

Thanks, Vicki,

I trust you'll understand why I feel like a stranger in the list of speakers today. Since, among other things, I work so far downstream of most of you. I'm a *DISABILITY* advocate, the closest thing you'll find, perhaps, to a national level lobbyist for people with a brain injury regardless of external cause, or age. So, I "do" everyone from the "shaken baby" to the elderly man who falls off a ladder while clearing gutters and the concussed rugby player, and the behaviourally dysregulated juvenile justice detainee in between.

And there's no more certain death to an audience's attention than bogging them, YOU, down in my preliminaries. But I should begin with what's becoming a depressingly familiar disclaimer; as you know from what you've just heard I'm not, nor have I ever been, a clinician, an allied health practitioner, a medical researcher. Look, my only real credential for being in this job? I'm hardly representative of recoveries from severe brain injury, though I have some glimpses of what *LIVING WITH A BRAIN INJURY* is like, but perhaps it's more in the nature of having a brain injury as a kind of housemate; a former housemate, one who moved out, and moved on. Or perhaps I did, I can't always tell. However it happened, in the way of housemates, my brain injury left a few things behind – half-empty cartons of milk in the fridge, odd socks, a pot plant or two. Less lost property than mementos, reminders. However it was, if it was me who moved, moved on, that's really all that...*QUALIFIES* me talk to you today.

In doing so, I want to excavate one or two of the contested spaces between what Brain Injury Australia/ what I say, and what I hear 'you' - by which I mean those of you who deal directly with patients-clients upstream of me – what I hear you say. What I'm hoping is you'll be so mesmerised

by the withering critique of practice you'll barely notice the compelling sub-narrative about how indispensable the use of the imagination is in *ACQUIRED* disability, as is the dispensation of hope. By imagination I mean not the staring-out-the-window, daydreaming of a desert island kind but something much more instrumental that, I believe, can give physicians, nurses, allied health professionals much more...play with their patients-clients.

Because in the 8 years I've been in this role, I've become convinced that anyone involved in the 'human services' business – my business and, perhaps, many/most of your businesses – has to not only at least try and transplant themselves in imagination into something of the life circumstances of their patient-client – as both a first principle and a starting point, as the foundation for (quickly) building rapport, but also evoke something of the world from whence they came.

Recently, I had someone contact me who'd, in essence, had a horse...fall on her head. Certainly a severe brain injury, and a non-compensable one. But she'd been able to afford her own rehabilitation specialist, someone senior, very experienced, experienced in brain injury, someone you'd imagine would be up on the latest evidence from research, someone well-acquainted with brain injury as a disability that often occurs in the prime of life, precisely at that point of entry into 'adult' life – as was the case with this young woman – and everything that promises, someone reflexly able, you'd imagine, to transplant himself, in imagination, into the life circumstances of a person trying to imagine what it would be like to come to terms with their recovery coming to an end, let alone the injury itself and, thus, someone to whom such experience had taught the light touch, the human, the humane touch with such a 'patient'.

When asked what kind of recovery she could expect, how long it would last – common enough questions, you’d imagine – he told her that she could QUOTE ‘bake a cake’ for the second anniversary of her injury and the way she was that day would be the way she’d remain for the rest of her life.

I should stop there to state the bleeding obvious. I didn’t witness the exchange. Perhaps no group of people understands better than you the vagaries of memory: that it ordinarily plays tricks; that posttraumatic memory positively bedevils; and to never underestimate the memory-distorting potential of early-stage grief. But I’ve heard often enough about consumers and family members being prescribed the myth of the ‘two years’ that the truth of such experiences takes on a, what, iterative quality. And look, chances are the cake-making advice came with, what, a bit more HAIR on it than she remembered. Somewhere, someone has done the ‘definitive’ research into how much – the 1, the 2 per cent of (just) the ‘bad news’, perhaps – consumers and family members take away from the countless hours of conversations and consultations with health professionals, what they take away from that deep and long crucible of such life-transforming events as these. And, given the context, can anyone really make misinterpretation-proof, as it were, what for the clinician counts as no more than an opinion informed by experience, by what she or he read somewhere, sometime. Well, no. But it’s been my repeat experience that statements – such as the cake-baking one – are hastily stored away by patients, their families, taken out regularly, a...MILLSTONE dusted off, re-examined, held up to the light of recovery

and recovery measured against it – in the hope they're proven wrong, or in dread, right.

