

'Ability'

Reintegrating into a Community after Traumatic Brain Injury



The NRMA/ACT Road Safety Trust

Churchill Fellowship

Nicholas Stuart

Churchill Fellow, 2016

Declaration

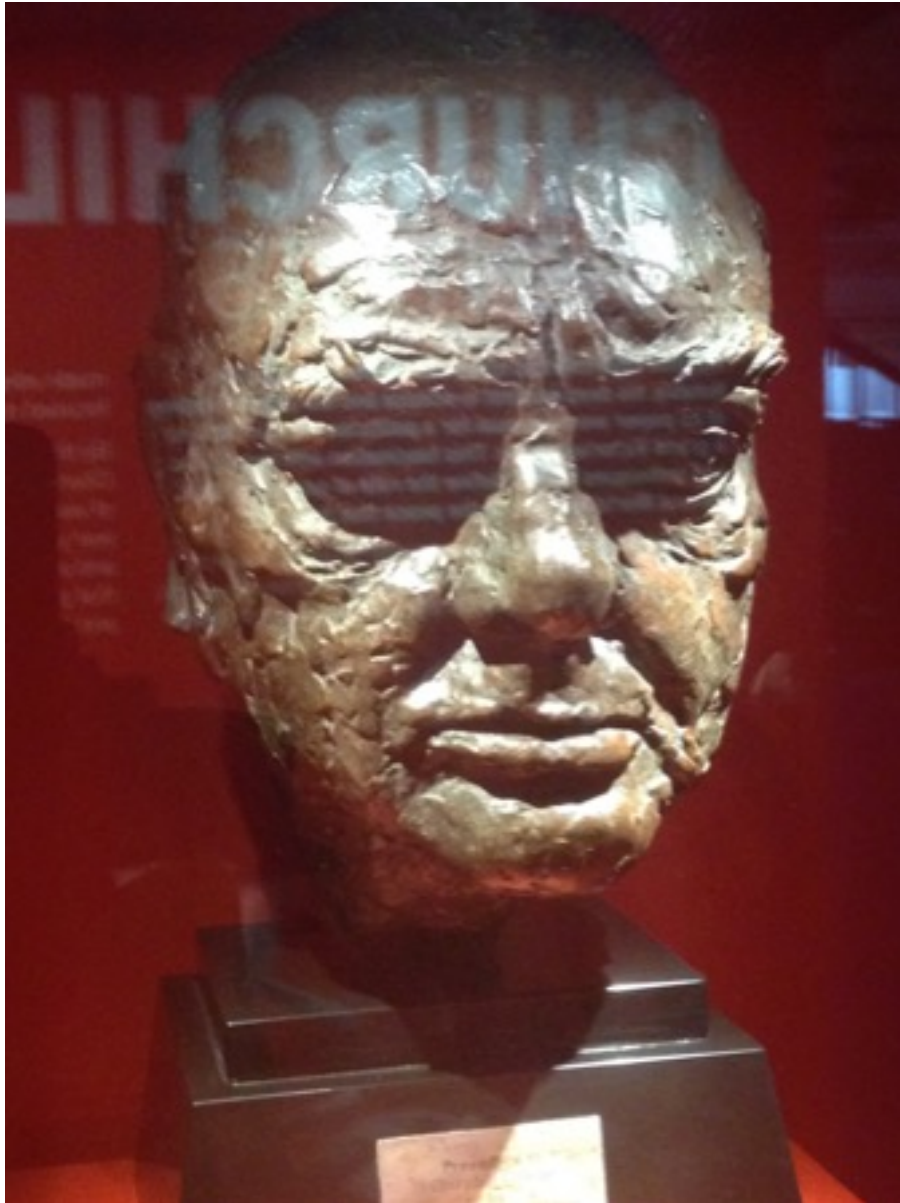
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(Signed)

(Dated)



This year marks the 50th anniversary of Winston Churchill's death. These photographs come from the recent exhibition "Churchill's Scientists", at the Science Museum in London, 25th March 2016 (located next door to Imperial College, London, where I'd been conducting an interview). Also on display were "historical objects . . . exploring how the culture of scientific achievement fostered by Churchill flourished after the war; invigorating scientific research across a wide range of fields [at this point followed a long list which included, towards the end] "nerve and brain function".

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Acknowledgements

I have been incredibly privileged to receive the 2016 *NRMA/ACT Road Safety Trust Churchill Fellowship*.

I first came across the existence of the Trust in 2011 when I became a Board Member of the *National Brain Injury Foundation* (NBIF, or Foundation). The Trust had previously been formally established in 1992 by the ACT Government with NRMA Insurance as an intelligent and effective way of resolving a financial problem. Subsequently its principal aim has been to enhance road safety for the benefit of the ACT road-using community and, in furtherance of this objective, the Trust has allocated more than \$20 million to over 400 innovative road safety projects since 1992. Most relevantly for the NBIF, it was the Trust's generous grant of \$750,000 that allowed the physical establishment of the Dorothy Sales Cottages.

The Cottages quickly became the main focus of the Foundation, which was responsible for administering the facility and deciding on eligibility criteria for admission. Catholicare was appointed the operator which took over responsibility for caring for the individual residents. The Cottages soon became the major source of funding for, and focus of, the Foundation. Although the NBIF still maintained other properties (including another boarding house in Hughes, a shop in the city, an office at Holder, and a umbrella interest in a separately-managed rehabilitation group in the outer suburbs of Canberra), a succession of other problems eventually combined to cause a perfect storm for the Foundation. It was at this point I became President.

It quickly became apparent that there were two possible courses of action: to either attempt to run the separate elements of the Foundation as individual business units, or to fold these into other organisations. In pursuing the first objective it became apparent that while it might be possible to preserve the organisation, a better solution would be to amalgamate with *Hartley Lifecare*, an organisation with which the NBIF had a great deal in common (both were located in the ACT as member-based, non-denominational, voluntary associations committed to the rehabilitation and care of others). After a considerable period of consultation and deliberation, the Foundation's membership overwhelmingly accepted a Board recommendation and voted to merge with Hartley (at which point they also became members of the new organisation), finally bringing to a close the existence of the NBIF as a separate entity.

The NRMA Trust has always retained a welcome proprietorial interest in the ongoing issues surrounding the Cottages. The Trust has more recently also been particularly helpful in facilitating the property transfer of the NBIF buildings to Hartley, allowing this to proceed as efficiently as possible.

Since its establishment the NRMA/ACT Road Safety Trust has, additionally, sponsored twelve Churchill Fellows. I have been the thirteenth. Unfortunately it appears this may not be a lucky number, as in 2014 a decision was taken to wind down the activities of the Trust and it may well be that I am the last such sponsored Fellow. I can only hope that once the findings of this research are implemented other organisations might be persuaded to restore similar funding. This will allow other Churchill Fellows to make the same wonderful journey of discovery that I have been able to make as a result of the Fellowship.

* * *

I have also been privileged to be associated with the NBIF, and I wish to particularly record my thanks to those associated with this organisation.

As briefly referred to above, I became a Board Member and later President of the NBIF at what was to prove a critical time for the organisation. By 2011 the Foundation's income stream was sufficient for it to operate, although not enough to enable expansion or development. There was a need for further investment, which we found we were hard placed to fund. There had also been a considerable degree of organisational turmoil following the (statutory obligatory) resignation of the person who had been the organisation's President for a decade. Discord became evident at both a Board and operational level, resulting in considerable turmoil and culminating in a serious legal case. The organisation was left without any full-time staff and I necessarily took over these duties in order to keep the NBIF running. Once I had also been voted in as President I was able to study our financial position in detail. It was obvious the organisation needed to change. There was an immediate need to adapt to the new setting if we were going to continue serving our constituency.

I had hoped that isolating our activities into self-supporting business units might allow us to re-organise the Foundation and allow us to continue as a viable organisation. In four cases (the Dorothy Sales' Cottages; the Hydrotherapy Pool; the Volunteer Shop and physical office itself) this proved possible. The stumbling block was Tanderra House, the Foundation's boarding house in Colvin Street Hughes. It was while exploring the possibility of getting Hartley Lifecare to take over the operations of Tanderra that I came to recognise both organisations had a remarkable symmetry in terms of our aims and objectives. The difference was that Hartley had remained vigorous and was being well-run. It was evident that we had a

great deal more in common than closing the one simple deal to manage Tanderra. Further discussions proceeded. Eventually a deal was formulated that was suitable to take to the membership see if the NBIF and Hartley should merge. After a long and exhausting process, this was finally approved at the Special General Meeting referred to above.

* * *

By this time I had also been fortunate enough to have been elected as a Director of the ***House With No Steps*** (HWNS), Australia's second-largest disability care organisation. This vibrant organisation demonstrates on a daily basis the extent to which a positive environment can transform lives as it cares for residents and other service users.

Ongoing involvement with this (successful) organisation completely changed my view of disability services. I began to see what *can* be achieved, rather than simply the difficulties besetting us on all sides. I also saw how good leadership can ensure that, even while running businesses with a turnover in excess of \$130 million dollars, core values can still be nurtured and cherished. In this regard I was invited to become Co-Chair of the HWNS Human Right's Committee. The fact that this is one of only two regular Board sub-committees (along with Finance) demonstrates how highly the House regards the need to maintain and recognising the individual rights of the people it supports. This position that gave me an intimate view of how sincerely the House emphasises its core values which, in turn, opened my mind to new possibilities.

Towards the end of 2015 I was invited to participate in one of the workshops through which HWNS was envisaging how it would be best placed to offer its services when the ***National Disability Insurance Scheme*** (NDIS) is rolled out in 2016 and beyond. Professor Luca Gatti facilitated this workshop, which considered (inter alia) how those with disabilities who are in need of services will be able to access them. This helped me realise that the most critical factor once the NDIS was operating will be information – ensuring that those who are in need of services are able to identify what's available (and appropriate) for them.

The brain is an incredibly complex organ and every individual with a TBI has their own individual requirements for support. People need to find their own way to recover, but what's vital is that they are not left to grope in the dark.

This critical insight has been absolutely fundamental in shaping this report, together with its findings.

* * *

What has always inspired me is the way so many people care for others with a TBI or some other form of disability. In this regard I'd particularly like to acknowledge all those who have worked with or contributed during my personal journey in this field; firstly by assisting my own rehabilitation after my injury in 1990, and later in my interactions with organisations in Australia.

Most significantly, however, I need to thank my family and in particular my wife, Catherine McGrath.

Anastasia, Eugenia and Maximilian are wonderful people. All their lives they have had to deal with, and compensate for, a father living with an acquired brain injury. This has never been easy and yet they have not just coped, but flourished in these most difficult circumstances.

To Catherine I owe my life. She found me in a coma in Bangkok and has walked beside me ever since. This has often not been easy and her support for me as I have spent the first half of this year working on this Fellowship provides just another example of that marvellous, ongoing support. Holding down one of the most intense jobs in Australian journalism as SBS's Chief Political Correspondent while I jaunted off overseas wasn't easy; simultaneously organising the family added extra stress to her life that she didn't need. She has coped brilliantly, yet again.

I could not have achieved any of this without her.

Executive Summary

I have come to realise that key findings of this report are obvious, although this doesn't mean their implications are always fully understood and recognised. The most critical factor in recovery after a Traumatic Brain Injury (TBI) is ensuring people have the vital support that's necessary to assist in their eventual recovery and re-integration into society. This need doesn't cease when a patient leaves (either) a hospital; the rehabilitation facility; or at some arbitrary point in time, like a two year mark. We now understand that plasticity means the brain is never fixed at any particular point in time. It continues to develop, and yet this (possibly obvious) insight represents a significant departure from the medical and scientific orthodoxy that dominated our understanding of TBI as recently as 15 years ago.

The point really is how can we best reintegrate people with a TBI back into the community. Obviously particular practices are better than others; the point is, how will we know which is most appropriate? This is particularly an issue in brain injury, where every case is different. It became evident as I researched the multitude of different approaches while on this trip that no particular prescriptive formulation will always work, however if people are equipped with knowledge they are more likely to be able to choose the right answers for them than if they are fumbling around in the dark.

This Fellowship was concerned with investigating the treatment of head injuries and, specifically, concentrating on ways of reintegrating people into the local community. There remain real barriers to further progress in this regard. Some of these are a result of a lack of support for particular programs either because services do not exist, while others are because of a lack of personalised treatment regimes allowing for changing abilities. Still more are because of the social environment of the person with a TBI and, as a part of that, the way society deals with and treats such people. The key here, too, is information. If people possess an understanding of complex issues they can begin to address the problem. If they aren't equipped with the tools they won't be able to begin.

That's why the following is a list of action items that have come to light as a result of this 2016 NRMA/ACT Road Safety Trust Fellowship. This executive summary picks out the key findings from each stop on my research journey. The most significant finding, however, is the final one; the need for the dissemination of information. Empowering people with the knowledge to take action themselves is vital, particularly in an area such as TBI where the boundaries of knowledge are moving so quickly. This has prompted me to found a new website to provide this requirement; *'Ability!'*

1. Cultural Awareness (Bangkok)

Recovery after TBI depends on more than the simply physical. The brain, our mind, is wired for social connectivity. Even within a country like Thailand, for example, different cultural and social groups deal with individuals who've suffered a TBI with very different expectations of recovery and the sorts of support that will be provided by society. This has particular ramifications for a multi-cultural society like Australia. There is an important need to explain the options for recovery and detail the possible 'journeys' that individuals and families will take to minimise stress and ensure the best possible outcomes for society.

There's an urgent need to explain the specific pathways for treatment and rehabilitation after a TBI to minimise confusion and assist with certainty for families.

2. Dissemination of Research (The Hague)

A massive number of researchers across the globe are working on Acquired Brain Injury (ABI), the broader intellectual discipline into which TBI fits. Their research is published and disseminated at conferences and in scientific journals. This information can, however, take years before it reaches practitioners and carers. There is also a tendency for potentially significant discoveries to remain in particular intellectual 'silos' instead of being widely disseminated amongst professionals concerned with brain injury.

There is a need for the latest research to be easily accessible so that information can be used to assist recovery, not simply by particular specialities but across disciplines.

