



Reconnecting lives

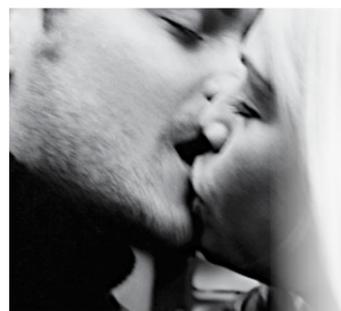
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THE UNMENTIONABLES



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bridging THE GAP



Jennifer Cullen, CEO of Synapse

We are fortunate to have freedom of speech and information. We can use Google to search anything we want and our social networks provide a platform - albeit a gratuitous soapbox - for us to instantly share what is on our minds (or on our dinner plates). From immigration policy, to climate change and budget cuts, we may sometimes complain about society or the Government, but the mere fact that we are able to do so is in itself a luxury.

No matter how open a community or family relationship is, there are always those taboo topics that are a little more challenging or controversial to discuss e.g., sex, drugs, death. The reality is that some of the hardest things to talk about are often the most important. As such, the avoidance of certain issues can have significant implications for one's health and wellbeing through misinformation, misunderstanding, prejudice, or just a lack of information altogether.

For example, suicide rates and suicidal ideation among lesbian, gay, bisexual, transgender (LGBT) youth is comparatively higher than among the general population, due partly to their perceived (or realised) acceptance, or lack thereof, by family and friends.

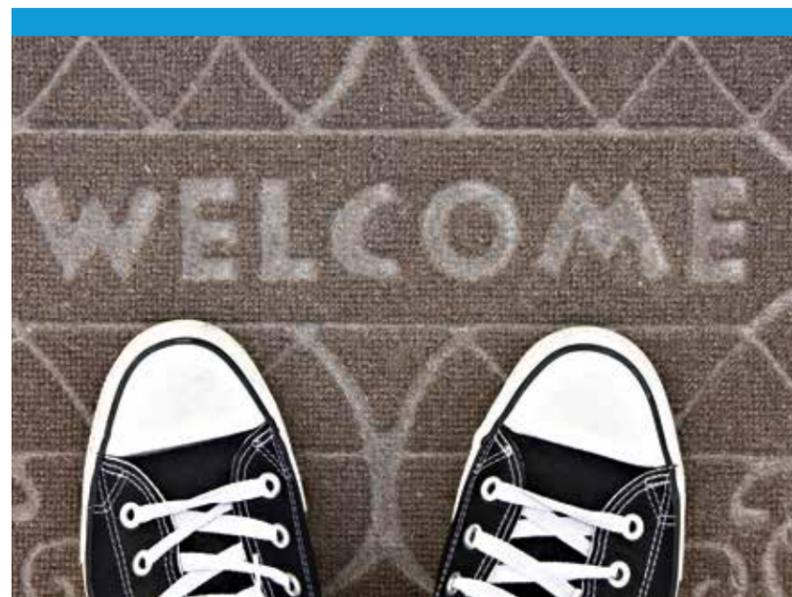
Our experience in the disability sector is that many of these important issues are barely ever discussed. I mean... why talk about an individual's sexual needs as an adult when it's difficult to even organise funding to cover their basic day-to-day support?! Just because someone has a disability, it does not change their basic human rights, nor their basic human needs or desires. The fact that we ignore many of these needs, or in some cases are legally prohibited in assisting people with a disability to experience them, is totally unacceptable.

In this edition, we want to facilitate the conversations that are labelled "too hard"... we want to show the community that it's ok to

talk about these things. The more we talk about them, the more awareness and understanding is created, and the easier the conversations become.

We believe everyone has the right to individualised support to achieve and maintain the greatest possible degree of involvement with society. This belief is the driving force behind all that we do, and our objective to see specialist and individualised services available to all in need is resolute. There is an urgent need to promote a fundamental change in service delivery, to be one based on the needs of the individual, where the cost of care is not just measured in dollars spent, but also in outcomes for clients. ▶▶

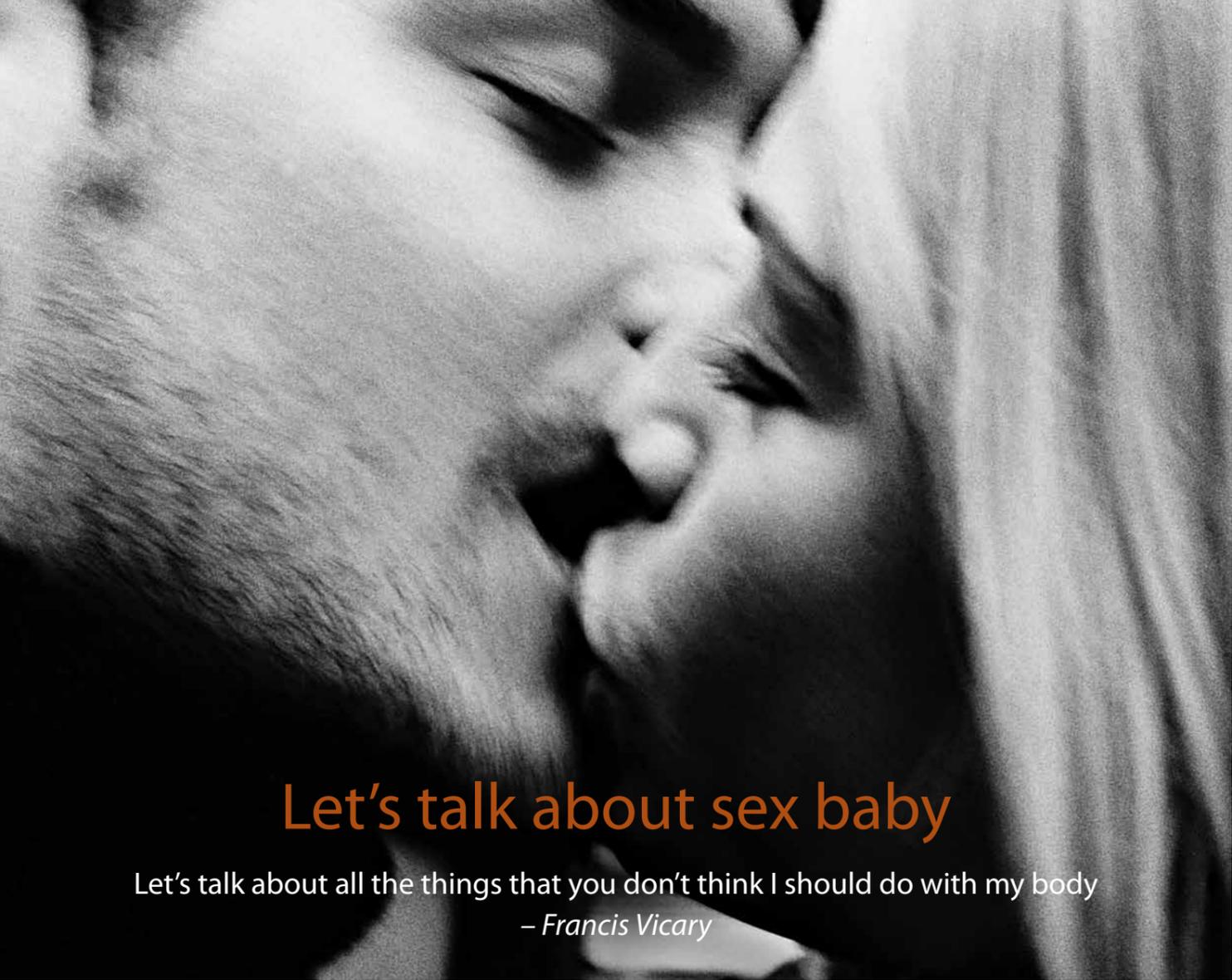
Jennifer Cullen
CEO of Synapse



This coming year will see a milestone event. Many organisations dedicated to improving the quality of life of those living with, or affected by a Brain Injury will begin to speak with one voice.

Together we will look to improve the support for every Australian currently living with a Brain Injury.

Together we will reconnect lives... right across Australia.



Let's talk about sex baby

Let's talk about all the things that you don't think I should do with my body

– Francis Vicary

Sex and sexuality are very contested spaces for people with disabilities. Services, governments, support workers and, even the best, most forward-thinking parents see sex as a “bridge too far”. Many people with disabilities are supported in every other aspect of their lives, but this is often delivered in a way that treats them as asexual.

Almost every person with a disability can tell you of a time when they sought to express themselves sexually, only to be thwarted by family members, support workers, services and government.

I am among them.

I have had cerebral palsy from birth, due to birthing trauma. This results in me having a physical disability which means I cannot independently dress, shower, feed myself or do any fine motor tasks. I can, however, socialise independently, speak my mind, study, work, pay taxes . . .

I was living in country North Queensland, working at TAFE and having a fling with a moderately important, intelligent public servant. I had sorted contraception, support

and succeeded in dating this person to the ‘interested’ stage . . . then my usually accepting family went ballistic! They rang me and said “no, no, no”. They rang my boss’ mother-in-law, who rang her daughter, who rang her husband, who came and said to me “They think you’re going to get SOME”. They even rang the ‘interested’ person.

If it wasn't so perverse, it would be funny!

Independence

My mother was the only one who moderately supported me and actually called my sisters off their hyper-protection of my virginity, but even she didn't really know what to do next.

As I'm a fairly independent and determined person and wasn't taking this thwarting of my sexuality quietly, I took my hard-won individual support package funding and set off to lead an independent life.

I was lucky. I had individual support funding, I could live in a regular apartment, and I had the academic credits and nous to see a PhD as an exit-strategy from the asexual, country Queensland wasteland to the bountiful “fruit” garden of a capital city and university campus.

There was a lingering concern. I was a 30 ¾ year old virgin and my medically-trained sister had led me to believe my bits might not work. So I used the Yellow Pages to get a nice man in a suit to come and relieve me of that worrisome cherry.

Game on!

After that it was game on! There was a hot and heavy long-ish term multi-night-stand with a person I'd known in the sector for years. Just in case you find this suspicious, I should add that he had not been involved in delivering any disability services to me for years. So started the passionate affair.

The need for positive support

Let me just state that all of this time I had support workers who were fabulous. They would cook dinners; squeeze me into spunky corsets and fishnets, and refilled my condom purse. I did have one who got squeamish at putting lip balm on my nipples. I helped her by getting her to put it on my finger, so I could apply it to my nipples. I sense my audience getting a bit uncomfortable here and thinking “uuurrrggghhh, details!” The details are actually

BIOGRAPHY

Francis Vicary is a well-known advocate for the rights of people with disability. Fran has a Masters in Literature and former CEO of the Queensland Disability Network. Through her role as the CEO of Queensland Disability Network, Fran was heavily involved in the development of the National Disability Insurance Scheme (NDIS). Fran was on the on the NDIS Advisory Group and the NDIS Expert Group, ‘National Approach to Choice and Control’. These groups help to steer the development of the National Disability Insurance Scheme (NDIS) by providing advice on progress with the foundation reforms required to improve the system of care and support for Australians with disability and their carers.

Fran has also dappled in academia as a lecturer and tutor in the Occupational Therapy Program at the University of Queensland. Fran is currently the Director Assistive Technology, Community Living and Learning for Yooralla, Victoria's largest disability service provider.

important because you need to know that I cannot dress or feed myself – so support is an important part of helping my life to happen.

Goddess of sexual kingdom

I used social media to re-invent a persona of a sexually intriguing woman who just happened to not dress, feed or cook for herself, yet managed to live alone and have a number of random, casual sexual encounters.

It was a space in which I had power and agency and could put utter trust in strangers who I had only chatted to randomly online. But you can find out a lot about men and how they will treat a woman when they let their guard down because they want to walk in your secret garden. It's easy to weed out the weirdos and not give them details.

I was the goddess of my own sexual kingdom and knights came to court me. Through the internet my encounters were the engineer, the logistics person, the skater boy, the young builder who bought pizza, the Greek guy who took his wedding ring off . . .

Why are we so prudish?

The reactions of my support workers were also very interesting. Even when they were committed Christians, like one special young woman was, they seemed to value me the whole person over their own beliefs.

This young woman, who sneezed so quietly and delicately that Freud would have been concerned, gave me dinner one night I was meeting someone and made me solemnly vow that I would “call her if I needed her”.

This thoroughly enlightened attitude begs the questions, if a committed Christian could honour and support my sexual expression then:

- why do so many people try to deny it?
- why don't we facilitate sexual contact for people with disabilities?
- why are we so (extremely) prudish about sex in general?

These are crucial questions that society must address if people with disabilities are to exercise their full human rights. Governments need to stop making ‘Safeguarding’ laws that effectively limit the sexual opportunities of people with disabilities. In some states of Australia, it is

an offence to have sexual relations with a person who has “an impairment of the mind”, rendering many people with disabilities celibate. Solicitation laws need to permit supports to be given to people with disabilities who require assistance to negotiate and organise the services of sex workers. Service providers and direct care/support workers need to get less prudish and start respecting the privacy and desirous needs of people with disabilities. And families need to understand that children with disabilities grow into adults who have the full range of adult physical and sexual needs. »

This piece was first published on The Guardian's comment website “Comment is free” at www.theguardian.com/us/commentisfree.

The author, Fran Vicary (below) works for Yooralla, Victoria's largest disability service provider. Visit their website at www.yooralla.com.au for inspiring stories and resources.



