Would BMA members consider a hike in their membership fees to allow full open access to the *BMJ* for everyone in the world?
Des Spence, p 49

PERSONAL VIEW **Bridget Taylor**

We must give children a voice in advance care planning

Advance care planning has become a key component of end of life care, but it involves far more than just conversations about whether or not to resuscitate. The wishes and preferences of the person concerned must be identified before they are too unwell to be involved in decision making. However, insufficient research and guidance exist on involving children and adolescents in advance care planning.

Retrospective interviews with the parents of children who had an advance care plan found the process helpful in assuring that the best care was obtained for their child, and in avoiding unnecessary suffering and preserving quality of life.[1] Perhaps unsurprisingly, these plans focused exclusively on medical interventions, covering decisions around resuscitation, artificial feeding, intubation and ventilation, antibiotic use, and admission to hospital. Parents reported "having peace of mind" and retaining a sense of control once they had signed the plan, but it is unclear whether their children experienced the same benefits. Were their wishes and preferences regarding medical and non-medical interventions identified and taken into account by those delivering their care?

Our daughter, Martha, had been receiving treatment for a life threatening condition for many years and was used to leaving hospital when there had been some improvement. When we realised that she was dying, we needed to explain to her why we were going to take her home even though her health had not improved. We anticipated that she was likely to ask questions, and we did not know how to respond. Supported by suggestions from the psychologist, I explained to Martha that if there came a time when she was not responding to treatment and would not get better, it would be best to go home.

She was an astute 9 year old, and she understood that this meant she was going to die, and wanted to know when. If I had not opened up the possibility of these painful conversations, Martha would not have experienced the joy she did in planning for a Christmas she was unlikely to see and could not have specified how she wanted her toys shared out after she died. She was able to request that I renew the dressing to her Hickman line after she died and that nobody else would touch it. I doubt I would have anticipated that this was important to her. However, her wishes made sense: they were consistent with how she had treated her body during life, and my grieving was eased by knowing I could fulfil her requests.

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For Martha, having her questions answered and her wishes and preferences sought helped to make her remaining life more manageable for her. Her fears were out in the open, and she was actively involved in decision making. We needed to know what mattered to her, and she needed to know that what mattered to her would be respected by us. In her dying Martha retained some of the control that was important to her.

As parents, we needed to have conversations with medical and nursing staff about resuscitation and care of the body after death, but we were too fearful. It is one thing to ask staff not to resuscitate an elderly parent, but it's different when it's your own child. Thankfully, with the advent of do not attempt cardiopulmonary resuscitation (DNACPR) forms, other parents won't be in the same situation. We knew what we felt was in our daughter's best interests but not what the doctors thought, and were too afraid to ask. But are DNACPR decisions ever made without burdening parents with the details? If so, how can professionals know if parents have concerns or questions that remain unspoken?

More importantly, how are children given a voice? How are their views and preferences heard and taken into account? Are parents given the support they need in broaching these difficult conversations with their child? Are they equipped to discuss any unrealistic expectations their child might have? Research in Scandinavia has shown that many (but not all) parents whose child had died from cancer regretted not having spoken with them about death.[2] What support is available to help parents engage in these conversations?

If conversations for advance care planning retain their focus on resuscitation and withdrawal of treatment, other things of importance to the child will be overlooked. For advance care plans to promote quality of life, the child's wishes and preferences need to be sought, whatever they may be. It is only then that choice and control can be maintained.

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References are in the version on bmj.com.

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BETWEEN THE LINES **Theodore Dalrymple**

Pick your own nits

If there is a single law of literary life, it is that nit pickers will have their own nits picked. My copy of *Essays and Studies* by W A Osborne establishes this clearly. Osborne (1873-1967) was professor of physiology at the University of Melbourne. Born of a Presbyterian clergyman in County Down, he was a rationalist with a particular dislike of Catholicism. He was an expert in nutrition, and advised Captain Scott before his ill fated Antarctic mission. Scott did not take his advice, however, with unfortunate results.

Osborne was also a literary scholar of distinction, speaking several languages fluently. He was undecided whether to take the chair of physiology or that of English, and perhaps preferred literary studies to scientific ones. He was always disappointed not to be elected to the Royal Society and that he received no decorations.

My copy of his collection of occasional essays—some delightful, some pedantic, ranging from the price fixing edict of Diocletian to the development of the gas mask—was inscribed by him to Major-General Sir Kingsley Norris, who was head of the Australian army's medical service. Since Norris was knighted in 1957, Osborne must have been at least 84 when he presented the book, published in 1946, to him.