3. Sub-cutaneous stability (Celle)

Evidence suggests that a (up-to) five percent improvement across the board in recovery is associated with particular procedures immediately post-TBI. These relate to the immediate stabilisation of the brain and body post injury.

Research should be conducted and an experimental test conducted under Australian conditions to determine if this procedure should be introduced in Australia to reduce the severity of TBI.

4. Brain Injury Identity Card (Aberdeen)

People with a brain injury typically lack the ability to properly communicate with others, particularly in cases of stress and tension. Their speech may be slurred and they may

additionally demonstrate reduced understanding of their surroundings. This can lead to increased difficulties when dealing with authority figures, including (especially) police.

The introduction of a simple, photographic Brain Injury Identity Card is recommended to assist quick identification of people with an ABI in circumstances where this may be necessary.

5. Brain Injury Community/Supporters Network (Launceston)

People with a TBI and their families have a continuing need for support once they leave the structured medical system. There is an urgent need to develop structures and facilitate networks to allow this to occur in the community.

Departure from the hospital system is simply the beginning of the journey of life after a TBI, not just for the individual who has suffered but also their family. There is a need for easily accessible, relevant and continuing support for these individuals.

6. Single Point of Contact/HATS Nurse (London)

The information that a person has suffered a head injury is often meaningless to family members and others concerned, including the patient themselves. In order to assist them to rapidly grapple with the ramifications of the injury there is an urgent need to ensure a dedicated, medically trained person is available to immediately communicate the sequelae of possible outcomes with those concerned.

Particular specialist medical staff should be identified and trained to provide assistance to family members and carers, from the point of recognition that a TBI has occurred right through that individual's medical journey for the years to follow.

7. National Statistical Database (Washington)

Despite its prevalence there is minimal statistical data available regarding TBI. This is because new techniques for identification of the condition have only recently been available. We now know, however, that ABI is widespread. Nevertheless, despite this prevalence, there is no readily accessible national database associating causes of ABI with treatment.

There is a need to establish a national database to identify the prevalence and causes of TBI and for actionable information that can be used to identify activities likely to increase or minimise its prevalence.

8. Lobbying to Raise Awareness of TBI (New York)

There are enormous costs associated with TBI. Until now these have remained invisible and been passed on to the community (as increased healthcare costs) and families (responsible for the burden of care). In a society where we place a monetary value on almost everything, it is not enough to simply ‘raise awareness’ of the dangers of specific activities. The community must be made aware of the specific social and financial costs of TBI so that it understands the burden of this condition.

Once causes of TBI have been identified there is a need to ensure steps are taken to minimise the dangers associated with it.

9. Emerging Ethical Issues (San Francisco)

As a result of recent advances in medical understanding, the ethical issues have become increasingly problematic. This is not simply in relation to experimenting on humans who might be otherwise unable to grant consent; it also bears on treatment regimes and even how long people should be kept alive if there is no or little hope of recovery. At the moment there are few ‘impartial’ guides to offer advice for families and carers, a situation that results in advice being requested from medical professionals who may not always be prepared to volunteer such advice.

The increasing nature of conflict over ethical requires a forum in which people are free to put forward their own ideas and solutions, in an appropriate and polite manner, in the hope of reaching a broad society-wide consensus.

10. E-zine: ‘Ability!’ (Los Angeles & Canberra)

The critical finding of this study is the need to reinforce communications between the different groups of people involved with TBI – researchers and scientists; neurologists; medical practitioners and surgeons; rehabilitation providers; family and carers of those with a TBI; and the individuals themselves. Whilst networked groupings of individuals specialising in ABI already exist (of which the Australasian Society for the Study of Brain Impairment¹ is perhaps the best example), there is no regular forum that enabling the different groups to come together.

There is a need for an internet based community hub to facilitate information sharing and other useful forms of communication between different groups concerned with TBI, Acquired Brain Injury (ABI), and rehabilitation more generally.

¹ See, for example; <http://www.assbi.com.au>

Report

Plasticity, my story . . .

I lived, as a child, in Papua New Guinea. At that time nobody ever used the word ‘colony’ but that's exactly what ‘the Territory’, ‘TPNG’, effectively was. It was run by an ‘Administrator’ and civil servants, *kiaps*. Australian government officials were sent up, normally for two years at a time, to run the country. In the early '60s my father, Ron Stuart, was a research officer working directly for the Reserve Bank's Governor, ‘Nugget’ Coombs, at head office in Sydney.

Coombs had a deep interest in indigenous cultures and their economic basis. Although independence wasn't even being discussed as a possibility, he realised the institution needed to understand much more about how Territory's economy functioned. He established a position for a research economist in Port Moresby and, in due course, my father was sent discover how the economy was working. He, accompanied by my mother Ruth and myself, went for two years. We stayed for six.

I didn't realise it at the time, of course, but this was also to prove to be the beginning of my life as firstly, an observer and more recently a journalist. When we left Port Moresby I'd wanted to become a New Guinean, but was told I couldn't be because there was no such country. This made absolutely no sense to a ten year old boy. It was obvious to me that this wasn't really Australia, I'd had spent far longer in Port Moresby than anywhere else and could speak creditable Pidgin. I certainly didn't feel ‘Australian’. It became quite apparent to me that the artificial constructs through which we lived our lives didn't match reality. This realisation continued later, when I became a journalist.

It was a marvellous childhood.

After a couple of years living in the midst of the small expatriate population, everybody appeared to know everyone else; their weaknesses, foibles, and most of all what sort of ‘person’ they were. Without television (and with servants to preform most menial tasks) weekends were spent blissfully; either entertaining in the garden, or up at Rouna Falls and the nearby cool hills of the Owen Stanley Ranges.

Life was still lived in an old fashioned way. Many people, particularly commuters from Queensland, travelled to the Territory by boat – my family was quite unusual in choosing to

fly back and forth from Australia. Someone's departure would occasionally be marked by a trip down to the wharf, a cabin party, fond farewells before rushing down the gangplanks, and then, finally, catching the brightly coloured streamers thrown down by departing friends. These formed a link between ship and shore; between those who were leaving and we who remained; an idea made tangible by the long strip of paper. I can still remember running down the wharf late one evening, holding on until the last moment. Who was on the other end I can't remember. Then the ship heaved suddenly and pulled the streamer from my hand.

I've no idea who was on the other end of that particular streamer, but the image has etched itself vividly in my memory, and this is the point. When someone left Port Moresby they passed out of my life as effectively as if they'd crossed the river Styx, which the ancient Greeks believed separated the living from the dead. When the ship sailed away it took people to another life, another world. I knew I'd probably never see my friends again and so got used to departures, recreating lives, and living for the present. Friendships crystallised and dissolved easily. I became lost in a revolving kaleidoscope of acquaintances I'd never saw again, but that was normal. We lived in the moment.

This departure at the wharf marked the end of relationships. This was just a fact of life: people were friends and then they were gone, never to be seen again. And life would start afresh . . .

* * *

I'm increasingly convinced the way I learned to interact with the world in my childhood established basic patterns that were later assisted my recovery after I suffered a TBI.

As a youth I learned things, society, was in a continual state of flux and always changing. I like to think this kept my brain fluid. My external environment was always changing, as it continued to do when we returned to Australia.

My first school had been at Ela Beach, on the seaward side of the narrow spit of land that protects Port Moresby harbour. Although it may have had an equivocal academic reputation I learned a great deal about life. Then, in 1970, my parents decided to travel around the world for a year instead of travelling straight back to Sydney. I was taken out school and learned a great deal more than I ever would have sitting behind a desk in the classroom and, once again, although there's no way of proving this I suspect the experience kept my brain ready to make new connections.

The experiences didn't favour my academic progress, however, and I was later extremely fortunate to be admitted to Sydney Grammar School (I suspect my results in the entrance exam were right at the cut-off point; nevertheless I was lucky and allowed to enter the school). With the encouragement of good teachers who accepted that students actually were capable of improving (and that our future life's course wasn't set in stone by an exam completed at the age of 12), I managed to thrive. Starting in 1F, I was promoted after one term to 1E, then 2D and 3C, from which point we were randomly allocated to unranked 'Groups' for administrative purposes. We were allowed to float into the classes supposedly commensurate with our assumed intellectual ability, as determined by tests. For me this meant I was in the top class for English and History, but buried in the middle (or towards the bottom) in Maths and Science.

Recognising that I had no interest in becoming a doctor, dentist, or veterinarian allowed me to drop Maths and concentrate on what I enjoyed. I'd developed a particular interest in military history, a subject not taught at school and not a career with an obvious career path, either. Nor was an appointment with the school careers advisor to offer any hint of what I should do when I left school. After administering an IQ and occupational aptitude test he suddenly asked me what sort of work I wanted to do. I remember looking at him quizzically. I'd thought *he* was meant to answer this question and identify the right occupation for me.

"I really don't know," I volunteered. "Perhaps a barrister?"

"Good," he said, "you can do that. Now skip off back off to class."

And with that, my single career guidance session was over and my life's course was, supposedly, set. The details remained to be determined by the particular mark I received in the HSC but the assumption was that I would proceed to university², study arts to develop myself as a human³, do law to provide me with an interesting⁴ career and, presumably, at some point (through a process that still remained, to me at any rate, obscure and unrevealed) find a wife and acquire a family.

I did well in the HSC and was accepted into Arts/Law at Sydney University. This was the point at which my life began to run off the smoothly greased rails that I fondly imagined would eventually see me donning a wig each morning before heading off to court from a harbour-side mansion in Clifton Gardens. When it came to selecting subjects I ignored

² Sydney if I had the marks, second preference UNSW, third preference Macquarie . . .

³ And because BA/LLB was more sought after and 'respectable' than a simple LLB.

⁴ For 'interesting', read 'lucrative'.

History, thinking instead that it would be more interesting to learn something about other subjects before burying myself in case law. Unfortunately these failed to ignite my interest and had, rather, the opposite effect. The Sydney University Regiment of the Army Reserve was, however, another matter entirely. After a couple of years polishing boots and yelling at other people I became an Armoured Reconnaissance Troop Leader with the 1st/15th Royal NSW Lancers. Soon I was devoting all my time to learning tactics instead of studying. My exams were a disaster. When I was offered 'posts' I didn't even bother sitting them. I decided to take a year off and spend it in the Reserves, in Australia and the UK.

By August, I was in London on holidays with an attachment to the 1st Queens Dragoon Guards. Walking out of the Military Attaché's office at Australia House I saw Kings College London was located directly across the road. I knew they ran a course in War Studies and wandered over to enquire about studying this. It turned out that, as an officer, I was fully qualified to enrol in the Graduate Diploma and enrolled that same day. Within a few weeks I was back doing something I loved. The Grad Dip and MA were run concurrently and I was invited to (and did) submit the long essay. This passed, allowing me to then complete the higher degree.

I returned to Australia with the realisation bearing down on me that I'd have to settle down and get a job. My mother had cut an advertisement for ABC Radio News Cadets out of the paper and showed it to me. I knew thousands tried out for jobs like this and so, confident I had no chance, put in my application. I had no right to be selected, but I was. I became a cadet journalist.

I worked on general rounds and spent time on rounds; finance, police and courts. I worked in the newsroom and at state (and later) federal parliament. I reported news and learnt how to conduct a probing current affairs interview. I was sent to China to report on the student demonstrations of 1989 and to the Solomon Islands, reporting on environmental issues. I began to discover the differences between radio and television; what it meant to work in a team and work alone. Eventually, in 1990, I was selected as the Corporation's Indochina Correspondent, based in Bangkok. I'd had a lot of luck and it seemed as if I'd finally fallen into my ideal job. Things were wonderful.

The key element in this long digression – and it's an important point for my own recovery after my head injury – is that my life had been full of change, rather than stability. Even though by now I was 30, my life had been made up of many different segments and experiences: study, the military, reporting. Even now my work as a foreign correspondent changed daily. There was nothing routine about either the job or the environment in which I

was working. I believe, fortunately, that this meant my brain continued to retain a degree of plasticity. It hadn't yet sunk into the established routines of middle-age.

Then, at the end of November 1990, I was driving onto the Sathorn bridge early on a Saturday evening. Another car, going too fast, smashed into the rear of mine. My hip, restrained by the seatbelt, was flung into the steering wheel and fractured in 29 places. A number of other bones and ribs were also broken. Surprisingly however, and thanks entirely to some amazing surgery later in Sydney, those bones eventually knitted together again.

My brain was another matter.

* * *

The impact of the other car threw my head forward. Although my body had been stopped by the seat-belt harness, when the skull stopped moving there was nothing to cushion the soft mushy matter that was my brain. It didn't have a harness. It continued travelling forward at 60 km-an-hour, before smashing into the bone when it's forward momentum was abruptly halted by the seatbelt. My head was then flung backwards and sideways, shattering the lateral connections between the hemispheres and causing a blood clot to develop at the base of the cerebellum.

Somehow I was taken from the car in the back of a tuk-tuk to a nearby hospital and, somehow, I kept breathing until I was being examined by doctor. Then I stopped breathing. The body slipped into a coma. It was kept on life support but that's when Nicholas Stuart, the ABC's Indochina Correspondent, effectively and for all practical purposes, died.

* * *

So that's my back-story. Why I'm vitally interested in brain injury; neuro-plasticity; and the factors affecting recovery after a TBI.

We all bring our own baggage to any examination of the brain.

Last year I was lucky enough to be a Press Fellow at Wolfson College, Cambridge. We lunched at long trestle tables and the exciting thing was you never knew who you might find yourself sitting next to. On this particular Sunday I'd been joined by a retired, distinguished

philosophy professor. We'd chatted before, normally about the media, but this time he asked me about my brain injury.

He was, it turned out, particularly interested in the 'mind/body problem'. I remembered back to my Descartes from first year 'trad & mod' philosophy:

“the difficulty of explaining how mental states, events and processes—like beliefs, actions and thinking—are related to the physical states, events and processes, given that the human body is a physical entity and the mind is non-physical.”

