NO HOLDS BARRED **Margaret McCartney**

Harm and the new benefits system

The BMJ readers can buy Margaret's new book, *Living with Dying*, for £7.99 (RRP £11.99) from www.pinterandmartin.com with code BMJ799

The Disability Living Allowance benefit started to become Personal Independence Payments (PIPs) in 2013. These payments, which are not means tested, go to people with long term disabilities who need help to cook, eat, travel, wash, or dress, for example.

The government's aim was to reassess each person receiving Disability Living Allowance to reduce "caseload and expenditure" by 20%.[1] After a "spending to save" philosophy the government gave two private companies, Atos and Capita, contracts worth about £500m[2] and £140m[3] to administer the assessments and, supposedly, to save £3bn.

Many in the media have focused on "benefit cheats." Anxiety is a common, unintended outcome of health and social care policies that is rarely taken seriously enough, let alone measured. The benefits system should be fair, of course, but criminals are rare. The uncertainty of the new PIP thresholds has created much fear, and my repeated observation is that guilt, embarrassment, and a sense of being made to "beg" all surround the copious form filling required when applying.

The Public Accounts Committee described the system as "nothing short of a fiasco"

Backlogs in carrying out assessments have led to months of worried sleeplessness that have gone largely uncounted. The Public Accounts Committee described the system as "nothing short of a fiasco," one creating stress and distress[4]—but evidence of harms is not being systematically collected. It is ethical to want to ensure that people with chronic conditions can participate in society. But it is self interest, too: firstly, because we, or people we care about, may become disabled; and, secondly, because a fairer society is better for us all.[5]

The first independent review of PIPs focused on problems with administration of the assessments[6] rather than their effect on people, families, or the NHS, which is called on to help with delays and uncertainties in the system.

We should answer the basic questions first, because social care is essentially healthcare. Where was the evidence that we could safely and humanely reduce our social welfare spending without causing harm? How do we know this new system works well enough?

Recent data show that £1.2bn, 0.7% of the total, is lost to benefit fraud. However, £1.5bn of benefits are underpaid, meaning a net shortfall in claims.[7] Changing the means by which benefits are made should surely work on a safety first principle. The confusing and slow claims system seems designed to exclude people, and it is often left to charities to help people get the funds they are allowed. Is this the kind of care that chronically ill and disabled people deserve?

Margaret McCartney is a general practitioner, Glasgow
margaret@margaretmccartney.com

Cite this as: *BMJ* 2015;350:h280

Twitter @mgtmccartney

IF I RULED THE NHS **Ruth Carnall**

Support doctors who lead change programmes

Everyone agrees the NHS needs more clinical leadership and "transformational change." Yet to many doctors the processes to support and approve major change consist of a mountain of bureaucracy focused on political risk avoidance. Continually saying, "Yes, we will support this if you can only produce this further proof," creates more hurdles, hindering change. Doctors who have led change programmes have to act like circus animals performing meaningless tricks and then being told that their act is not good enough. So in my benign dictatorship I would insist on "yes" meaning "Yes, we will turn all our efforts to supporting you," while "no" responses would be based on evidence, explained clearly, and accompanied by support.

Let's assume instead that the real world continues, with yet more assurance processes, tests, inspections, and regulations. I firmly believe that it remains possible to make radical change in the NHS. Doctors can effectively articulate a powerful case for change that, while based on evidence, also has emotional resonance. This means being honest about unacceptable or unsustainable care. There are good examples: doctors have presented

Doctors can articulate a powerful case for change that, while based on evidence, also has emotional resonance

data on unnecessary deaths from strokes; they have demonstrated that people are more likely to die in some hospitals if admitted at nights or weekends; and they have explained how hundreds of people with diabetes lost their limbs unnecessarily because of inadequate care out of hospital. Such statements demand action and condemn inaction. Doctors who lead change may experience huge personal exposure and are often attacked by colleagues, by their organisations, and in their communities; and then if they are still standing the process described as "assurance" can finally beat them. Is it any wonder many give up at this point?

At present, almost every doctor faces a continual stream of patients in need. How can we make it possible for doctors to lead change? Firstly, we should recognise that we handle change badly at the moment and that we will need to provide more support and resources. NHS England chief executive Simon Stevens endorsed this in his *Five Year Forward View*. Can it be followed through? We need to assess cases for change, leadership commitment, and capability, and if the answer is "yes" then we should back it with everything we have got.

Exposing doctors to leadership early on is crucial. The Prepare to Lead scheme for junior doctors in London was massively oversubscribed but has now run out of funding. We can and should provide real training, coaching, and mentoring to doctors who are willing to be leaders. But most of all we need an honest discussion about which of the compelling cases where change is needed we are going to back, and then we need to say, "Yes, we will support you"—and mean it.

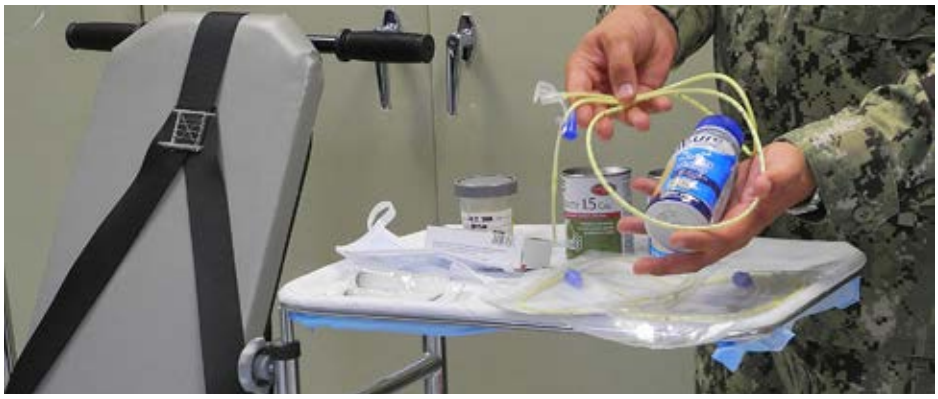
Ruth Carnall is managing partner, Carnall Farrar, and former chief executive, NHS London
ruth.carnall@carnallfarrar.com

