# comment

When I drink I consider many things: how lovely life is, how witty my jokes are, and that cleaning up can wait until morning. This is, clearly, why I'm not chief medical officer

**NO HOLDS BARRED** Margaret McCartney

PPA COLUMNIST OF THE YEAR

# Stop promoting certainty despite fuzzy science

vidence and public policy mix like Baileys and diet cola. For months I've bravely wrestled with my gin choice (Harris or Hendrick's? Blackwoods or the Botanist?)—despite Public Health England's advice to the nation that all regular alcohol is bad. <sup>1</sup>

As a collector of gins and a peruser of tonics I've maintained my cheer, which was threatened when the chief medical officer for England informed a select committee, "Do as I do when I reach for my glass of wine—think, 'Do I want the glass of wine or do I want to raise my own risk of breast cancer?"

When I drink I consider many things: how lovely life is, how witty my jokes are, and why it's a good idea to leave cleaning up until morning. This is, clearly, why I'm not chief medical officer. But, thinking soberly, is all alcohol harmful?

The Department of Health says yes: "Drinking any level of alcohol regularly carries a health risk for anyone." Yet expert advice from Sheffield described J shaped curves for mortality versus alcohol intake: at low intake, the risks seem outweighed by benefits. Caveats and uncertainty exist, and benefits of drinking small amounts may be overestimated. But a conflict remains between an easy message and a correct one.

"People have a right to accurate information and clear advice about alcohol and its health risks," say the new guidelines. <sup>4</sup> This is true. But



the recommendations have distilled complexity into soundbite snacks—high on instant satisfaction but poor on long term nutritional value. Since the news reached the media, alcohol is terrible and cancer is everywhere, with little explanation of uncertainty and caveat.

And now, yet more press delight over public health, with a rumpus over diet. "Fat is our friend," and "You can't outrun

a bad diet,"<sup>5</sup> we hear—but evidence shows that exercise in addition to diet does result in greater weight loss. The evidence around high fat, low carbohydrate diets contains multiple uncertainties and can't reasonably promise to "reverse obesity and type 2 diabetes," as proponents claim. A recent systematic review found otherwise.

But this doesn't mean that I believe the current guidelines on diet to be highly evidence based: to reduce the large uncertainties will require multilateral effort. This won't happen while certainty is promoted despite fuzzy science.

The most interesting statement on alcohol from Public Health England was that it found "little evidence regarding the impact of any guidelines in changing health behaviours." To which I reply: what, then, are the harms of having a debate about false certainty in public? Pass the gin.

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

► Follow Margaret on Twitter, @mgtmccartney Cite this as: BMJ 2016;353:i3218

the **bmj** | 16 July 2016 **107** 

PERSONAL VIEW Scott A Murray

# Set a low bar for starting palliative care

Dying patients and their families most need support early on

bout two years ago, death tapped me on the shoulder. I'd been coughing on and off for a year but didn't want to think about a danse macabre. Eventually I went to my GP. The x ray report could not be ignored. Neither could the computed tomography scan, which confirmed lung cancer.

Tough luck, I thought, because I've never smoked. And, how ironic: I teach palliative care to medical students and routinely ask them what they'd wish to die from. The smart choice is cancer, because end of life services are much better developed for that. I'd also led the Making a Difference campaign in *The BMJ* to extend palliative care to all conditions.<sup>2</sup> But now cancer was fighting back in a rather underhand way.

Discussions, tests, questions, and decisions came quickly while I tried to work and make sense of things. The surgeon suggested a lobectomy and clearance of nodes, and my wife

encouraged him to take enough out. I got a sick note and succumbed to treatment.

Arriving at the diagnosis was a particularly stressful time. But I'd been forewarned: our research team at Edinburgh had been interviewing people with lung cancer, 3 glioma, 4 and bowel cancer, 5 at the time of diagnosis and again later, along with their families.