Descartes believed sensations were communicated through the brain to some kind of 'immaterial spirit'. I pointed out that for me, this was no longer a philosophical issue. Both the old Nick and the new Nic use the same body yet we are utterly different people. The corporeal exists, but ideas (and, for me, the immaterial spirit) are not present in the world. The physiological beats the theoretical every time.

My attributes changed dramatically after the accident and the person I was before the injury isn't the person I am now. My philosopher friend found this difficult to accept. He was breaking the old philosophical rule of Occam's razor: use the simplest explanation possible. Don't invent assumptions you don't need. Instead he was asking me to prove that spirits *didn't* exist. I had instead come to rely purely on the physical to explain how the mind worked.

I'd tried suggest this to listeners of the ABC's Health Report, some seven years after the accident.

Norman Swan: Nicholas Stuart was the ABC's correspondent in Bangkok. At the age of 30, he had already reported from China at the time of Tienanmen Square, and from Rangoon, where Aung San Suu Chi had just been arrested. He knew he'd be one of the few people lucky enough to have both a brilliant career and a fascinating life.

Seven years ago, Nick's day began as life does for a foreign correspondent. He woke that morning in Hanoi and flew to Bangkok, where rumours of a military coup were in the air. He had just visited a senior diplomat and was driving home, when another car smashed into the rear of his Toyota. He was left on the side of the road in a coma.

Nick suffered significant physical injuries, but damage to his brain has proved a far more lasting incapacity. He briefly returned to Bangkok, but it didn't go well and he was later recalled, and his subsequent efforts to work have failed.

Here is Nick, in an attempt to explain the nature of his brain injury.

Nicholas Stuart: When someone calls 'Hey Nick!' I always answer. But I don't feel like the Nick Stuart who died that day in Bangkok. You see he, that is, I, completely stopped breathing while a doctor examined me. And so the first Nick Stuart died. I'm not sure if I would really have liked him. He was, well, lazy. He wasn't really a nice person. But he was a good journalist. Even if I do say so myself. And I think I'm a good judge because I know a lot about him. But he's not me. Not now.

My first memories are just haphazard snatches as I emerged from my coma. In the movies, one minute you're in a coma and the next you're out. But that's not really the way it happens. It's actually more like childhood. First you'll remember a split second, or a mood, but it's not until later that you can put them together into a sequence that you can comprehend. But let's go back to the moment when I, the person I am now, was born.

I don't remember that crash at all. I was driving towards a bridge when my little Toyota was hit by another car, which sped up from behind. My car was badly mangled by the impact. The driver who hit me fled the wreckage, I think he was drunk, but I don't know. His father appeared a few days later at a police station, paying people off with a large wad of money. I'm not really angry about that now, other things seem more important.

They've got small motor bike taxis in Bangkok, called tuk-tuks. It was a tuk-tuk driver who saved my life, stopping on the bridge where my car was just a twisted, broken wreck, and taking me to hospital. I'm told that as the doctor examined me, I stopped breathing. I was put on life support and left on a bed in the corridor of the overcrowded hospital.

I hope the tuk-tuk driver got my wallet, but how do you ever pay someone for saving your life?

The accident happened on a Saturday, and it wasn't until Monday that my secretary received a fax saying they'd found a badly injured man who had the business card of the ABC correspondent in his shirt pocket. She came and identified me, assured the hospital that they'd receive payment, and so began the birth of me, the new Nic Stuart.

The new Nic's first memory was from the Bangkok Nursing Home. There, I was in a coma for more than a week before being airlifted back to Australia.

The woman who is now my wife, Catherine McGrath, had dropped everything, left her job, left Australia to come to Bangkok the minute she heard I was badly injured. She talked to that body as if it was aware, and eventually it began to respond. Cath was always there, so I didn't really focus on her. I accepted her, she became part of the scenery. I treated her the way we treat people we rely on most of all, by ignoring them. But more about her later.

Let's go back to the important part of the story: my broken and shattered bones. Because that's what we talk about when we deal with injury. Not true recovery, but physical recovery. As soon as I was flown back to Australia a professional medical system took over. And it was a professional medical system, very professional, very thorough, very effective. I was patched back together in the orthopaedic ward at the Royal North Shore Hospital in Sydney. My limp is very slight now, a real tribute to the surgeon who spent eight hours putting my hip back together.

But physical medicine can't repair a brain injury, you have to learn to live with it.

I hope I don't sound too bad now, I don't think I do. I look quite normal. But what I lack is the mental sharpness that I used to have. That doesn't normally matter in a conversation, but it does when you're working, or trying to work. My long-term memory is OK, but it's very difficult for me to lay memories down, transferring them from the here and now so I can access them later.

I like to think the psychological counselling that I received at the Royal Ryde Rehab. Hospital in Sydney helped me, although I wasn't really ready to face my psychological problems. By the time I left, I felt I had regained the skills that I'd need to live in society.

But that wasn't true. At some point you're cast off, and at some point you have to deal with the real world again. That's hard. And it's here, if we're talking about complete rehabilitation, that the real problems begin.

I went back to my job, reporting in Bangkok. But I wasn't really able to cope and my work wasn't up to its previous standard. It was as if I was

living in a dream, although I do remember the minute that I realised I was really alive.

It was a year after my accident, in 1991. I was desperate to get back to reporting. The ABC had taken a risk sending me back to IndoChina. The UN hadn't arrived in Cambodia yet and war was ebbing and flowing close to the capital, Phnom Penh, as the rival factions tried to gain some advantage in the peace negotiations. Just before Christmas I was crouching low on a hotel balcony in the centre of the capital, as the bullets sprayed around us. It was as I watched death being dealt out down below that I was finally shaken out of the dream-like state that I had been inhabiting since emerging from the coma. I finally realised if I died now, I wouldn't come back. This wasn't dreaming any more, I had to make this life work.

I was desperate to recover. I wanted so badly to be a proper foreign correspondent again. But my work wasn't as concise as it had been, my voice was thin. In time, the ABC recalled me and I had to stop pretending that I could still be the old Nick Stuart, foreign correspondent. I had to find a new life, one that was appropriate for the new person that I had become.

I tried working at a desk job. I lasted a year before being made redundant. I did have the support of the Commonwealth Rehabilitation Service, the CRS, but I didn't want that. I didn't want help, I wanted to be a success again. So I ended up turning back and relying on those people who are the only people that can really make your life a success. Those people who are close enough to you to allow you to turn on them. The people who understand your frustration; those people who will listen to your bitter anger as you rail against the world because you remember who you once were, but can never be again. Your family and friends.

There are no surgical answers for the brain injured, and I'm not happy with the various organisations that try to provide care to people such as myself. I don't think the system works.

When you're brain injured it takes you a while to get around to trying to say what you want to say. But that's why I'm doing this piece for the Health Report. To tell you that it does matter to those that are damaged that you do go to see them in hospital; that when you judge the body lying in the bed, you remember the way they were, how they were when you first loved them, when they were whole people.

And after that time, continue to remember them, because some of the best treatment that I've had has come from non-medically trained friends and acquaintances.

I still remember vividly every time someone came to see me all those years ago in hospital. Receiving those visits was real therapy, it helped me feel that I was still valued. And since then, the recognition has been so important in helping in my recovery.

On the day that Bob Carr was elected I went in to the State Parliament. I was there, standing in the background, watching my wife work when he, in the midst of the throng said, 'There's Nick Stuart.' Then he was swept away and I haven't seen him since, but I remember that moment. Like when Tim Fischer came to visit me in hospital. He still takes the time to ask after me when my wife interviews him.

She's the one on TV now, and I'm happy about that. But I'm particularly happy that behind the journalist that she is, the great journalist, there is a real human being, one who's helping me become the new person that I want to be.

We've just had our second daughter. And neither Eugenia, nor Anastasia know or really care that their Dad used to be someone different. They just want me to be their Dad.

So I can finally accept now the old Nick Stuart, the foreign correspondent, did die on that bridge, seven years ago in Bangkok.

The key point was that the brain, our massive collection of neurones and synapses, is responsible for our personality as well as our intelligence.

* * *

My accident transformed me. I no longer had the capacity to work as a journalist. What I did have, however, were the contacts to support me as I pursued this path. It's a long story. I began by doing a couple of (theoretical) courses, Advanced Journalism Theory at UTS and Advanced Industrial Societies at UNSW, and then commenced a thesis looking at '*the factors influencing the creation of news*' using the ABC as an example. After accompanying Catherine to Singapore I dropped the thesis and taught journalism for a semester at the University of Canberra and then moved to the Canberra Institute of Technology where I helped establish the journalism course.

But teaching wasn't me. It was fun but it wasn't really involved with news, which is a trade, a craft, rather than a dry profession regulated by rules that can be reduced to technical formulae. I desperately wanted to return to journalism and, thanks to a friend, got the opportunity to submit a couple of articles to the education section of the Canberra Times. This contact then developed into me providing analysis pieces, then comment articles, until finally I was put on as a regular contributor. But there was no full time work available, not for me, anyway, and so I wrote three books: "***Kevin Rudd - an unauthorised political biography***"; "***What Goes Up***", a detailed analysis of the factors that led to Labor's victory in 2007; and "***Rudd's Way***", an examination of failure.

I've now worked in radio, television, print and publishing and kept my own web-page. I know journalism is all about making stories, but thanks to this Fellowship I've now come to realise it's about more than simply the story: it's about creating a community.

I was at Cambridge, studying news reporting, when I was interviewed for the Churchill. I'd gone to be a Press Fellow at Wolfson College. My supervisor, John Naughton, had originally trained as an electrical engineer before becoming a journalist. I'd chosen to study with him because of his understanding of the internet and the way it's transforming journalism. My Fellowship kept offering me new ways of seeing how this technology could be harnessed to fill the needs of people with TBI.

This is the biggest insight I've had as a result of my Churchill. Recovery after brain damage requires not just physical repair but also re-assimilation into society. The internet means that, quite suddenly, it's possible to achieve economies of scale when it comes to forming communities of people who need particular information.

The easiest way to explain this is by considering the daily newspaper. It provides a broad view of the world, but a necessarily shallow one. This cannot satisfy people who have ‘deep’ information needs. When someone is affected by TBI, for example, their initial focus will be on the nature of the injury itself and what it means. They possess a sudden ‘deep’ need for very specific information, but then they’ll quickly move on. They may then change to subsequently wanting lots of information about, say, law cases, recovery options, and the best environment for recovery. Their needs are like a colonnade, with people requiring sequential knowledge to answer their specific needs and then quickly moving on.

This is the key discovery from my Fellowship. The initial aim of my research was to bring back knowledge that could assist people with a TBI reintegrate into the Canberra community. This journey has assisted the realisation that enormous strides are rapidly developing our knowledge of the workings of the brain. Rather than being a static field this is one in which great advances are still being made. This means there is an enormous need for the dissemination of information in a regular forum that people can easily access. The internet offers the ability to create such a forum for an exchange of insights into methods of recovery.

The internet enables the accretion of small pieces of knowledge, bit by bit, to form a colonnade of information. This is ideal for people (and supporters or carers of those) with a TBI. The real need is not for more research, but for the regular dissemination of cutting-edge information that will enable individuals to seize control of their recovery.

This is where I’ve realised that I can contribute something worthwhile: by using my own journalistic skills to help to create this community resource and sharing the information that people so desperately need.

* * *

The most important part of a story is always the beginning. As a reporter I’ve always found that if one gets this right, the events then will flow naturally until you reach the end. Start in the wrong place and you’ll spend ages trying to fix things. All too often the actual departure point is only obvious once you’ve reached the end.

This has been a long research trip and it’s taken me a great deal of time to work out where I should begin. Occasionally I’ve thought I’ve reached the peak and begun unpacking my flag, only to glance up and see there was further to go: I’d reached a false crest. Perhaps, in some

ways, this is actually the biggest ‘finding’ off my entire project: there is no endpoint for dealing with head injury. The need goes on and on.

The journey of discovery laid out in this report ranges from hard-edged specifics of detailed medical procedures, through to the broader social aspects of healthcare, and finally, to the new communications possibilities offered by the internet.

Each of these insights evolved as result of different processes and so I've structured this report around each one separately in turn. All are equally important; each requires action from seperate constituencies. Bundling them together would require creating fabricated links where none exist and that's why I've attempted to limit each one to bite size, actionable, chunks.

Hopefully the following sections outline things that can be done, actions that can be taken, and lives that can be improved . . .

Research Project

Thanks to the Churchill Fellowship Trust I was able to visit Bangkok (where I visited and spoke to administrators of the *Bangkok Nursing Hospital*); Holland (where I attended the *Eleventh Biennial World Congress on Brain Injury*); Germany (where I visited the *Allegemines Krankenhaus Celle*); the United Kingdom (where I witnessed the operations of *Headway UK* and met with hospital researchers and family members of people with a TBI); and the United States (where I met with the peak body for brain injury, medical and communications academics, and others researching *BIA*).

My program was intense. I'm most appreciative of the Churchill Trust for allowing me the flexibility to extend my research project as its dimensions began to change as the focus sharpened.

Before any journalist begins their research, they normally have the framework of their eventual story in mind. Unfortunately, as you begin investigating, it often becomes apparent that the actual story you've set out to write isn't the one you've discovered after completing research. After my stop initial couple of stops I was quite certain what my story was. The research in Thailand, Holland and Germany seemed to bear out my (unwritten) initial thesis, which was the need for greater focus on long-term recovery and re-integration into the community. This seemed to be a critical area, as well as being one where practical outcomes had not kept pace with medical research. What hadn't yet become obvious to me was the way in which this could best be achieved.

This was when I began to focus on the need to disseminate my insights. Finding a way to continue communicating the latest knowledge, including other people's discoveries, took over from merely plucking out a couple of findings and pushing them forward. What seems to be far more important is the need to ensure advanced knowledge continues to be transmitted.

That's why the key finding in this report is the final one: the need to establish a new form of communication that will allow people with brain injury to keep abreast of what's happening and the advances in knowledge that are being made in this area.

Bangkok

The Need for specific Cultural Awareness

Background

Last December I attended the *National Disability Services (NDS)* CEO Meeting in Sydney as a Board Member of the *HWNS*. Around 400 delegates from most of the significant disability service providers in Australia had gathered to hear from the relevant Minister, Christian Porter, and senior officials from the *National Disability Insurance Authority (NDIA)*. Although I was present as a delegate, rather than a journalist, while I was waiting for the Minister to speak I did what I usually do when reporting these sorts of forums and examined the audience.