Brain injury & sexual changes

Acquired Brain Injury can have a number of consequences for an individual's sexual functioning.

Impulsivity, disinhibition and lack of awareness may lead to rehabilitation staff getting unwanted sexual attention from the person with a brain injury. The medical team, family and friends need to have a common response to inappropriate sexual behaviour that will assist the person to regain control over basic impulses.

Families and partners may have trouble understanding these sexual changes and can react negatively. It is therefore important to understand how impulsivity, disinhibition and lack of awareness can cause sexual changes. Encourage the person with the brain injury to take control over these impulses, if this is a reasonable expectation. All members of the family should work to become comfortable in discussing sexual issues and applying consistent responses to inappropriate behaviour.

Sexual changes after a brain injury include:

- reduced or increased sexual drive
- inability to achieve or maintain erection
- inability to orgasm or premature ejaculation
- pain and discomfort during sex
- hypersexuality (increased desire for sex)
- sexual disinhibition
- reduced sexual responsiveness or desire for intimacy.

Such changes may be a direct result of damage occurring to particular brain structures underlying sexual functioning. Other biological causes include damage to genital organs, muscles and bones, spinal cord and peripheral nerve damage, medical conditions, hormonal disturbance and medication side-effects.

There are also psychological changes, such as:

- Low motivation
- Effects of medication
- Diabetes or hypertension (can lower sex drive)
- Depression, stress or anxiety
- Emotional reactions and personality changes
- Cognitive problems e.g. distractibility, perceptual disorders and memory problems
- Loss of self-confidence or poor social skills
- Impaired self-control
- Social avoidance and isolation
- Relationship breakdown.

You can seek advice from a Neuropsychologist with regards to these changes, and they may be able to assist you in managing them.

Talking about sex can be embarrassing, but it is important for the person with brain injury and their loved ones to discuss the various issues and seek professional advice. »



We're not here for your inspiration

A bad attitude? Stella Young says it sounds more like blaming the victim.

I don't know Scott Hamilton personally, but that guy is really starting to burn my crumpets.

You've heard of him, I'm sure. He's the one who said "The only disability in life is a bad attitude." You know, that quote that's plastered all over pictures of disabled people doing completely normal things and shared far and wide on social media.

Hamilton is a figure skater who has had cancer more than once and has survived after lots of treatment. Good for him. Although how it qualifies him to make such a bold sweeping statement about disability, I can't quite grasp. I'll get to that in a moment. Firstly, I want to address the images that his slogan so often accompanies.

Those images constitute what's called inspiration porn.

Inspiration porn is an image of a person with a disability, often a kid, doing something completely ordinary – like playing, or talking, or running, or drawing a picture, or hitting a tennis ball – carrying a caption like "your excuse is invalid" or "before you quit, try".

Increasingly, they feature the Hamilton quote.

There's the one of a little girl running on a set of prosthetic legs alongside Oscar Pistorius, also using similar prostheses. Those legs, for the record, cost upwards of \$20,000 and are completely out of reach for most people with disabilities. The Hamilton quote is plastered across the photo.

And there's another one of a little boy running on those same model legs with the caption, "Your excuse is invalid". Yes, you can take a moment here to ponder the use of the word "invalid" in a disability context. Ahem.

Then there's the one with the little girl with no hands drawing a picture holding the pencil in her mouth with the caption, "Before you quit. Try."

I'd go on, but I might expunge the contents of my stomach.

Let me be clear about the intent of this inspiration porn; it's there so that non-disabled people can put their worries into perspective. So they can go, "Oh well if that kid who doesn't have any legs can smile while he's having an awesome time, I should never, EVER feel bad

about my life". It's there so that non-disabled people can look at us and think "well, it could be worse... I could be that person".

In this way, these modified images exceptionalise and objectify those of us they claim to represent. It's no coincidence that these genuinely adorable disabled kids in these images are never named: it doesn't matter what their names are, they're just there as objects of inspiration.

But using these images as feel-good tools, as "inspiration", is based on an assumption that the people in them have terrible lives, and that it takes some extra kind of pluck or courage to live them.

For many of us, that is just not true.

When I was 15, a member of my local community approached my parents and told them she wanted to nominate me for some kind of community achievement award. My parents said, "Thanks, but there's one glaring problem with that... she hasn't actually achieved anything out of the ordinary."

They were right. I went to school, I got good marks, I had a very low key after-school

job, and I spent a lot of time watching Buffy the Vampire Slayer and Dawson's Creek. I wasn't feeding orphaned Chlamydia-infected baby koalas before school, or setting up a soup kitchen in the main street, or reading newspapers to the elderly at the local hospital. I was doing exactly the same things as my non-disabled friends. When my parents explained all this to the well-meaning nominator, they said "yes, but she's just such an inspiration".

And there's the rub. My everyday life in which I do exactly the same things as everyone else should not inspire people, and yet I am constantly congratulated by strangers for simply existing. It happened twice last week.

I was on a train with my earphones shoved in my ears completely ignoring my fellow commuters (as is my wont early in the morning) while reading inane things on twitter. A woman on her way to getting off at her stop patted me on the arm and said "I see you on the train every morning and I just wanted to say it's great. You're an inspiration to me."

Should I have said "you too"? Because we were doing exactly the same thing; catching public transport to our respective places of employment. I was just doing it sitting down. Should I have pointed out that, in many ways, that requires less effort, not more?

That's the thing about those kids in the inspiration porn pictures too - they're not doing anything their peers don't do. We all learn how to use the bodies we're born with, or learn to use them in an adjusted state, whether those bodies are considered disabled or not. So that image of the kid drawing a picture with the pencil held in her mouth instead of her hand? That's just the best way for her, in her body, to do it. For her, it's normal.

I can't help but wonder whether the source of this strange assumption that living our lives takes some particular kind of courage is the news media, an incredibly powerful tool in shaping the way we think about disability. Most journalists seem utterly incapable of writing or talking about a person with a disability without using phrases like "overcoming disability", "brave", "suffers from", "defying the odds", "wheelchair bound" or, my personal favourite, "inspirational".

If we even begin to question the way we're labelled, we slide immediately to the other end of the scale and become "bitter" and "ungrateful". We fail to be what people expect.

Which brings us back to Scott Hamilton and his mantra. The statement "the only disability in life is a bad attitude" puts the responsibility for our oppression squarely at the feet, prosthetic or otherwise, of people with disabilities. It's victim blaming. It says that we have complete control of the way disability impacts our lives. To that, I have one thing to say. Get stuffed.

By far the most disabling thing in my life is the physical environment. It dictates what I can and can't do every day. But if Hamilton is to be believed, I should just be able to smile at an inaccessible entrance to a building long enough and it will magically turn into a ramp. I can make accessible toilets appear where none existed before, simply by radiating a positive attitude. I can simply turn that frown upside down in the face of a flight of stairs with no lift in sight. Problem solved, right?

I'm a natural optimist, but none of that has ever worked for me.

Inspiration porn shames people with disabilities. It says that if we fail to be happy, to smile and to live lives that make those around us feel good, it's because we're not trying hard enough. Our attitude is just not positive enough. It's our fault. Not to mention what it means for people whose disabilities are not visible, like people with chronic or mental illness, who often battle the assumption that it's all about attitude. And we're not allowed to be angry and upset, because then we'd be "bad" disabled people. We wouldn't be doing our very best to "overcome" our disabilities.

I suppose it doesn't matter what inspiration porn says to us as people with disabilities. It's not actually about us. Disability is complex. You can't sum it up in a cute picture with a heart-warming quote. So next time you're tempted to share that picture of an adorable kid with a disability to make your facebook friends feel good, just take a second to consider why you're really clicking that button. ▶▶

This article by Stella Young featured on the Ramp Up website at www.abc.net.au/rampup on the 2nd July 2012.



RAMP UP - www.abc.net.au/rampup

Ramp Up is a website which featured as an online destination for news, discussion, debate and humour for everyone in Australia's disability communities. While Ramp Up is now discontinued, the website remains at www.abc.net.au/rampup/ as an important resource. Ramp Up was produced by the ABC with the assistance of the Department of Families, Housing, Community Services and Indigenous Affairs.

Introduction to brain disorders

Over 1.6 million Australians are affected with some form of Brain Disorder - that's over 1 in 12 according to statistics from the World Health Organisation (2006). Brain Disorders (technically called Neurocognitive Disorders) are a complex spectrum of disorders that refer to any type of (organic) damage to the brain or neurological disruption occurring after birth.

The Diagnostic and Statistical Manual of Mental Disorders 5 has recently moved to the term 'Neurocognitive Disorder' as a descriptor for this condition which includes Brain Injury, with causes including (but not limited to) trauma, vascular disease, Alzheimer's disease, Parkinson's disease and infections.

The term Neurocognitive Disorder, however, provides a diagnosis for people experiencing cognitive symptoms alone, without memory or physical impairments. This means that many individuals who are not currently receiving recognition or services (due to the lack of memory or physical impairments) will have this opportunity for understanding.

With your help we want to show the community how to send a message of support to all those adults and children living with a Brain Disorder:

- When "one punch doesn't kill"
- As a result of falls, motor cycle and motor vehicle accidents, and other trauma
- As a result of degenerative diseases, brain tumours, Dementia, Parkinson's, Huntington's, Multiple Sclerosis, Cerebral Palsy and other brain illnesses
- As a result of stroke and other cardiovascular diseases
- As a result of alcohol, drug abuse, concussion or repeated knocks to the head from sports.

Through our work and the work of our affiliates across Australia, we know that the current statistics don't mirror society. They grossly underestimate the real numbers, and many people with a Brain Disorder are either misdiagnosed or undiagnosed.

Unfortunately it is often the most vulnerable people in the community affected, but never diagnosed, including:

- Indigenous Australians
- Homeless people
- Survivors of domestic violence
- Soldiers who survive the ravages of war
- People in the criminal justice system.

Around twice as many people are diagnosed each year with Brain Disorders compared to breast cancer and yet very few people know about Brain Disorders (AIHW, 2010). Recognition of brain disorders, prevention strategies and long-term support for those affected are all long overdue. ▶▶



Sex work & disability: it's time to talk

Decriminalising sex work will give people with disability greater control and choice when it comes to expressing sexuality, writes Kelly Vincent.

DI don't think it's any secret that for some people with disabilities, access to relationships and appropriate sexual expression can be fraught with obstacles. But then, maybe it is a bit of a secret, because disability and sex are rarely spoken about together.

Our society tends to put sex and disability into the same category as old people and sex – Australians just like to pretend it doesn't happen. Often people with disabilities are cast as 'innocent victims' or 'eternal children'.

Well, I have a disability, and I'm not (entirely) innocent, or a victim, or a child. And while we're breaking stereotypes, guess what? People with disabilities have sex all the time!

Are you okay? Or are you too shocked to read on? Calm down, because basically all I'm saying is that many adults with disabilities have adult desires, just like everyone else, and probably just like you – and your parents for that matter.

But many of us would like to have more opportunity to express our adult (read sexual if you can take it) feelings.

People with disabilities can encounter many obstacles to achieving sexual expression. For instance, those living in group homes are rarely afforded the dignity and privacy needed. This is a real-life example that I heard about from a support worker who works with a man with a spinal cord injury. His injury causes severe physical limitation and he is prohibited from self-pleasuring by a matronly nurse (a colleague of the support worker) who stands at the foot of his bed for long periods of time. Self-pleasuring is one of the only things left that he is able to do for himself and enjoy, and he is perfectly capable to know when is and is not an appropriate time.

Here's another real-life example. A young woman with a physical disability told me that she had a man stay in her bed overnight only to have the head of her disability support provider

agency call her the next afternoon, making fun of the situation and saying "I'm sorry – we just thought you were a good girl".

None of this paternalistic control would be accepted by adults without disability, so why should it be tolerated by the rest of us? What is it about disability that makes it okay for someone providing a service (in this case a support worker) to impose personal beliefs and limitations on what is perfectly normal, legal behaviour?

This, in part, is why I have launched a campaign about sex and disability. I am calling for Governments to create a culture within disability services that ensures people with disabilities are treated with age-appropriate dignity and respect. This culture would recognise that people with disability have varied sexual preferences and also have the right to legal and safe pursuit of those preferences.

Another reason I have launched this campaign is to highlight the benefits that decriminalising sex work in South Australia could have for people with disabilities.

Of course, not all people with disabilities want or need to engage the services of a sex worker. Many of them are able to satisfy their sexual needs by themselves or with their partner.

But the reality is that some people with disabilities do use the services of sex workers, just as non-disabled people do. There are people whose physical or intellectual disability, communication disability or living situation makes it difficult or impossible to find a sexual partner. These people can benefit greatly from the opportunity to receive safe, healthy sexual services from a specifically trained sex worker.

I know this is true because I have spoken to many people with disabilities who use the services of sex workers. And I've spoken to many more people with disabilities who say they would like to use the services of a sex worker if it weren't illegal to do so in South Australia.

That's why I asked that South Australian Parliamentarians consider the needs of people with disability when voting on Labor MP Steph Key's Bill to decriminalise sex work.

Decriminalising sex work obviously doesn't mean every person with disability will use these services. Of course it is up to the individual. But decriminalising sex work will give people with disabilities a choice, and allow for training of sex workers on the needs of people with disabilities to be done comprehensively and openly. This can only be safer and better for everyone involved.