However the cake was prescribed, whatever was said, I have so many problems with 'it', it's hard to know where to start. That, first, it's wrong. As I understand it, recovery – in some shape or form – can continue beyond 2 years post-injury; for 5 years, for 10 years or more. Second, you want to learn the first rule you'd know if you'd ever spent a day in your life in the company of people recovering from brain injury? Prepare to be surprised: that the very nature of bell curves is they comprise both normal distributions and outliers. Third, I would have thought that the only mental set professionals could bring to dealings with patients and their families – one that would truly reflect the state of the neurosciences – is one of a general uncertainty that, to paraphrase a former United States' Secretary of Defence, what's known about the brain, brain injury and the brain's ability for repair and recovery are easily outstripped by both or either of the 'known unknowns' and the 'unknown unknowns'.

Fourth, and this comes at how crucial hope is in the recovery from, and adaptation to, brain injury, why would anyone – their imagination bypassed, or otherwise – consider saying such a thing at all, even out of the most pressing need to inject realism into a patient's prospects for recovery, or even – and I'm bending over backwards here, I know – as some perverse reverse psychology, that the patient will somehow, with a drop-dead date threatening, work even harder with the recovery time they have to spend.

Though it mightn't sound like it, I've given some thought over the past few weeks to the place of hope in recovery from injury, from acquired disability. I'm intrigued – as someone working in disability advocacy from

a background in journalism (where ‘bad news’ is nothing less than stock in trade) – by the public’s, our preferences (insofar as the media mostly serves them) for narratives about individuals ‘overcoming disability’ (a bit like ‘beating’ cancer) and by the relentless parade of what I’ve seen referred to as ‘super-crips’ (‘super-cripples’). What ‘we’ seem to most crave are those odds-beating, expectations-defying, outlying (back to bell curves) recoveries. And what fuels them all, perhaps, is the hope that triumphs over experience. Trumps experience.

Hope is commonly defined as the desire for something combined with the expectation of obtaining it. But that doesn’t quite capture what, for instance, differentiates it from just plain wishful thinking. One can want to win the lottery and even, in delusion, expect to win. It doesn’t seem to me that you can hope – hope (just) for the best - always from the position of one’s...couch. Hope, instead, is...active. Hope implies that obtaining what’s desired involves – it is the return on, even if the fortuitous return on - *effort*.

(I take you back to my opening disclaimer – that I’ve never worked where many of you do.) Even so, it is hard for me to imagine – as it must have been for this young woman after her 2 years’ worth of recovery – a literally *hope-less* physiotherapy...speech therapy and other therapies delivered in despair. Surely, one aim of, perhaps the core aim of, any therapy is to enable the client, and his or her family, to live in hope – realistic hope – for as long as possible? Let me put it a different way. Persevere. Perseverate. Many people living with a severe brain injury would describe it as ‘a’ – no, ‘the’ – watershed event of their life – when everything changes, where nothing after will ever be the same as before.

Geographically speaking, a watershed's a line, a strip of land that separates two bodies of water – two lakes, two rivers. What many? most? people profoundly disabled by their brain injury feel most keenly is having been cut adrift of both their past, and ITS imagined future, marooning them on an alienating, and seemingly fixed, present - in concrete terms; that they cannot do, or think, or feel as they once did.

And when I..."train" people in brain injury – particularly those people about to wade into the muddy waters of the psychosocial outcomes of brain injury - what I invariably ask of them is to reach for any and all continuities with their patient's, their client's past. To try and tap any wellsprings of work, diversions, interests, pre-injury pastimes and passions – as a means of...breaching that watershed. Believe me, you'd be surprised - as surprised as I was during my return-to-work rehabilitation - by how uninterested many professionals who work with people with a brain injury how uninterested they seem to be in...excavating what person the person in front of them was...BEFORE. There's, believe me, nothing more RE-disabling than being thought nothing else than the sum total of your...impairments.

I ask you to change places with the mother, the father, the wife, the husband – the bad news broken, the bad news coming to grips with – making that lonely, sometimes daily, trek, in trepidation, through the front doors of a hospital, a rehabilitation unit. These places must seem like black boxes, with all the mysteriousness and hierarchy of a Catholic mass. And if your only point of reference is the hospitals of Hollywood – clinicians their high priests, god-like in wisdom. Little wonder, then, that patients and

families hang on their every word. I don't think this can be overstated once, in imagination, you're able to...trade places.

In further adventures of the bleeding obvious, the last Roy Morgan Research “Image of Professions Survey” – conducted in 2014 – scored “car salesMEN[sic]” lowest for ethics and honesty, who were just below advertisers, who were just below real estate agents, who were just below politicians. But at the other end of the scale, 91 per cent of respondents rated...nurses as the most ethical and *honest* profession, followed by...doctors, pharmacists then High Court judges.