Very often on these sorts of occasions, it's not what you *do* see but rather what's missing that's most revealing. As a reporter I've attended a large number of military seminars and, as you'd probably expect, these are dominated by a particular type of Australian – the sort that many would like to categorise and dismiss as 'middle-aged, anglo white males'. It's a stereotype because it's true.

What came as a surprise, a big surprise, was to realise that a similar, quite pronounced cultural and ethnic homogeneity was evident at the *NDS* meeting. It seemed, in fact, that there were even fewer Australians from a say, non-WASP background than even at similar military forums. The danger is that this may result in an unconscious cultural skewing of services to people with disability.

Bangkok

I had been particularly interested to see what developments have occurred in an immediate post-accident treatment of head injury in Thailand after my own accident in Bangkok. In both cases the hospitals concerned have been dramatically physically transformed. The format *Bangkok Nursing Home* has, particularly, become a major institution capable of high-quality care.

Because medical care is not provided free of charge in Thailand, and because a large number of wealthy Thais are ethnically Chinese, significantly different cultural groups can have very

different expectations of the way care can best be given to people after a head injury. I was informed that this would often mean that families from particular ethnicities would seek to intervene in what might be considered ‘best (medical) practice’ because it was not perceived as either appropriate for the best form of care for their particular circumstances.

This was not necessarily in relation to physiological treatment but it was particularly relevant with regard to post-operative care including, especially, the return home. What came as a particular surprise to me was doctors’ frustration with family is from particular ethnicities (rather than social, or financially determined backgrounds) who insisted on caring for people with a TBI in ‘their own way’. I was told that whilst this often suited the hospital and the medical system (including, particularly, statistical data suggesting TBI was not a massive problem), it was not in the best interests of the patients.

It was believed that such families required much more information if they were going to be able to make effective decisions on behalf of those with a TBI. Without this is the danger was that many patients would return to the home environment without proper support for continued rehabilitation. Such patients are effectively being consigned to a future without options, despite the best wishes of their families to care for them.

Recommendation 1: Cultural Awareness

Similar factors are at work in Australia. Recovery after TBI depends on more than the simply physical. The brain is wired for social connectivity. Different cultural and social groups Will naturally seek to deal with individuals who’ve suffered a TBI with very different expectations of recovery and the sorts of support that will be provided by society. This has particular ramifications for a multi-cultural society. There is an important need to explain the options for recovery and detail the possible ‘journeys’ that individuals and families will take to minimise stress and ensure the best possible outcomes for society.

There’s an urgent need to explain the specific pathways for treatment and rehabilitation after a TBI to minimise confusion and assist with certainty for families. These need to be culturally appropriate.

The Hague

The need for a regular Australian forum on TBI

The Eleventh Biennial Conference of the *International Brain Injury Association* was held in The Hague from Tuesday 1st to Saturday 5th of March, 2016. The *IABA* kindly allowed my attendance at the conference as a journalist, which permitted me to attend all the sessions in addition to reporting on them. I also wish personally to thank Assistant Professor Ulla (Jørgensen) Konnerup from Denmark, who facilitated my attendance at the Conference Dinner.

Professor Konnerup's experience provides a glimpse into both the wonderful opportunities presented by this conference and some of its personal frustrations. Originally a speech therapist, her research interests have evolved to encompass socio-cultural learning, including specifically "avatar-mediated rehabilitation in the context of people suffering from aphasia".

When she told me this my eyes glazed over and I nodded politely, as if I was fully aware what this meant. She responded, "you don't know what I mean, do you?" I admitted I had no idea. Then she explained how it involved using the virtual world of Second Life to give people the opportunity to role-play, experiencing different methods of reacting to others without some of the disadvantages of doing it in real life. Suddenly I could understand exactly why Prof Konnerup was so enthusiastic about her project.

When people have a head injury one of the critical requirements is to re-learn how to interact with other people. Many, including myself, have lost the ability to dream and yet there is increasing evidence that dreaming is an important part of developing our skills to communicate and become involved with other people. This is an interesting insight and 'playing' roles may offer significant benefits to people with a TBI in particular. As a journalist I also immediately realised this idea makes a good 'story' - it is, in other words, 'actionable'. For medical professionals, however, this idea is lodged on the periphery of their concerns. It is about rehabilitation, but (very appropriately) the IBIA had categorised this as a social or psychological finding, rather than physiological. As a result, Professor Konnerup was offered the opportunity to present her findings, however this was during a break in the main proceedings. Additionally, there were numerous other researchers who were equally as excited about their own ideas presenting at the same time and, as a result, many of these presentations were bypassed by conference attendees. (The conference program itself can be

found at http://www.internationalbrain.org/media/files/files/ff533e1e/2016_On_Site_Program_FINAL.pdf.)

I did make an important discovery at the conference, but it was not the one I was expecting. I had attended to ensure that I was fully up-to-date about discoveries in the field: I realised, however, that this is not my field of expertise. There were just so many good and worthwhile ideas that it was impossible, even for specialist, to keep abreast of the myriad of developments regarding head injury. What was needed, rather, was accessibility – and easy guide that would allow the right people to get across the right breakthroughs.

The difficulty was not so much the existence of silos where individual researchers quarantined their knowledge and were unwilling to share with others. The problem was rather the opposite. There was so much information that it meant specialists were becoming buried in their own small area of research without being able to stand back and take a broader perspective. Although the professional journals (such as, for example, *Brain Injury*) do publicise many scientific developments they are, essentially, medical journals. As a result they do not have a mandate to deal with many other issues that are of interest to the brain injured community.

This insight dovetailed with academic work that I have been doing on the effect of the internet on journalism. The net is not destroying journalism. What it is doing, however, is enabling new communities to form. These are no longer linked by geography and resources, instead being brought together by interest and need. The corollary of this is that there is now the possibility of creating a community based on interest, because distance is no longer a prohibiting factor in communications. There is an urgent need for a journalistic e-bulletin to inform different stakeholders about the current situation in regard to brain injury research.

Recommendation 2: Dissemination of Research

A massive number of researchers across the globe are working on Acquired Brain Injury (ABI), the broader intellectual discipline into which TBI fits. Their research is published and disseminated at conferences and in scientific journals. This information can, however, take years before it reaches practitioners and carers. There is also a tendency for potentially significant discoveries to remain in particular intellectual ‘silos’ instead of being widely disseminated amongst professionals concerned with brain injury.

There is a need for the latest research to be easily accessible so that information can be used to assist recovery, not simply by particular specialities but across disciplines.

The Age - Comment

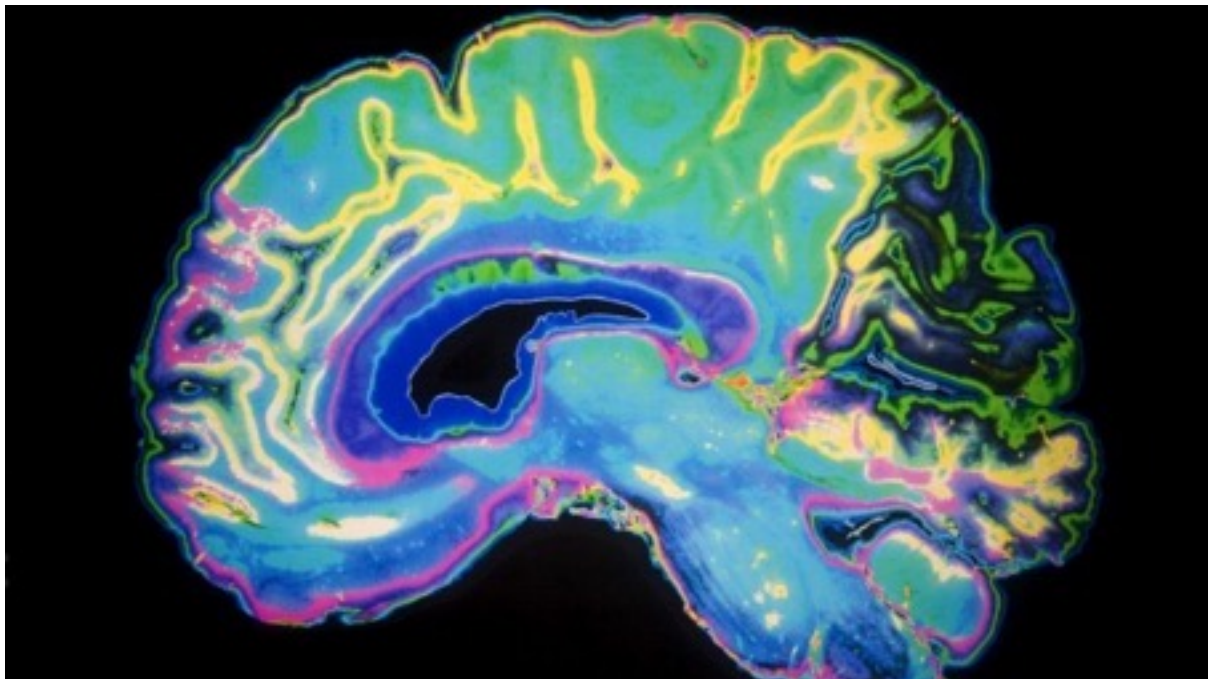
New ways of seeing brain injury

March 7, 2016



Nicholas Stuart

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No matter how skilful the surgeon, no matter how precise the scalpel; it can never be enough.

The rock stars of brain injury are easy to pick. The fans start gathering at book signings well before the authors turn up, and there's always someone at the World Congress on Brain Injury, staged last week at the Hague in the Netherlands, keen to hear more information about the details of a particular operation. Then, at the cocktail reception and perhaps to rub in just how singularly talented some people can actually be, paediatric rehabilitation physician Peter de Koning picked up his electric guitar until the congress was, quite literally, rocking. (And, at this point, it's probably important to note that this is not the same Peter de Koning as the one who had the 1995 one-hit wonder, "It's always spring in the eyes of the dental assistant", although this might be a natural mistake to make.)

The point is these are the technical experts; remarkable neurosurgeons with razor sharp skills, imagination and precision. As it should be, their extraordinary ability is applauded, and it's easy to see why these skills are so widely admired.

This is our usual model of medicine and it's best described as the "orthopaedic model". Brilliant surgeons; incredible pressures; working against the clock until finally, success or the tragic failure of a body convulsing into darkness. And this is the image we conjure up when thinking of heart transplants or other operations, because it's terrific to realise that medicine's come so far since the days patients veins were opened to drain away disease. So much has been achieved it's only right to pause for a second to congratulate ourselves on the successes. Brilliant technicians deserve every plaudit. And yet, and yet ...

This was the other message coming from the conference. No matter how skilful the surgeon, no matter how precise the scalpel; it can never be enough.

I'd been attending the 11th biennial meeting, but when you think about it, 22 years isn't actually very long to have spent attempting to grapple with our most complex organ. Although we know so much more about the brain today than we did even a decade ago, there's so much more to learn and this was the critical message from the keynote speech.

Professor Andrew Maas, himself a neurosurgeon who has experienced the huge variations in outcomes from brain injury, spoke urgently against any moment of self-satisfaction. With forensic skill he reviewed hundreds of instances of the supposed "gold standard" in research, the "Randomised Controlled Trial". Penetrating through the self-serving verbiage that's so necessary to achieving academic recognition, he found there was only one recent instance where a statistical correlation had been found and that was that the treatment had actually failed, killing patients who might otherwise have lived⁵.

Maas didn't assert scientific method is useless. He did, however, point out the flaws in the process and emphasise that it doesn't seem to be having the effect of our understanding of this vital organ. The difficulty is that the complexity of the brain

⁵ For a well-argued, contrary interpretation of exactly why Randomised Control Trials actually *are* important, see an article by Frank Bowden of Canberra Hospital in Inside Story; <ical://occurrence/A036066A-F0E4-4FFD-9C79-18475172F956?method=show&options=more>.]

means no injury can ever be exactly alike, but the problems don't stop there. We measure what we can; raw numbers provide one of the few robust ways we can generalise and search for patterns that might represent progress. But these figures rapidly degenerate into numbers with limited utility when treatment patterns cannot be replicated exactly, any way.

Two specific factors complicate treatment even further. The first is the different outcomes from brain damage. It would be nice to be able to have a standardised measure that is more precise (or accurate) than the Glasgow Coma Score; a simple number between one and 15. The second is related to outcomes after injury.

By their nature, randomised controlled trials focus on periods of up to two years, and this has been the model. The assumption has been that the capacity for progress will diminish dramatically as time progresses, with the result that we don't bother thinking of intervention in such cases except to stabilise patients. The assumption is that nothing can be done and progress will be minor. This absolves us from working with such patients.

The trouble is that the lives of people with an injury don't conveniently stop at the conclusion of the studies. This period represents the majority of time spent by people with an injury and their supporters: discerning how this can be made more worthwhile is vital for anyone calling themselves researchers. The difficulty, however, is obvious. Wider trials are, by definition, virtually impossible. The researcher is forced to probe individual situations, looking for particular interventions that may (and it's virtually impossible to prove) have had an effect.

Maas identified a critical issue: the structural process of the study (the scientific method) almost inevitably guarantees that particular results (and ones that are, in fact, not especially useful) will be produced and replicated, time after time. It's a shocking accusation. It's made more powerful by the fact that it happens to come from somebody who's proved themselves a master of research.

We should expect Maas to be emphasising how marvellous things are, instead of cutting the current process down. Nevertheless, in doing so the professor may have made a greater contribution to the broader situation of people with a brain injury by allowing them to still be considered patients years after their injury, rather than being locked into a fixed and static framework at this critical period of life.

That this will offer new directions for study is now almost guaranteed. Maas' extraordinary intervention has opened up new ways of thinking about longer-term post-injury outcomes. And exciting work is already being done. A Danish study considered, for example, how highly disabled people can use computer worlds like Second Life to experience and develop strategies for living. There's much, much more research to be done ...

