STANDING COMMITTEE ON COMMUNITY AFFAIRS

SUBMISSION TO
References Committee

Inquiry into concussions and repeated head trauma in contact sports

Background

My name is Kathy Strong and I represent and provide a voice for my late husband Terry who passed away on the 12 December 2021. He was 68 years young when he passed away. Terry represents the grass roots, amateur rugby league player who played in an era where the game would be described as combative and tough. He enjoyed growing up on a dairy farm in Lismore with 4 brothers and a sister. His father instilled in him the value of hard work and strong physical and mental health. Work was hard on the farm and he learnt some tough life lessons, but he enjoyed a strong sense of family and community. He was taught never to sit idle and this was how he lived his life. We were happily married for 44 years and devoted to each other.

It was Terry’s wish that upon his death his brain be donated to the Australian Sports Brain Bank to aid research into preventing and treating brain disease and to hopefully provide answers to the family as to the underlying cause of his death. We were shocked but not surprised by the results of the autopsy. In 2020 he was diagnosed with and was receiving treatment for Lewy Body Dementia (a definitive diagnosis can only be given post mortem) and REM Sleep Behaviour Disorder. In August 2021 he broke his hip and following treatment in hospital his dementia rapidly progressed.
The brain autopsy was performed by A/Prof Michael Buckland, Neuropathologist, Royal Prince Alfred Hospital Sydney.

Autopsy Summary

* **the dominant pathology is severe (high-stage) chronic traumatic encephalopathy (CTE)**
- the pattern of the tau deposition in the CTE lesions were somewhat unusual and differed from the almost pure neuronal tau seen in younger brains which suggested the CTE lesions have developed over a significant period of time (many years).
* **Cavum septum pellucidum**
* **probable coexistent FTLD-tau,** indeterminate sub type
    - predominant basal ganglia involvement
* **brain stem predominant Lewy body disease**
* **low stage Alzheimer disease neuropathologic change**
* aging-related tau astrogliopathy (ARTAG)
* small vessel disease
    - hyaline arteriolosclerosis, subcortical white matter (moderate)
    - medial calcific sclerosis, deep grey nuclei (severe)
* vascular injury, 3-4mm lacunar infarct, putamen (old)

As a family we are appreciative of the ongoing support provided by the Sports Brain Bank and Concussion Legacy Foundation Australia. The opportunity to connect and share our family's CTE story with others of similar experiences has been comforting and worthwhile.

Sports History and club practices at the time of injury with regard to monitoring and reporting

Terry was a very fit, healthy man, always involved in sporting activities. He played golf, grade cricket in his 20s ran in the City to Surf on 3 occasions, walked 4km regularly, worked out in a home gym, enjoyed fishing, kayaking and swimming. Upon retirement in 2013 he took up lawn bowls, joined the local gym and dragon boat club. He took great pride in being fit and always maintained a healthy weight of 78kg, so it was a great shock when he was diagnosed with dementia.

Terry played rugby league football during his high school years and 1st grade club football and representative football for Group 6 in the 70's and early 80's. His last game of football was in 1984. Terry loved the game and joining the football club was a way of making new friends and fitting into a new community when the family moved off the farm and started a new life 800 kilometres away. He accepted that injuries were part of the game because he loved the game. Of course, way back then he wasn't aware of the risk concussions have on the brain and I don't believe it would have stopped him from playing. He played centre and second row and his brother described him as a strong defensive player, always going in low for tackles and often copping a few knees and hips to the head. He was often concussed. Head high tackles were a frequent part of the game. It was no wonder Terry had arthritic knees and needed a shoulder replacement in 2017. During his football career he suffered many concussions and usually played through them. On a couple of occasions he was knocked out and unable to return to the field. Terry also played touch football, was elbowed and suffered a broken jaw and concussion.

During this era of football most players were given smelling salts and sent back on and no advice was given to players in regards to taking time off work or seeking medical advice, nor were they stood down from the next game. Terry was on a contract and only paid for the games he won so that was definitely an incentive to return to the field. The only records kept on the games relate to tries scored and goals kicked, nothing on the injuries sustained by players. A number of the players Terry played with have passed away or are suffering from motor neuron disease or dementia.

The football club at the time provided no advice to players on seeking medical treatment after the game, potential risk or recovery periods. There was no monitoring and reporting of concussions. Even today there are repeated incidents where officials and medical personnel do not take precautionary and conservative measures in this area because it will affect the game. Recent incidents in Rugby Union, international fixtures and the NFL still convey the focus on a return to play model rather than a conservative approach that could maintain health long term.

Today's game would benefit from comprehensive record keeping. If there are incidents of repeated head trauma the player should be advised by an independent medical official and be required to have mandated time off the field. These mandated time frames should be established and enforced across all professional, amateur and youth sports. (If only Terry had been give this advice he might still be with us today). Strict concussion protocols should be followed by trainers and coaches. There should be some form of player insurance available. There was no financial support I could access for Terry and at the time of his illness there was little information available about CTE.

Diagnosis and resulting mental, physical, social and professional impacts

The autopsy report indicated Terry had suffered from CTE for many years. The incidents over his final years did not reflect his identity and personality. These incidents are difficult to relive but need to be told to provide an insight into what it is like for CTE sufferers and their families. It was like a roller coaster ride, so many ups and downs and fluctuations in his cognitive ability, executive thinking and alertness.

