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# HealthWatch Newsletter

*for Science and Integrity in Healthcare*

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## Numbers are more important now than ever

**A**t a moment in history when mortality rates, infectivity ratios and testing levels are the stuff of the daily news diet, it is fitting that HealthWatch would have looked to a brilliant statistics communicator for this year's Award. So we are delighted to announce that Professor Jennifer Rogers has agreed to receive the 2020 HealthWatch Award at our AGM in London this October.

Jennifer Rogers is head of Statistical Research at the research organization PHASTAR, previously associate professor and director of statistical consultancy services at the University of Oxford, with a special interest in health. She excels at explaining statistics, regression to the mean, and how statistics and percentages can be misinterpreted in advertising and newspapers. She has performed TED talks, consulted for the BBC debunking fake statistics, and has

taught journalists how to understand statistics. We are looking forward to hearing Professor Rogers' take on how numbers have been used and abused in the press.

We also hope to welcome back our newest patron to our next AGM. We are glad to report that 2018 award winner Dr Sarah Wollaston has agreed to join our illustrious list.

Date and details of our next AGM to be announced in due course. Look out for news on our website.

### News in brief

#### What HealthWatch has achieved in 30 years

At the bottom of our website's [homepage](#) you can now see a moving carousel displaying HealthWatch's achievements over the 30 years since we were formed. These are all the more notable when you consider that, unlike many charities, HealthWatch has no salaried staff and all work is done by volunteers. Discussions are continuing as to whether the charity could benefit from a name change or other refresh – suggestions from members or the public are welcome by e-mail to [newsletter@healthwatch-uk.org](mailto:newsletter@healthwatch-uk.org)

#### HealthWatch research highlights transparency gaps in treatment assessments

Research funded by HealthWatch has revealed a need for more openness in the way new treatments are assessed. The study, by Till Bruckner of TranspariMED, Bristol, looked at how the effectiveness of a new breast cancer drug was assessed by three different European health technology assessment agencies (HTAs). He found survival data that was redacted in the assessment by the UK agency NICE, was clearly shown in reports from German and French agencies. Read more [here](#). The HealthWatch Research Fund supports projects in line with the charity's objectives. Find out more and apply on the HealthWatch website [here](#).

#### Breast screening has stopped – and that's a good thing

"Mobile mammography screening vans are parked and silent" writes HealthWatch's chair Susan Bewley in a provocative *BMJ* blog, as she calls on the NHS to stop and think hard before they resume a costly programme that has failed to deliver on women's health. Routine screening for breast cancer has been quietly paused in the UK and other countries along with other non-essential services during the pandemic. Read the full article [here](#).

#### UK bans spine-straightening rod implants

Magec rods are supposed to straighten curvature of the spine but experts have warned they break too easily. They have now been [banned](#) by the UK's Medicines and Healthcare products Regulatory Authority. The devices were featured in an investigation by BBC's Panorama and the [International Consortium of Investigative Journalists \(ICIJ\)](#). Since their approval for the UK market in 2014 they have been implanted in thousands of children, despite having had minimal testing. An immediate, indefinite ban on all NuVasive-produced Magec rods came into effect on April 1, and patients with the implants are to be followed up as soon as possible.

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### COVID-19 primary care evidence made clear

The University of Oxford's Centre for Evidence-Based Medicine has created a [COVID-19 Evidence Service](#) that is churning out excellent rapid reviews of primary care research related to the coronavirus pandemic. HealthWatch volunteers have been helping by writing linked lay summaries to key articles for non-medical audiences. These summaries are being supplemented over time and can now be found on a dedicated [COVID-19 page](#) on the HealthWatch website.

### Pandemic research in depth

For a deeper dive into coronavirus research, TranspMED has compiled a detailed [overview of clinical trial information sources](#). Over 500 clinical trials of potential COVID-19 interventions have already been launched worldwide. This is a great aid for anyone searching for the latest data, and should help avoid research waste and duplication. It is a living document that is being continuously updated, and has been made freely shareable online.

### Mind the gaps in device regulation

Prostate cancer deaths have been steadily increasing since the early 2000s. Could it be that multi-needle biopsies, increasingly used for diagnosis and now recommended by NICE, actually cause a pre-existing tumour to spread? In a [rapid response letter](#) published online by the *BMJ* in March, HealthWatch chair Susan Bewley and orthopaedic surgeon (retired) David Stainsby explain the concerns and call for an independent review into the widespread use of multi-needle prostate biopsy over the past 20 years.

### Report lockdown experiences

A global survey is collecting data on the impact of the COVID-19 lockdown on the educational process, professional opportunities, and wellbeing. It is led by the London School of Economics Department of Health Policy, in collaboration with Healthbit.com. The survey's main target is university students and staff, but any member of the public can take part. It takes about 5 minutes and is at <https://www.healthbit.com/the-lockeddown/> You can read about the rationale for the study in "[The Locked-Down: We need more than headline statistics to understand the impact of Covid-19](#)" by Leeza Osipenko, the project's leader at LSE and one of our newest committee members.