Read more: <http://www.theage.com.au/comment/new-ways-of-seeing-brain-injury-20160307-gnc6wi.html#ixzz45t2MDmtE>

Celle

The need for subcutaneous treatment regimes

The critical role of information with regard to TBI was emphatically demonstrated by my trip to Germany immediately following the IABA conference. Notwithstanding prostitution's claim to be the oldest profession, medicine is undoubtedly one of the most ancient. Ancient finds uncontroversially demonstrate attempts made to ameliorate or combat disease. Today we can confidentially look back on such attempts at treatment secure in the knowledge that we possess far greater understanding of how to deal with medical issues.

This is not at issue, nevertheless treatment regimes are affected by so much more than simply achieving the best outcome for patients. Although this is undoubtedly the objective sought by medical professionals, the reality is that this is balanced up against political requirements (such as the need to curb expenditure) and operational ones (the willingness - or rather the lack of it - of a naturally conservative profession to question its operating procedures). Unless some form of external pressure is brought to bear on the quite natural stasis that tends to dominate procedures it is difficult to dislodge tried and proven methods.

At this point it is important to reiterate my own lack of professional qualifications in this particular field. I am not qualified to confidentially assert that any particular form of treatment is better than any other: that's a job for professionals. Nevertheless what became apparent from my visit to Germany was that (a) TBI cases are treated differently from *ab initio* identification, (b) statistics would appear to bear out that this provides better outcomes by a measure of around five percent, (c) this finding has been previously reported in medical journals in Australia, but (d) there has been a lack of will to follow through with these procedures and change the treatment regime for people with a TBI in this country.

The key issue is the immediate, on-the-scene treatment of a suspected TBI. A (necessarily simplistic overview) has, in Germany, a doctor travelling to the scene (often by helicopter alongside first-responders) and immediately stabilising the injury. This treatment involved relieving internal pressure on the brain *regardless of whether this appears to be required or not*. This is, in other words, the opposite of traditional medical practice in Australia, where treatment is (for sound ideological reasons) limited to the minimum degree appropriate.

At issue here are fundamental differences in the way the profession views treatment. As such there could be expected to be only limited interest in following up these differences from the

medical body here. While I was in Germany I was shown a detailed, academically reputable study that reinforced the headline findings asserted here: the difficulty is that this was carried out by a drug company to prove the efficacy of a particular drug treatment. The findings, however, failed to do this and suggested either that there was no effect of using the drug or even the reverse, that its use was retrograde. As a result the information has not been published and cannot be quoted from here.

Australian research into this issue was carried out about a decade ago. This appeared to have similar findings to the German ones, however this has not overcome the institutional inertia that has fixed treatment in place.

Obviously this issue is worth a Churchill by itself, because if it was found to be the case it would have a dramatic result on outcomes for people with a TBI. I am not qualified to assert anything other than this issue is in urgent need of research. This is, however, the point that needs to be emphasised.

There is the prospect of a better treatment regime, however this has not been examined in any focussed way in Australia. There has not been an appropriate forum to draw attention to the possibility of change; nor any follow-through by the medical profession.

There is no doubt that an overabundance of severe socioeconomic consequences, e.g. loss of job, accommodation, family, are found in patients that have difficulty returning to normal life after a mild TBI, and no injury is the same. Nonetheless there would appear to be little doubt that treatment regimes would benefit by being challenged at every stage, and no matter which primary professional group is perceived to hold responsibility (first-aid, emergency, surgical, rehabilitation or social and community workers). This can only happen if an informed community has a forum in which to share such information and lobby politically for change.

Recommendation 3. Sub-cutaneous stability:

Evidence suggests that a (up-to) five percent improvement across the board in recovery is associated with particular procedures immediately post-TBI. These relate to the immediate stabilisation of the brain and body post injury.

Research should be conducted and an experimental test conducted under Australian conditions to determine if this procedure should be introduced in Australia to reduce the severity of TBI.

The Age - Comment

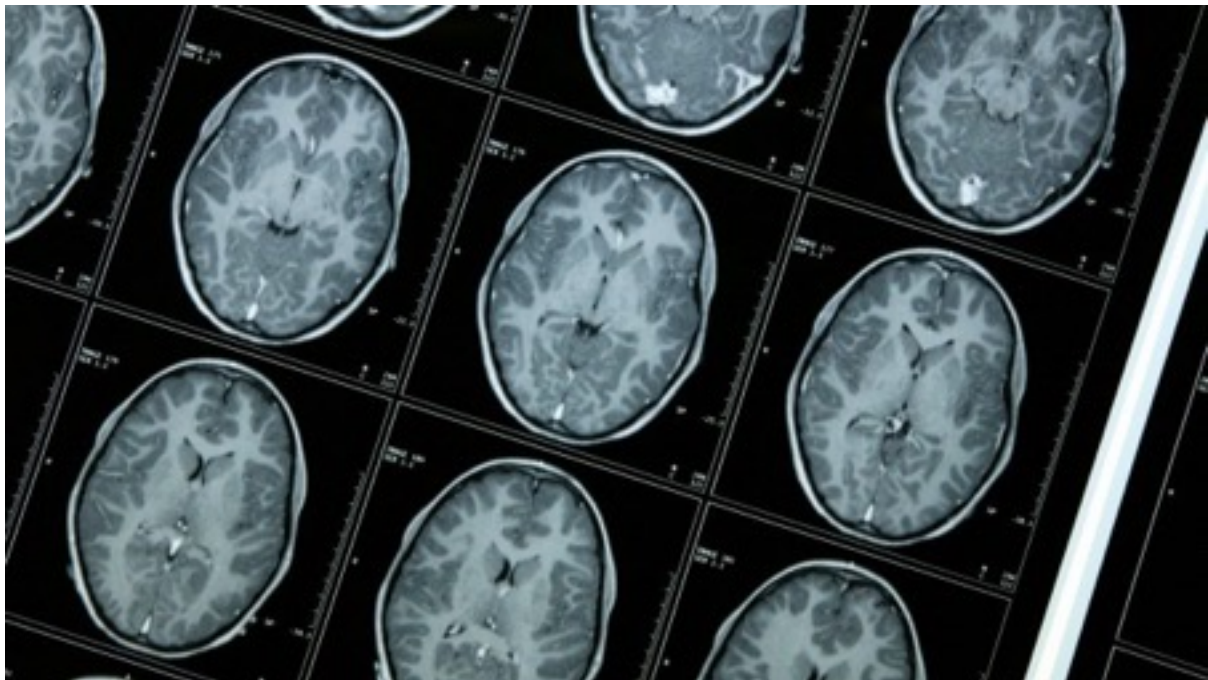
Intubation offers new hope in treatment of brain trauma

March 14, 2016



Nicholas Stuart

Australia and Germany both pride themselves on their medical care but head injuries are approached differently in each country. What can be learnt from this?



Could routine intubation improve the recovery rates in brain trauma cases? *Photo: Michele Mossop*

It's incredibly difficult for a journalist to make "intubation" sound even marginally interesting, let alone to pretend it's fascinating enough to weave an entire column around. It's even more problematic once you know what it actually involves: inserting a tube into a part of the body (for example the trachea, or windpipe) to remove pressure or open an airway. This is the sort of thing we can normally leave, quite confidently, to doctors. That's fine. They're professionals. They do the best job of dealing with traumatic head injuries, whether as a result of a falling horse or a car crash.

Accept, however, that between 5 and 10 per cent more patients might survive similar injuries in countries that automatically intubate head injury casualties, and you might want to ask if the specialists have thought of etching this particular procedure on to their agenda. The medicos aren't ignoring best practice; it's something far simpler. We're trained to think inside the box. Sometimes, however, if we want a real breakthrough, it's worth reinterrogating our fundamental assumptions (even about things we think we "know" for sure).

So, let's start at the beginning. Quite sensibly, doctors don't normally act unless there's a need: any intervention risks something going tragically wrong. That is why, in Britain for example, intubation is normally restricted to the most dangerous cases, where a failure to act will almost certainly result in death. But, as you'd suspect, because the procedure is reserved for the most serious patients, survival statistics aren't particularly brilliant. As a result, intubation has become a technique of last resort, restricted to the most dire cases.

Surprisingly, though, this isn't the case in Germany. Somehow or another, that country eventually came to adopt a very different standard operating procedure. A doctor is sent as a first responder (by helicopter) to where the patient had their injury. Secondly, every casualty is intubated as a matter of course. And so, bit by bit, utterly dissimilar techniques have come to be adopted as standard to deal with head injuries.

It could almost have been a planned controlled trial, except, of course, it wasn't. In fact, nobody even noticed the difference – until recently.

That was because a major technical company began focusing on and collecting information about this first stage of treatment. It was interested in introducing a new treatment and was hopeful a successful trial would provide firm back-up demonstrating the efficacy of its technique. In fact, however, the reverse occurred and the study was brought to an abrupt conclusion.

The only problem was there are important findings involved in the results. One of the researchers involved is convinced intubation does have a significant effect in keeping patients alive and that the early research was already proving there were dramatically different results between the jurisdictions, based simply on the background data.

Think about how important this is. If the assumption is correct, it means that releasing pressure on the brain at an early stage of the injury could have a massively

significant effect on recovery rates. The findings were suggesting that adopting this method could result in a dramatic, 5 per cent, across-the-board improvement in the rate of recovery.

The difficulty is, of course, the findings haven't been made public, for obvious reasons. They represent an intellectual property investment by a medical company that has no desire to divulge what it's attempting to achieve. The results are also circumstantial, rather than conclusive. And this is the problem with knowledge. It's sticky.

Although there's a plethora of information around, something special needs to happen to translate understanding into knowledge. Recognising that an event is occurring isn't the same thing as acting on that information.

Creating change is about actively changing society – something that is far more difficult than just carrying on down the same path. These connections don't necessarily occur simply because someone has kept pushing steadily down a familiar route; it's often what appears to be a side detour that offers a new breakthrough, because an old problem has been suddenly seen in a different way.

As alert readers will be aware, I'm fortunate enough to be travelling through Europe at the moment. That's how I found out about the intubation study. Obviously, it hasn't yet been published and so the only way I found out about it was when someone in the know offered to discuss what they believe are the critical findings.

Physical contact encourages trust that cannot be brokered electronically; speaking allows the sort of unfocused chat that can lead from one revelation to another. The internet is a blunt, unfocused way of curating knowledge. The reality is that we will continue to require human contact to really progress our understanding.

I've been lucky enough to receive a Churchill Fellowship, which has given me the opportunity to investigate the different ways we treat brain injury. Hopefully, I might be able to bring some of this knowledge back to Canberra. What's really terrific is that this scholarship isn't about (directly) extending your own skills: the idea is very firmly focused on the community. It's about creating change and making a difference in your local area.

I'm still finding out more detail of the intubation study and if it might offer any insights to us. However, the initial indications are positive. People who know far more than I ever will say the hypothesis seems to stack up: the critical questions and issues lie elsewhere (resources, training and cost). It will take a long time to work through, but imagine if a life could be saved

Read more: <http://www.theage.com.au/comment/intubation-offers-new-hope-in-treatment-of-brain-trauma-20160313-gni3yu#ixzz45t144thh>

Inverness

Every recovery setting is local and individual

It's easy to fall into the trap of journalistic oversimplification when it comes to Scotland. That's because the oil money that once fuelled the North-East is vanishing along with jobs and this makes for a simple storyline. The once-thriving port city of Aberdeen still bustles with foreign accents, but people are being laid off and the half-completed buildings lie abandoned. Further to the North, Inverness was only a peripheral beneficiary of that boom but there were, nonetheless, some remittances and the prospect of better conditions 'trickling down'. Today that's changed and there's virtually no growth evident in the town's centre. Scotland's attempting to find a way forward but the traditional western model, growth and jobs, no longer resonates.

This was where I met Brian Clingan, Director of Services for *Headway UK*. His experience is a microcosm of many who work with brain injury, having both worked in this sector and been involved as a supporter of a close family member who received a TBI. This meeting provided a key insight that was subsequently reinforced in all my meetings and travel throughout the UK: although the clinical experience of head injury is universal, procedures for recovery and reintegration into the community need to be adapted to local conditions. What works in one area may not work elsewhere, and so much of the post-medical phase of recovery depends on the enthusiasm of individuals.

Clingan explained that this realisation had been critical to the success of *Headway* and its organisational structure. *Headway* is the closest relation to two of the organisations I have worked with in Australia - the *NBIF* and *BIA* - however it has a structure that appears far more robust in accomodating itself to the different levels of community involvement in different locations. The key to success in developing a network is to both recognise the positive contribution that local organisations can make, while still utilising a national body to provide a framework off which such community groups can hang. My time with *Headway* dramatically reinforced the huge advantages a professional, funded, and national group can bestow on a regional network of volunteers.

Critically, *Headway* does not prescribe the type of group that's appropriate for particular areas. It provides ready-made structures appropriate for the situation and number of people desiring to be involved, including everything from small groups of individuals to larger organisations that form part of the *Headway* network. This combines the advantages of size with flexibility. It also offers legal protection for the umbrella organisation, by restricting its liability for the actions and decisions of smaller units. This means individuals in the groups are able to feel

empowered and able to influence their own activities, while still reaping the benefits of the larger network.

The advantages of this model cannot be over-rated for Australia. Each state has at least one, often several, community organisations devoted to brain injury, in addition to the umbrella grouping of *BIA*. Between 2010 and 2014 there was a serious attempt to find synergies between the various organisations; this, however, was not achieved and the different groups ended up going their own way. The adoption of a more flexible model (such as that of *Headway*) might prove to be a more appropriate format to resume such a co-operative process in future, with *BIA* taking over a role of establishing smaller, local groups in the wider community and working in with other established service providers.

There can be no doubt about the need and advantages of having such groups operating in the wider community. Although hospital outreach and government health services do exist to meet this need, this is necessarily limited. For individuals and families with TBI the requirement for support inevitably changes over time and, no matter how enthusiastic a young health-worker may be, they often lack experience, time or contacts to assist with particular issues. Forming flexible networks of people who have met similar challenges promotes resilience.