There is also a rather moving typed letter addressed to Norris, dated from Magnetic Island, Queensland, on 4 December 1965, when Osborne was 92:

> *Dear Norris,*
> I am now living at the above address, "wearing out life's evening grey." I have just realised that I shall never be able to travel southward again and face the climate of Melbourne. This means a long farewell to that city and my many friends there. I particularly wished to see you . . .
> The memory of that dinner [at the club you gave for me] will remain with me for the short time I have yet to live as particularly sweet and vivid and I thank you from the bottom of my heart . . .

It is clear that Osborne had difficulty with his typewriter, which must have been a temperamental instrument, and his signature is that of a man who can no longer firmly hold his pen. In the circumstances I hesitate to mention that "grey" in the quotation should be spelt "gray," for fear of being thought a nit picker.

The first essay in the book is on scientific errors in literature and art. After enumerating various astronomical howlers, he goes on to zoological ones: "That extinct animals were of enormous size is still a popular belief; but no skeleton yet unearthed is as large as the sperm whale of today. Sir Kingsley (for I at first assumed it was he) has crossed out the word "sperm" and written "blue" in the margin in pencil.

"Anyhow here goes." The word "goes" is heavily scored out in ink, as if it were offensive, being in the context vulgar, and is replaced by "is an attempt."

In his essay on the horrors of sibilant sounds in English poetry, Osborne writes: "One can as an exercise in English turn out verse without an 's' sound but the art is unconcealed. Anyhow here goes." The word "goes" is heavily scored out in ink, as if it were offensive, being in the context vulgar, and is replaced by "is an attempt."

Looking closely at the writing, however, it occurred to me that it was not the recipient who had corrected the text, but the author himself, who did not want to be discovered in error or vulgarity. What a joyous discovery for a pedant, a nit picker, such as I.

Theodore Dalrymple is a writer and retired doctor

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MEDICAL CLASSICS

TB Sheets

A song by Van Morrison on the album *Blowin' Your Mind!*, released in 1967

LAURENT GILLIERON/AP/PA

Nobody, perhaps, has ever captured the grief, anger, and guilt intermingled in witnessing a loved one die quite as honestly and viscerally as Van Morrison does in his iconic blues track "TB Sheets."

Ever since it was recorded in a New York studio in 1967, Morrison's 10 minute song about the death of a girlfriend from tuberculosis has generated rumour and myth. Sources variously claim that the song was prompted by the death of Morrison's girlfriend from a brain haemorrhage, or his cousin—the "Gloria" of the hit single—from cancer, or an unnamed school friend from TB. Notoriously secretive, the singer has declined to dispel the fog. Stories suggest that Morrison, 21 years old at the time, finished recording the song in tears; and that the ensuing album *Blowin' Your Mind!* was released without his consent. None of it matters. Autobiographical or not, the song speaks for itself.

Against the background of a wailing harmonica and a lulling bass, Morrison speaks his lyrics in a one sided conversation as he backs away from his lover's deathbed. His tone is alternately hectoring and pacifying; his words veer from accusation to excuse. "Now listen, Julie baby," he scolds, "It ain't natural for you to cry in the midnight." He has been negligent and feels guilty: "I see the way you jumped at me, Lord, from behind the door." His mumbled apologies and staccato laughs shield his shame. "Ha, ha, I cried, I cried for you, ha, ha." Yet there is nothing to laugh about in death: "I know it ain't funny, it ain't funny at all, baby."

Bitterly cruel and searingly frank, the song depicts a lover's desperation to escape the claustrophobic sick room and flee the intimacy of death. The sunlight shining through the window—a symbol of life outside—"numbs" his brain. He is gasping for air—in a mocking echo of the dying girl—as he pleads, "let me breathe." But most brutal of all is the disgust and terror encapsulated in the refrain: "I can almost smell your TB sheets."

With a total absence of sentimentality, the visitor refuses to stay or even to fetch a glass of water. Almost yelling in anger, he turns on the radio—"there you go, there you go"—and mutters empty platitudes—"You'll be all right." In Morrison's harrowing scene, the carer is not caring, the lover shows no love, the survivor chooses his life over her death. Through apparent lack of feeling, the song conveys true feeling. Its anger is directed at the disease, at death; the embarrassment is the natural embarrassment of the one who lives on. And the TB sheets will become the sheets of music which help the singer survive.

In this guttural, grotesque, and intense song, Van Morrison depicts a lover's loss as truthfully as any poem could hope to do.