#### **Most traumatic**

Most patients found the times before treatment or diagnosis more stressful than any other. As patients looked back just before they died or as bereaved relatives reflected afterwards, they often reported the time around diagnosis as the most traumatic. Psychological and existential distress seem most acute at diagnosis, at the return home after initial treatment, at recurrence, and around the time of dying—and the early stage is often the worst of all. Family members also went through a similar rollercoaster of

Psychological and existential emotions starting at that time. 7
So, people arriving at a diagnosis

Psychological and existential distress seem most acute at diagnosis. Family members also went through a similar rollercoaster of emotions starting at that time

emotions starting at that time.<sup>7</sup> So, people arriving at a diagnosis of life threatening cancer need early psychological and existential support.

When death tapped me on the shoulder I benefited from a palliative care approach from generalist clinicians. This meant easy access and friendly support on the telephone, without anyone mentioning the phrase "palliative care." After 18 months my GP removed the electronic tag on my record that indicated a palliative care approach. I was no longer on the palliative care register. I felt relieved, but that harks back to an association with dying. Palliative

**ACUTE PERSPECTIVE** David Oliver

### End of life care in hospital is everyone's business

Palliative care: do we need more specialist clinicians, or more generalist staff better trained in it? My answer is both.

About 500 000 people die each year in England and Wales. Yet the UK has only an estimated 519 specialist palliative medicine consultants and fewer than 5000 crucial specialist palliative care nurses. 12

A national audit of end of life care in hospital by the Royal College of Physicians found a median of one palliative medicine consultant and five nurse specialists for every 1000 adult hospital beds.<sup>3</sup>



Many recently qualified doctors report feeling underprepared for end of life care Some of us will die suddenly.
Others may have only weeks
to prepare after an unexpected
terminal diagnosis, but most will die
with or from long term conditions.
Multiple contacts with health and
care practitioners give us many
opportunities to discuss and plan for
our deaths.

Despite concerted campaigns to improve care in the last year of life and get more people to make advance plans, these opportunities are missed. <sup>45</sup> Only 4% of 9000 patients in the hospital audit had any form of advance plan made before admission.<sup>3</sup>

Nearly half of us die in hospital.<sup>6</sup> We don't have sufficient hospice places, staff, or funding to support everyone to die in other settings. Some people may wish to stay in hospital at the end, <sup>7</sup> and a death in hospital need not be a bad one. We have—in the words of one campaign—"one chance to get it right." And, despite very poor experiences reported by, for instance, the NHS Ombudsman, <sup>9</sup> we seem to get it right more often than not.

The latest national survey found that two thirds of 21 000 bereaved people thought that the quality

**108** 16 July 2016 | the **bmj** 



care should be for everyone who needs it, when they need it; and earlier is better than later, when relationships can be built and when there's time to think and plan and to enjoy the remaining life to the full.

#### **Clear clinical implications**

Acknowledge to patients facing a brush with death that they will find this initial time very challenging but that you will help them and be there for them. Explain the ups and downs that affect most patients with their condition (and family carers), and invite them to make regular contact with someone for support.

In other words, trigger a palliative care approach, but don't

necessarily use the phrase. After all, we don't have to use the word "gastrectomy" to explain that operation to a patient. In Scotland we now use the term "anticipatory care" to describe care planning in primary care with daily routine electronic communication of a key information summary to all other care settings.<sup>9</sup>

Most people in Scotland die with a care plan in place. Let's be ready to offer care planning when a life threatening illness strikes. Waiting for death misses the point.

Scott A Murray is St Columba's Hospice chair of primary palliative care, University of Edinburgh Scott.Murray@ed.ac.uk
Cite this as: BMI 2016;353;i3598

of care had been outstanding, excellent, or good, although one in 10 rated it as poor. Hospices offered the best experience overall, and symptom control was easier to achieve in hospital than at home.

However, the Royal College of Physicians audit found major gaps in documenting basic aspects of care in patients whose death could reasonably be anticipated. These included patients or loved ones discussing their own concerns and choices; spiritual care; clear plans around eating, drinking, artificial nutrition, and hydration; and control of common symptoms. Only a third of hospitals had face to face specialist palliative care seven days

a week. Many patients were unable to see specialist doctors or nurses.

Many recently qualified doctors report feeling underprepared for end of life care.<sup>11</sup> The National Council for Palliative Care and Marie Curie have highlighted similar training gaps among nurses.<sup>112</sup>

Without substantial and un-promised increases in staff numbers in specialist palliative medicine and nursing, getting the basics right must be everyone's business.