However, the obstacles for people with disabilities do not end there. Even if sex work is decriminalised tomorrow, South Australians would not be able to use their existing disability funding to access sexual services if they wanted to.

This is because of the current stringent regulations on how the funding can be used – it can only be spent on a limited pool of 'approved' service providers, which includes occupational therapy or equipment supplied by particular companies.

Twenty years ago remedial massage wouldn't have been on this list of 'approved' services, because 20 years ago remedial massage was considered a controversial and out-there therapy

for dreadlocked, tie-dye clad type of folk only. Things change. It's time our attitude to sex work changed too.

It's time we recognise that for some people with disabilities, sex work could be very beneficial to their mental and physical wellbeing. And it's time we recognise that by giving people with disabilities the option to pay for this service with their funding if they want to, we're also respecting their dignity and trusting them to make their own decisions. Allowing this is the other consideration I'm asking of South Australian Parliamentarians.

I think the wonderful thing about this campaign is it's all about choice. If these things I suggest become a reality, nothing will change in the lives of people with disabilities who are already happy with their sex lives, or for those who don't want to use sex workers or for those who don't want to have sex. But for those who don't fall into those categories, these simple changes could make a world of difference. **»**

Kelly Vincent is the Dignity for Disability MLC in South Australia. Dignity for Disability is human rights-based organisation that aims at ensuring representation in Parliament for people with disabilities, in particular. Visit their website at: www.d4d.org.au

SEX & DISABILITY: THE LAW, BELIEFS & ETHICAL CONSIDERATIONS

Sex is one of the great joys of life, so rediscovering this should be a key part of rehabilitation when recovering from a brain injury. However, there may be challenging behaviours, personality changes or severe physical or cognitive impairments which can make sexual relationships a tricky business. If we believe that people with a disability deserve as normal a life as possible, then addressing sexual needs should be part of any support provided, but the use of sex workers does pose a number of issues that need to be addressed.

One of the first hurdles regarding sex workers and clients with a disability is the legal minefield. Can sex workers legally operate in a given area? Can family members or support workers legally employ a sex worker for someone with a disability? If we use Queensland as a test case, sex workers can legally operate in a registered brothel, or as sole operator. Section 229H of the Criminal Code talks about knowingly participating in provision of prostitution – an issue when it comes to organisations supporting individuals to access sex workers. It also says that if an adult who has 'an impairment of the mind' is engaged in the provision of prostitution, then the offender is liable to a maximum 14 years imprisonment. This potentially leaves support organisations, and carers, in a situation where they aren't able to meet the sexual needs of their clients.

Picture this scenario. A client with a disability may be asking for a sex worker, can pay, and is legally entitled to make this decision, but there may be too much legal risk for a carer or service provider.

The next hurdle? Very few service providers declare whether their support workers are able to arrange a sex worker to see a client. Workers may also be reluctant to even broach the issue with a manager for fear of how they will be perceived. In a family setting, religious beliefs, negative attitudes toward sex work or simple awkwardness may mean sexual needs go unaddressed, or are swept under the carpet.

Some people raise concerns over whether the use of sex workers is justified, as it could possibly exploit the sex workers themselves – research indicates a significant percentage are victims of childhood sexual abuse, and there is evidence of modern day slavery occurring within the industry. Naomi Jacobs is a disability rights advocate in the United Kingdom who believes a reliance on sex workers to meet the sexual needs of people with a disability is not truly empowering. She says 'When we are seen as equal people, equally sexual people, we will be empowered to move on from the idea that we can only have sex by exploiting others.'

Any informed debate and response needs to deal with all of these issues to ensure quality of life for all concerned.

Sex & disability less of a taboo

In a recent Australian case a person who experienced catastrophic injuries in a motor vehicle accident, including brain injuries, was awarded compensation that included funds to access the services of sex workers. Approved by a Queensland court, the insurance company agreed to cover the cost of sex workers' services to address this person's ongoing needs for safe sexual expression. Also in the news recently, Scarlet Harem, the Sunshine Coast's first legal brothel, received an award from the Sunshine Coast Access Advisory Network for going above and beyond in providing accessibility and customer service.

These are examples of a greater acceptance within the disability sector and wider community that the rights of adults with disability include the right to access a sex worker if that is what they want to do.

"If you deny sexual expression to human beings, cut them off from that aspect of their personalities and of their happiness, then you end up with a lot of very frustrated and very unhappy people" according to former High Court Judge, the Hon. Michael Kirby. "I applaud the work of Touching Base in facing up to reality, challenging the hypocrisy in society and its laws and recognising the needs of people to have opportunities for sexual expression, including people with disability."

Touching Base is an Australian organisation that focuses on the rights of sex workers and people with disability. Its membership includes sex workers, people with disability, and their supporters. Their website includes stories from clients, such as Elizabeth's. . .

"I am a woman in my mid twenties and I have Cerebral Palsy and until recently I had never had a sexual experience. . . I was sad that I didn't have a boyfriend and after many episodes of depression and experiencing jealousy of any friends who had boyfriends, I talked to my Mum and we decided to do something about it.

"For me it's extremely difficult and frustrating to meet young men and engage in a relationship because I always have my parents or carers hanging around. I do try, but nothing much happens. Mum and I decided that a "professional person", a sex worker, was probably the best approach. I wanted the experience to be enjoyable and positive and a sex worker would have the experience to ensure this.

"I would really like to be in a relationship eventually and while I am content with a professional person for now, I will feel better if I know what it's all about, when I do find someone. I don't want to settle for the first person who comes along because I don't know any better."

Visit the Touching Base website at www.touchingbase.org to learn more about their work in terms of access, discrimination, human rights and legal issues when it comes to sex work and disability. **»**



We need to grow up our kids better

Grannies in some Indigenous communities are burning out as they take responsibility for an issue no one else will

- Dr Janet Hammill

“Kids on the grog, fightin’, breakin’ into houses, terrorisin’ the street, fillin’ up the jails, they got no respect. . . We need to grow up our kids better. These kids are hard headed, I don’t know what’s up with them.”

So said a grandmother when I was researching “granny burnout” in Indigenous communities. Other grandmothers present nodded their heads in agreement as it is a familiar comment from other carers trying to cope with escalating family dysfunction including family violence, truancy, child sexual abuse and imprisonment. The incidence of sexual abuse of very small children during summer in 2003 caused women

from Cherbourg Aboriginal Community to go public on national television about their distress.

The warning signs that should have been heeded, were increasing numbers of children being placed in foster homes, detention centres and jails because they presented their families with special challenges. The grandmothers have been unable to manage them and neither can the parents, however these children are probably the fastest growing population in urban, rural and remote communities. This heavy reliance on grandmothers means that often their own health becomes compromised

with the burden of family dysfunction as they struggle to make ends meet on a pension, while other family income may be used to satisfy addictions that have become hard wired into brain circuits.

An inter-generational disability

It is an unfortunate reality that an unhealthy environment in the womb can have consequences across many generations. This can especially be true when mothers drink alcohol during pregnancy. This is not to blame mothers who drink, but highlights failure by policy makers and the alcohol industry to present a strong message. Fetal Alcohol Spectrum Disorders (FASD) are Australia’s foremost human rights issue, contributing to developmental disorders, dependency on alcohol in adult life, and social problems that will span generations.

The burden weighs heavily on families, community, support services and the entire nation. It can be seen in increasing numbers of children and young people being placed in out-of-home care, students falling through the gaps in education, individuals suffering mental health problems, as well as people with disabilities being imprisoned. These problems are usually transferred to the next generation as well, and become more intractable the longer they are neglected.

A personal case history

A youth, I’ll refer to as ‘Jack’, came to my house in 2002 in the company of other youths. In due course the other youths departed but Jack stayed as he had no place to go.

WHAT IS FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Dr Janet Hammill is a Research Fellow at the Centre for Public Health at Queensland University of Technology, an Indigenous ethnographer and acclaimed participatory action researcher. She was funded by the NHMRC for both her PhD and an Indigenous Capacity Building Grant. Her work focuses on neurodevelopmental problems that are ongoing issues in many Indigenous communities.

At 14 Jack was small for his age. He was abandoned by his natural mother as an infant and was reared by an unrelated grandmother who passed away after a lengthy illness when Jack was about 10 or 11. Before her death, Jack’s father in a distant community, took his own life. Piecing together Jack’s story from his own accounts and from others, Jack is the third generation of alcohol exposure and first generation of marijuana and inhalant use. Suicides have become regular tragedies in his family.

Since Mum’s death, Jack mostly drifted between families and street youth. He entered the detention centre as soon as he was old enough. Like many youth from rural communities, Jack found the city exciting – he began sniffing paint and thinners, became homeless and again came into conflict with the criminal justice system. Jack appeared in court numerous times, and on one occasion when he was bailed out to my care, I insisted his bail was conditional on his being assessed for developmental birth injuries.

Now 27, Jack was released from prison almost a year ago looking healthy and fit. Initially he went to stay in a very toxic community and kept himself occupied by catching fish, turtles and crawfish. After hours he took to the drink, marijuana and whatever was being offered. He was reassessed for his disability and gained a disability pension plus just one day per week on a program which he enjoyed. A few months ago some friends turned up in a stolen car and he hopped a lift back to Brisbane. Jack is somewhere in the city shooting up, looking very bony and his only salvation will be incarceration again.

Conflict with the criminal justice system

As with other types of brain injury, some cognitive problems greatly increase the chances of contact with the courts and prisons:

- Impulsivity
- Poor judgment and disregard for consequences
- Difficulty with planning and responsibility
- Poor control over anger and emotions
- Vulnerability to peer pressure
- Suggestible in court (e.g. false confessions)

Lack of awareness & services

Because foetal alcohol damage has been rarely diagnosed, affected children’s problems and needs have not been met and their life courses have taken them via negative pathways

and sometimes an early demise. There are no precise health promotion initiatives that educate or tell users that unborn children have rights to good health from conception. Likewise there is little understanding of why some mothers self-medicate on these substances.

A famous case often quoted is that of Donald Dillbeck who had been diagnosed with Fetal Alcohol Effects and was charged with premeditated murder. Convicted of first degree murder, armed robbery, and armed burglary, he was sentenced to death on March 15, 1991. Dillbeck is currently on Death Row and the Florida Supreme Court found that he should have been allowed to offer his diagnosis as evidence of diminished capacity.

Lack of government action

Alcohol consumption can not only cause FASD but is linked with miscarriage, stillbirth, pre-term delivery and sudden infant death syndrome. Yet in Australia we continue to have difficulties in gaining legislation to raise awareness, although this has happened with the tobacco industry. As an example, for over 20 years Australian wine sold in the USA has had to carry a warning about the risks of drinking during pregnancy, but this still hasn’t happened here.

Failure to assess or screen for substance related birth injuries have denied children the special structures and services which could potentially improve their quality of life and life chances but scarce resources are spent repairing structural damage done by drunks and teenage vandals. There are far too few special education teachers and early childhood specialists and far too many newly qualified teachers. Early identification and intervention is almost unheard of in most Indigenous communities in Queensland even when the signs of developmental disabilities are known as is the family histories of substance abuse across generations. Inevitably, accompanying this is the related behaviours underlying addictions to substances, gambling, violence and child abuse. It has evolved from generations of poor expectations for life outcomes and aspirations generally.

Community members repeatedly state “our children are our future”. Given the present situation, will the children now navigating the landscape of risk, be able to forge a pathway to succeed those who went before them? »

Enforce the law or give support?

Law enforcement is not the way to respond to public space issues and homelessness according to a report by Lucy Adams, Manager and Principal Lawyer of Justice Connect’s Homeless Law program.

Some people already run the risk of contact with the criminal justice system due to challenging behaviours, and homelessness is another area that is criminalised as well.

The report recommended that law enforcement should not be seen as the obvious solution, and there was an urgent need to distinguish between health problems and criminal ones. It argues that enforcement-based approach is often based on community discomfort, instead of a thoughtful approach based on evidence as to what will work.

“Health, housing and service based responses to homelessness and public space offending aren’t cheap, but in most cases they’re cheaper than enforcement,” said Lucy Adams. “Enforcement is costly for government, police and courts and we should carefully evaluate the full cost in comparison to alternative approaches.”

The report sees enforcement as a blunt instrument for dealing with a vulnerable community, with prison being a harsh substitute for supported housing, mental health care or treatment for drug dependency. »

Polio, sex & love

“The Sessions” was a 2012 film about the true life story of Mark O’Brien who was paralysed and living in an iron lung due to polio as a child. At 38 years of age he decided to lose his virginity before he died. He employed a sex surrogate, a professional who engages in education and intimate physical relations or sex to achieve a therapeutic goal.

“The Sessions” is an accurate portrayal of Mark’s experiences, which were also detailed in the 1996 short documentary “Breathing Lessons: The Life and Work of Mark O’Brien” which won an Academy Award for Best Documentary Short.

Mark wrote a number of articles and often talked frankly about his situation: “My desire to love and be loved sexually is equaled by my isolation and my fear of breaking out of it. The fear is twofold. I fear getting nothing but rejections. But I also fear being accepted and loved.”