### Join a transparency project

The charity Sense about Science plans to hold the government to its commitment on transparency of evidence in policy making. Their new project will assess the UK government's COVID-19 policies, by scoring them against the Transparency of Evidence framework. If you can spare about 90 minutes to volunteer to help score the selected policies, e-mail [sam@senseaboutscience.org](mailto:sam@senseaboutscience.org)

### Reporting coronavirus ads to the ASA

A pandemic of an incurable disease has provided such rich pickings for the purveyors of unproven remedies, that the Advertising Standards Authority has set up a dedicated system for reporting them, and very handy it is too. On the ASA's website look for the "[Report a coronavirus ad](#)" button, click it and fill out a very simple online form.

### Naturopathy videos fail to impress

Les Rose, retired clinical science consultant and veteran HealthWatch campaigner found some new videos on the College of Naturopathic Medicine website, with tips for fighting the coronavirus. They include things like: drinking cold beverages "slows down the digestive system, which can impair the immune system"; and advice to avoid dairy produce as it "makes the body produce extra sticky mucus that viruses get caught in". He showed them to David Bender, HealthWatch's secretary and an emeritus professor of nutritional biochemistry, who was not impressed with some of the dietary advice. His detailed critique can be found online at Les's [Majikthyse](#) blog.

### Dishonest research – Wilmshurst webinar

A shocking account of misconduct in clinical research is now available online. Dr Peter Wilmshurst, a consultant cardiologist and past HealthWatch Award winner, recounts his experience as a whistle-blower in a webinar recorded on 28 April. His 1hr talk, "Dishonesty in medical research: clinical trials in the post-truth era", is on [YouTube](#) and is part of the Cardiovascular Webinar Series given by the [International Society for Heart Research](#). We thank them for freely sharing the recordings.

### Success over ineffective autism 'cure' challenge

Strict conditions have been placed on the Society of Homeopaths if their members want to retain their accreditation with the UK Professional Standards Authority (PSA). The conditions include forbidding registered members from practising CEASE therapy – an unproven and potentially harmful treatment for autistic children based on anti-vaccine misinformation. If instances are found of the Society's members offering CEASE therapy, dietary supplements, sharing anti-vaccine misinformation or claiming to be able to cure any named conditions, they can be reported to the [Good Thinking Society](#) who will be pleased to follow up.

### Talking stats with the Winton Centre

[Risky Talk](#) is a new podcast series presented by the great statistics explainer David Spiegelhalter. Recent episodes discuss genetic risk, and of course coronavirus. The 25 minute programmes are produced by the [Winton Centre for Risk and Evidence Communication](#) at the University of Cambridge. See their website for news on their latest initiatives including e-learning courses for medical professionals and practical help for clinicians sharing treatment decisions with their patients.

## Popular health

## Mindfulness – an evaluation

**D**espite, or perhaps because of, our unhealthy lifestyles in the West, healthy living or wellness has become a huge industry. Physical health stole a march, literally, with jogging, gyms and ten thousand steps on smartphone pedometers. Mental health is now catching up, with an increasing focus on healthy habits of the mind. On the iPhone health app, which counts steps and physical activity, Mindfulness is the only direct mental health parameter that is ‘measured’ (in minutes), though sleep which has clear physical and mental health benefits is also measured.



Whilst technology such as cars, fridges, and washing machines has given us more ‘leisure’ time since the 1950s than previously,(1) technology in the form of screens has filled our mental space more than ever before.

Psychologists have charted how we have become more distracted, and less able to give full attention to people around us.(2) The current popularity of Mindfulness coincides with the advent of smart phones, tablets and social media, which use behavioural nudges to create dependency, with a reduction in how we attend to the real world around us. Mindfulness popularisers claim that it enables us to step back and be more aware of our surroundings. Increasing anxiety among younger people also is met by the Mindfulness claim to be non-judgmental and compassionate in the present moment, rather than worrying about the uncertain ‘what ifs’ of life.

The current Coronavirus pandemic will impact how we respond to the claims of Mindfulness. Anxiety rates are increased enormously, and online activity and the use of social media has surged. When our social distancing is compromised by walking past someone on a narrow pavement, we become aware of our breath. And social distancing enormously slows up our lives and creates time for solitude.

Mindfulness is an updated form of Buddhist (Vipassana or ‘insight’) meditation,(3) where the subject focuses attention on bodily sensations, such as sights and sounds, but which can also be an awareness of thoughts ‘observed’ as if passing through consciousness without causing emotional reactions. There is an associated attitude of non-judgmental self-compassion that helps avoid the distress caused by some negative thoughts. If the mind starts to become distracted or lose focus it can be brought back to an anchor point of awareness, such as focusing on ‘the breath’. This is a practice which can then be rolled out into life in general, which manages our distractedness with trained awareness.