David Oliver is a consultant in geriatrics and acute general medicine, Berkshire davidoliver372@googlemail.com
Cite this as: BMI 2016:354:i3888

#### THEBMJ.COM BLOGS Angela Coulter

## At last, some better news on shared decision making

Shared decision making has now entered common parlance. But a recent review from the Care Quality Commission found hardly any change over the past 10 years in the extent to which patients feel informed and involved in decisions about their care. And this is despite the almost universal consensus about the need for person centred care, of which shared decision making is the prime embodiment.

Guidance from the General Medical Council, the Supreme Court, and the Mental Capacity Act now speaks with one voice—shared decision making should be the default, with few exceptions. Yet many practitioners have continued to resist these blandishments to cede decision making power to patients.

## Latest results show an encouraging upturn in the number of people who said that they were "definitely" involved in decisions

But maybe the tide is turning at last. The latest results from the annual survey of patients' experience of hospital inpatient care show an encouraging upturn in the number of people who said that they were "definitely" involved in decisions about their care "as much as they wanted to be."

Last year the National Institute for Health and Care Excellence convened a group of stakeholders to discuss what needed to be done to embed shared decision making in mainstream practice. The group's consensus statement called for stronger leadership to change clinical practice, training in shared decision making knowledge and skills, better provision of patient decision aids and incorporation of these into clinical guidelines, routine measurement of patients' experience of decision making, and more research into implementation strategies.

Recently the group reconvened to review progress. We heard from projects around the country, including NHS England's Right Care programme, which encourages commissioners to promote shared decision making; NICE's work on integrating patient decision aids into its clinical guidance; and the Academy of Medical Royal Colleges' attempts to tackle overuse by actively involving patients.

This all amounts to a useful ragbag of initiatives rather than the coordinated strategy that the collaborative is calling for, but it's a good start and does seem to be bearing fruit.



the **bmj** | 16 July 2016 **109** 

#### **OBITUARIES**

#### **Thomas Oswald Candler**

Former surgeon and general practitioner Bideford (b 1920; q Cambridge/Middlesex Hospital 1943; FRCS, FRCGP), died from old age on 25 February 2016. Thomas Oswald Candler



("Tom") qualified during the war and trained in surgery before entering general practice in Bideford at the start of the NHS. He continued working as a surgeon as well as a family doctor. He embraced modern general practice, welcoming medical students and trainee GPs and becoming a champion for the new health centre. In retirement, he supported his wife, Stella, who had Parkinson's disease. Their garden was often opened for charity, and Tom won prizes for his grapes. He designed and made exquisite pieces of marquetry, much cherished by friends and family. Predeceased by Stella, he leaves three children, seven grandchildren, and 11 great grandchildren. Hilary Richards, Clive Richards

Cite this as: *BMJ* 2016;354:i3782

#### T Butter Learner

Retired general practitioner (b 1922; q Edinburgh 1945), died from pneumonia on 7 May 2016. Nina Avis Mellon initially trained in obstetrics

and gynaecology before

**Nina Avis Mellon** 



moving back to the West Indies. After working briefly in Barbados she moved to what was then called the Colonial Hospital in Port of Spain, Trinidad, She married George "Pie" Wilson in December 1947, and the couple moved to the south of Trinidad, where he was working in the oilfields. Avis worked as the local GP until they both retired and moved to Budleigh Salterton in 1983. In recognition of her involvement with family planning and other community health projects she received an award from the Trinidad Medical Association. Predeceased by Pie and a daughter, she leaves two sons, six grandchildren and two great grandsons. **Helen Cordy** 

Cite this as: BMJ 2016;354:i3772

#### Michael Stephen Arnold Townsend

General practitioner (b 1940; q Sidney Sussex College, Cambridge/St George's Hospital, London, 1965; FRCGP), died from caecal carcinoma on 14 May 2016.