Mark died in 1999 at the age of 49. »

The M word & other behaviours

When acceptable private behaviours go inappropriately public



From the moment of birth until the time of our passing we all have a need for, and benefit from, the healing, nurturing and comforting qualities of human contact. Research has strongly evidenced our need as human beings for intimacy, connection to others, social and sensual expression.¹

A hug or touch can result in the release of oxytocin, dopamine, and serotonin, and a reduction in stress hormones. These hormones can benefit both those who are doing the giving, and those receiving touch, so why is it that the topic of intimacy, and in particular self-touching, is so taboo?

For those who may feel uncomfortable with such open dialogue I will preface this article with the warning that I will be discussing the “The big M” word. . . masturbation, so if you find this offensive you may want to turn the page now.

To touch, to be touched, and to feel intimacy and physical contact are as essential to our physical and emotional wellbeing as eating and breathing. As human beings we have social and sensual needs which require an outlet and natural expression, and in most instances these needs and behaviours are privately expressed

and considered completely normal and acceptable. However, tolerances and acceptance for these human needs can be significantly challenged, or be cause for embarrassment or discomfort, when these “private” issues become not so private.

The term “disinhibited behaviour” can have a number of interpretations but has particular significance when associated with sexualised behaviours.²

Generally speaking, disinhibited behaviour is identified as a lack of restraint, impulsivity, poor risk assessment and disregard for social conventions. These behaviours commonly occur with little or no ability to curtail or control them based on social appropriateness, acceptance or disapproval of those around the person, or consequences of the actions.

Disinhibited behaviour can have a sudden onset due to a brain injury, or conditions such as autistic spectrum disorders, intellectual impairment, or degenerative conditions like dementia. In most cases, there is injury to parts of the brain responsible for regulating impulse control, making decisions, and awareness for consequences.

Individual levels of modesty, cultural norms and social standards dictate which behaviours are “appropriate” and those which are considered private and not observed by others. For example, in some countries the simple act of hand holding in a public place may be deemed highly inappropriate, while in other countries this would not raise a second glance.

The consequences

Consequences for disinhibited behaviours can range from simple embarrassment or social exclusion, to legal implications, fines, or even prison sentences.

The topic of sexual expression for those with a disability remains controversial and is strongly debated from both sides. The ability to provide “appropriate” methods of sexual expression or outlets is filled with legal and ethical constraints and often ends up being an issue which is managed on a case-by-case basis dependent on the opinions and comfort levels of those directly involved with the individual.

So, how do you manage the natural physical needs and desires of a person whose physical abilities remain fully active and “normal”, when their self-regulation and self-awareness are impaired?

It is fairly common to have a loved one or family member who engages in overt sexual conversation or behaviours, undresses in public, or masturbates in front of others. What can we do in these situations?

What won't work is wishing they would stop engaging in the behaviour, telling them to stop, or trying to shame or punish the behaviour.

In some instances the individual may possess just enough awareness to know that the behaviour is inappropriate, in which case it's likely they will be reactive, defensive and even aggressive if confronted or challenged, especially whilst the behaviour is occurring.

In my situation, our adult son would sneak away down to the backyard to engage in self-pleasuring behaviours and if anyone were to approach he would become extremely agitated and angry at the thought of being “caught”. However the possibility of being “caught” was not a sufficient deterrent for him to cease the behaviour – in fact it only served to heighten his anxiety for being discovered and his reactivity towards others.

We learnt that if he was quiet in the backyard for any length of time that we should make sure we made some noise that would pre-empt

our possibility of coming into his space so he could have time to finish what he was doing or quickly replace his clothing.

While this assisted with preventing outbursts of behaviour, we were still concerned as our yard borders a public park and is not fully screened from view. If his actions were seen by families of young children there could be police involvement, or he could get angry at people in the park for interrupting him.

We worked on the fence to make our yard less visible, but this did not address potential issues in other environments.

We quickly realised that it would be necessary to take our own personal embarrassment and emotions out of the equation and address the issue more broadly. Providing appropriate times, places, opportunities and resources (reading material, oils or sensory experiences) may be something that many people may find confronting or embarrassing to consider doing, but when faced with the alternative of a loved one facing legal consequences it is by far an easier path.

Using behavioural modification techniques and providing more appropriate times, places, and environments when behaviours could be undertaken privately and uninterrupted, did assist with redirecting these behaviours from less suitable times and places. The behaviours went from happening at less suitable times and places, to times and places where it is more appropriate, and would not create problems for our son or the community.

Discussing and encouraging appropriate places like the bedroom, bathroom or shower for “personal” behaviours was helpful. Removing the likelihood of getting ‘caught’ also reduced the anxiety he experienced and therefore reduced the potential for angry outbursts. This was a positive result for what had been a confronting and potentially legal issue for our son.

While there is no one quick fix answer, approaching the issue with respect for individuals’ rights and needs to express physical and intimacy needs is paramount, as is removing our own judgments or sense of embarrassment.

My suggestion would be if it's not “behind closed doors” then we really do need to be as open as a door, to solutions.

Connect with Synapse if you would like more information, or visit <http://synapse.org.au> »

Thanks to the parent of a Synapse client for sharing her story, and insights from her background in behavioural analysis and positive behaviour support.

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I can't

Many of us have limiting beliefs about ourselves and our capabilities. They lurk in our minds, just waiting to sabotage some of our best efforts. How many times do we have success after success, until something happens in our mental processes which then prevents us moving in that same direction? The next step is often to give up, as no matter how hard I try, something is blocking me.

Of course, sometimes this happens because my goal setting is not clear and precise, or my goals are dependent on another person or things outside of my control. Sometimes I might unconsciously find my present situation easier than impending changes. The theme? If I think I can't do something, then I can't. I think it might have been Confucius who said “The person who says I can and the person who says I can't are both right”. Whatever I think about myself, I will find that there is evidence to support it.

A person is going to believe that he or she can do something before he or she actually goes to do it. Commitment occurs, then the brain goes through the feedback mechanisms to guide behaviour to meet the map. Beliefs are only a map. It is only a partial representation of the territory. Therefore, a well-formed belief is not going to be based on the statistics there are to support it, rather on primarily one factor: how well it serves the individual.

Our beliefs are very powerful, helping us to get a sense of certainty and direction in an unpredictable world. They are so powerful, in fact, that we sometimes don't remember that they're not necessarily “true”.

At some point in our lives our beliefs might have been useful. It is then that they become limiting beliefs. “Don't go across the road” was a useful belief when I was a small child. However, now I am an adult, I need to modify that belief, or ditch it altogether.

In my work, I have met limiting beliefs in many people, even myself! One way forward is to use this question: “How do you know that?” or “How do I know that?”

This will help to discover that there is good evidence for maintaining the belief, or not enough evidence to make it worthwhile sustaining it.

As a person with an Acquired Brain Injury, I struggle with the attitudes I've been taught, many of these attitudes buried in deep beliefs about me, and my capacities. However, if I find beliefs that are no longer useful, then it is good practice to change them or replace them with some beliefs that will strengthen me. Like goals, it is most useful to write them down, and write them down in a positive way.

I once had a mentor who taught me “Fake it until you make it”. Milton Erickson, an extraordinary communicator and therapist, used to say “You can pretend anything and master it.” So the next step is to act as if the new positive belief is true. Take courage as you explore (and change?) your limiting beliefs!

- Rick Bowie »

Dancing like everyone's watching



Sometimes it seems that anything you do in a non-normative body is somehow political. Stella Young feels this is particularly true for a wheelchair user on the dance floor.

I am never more aware of my body than I am at around midnight on a Friday. More often than not, I'm on a dance floor, feeling music pulse through my body and moving it accordingly. I'm surrounded by people. They're dancing. I'm dancing. But in a body that looks like mine, one is never just dancing.

I'm less than a metre tall, and I'm a wheelchair user. My dancing takes place in this body and in this chair. Let me be clear, there are many disabled dance practitioners who are exceptionally talented and internationally recognised (if you ever want to fall down a rabbit hole of disability dance brilliance, look no further than AXIS Dance Company,

who work with incredible artists such as Alice Sheppard, Rodney Bell and Marc Brew). But I am not one of them.

I dance because it's fun. But I also dance because it's political.

Just as I am aware of my body in those moments, the way my muscles feel as I move, I'm equally aware of the able-bodied gaze. Heck, I'm aware of it when I'm in the supermarket, on a tram or wheeling through the streets. But there's something extra at play on the dance floor, and people not only look, they comment.

It is not uncommon for someone to stop me while I'm dancing, and tell me what great exercise it must be for "someone like me". One woman recently commented that it must be "better than rehab". Because anything physical

I do with my body must have a therapeutic or 'healing' purpose. I couldn't possibly just move my body for the sheer joy of it. There's often a subtle assumption that we disabled folk don't do things with the same motivations as non-disabled people, as though Normal People Things would not be important or meaningful to me.

Another fellow dancer recently leaned down to me and shouted that it was "great to see me out". I asked him what he meant and he replied, "It's just so awesome that you don't care what people think." Right. Because, presumably, if I did care what people think I'd have enough sense not to be shaking my crip booty before the delicate eyes of the general public, right?

Rather than explain to this gentleman that,

in fact, I do care what people think (I'm just not self-hating enough to assume people find me disgusting), I dismissed him with a not-particularly-polite invitation to go away.

These comments remind me that people are surprised by my presence; that the dance floor is not for me. Why? Perhaps it's because a dance floor is not merely a place for moving, but also for sensuality and sexuality. From traditional courtship behaviour to straight-up cultural metaphors, dance and sex are inextricably linked.

Given the way our culture continually asexualises those of us with non-normative bodies, it's little wonder our presence in such sexually charged spaces is met with surprise. The words of the late Maya Angelou spring to mind. In her poem, *Still I Rise*, she wrote:

Does my sexiness upset you?

Does it come as a surprise

That I dance like I've got diamonds

At the meeting of my thighs?

Perhaps that's it. I'm just not supposed to be so damn showy. The man who told me it was awesome I don't care what people think was actually expressing surprise to see me behaving as though I belonged on that dance floor, as though my presence was an act of defiance and not enthusiasm. Even here, in this space where culture has taught us we can dance away our cares and leave our troubles behind and surrender our souls to music, my presence is assumed to be a lesson for non-disabled people.

I recently delivered a TEDx talk on the way we as a society objectify disabled bodies for the purposes of "inspiration". We are positioned firmly as "other" so non-disabled people can distance themselves from the idea that disability is simply part of the human condition. In the make-up room before I went on stage, a woman tidied up my hair, redid my lipstick and, before I could object, painted a generous amount of foundation over a surgical scar on my right arm. "Just to make it less obvious," she said.

I didn't argue with her, but I did have one of those all-too-familiar thoughts: a reminder that I'm supposed to not like that part of my body, that I'm supposed to feel ashamed. And to be fair, that's her job; to cover the things society deems imperfections. Her assumption that I'd want them covered was a reasonable one, given the social context.

Still, it took me back to one particular recess at high school. Sitting on the oval in our summer school uniforms, a friend looked at my bare shins and said, with no small degree of disgust, "Aren't you embarrassed about those scars on your legs? If I were you I'd never wear summer uniform."

It had genuinely not occurred to me that I should be self-conscious about those parts of my teenage body. Acne and braces, sure, but not

my scars. They'd been a part of my body since childhood, a part of my story. All the same, I wore winter uniform the rest of the week, or until the Wimmera heat got the better of me.

Bodies that fall outside socially constructed beauty norms are not bodies we're expected to feel proud of. They are certainly not bodies we are expected to show off. Even in the so-called body positive campaigns that seek to showcase the diversity of women's bodies, such as Dove's Real Beauty campaign, the bodies of physically disabled women are conspicuously absent. Disabled women, perhaps, are not included in the definition of "real women".

By deliberately placing my disabled body in contexts where it is not expected, I subvert expectations. It is not always my intention - living your life with the express purpose to challenge people is exhausting - but I have learnt that it's a consequence of doing what I want to do. To live unapologetically in a body you're consistently told you should be ashamed of is a political act. Life as a disabled woman means I am both spectator and spectacle.

It has taken me a long time to learn that my body is not defective, or wrong, or less than. But it's also more than those things. It moves and feels and responds to touch and lust and music, in exactly the same way those bodies which are given leave to claim such privileges. I dance as a political statement, because disabled bodies are inherently political, but I mostly dance for all the same reasons anyone else does. Because it heals my spirit and fills me with joy; each foray onto the dance floor brings the possibility of that delicious frisson that comes from locking eyes with someone and knowing, in that moment, that you're dancing just for each other; because it makes me sweat and move connect with people and feel like I've landed in my skin when I finally stop. And I dance because, in the end, dancing is a way for my body to have a conversation about these things, the pulsating waves of a hundred people sharing thoughts and dreams and ideas about what it means to be alive.

It's my body, and I'll bloody well dance if I want to. ▶▶

Stella Young was Editor of Ramp Up, a website for everyone in Australia's disability communities. Ramp Up is discontinued but the website remains at www.abc.net.au/rampup/ as an important resource, and was produced by the ABC with the assistance of the Department of Families, Housing, Community Services and Indigenous Affairs.



Einstein's brain

What happened to Einstein's brain? He died in 1955 after an incredible life of amazing scientific theorising, and had asked to be cremated without a ceremony — which happened as requested, except that his brain was missing.