**T**HE PREVALENCE of the belief that we are stressed more than ever before in history, and the assumption that stress is always harmful and to be avoided needs questioning. Mindfulness type health beliefs are not new. In 1986, Anatoly Dyatlov believed that his daily walk to work was important both for his physical and his mental health, since if negative thoughts intruded he could ‘walk a bit faster’. This story (4) has been recorded

in answer to the question, ‘But where was Dyatlov?’ since he had just received an urgent phone call from work, which might have suggested to him that on this occasion driving his car would have been wiser, and that negative thoughts are sometimes appropriate. He was the nuclear engineer responsible for shutting down the turbine at Chernobyl, the failure of which led to the meltdown of reactor four. Whilst sustained levels of stress are undoubtedly bad for our health, the fright and flight response of adrenaline evolved for good reasons of survival and trying to suppress negative cognitions by appreciating the sound of the birds clearly is not always appropriate. I doubt Mindfulness advocates would disagree, but there seems to be an enthusiasm for the practice of Mindfulness which inhibits discussion about some of the tradeoffs and limitations of Mindfulness. At best it is not a panacea, at worst it might be no more than a way of achieving a bit of down time, with an associated failure to employ critical faculties in evaluating our own thoughts and actions.

Despite thousands of research papers on Mindfulness few are high quality, and those that are find it difficult to distinguish between the unique characteristics of Mindfulness, and non-specific factors such as taking some time out of

business and sitting down quietly. Can specific components of Mindfulness be abstracted out for experimental purposes whilst still calling the practice Mindfulness? Mark Williams who founded the Oxford Mindfulness Centre in the UK and has perhaps been responsible directly or indirectly for more research on the subject than any other individual, told me on the phone that the evidence for Mindfulness has been overblown by popular enthusiasm in the media. As with all mental health therapies evidence is very hard to gather definitively, and question marks remain even whilst the absence of compelling evidence is not the same as evidence that it doesn’t work. It is just a very difficult area to research.

The popularity of Mindfulness then rests on a thin suggestion of evidential support combined with a large dose of inherent intuitive plausibility in a world which is seeking to find solutions to our distracted and anxious modern existence.

There are, however, reasons to question this plausibility based on an analysis of the proposed psychological benefits, using contemporary models of the basic science

*“Social distancing enormously slows up our lives and creates time for solitude.”*

of neurology and psychology. The Buddhist framework for Mindfulness rests on the idea that the mind has two modes, the Doing mode and the Being mode. Buddhism is a monistic belief system which says that all reality is one, and that we need to escape distinctions in life which are in reality illusory, and which create in us desires which cause suffering.

Doing mode therefore is the busy problem-solving activity of the mind, which deals with desires and creates suffering through unfulfilled desires. Being mode is the passive observing of the flux of life's difficulties (awareness), in a non-judgmental way which frees us from unfulfilled desires which cause us pain. Buddhism has frequently been compared to the ancient Greek philosophy of stoicism, where desires and sufferings are just accepted as they are.

**M**ODERN PSYCHOLOGY has also observed two ways in which the mind works, which also include awareness. They are described in various terms, such as fast and slow thinking,(5) intuitive and reflective modes, and focused-attention or mind wandering mode for example. The common distinction is that the mind wandering mode is where the brain is in a relaxed state dominated by lower frequency brain waves which link different areas of the brain making intuitive connections, and which have a strong emotional influence from central brain areas such as the amygdala. This contrasts with the activity of the focused-attention mode which generally has higher frequency brain waves, is more energy demanding and occurs in the command and control centre of the brain's pre-frontal cortex (PFC).(6)

Sometimes, if we have spent enough years practising something, we might experience a flow state in which a highly refined skill is accomplished intuitively and seemingly effortlessly. The tennis player John McEnroe seemed to watch for when his opponents seemed to be 'in the zone' and would intentionally compliment them on their strokes: "Nice forehand!" In doing so he would wake them up to what was happening at a more relaxed and intuitive level, thus disrupting the flow. *Thinking* about how good your forehand is seems incompatible with *having* a good forehand.(7)

This seems to create paradoxes for Mindfulness. Doing-mode would appear to be our distracted mode, from which being-mode saves us by focused awareness. Yet McEnroe hopes to distract his opponents by increasing their awareness.

Focused-attention mode might seem to correspond with the doing-mode, as the analytic problem-solving mode run by the PFC. Being-mode might correspond with the more leisurely mind wandering mode where intuitive connections are made. However, this conflicts with the idea that doing-mode is distracted, and being-mode is aware. Rather, intuition operates beneath our conscious awareness and PFC activity is behind the focused attention

mode (attention being synonymous with awareness). The anchor points of Mindfulness such as focusing on the breath would seem to involve PFC activity.

I asked Mark Williams about the apparent contradictions, and he acknowledged that no one has studied how Mindfulness maps onto the fast and slow activity of the brain and agrees there is not a straightforward correspondence. Why has no one studied this? Is it because it is intrinsically awkward for Mindfulness enthusiasts, and raises unanswerable questions?