After doing house appointments at St. George's Hospital, Michael Stephen Arnold Townsend returned to his hometown of Spalding, Lincolnshire, to join the practice of Drs Cadas, Nowlan, and Aitken. From 1980 he was involved in the Boston vocational training scheme. He represented the Holland division of the BMA at the annual conference from 1971 to 1988, and was treasurer of the Lincolnshire local medical committee from 1974 to 1999. He retired from the practice in 2000 but continued to do locum work for a further seven years. Outside work he enjoyed skiing and for 30 years had his own canal boat, enjoying cruising canals in Britain and France. Predeceased by a daughter, he leaves Liz, his wife of 49 years; a son and daughter; and three grandchildren.

**Robert Townsend** 

Cite this as: BMJ 2016;354:i3770

#### Barbara (Basia) Howells

Former general practitioner Whetstone, London (b 1933; q Royal Free Hospital, London, 1957; DCH), died from complications arising from lymphoedema after breast cancer on 15 December 2014.



Basia Kaja Zamoyska was born in Warsaw and came to England aged 7 in 1940. Basia excelled academically and secured a scholarship to study medicine at the Royal Free Hospital. One of her preregistration house jobs was at Barnet Hospital, where she met her future husband, Hilary Howells, a resident anaesthetist. She became a partner in general practice in Whetstone, north London, and worked as a GP for some 35 years. With the cooperation of local health authorities she conceived and set up the Oakleigh Road Health Centre, where she worked until her retirement. For 10 of those years she was joined in partnership by her daughter, Jane, who continues in practice there. She leaves her husband, three daughters, and seven grandchildren. Hilary Howells, Jane Howells

Cite this as: *BMJ* 2016;354:i3777

#### Robert George (Rob) Jones

Honorary professor in old age psychiatry University of Nottingham (b 1947; q Manchester 1970; FRCPsych), died from a cerebellar haemorrhage on 23 May 2016. After training in



psychiatry in Manchester, Robert George Jones ("Rob") moved to the new medical school in Nottingham in 1980 to join the innovative department of healthcare of the elderly. He helped develop and for many years supported the joint attachment in old age medicine and psychiatry for Nottingham's medical students. His research included influential studies of outcomes for care home residents and community care provision, as well as participating in major national studies. He provided a clinical service to deprived areas of Nottingham city for more than 30 years. Universally regarded with respect and affection by colleagues and family, he had an irrepressible interest in people. He leaves his wife, Diane; four children, and nine grandchildren.

Tom Dening

Cite this as: *BMJ* 2016;353:i3388

#### **Peter Alan Trott**

Former consultant in cytopathology, Royal Marsden Hospital, and director of pathology, London Clinic (b 1934; q Cambridge/Guy's Hospital, London, 1966; MRCS Eng, FRCPath), died from chronic



respiratory failure on 6 November 2015. During his national service, Peter Alan Trott was posted to Singapore, where he contracted a virulent polio infection. He met Celeste, his first wife and the mother of their two daughters, during treatment in Stoke Mandeville Hospital. Peter pursued histopathology with determination and was appointed to the Royal Marsden Hospital in 1974. He developed an efficient cytopathology service, with particular emphasis on fine needle aspiration cytology of solid tumours. During part time work at the London Clinic, he established a similarly successful pathology service. Peter enjoyed driving fast cars to visit his family in Norfolk, where he eventually retired. He was a great colleague with a wonderful sense of humour. Alan McKinna, Rosemary Millis

Cita this as PM/2016/25/6/2771

Cite this as: BMJ 2016;354:i3771

**110** 16 July 2016 | the **bmj** 

### John Corbett McDonald

Occupational epidemiologist whose work led to the "universal recognition of the toxicity of asbestos"

John Corbett McDonald (b 1918; q 1947; MD, MSc, DPH Lond, DIH Eng, FRCP Lond, FRCP Can, FFCM, FFOM, FFPHM), d 25 April 2016.

In the study of work related diseases, John Corbett McDonald was a pioneering investigator, whose research and techniques in many ways defined occupational epidemiology. His best known role from the mid-1960s onwards—analysing the effects on health of different forms of asbestos—yielded controversy in a highly contentious area.

McDonald produced research that was "groundbreaking and vital to our understanding of asbestos health effects," says Bruce Case, a pathology professor who worked with him at McGill University in Montreal, Canada.