The brain was sitting in a jar of formaldehyde in the pathologist's office. After performing Einstein's autopsy, the pathologist, Thomas Stoltz Harvey, kept the brain for his own study. The executor of Einstein's estate claimed that Einstein's son had made this request. Einstein's brain was removed, weighed and preserved by Thomas during the autopsy.

Thomas claimed he hoped that cytoarchitectonics would reveal useful information. He photographed the brain from many angles. He then dissected it into roughly 240 blocks and encased the segments in a plastic-like material called celloidin. Harvey may also have removed Einstein's eyes, and given them to Henry Abrams. He was apparently fired from his position at Princeton University shortly thereafter for refusing to relinquish the organs.

Over time, he donated these samples to other researchers. Marian Diamond studied Einstein's brain and found that it had 73% more glial cells than average. These cells provide nourishment in the brain and the increase could be because Einstein's brain was working a lot harder than the average one. Scientists from McMaster University discovered that Einstein's brain was 15% wider than normal in the inferior parietal regions which could allow more powerful visualising abilities.

Study revealed that both hemispheres were much more developed than most. This would have given Einstein some powerful visualisation skills, given that these regions of the brain are largely responsible for visuospatial cognition, mathematical thought, and imagery of movement. They also found that Einstein's brain lacked the groove which usually runs through part of this area, which suggests that the neurons might have been able to work together more easily given their proximity. The brain is currently in Princeton Hospital.

Einstein was quite humble about his cognitive abilities and usually downplayed them, claiming to simply be passionately curious. Here are few quotes from that amazing brain:

- "Imagination is more important than knowledge"
- "Gravitation is not responsible for people falling in love"
- "The hardest thing in the world to understand is the income tax"
- "Reality is merely an illusion, albeit a very persistent one"
- "I want to know God's thoughts; the rest are details"
- "The only real valuable thing is intuition." ▶▶

Masturbation

Attitudes toward masturbation have seen considerable changes in the West over the past few centuries. As late as the seventeenth century in Europe the practice was commonly employed by nannies to put their young male charges to sleep. Things changed though, with the Victorian era when many believed masturbating could cause impotence, gonorrhoea, epilepsy, death, cognitive decline, blurred vision and headaches.

The founder of The Scout Association, Baden-Powell, warned scouts in 1914 that they should run away from the temptation by performing physical activity.

Today, masturbation is widely seen as a healthy activity although the Roman Catholic church still forbids it. Thomas Szasz summed up the healthy changes in perception that occurred in the 20th century: "Masturbation: the primary sexual activity of mankind. In the nineteenth century it was a disease; in the twentieth, it's a cure."

However, there is still hangover from more repressive times. Research in 1994 found that half of adults feel guilty about masturbation, and a 2000 study found that adolescent males were still frequently afraid to admit to masturbation.

Impulsivity issues can lead to problems with public or inappropriate masturbation after a brain injury. A family member may need to be told that masturbation is an appropriate way to deal with sexual urges, but in the privacy of their own room. It is important to establish ground rules to protect the rights and privacy of others, so when, where and how need to be discussed.

In some cases, a partner or spouse may continue in a caring role but no longer wish to maintain a sexual relationship. In these cases, it may need to be stated clearly and consistently that masturbation will be the only option to sexual urges. ▶▶



My impulsivity made me do it!

Injury to the frontal lobes of the brain can affect our brain's ability to control our impulses. We usually take these abilities for granted, but of course we have to learn how to curb our impulses all through childhood, and realise there are consequences to our actions. If a brain injury affects this area the results can be dramatic.

An inability to control urges leads to impulsive and often inappropriate social behaviour. For example a previously shy person may become quite extroverted and talkative if the brain injury has led to mild disinhibition. In more severe cases, a person may make crude or sexually inappropriate comments to strangers, become dependent on alcohol or other drugs, start gambling, and come into contact with the police and justice system.

When other people do not understand the reasons for this behaviour it often leads to rejection and criticism from others. Impulsivity can therefore lead to social isolation as the person alienates existing friendships and cannot make new ones. Other inappropriate behaviours may include:

- Sexual inappropriateness
- Acting without thinking
- Inability to save or regulate finances

- Sharing personal details inappropriately
- Irritability
- Aggressive outbursts
- Over familiarity with strangers
- Asking personal questions despite the discomfort caused.

Lack of insight

Another common outcome from a frontal lobe injury is lack of awareness. This can make it difficult to analyse one's own behaviour or to gauge other people's reactions. This complicates the issue of impulsivity as people with a brain injury may refuse to acknowledge that they behave inappropriately. They may be unable to understand their own limitations or the consequences of their actions. This lack of insight can lead to an inability to understand other people's behaviour or motives, or to empathise or imagine how someone else is feeling.

Strategies for carers

Impulsivity often arises in situations where the person is confused or fearful. These can be minimised by a predictable daily schedule. Also, any outbursts should not be automatically written off as impulsivity and ignored. They may be indicating a cause of fear or confusion that needs to be dealt with.

X-RATED BEHAVIOURS

Sexually inappropriate behaviour can occur when a brain injury leads to a heightened sex drive and/or sexual disinhibition. Challenging behaviours could include making sexual jokes to strangers, touching strangers in public, masturbation in public areas, and making unwanted advances. Families and partners can have trouble understanding these sexual changes and react negatively. A good understanding should be gained of how impulsivity, disinhibition and lack of awareness can cause sexual changes. Where self-awareness and memory are intact, support can be provided in relearning what is and isn't appropriate behaviour.

Professionals can provide a range of coping strategies. Following assessment, specific treatment of sexual problems may involve education, learning new skills and behavioural techniques, physical rehabilitation, aids and medical treatment. Specific forms of treatment may include psychological support, medical and surgical approaches.

When lack of awareness is not an issue the person may apologise later. Try to be sensitive to this, despite any lingering anger or annoyance on your part. Prolonged complaints about the behaviour afterward are not likely to help, as usually the lack of control was not by choice on their part.

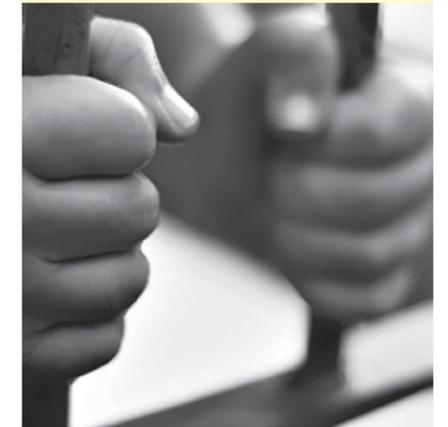
If attention-seeking behaviour such as yelling or interrupting occurs, explain that this is not a good way to get your attention, and advise on an alternative strategy.

One of the most difficult strategies on handling impulsivity is to recognise that any challenging behaviours have arisen from a

physiological cause — the frontal lobe injury. Try to remember it is the impulsivity that is at fault, not your loved one. Generally they will not be speaking or acting intentionally to annoy you or hurt your feelings. Separating the person from the behaviour can go a long way to coping with the situation.

In serious cases your local Brain Injury Association may be able to put you in touch with any specialists in behavioural issues. Also in some cases medication may play a useful role. Consult your rehabilitation specialist or GP to see if it could assist. ▶▶

Brain injury & prisons



Research in Canada is backing up similar findings in Australia – at least half of the inmates in prison have already acquired at least one brain injury, and in many cases have a history of multiple injuries. As regular readers of Bridge will know, each brain injury makes us more vulnerable to future injuries, and a significant number of inmates are being imprisoned instead of receiving support.

Dr Colantonio was the lead author of the study published in the Journal of Correctional Health Care in July 2014, and believes underlying brain injuries are being overlooked in the criminal justice system, with 43% of Ontario prisoners having suffered at least one brain injury.

"It's not enough just to screen for the injuries," says Dr. Angela Colantonio. "Ethically we should be providing the supports necessary to address the underlying conditions."

The huge issue of course, is whether justice systems world wide are responsible for a grave injustice – there is increasing evidence that many inmates are behind bars largely due to behavioural issues that were never addressed after acquiring a brain injury. We may be punishing people for what is a medical issue, not a criminal issue, and simply escalating the behavioural issues to a dangerous point. ▶▶



Etanercept – miracle drug?

An existing arthritis treatment is showing promise as a treatment for brain injuries even years after the event

At the age of three, Joel was a bright happy little boy with steely determination and a wicked sense of humour. A bout of gastro enteritis – typically considered a mild childhood illness – resulted in hospitalisation for intravenous fluids to rehydrate him. The situation became serious several hours after admission. Joel was becoming deeply comatose with life-threatening fluid increasing in his brain, as his mother – a Registered Nurse – was sitting with him, thinking Joel was merely asleep. Fortunately Joel’s mother and medical staff were able to resuscitate him when he had a seizure and stopped breathing. Joel was placed on life support and airlifted to Townsville hospital where the diagnosis confirmed life-threatening cerebral oedema.

Immediate treatment to reduce the fluid in

Joel’s brain helped, but Joel’s family was told that he would be unlikely to survive. After eight days on life support, 11 days in ICU, and eight weeks in hospital, Joel returned home to Bowen in North Queensland, with a significant brain injury.

Support through childhood

The middle of three children, Joel was fortunate to be surrounded by a loving family who provided him with plenty of stimulation. He was able to regain some of the losses from his brain injury, but he was left with cognitive deficits, untreatable seizures, extreme fatigue, speech deficits, and limited mobility. Combined with severe behavioral problems, there was significant strain on his family, with his mum left to raise him and his two siblings alone only

two years after his injury. Despite these severe issues, Joel maintained his determination and engaging demeanour.

The adult years

At the age of 18 years, Joel moved into supported accommodation with 24 hour care as Joel’s disabilities were even more significant than when he was a child. Walking became increasingly difficult, with carers physically holding him up to just walk a few metres. His speech was hard to understand for those who did not know him, and poor memory, poor concentration resulted in high levels of aggression. A poor cough reflex meant that upper respiratory infections often led to pneumonia, and frequently choking incidents were feared to end in his early death. Daily focal seizures were poorly managed with massive doses of anticonvulsants which both sedated and further clouded Joel’s thinking and social interactions. However, Joel still remained happy and engaging, with a passion for his favorite footy team – the Brisbane Broncos, music, cars and pretty girls.

Stroke reversal

In April 2014, 60 minutes aired a story called “Stroke Reversal” which showed a woman making an almost miraculous recovery following a new “controversial treatment” in the USA. The relevance to Joel’s situation was immediate, and Joel’s mother, Coralie, set about

THE GOOD NEWS ABOUT ETANERCEPT

A USA study indicates that in 80% of cases it appears to have a positive effect on reducing the TNF levels in the brain that occur following a brain injury, and there are promising signs as a treatment for Alzheimers disease too. The study, conducted at the Institute of Neurological Recovery, found improvements in cognition, spasticity and motor impairment.

The good news is that there is substantial evidence that it can lead to improvements even many years later, with the benefits often showing within minutes after the first injection. Scientists looking at inflammatory processes within the brain following injury, including many in Australia, have for decades shown that inflammation not only increases symptoms of brain tissue injury but is responsible for a whole range of symptoms, quite separate to the initial injury as levels of TNF can remain elevated in the brain permanently. Scientists believe Etanercept reduces these levels almost immediately, and current evidence suggests the effects appear to be long lasting with no need for ongoing treatment.

researching this treatment then contacting the Institute of Neurological Recovery clinic in Los Angeles, which assessed Joel’s medical history and passed suitability criteria for treatment. 93 days after the 60 minutes story aired, considerable research, serious fundraising and a new mortgage on the family home, the family and carer set off for LA.

Effects of treatment

The effects of the first treatment of Perispinal Etanercept were immediate and dramatic. Joel could speak more clearly and walk unaided for the first time in 23 years. He had two subsequent treatments, each a week apart with less dramatic but equally significant improvements. Joel has maintained all gains made in the three months since the treatment, including: improved mobility, concentration, memory, swallowing, cough reflex, speech, cognitive clarity and emotional regulation. He also now has fewer seizures and is less aggressive.

Joel now often says “I feel great” and “I can think!” and is asking questions about his new world and taking part in conversations. Above

all he is happy! Some medical sceptics attribute Joel’s improvements to the placebo effect, but Joel’s answer to that is a resounding no – his improvements are not imagined.

There is potential for further gains so Joel’s family continue to consider another trek to LA but look forward to this treatment being available in Australia – not just for him but the thousands of others affected by stroke and brain injuries it could possibly help. ▶▶

Follow Joel’s progress on his Facebook page: Hope4Joel FURTHER READING

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THE NOT-SO-GOOD NEWS ABOUT ETANERCEPT

Perispinal Etanercept is a very expensive treatment, with each injection costing up to \$6,000. In the personal story featured, three injections were made, along with the costs of travelling to the USA for the perispinal injection until more doctors are trained for this procedure.

Results from the treatment are very individual, due to variability in the nature and extent of each brain tissue injury. Of those who do benefit, some experience additional gains with second or third treatments. This variability in results is likely to be associated with the amount of excess TNF each individual has from their original injury.

To date the research mentioned has mainly been conducted by scientists associated with the institute providing the treatment – this does not negate their findings but the ideal is for other independent studies to replicate the findings – such research is on the way given the strong results so far.