Headway demonstrates what is being achieved in the UK, operating in both major urban centres and disaggregated rural settings (such as around Inverness). The opportunity exists to deploy a similar structure here in Australia. Using the *Headway* model offers a method of introducing new supports for those with TBI and without challenging the services of already existing Brain Injury service providers.

Recommendation 4. Brain Injury Community/Supporters Network:

People with a TBI and their families have a continuing need for support once they leave the structured medical system. There is an urgent need to develop structures and facilitate networks to allow this to occur in the community.

Departure from the hospital system is simply the beginning of the journey of life after a TBI, not just for the individual who has suffered but also their family. There is a need for easily accessible, relevant and continuing support for these individuals.

London

Identifying the problem is half the battle

Although the most significant finding from my time with *Headway UK* was undoubtedly the need for a similar network in Australia, this was far from being the only issue relevant to our own situation back home. Two simple examples provide clear examples of ideas that could be deployed here as well.

The organisation's London HQ co-ordinates the activities of local groups. In order to be able to enhance its own influence it needs to offer something in return. Naturally it provides broader coordination advantages and offers a public face advocating for people with TBI. Additionally, however, it also offers a number of other services which could be easily and successfully replicated elsewhere.

One of these, boosting recognition of both *Headway* and brain injury, is the Brain Injury Identity Card. People with a TBI may have slurred speech and may additionally demonstrate reduced understanding of their surroundings, particularly in cases of stress and tension. There is a need for rapid identification to avoid increased difficulties when dealing with authority figures, including (especially) police. This is a very simple form of identification. Although issued by a GP, there is no test or hurdle to be jumped in order to become a bearer of the card. Nor does the information on the card provide any indication of possible consequences; its only function is, effectively, to provide a 'trigger warning', suggesting that the person they have difficulties with particular tasks. Nevertheless, and particularly in highly charged situations, this sort of identification can provide great assistance in defusing tensions. It's easy to think of recent cases in Australia (and, perhaps more so, America) where individuals with brain injury have been dealt with harshly by police who have been unaware of why this person has been failing to act as directed. Providing the identity card offers a simple step towards avoiding such possibilities. There is every indication that people with brain injury are (normally) particularly happy to identify as such.

Recommendation 4. National Brain Injury Identity Card:

A simple laminated, nationally recognised card should be distributed carrying a photograph of the bearer, and identifying them as a person with a head injury.

The introduction of a simple, photographic Brain Injury Identity Card is recommended to assist quick identification of people with an ABI in circumstances where this may be necessary.

A single point of contact is vital

A far more substantial recommendation from the point of view of recovery after a head injury is the introduction of HATS nurses in hospitals. These people, normally experienced nurses with considerable understanding of the (often catastrophic) effect of head injury on both the individual and their family, are currently being introduced in the UK as a direct result of advocacy from *Headway*.

The theoretical insight behind this intervention is similar to the breakthrough in Germany (*Recommendation 3*) that attempts to immediately involve a senior doctor to supervise treatment, however this revolves around support and assistance for family members. One of the major issues with TBI is that it will have long-term, ongoing and often dramatic effects on the social situation of other family members, as well as the individual who has suffered from the injury. The current situation in Australia is predicated on the primary responsibility of institutions (hospitals and rehabilitation facilities) to properly care for people in their charge. This, however, inevitably results in a less effective ‘package’ for those affected by TBI. Instead of having a dedicated and experienced person who is well-informed about this specific issue and its likely sequelae, family members are necessarily forced to liaise with a myriad of staff who may, or may not possess a detailed and full range of information to properly brief them. Even if such people are aware of the outcomes in, say, a hospital setting they often don’t have a full range of information (let alone experience of) about rehabilitation and later life-long issues and supports (or the lack of them).

There is a need in Australia to recognise TBI as a separate speciality in regard to providing such information. Hospitals can only care for the immediate medical treatment of the injury; this is necessary but far from sufficient.

Recommendation 5. Single Point of Contact/HATS Nurse:

The information that a person has suffered a head injury is often meaningless to family members and others concerned, including the patient themselves. In order to assist them to rapidly grapple with the ramifications of the injury there is an urgent need to ensure a dedicated, medically trained person is available to immediately communicate the sequelae of possible outcomes with those concerned.

Particular specialist medical staff should be identified and trained to provide assistance to family members and carers, from the point of recognition that a TBI has occurred right through that individual’s medical journey for the years to follow.

Washington

Identifying a national picture of the problem

As the son of an American mother and British father, Winston Churchill made the amusing comment that the US and UK are “two countries divided by a common language”. This remark came particularly to mind while engaging with the peak body for head injuries in Washington right after meeting with *Headway* in London.

There’s a national tendency to assume that the countries of the ‘anglo-sphere’ deal with issues in a similar way. While this may be true with regard to some issues it is most emphatically not the case with regard to healthcare. Both *Brain Injury America* and *Brain Injury Australia* share the initials BIA, however from this point on their activities differ widely. These jurisdictional issues massively complicate any attempts to translate particular treatments for TBI within Australia from one state to another, let alone internationally.

Organisations such as *BIAmerica* operate in a very different fiscal setting to Australia. Philanthropy provides a far more significant basis for the ongoing operations of the organisation and, additionally, it is not operating in a setting where the government is providing the mainstay of health funding in a coherent way. This doesn’t mean, however, that its work is irrelevant to the Australian situation. What *BIAmerica* has done exceptionally well is mobilise a support-base that can ensure brain injury is kept on the agenda for federal funding, while concurrently co-ordinating and providing information to the plethora of regionally based support groups of people dealing with TBI.

In particular, *BIAmerica* has used information as a tool to (a) achieve political change and (b) unite a constituency to support its lobbying efforts. Although resources are stretched, by concentrating on its presentation as a highly professional organisation, with a detailed awareness of the issues affecting this subject, *BIAmerica* has been able to amplify its voice and have a real political effect.

A key to this has been research. By emphasising its role as subject matter experts and coordinating relevant information and then disseminating this knowledge widely, the organisation has become a political player. This has been critical in achieving outcomes and spreading awareness of TBI. Armed with this information *BIAmerica* has then been equipped to highlight specific issues facing people with brain injury, and this has obviously been a key to successful lobbying efforts.

From my own observations it is the President/CEO of *BIAmerica*, Susan Connors, who's particularly responsible for driving this organisation's agenda. This mirrors the situation of not-for-profits in Australia which, because they are small, have a great dependence on the individuals in leadership positions. The world of not-for-profits is Darwinian. Most are forced to rely on their own capacity for fundraising, and balance this need against their primary objective.

Communications are very much self-directed. Organisations quite naturally want to share information with their members and grow, however a serious difficulty in the not-for-profit sector is that a dollar taken by one institution means it is not available for another. This lends a hard edge to any other forms of cooperation. Equally, for members of the public, parliamentarians, and even others working in the sector, it becomes often hard to judge how much value the organisation is actually adding.

It should be stressed here that *BIAmerica* is definitely *not* one of the sub-standard organisations and I was highly impressed with all the staff I saw at work and with their dedication to duty and the aims of *BIAmerica*. I know, however, that I would not necessarily have the same feelings about all the not-for-profits in Australia. With the demise of the Australian Democrats it's now the role of the media to 'keep the b—'s honest'. It struck me that as there are few journalists systematically examining these bodies the press is failing in its duty to shine a spotlight on the sector. This is a critical role that must be addressed.

In conjunction with this there is a need for more detailed information about the sector. This is a massive task that *BIAmerica* is addressing in many ways. As a first step there is a need for a National Statistical Database that collates granular information about TBI in Australia. Once established this would provide not only an invaluable resource to anyone wanting to study the dimensions of the problem, but also a political tool for achieving change.

Recommendation 7. National Statistical Database:

Despite brain injury's prevalence, there is minimal statistical data available regarding TBI. This is because new techniques for identification of the condition have only recently been available. We now know, however, that ABI is widespread. Nevertheless, despite this prevalence, there is no readily accessible national database associating causes of ABI with treatment.

There is a need to establish a national database to identify the prevalence and causes of TBI and for actionable information that can be used to identify activities likely to increase or minimise its prevalence.

Creating a national voice

What is interesting is the way BIA uses the media (and at this point it should be noted that what follows are my own conclusions, post my visit, rather than ideas that were tested with BIA at the time). The organisation has been particularly successful garnering national media attention by becoming a go-to organisation representing the concerns of people with a brain injury. In this way it has used the media to magnify its voice. A second strand in the organisation's media strategy has been the development of its own, high quality publications that provide information on brain injury as well as creating a support base by linking people who are interested in the activities of BIA.

This has been particularly successful, and gave rise to the following recommendation that I believe is particularly relevant in the Australian situation.

Recommendation 8. Lobbying to Raise Awareness of TBI:

There are enormous costs associated with TBI. Until now these have remained invisible and been passed on to the community (as increased healthcare costs) and families (responsible for the burden of care). In a society where we place a monetary value on almost everything, it is not enough to simply 'raise awareness' of the dangers of specific activities. The community must be made aware of the specific social and financial costs of TBI so that it understands the burden of this condition.

Once causes of TBI have been identified there is a need to ensure steps are taken to minimise the dangers associated with it. New York

I have now realised, that there is a corollary to this. BIA has effectively utilised the old media model. This depends on other organisations (the mass media) to publicise the lobbying efforts more widely and uses its own publications simply to publicise its efforts in order to unify individuals and organisations that are in sympathy with the overall objectives of BIA. This is terrific, however (after my trip to the west coast and research into the use of the internet) I now believe that much more can, and indeed must, be done in this regard to remain relevant in a modern, connected world.

Los Angeles

Connecting the World

Los Angeles was a drop-off point on my way to San Francisco. I only stayed there briefly, in a motel in a suburb (theoretically) within walking distance of the airport – except that nothing is within walking distance of anywhere else in that city. When I arrived, by taxi, at my motel late in the evening, I asked if there was anywhere nearby I could go and grab a bite to eat. The receptionist looked at me with something approaching horror.

“You don't want to go out walking here,” he insisted. It was then I realised where I'd heard the suburb's name before; in a Quentin Tarantino movie about mobsters. Ironically though, this was to add an extra dimension to my stay in the city.

I'd always intended to speak to academics at the UCLA who are developing methods of teaching journalism to the wired, internet generation. Isolation is a major problem for people with TBI. It's not simply the case that they find it difficult to access traditional News; the problem is often that conventional hierarchies of News organisation are irrelevant to them. This results in the sort of atomisation of society I experienced when checking into the motel. Without effective communications it's inevitable that people with TBI will become isolated and thrown back on themselves.

My discussions at UCLA proved interesting, nevertheless the important realisation that came from them is that people with TBI remain peripheral to the concerns of the news media. The only way to change this is to develop an organisation that is specifically dedicated to both informing and lobbying for people with brain injury or other disabilities.

At the same time, however, it's important to note that's the internet is enabling this very possibility. The media is about the creation of a community of interest. In the past we have tended to view this geographically, and that's why newspapers have flourished. They have defined the boundaries and delineated areas of concern for our society. Now the internet is offering a new and more intimate way of achieving this.

Communities are no longer linked by the mass media alone. Individuals can connect with others through the internet, forming new societies brought together by shared interests and concerns. This offers both a challenge and opportunity for people with a disability. If such a media community is to exist, however, we will need to create it for ourselves.

San Francisco

“More research is needed . . .”

A long time ago, way way back in 1990, Catherine and I both worked on an environmental television program (“*Survival*”) that was produced by ABC TV’s Science Unit. As journalists we’d been trained that each story should, as far as possible, move towards a conclusion; that’s the way news works. The Science unit was very different. Populated by scientists, it sometimes appeared to us that their predilection was, in fact, for the reverse. Instead of coming to a conclusion stories always seemed to end with the assumption (and, at times, even the words) “more research is needed . . .”.

This is nowhere more the case than with TBI. Our knowledge of the way the brain works remains in its infancy.

The best way to understand how the mind works sometimes appears to be by examining what happens when the properly functioning system is disrupted. The insights we gain here, at the edge of the frontier of knowledge, are the ones that reveal deeper insights than exposed by simply concentrating on the “normal”⁶.

This goes some way to explaining the importance of studying Traumatic Brain Injury (TBI)⁷ and the work that is being at the San Diego Medical Centre. There is, nevertheless, a much broader dimension to this issue than can be addressed by simple clinical medical models of the working brain. Experiments simply open the door to further questions, because the real challenges of brain injury are not posed by physiology. They are, rather, ethical and moral: they are, in fact, to do with the very essence of humanity itself.

The answer to the great riddle, ‘who am I?’, is hidden deep inside the bundled collection of neurones and synapses that we know as our brain. Any attempt to comprehend what it is to be human requires some understanding of how the mind works and yet, despite the brain’s central, fundamental and critical role in forming our personality, we still know virtually nothing about how the healthy brain works.

⁶ See, for example, Norman Doige, *The Brain that Heals Itself*, pp

⁷ Technical terms and abbreviations are defined in an Appendix at the end of this report.

Focussing on the injured brain offers remarkable opportunities for us to learn more about the mechanics of how the mind works, but doing this necessarily treats people as laboratory fodder. Recent medical discoveries are also posing further deep ethical and philosophical dilemmas for quandaries about what it is to be human. There are no simple answers to such questions. Increasingly, however, it will not be possible to defer them for much longer.

I interviewed Linda Isaac in my capacity as a Churchill Fellow. Because I am also a journalist, however, we were both very aware that the research she was conducting could easily be skewed to create sensationalist news reports. It is, to some extent, a matter of “pick your headline”. The stimulation that was being administered can be framed in very different ways: either as torture (“Researchers use electricity to shock patients”), or by overly focussing on the positive (“Previously comatose patients open their eyes - a huge leap on the path to recovery”). Neither headline really encapsulates what is occurring, nevertheless (at least as far as some journalists might be concerned) both interpretations have the advantage of containing more than a grain of truth.

* * *

The significance of this fact is that it allows us to begin unpacking some of the more complex issues relating to the treatment of TBI. Because most institutions have been aware of the potential for such stories to suddenly whip into firestorms, most of the organisations dealing with research into TBI prefer to minimise contact with the media. This is not the case for lobbyists and pressure groups, which often have an almost messianic belief that terrible things are being done in the name of science. The debate has become polarised and, instead of working together in an attempt to discover more about the brain’s functioning, some people become almost completely absorbed into a world-view that is at odds with that of broader society.

