

Imagining Hope from Dante's *Inferno*: Observations on 'Person-centred Practice'

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Look, I'm hardly what you'd call on the speaking circuit, but I've gone enough rounds with rubber chickens to know only an idiot with a death wish would get between anyone and a *buffet* dinner – a set of bottomless (very gourmet, I'm sure, but still bottomless) chafing dishes. If it's any consolation, I won't be holding you back for too long.

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. I've never worked in disability services. Look, my only real credential for being in this job? I'm hardly representative of recoveries from severe brain injury (and I'll come back that in a moment), 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 what I want to, the only thing I really feel *qualified* to, talk to you about tonight.

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 clients in rehabilitation and recovery, whether as part of delivering services and supports, or for

research purposes – what I hear you say. What I'm hoping is you'll be so mesmerised by the withering critique of practice (I'm armed with a feather, really) 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 service providers, researchers much more play with their clients, their subjects. Because in the 6 years I've been in this role, I've become convinced that anyone involved in the 'human services' business – *my* business and, perhaps, many of *your* businesses – has to not only at least try and transplant themselves in imagination into something of the life circumstances of their client, their customer – 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.

Soon after I started in this job, 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 (indeed, someone known to Brain Injury Australia), 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

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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 '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. No group of people understands better than you the vagaries of memory: that it ordinarily plays tricks; that post-traumatic 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 an iterative quality.

And look, chances are the cake-making advice came with, what, a bit more hair on it than she remembered. Somewhere, someone (someone in this room, indeed) 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, how much 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. Well, no. But if you're looking for an object lesson in perseverance, it's been my repeat experience that statements – such as the cake-baking one – are hastily stored away by consumers, 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 consumers and 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 is radically 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 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 desire to win the lottery and even, in delusion, *expect* to win. Hope, instead, is active. It implies that obtaining what's desired involves effort, takes work. (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 *hopeless* 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. I think it's fair to say that what

many – most – people disabled by their brain injury feel most keenly is having been cut adrift of both their past and their imagined future; concretely, that they cannot do, or think, or feel as they once did. And when I ‘train’ people in how to work in the field of brain injury, what I invariably ask them is to reach for any and all continuities with your client’s past, try and tap the wellsprings of work, diversions, interests, pre-injury pastimes and passions, as a means of breaching that watershed.

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 the only point of reference is the hospitals of Hollywood – clinicians and allied health their high priests, god-like in wisdom. Little wonder, then, that consumers and families hang on their every word. And while I am not sure that the nation’s hospitals and 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 – gave up hope, told them that they, or their loved one, would be unlikely/ would *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 a lead from Dante, damning them to an alienating present.

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 ABC [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 ‘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, 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, 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. For those of you who know Sydney at all well – half of those 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 – whether it's transplanted here to Perth, to Adelaide, to Melbourne – 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 A\$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 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.

It's not my wish to turn you all into *de facto* social work counsellors of your clients, your subjects. Neither is this meant as some stricture about bedside manners. But 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. (And metropolitan Australia's internal borders around desirable real estate, the lack a concerted mix of incomes, of public with private housing, for example, just don't help.)

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; to grossly stereotype, the bogan reared on thrash metal who likes nothing more than fooling around with cars. 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.