There is also the need for rigorous clinical trials to provide sufficient evidence to have it registered as an approved treatment for brain injuries – research like this is on the way as researchers at Queensland’s Griffith University hope to begin Australian trials on perispinal Etanercept early next year. Etanercept is currently “off-label” so the responsibility is on the doctor to use informed judgement before using a drug for an off-label purpose – such use is legal and common when scientific evidence, safety, and other treatment options are considered. Approval as a brain injury treatment could pave the way for Etanercept to be a common treatment in hospital and/or rehabilitation units.

Perispinal injections are still a very new procedure, so travel to the USA has been necessary until doctors can be trained in other countries. Travel adds substantially to the cost of treatment.

Evidence-based treatment

Historically, medicines relied more on patient testimonials, case reports, personal opinions and word-of-mouth. An evidence-based approach to medicine aims to accurately determine how well a medication will work for as many people as possible, and what side-effects could occur. Ideally these tests will be randomised, double-blind, placebo-controlled trials with a wide range of people – this means a lot of effort is put into selecting a broad sample of people and ruling out any placebo effect (when people feel better because they have faith in the drug, even if they unknowingly aren’t actually receiving the drug). This goes a long way to explaining why it is costly and time-consuming to get medications on the market and approved for use.

What about alternative medicines?

The evidence, particularly that behind drug treatments, has improved; but there are still many types of treatments like surgery, physical therapies, natural therapies, dietary advice and counselling, that haven’t been properly tested. This doesn’t mean they won’t be useful, at least in some situations. But generally if a new treatment is tested and found to work for the majority of people, with a minimum of side-effects, then it should eventually be established as an evidence-based treatment and be approved by the relevant government bodies regulating drugs.

What about drugs that aren’t approved yet?

What about treatments that seem to work, but haven’t been accepted as evidence-based treatments and/or approved for use yet? This could be due to a number of reasons, including:

- the treatment does actually work, but has not undergone enough rigorous research to be approved for use yet
- it only works for a small percentage of people
- the side-effects outweigh the benefits
- it works due to the placebo effect.

The rigorous clinical trials that provide the evidence to approve a drug are time-consuming and expensive, so there are often smaller and more cost-effective studies at first that continue to provide further evidence that a drug indeed works. The road to approval for use can take years, a sad reality when a new treatment may hold huge promise not only people affected by various disorders, but their families as well.

An evidence-based approach should not necessarily discourage people from looking at alternatives to western medicine, or trying drug treatments that haven’t been approved yet. But it does encourage personal research, healthy scepticism, and weighing the potential benefits, costs and risks before seeking treatment. ▶▶



Depression & suicide

Having an acquired brain injury can have a major impact on someone's life, to the point they may contemplate committing suicide.

It is particularly important for family members, friends and those who care about the injured person to know the danger signs, ways of being helpful and who you can turn to for advice or referral.

Looking out for the first signs

A suicide attempt is rarely made following a sudden or impulsive decision. Rather, it is more

common for individuals to shift between the stages on a continuum which range from the initial thoughts about suicide to committing suicide. The stages may be bi-directional (i.e. a person may move forward, return to an earlier stage or no longer consider suicide as an option):

- planning
- organising means
- suicide attempt
- commit suicide.

Some may engage in self-harming behaviour

which has the potential to lead to death, while the actual goal is not to die. It is important to be alert to cues that someone may be considering suicide. Things to look out for are:

- making statements like 'It would have been better if I had died' or if they make threats about committing suicide
- becoming very withdrawn or depressed.

If the person with a brain injury has tried to commit suicide before, you should be particularly aware of cues and try to assist them to seek professional help.

There are various factors which indicate a higher risk of suicide. The brain injury survivor may have access to lethal means and the development of a specific plan. Drug abuse, engaging in extreme behaviour and catastrophic reactions to relatively mild stress can also increase the risk factor. In some cases a final crisis may act as a precipitating event.

Interventions for individuals at high risk

These interventions include:

- crisis intervention (levels may include immediate support e.g. telephone counselling, referral to a psychiatrist, closely monitoring

the person or moving the person to a less stressful environment)

- medical/psychiatric treatment (including medication)
- hospitalisation
- psychological therapy
- mental health case management
- linking into support systems (e.g. family and community organisations).

Specific crisis intervention strategies

The general aim is to lower the level of lethality or very high risk of suicide by working to increase the individual's psychological sense of possible choices, and to increase their sense of being emotionally supported.

Strategies may include the following:

- Establish rapport (e.g. 'I'm listening and I want to support you')
- Explore the person's perception of the crisis
- Focus on the immediate past (e.g. a recent significant event or problem) and immediate future
- Develop options and a plan of action — increase the options available to the person and the number of people available to help (professionals and family members)

- Arrange removal of the potential means of suicide where possible
- Encourage the person to develop a plan which includes resources and support in the immediate future — write down the steps of a personal safety plan to be carried around by the person (e.g. in their wallet)
- Try to increase the person's investment in the future by involving them in small and meaningful activities (e.g. tasks around the house and garden)
- Monitor their emotional state and establish a follow-up plan
- Try to involve appropriate people in the person's natural support system.

Effective communication

It is recommended that people offering support to a distressed individual avoid using the following techniques:

- False reassurance e.g. 'Everything will be fine, don't worry'
- Inappropriate use of alleged facts e.g. 'You'll recover from your brain injury within a year'
- Confrontation, e.g. 'It is time for you to accept that you will never walk again'
- Minimising a person's feelings e.g. 'Come on now, it's not that bad'
- Probing or intrusive questioning (e.g. 'Why do you think your girlfriend left you?')

A combination of the following techniques can be used to convey support:

- Active listening (nodding and minimal responses such as 'okay', 'sure')
- Meaningful eye contact and supportive body language
- Reflection of feeling (e.g. 'You sound really upset', 'I can see that you are frustrated')
- Reflection of content (e.g. 'It sounds like you want your family to give you more space')
- Paraphrasing and summarising, (e.g. 'At the moment you're feeling overwhelmed')
- Asking permission (e.g. 'I want to help you — can I come and sit near you?').

Support for the supporter

Working with, or being close to, someone who is at high risk of committing suicide, can be extremely stressful. It is very important that carers receive their own support and take care of their own emotional well-being. Support for the person working with the distressed individual may come in the form of debriefing from other professionals. Relatives and friends may also benefit from seeking professional help to express their feelings and receive advice. **DD**

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Brain injury & mental health

Are you out of your tree? A stubbie short of a six pack? Loopy? Around the bend? Funny in the head? Or are you just a lunatic? Although the terrible stigma attached to mental health disorders is being reduced, these words still show that mental health disorders are still one of the "unmentionable" topics.

In the Middle Ages, Christian Europe saw mental health disorders as a mixture of the satanic, divine and humoral, while the more advanced Islamic world was developing psychiatric theories and treatments (their first psychiatric hospitals built in the eighth century!).

The early modern period in Europe saw a mixture of madhouses, witch-hunts and imprisonment as solutions, while the 18th century saw mental health disorders treated increasingly as a physical problem, with more humane treatments being proposed.

Insane asylums were all the rage in the 19th century, and the second half of the 20th century finally saw the dramatic impact of medications and a move toward keeping people in the community instead of institutions if possible.

A brain injury makes us much more vulnerable to developing a mental health disorder. In 2009, Professor Robert Robinson (Head of Psychiatry USA) provided the following figures on mental health issues after a traumatic brain injury:

- Depression: more than 30%, averaging 5.8 months
- Mania: 10%
- Irritability and aggression: 35%
- Pathological laughing and crying: 24%
- Alcohol abuse and dependence: 22%.

The good news is that there are plenty of treatment and support options available now. The stigma of having a mental health disorder is slowly disappearing too, as we realise that schizophrenia, depression, panic attacks and anxiety disorders can strike anyone at any age — it isn't a sign of a weak character, lack of intelligence or emotional laziness!

So what can be done? Professor Robinson reported that the amount of social support had a major influence on improving mental health, so family and friends can make a big difference. Major depression was a frequent cause of aggression, so if the depression was treated the aggression would usually diminish. Antidepressants appeared to dramatically shorten the length of depressive episodes in the majority of cases. And don't forget there are medical and psychological therapies for every mental health disorder.

A brain injury has such a huge wide-ranging affect on everyone's lives that is easy for emerging mental health issues to slip under the radar. **DD**

Turning gay after a brain injury?

In the UK, Chris Birch suffered a stroke after a freak accident and says he became gay as a result. Formerly a burly rugby player, he broke up with his fiancée and now lives with his boyfriend. He lost eight stone in weight and became much more conscious of dressing fashionably. He quit his job in banking and now works as a hairdresser.

In his own words, Chris said “I was gay when I woke up and I still am. It sounds strange but when I came round I immediately felt different. I wasn’t interested in women any more. I was definitely gay. I had never been attracted to a man before – I’d never even had any gay friends.”

In reality, this sort of sexual reorientation is rare – a far more common sexual change is simply a reduction in sexual drive, and to a lesser extent, an increased sexual drive. But in keeping with rare (and in this case more disturbing) cases, a 40-year-old man experienced uncontrollable paedophilia due to a brain tumour. The New Scientist magazine reported that the man began using child pornography web sites and using sex workers for the first time in his life. The man stated that he knew the behaviour was unacceptable but that the pleasure overrode the restraint.

The brain tumour was located in an area of the brain related to judgement, impulse control and social behaviour. His wife had him forcibly evicted when she discovered her husband had made subtle sexual advances towards young children.

These behaviours immediately stopped once the tumour was removed, but some years later he complained of headaches returning and began collecting pornography again. An MRI scan revealed tumour regrowth and it was removed, and once again the behaviour disappeared. ▶▶



Inappropriate sexual behaviours

These behaviours can be very distressing for partners and family.

Disinhibited sexual behaviour can include:

- sexual conversation or content
- comments and jokes of a personal or sexual nature
- inappropriate touching or grabbing
- sexual propositions
- exposure of genitals in public
- masturbation in a public place
- sexual assault.

Disinhibited sexual behaviour can be defined as a person not following social rules about when and where to say or do something. This means that sexual thoughts, impulses or needs are expressed in a direct or disinhibited way, for example:

- in inappropriate situation,
- at the wrong time
- with the wrong person.

THINGS TO TRY

Talk about behaviour

Talk to the person about their behaviour and what you expect. Let them know if behaviour is not appropriate — if they don’t know, they can’t change it. Let them know how the behaviour makes you feel e.g. “I feel uncomfortable when...”

Let other people know what strategies to use so there is a consistent response.

Provide feedback about the behaviour

Provide the person with frequent, direct and clear feedback. Feedback should:

- be immediate and early
- be direct

- be concrete and describe the behaviour
- give direction
- be consistent
- not reinforce or encourage the behaviour
- help the person to learn
- not be demeaning or humiliating
- not impose your own values

Manage the environment

Some individuals have limited insight and awareness about sexually disinhibited behaviour, and/or very limited capacity to change behaviour due to severe cognitive and behaviour impairments. In this case you may need to find strategies to manage the environment. For example:

- Try to predict situations where the behaviour is more likely
- Work out strategies ahead of time
- Restrict any opportunity to engage in inappropriate behaviour (planning, proximity, opportunity and means)
- Limit any “at risk” social activities e.g. crowded clubs or pubs or where alcohol is being consumed
- Provide cues about behaviour — what the person should and should not do — before, during, and after social activities
- Provide alternative activities (e.g. small groups versus large groups)
- Keep a comfortable distance so the person cannot touch, grab or get too close (e.g. when providing personal care).

Provide supervision & structure

- Provide one-to-one support and supervision in any “at risk” situations

- Provide cues and prompts about appropriate or inappropriate behaviour
- Redirect, distract or divert the person (e.g. more appropriate topics of conversation, or change the activity or task).

PLAN AHEAD

If a person has a history of severe disinhibited sexual behaviour (exposure, masturbation in public, or sexual assault), it is essential that you plan ahead regarding personal safety. Consider:

- having two people provide care
- limiting home visits
- supervising children
- limiting access.

In the person’s home

- always visit with another person
- make sure someone knows you are there when you visit
- take a mobile phone with you, and carry it at all times
- have your car keys in your pocket
- get familiar with the home, so you know where the doors are located
- keep a comfortable distance. For example, sit across a table, sit close to the door or exit.

ADDRESSING SEXUALITY NEEDS

A person may need others to give them space and privacy to express their sexual needs (e.g. privacy to masturbate, watch videos or to have a sexual relationship). Useful tips are:

Remember that sexuality is a normal part of life and just because the person has a disability because of their brain injury, does not mean they don’t have normal sexual needs.

WHY DOES IT HAPPEN?

Most people with brain injury do not have increased sexual libido after an injury. In fact decreased sexual libido is more common. There are a number of other reasons for disinhibited sexual behaviour:

- **Decreased awareness and insight, and poor self-monitoring of a person’s own behaviour (e.g. not realising conversation or behaviour is offensive to someone else)**
- **Impulsivity and disinhibition, resulting in behaviour that is not controlled by the usual social or interpersonal rules**
- **Thoughts, which are usually private, may be spoken out aloud**
- **Acting too hastily or on an impulse**
- **Not thinking about the consequences of behaviour (e.g. impact on relationships).**

Changes in communication skills can result in:

- **Inappropriate choices of jokes, comments, questions, or conversations**
- **Misunderstanding social relationships —believing a relationship is closer than it is**
- **Not picking up verbal and non-verbal cues and feedback from others (e.g. not picking up disapproval, dislike or fear)**
- **Awkward expression or inappropriate use of language**
- **Difficulties with social communication skills such as eye contact, social distance, space, and appropriate touching, may also cause social behaviour that makes others feel uncomfortable or threatened.**

Inability to express sexual needs may mean that:

- **Opportunity to maintain or form relationships is reduced**
- **Relationships are still just as important to the persons’ identity and self-esteem.**
- **Impaired cognitive, communication, and behavioural skills can reduce ability to make and keep new social and sexual relationships.**

Limited social opportunities and isolation can result in lack of understanding of appropriate behaviour.