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FROM THE FRONTLINE **Des Spence**

Take down the *BMJ* pay wall

The *BMJ* is owned by the BMA. The *BMJ* sometimes publishes articles that openly question or counter BMA policy. It's also willing to confront vested interests and to offend the great and good. The *BMJ* is no trade association rag but a global independent medical institution and fearless defender of medical free speech. It is the intellectual soul of the British medical profession. The *BMJ* has never censored what I write, even when it clearly makes the editor's toes curl in discomfort. I write not as a sycophantic employee but, being a member of the BMA, as a small shareholder of a publication I believe in. The *BMJ* champions open access to research,[1] but should it go further?

Before 2004 the *BMJ* offered free access to all of its articles online. Since then an electronic pay wall has been erected because the BMJ Group is a profit making limited company. Original research is open access, but the rest of the content is not. Doctors, let alone the public, struggle with primary research; what everyone wants is interpretation of the evidence—that is, opinion. To get past the pay wall as a BMA member you need a password, often an irritation to doctors. Otherwise you pay £20 (or $30) for an article, however old it is. Fees are waived for poor countries, but this still shuts out many potential readers; traffic to bmj.com has reduced, debate is limited in the rapid responses, and sometimes the site seems clinical and sterile.

Protectionist pay walls are a long term folly that may ultimately see the influence of the *BMJ* decline

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Medicine affects us all. It is contentious, political, and emotional, and everyone has a right to comment. Doctors aren't interested in the profitability of the *BMJ* but want open debate: from BMA members and non-members, from the UK and international doctors, and, importantly, from patients. We should end the intellectual protectionism and make the *BMJ* fully open access.

Amid the general poverty of medical reporting, the need for an open and impartial medical source has never been greater—a void that the *BMJ* could fill. This would raise its profile, establish a precedent, increase traffic to bmj.com, and, importantly, help repair the public image of doctors. Removing the pay wall has revenue implications for the *BMJ* and the BMA: loss of subscription revenue would take a slice out of the £10m profit the association gained from the BMJ Group last year. Pharma advertising may be ethically questionable, but it would be essential under this scenario. Could advertisers pay a higher rate? Or would BMA members consider a small hike in their membership fees to allow full open access to the *BMJ* for everyone in the world?

The *BMJ* is a rare counterweight to the enormous corporate marketing machine of medicalisation. Open access to all medical knowledge is such an important principle, and protectionist pay walls are a long term folly that may ultimately see the influence of the *BMJ* decline. We, the share owning BMA membership, should be allowed to decide the purpose and future of the *BMJ*.

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NOTHING'S SACRED **Colin Brewer**

Beau de Jour

Do you remember that "Belle de Jour: Diary of a London Call Girl" stuff from a couple of years ago? Brooke Magnanti financed her paediatrics doctoral degree at Bristol through prostitution and then made more money from her memoirs—but it's not only women who sell their bodies. Years ago, when I worked in a tropical university hospital, I met a senior clinician with the following story.

When he qualified in London in the mid-1940s, homosexuality was illegal and difficult to find if you didn't know the right people. Consequently, after doing his house jobs, he headed for New York, where homosexuality was also illegal but much less hidden. For a few months, he had a very enjoyable time. Even at around 60 years old, when I knew him, he looked pretty good for his age and must have had no shortage of propositions in his 20s (and of course Americans just love those English accents). Soon, however, it was time to think about his career, but he had spent a lot and didn't even have the cost of the return trip.

He decided to start charging for what he had previously done willingly and for nothing. As in all classic American success stories, he built (or at least embodied) a better mousetrap, and the world duly beat a path to his door. When he had enough money he returned to London, got his postgraduate qualifications, and eventually had a distinguished academic career in tropical medicine.

There's a touching circularity to the story. Once, when he had to go to a conference, he asked if I would house sit at his residence (the best on campus and scene of many a medical party). I stayed the night before he left. Sleeping in the guest bedroom, I was woken by a tapping on the window. I could vaguely see a figure moving away. Slightly alarmed, I went to his bedroom to find him opening the veranda door to a local youth. Over breakfast, he explained that he had changed from being a provider of such personal services to a consumer.

Over breakfast, he explained that he had changed from being a provider of such personal services to a consumer

One scene in Bunuel's film *Belle de Jour* always puzzled me. It's when Catherine Deneuve (playing the sexually unsatisfied wife of an insufficiently attentive surgeon) tells the brothel owner that her client, a distinguished gynaecology professor, wants an inkwell. I couldn't imagine a fetish involving ink, but now I realise it wasn't anything sexual. He was obviously writing his memoirs.

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