McDonald, who developed the use of tissue indicators of exposure, believed in the "big study." He created a reliable national system of surveillance for work related respiratory disease (the SWORD system) as a basis for control and simple epidemiological research in the UK. It was first used by chest physicians to report cases of work related disease, then adapted and expanded for use by other clinicians.

Belfast born McDonald joined the Public Health Laboratory Service in Colindale (where he was head of the epidemiological research laboratory from 1960 to 1964) and worked on the epidemiology of viral diseases, particularly influenza. In 1976 McDonald returned to the London School of Hygiene and Tropical Medicine as professor of occupational health.

#### Asbestos and mesothelioma

McDonald attended the seminal New York conference on asbestos in 1964, four years after studies had established the link between asbestos and mesothelioma in South Africa.

For decades he studied the effects on Quebec's miners, millers, and factory workers of different forms of asbestos—once the "mineral gold" that enriched Canada's economy. McDonald worked on a series of cohort studies, many with his wife, Alison, who was also an epidemiologist and played a key part in the success of these studies.

In 1973 he showed that previous industry conclusions that lung cancer was unrelated to asbestos exposure were false, and that mesothelioma among chrysotile asbestos workers was "fourfold greater than expectation."

He later concluded with Case and others that 27 mesothelioma deaths "could be attributed with reasonable certainty to occupational exposure in the Quebec chrysotile production industry."

McDonald discovered that different occupational populations had different risks in terms of cancer. Importantly, he showed that much of the risk of mesothelioma was related to the presence of other fibres ("contamination" by tremolite asbestos for the most part).

This did not suggest that there was no health risk from chrysotile asbestos, but rather that "greater exposure to tremolite asbestos conveyed greater risk," explains Case. This was important, says Case and led to further understanding of mesothelioma risk factors in places like Libby Montana and northern California, and to "extensive work there to mitigate that risk."

But the so called tremolite hypothesis and evidence of differential risk was seized on by pro-asbestos groups defending a much criticised industry.

They pushed for continued mining and exports of "pure" chrysotile asbestos from developing countries, while quoting "dishonestly" and "selectively" from McDonald's studies.

McDonald and his department faced criticism from anti-asbestos activists and questions over industry funding for the epidemiological research on asbestos.



Corbett
McDonald
showed in
1973 that
previous
industry
conclusions
that lung
cancer was
unrelated
to asbestos
exposure
were false

#### **Research integrity**

In 2012 a research integrity probe by McGill found that there was "no evidence of scientific misconduct" and concluded that industry sponsorship had been openly declared and acknowledged. It also said that the research by McDonald and others "generated the information that led to the near complete disappearance of the asbestos industry in the developed world and the universal recognition of the toxicity of the product."

In 2005, aged 87, McDonald had to have a leg amputated after being hit by a motorbike when crossing the road. Although it was assumed he wouldn't walk again, he did so and remained active in teaching and research well into his 90s. Case recalls interviewing the eminent epidemiologist Richard Doll about asbestos research history in April 2004 and asking him who made the greatest contributions to the knowledge of asbestos exposure and disease. "Doll looked puzzled for a moment and then said, 'You mean—besides Corbett McDonald'?"

McDonald leaves his four children.

Matthew Limb, Croydon limb@btinternet.com
Cite this as: BMJ 2016;353:i3161

the **bmj** | 16 July 2016

#### BURDENSOME NHS REGULATION

## Studies must show value of regulatory schemes

Senior management are often insulated from the daily difficulties and waste from the excessive regulation described by Edwards (Editorial, 25 June). It's often unclear how large the lack of trust is and how regulation tackles this. How professionals and managers respond to inspectors' requirements is also a problem.

We assessed the ISO/UKAS accreditation, currently spreading outside laboratories. Its costs were high and assurances minimal: "Fewer than 1% of noncompliances were likely to have consequences for the validity of results or quality of service."

Others found only two studies suitable for a Cochrane review.

We need more studies showing the cost, effectiveness, and value of regulatory schemes. These should require proof, as with other treatments that consume clinical budgets.

Ian G Wilson (iang.wilson@belfasttrust.hscni.net) Cite this as: *BMJ* 2016;354:i3780

#### PROSTATE CANCER SCREENING

## Public Health England advice on PSA testing

Public Health England (PHE) seems to take quite a different route from Haines and colleagues (Analysis, 4 June) in its *Updated Guidance for GPs on PSA Testing for Prostate Cancer*.