Encourage the person to access information and advice regarding sexual activity and choices (contraception, sexually transmitted infections, safe sex practices). Information is available from:

- Family planning
- General practitioners
- Rehabilitation services.

EXTRA RESOURCES

- See other ABIOS fact sheets at www.health.qld.gov.au/abios/
- “You and Me” by Grahame Simpson, Brain

injury Rehabilitation Unit, South Western Sydney Area Health Service, 1999

- Talk to a Psychologist, Psychiatrist, Social Worker, or other professional. ▶▶

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Drug dependence & the family

Dependence on alcohol has a lot of stigma attached to it – it tends to skyrocket when drugs like marijuana, speed or heroin are involved. After a brain injury, any pre-existing dependency on alcohol or other drugs can be made worse by lack of employment, loss of friendships, impulsivity and depression.

Feeling powerless to help is one of the most distressing aspects when a family member is heavily dependent on drugs, but a harm reduction approach can be very proactive. It involves taking steps to reduce the chances of harm resulting from drug use, and keep the person in the best health possible until a choice is eventually made to decrease or cease drug use.

If the person is living at home, family members can learn the signs of drug overdose, how to treat it, and have relevant ambulance phone numbers on hand. Encourage the person, and their friends, to become acquainted with the same information so they can take care of each other should an overdose occur.

If your family member is homeless, try to maintain contact and keep an eye on their health. Encourage them to seek treatment for any sexually transmitted infections, scabies, lice and other common problems.

If the person is injecting drugs, encourage them to know the signs of hepatitis C. There is quite a lot of information available from Needle & Syringe Programs on how to inject drugs with greater safety – these government programs do not encourage drug injection but work with people who are injecting to minimise the potential harms until they choose to stop. Contact the Health Department in your State for details.

If people have contracted hepatitis C, their liver and immune system are vulnerable and can be easily affected. It is important to avoid viral illnesses such as the flu, which affects the immune system.

Dental care can be neglected but is very important. Many people don't realise there are free public dental services for anyone on benefits.

The possible spread of infection at birth to infants from their mothers also needs to be considered, particularly for pregnant drug users.

Mental illness often goes hand-in-hand with drug use but unfortunately there are very limited services available who can help with both issues when combined. Talk to your doctor or Brain Injury Association about how to contact these health services.

Don't be afraid to broach the topic of depression and suicide or seek help immediately if you think your family member may be affected. If they are at risk of harming themselves, contact your local Area Mental Health team. If the risk is immediate, or there is a threat to your safety, then contact the police. 🗨️



The war against drugs

Fighting the good fight or an immoral delusion?

Virtually all of us are into psychoactive drugs (drugs that can change our perception, mood or consciousness). While most of us will balk at injecting heroin or snorting cocaine, it is rare to find someone who does not regularly use tea, coffee, cigarettes or alcohol.

The 'war against drugs' had its beginning in the prohibition era in the USA during the 1920s with an attempt to prevent the drinking of alcohol. The campaign was largely a failure as drinking continued and organised crime became heavily involved in the production and distribution of alcohol. Health risks also increased due to the poor quality of the alcohol being manufactured.

Many people claim that the war on illegal drugs has led to the same situation – those who want to use illegal drugs continue to do so, organised crime makes a lot of money from both manufacture and distribution, and users suffer the health consequences of poor quality control over the end product.

Are we winning the war on drugs?

This does not appear to be the case. There is wider variety of drugs, used by more people and at younger ages than before. A substantial percentage of our prison populations are there for using illegal drugs, but imprisonment does not seem to act as a deterrent as re-offending is very common.

The issue is complicated by the fact that legal drugs such as alcohol and cigarettes have huge social costs to society but can be freely used by any adult with no restrictions.

The war on drugs has caused untold damage

to the USA. It has greatly inflated the prison population, directed massive amounts of money into law enforcement instead of treatment programs, and generated huge incomes for drug cartels and caused social problems in other countries as a result. Health issues range from overdoses to HIV, hepatitis C and other diseases.

In June 2011, the Global Commission on Drug Policy released a critical report on the War on Drugs, concluding: "The global war on drugs has failed, with devastating consequences for individuals and societies around the world. Fifty years after the initiation of the UN Single Convention on Narcotic Drugs, and years after President Nixon launched the US government's war on drugs, fundamental reforms in national and global drug control policies are urgently needed."¹

Why do we use drugs?

It is common to think that drug use is a recent invention or outcome from a supposedly decadent western society, but drugs have been part of the human experience since earliest history. This does not necessarily mean we should use drugs, but recognises that humans have always been curious and engaged in risk-taking behaviour such as mountain climbing, space travel or motor racing.

Alternatives to a war on drugs?

A war against illegal drugs could possibly be won, but only with massive law enforcement and the permanent imprisonment or execution of anyone involved with drugs deemed to be illegal. No government will go this far as it

would be a clear contradiction of human rights even for totalitarian regimes.

An ongoing debate in many countries is whether the major emphasis should be on treating drug use as a criminal issue (e.g. war on drugs as typified in the USA and Russia) or as a health issue, such as Holland where more effort goes into treating drug use as a health issue.

The first alternative is to keep certain drugs illegal but focus more on harm reduction – an approach adopted by Australia. More money is channeled into treatment programs and ensuring that if people choose to use illegal drugs, they are aware of the consequences and will at least know how to reduce the potential harms that can result.

Others advocate for making most, if not all, drugs legal but subject to varying degrees of regulation and control. The premise is that drug use should not be seen as a criminal issue, but more as a health issue. This is not to say that drugs such as heroin or speed should be freely available for sale – an example would be supply being strictly regulated by government clinics to known users who would have to register and undergo regular health checks and be offered treatment if wanted. This has already been happening in a very limited way in Australia with methadone clinics for heroin users.

Many of the health issues faced by users of illegal drugs are often not caused by the drug itself, but the poor quality of the drug (they are often mixed with 'fillers') and not being aware of ways to reduce potential harms.

Won't harm reduction increase drug use?

Harm reduction does not promote drug

use as a lifestyle option – it deals with the complex issue of minimising harm to illicit drug users until they reach a point where they choose, or are able, to cease their use. The aim of decriminalising certain drugs is not to encourage their use, but ensure that the drug can be regulated and reduce costs to society as a whole.

The brain injury perspective

Whether the drug is legally sanctioned or not, many people use drugs to enhance their lifestyles in some way. On the other hand, a certain proportion of people will have problems with their drug use – again, whether it is a legal drug or not. A brain injury can easily tip the balance and lead to a lot more problems than perceived benefits when it comes to alcohol and other drugs.

Brain injuries can be a recipe for drug problems – impulsive actions, inability to weigh the benefits and costs of drug use, unemployment, loss of friendships, boredom and depression.

While drugs may provide a temporary relief, they can play havoc with an injured brain that is already struggling to cope with everyday life. If a heavy dependency develops then a brain injury makes it harder to cease drug use, and support services are usually unaware of how a brain injury impacts on drug use. Seeing drug use as a treatment issue, and not a legal issue, for people with a brain injury will at least reduce the chances of them being imprisoned, and instead receiving support and treatment. 🗨️

¹ War on Drugs, The Global Commission on Drug Policy, 2011. p. 24.

Smoking pot for a brain injury?

Cannabis has attracted so much negative publicity with the "war on drugs" that we are only slowly discovering the many economic and medical benefits it may hold.

The medical use of cannabis dates back at least to 2737BC when Emperor Shen-Nung (who also happened to be a pharmacologist) included cannabis in his book on medical treatments – cannabis is still one of the 50 fundamental herbs in traditional Chinese medicine.

Research is steadily revealing that cannabis may be a possible treatment for many ailments such as PTSD, cancer, lack of appetite, vomiting, pain and insomnia. There are inherent risks with smoking cannabis, and any approved treatments will need to find a safer method of administration, and ensure the benefits outweigh any negative consequences.

Research in Israel at the Tel Aviv University indicates that cannabis in low doses can protect the brain after injury. Professor Same at Sackler Faculty of Medicine says that very low amounts of cannabis can protect our brain cells from long-term damage in the days after a person acquires a brain injury.

The doses are incredibly small – less than 0.1% of the amount of the drug received from one marijuana cigarette – and trigger processes in the brain that both prevent cell death and preserve our cognitive functioning.

It is interesting to note that these protective qualities also emerged if the doses were taken before the brain injury occurred. The researchers theorise that possibly the drug is causing minute damage to the brain, which triggers the brain's defences against injury.

Further research is underway to see if this same affect could prevent damage to the heart and reduce the chances of heart attacks. 🗨️

Journal Reference: Miriam Fishbein, Sahar Gov, Fadi Assaf, Mikhal Gafni, Ora Keren, Yosef Same. Long-term behavioral and biochemical effects of an ultra-low dose of Δ9-tetrahydrocannabinol (THC): neuroprotection and ERK signaling. *Experimental Brain Research*, 2012; 221 (4): 437 DOI: 10.1007/s00221-012-3186-5

Domestic violence & women with disabilities

Women with disabilities are more likely to experience domestic violence and for longer periods of time

Women with a disability may find it harder to seek help or defend themselves. Sometimes the abuser is also the main carer of a woman with a disability.

Domestic violence means violence that occurs in your home. Around one quarter of married women and women in de facto relationships in Australia experience domestic violence at some stage. Compared to women without disabilities, women with disabilities are more likely to experience violence and for more extended periods of time.

Types of violence

The different types of domestic violence experienced by women with disabilities can include:

- Hitting, punching, choking, kicking, pushing, burning with lit cigarettes
- Threats, such as threatening physical harm or threatening to have the woman institutionalised
- Threats against the woman's children, pets or guide dog
- Verbal abuse such as criticisms, putdowns and insults
- Taking control of the woman's disability aids against her wishes, such as moving her wheelchair around

- Damaging or threatening to damage belongings, including disability aids
- Neglect, such as refusing to wash or feed the woman or to hand over medications
- Performing care in cruel ways, such as washing her in cold water
- Refusing to offer help until the woman consents to sex
- Unwanted sexual advances, ranging from unwanted touching to rape
- Withholding information
- Making decisions on the woman's behalf without her consent
- Taking control of the woman's finances without her consent, including withholding money or not allowing her to shop for herself
- Isolating the woman from family, friends and services.

The abusers

According to Western Australian research, the abusers are:

- Male spouse or partner - 43 per cent
- Parent - 15 per cent
- Female spouse or partner - 11 per cent
- Other relative - 8 per cent
- Child - 7 per cent
- Another person e.g. a neighbour - 6 per cent
- Carer - 4 per cent

- Work colleague - 2 per cent
- Healthcare professional - 2 per cent
- House or flat mate - 1 per cent
- Clergy - 1 per cent.

Reasons for the violence

Compared to women without disabilities, women with disabilities are more likely to experience violence and for more extended periods of time. Some of the many reasons for this include:

Social myths - people with disabilities are often dismissed as passive, helpless, child-like, non-sexual and burdensome. These prejudices tend to make people with disabilities less visible to society, and suggest that abuse, especially sexual abuse, is unlikely.

Learned helplessness - people with disabilities, particularly people with cognitive disabilities or those who have been living in institutions for a long time, are encouraged to be compliant and cooperative. This life history can make it harder for a woman to defend herself against abuse.

Lack of sex education - there is a tendency to deny sex education to people with intellectual disabilities. If a woman with no knowledge of sex is sexually abused, it is harder for her to seek help because she may not understand exactly what is happening to her.

Dependence - the woman may be dependent on her abuser for care because her disability limits her economic and environmental independence.

Misdiagnosis - authorities may misinterpret a cry for help; for example, a woman's behaviour might be diagnosed as anxiety rather than signs of abuse. In other situations, workers may not be aware that domestic violence also includes financial or emotional abuse, or may not be sensitive to the signs.

The abuser takes control - if the woman seeks help, follow-up may be difficult because the abuser isolates her and prevents her from using the phone or leaving the house.

Why help isn't sought from authorities

One US study found that women with disabilities tend not to report the abuse themselves. Some of the many reasons why women with disabilities may not seek help from authorities and support agencies include:

- Shame
- Belief that she somehow deserves to be abused
- Belief that she is being abused because she is disabled
- Not knowing that she has any rights or that there are laws to protect her
- Not realising that the treatment she receives is abusive, because she has been treated this way her whole life
- Staying where she is and enduring the abuse

FEAR CAN STOP WOMEN FROM SEEKING HELP

Common fears include:

- Fear that no one will believe her
- Fear that no one will be able to help her
- Fear of being punished by the abuser for reporting the violence
- Fear of being shamed, punished or shunned by her family, friends and community
- Fear of loss - e.g. afraid of losing her home or having her children taken away from her
- Fear of being institutionalised
- Fear of having no one to help her if she leaves the relationship.