This apparent lack of a theoretical framework for Mindfulness is compounded by the attempt to apply Mindfulness in practice, which raises further problems.

While it is true that technology has increased our cognitive distractedness, it is not clear that Being mode is a coherent solution, not least when there are many other more plausible solutions available. Learning to play a musical instrument or tennis would create focused-attention, listening to music or meeting up with a good friend might help mind wandering conditions. Sleeping well is recognized as perhaps the best way of relaxing the mind and reinvigorating it for the next day's challenges. Social media seems to have a bias to negative emotions because algorithms follow our human tendency to be motivated by negative feedback.(8) It is not simply that we need a bit of down time from this distractedness, or even awareness of this negativity. Switching off devices and

deleting social media accounts to avoid this downward spiral are perhaps more practical solutions.

We are led to believe that a failure to attend to the sensations of the present moment results in a diminished experience of

existence. 'The raisin' is an illustration of how if we attend to the textures and flavours of a raisin with full attention, we will be amazed by an experience we normally take for granted. Apparently, we too often go into autopilot in life, as when driving a car we find ourselves at home without having accomplished the errand we set out to do. Or we find our mind wandering onto concerns other than the present and find ourselves anxious. If we were to focus on the experience of washing the dishes we might stop worrying about tomorrow's agendas.(9) Except, except, except ...

**E**XCEPT, when we eat a meal with friends there are a large number of present moment experiences that we could attend to, the taste of the raisins in the food being one. But we are manipulating cold Sheffield steel in our hands, we are breathing, we are trying to hold a conversation, and maybe thinking of whether the wine glasses of our guests are replenished. Our minds move their focus of attention according to emotional and social appropriateness. At some point, someone may mention how the raisins add something to the meal, and our attention switches for a moment of appreciation, before

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*"Jordan Peterson encourages skateboarding down concrete steps – I can see that this might provide sufficient distraction, if only by giving you something else to worry about."*

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returning to the conversation, perhaps forgetting to check everyone's wine glasses.

Except that going into autopilot when driving a car is a natural consequence of doing a single task repeatedly. It is called 'learning' and means we do not have to consider the details each time. It actually makes us safer drivers, because we can attend to road conditions rather than directions. If we are regularly given tasks to do en route we will soon learn not to forget them, instead of recurrently finding ourselves at home without having completed the task and ridiculously having to head off again. We learn repeated things so that we do not have to think about them each time.

Except that whilst an anxious wandering mind may be prone to unproductive or even destructive ruminations, it has also been observed repeatedly that having a shower is a good place to have 'Eureka!' moments because it facilitates relaxed mind wandering (a good thing). Imagine if instead of creatively puzzling over some experience we felt duty bound to focus our awareness on the water and the soap of the present experience. It is exactly because we do not have to pay attention to these things that our minds can wander freely and creatively.

**E**XCEPT that whilst it is possible that washing the dishes may facilitate a focal point for a distressed mind prone to anxious ruminations, the very mundaneness of the task is what enables the mind to wander. As a clinician advising someone how to deal with anxious or panicky thoughts, I would recommend something more engaging than washing the dishes as therapy. Jordan Peterson encourages skateboarding down concrete steps (10) – I can see that this might provide sufficient distraction, if only by giving you something else to worry about.

In other words, the slightly moralising tone that often comes from true believers in Mindfulness simply fails to

address the real ways our minds engage with the world. Sometimes we need to concentrate hard, sometimes relaxing is beneficial, sometimes we have to be dimly aware of wine glasses, sometimes we need to switch our attention to urgent concerns, and sometimes we need to distract ourselves from anxious thoughts. The one size fits all present awareness of Mindfulness lacks nuance, wisdom or a sense of responsibility for how we should direct our attention at any moment. A passive observation of current experience may be pleasant, and it may have its place watching the sunset on holiday, but it doesn't help us with the complex way our mind interacts with the world around us.

*James May, GP and Vice-Chair of HealthWatch  
Kennington, London*

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## Public health

# We need to talk about Alzheimer's

**N**o searing personal experiences made me want to write a book about Alzheimer's disease. It doesn't run in the family and though both my grandmothers got vascular dementia, it killed them quite quickly (as it usually does) and I was abroad for most of the time. Professionally, I've probably seen fewer Alzheimer patients than most psychiatrists because I trained in the 1960s when few people lived long enough to reach the really high-risk age-group. (About a third of us by 85, rising to 50 per cent a decade later.) Alzheimer's, though, always seemed to me a particularly unpleasant and protracted way to die, the personality crumbling long before the body does.