I never knew when to expect the vivid dream enactment and hallucinations. The following are specific examples of the social, physical and emotional changes that the family encountered. **The dot points outline his aggressive behaviours, cognitive decline and incidents that occurred, usually on more than one occasion, and over a 2 year period increasing rapidly during his 4 months in hospital.**

- Repeated accusations of infidelity
- physical assaults in the context of protecting the family from the images of his REM sleep disorder
- fashioning weapons in preparation
- jumping out of a window after an ‘intruder’
- wandering during the night and leaving the house
- paranoia, suspicion and misinterpreting what others were saying
- aggressive outbursts
- suffering physical injury as a spouse
- frequent headaches and self medicating on panadol
- suffering anxiety and feelings of worthlessness
- hallucinations; snakes, spiders, bears, mice or children in the room
- poor memory and concentration
- unable to follow simple written or oral instructions
- disjointed speech and comprehension
- becoming more disengaged in conversations and losing confidence
- incontinence which caused him a great deal of anxiety and frustration
- sleeping 2-3 hours a day
- mood swings
- difficulty regulating his body temperature
- Parkinsonism

Terry was always unaware and had no recollection the next morning of his aggressive behaviours. I was starting to fear for my safety. I realised seeking medical help was going to be slow and difficult, so I began researching his symptoms on the net and suggested to the doctor he might have REM sleep behaviour disorder. I discovered quickly that not a lot was known about this sleep disorder and Lewy Body Dementia, even within the medical profession. The doctor finally referred him to a psychologist (he thought he had mental health issues). The psychologist suggested it could be sleep apnea and recommended a sleep study. We obtained a referral but then COVID hit and his sleep study was postponed. After a particularly violent incident I contacted the sleep doctor and he immediately recognised it as REM Sleep Behaviour Disorder. He contacted our family doctor and told him to immediately prescribe clonazepam as ‘**men have been known to kill their wives while experiencing a REM episode’**. He recommended Terry have an MRI and see a neurologist. Finally our family doctor recognised the seriousness of Terry’s condition.
I was now beginning to notice major changes in Terry's cognitive behaviours and executive thinking. Fortunately Terry was referred to a neurologist who recognised the symptoms and diagnosed Lewy Body Dementia. Terry was relieved he now had a diagnosis, it gave him a reason for his extreme behaviours. The sleep doctor recommended he see a geriatrician. On his first visit we asked if his behaviours could be related to the numerous concussions he experienced as a child and playing football. At that stage not much was known about CTE so it wasn't something the geriatrician knew a lot about. She prescribed an exelon patch which helped with the cognitive issues and hallucinations.

We were managing his behaviours as best we could with help from the medication and trying to avoid the triggers that caused the extreme behaviours. Many of our friends weren’t aware he had dementia as I was able to cover for him if an issue arose and I had always managed the finances and organisation of trips, social events etc.

Most of his behaviours were at night so unfortunately I copped the brunt of it. It was very distressing for Terry to know that he was being very aggressive towards me and making such wild accusations. It was so sad to see such a wonderful, kind man turn into someone that at times I didn’t recognise. It was always best if I didn't tell him about the worst incidents and I would have to remind myself it wasn’t him behaving this way it was ‘Lewy’.

I couldn't share what I was going through with friends because I wanted to protect his dignity and privacy. He was frustrated he had to give away his golf and lawn bowls and had difficulty completing household chores. At times I felt isolated and alone, especially as this was occurring during COVID. I lost my independence because I couldn’t leave him at night. We always tried to remain engaged with our friends and family, but our sons were becoming very concerned for my safety and their father’s gradual withdrawal from enjoying family events. It put a terrible strain on our marriage and family. Lewy Body Dementia and CTE are awful diseases! Studies from Boston University have shown a link between CTE, REM Sleep Behaviour Disorder and Lewy Body Dementia

Sadly on August 2021 Terry fell onto a concrete platform while guiding the dragon boat into the shed after a training session. After admission to hospital and the administration of strong painkillers he had a major psychotic episode while waiting for a hip operation. The decision was made to patch his hip instead of a hip replacement because of his adverse reactions to anaesthetic. He was in ICU for 2 weeks and transferred to the Geriatric Unit. Due to his violent outbursts and acting out he was assigned a permanent wardsman. He remained in hospital for 4 months. My dear, wonderful husband of 44 years became a shell of a man and I watched him being slowly tortured by his brain. He was at times delusional, psychotic and paranoid. Every time I visited him he was living in a different reality. I'm grateful for the wonderful care and compassion he received from the doctors and nurses at Shoalhaven Hospital but after 4 months of Terry being under extreme stress and his body shutting down it was decided to begin palliative care and he sadly passed 4 days later.

It is time the long term effects of concussion and repeated head trauma are investigated and addressed. The impact of concussions on the individual and their family needs to be examined and supported with greater financial assistance for research and clinical trials and government needs to ensure sporting associations are responsible and accountable for the welfare of players. Without awareness, research, and a determination to make sport safer for players the unspoken events mentioned above which affect the long term health of players and impact their families will continue to occur across the country.