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Twins' tragic death spurs an important ethical debate

July 11 2003

The deaths of conjoined twins Ladan and Laleh Bijani, after a failed operation to separate them, raises the question of what treatments people might justifiably request of their doctors. The short answer - treatments that are in their best interests - leads to a harder question: Who defines best interests?

The elements of the best interests test include the likelihood of treatment reversing the condition, how burdensome the treatment might be, and the resulting quality of life.

Clearly, each element of the test can be interpreted differently by both doctor and patient. A 50 per cent chance of survival (the risk widely reported in the case of the Bijanis' surgery) was deemed by several surgeons to mean that a separation operation was against the twins' interests. The twins themselves competently accepted this risk and felt surgery was in their interests.

What is at issue here is not so much a scientific objective appraisal of risk but the value that different people place upon that risk. When should the values of surgeons prevail over those of their patients, and vice versa?

Certainly, in the case of a previously healthy person with appendicitis, a surgeon would be on shaky ground refusing to operate. The key elements supporting surgery in this case would be its life-prolonging properties and that society could reasonably expect it to take place.

The Bijanis' surgery was never aimed at prolonging life. So we are left with the notion that a societal determination of reasonableness might act as a guide to resolve disputes arising from a discordance of values between doctor and patient.

The legacy of the deaths of the Bijani twins ought to be

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increased debate in our community about what constitutes reasonable medical treatment in cases where the assessment of best interests leaves doctors and patients at an impasse.

Dr Paul Biegler (MBBS MBioeth FACEM), Brighton

When 'tis folly to be wise

I question the idea that early diagnosis for all pregnant women is helpful. It is only of real value if the parents will terminate; foetal treatments are rare.

After two healthy daughters, our unborn son was diagnosed abnormal at a routine ultrasound. We were told information would help us "prepare". This was our preparation: months of grief!

We tried to lower our girls' expectations of a healthy baby. We changed to a bigger hospital and had more ultrasounds and consultations. Some ultrasounds were made difficult by my shaking - from sobbing. I bought no clothes for him, as these don't fit around tubes.

After all this angst he was stillborn and we were relieved. Just because we didn't want a disabled child didn't mean we could terminate him. The only time our son lived was inside me, and we lost all joy in that for the last four months. If we were to have a disabled child we have the rest of our lives to get used to it - why start before you can even hold them?

The next pregnancy, as two educated professionals, we chose ignorance and were delighted with both the pregnancy and another healthy daughter.

Libby Strahan, Blackburn

Much more than just 'boffins'

I am impressed with *The Age's* coverage over the past week of the prestigious international genetics conference taking place in Melbourne. I am unimpressed, though, by your labelling of three eminent Australian scientists on yesterday's front page (10/7), as "boffins". Why not scientists, geneticists, or even molecular biologists?

To me, boffin has a very negative connotation of the mad scientist, working long and lonely hours in the laboratory on work that is irrelevant to the outside world. The three expat scientists pictured do not appear to fit this gross generalisation.

Moreover, this kind of attitude does nothing for science's image problem. How many students are going to be inspired to go into science when the front page of *The Age* labels three Australians who have made it to the top of their field, in careers overseas, as boffins? As a PhD student in molecular biology, it strengthens my desire to leave Australia and do research in countries where science and knowledge

are valued commodities, thus undoing all of the Government's hard work to reverse the brain drain - the actual point of the article on yesterday's front page.
Catherine Osborne, Parkville

Tricky grey matter

In an otherwise well-argued discussion about future genetic research into the human condition, I was astonished to read Dr Francis S. Collins' conclusion that "we are also creatures with free will, with a spiritual nature" (*The Age*, 9/7).

Unless Dr Collins is suggesting some divine spark that marks us as different to every other living species, free will must be an illusion and our spiritual nature merely a brain construction easily replicated in (ie, passed on to) future generations. We cannot, on the one hand, be the product of the genetic code like every living thing, and at the same time have some special insight into the world not caused by that same genetic code.

I recommend that Dr Collins consider some of the latest research being undertaken into the human mind, the concept of self, and the illusion of consciousness. The real scientific challenge for the future will be to unravel these tricks of the brain that convince each and every one of us that there is a little person inside us, running our daily lives and making free choices.
Tony Fioretti, Stirling, SA

Beyond the brain

Your article "Science set to conquer the mind" (*The Age*, 9/7) highlights a common confusion held by contemporary intellectuals. Nobel prize-winning geneticist Sir John Sulston claims that "understanding what makes the human mind tick" will be conquered by the end of the century. However, the study of the mind or human consciousness is not the province of genetic science but of epistemology.

Genetics may well have much to say about the nature of the human brain, but the brain is not consciousness or the "I". Consciousness is the faculty of awareness - the faculty of perceiving that which exists. The only way to study consciousness is by observing what your mind does when it is conscious.

Considerable work has already been done in this field by philosopher Ayn Rand, whose treatise, *Introduction to objectivist epistemology*, is a brilliant dissertation on the nature of abstractions and concepts.
Malcolm Sedgman, Glen Huntly

So who will leave the toilet seat up?

Maureen Dowd (*Opinion*, 10/7) is right: the average bloke is totally paranoid that in eons to come the male chromosome may vanish altogether. I lie awake for

hours at night worrying about it.

I also worry about what it will mean for women. What will happen to the world economy if they suddenly stop spending the billions of dollars they do each year in trying to gain the attention of the lowly male? Will cosmetics disappear overnight, along with pantyhose, lingerie and all their other secret paraphernalia? Or will the answer to the world's greatest mystery be finally revealed - that women really do groom themselves to impress each other rather than men?