I am very concerned that, notwithstanding the lacking evidence, PHE has implicitly advised men to request screening from their GP: "If you do not have the PSA test you are more likely to die of prostate cancer than men who do have the PSA test. You are also more likely to experience the complications of advanced incurable prostate cancer."

Its information leaflet for GPs states, "Evidence suggests PSA screening could reduce prostate-

#### LETTER OF THE WEEK

## The Goldilocks problems in regulation

Edwards highlights overregulation in healthcare (Editorial, 25 June). Although regulation is necessary, this is just the



first "Goldilocks" problem—making sure that it's not too little or too much. The second is getting the quality of regulation just right.

GPs often need initial accreditation in many tasks that they want to or need to do, and they may be expected to get their knowledge and competence reaccredited regularly. Many requirements for accreditation are not fit for purpose because there's too little or no linkage between a GP's learning needs and the desired benefit for patients.

Typically, linkage is poor between learning needs and learning objectives; learning objectives and course content; content and the desired change in GP performance or patient outcomes; and this desired change and the stated learning objectives. Hence, learning requirements for accreditations/reaccreditations are often poor quality or are over-engineered and waste learners' time.

The proliferation of poor quality accreditations/reaccreditations is an expensive misuse of scarce NHS resources (eg, GPs' time), and they contribute to the time consuming bureaucracy that can make GPs feel overwhelmed.

All doctors should give robust feedback to accreditors that the quality of processes must be improved by following the best quality improvement and learning principles. And we should stop most mandatory retraining unless we're confident that it's necessary and effective.

Terry Kemple (tk@elpmek.demon.co.uk)
Cite this as: BMJ 2016;354:i3778

cancer related mortality by 21%."

Perhaps the authors and other authorities in this field could enlighten PHE and prevent further pressure on general practice to provide unevidenced PSA testing of asymptomatic patients without risk factors, with all of the negative cost/resource implications for patients and the NHS.

Bastiaan Kole (bastiaankole@gmail.com) Cite this as: *BMJ* 2016;354:i3796

#### **Authors' reply**

We thank Kole for his response to our article (Analysis, 4 June).

PHE's advice that "you are more likely to die of prostate cancer and/or to experience the complications of advanced incurable prostate cancer if you do not have PSA screening" relies on incomplete trial data.

The trial seems to contain biases favouring screening. Absolute differences in prostate cancer specific mortality showed a mortality reduction of only 0.11 per 1000 person years—despite the stated 21% reduction in relative risk. To emphasise the large relative risk reduction of dying from prostate cancer, not the small absolute reduction, is misleading. Withholding independently verified details on the men in the trial in each arm who died is unreasonable.

Imminent results from the ProtecT study will influence decision making about PSA screening and treatment. We urge doctors, medical groups, and government public health groups to increase pressure to release these trial data.

Ian E Haines (ian.haines@monash.edu) Richard J Ablin, George L Gabor Miklos Cite this as: *BMJ* 2016;354:i3795

#### TRANSITION TO ADULT SERVICES

### Transitional care evidence and national guidance

A Cochrane review, published since the 2016 NICE guidance (Guidelines, 14 May), finds limited evidence on how to deliver transitional care.

Such care is a complex intervention crossing medical, social, and educational disciplines and paediatric and adult services. Prospective research from early adolescence (as current guidance advocates) to the post-transfer period in adult care is financially challenging, and we await follow-up data from a current prospective study.

NICE urges "developmentally appropriate" care, but its definitions for young people are lacking. In an editorial Scal proposes reframing transition within adolescent healthcare and advocates "a developmental milestone rather than a healthcare crisis."

An ethnographic study in three UK hospitals reported wide variation in operational definitions of "developmentally appropriate" healthcare. Progress in transitional care research, and in service delivery, may be enhanced by adopting a greater developmental focus (a "life course approach") rather than the prevailing institutional focus.

Janet E McDonagh (janet.mcdonagh@manchester.ac.uk) Albert Farre, Susie Aldiss, Katie Biggs, Fiona Campbell

Cite this as: BMJ 2016;354:i3710

112