If whatever’s happening is framed in the right way, however, a new consensus can be created that that is of much greater advantage. The question then becomes; ‘how is this to be done?’

* * *

There is increasing evidence that our very capacity for thought itself is completely linked to our physiological behaviour (even down to that very instant when your mind wanders off somewhere else, any you loose your train of thought⁸). The important work that's being carried out in the San Diego Medical Centre is revealing more about the workings of the mind. This depends, however, on electrically stimulating a specific part of the brain.

The issue is that those being studied are unable to grant permission for these experiments. Instead, the Centre has ensured appropriate clearances have been obtained from the next-of-kin. I am absolutely convinced that not only has it taken every step possible to be *seen* to be behaving ethically, but also that it *is* behaving in a completely responsible manner. As a society we have moved, however, beyond the former religious and ethical certainties which once determined the norms of behaviour when it comes to these issues.

The following discussion is, but its very nature, highly controversial and it should be emphasised that my aim and objective is simply to consider how some of these issues may best be addressed.

Before I left for the Churchill, I was contacted in Canberra by couple whose son had been badly injured on Hindmarsh Drive. The implicit question they were asking was, 'what sort of life would their child have if he remained alive but forever in a coma? At what time is it appropriate to turn off a life support system?' There can be no simple answer to this question. Indeed, on very the day I wrote this part of this paper a comment piece appeared in the Fairfax press written by Roman Catholic Bishop Peter Comensoli. This suggested that while palliative care might be acceptable, he believed that euthanasia never could be (<http://www.canberratimes.com.au/comment/growing-euthanasia-statistics-should-be-a-warning-20160419-go9rr8.html>). This involves, I believe, a convenient elision of the central issue: what makes us human?

The prospect of prolonging life, seemingly indefinitely, is wonderful, but it offers numerous challenges. We have, today, a much greater understanding of the workings of the brain and the nature of consciousness. We can watch the flickering radiography that demonstrates the workings of the mind. It's also possible to see the converse of this; the blankness of nothingness.

There is no simple answer to that seemingly basic question, 'what makes us human?' If it is consciousness alone, then it seems that a bee is more qualified than the inanimate bodies lying

⁸ See, for example, this work from UC San Diego, where : <http://www.nbcnews.com/health/mental-health/study-finds-where-you-lost-your-train-thought-n557776>

with their eyes permanently closed in San Diego.⁹ In the past the answer to these sorts of issues could be found in dogma, but that's not the case today. Skepticism about religion has led to the emergence of wildly differing views and arguments are proposed often with little regard to the facts.

The increasing nature of conflict over such issues needs an appropriate forum in which people are free to put forward their own ideas and solutions.

In this regard it is worth quoting in full a couple of paragraphs from “***Do No Harm - stories of life, death and brain surgery***”, by Henry Marsh. These reflect the ethical dilemmas that confront a medical professional on a daily basis:

“‘Informed consent’ sounds so easy in principle — the surgeon explains the balance of risks and benefits, and the calm and rational patient decides what he or she wants — just like going to the supermarket and choosing from the vast array of toothbrushes on offer. The reality is very different. Patients are both terrified and ignorant. How are they to know whether the surgeon is competent or not? They will try to overcome their fear by investing the surgeon with superhuman abilities. I dislike terrorizing patients when I know that they have to have an operation. What was certain was that the risk of the operation was many times smaller than the risk of not operating. All that really matters is that I am as sure as I can be that the decision to operate is correct and that no other surgeon can do the operation any better than I can.”

Recommendation 9. Emerging Ethical Issues:

As a result of recent advances in medical understanding, the ethical issues have become increasingly problematic. This is not simply in relation to experimenting on humans who might be otherwise unable to grant consent; it also bears on treatment regimes and even how long people should be kept alive if there is no or little hope of recovery. At the moment there are few ‘impartial’ guides to offer advice for families and carers, a situation that results in advice being requested from medical professionals who may not always be prepared to volunteer such advice.

The increasing nature of conflict over ethical requires a forum in which people are free to put forward their own ideas and solutions, in an appropriate and polite manner, in the hope of reaching a broad society-wide consensus.

⁹ See, for example, a New York Times report on an Australian research into the possibility that bees possess awareness; http://www.nytimes.com/2016/04/19/science/honeybees-insects-consciousness-brains.html?module=WatchingPortal®ion=c-column-middle-span-region&pgType=Homepage&action=click&mediaId=thumb_square&state=standard&contentPlacement=9&version=internal&contentCollection=www.nytimes.com&contentId=http%3A%2F%2Fwww.nytimes.com%2F2016%2F04%2F19%2Fscience%2Fhoneybees-insects-consciousness-brains.html&eventName=Watching-article-click

Canberra

Connections

Acquired Brain Injury is not, for most people, a slowly-developing condition allowing them, partners and carers plenty of time to understand its nature. The trauma of the injury can be compounded by the sudden need to make critical, quite literally ‘life or death’ decisions relating to the continuance or withdrawal of life-support for those suffering an ABI. Individuals are also required to rapidly adjust to the contours of new life trajectories, not simply for their loved ones, but also their own plans and expectations are likely to be thrown into turmoil.

End of life issues are necessarily traumatic. What this report has attempted to make clear is that nobody is ever the same after a brain injury. Their neurones and synapses are obviously (and sometimes irretrievably) altered and rearranged. But the ongoing effect of a brain injury is much more than just this. Individuals require ongoing support.

In his bestselling book *Being Mortal*, Atal Gwande beautifully illustrates the challenges for both doctors and patients. With well-grounded and persuasive logic, Gwande speaks of the need to ‘de-medicalize’ death and dying, especially where decisions about the viability of continuing medical support have to be made. This makes instinctive and logical sense: the question is how is this to be done?

Physicians are recognizing that their prime objective – extending life – must be balanced against the expressed priorities of their patients, which often include the quality and not just the length of remaining life. Instead of being confined to the medical sphere, healthcare becomes a joint negotiation between the medical practitioners and the individual concerned (and their carers).

In order to fully participate in this process people without medical training need to be assisted to envisage the future, because otherwise they will be unable to make informed decisions. The difficulty is that, at times, even the medical staff maybe uncertain and unable to properly advise on future options. Basically, the information just isn't available.

Additionally, TBI represents one of the most difficult conditions to treat. The corollary of this is that information, both on possible methods of treatment and the degree to which a person may eventually ‘recover’, or at least resumption a more normal life, is equally murky. Both the

individual concerned and their carers are effectively flying blind. They need, not necessarily an air traffic control, so much as waypoints to guide them.

TBI is no longer an exceptional experience. Informing the person with the injury, their family members and carers is a vital part of this public health challenge. It is vital that the ‘trauma’ associated with TBI does not extend beyond the occasion of the injury itself. The way to achieve this is with information. We need to provide this just as thoroughly as a surgeon would conduct a pre-operative checklist. Routine governs medical procedures and similarly, information needs to be conveyed to those who need it in a timely manner.

The full potential of the internet has not been realised by the so-called ‘legacy media’, because it does something very different. Mass media is involved in the creation of audiences, tying people together by convincing them of what they have in common. The internet, on the other hand, is about people seeking information out. The key is to nurture such communities of interest by providing the information they require.

Carers of people with a TBI have a massive requirement for information but unfortunately this is not being currently provided from a single source. This needs to happen. Although networked groupings of individuals specialising in ABI already exist (of which the Australasian Society for the Study of Brain Impairment¹⁰ is perhaps the best example), there is no regular forum that enabling the many different groups to come together. It is my intention to start this as a direct result of this Churchill Fellowship.

Recommendation 10. E-zine: ‘Ability Connections!’

The critical finding of this study is the need to reinforce communications between the different groups of people involved with TBI – researchers and scientists; neurologists; medical practitioners and surgeons; rehabilitation providers; family and carers of those with a TBI; and the individuals themselves.

There is a need for an internet based community hub to facilitate information sharing and other useful forms of communication between different groups concerned with TBI, Acquired Brain Injury (ABI), and rehabilitation more generally.

¹⁰ See, for example; <http://www.assbi.com.au>

The Age - Comment

To make sense of the world, we need to push boundaries and make connections

April 11, 2016



Nicholas Stuart

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In our society, beliefs pose as facts, shouting replaces logic, and public opinion becomes the arbiter of correctness.

A thick mist blocked the view down through the valley and across the water to San Francisco, but Professor Richard Norgaard just seemed to shrug slightly. He knew the view was there and he's spent a lot of time – it must seem like most of his life, really – aware of things that others can't quite seem to grasp. It's the way we go about making sense of things.

He picks up an old, used, blue paperback. It's one of his own books that he's picked up from a second-hand shop. "Let's give it another life," he says, grinning, placing it into my hands. He flicks through, looking at where its one-time owner has underlined sentences, and laughs gently. "I don't think he got much beyond the star here at page 83," he says, before quickly correcting himself. "Oh, no, he started underlining again at page 137. That's OK."

It's a second edition, printed just one year after the first had sold out in 1994. Norgaard, one of the first environmental economists, is confident about his reputation and can afford to be dismissive. For years he was denied tenure. He'd made the mistake of challenging economic orthodoxy and, in the tight world of academe, his broader views stretching across intellectual disciplines to apply insights from one area in another field often weren't welcome.

Today, however, Norgaard appears relaxed – until he begins speaking about his new project, which investigates the way economics has become the new religion, providing the frame of reference we use to make sense of the world.

Knowledge – in the sense of a true understanding of the way the world works – is a difficult thing to grab hold of. Today, thanks to the internet and explosion of "knowledge factories" such as universities and think-tanks, you'd think we'd have a full and serious comprehension (far better than ever before) of all the factors that drive society. Instead, we have furious disagreement, even over simple scientific facts such as climate change. Beliefs pose as facts before being injected into public debate, shouting replaces logic, and public opinion becomes the arbiter of correctness.

The problem isn't that we lack facts: it's all to do with the way we construct knowledge. We can, for example, narrowly focus on a particular subject and gain a great deal of understanding about it. Norgaard's book describes how those who have studied an issue closely inevitably become respected specialists in that field (after all, they "know about it").

Journalists make sense of them is construct a broader model that allows us to incorporate different elements. That's exactly what many subject specialists are not prepared to do. They have invested a great deal of time and effort in establishing their mastery of a particular subject or, as is often the case with think-tanks, have their own particular interpretations and models to push. There's never been a great deal of financial advantage to be gained by rowing against the intellectual tide, because you never know how long you'll have to wait until you can be proved right.

University learning particularly encourages intensity and detailed focus as research students are steered away from generalisations. Instead, they're urged to make their

reputation in one area by establishing their territory with research papers and books in much the same way that animals mark out their territory in a more elemental way. Breadth is replaced by depth.

The point that Norgaard is making is that society needs more. Knowledge is like a patchwork quilt rather than a clean white sheet. He's still pushing the boundaries, making connections, and peering into the future to see what's there. This isn't, unfortunately, the way our society normally works. We're encouraged, instead, to concentrate on the particular and examine the detail rather than make the necessary leap that reveals new insights. The trouble is that no matter how many individual nuggets of knowledge are uncovered, they'll be useless by themselves.

What we need to do to m are lucky because others are always ready to correct us when we're wrong (which, perhaps surprisingly, appears to be much of the time). I've been doubly fortunate. Attentive readers will have noticed that recent columns have been submitted from far more exotic locations than Fyshwick. A Churchill Fellowship has provided a wonderful opportunity to make exactly the same sorts of lateral connections Norgaard's work is based on – although at a far less intellectual level.

This is one of the secrets of the Churchills (which are currently open for new applicants). They're not rewards for time served and neither are they intended for particular categories of people, like academics. They are about making a difference to the community. It's a recognition of the problem being referred to above, where knowledge is contained in silos and not shared more broadly, allowing new insights to be shared.

What I've discovered is that even where you'd expect similar best-practice procedures to be implemented around the world (such as in the medical treatment of head injury) the reality is very different. Different countries have different ways of dealing with patients and, perhaps unsurprisingly, some other places seem to do it better than we do.

This is the second challenge of the Churchill; making a difference. I've enjoyed this journey very much, but I'll only have achieved the objective of the fellowship if the things I've learnt can be shared and implemented. This is a task that won't stop when I return.

But my experiences have exposed me to other issues arousing new, and still unresolved, quandaries. How, for example, is it possible that the US can send people into space and yet be so desperately short of baristas who can make a decent cup of coffee? Why is everyone so polite? Perhaps I need another Churchill to allow me to investigate.

Read more: <http://www.theage.com.au/comment/to-make-sense-of-the-world-we-need-to-push-boundaries-and-make-connections-20160411-go3ciy.html#ixzz45sIYWBqA>

Definitions

ABI & TBI

Perhaps reflecting the extent to which knowledge is still developing in this area there are, surprisingly, no widely accepted, definitive definitions of either Acquired Brain Injury (ABI) or Traumatic Brain Injury (TBI). The situation is, in fact, rather the reverse, with different groups alighting on particular meanings in the hope of gaining relevance by either (a) claiming huge numbers of people are affected by ABI (and hence it is an issue that needs to be addressed), or, alternately, (b) choosing to limit the definition to a particular exclusionary subsets of head injury (again, for representational reasons). Thus any definition of ABI/TBI is, essentially, politically loaded.

The Brain Injury Network of America (BINA), an organisation dedicated to representing people with an ABI, has adopted the following, inclusive, definition:

*“The position of the Brain Injury Network is that **acquired brain injury** (ABI) includes traumatic brain injuries (TBI's), strokes, brain illness, and any other kind of brain injury acquired after birth. However, ABI does not include what are classified as degenerative brain conditions such as Alzheimer's Disease or Parkinson's Disease.”*

Although dated, this organisations website still possesses the best summary of the large number of working definitions of ABI/TBI at:

<http://www.braininjurynetwork.org/thesurvivorsviewpoint/definitionofabiandtbi.html>

This organisation's position is that TBI's are a subset of ABI's and as such it endorses a definition originally formulated by the US Department of Defence:

“A traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force that is indicated by new onset or worsening of at least one of the following clinical signs, immediately following the event:

Any period of loss of or a decreased level of consciousness;

Any loss of memory for events immediately before or after the injury;

Any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking);

Neurological deficits (weakness, loss of balance, change in vision, praxis, paresis/plegia, sensory loss, aphasia, etc) that may or may not be transient;

Intracranial lesion.