But my greatest concern is who will women have left to blame for all that ails them. Will the X chromosome mutate to create a kind of underclass female to criticise and ridicule in the absence of the male? Could they be trained to occasionally leave the toilet seat up, in case the higher-class women start running out of things to complain about? As a mere male, my head just swims. But I'm sure Maureen has got it all worked out.

Don Bruce, Watsonia

Why we tried to screen Ken Park

We would like to explain a few things about why we took the action we did to screen the film *Ken Park* :

- We're not on about a censorship exemption for film festivals; that's an issue for film festivals to fight.
- We want to uphold the right of adults to read, hear and see what they choose, unless it does demonstrable harm to children. *Ken Park* should have been released with an R18+ classification.
- We want the nonsense removed from the current classification guidelines restricting how legal teenage sex can be shown, and in what form.
- We want to see the classification system return to being an advisory system for consumers, instead of an ideological battleground.
- We want an end to politically conservative appointments to classification boards, so the decisions are made by competent people with no axes to grind and with some understanding of Australia as a country of diverse communities.
- We want the major political parties to stop rolling over to appease what is actually a fairly small but active alliance of wowser groups, and act on the understanding that Australians are mostly pretty tolerant and intelligent people able to make their own decisions.

Christina Andreef, Martha Ansara, David Marr, Jane Mills, Margaret Pomeranz, and Julie Rigg, Sydney

Where freedom still reigns

The other night I watched the film *Ken Park*. I watched it in a public cinema, and I watched the uncut version. The cinema was two-thirds empty, and when the final credits rolled, the audience quietly shuffled out, seemingly indifferent to the film's banal salaciousness. No one seemed upset or offended.

I live in Hong Kong, the city where last week half a million citizens took to the streets to demonstrate concerns that their freedom of speech would be grossly compromised by proposed anti-subversion laws. Australians, apparently self-assured in the security of their political freedoms, have expressed sympathy for these protesters. Yet it seems deeply ironic that as laws that challenge the fundamentals of free speech are emotionally protested against in Hong Kong, people here are able to watch a film that has been arbitrarily banned in Australia.

Chris Baker, Kowloon, Hong Kong

All about publicity

The Age editorial (9/7) on David Irving's film *The Search for the Truth in History* hits the nail on the head. The Melbourne Underground Film Festival didn't select it above others for its quality or originality, just the controversial content - free publicity for the festival guaranteed. Similarly *Ken Park*; what bait to dangle before the censors!

M. A. Mitsikas, Malvern East

Hearts bleed for a religious zealot

David Hicks was a member of a group of international radicals, terrorists and religious zealots. He was captured in a camp operated by the Taliban and al-Qaeda, and now our papers have dozens of letters from those bleeding their hearts across the pages about his civil rights.

The response one reads in the press on Hicks is sickening political and civil rights garbage.

Public sympathy for Hicks - and not Australia's military veterans, the sick and elderly - demonstrates that we have lost our direction to social misfits who dominate the press as well as all the nooks and crannies of our social and political depths of reasoning. Why?

Robert S. Buick, Mountain Creek, Qld

4WDs: tax the brutes

Andrew Leigh (Opinion, 10/7) is spot on in his argument that the number of four-wheel-drives should be reduced. But we need to go further. First, ban bullbars from Victoria's roads. Second, heavily increase taxes on the machines when purchased in metropolitan areas - a slight increase in tax won't do much to stem the tide of rich, selfish drivers purchasing them.

David Hammerton, Fairfield

Crash hazards

Not only do four-wheel-drive vehicles increase the chances of death or injury in other vehicles in the event of an accident, it is also clear that they increase the chances of accidents by obscuring the vision of drivers in conventional vehicles on the road and in situations such as when parked near driveways, certain intersections and parking bays. They certainly should be taxed at the same tariff rate (farmers exempted) - and possibly at a punitive level to compensate society for their contribution to the road toll.

Peter Goodwin, Balwyn

The other arms race

There are two arms races being fought on Australian roads - the four-wheel-drive race that Andrew Leigh addressed, and the power race between Holden and Ford. Two of our major car manufacturers are locked in a battle that is providing consumers with bigger, heavier and more powerful motor vehicles than ever before.

Some of these vehicles guzzle petrol like there is no tomorrow and seem to offer consumers nothing more than the ability to fry their tyres on a Friday night on our suburban streets. And the Australian motoring press gushes that there are bigger, heavier, more powerful models yet to come . . . In a country with 110 km/h limits on most freeways, regular hand-wringing about the link between speed and road accidents, and chattering politicians lecturing us about environmental waste, why is this stupid spiral allowed to continue?

Denzil Bourne, Jerrabomberra, NSW

Chutzpah!

Maria Vandamme (A3, 9/7) complains about "all those Jewish pianists supported by millions of Jewish dollars" in New York (how else could talentless hacks such as Rubinstein and Horowitz have achieved such success?). But she seems to have few qualms about soliciting Australian Jewish dollars to fund Australian pianists. What chutzpah!

Michael Hopf, Kew

Jews and the arts

I wish to clarify one point in Wednesday's A3 article on the Melba Foundation, which may have been misconstrued by some readers. The comment was meant to highlight the significant philanthropic contribution by the New York Jewish community and their support of the arts. The reality of philanthropy in New York - and Australia - is that it has been led by Jewish families who value learning and culture.

Just one example is the New York State Library, established by donations from European emigrants, most of whom were Jewish. This offers a healthy model that all should emulate: the support and nurture of our most valuable resource, our youthful, developing talent.

Maria Vandamme, Elwood

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