- may seem like a slightly better option than poverty, homelessness or institutionalisation
- Belief that the police and the courts don't take domestic violence as seriously as other kinds of violence
- Prior bad experiences with authorities - for example, a woman with a psychiatric illness may have had an upsetting experience with police in the past, which is why she won't consider contacting them for help
- Isolation - for example, the abuser may not allow her to use the phone or leave the house
- Lack of access to information, because the abuser chooses to withhold information from her
- Fear of negative outcomes.

Barriers to getting help

Disability policies tend to rely on family members taking care of the person, which is disastrous if the carer is also the abuser. Since the abuser is often the caregiver, the woman is denied information and access to help services.

The wide range of disabilities means there is no distinct 'group', so there is no 'one size fits all' policy to adopt nor any easy way to access all of the women who need help. Domestic violence workers may not be educated about the issues facing women with disabilities, and disability workers may not be educated about domestic violence.

The various agencies that help people with disabilities aren't cross-referenced as thoroughly as they could be, which creates service gaps. For example, a woman might be referred back and forth between two agencies, such as sexual assault services and disability services, without receiving help from either because she falls outside the guidelines of both agencies.

Studies and statistics on women with disabilities and domestic violence are few and far between, so agencies may not be aware of service gaps.

Where to get help

- Your doctor
- Police - phone 000
- Ambulance- phone 000
- Domestic Violence Crisis Centre (national number) Tel. 1800 633 937
- Women With Disabilities Australia - phone 036244 8288
- National Sexual Assault, Domestic Family Violence Counselling Service - free national telephone counselling hotline 24 hours seven days a week) phone 1800 737 732.

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Report on forced sterilisation

The Senate Community Affairs References Committee tabled the report of its inquiry into involuntary or coerced sterilisation of people with disabilities in Australia in 2013. The Committee made wide-ranging findings, including recommendations to strengthen the law and better educate medical practitioners, courts, people with a disability and their families about their rights and responsibilities

"This is a very personal and emotional issue, we are particularly grateful to those people across the community who made submissions, attended hearings and took part in this discussion, including many women with disability who were prepared to talk to the committee about their personal experiences," Committee Chair Senator Rachel Siewert said today. "This is a deeply personal matter for many individuals and their families, but ultimately, the human rights implications of undertaking an operation against an individual's free will are clear. . . When a person with a disability has the capacity to consent, either on their own or with appropriate support, sterilisation should be banned unless they give that consent."

The Committee made 28 recommendations that attempt to address the broad range of issues and concerns, some of which were:

- State and Territory legislation needs to be improved regarding the capacity to make decisions
- Improved court support including Legal Aid and Family Courts
- Each jurisdiction enact legislation prohibiting the performance or procurement of unauthorised sterilisation procedures
- Legislation is needed to make it an offence to take a person with a disability overseas for sterilisation
- Sexual and reproductive health needs of people with a disability must be discussed openly and planned for rather than ignored

"I am very pleased that the committee approached its inquiry from the perspective that people with a disability are entitled to seek loving relationships just like everyone else and to express their sexuality, just like everyone else" said Sue Boyce, Committee member and Queensland Senator. "The implementation of education, training and community awareness about independent decision making and the right to bodily integrity should significantly improve life for people with a disability, especially with improved community understanding, awareness, and acceptance of the right of the disabled to their sexuality." **DD**

Download and read a full copy of the report at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/First_Report

Memory problems?



Helen Lee reports on a free online tool for improving short-term memory issues

Wikipedia, defines memory as the process in which information is encoded, stored, and retrieved. Encoding allows information that is from the outside world to reach our senses in the forms of chemical and physical stimuli. In this first stage we must change the information so that we may put the memory into the encoding process. Storage is the second memory stage or process. This entails that we maintain information over periods of time. Finally the third process is the retrieval of information that we have stored. We must locate it and return it to our consciousness. Some retrieval attempts may be effortless due to the type of information.

Personally, I had some severe issues with both short-term and long-term memory. Whether the problem was from dysfunctional encoding, storage or retrieval, I am unsure. But I can tell you, that the impact on my life was phenomenal!

In my first year out of hospital, I remember one day asking my husband, "What do we have on for today, Wayne?" I could not remember if we had to pick my children from school or any doctor or therapist appointments. Each day was a complete mystery to me. I relied (and still do, to a degree) on Wayne for grocery shopping, driving, financial management and even the laundry! It was all I could do just to maintain a standing position without falling over because I had no sense of balance at all.

I was introduced to a website called Luminosity (www.lumosity.com) by a nursing friend who used it to maintain her own memory. The free tools on this website are designed to help ordinary people as they aged as

forgetfulness is a natural part of ageing.

Theoretically, the less you use your memory, the more likely you are to lose it. Lumosity is a computerised brain training program using neuroscientific theory which is personalised for each user to address issues including memory, attention, speed, flexibility and problem-solving.

You can choose which aspect of cognitive function you wish to exercise. The exercises appear to be simple interactive games but they have been designed by neuroscientists and can make a difference with just 10 to 15 minutes exercise each day.

The exercises have been evaluated through independent research studies which are posted on their website.

Other cognitive skills that can be improved are doing figures in your head, ignoring distractions, inhibiting inappropriate initial responses, making quick and accurate estimations, and more. Lumosity can track improvements and give you feedback on how you compare with other people in your age group.

When you first sign up with Lumosity, you will need to have an email account and a password. There is no charge. Personally, I feel that I honed many diverse aspects of my cognitive function.

Another on-line brain training program is Brain HQ but you need to pay for it though – approximately \$200 a year.

I highly recommend these types of applications for anyone hoping to improve their cognitive function, not just those of us who have acquired a brain injury. **DD**



Euthanasia

An individual right or the thin end of the wedge?

Euthanasia is when someone intentionally ends their life in order to relieve pain and suffering. It has been a hotly debated issue for many years throughout the world.

A brief history

The ancient Romans and Greeks practised euthanasia and often used hemlock, a poisonous plant. It was a widely supported practice but it is interesting to note that there was debate even back then. Hippocrates (author of the Hippocratic oath taken by many physicians worldwide) stated he would never give advice or a drug that would lead to someone's death. In 19th century Europe, drugs like morphine were used to ease suffering and it is argued these often hastened death, although this wasn't expressed as the main objective. In Nazi Germany, about 70,000 "handicapped" were murdered with gas vans and killing centres, but proponents of euthanasia argue this was murder and not euthanasia as there was no consent involved. Currently some countries have legalised voluntary euthanasia but in most countries it is still a criminal offence.

For & against

Supporters of euthanasia say people should have the right to end their own life, make their own decisions and avoid undue suffering. Others argue for the sanctity of life, whether it is based on religious or humanistic grounds. Common arguments against euthanasia are:

- not all deaths are painful
- alternatives, such as ceasing treatment and pain medications
- the distinction between active and passive euthanasia is morally significant
- legalising euthanasia is the thin end of the wedge.

Dr Philip Nitschke

The debate in Australia is frequently public as Dr Nitschke is an Australian who has become internationally famous as an advocate of euthanasia. He founded a pro-euthanasia organisation called Exit International and campaigned to have a legal euthanasia law passed in Australia's Northern Territory although it was quickly overturned by the federal government. "It seems we demand humans to live with

indignity, pain and anguish whereas we are kinder to our pets when their suffering becomes too much. It simply is not logical or mature. Trouble is, we have had too many centuries of religious claptrap" according to Dr Nitschke.

Exit International has established a long-term goal of responsible and ethical law reform. Its short-term goal is providing accurate information on how to end one's life. The organisation emphasises that ending one's life in the context of suffering and illness is legal, but that currently assisting a loved one to die is illegal.

Australian censorship

Dr Nitschke coauthored a book called the "Peaceful Pill Handbook" providing instructions on how to end one's life. In 2009 the Australian Government added this publication to their blacklist so that it is blocked on the Internet.

In 2010, a tv commercial was banned as an actor depicted a dying man requested voluntary euthanasia. **DD**



Living well, dying well & disability

Dr Di Winkler

In modern western society, we do not have conversations about death and dying. This topic inspires fear and denial. A recent survey by Palliative Care Australia found 37% of respondents did not feel their loved ones had enough information to carry out their wishes at the end of life. Whilst most people say “I’d like to die at home”, this study showed 46% die in hospital and 15% die in a nursing home. Starting conversations with our family and friends and having a plan about our future care wishes will significantly increase our chances of dying well. This planning also reduces the stress

on the people left behind – it makes difficult decisions simpler at a difficult time.

Advance care planning

The technical term for this plan is an Advance Care Plan, which “involves talking with friends and loved ones about your future health care wishes, documenting what you may or may not want, and can include appointing a substitute decision maker. It enables you to take control of your future health care and treatment if you are not able to communicate your wishes”.

Whilst Advance Care Plans often focus on medical and legal issues related to power of

attorney and ‘do not resuscitate’ orders, there is much more to planning a good life to the very end. A comprehensive plan involves answering questions like:

- What do you want when you are no longer independent?
- Who’s going to make sure your plan is followed?
- What do you want your loved ones to know?
- What do you want to hear at the very end, and from whom would you like to hear it?

There are a number of tools to help you work through these important questions including

Five Wishes, Good End of Life and Respecting Patient Choices. Depending upon where you live in Australia, there are different documents that you can complete.

Advance Care Planning with people with a disability

Avoiding conversations about death and dying is also a significant issue for people with disability. Planning a good end of life is yet another area where people with disability may be marginalised and disadvantaged. In our work with young people living in or at risk of admission to nursing homes, death and dying is often a taboo topic. Many people in this target group have degenerative neurological conditions and a limited life expectancy. Others have severe Acquired Brain Injury and, due

to their limited mobility, are at a high risk of a premature death from complications such as pneumonia. Many of these people are socially isolated and are less likely to have close friends or relatives with whom they can start these conversations, or have someone who can advocate for them within hospital settings. Our research has found that more than half of people with a brain injury living in group homes do not have a best friend in whom they can confide, and 60% receive a visit from a friend less than once per year. This research has also found that 25% of this group were hospitalised in the preceding 12 months. They live with a range of complex health conditions that can cause premature death, including pressure areas (10%), urinary tract infections (10%) and chest infections (18%).

Having the conversation

The earlier the conversation starts the better – it is much easier to have these conversations when the person is in good health. The more they deteriorate, the harder it can be to discuss death and dying. Making a plan is integral to enabling people with disability to live well until they die. However, our workshops and conversations with families, service providers, and peak bodies tell us that Advance Care Planning is not always offered to people with disability. While individual planning in the disability sector has a strong focus on living well – dying well is often not addressed, even when people have a degenerative condition or are susceptible to life threatening illness. A holistic approach to comprehensive advance care planning needs to be built into state-based planning processes, and the National Disability Insurance Scheme.

Hospital readiness

Hospital readiness is critical for people with a terminal illness, people with degenerative neurological conditions and people with disabilities who have secondary health conditions that may require acute hospital care. Ideally, the person and their support network need to think through issues regarding how active any medical intervention should be, and have a written plan prior to any hospitalisation. A personalised hospital information pack should be kept up to date and ready to take in the event of any hospitalisation of a person with disability.

This kit should include a one-page summary of the person’s medical history, medication and contact information for their GP, and any specialist doctors. Other essential information includes details of who has been appointed Enduring Power of Attorney, Medical, health insurance information, and decisions regarding a ‘do not resuscitate’ order or how active medical intervention should be. For people

with cognitive or communication issues, this hospital pack should also include details regarding their means of communication where available, and key likes and dislikes.

Avoiding a ‘disenfranchised death’ when death is near

People with disability are at significant risk of a ‘disenfranchised death’, which is when death is not openly acknowledged with the dying person. The dying person is socially excluded from the process of dying and deliberately excluded from the decision-making process surrounding terminal illness. In their last days, many people want quiet reassurance. They want to know that whatever they are worried about is going to be fine. A disenfranchised death can leave a person feeling lonely, disempowered, frightened and anxious in their last days.

Dealing with death

Some people find the prospect of being with someone when they die to be frightening – it is not always comfortable – but it is also a privilege. One useful brochure about what to expect and practical guidance when death is close is available from St John of God. Support workers based in residential settings who have attended our workshops have told us of the grief they experience in supporting people in their last days, and the impact on other residents. It is important to ensure that there is support and counselling available to staff and other residents. It may also be necessary within a work environment to identify those staff who feel they have the capacity to be a key worker at the end of life, versus those who may need to withdraw from this role.

Start the conversation now

In our homes and in our workplace, how do we start the conversation of dying well? Some useful resources for both people with and without disability include Judy MacDonald Johnston’s TED Talk, the Deathtalker website and a lovely coffee table book called Dying to Know.

Making a plan and supporting someone to die well may be the greatest gift you can give them. Now is the time to begin these conversations so that we all increase our chances of having a good end of life. 📖

References: The Summer Foundation is committed to growing a movement that will resolve the issue of young people living in nursing homes. There are three key areas of focus: research providing an evidence base for policy change, supporting people to share their stories, and keep the issue on the political agenda. Find out more about the Summer Foundation at www.summerfoundation.org.au



You matter because you are. You matter to the last moment of your life; and we will do all we can to help you die peacefully, but also to help you live until you die.”

— Dame Cicely Saunders, nurse, physician and writer, and founder of hospice movement (1918 - 2005)

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