I've just finished reading an anthology of research into placebo (from the Latin “I shall please”)...inert pills, sham surgery, dummy acupuncture and the like. What struck me, among all the theorising about best practice randomised controlled trials, was how little credit was given to key contextual factors: for instance, the physician's role play as heroic healer; that what the physician prescribes, what he or she says about a patient, a patient's *prognosis*, produces a different, MORE, response expectancy – to use the jargon of psychology (that a patient's, a patient's *family's*, experience of healthcare depends partly on what they *expect* to experience) – that what a physician says produces “more” response expectancy than what might be said by, say, a hospital orderly, a hospital administrator or its CEO.

I hope this comes across as, well, a little more nuanced than my wagging a finger at you; “be careful/ watch what you say”. But while I am not sure that the nation's hospitals or rehabilitation units should necessarily be in the business of dispensing hope – let alone forlorn hope, false hope, hope

against hope – neither do I think they should resemble the hell of the 14th-century Italian poet Dante’s Inferno, with ‘Abandon all hope, you who enter here’ inscribed over their front doors. But Brain Injury Australia hears regularly from consumers or family members that health professionals – within days, weeks of injury, *too early, too soon* - gave up hope, told a family member that their injured love one will be unlikely to, will never be able to do x or y, walk or talk – curtailing, dashing, hopes, cutting people off from both their past and future; and, taking my lead from Dante, damning them to an alienating present.

I don’t mean to piss in your pockets, but I can only...imagine what it would be like - in an age of the quick fix, the miracle cure – how DIFFICULT IT MUST BE to prescribe uncertainty, to counsel patience – that’s P-A-T-I-E-N-C-E; for instance, that (as I’m wont to say) recovery from brain injury’s a marathon, not a sprint. Perhaps it’s no surprise but the research suggests that, while physicians who share their uncertainties reduce the power differential with their patients, it’s at the cost of patient satisfaction. Uncertainty is negatively associated with perceptions of self-confidence, competence and likeability. And those associations were stronger when the physician was...a woman.

With all that in mind, I want you to transplant yourselves, in imagination, into as much as you can conjure of my life circumstances post-injury. Aged 32. At the fag end of the prime of life, the browning ends of my salad days, and the results of my second neuropsychological assessment. I was 3 months into a ‘graded’ return to work at the Australian Broadcasting Corporation – you know the kind of thing; 1 day a week, then 2, then 3

etc. I can, I think I can remember – during the loopy fog of that time (my memory wasn't crash hot) – individual days, incandescent instants when I thought I was stepping up in recovery, that damaged synapses were somehow re-firing, or new ones swung into operation. And this accelerated recovery hadn't hit that slow, abject taper that – at the time – I thought began 6 months post-injury.

A second neuropsychological assessment was my recovery's dead reckoning. The standardised tests found that my Performance IQ had QUOTE 'declined significantly', that my 'attention, concentration and memory' were QUOTE 'significantly impaired', and that my 'academic potential' would be QUOTE '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, I thought, still sometimes think, dumber. Permanently. So, whenever I choose to remember the neuropsychologist (one of the many luxuries of occupying the high ground of an exceptional recovery is that I get to choose what I remember, and forget) I've always reconstructed him in memory as wearing a labcoat, perhaps with a stethoscope slung around his neck. However he was – and his report was professional and detailed – 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.

But I certainly remember the sunset.

I took the report and headed home on the train. Walking westward down the street near where I lived in Sydney's Inner West, I was asking then, as I'd been asking with every step down from the neuropsychologist's office, what would being 'significantly compromised', intellectually, turn me into? I looked up into the sunset, one of those sunsets where the colour was so brilliant, so bright, as to be gaudy – hot pink clouds, with fluorescent orange linings. The colours were so unnecessarily bright, they made me smile. Though, at some other time, they might have made me laugh. I thought then, as now, mostly: if this is what being 'significantly compromised' feels like, amounts to, I can probably live with it. And I turned the corner to home. Though it's a delicate distinction, I know that this was an expression of resilience, not resignation, not a hope fail, a failure of hope.

Let me explain. Colleagues will regularly say that 'brain injury doesn't discriminate'. And if you're working in injury prevention, for example, I imagine that you'd 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 that you are trying to prevent. It's always been my understanding, though, that brain injury – like other disabilities – tracks social-locational disadvantage: that those people at the greatest risk of a brain injury are drawn from exactly 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. To...bring it *HERE*, to bring it...home – half of the greater Sydney metropolitan area's young, risk-taking, severe traumatic brain injuries occur between the longitudes of Parramatta and Penrith.