Slowly and inexorably (and with no cure on the horizon) Alzheimer's destroys everything about people that makes them individuals – relationships, quirks, sense of humour, the ability to discuss ideas and recent events. In care homes, Alzheimer's patients sit silently in armchairs, perambulate aimlessly or, in the final stages, lie in bed looking increasingly like survivors of Belsen. Many seem disturbed by terrifying delusions or hallucinations and scream at their underpaid but mostly kind and conscientious carers. That,

as well as the relentless deterioration, is very painful and stressful for family members who visit them, at first dutifully but often with increasing reluctance and despair. Yet the media are full of heart-warming accounts of smiling Alzheimer patients community-singing 'Clementine', or similar activities in which most HealthWatch members would never want to participate (or be remembered by) when healthy; especially as by that stage, most patients will have forgotten the occasion within a few minutes. The



average interval from diagnosis to death is about seven years. I would hate to die like that and to inflict it on my nearest and dearest. Even if my demented self didn't seem particularly concerned, I would rather not spend several years receiving expensive care when I had lost the ability to understand why I needed it.

It didn't take me long to realise that many other people shared these feelings and in the early 1980s, when I was always looking for ideas for my regular column in *General Practitioner* magazine, I had the opportunity to do my own little public opinion survey. One of my jobs then was consultant psychiatrist to an STD clinic but there wasn't actually much psychiatry to do or teach and I spent most of my sessions helping out with STD diagnosis and treatment. Most STDs are easy to diagnose and treat and I often saw six or seven patients an hour, so I devised a dementia questionnaire for them. In those days, the NHS paid for dementia care, most patients being nursed in dementia wards in the old asylums.

I asked my patients to choose from three options if they were ever admitted to such a ward: active euthanasia as soon as possible; passive euthanasia by the deliberate non-treatment of any life-threatening illness and generous sedation; or to be resuscitated and treated just like any other patient if they got a serious illness. None of them chose option three. They were about equally divided between options one and two.

By the time I wrote the book, several large surveys in different countries had confirmed the results of my amateur one. The reason I asked the neurosurgeon Henry Marsh to write the foreword was that in the opening paragraph of his autobiography 'Admissions', he had written: "... my most precious possession, which I prize above all my tools and books, and the pictures and antiques that I inherited from my family, is my suicide kit, which I keep hidden at home. It consists of a few drugs that I have managed to acquire over the years". First on the list of his reasons for taking it out of its hiding place was "the early signs of dementia" and I knew that he spoke for many doctors. Since I first became active in the assisted dying arena, one of my main arguments has been that patients should be able to share the comfort that most doctors have of knowing how to end their lives if illness makes life intolerable or looks as if it will soon do so. In the book I provide anecdotal but persuasive evidence that more doctors choose this sort of rational suicide than official figures indicate.

Only a small minority of people read serious books about death and dying. Barely 4 per cent (overwhelmingly white, middle-class, unreligious and well-educated) make carefully considered 'living wills' while they are still relatively young and healthy, yet it's clear that only a small minority (largely religious and less educated) would wish to

be kept alive when dementia is well-established. Unfortunately, that is the default position of medicine, sometimes even in defiance of clear instructions in a living will. Physicians who don't 'strive officiously' to keep Alzheimer patients alive when they get pneumonia or a heart-attack risk criticism and worse. A small but increasing number of British citizens who don't want to risk this scenario exercise their right to go to Switzerland for a medically-assisted death before Alzheimer's removes their capacity to consent. Others join the growing DIY movement to obtain the knowledge and materials that enable them to dispense with medical assistance.

THE ARGUMENTS against choosing the time and manner of our deaths are largely religious. For most British residents, religion is now a small and steadily diminishing concern but other surveys show that religious doctors are over-represented in British palliative care and recent BMJ correspondence revealed that dissenters from the palliative party line risk their careers if they speak out. I believe this mainly reflects the enormous influence of Dame Cicely Saunders on the development and ideology of

palliative care both here and abroad. She was a pioneer and a real force for good in a neglected field but she had a sudden Evangelical conversion in her twenties and followed St Augustine in her horror of rational suicide. For Catholics, it is still one of the gravest sins, officially meriting refusal of a funeral service and burial in unconsecrated ground. At assisted-dying conferences in the 1990s, palliativists whispered to me that when Dame Cicely died, they would feel free to argue the case for assisted dying, supported by over 90 per cent of respondents in the latest British survey. She died in 2005 but still apparently rules her acolytes from beyond the grave. Thus, in an age when patient

choice and autonomy are increasingly important and accepted, most British palliativists discount the range of views held by their patients on this crucial issue and deny them the choice that they have in other religiously contentious areas such as contraception and abortion. As Henry Marsh asks: "what right have doctors, priests or politicians to order us how to live, or how to die?"

