors, and the international experts, some of whom are, to a large extent, driven by ego and vanity. No, I mean the many thousands of jobbing doctors who work in the unfashionable parts of medicine in the unfashionable corners of the country, delivering day to day services, and who care deeply about the health service and their patients. I have tried to research and understand what sustains good medicine.

What we really need is a rallying call, like Kipling's poem *If*— for doctors. I have tried, but clumsy diatribes are rarely poetic

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The General Medical Council guidance *Good Medical Practice* is sterile and passionless.[1] What we really need is a rallying call, like Kipling's poem *If*— for doctors.[2] I have tried, but clumsy diatribes are rarely poetic. I can offer some words, phrases, and maxims discovered during my excursions into good medicine. Adjectives like creative, brave, efficient, organised, honest, humble, genuine, warm, flexible, open, empathetic, caring, and adaptive. Qualities like hard working, listens, takes ownership, is outspoken, is an advocate, accepts uncertainty, team working, and, of course, has a sense of humour. Doctors have offered phrases such as "knowing when enough is enough," "interested in patients as people," "know what you don't know," "listen more, intervene less," "look at the person not the evidence," "doing what is right, not what is easy," "intolerance of the intolerant," "empower health, not illness," "our weaknesses are our strengths and our strengths are our weaknesses," "if its benefits aren't obvious, don't do it," "leadership is earned, not given."

Now this might all seem nauseatingly trite, but we should unashamedly celebrate good medicine and good doctors.

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References are in the version on bmj.com.

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DRUG TALES AND OTHER STORIES **Robin Ferner**

Enhancement

Chemical enhancement of performance is not new. In battle, for example, the word "assassin" is believed by many to come from "hashish," which was used to inspire fanatical devotion in Arab soldiers.[1] The Royal Navy might have been encouraged to find Dutch courage by De Ruyter, the 17th century admiral, who swept the British from the North Sea. And rum, Churchill said, was one of the great naval traditions, along with sodomy and the lash.

The navy may have abandoned these traditions, but the quest for performance enhancing drugs continues. The rules of the World Anti-Doping Agency point to the many and varied aids—or supposed aids—to athleticism. Supervised micturition, sophisticated detection, and rigid regulation should keep athletes pure from the many banned substances whose use might shave seconds off their marathon runs or add grams to the weights they lift.[2] In addition to the long list of anabolic androgens, stimulants, diuretics, and so on, the code specifically bans any pharmacological substance not currently approved for human therapeutic use. This raises the question of what a "pharmacological substance" might be.

The Olympic Games are, I suppose, important. They have taken over the newspapers and will leave a legacy of pop venues, housing estates, and Anish Kapoor's sculptural helter-skelter (provided it is not stolen by some local scrap metal merchant). But the desire for enhancement is more parochial. It seems that students are buying modafinil in the hope that it will improve their memory; it seems to work in mice,[3] so may help in the rat race. Despite warnings from the United Kingdom Medicines and Healthcare Products Regulatory Agency that unscrupulous sellers are raising little more than false hopes,[4] men are succumbing to email promises of sexual performance maintained—for hours and for years. And I see on the back of the women's magazine *Good Housekeeping* an advertisement for Lancôme Génifique, a "youth activating concentrate" whose formula "stimulates the skin's surface so that the presence of proteins characteristic of young skin increases." It's all rather confusing, and I think I need another cup of strong coffee to clear my mind.

Students are buying modafinil in the hope that it will improve their memory; it seems to work in mice so may help in the rat race

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