

I've been asked to 'comment on the burden of injury and meaningful outcomes'. Well, I'm not going to do that...I'd rather talk briefly about two things: hope and the imagination.

Firstly, I wanted to thank Russell Gruen and the National Trauma Research Institute for the invitation to speak. I don't want to bog you down in my preliminaries, but this was a real struggle to write because Brain Injury Australia and its Member Organisation's patch is really the *sub*-acute end of things, the *disability* end of neurotrauma. The NTRI, along with the Victorian Neurotrauma Initiative – to their eternal credit – are two of the very few organisations in the head/ brain injury area to have reached across the aisle, the gulf that often separates clinicians from consumers, and their advocates. Sometimes the (almost) automatic posture adopted is adversarial; clinicians are arrogant and removed, advocates – ratbags and whingers, consumers – sometimes ungrateful.

*Never look a gift horse in the mouth...* I've been asked to "comment on the burden of injury and meaningful outcomes". Well, I'm not going to do that. For at least two reasons – firstly, Rod [McLure] and Jennie [Ponsford] can, have done it better than I ever could. Secondly, one of the hazards of my job – someone referred to me last week as a "lobbyist" for people with a brain injury – one of the hazards of my job is catastrophizing brain injury – weighing injury in "burden", and as more burdensome than other disabilities. Make no mistake: barely concealed beneath the disability advocacy sector's bonhomie, the spirits of co-operation, all the polite talk of strategic partnering and – urk – "synergies", this is a competitive business – and it is a business – that competes in burden.

So in an exercise of wilfulness and self-indulgence I'd rather talk briefly about two things: hope and the imagination. Imagination: because in the 7 years I've worked in this sector, initially as a volunteer, in the last 18 months in a paid capacity, I've become convinced that anyone involved in the "human services" business – my business and, I think, your business – has to at least try and transplant themselves in imagination into the circumstances of their client, their customer, or their patient or their patient's family – as both a first principle and a starting point. Brain Injury Australia doesn't hope to turn you all into de facto counsellors or social workers. I've never worked in hospital. I've been a patient in what I imagine was a neurotrauma unit but, thankfully, I can't remember any of that. (My family can remember it all too well.) So, in preparing for today, in trying to imagine what delegates to a trauma conference would want to hear from a consumer lobbyist-activist, I determined to share one recent contact from a "constituent". Importantly, it doesn't involve the acute end of care. But it's right in that gap between what "we" say 'v' what we hear "you" say. For instance, "we" regularly say that no two brain injuries are [exactly] the same. Often I say this as the shortest road to counselling patience with families, especially when they discover that I've had a TBI – I'm hardly a representative sample. Because there's no guarantee that their son, daughter etc. will "turn out" like me.

The other thing "we" say, again often as a means of counselling patience, is that – and I think this is a true and accurate reflection of the state of the science – what's *known* about the brain, brain injury, about recovery from brain injury is more than matched – to paraphrase a former United States Secretary of Defense – by "unkown unknowns", perhaps also by the "known unknowns".

I had someone contact me the week before last who'd – in effect – had a horse fall on her, around a year ago. Certainly a severe TBI. She'd been able to afford her own rehabilitation specialist, someone known to Brain Injury Australia – someone very senior, very experienced, experienced in TBI, someone you'd imagine would be, well, up on the latest evidence. When asked what kind of recovery she could expect and how long it would last – common enough questions, you'd imagine – he told her that she could, quote, "bake a cake" in time for the second anniversary of her accident and the way she was that day would be the way she'd remain for the rest of her life. Again, someone

very senior, very experienced, experienced in TBI, someone you'd imagine would be, well, acquainted with TBI as a disability that often occurs in the prime of a person's life, precisely at that point of entry to "adult" life and everything that promises, someone to whom, you'd imagine, experience had taught a light touch on such statements, a human, a humane touch, someone who'd learnt to transplant himself, in imagination, into the circumstances of someone trying to imagine what it would be like to come to terms with their recovery coming to an end. Even if the second anniversary business was true, would anyone – their imagination bypassed, or otherwise – consider saying it at all, let alone in that way. Without...style.

And...I wasn't an eyewitness to this exchange. Its retelling perhaps came with the distorting effects of early-stage grief. But because I've heard the "you've got two years' worth of recovery to spend" prognoses before, their truthfulness grows with repetition (admittedly most of them come with a little more...hair on them than was the case here.)