That's not the world I came from. And I'd hazard a guess – and whether it's transplanted to Melbourne, to Adelaide, to Perth and beyond – that most of you don't come from that world either. I'm no bleeding heart (10 years, 10 months, 10 weeks in journalism will drain that out of you) but many, perhaps the majority, of Brain Injury Australia's constituents were already born behind society's eight ball. Their brain injury also, mostly, serves to add, and add significantly, to their disadvantage. Less than 1 in every 5 of the 450 clients of New South Wales' Lifetime Care and Support Scheme with a traumatic brain injury comes from postcodes with a mean taxable income of \$55,000 and above. (Incidentally, similar social-locational indices apply to stroke.)

Call me quaint, but in a broader culture of creeping – some would say, galloping – competitive individualism (of sink or swim, with some safety nets) – I just don't reckon that society's capacity for overcoming, its quantum of resilience (of rebounding from adverse events, from trauma), gets shared around equally; between individuals, between communities. And I do wonder, should 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. It's perhaps nothing more or less than a perfectly natural expression of where income inequality meets real estate purchasing power, but Sydney's - and my sense is a similar residential apartheid applies to Melbourne - Sydney's northerners and easterners get a nosebleed adventuring south of Parramatta Road or west of the Harbour Bridge (unless it's for the purposes of 'ethnic' food tourism). Sydney's southerners and westerners dare not stray north or east, unless it's to the beach. And you know what happens then – the 2005 riots at Cronulla, for example.

I promised I wouldn't tell you my troubles. We simply haven't got time for me to inflict upon you my continuing professional-personal crisis of relevance, but it did take me way too long in this job before realising I belonged to the exclusive club of brain injury's...acceptable faces. Its "members" need: to have made a...superior recovery; to be able - give or take some - pick up their pre-injury life where they left it; (where brain injury tracks social-locational disadvantage) its members need to live in the more genteel parts of metropolitan Australia; to have injuries that are compensable. And its "members" need to be free of the cultural or racialoverlay that's going to make ticking the box of consumer representation more...challenging. Though I've always thought the truism that "no two brain injuries are the same" is overplayed, perhaps the most generous thing you can say about consumer representatives in brain injury is they tend not be as heterogeneous as their...base.

When I first started in this role, I think the almost reflexive view of, for example, (some?) clinicians was that consumer representatives are ratbags and whingers...Ungrateful. With axes to grind. The expectation was, remains, that consumers could and should represent the lived experience of brain injury above and beyond their own. A not unreasonable view, perhaps, of what it means to be "representative". One of the many luxuries of occupying the high ground of a superior recovery is...transcendence, for me and my kind, is easy. I don't mean to be churlish about the opportunities granted to me but consumer representation in brain injury remains a very small merry-go-round of largely the same faces going up, down, and around the exception rather than the rule in recoveries.

Look, any numbskull can read the riot act. If it were some other forum, with - say - less constructive ends in mind, I could have regaled you with no end of consumer representations that were an afterthought, were token, were window dressing or worse. I hope I haven't left you with the impression that I want to turn you all into de facto social work counsellors of your patients-clients-research subjects. Neither did I intend for this to be some stricture about bedside manners. I've got other, bigger, fish to fry. I field around 400 inquiries a year. And when people in the human services business complain that their patient, their client 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 into the world from where their patient, their client, comes. It's been my impression that, unless you do so, you won't get past first base.

Everything else, sorry almost everything else, comes down to rapport (what psychology judges the intense harmonious accord between therapist and subject). Rapport, and how quickly you can build it. And build it, build it quickly, with someone with whom – on the face of it, on first look – someone with whom it would appear you have nothing in common. Before entering journalism, I had all the interpersonal skills of a length of wood. Rapport is the indispensable condition of journalism. You've not only got to be able to talk to anyone, but – more importantly – get them to talk to you, when it's often the last thing that they'd contemplate doing. And get them to tell you what you really want to know, what they often precisely don't want to tell you, what they've only ever told the person they're sleeping with, and tell you quickly, by deadline.

So, again, when I choose to remember my neuropsychologist, I now realise I've never really forgiven him for letting, not me but the next someone like, or unlike me, or the next, or the next – someone with perhaps fewer resources – simply to take this kind of report and walk off into their 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. And when I choose to remember, I'm reminded that no one escapes a brain injury of that quality completely unscathed. Some people have glass jaws. I've now got a glass IQ. And I'll long wonder whether this speech tried a little too hard to be too smart by half.

Thank you.