Colin Brewer

Retired psychiatrist, London

Note: Colin Brewer is the convener of the medical group of *My Death, My Decision (MDMD)*. Unlike *Dignity in Dying*, MDMD campaigns for assisted dying laws that are not restricted to those who are terminally ill with a prognosis of six months or less. Its medical patrons are Sir Iain Chalmers, Dr Phil Hammond, Dr Henry Marsh, Prof David Nutt and Dr Wendy Savage

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## Dentistry

## When dental implants go wrong

Keith Isaacson reports on a talk given by Dr Michael Norton, dental implant expert, at the Medico-Legal Society, on the 14th November 2019

**A**ware of my dental background and of HealthWatch's ongoing work on Medical Devices, it was kind of Diana Brahams to invite me to attend this Medico-Legal Society meeting last November. Diana is the editor of the Medico-Legal Journal and for many years a committee member of HealthWatch, so she knew I would be interested in a talk by Dr Michael Norton, a renowned implant surgeon.

Dental Implants have improved significantly over the past 20 years. Some technical detail: the process involves drilling into the bone and inserting a tapered metal post. Titanium is used for the post as this can be integrated with the bone. The post has a prepared hole at the top which is designed to accept a screw which forms part of the replacement crown or bridge. The crown is usually fixed three months after the implant is placed.

My personal experience is limited to working with implants placed as an adjunct to orthodontic treatment. The patients that I see have most of their standing teeth. At the meeting most of the cases presented by Norton had lost most or even all of their teeth. These patients may be having difficulty with dentures or just wish to have a permanent replacement in their mouth. They are expensive – in the region of two thousand pounds for a single implant. A full mouth of implants is going to be at least £20,000.

Michael Norton has over 30 years in the specialty. Involved with dental implants since 1990, he now practises in Harley Street, London exclusively in implantology. He is frequently called as an expert witness.

In the course of his presentation Dr Norton showed us many disturbing cases in which implants had failed. He then went into the reasons for failure and itemised errors in assessment, diagnosis and treatment planning.

- Poor clinical examination – not only of the state of the patient's existing teeth, but also the condition of the gum and surrounding soft tissues – cheeks, lips and tongue. The patient's medical history and current medication are vitally important;
- Failure to take a Cone Beam Computed Tomographic scan (CBCT), which is a three-dimensional X-ray;
- Failure to analyse the way in which the teeth in opposing jaws interact;
- Failure to make a template prior to surgery to ensure that the implant be positioned correctly;

The preliminary radiographic examination was discussed in detail. The most commonly used X-ray is the Dental Panoramic Tomograph – this is a two-dimensional image

of the teeth and surrounding bone in both jaws. These are good for showing the extent of problems in the bone surrounding the teeth (periodontal disease) and possible decay in the teeth. This also gives an indication of how deep the implant can go to avoid nerve damage. The lower jaw has a nerve that runs through it and which provides sensation to the teeth and lower lip. If damaged, it can cause anaesthesia of the lower lip which may be permanent. What these radiographs do not show is the thickness of the mandibular bone. Michael showed three-dimensional CT scans of several mandibles with different thickness of bone. Practitioners who do not use CT scans rely on what they can see. They also judge the thickness of mandibular bone by feeling, however the true thickness may be disguised by thick fibrous tissue overlying the bone.

All too often practitioners do not make a through clinical examination, thereby missing decayed teeth and pockets. They may also fail to make a full periodontal chart and scoring by a standard scale. All diseased teeth should be removed before the implant is placed – this point was illustrated with several post-operative cases in

which teeth with obvious caries had been retained.

The surgery must be carefully planned. This requires elaborate work with X-rays and in the laboratory to prepare a surgical template, which gives an accurate guide to the surgical approach to guide correct drilling to exact depth to enable placing the implants into precise pre-planned positions.

**C**OMMONLY patients turn out to have been poorly advised (“had I only known ...”) and poor or no notes are kept. One clinician alleged having given written notes to his nurse for computer entry, then failed to check it had been done. In addition, the X-rays are frequently inadequate and implants may be placed where there is insufficient bone.

The choice of implant is most important. Of the 300-500 different makes available world-wide, Norton considered that only about five premium products are of adequately documented quality. Some others are smothered with impurities.(1) In cases where implants have failed they are

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*“Of the 300-500 different makes of dental implant available world-wide, Norton considered that only about five premium products are of adequately documented quality.”*

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often those which have been discontinued or are not identifiable.

Dr Norton was able to show radiographs which demonstrated that totally different makes of implants were used in the same mouth. He commented cynically that the dentist might open the drawer and pick out whatever happened to come to hand!

The patient notes often lack any documentation of the implant used. As repair of failed implants depends on the availability of spare parts, this is impossible to achieve without the correct documentation, necessitating the need to drill out and replace the entire implant.

In response to my question concerning the registration of implants, Norton explained that currently, it is only the

size of the implant which is usually recorded. Although implants do have batch numbers, this information rarely gets transferred to the notes. Unfortunately, despite a campaign for all dental implants to be registered, this has not been implemented by the Association of Dental Implantology and the Academy of Osseointegration.