Besides, I've got some experience a little closer to home: the results of my second neuropsychological assessment as part of return-to-work rehabilitation. The standardized tests found that my Performance IQ had "declined significantly", that my "attention, concentration and memory" were "significantly impaired", and that my "academic potential" would be "significantly compromised". This, for someone working full-time as a journalist, in postgraduate study part-time, and coming from a family of intellectual over-achievers – rendered dumber, permanently. However the neuropsychologist was – and his report was professional and detailed – I've always reconstructed him in memory as wearing a labcoat, perhaps with a stethoscope slung around his neck. And I've never really forgiven him for letting not me – but the next someone like me, or the next or the next – simply take this kind of report and walk off into the sunset. It is, I believe, no exaggeration to liken it to saying; here's a hand grenade. I want you to hold it for me while I take out the pin. Now goodbye and good luck. I think he walked me through the report. I can't remember whether he offered me any counselling to go with it. I can't remember him offering me any hope. Some people have glass jaws. I retain my glass intellect.

Though it mightn't sound like it, I've given hope some thought over the last few weeks. And while I am not sure that the nation's trauma units should be in the business of *dispensing* hope – that's probably not their role – I am sure that they shouldn't resemble the hell of the Italian poet Dante's Divine Comedy – written in the 14th century – with "abandon hope, all ye who enter here" inscribed over their front doors. The very first time that many, perhaps most, family members hear the expression "brain injury" is upon entering hospital to visit their son or daughter, sister, brother, mother, father. (One of the things that family members complain most bitterly about is the dearth of information – good, bad or indifferent – about brain injury, especially in acute care. Brain Injury Australia, and its Member Organisations, must accept some of the blame here. As challenging as this work would be – given the uncertainties, the sensitivities – the head injury/ brain injury sectors need to bite the bullet on the production of evidence-based, nationally agreed, plain English information for families in this setting. Take that as an open invitation, an expression of interest on Brain Injury Australia's part.) For families in this situation, it wouldn't – I imagine – take them long to enter the first of Elisabeth Kübler-Ross' five stages of grief; denial – not *my* son, not *my* daughter.... Trauma units must seem like black boxes, with all the mysteriousness and heirarchy of a Catholic mass. And if your point of reference is the hospital of television, clinicians are its miracle-working high priests, god-like in their wisdom.

I wonder what it would be like to any of you to say – given the uncertainty about outcomes from brain injury at so early a point in stabilization, let alone recovery – to say that I (the clinician) am unsure, even that I/ "we" don't know [what to expect, what to hope for]. And what it would be like

for a family member – who wants, no, expects – since hope is at once the desire of something combined with the expectation of obtaining it – what it would like for that family member who expects nothing less than their loved one to be restored to them the same person they were before they got in the car that morning – what it would be like to be ...counselled in patience. And nothing more. While I don't think that trauma units should be in the business of dispensing hope, let alone false hopes, forlorn hopes or hopes that promise triumph over experience, neither – it seems to me – should they be curtailing hope, even if the intention – however sincere – is to inject...realism. From time to time, Brain Injury Australia will hear from a consumer or a family member that they were told – within a few days, a few weeks of injury – that they or their loved one would not/ never be able to do x or y.

One last pass at the imagination: colleagues who work in the sector – especially those who work in injury prevention – will say that “brain injury doesn't discriminate”. And if you're working in injury prevention, I imagine that you want to try and capture as many pairs of ears and eyes to your message as possible, to include as many people as possible within the ambit of risk of the injury you are trying to prevent. It's always been my understanding, though, that TBI tracks social disadvantage; that those people at the greatest risk of a TBI are drawn from the same populations as those at risk of any injury – from backgrounds of low income, low levels of education, high levels of unemployment, poor housing and so on. For those of you who know Sydney at all well – half of the young TBIs in the Sydney metro area occur in its “Greater West”, between the longitudes of Parramatta and Penrith. That's not the, well, “world” that I come from. And I'd hazard a guess – whether it's transplanted to Perth, to Adelaide or Melbourne – that most of you don't come from that “world” either. This isn't sentiment, or hand-wringing but a reflection of pure pragmatic reality: many of Brain Injury Australia's constituents were already born behind society's eight ball (or the wrong side of Sydney's Parramatta Road.) Their brain injury serves to *add* – and often very significantly – to their disadvantage. I do worry about what appears to me to be an increasing disconnect – and perhaps this applies to other cities, other regions, other states – I do worry about the increasing disconnect between the lives of Brain Injury Australia's constituents and those who ...tend them, the clinicians, the allied health professionals, the service providers. (Sydney's northerners rarely venture south of Parramatta Road unless it's for the purpose of “ethnic” food tourism. Sydney's southerners and westerners dare not venture north or east, unless it's to the beach. And you may know what happens then – the 2005 riots at Sydney's Cronulla, for example.) Again, it's not Brain Injury Australia's...hope to turn you all into de facto counsellors of your patients. Neither is this meant as some stricture about bedside manners. I'm no bleeding heart, but when people in the human services business complain that their patient, their client, their customer with a brain injury is unreachable – whether it's in the context of rehabilitation or in what's commonly a life-long struggle to adapt, to come to terms with disability – it's often the case that they haven't done the work of the imagination necessary, to at least try and enter the world from where their patient, their client, their customer comes. It's been my impression that, unless you do so, you won't get past first base.