Cite this as: *BMJ* 2015;350:h704

thebmj.com
Read previous articles in this series at http://www.bmj.com/specialties/if-i-ruled-nhs

The US is wrong to medicalise hunger striking

Force feeding should play no part in the care of mentally competent patients, says **W John Kalk**, who treated hunger striking prisoners in South Africa during the apartheid era



AMNESTY

So many individual physicians who have attended the prisoners in Guantanamo have failed to recognise, or have chosen to ignore, unethical treatment of prisoners for whom they should be personally responsible

In 1998 I was asked by the Johannesburg Hospital to assume responsibility for the medical care of political prisoners admitted because of acute complications of hunger strike. Some 20 detainees, all young black men whom the apartheid government considered a "high security risk," had been held in so called "preventive detention" by police for up to 32 months, some in solitary confinement.

The hunger strike was their protest against being held without charge under emergency regulations. The police medical services in Johannesburg had been unable to cope with large numbers of increasingly ill prisoners, who were admitted to local hospitals. In the Johannesburg Hospital they were housed in a single ward where they were guarded by heavily armed police and were periodically shackled to their beds. At that time there were some 700 such detainees on hunger strike throughout the country.

Hunger strikers were patients

The ethical and medical principles that we applied in the Johannesburg Hospital in the management of these prisoners have been published.[1 2] In essence, they were our patients: the medical and nursing staff agreed to accept the principles of full clinical independence and confidentiality with patient participation and consent in all clinical decisions. Our approach was explained to the detainees. We promised that we would follow the ethical provisions of article 6 of the World Medical Association's (WMA) Declaration of Tokyo,[3] which deals with hunger strike. We outlined the potential medical consequences of hunger strike. We did not exert pressure to end the hunger strike. Many prisoners accepted a psychiatric assessment; all were considered to be mentally competent.

I interviewed each prisoner to find out if he wanted resuscitation should he become too ill to make a decision. We kept these advance directives separate from the clinical notes. We told prisoners that their wishes would be respected, and that they could change them at any time.

The nursing and medical staff were subject to intermittent intimidation by police guards, who had written orders explicitly permitting them to interfere with the prisoners' medical care and privacy. Ongoing negotiations with senior police resulted in the incremental provision of basic rights such as having visitors, books, and access to news media. No prisoner was discharged back to police detention without charge.

Forcible feeding

Hunger strike and force feeding prisoners are again news after the revelation that a US naval nurse had in July 2014 refused to continue force feeding detainees at Guantanamo Bay,[4] and following the recent publication of the US Senate report on the treatment of prisoners.[5] The WMA's Declaration of Malta states: "Forcible feeding of [mentally competent hunger strikers] is never ethically acceptable. Even if intended to benefit, feeding accompanied by threats, coercion, force or use of physical restraints is a form of inhuman and degrading treatment."[6]

The US military's approach to prisoners in Guantanamo raises the potential conflict of choices available to all practicing health professionals involved in the care of prisoners everywhere—whether or not to follow accepted ethical guidelines in patient care.[7] The repeated use of restraint chairs to facilitate forced nasogastric feeding at Guantanamo is well documented, despite being outlawed by international conventions to which the American Medical Association is a signatory.[8] In support of this practice, a so called medical "instruction" from the US Department of Defense in 2006 incorrectly medicalised hunger strike in mentally competent prisoners by conflating it with suicide.[8] The goal of prisoners on hunger strike is not to die, as is the case in suicide, although some are willing to risk death; rather their objective is to draw public attention to their perceived injustices in the only way open to them.

It has been reported[8] that US military physicians have justified their position on the premise that they must obey orders from superiors, implying that military doctors can abrogate their personal responsibility for unethical management of the patients under their care who happen to be prisoners. In so doing they breach ethical codes, and are complicit in "aggravated assault"—that is, torture.[8]

US medicine must ask: why is it that so many individual physicians who have attended the prisoners in Guantanamo have failed to recognise, or have chosen to ignore, their professional and ethical obligations by condoning or even participating in unethical treatment of prisoners for whom they should be personally responsible? At stake here is their professional integrity, as would be the case in civilian practice.

The Johannesburg approach to hunger strike among prisoners offers an alternative.[1 7] Very recently, Physicians for Human Rights have suggested that health professionals who have been directly involved in the torture of prisoners may have committed crimes against humanity.[5] It is crucial to keep in mind the fundamental right of all patients to humane treatment, even at the risk of conflict with the organs of state authority.

W John Kalk is locum consultant endocrinologist, Medway Maritime Hospital, Gillingham, Kent ME7 5NY, UK
wjohnkalk@gmail.com

Cite this as: *BMJ* 2015;350:h669

thebmj.com

- Editorial: Torture and doctors' dual obligation (*BMJ* 2015;350:h589)
- News: Doctors should refuse to assess Saudi blogger's fitness for flogging, human rights group says (*BMJ* 2015;350:h492)
- Vincent Iacopino, Physicians for Human Rights, on the Saudi blogger's flogging case (bmj.co/iacopino)