*Keith Isaacson, Consultant Orthodontist (locum)  
Great Western Hospital, Swindon*

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### Book review

## Health Advocacy Inc: how pharmaceutical funding changed the breast cancer movement

**Author: Sharon Batt. Originally published in hardcover July 2017, by UBC Press. Now available in paperback 2019, £21.99, and Kindle edition, £17.99, from Amazon. Reviewed here by Till Bruckner.**

**H**ow to obtain and maintain funding to sustain operations regularly tops the agenda of think tanks, advocacy groups and other non-governmental organisations (NGOs). The next question is, who the organisation can – and cannot – accept funding from, and on what terms, without endangering its values and the value of its work?

Sharon Batt's book, *Health Advocacy Inc.: How Pharmaceutical Funding Changed the Breast Cancer Movement*, explores this debate through the lens of breast cancer patients' groups in Canada. The author was actively involved in the movement before writing the book, and has conducted numerous interviews with protagonists over the course of several years.

While Batt openly favours one side in the debate, her dual insider/outsider status and meticulous research and analysis, combined with a willingness to give a voice to both sides in the argument, make her book a must-read for everyone interested in the challenges of maintaining non-profits' independence in the face of a funding landscape in which donors increasingly seek to generate 'return on investment.'

#### *Patient interests versus industry interests*

Like other NGOs, patient groups come in a variety of shapes and sizes. Many groups focus primarily on providing advice and support to people suffering from a particular disease (think local coffee meetups bringing together women with breast cancer for mutual support). But most groups at some point also find themselves drawn into advocating patient interests, and some also conduct policy research.

A [recent systematic review](#) found that pharmaceutical industry funding of patient groups is common, that transparency of such financial relationships tends to be weak, and that industry-funded groups tend to adopt positions favourable to their sponsor.

Within the field of public health, what is, and what is not, in the patient's interest is highly contested. Patients want access to high quality medical care, so patient groups often push governments to purchase newly developed

drugs from pharmaceutical companies and provide them through public health systems. However, research shows that many expensive new cancer drugs coming onto the market have severe side effects, but [provide no benefit to patients](#).

Thus, the interests of pharma companies (to maximise profits from the sale of new drugs) and those of patients (access to high quality care) are not necessarily aligned. At the same time, even running a coffee meetup requires money from somewhere.

#### *The funding trap*

This book provides an insider's view of the often heated and bitter debates between and within Canadian breast cancer groups, against a backdrop of declining government funding for NGOs over the past two decades.

Patient groups soon discovered that the pharma industry was often the only player left in town who was willing to fund their operations. Around the same time, private sector philanthropy worldwide began shifting its approach from funding 'good causes' to supporting NGOs whose activities generated 'impact' favourable to their corporate interests.

As Batt sees it, 'the federal government reversed long-standing policies to support community-based advocacy, and in parallel, the pharmaceutical industry actively undertook a process of co-optation' of patient groups. As a result, 'groups that defined their role on behalf of patients as independent watchdogs vis-a-vis the pharmaceutical industry saw their power and numbers dwindle; the dominant advocacy voices for patients were pharma-funded.'

What makes the book stand out from the vast literature on these dynamics is its wealth of personal vignettes and



in-depth case studies. For example, take the following quote from an NGO worker:

*“If I have to stand up in front of a classroom of nurses and tell them that I’m here by virtue of [drug company] AstraZeneca, I’m going to throw up. I’m just not going to do it. So if you want to take the money, take it, but AstraZeneca or anybody else is not going to get their logo on my stuff.”*

She ended up securing funding for her project from a commercial bank instead, noting that this funding source too was not unproblematic:

*“I think I don’t want to know where [the bank] has its money invested... But the difference between that and pharma funding was [that pharma companies] had an immediate agenda.”*

### **Losing their inner compass**

Some NGOs refused pharma funding outright. Others decided to take industry money, but attempted to draw clear red lines to avoid being co-opted by their new funders. Yet others, Batt contends, completely lost their inner compass.

She describes the case of one group funded by a drug company’s foundation that effectively ended up becoming a conduit for direct-to-consumer advertising for particular drugs by stealth. In addition, that group’s advocacy focused on ‘having new drugs approved ... as quickly as possible – as opposed to focusing on drug safety, efficacy, [or] price.’

Batt cites a report that the group published, ranking Canadian provinces on how fast they gave patients access to new (and therefore very expensive) breast cancer drugs. The ensuing media coverage generated public pressure for faster provision.

Batt sees this approach to advocacy as highly problematic, and not necessarily in patients’ best interest. ‘The type of rich ethical [debate about surrogate endpoints](#) ... and rising drug prices ... is entirely missing; instead, the report reinforces the discourse that equates longer life with better access to new drugs.’

### **The slow process of “mission creep”**

The book chronicles a slow process of ‘mission creep’ that led to the gradual erosion of many groups’ autonomy and integrity along three dimensions:

1. Discussions between patients with diverse perspectives gave way to homogenous discourses reflecting industry framings of healthcare issues.
2. The entire advocacy landscape changed. NGOs rejecting pharma money disappeared, or were marginalised due to lack of resources, and internal critics of industry money were silenced, removed or left the movement.
3. Groups lost their agency as ‘leaders surrendered decision-making control within their own organisations... [and] groups began sponsoring

projects with hidden policy backstories far removed from their personal experiences.’