External forces may include any of the following events: the head being struck by an object, the head striking an object, the brain undergoing an acceleration/deceleration movement without direct external trauma to the head, a

foreign body penetrating the brain, forces generated by events such as a blast or explosion, or other force yet to be defined.”

BINA further notes that:

“Unfortunately, in a some places TBI is being redefined by governmental entities to include conditions such as strokes, and this is wrong. (One state that has done this is the state of Ohio.) If people could remember that the word traumatic in the definition of TBI refers to the cause of the injury, not the result, this might help clear the air.”

As a Board Member of Brain Injury Australia I was present at the 2013 annual meeting where the organisation resolved to retain the following, simple and similarly inclusive definition of ABI:

“Acquired brain injury - or "ABI" - refers to any damage to the brain that occurs after birth (with the exception of Foetal Alcohol Spectrum Disorder, FASD). That damage can be caused by an accident or trauma, by a stroke (where blood supply to the brain is stopped by a clot or bleeding), a brain infection, by alcohol or other drugs or by diseases of the brain like Parkinson's disease.”

The organisation has not, however, formally adopted a definition of TBI except in noting it as a subset of ABI's.

Academically, the most often cited definition for TBI is that of the American journal, ***Medscape***, viz:

“Traumatic brain injury (TBI) is a nondegenerative, noncongenital insult to the brain from an external mechanical force, possibly leading to permanent or temporary impairment of cognitive, physical, and psychosocial functions, with an associated diminished or altered state of consciousness.”

This paper accepts this above definition, interpreted within the broader context of the BINA commentary. Nevertheless (and because this paper has been sponsored by the ACT/NRMA Road Safety Trust) rather than embrace the extended definition of TBI I have chosen to limit my scope further, examining what happens specifically to victims of road accidents. This does not mean the findings lack wider applicability, simply that the research context has required a narrower focus. It seemed obvious to emphasise the plight of car-crash victims and their families.

I believe, however, that the principles upon which this paper is based can (with suitable modifications as required) be applied to all people with an ABI, particularly where the physiology of the injury is similar. Readily identifiable examples of this include, for example, sporting accidents, injury as a result of military operations, and domestic violence or assault.

Select Bibliography

The following is a (very) short list of useful, easily accessible, and relevant books and web-sites that I have referred to in the text, together with contacts for organisations consulted or visited. Most of these have specialist information packs that are designed for individuals who have suffered an ABI or their families and carers.

Particularly helpful books

Sharon Bagley	<i>The Plastic Mind</i>
Mark Costandi	<i>50 Human Brain Ideas</i>
Norman Doige	<i>The Brain that Changes Itself</i>
“ “	<i>The Brain's way of Healing</i>
Christine Durham	<i>Unlocking My Brain</i>
Encyclopaedia Britannica	<i>The Brain</i> (book)
Atal Gwande	<i>Being Mortal</i>
Daniel Kahneman	<i>Thinking, Fast and Slow</i>
Ray Kurzweil	<i>How to Create a Mind</i>
Tony Moore	<i>Cry of the Damaged Man</i>
John J Randolph	<i>Positive Neuropsychology: Evidence-Based Perspectives on Promoting Cognitive Health</i>
Sarah A Raskin	<i>Neuroplasticity and Rehabilitation</i>
Larry Sidentop	<i>Inventing the Individual</i>
Dick Swaab	<i>We are our Brains</i>

Journals

<i>Brain Injury</i>	Official Journal of International Brain Injury Association
<i>Brain Impairment</i>	Official Journal of Australian Society for the Study of Brain Impairment
<i>Medical Journal of Australia</i>	Leading Australian Peer-reviewed Medical Journal

Websites:

Organisations with which I have been or am personally connected as Board Member:

The National Brain Injury Association; now incorporated into Hartley Lifecare:

<http://www.hartley.org.au>

House With No Steps:

<http://www.hwns.com.au>

Brain Injury Australia:

<http://www.bia.net.au>

State-based and specialist ABI organisations in Australia (including former members of BIA):

Queensland:

<http://synapse.org.au>

New South Wales:

<http://www.biansw.org.au>; now,

<http://synapse.org.au/about-synapse/unification/new-south-wales.aspx>

Victoria:

<http://www.brainlink.org.au>

Tasmania:

<http://www.biat.org.au>

South Australia:

<http://www.binsa.org>

Western Australia:

<http://www.headwest.asn.au>

Other particularly relevant Australian organisations:

Australasia Society for the Study of Brain Impairment:

<http://www.assbi.com.au/what%20is%20assbi.html>

Brain Foundation:

<http://brainfoundation.org.au>

Brain Injury Centre:

<http://www.braininjurycentre.com.au>

Families 4 Families:

<http://families4families.org.au>

Journey Beyond Road Trauma:

<http://www.journeybeyondroadtrauma.org>

National Disability Insurance Scheme:

<http://www.ndis.gov.au>

Organisations visited:

Allegemeines Krankenhaus Celle:

<http://www.akh-celle.de>

Bangkok Nursing Home:

<http://www.bnhhospital.com>

Brain Injury America:

<http://www.biausa.org>

Columbia School of Journalism, New York, Science Environment and Health program:

<http://www.journalism.columbia.edu/page/199-master-of-arts-in-journalism/200>

Headway UK:

<https://www.headway.org.uk>

International Brain Injury Association:

<http://www.internationalbrain.org>

Santa Clara Valley Medical Centre, Jerry Wright, Director of Research:

<https://www.linkedin.com/in/jerrywright>

UC Berkeley, Graduate School of Journalism, Public Health and Journalism program:

<http://sph.berkeley.edu/concurrent-degrees/mjmph-graduate-school-journalism>

UCLA Annenberg, Specialised Health Journalism program:

<http://annenberg.usc.edu/journalism/specialized-journalism-MA>

Philosophical and Ethical Considerations

The disclaimer for this report is the standard one found on published academic papers: “the author reports no conflicts of interest in preparing this paper and no individual cases are cited in this report, which relies on instead on interviews with researchers and practitioners”. Nevertheless, because this report deals with issues that touch upon new boundaries of understanding, I believe it is important to state my own perspectives on these issues.

This question took on a particular relevance for me as a result of my final research in San Diego. Do these bodies possess a soul and if so, where was it and how was it possible to justify painfully stimulating the cadaver? At what point should a person be considered to have ‘died’? We use cadavers for research purposes so why should the still alive bodies of ‘brain dead’ people be used in the same way?

These questions opened others that had been nagging at me all the way from Germany. At what point is it not worthwhile saving a person who has significant TBI? If resources are scarce how should they be allocated and what conditions are more deserving than others? Should set sums of money be spent on assisting everyone or are some people, children for example, more deserving than others? Decisions on issues such as this are being made, in medical settings, all the time.

Addressing brain-damage requires a consideration of the essence that makes us human.

This is a philosophical issue, and not one that can be properly addressed here. We bring a number of assumptions (religious or humanist, biological or social) to any discussion considering this issue. This is the key point. Until now we have had little solid information on which to base our arguments, nevertheless the frontier of knowledge is moving quickly. As it does so previously unchallenged assumptions are moving into focus. Certainty born of ignorance disappears and we are forced to discard previous shibboleths.

During this trip I was exposed to a great deal of scientific information. As has been stated in the body of the report, there is an enormous amount of new knowledge available and it is vital that this is disseminated more widely. Philosophically speaking, however, there is no doubt that what we now know about the workings of the brain is rendering traditional assumptions and understandings invalid.

Some philosophers (of whom the US's Daniel Dennett is a significant example) insist that consciousness can be entirely explained through physical interactions in the brain. This means there is no single location in which our consciousness takes shape: it is, rather, the sum of all the interactions in our 'grey matter'. Modern Australian philosopher David Chalmers (under whom I studied at Sydney University in the 1980's), however, argues instead that consciousness (a mental state) is not reducible to physical systems¹¹. Chalmers argues, for example, that while mental states are caused by physical interactions in the brain, these cannot by themselves explain the resulting 'feelings'.

Such a construction obviously fails the test of Occam's razor (*numquam pond des pluralities sine necessitate* which might be extremely loosely translated as, 'don't invent things you don't need'). Far more importantly for the purposes of this report, however, I believe such a formulation also fails to account effectively for personality change after a TBI.

If brain injury results in a person possessing utterly different attributes from those pre-injury, where then has the 'personality' of that earlier being gone? How has it changed? What constants can be said to remain?

I know I've changed as a result of my injury. I certainly don't possess the same attributes as prior to the TBI; I've therefore effectively become a different 'person'. On this voyage of discovery I've seen many other individuals in a far 'worse' state than my own – how can they ever 'recover' to again become the person they were prior to their injury?

I have thought long and hard about these issues and have the dubious benefit of specific personal experiences which have provided their own insights. I do not, however, believe there is any necessity to share my own personal convictions and beliefs concerning brain damage with others. This is not a philosophically-oriented report. What makes this particular important is that I'm proposing to provide a new forum at which all views will be welcome to be heard, as long as they are respectful of others and remain factually based. That's why this is not the place to detail the particular long and arduous process over the past two and a half decades that has resulted me adopting any particular philosophical positions. The critical factor is that society has not yet reached any consensus on these issues, and yet we are learning so much more about the way the brain works that it is inevitable we as a society will need to come to terms with issues such as this in order to provide a sound basis for the way we treat brain injury.

The most critical issue is to construct a framework that will allow the development of useful debate in this field.

¹¹ Chalmers is distinguishing here between areas of the brain that appear particularly engaged with the formation of particular emotions and an (unlocalised) 'consciousness' that can perhaps best be understood as the sum of all the parts. Scientists do assert brain-imaging allows us to pinpoint with precision where feelings are located within our heads: Chalmers is positing the existence of something 'more'.

The disability field is fractured. This is nowhere more the case than with brain injury.

Since my own injury I've been forced to consider this issue from a number of perspectives. The biggest challenge came when I became President of the NBIF. As recounted earlier, the organisation faced an existential crisis brought on by funding – or rather the lack of it. Despite theoretical assets of just under \$5 million and a recurrent income of more than \$120,000, the NBIF could no longer continue to operate as it had been. It was spending more money than was coming in and was failing to provide the best quality care and support to people who depended on it. The reality is that funding is scarce and it drives our decisions; particularly in this sector.

It had become my firm belief that the organisation needed to fold into Hartley Lifecare.

Achieving this meant it would be necessary to build a coalition of the membership who would be prepared to support such a course of action at an Extraordinary General Meeting to decide the future of the Foundation. Because of this need, I made strategic decision not to attempt to deal concurrently with any of the many ethical implications of advances in scientific knowledge about brain injury since the NBIF was established. The reason for this was that I believed many of the members did not share my own thinking or personal experience. Many worked from insights based (essentially) on medical knowledge as it had developed to the mid-1970s and held a firm belief that people (together with their personalities) remained 'locked in'. They were still there, it's just that we couldn't reach them. Others were carers and relatives of people with brain injury who understood that their loved one had changed so much that, for all effective purposes, the people they remembered had died. Their reactions to this were, however, complex. Some ignored the bodies, others spent a great deal of time with them.

At the House With No Steps I have also become aware that fellow Board Members have very different assumptions about disability, although this reflects issues concerning the way disabled people are reintegrated into the community. The key point is that everyone is coming to these questions with an open mind and good heart: they are willing to be persuaded by evidence, they just want to see it. These issues are, however, highly fraught ones, which is why I don't seek to force other people to adopt my position; simply to welcome discussion and debate and to be prepared to change their mind when more data becomes available.

We like to pretend ethical and philosophical issues don't significantly impinge on medical science. In the case of brain injury, however, they are (or should be) at the very centre of the debate. Because different approaches can radically alter the way we frame possible options for

people with TBI, it seems worthwhile to openly articulating some of the fundamental issues that need to be further canvassed.

1. Is a person's 'being' simply their neural activity? Do things that do not exist physically, such as 'souls', actually exist?

A fundamental pillar of Western philosophy is the concept of the duality of life, the so-called 'mind/body problem'. The person that I am today bears only tenuous links to the ABC Correspondent who lapsed into a coma in the Emergency Room in Bangkok, so who am I? Should we use physiology alone as our guide when dealing with brain damage?

2. Do hard choices need to be made about the allocation of resources for treatment?

We do not live in an ideal world. The cost of treatments and the possibility of engaging in a positive and constructive social life are issues that must be addressed when dealing with people with a brain injury. There are a limited number of dollars available for healthcare and informed choices need to be made about what this money should be spent on. Australian society has effectively already moved to a situation where most people (after counselling) move towards an acceptance that, when a body cannot exist without life support, this should be removed. Is the kindest course of action to allow patients to die and if so what criteria should be used?

3. Can there be any guarantee of recovery?

I have been extremely fortunate in so many ways. The support of my wife has allowed me to have a positive life, however this would not be possible without her, or had we not been lucky in so many other ways. Notwithstanding this report, the reality is that many or perhaps most people who suffer ABI's do not recover to lead positive lives. In a society where we are increasingly planning the burden of care back to families we need to ensure that they are aware of all the changes that may take place as a result of a head injury. People need to be equipped with as much information as possible so they can make such decisions.

4. We are still learning about the brain and must base our actions on knowledge, by teasing out previously unaddressed philosophical ramifications of decisions regarding treatment.

One of the most exciting features this study has been the fact that this is a new field. Our scientific knowledge and understanding of brain injury is continually developing. The vital issue is to transfer what particular people know into practice. Such advances are not simply medical: they also come from carers and people with a brain injury themselves. This reinforces the importance of Recommendation 1, the establishment of an e-zine that can connect the different groups that deal with head injury. This has now become, for me, a key ethical obligation that I have been convinced of as a direct result of my Churchill Fellowship.