The book concludes that:

*“[T]he breast cancer movement in Canada has failed in the [original] idealistic goal... of keeping medical science honest. Rather than providing a check on the self-interest that tempts actors in the system to stray from medicine’s main goal – alleviating suffering – patient organisations have themselves been led astray. Instead of critiquing marketing [strategies that distort the truth about a drug’s benefits or risk, high prices, unpublished results of clinical trials, or strategies that offer drugs as the sole antidote to illness](#), PHANGOs – pharma-funded NGOs – protest government regulation of drugs, heartless bureaucrats, and perceived barriers to addressing novel treatments of uncertain value... [T]he research evidence doesn’t support the claims on which they are based.”*

Batt’s overarching argument has an explicit left-of-centre bias. In her view, government funding of activism is a legitimate means of redressing power and resource differences between different social groups, which is ‘in the long run necessary to sustain democracy.’ In contrast, corporate funding promotes advocacy positions that ‘fit within a corporate values frame,’ she writes. Pharma-funded groups simply ‘don’t challenge the injustices of capitalism.’

Conservatives and libertarians are bound to disagree (as are those on the radical left). After all, government bodies also use non-profit funding to promote bureaucratic vested interests and the ideologies and policies favoured by those who hold political power at any given time. Seen from that perspective, removing corporate money from the NGO funding mix would allow the government and a handful of unaccountable mega-foundations alone to decide which advocacy groups’ concerns get amplified with money – arguably not a recipe for healthy pluralistic debate.

To Batt’s credit, she never falls into the partisan trap of framing the issue as a moralistic struggle of good versus evil. While she stakes out a strong position, she treats the topic with the nuance it deserves. Drawing on a wealth of ethnographic material, she chronicles how decent people and committed organisations struggled to support and represent breast cancer patients over many years, despite financial constraints and funder attempts at co-optation.

Academics, funders, policy researchers and campaigners of all political stripes will find a lot to like, learn and think about in this meticulously researched and well-written book.

*Till Bruckner*

*International development expert, Founder of TranspariMED and Advocacy Manager for Transparify*

*This book review is published under a Creative Commons license (CC-BY 4.0). It was first published online at <https://onthinktanks.org/articles/the-funding-trap-can-advocacy-groups-avoid-being-corrupted-by-corporate-money/>*

## Last word

## Getting on that list

**A**t the beginning of the COVID-19 lockdown I was delighted to hear the government had listed vulnerable people to give them priority access to online supermarket shopping, and looked forward to receiving my official letter, as described on TV. Three weeks passed without the expected post arriving.

I tried to convince myself it was a good thing not to be seen as 'at risk', despite having progressive lung disease. And then there was that hospital referral after I coughed up an impressive quantity of blood ... still, I'm not on oxygen, so presumably not seen as 'severe' enough to be listed.

On the other hand, the government list only takes account of single health issues. So the two radical cancer treatments I have had, with accompanying treatment-induced side effects, including midline lymphoedema (also progressive) which means compromised immune system and pelvic radiation disease, plus osteoporosis, fractured vertebrae, osteoarthritis, hip bursitis (bilateral), extreme sensitivity (Allodynia), constant pain ... and the fact I'm registered disabled seemed not to apply.

When I tried to order food online I found supermarket access blocked; there were no free slots available – and one supermarket apologised but said I was not old enough. I'm 81! I filled in the government priority online form, hoping to get on the list, but heard nothing.

And then my computer died, so I began to feel seriously isolated and concerned.

Fortunately, help appeared. A series of telephone calls, lined up like buses; a chance suggestion that led to a charity which offered volunteer shopping, enquiries from the local council (because I am on the dustbin carry out list) and others. All expressed surprise that I was not on

the government vulnerable list as I gasped and coughed my way through our conversations, the high pollen count exacerbating my lung symptoms. So, when I had the use of a mini iPad, I emailed the local MP.

They were keen to help. They told me to contact my GP, "They will be able to put you on the list more quickly than us". I called and listened patiently to the recorded message telling me not to come to the surgery, and so on, and they were experiencing high call volumes ...

Finally, the receptionist said she had looked on my records and I was not on the government list. I explained that I knew this, and asked how the list was compiled. Apparently, those on the list had a special icon on their medical records. "It's nothing to do with us." I relayed this information to the MP's office who then filled in a second online application for me and asked me to telephone the GP surgery to ask if they wanted a copy. No, they didn't. "Nothing to do with us," was the perplexing response.

As requested, I rang the MP's office to update them. "Let's give the online application a few days," they suggested, rather overconfidently, I thought. And wondered, should I have mentioned that head trauma with the subdural haematoma (and another on the other side where my brain had bounced) and hairline skull fractures? Probably no point.

*Mitzi Blennerhassett, Medical Author, Yorkshire*

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