Joint Position Statement of the Concussion and CTE Coalition February 2024

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Concussion and Chronic Traumatic Encephalopathy in Australia

Summary

- Research has identified an increasingly strong causal link between repeated head injuries and chronic traumatic encephalopathy (CTE).
- Traumatic Encephalopathy Syndrome (TES), the in-life signs and symptoms of CTE, can be evaluated by a specialist clinician but CTE is only confirmed after death by neuropathology testing.
- TES is characterised by a range of significant impacts on cognitive function and comprises the typical pattern of dementia.
- There are several different populations at risk of TES/CTE, including domestic and family violence survivors, military personnel, and contact and other sports participants.
- Each at-risk population has specific needs in terms of services and supports.
- The establishment of a national registry for concussion and CTE is important to quantify the extent of the problem.
- Improving community awareness of the risk factors for TES/CTE, and promoting prevention measures are urgent national priorities.
- In-life research into TES will facilitate improved approaches to detection and management, as well as targets for cure.
- Developing tailored supports and services and funding ongoing research into TES and CTE are equally urgent imperatives.

Background

Traumatic brain injury (TBI) results from an impact to the head and its severity can range along a continuum from mild (a brief change in mental status or consciousness) to severe (extended loss of consciousness, prolonged amnesia, or death). The impact can be direct, as in a forceful blow, or indirect, as in a whiplash. Repeated head injuries can take the form of smaller impacts without symptoms (subconcussion) or result in symptoms (concussion). Concussion can trigger reactive changes within the brain, called mild traumatic brain injury (mTBI). Increased exposure to repeated TBI increases the risk of neurodegenerative disease in later life. International research findings have established strong circumstantial evidence for a causal link between repeated TBI and the neurodegenerative condition known as CTE.[i] The incidence and prevalence of CTE in the Australian community remains unknown, but worldwide it is understood that a greater than 10-year exposure to repeated brain injury, markedly increases the risk of CTE and that this risk rises in a cumulative fashion as more TBI is sustained.[ii]

CTE is a type of dementia that was first identified in 1928, when a group of boxers were described as having 'punch drunk syndrome', also referred to as 'dementia pugilistica'.[iii] [iv] The condition can be provisionally diagnosed by clinicians but can only be definitively confirmed by tissue examination after death. CTE may affect brain function over time and can result in changes in mood, personality, behaviour, and cognitive function. During life, this is referred to as Traumatic Encephalopathy Syndrome (TES). Characteristically, people with TES can experience irritability and anger, often in response to no apparent or insignificant triggers. This can result in those around a person with TES treading carefully and being mindful of their interactions with the individual. A person with TES may not be fully aware of their symptoms, and it can be important for their doctor to understand the perspective of those supporting them.

Participants in contact sports are the most commonly researched at-risk cohort, but research shows that family violence survivors and military personnel who experience TBI are at an even higher risk of developing TES.[v] There are no accurate statistics on the incidence of TES or CTE in Australian Indigenous communities but, in the context of TBI and dementia, it is notable that head injury as a risk factor for dementia is present at higher levels for Indigenous individuals compared with their non-Indigenous counterparts.[vi]

Issues

There is an expanding body of international research on TES and CTE alongside an increasing mainstream media focus on the condition in relation to contact sports. Despite this, there is limited community awareness about the risks and consequences of TBI, TES and CTE in contact sports. Community understanding about the impact of these conditions in other vulnerable populations, including survivors of family violence and war veterans, is even more limited.

There are no nationally agreed and adhered to guidelines for the reporting and management of brain injuries in Australian sporting codes at all levels, and consequently there is likely to be significant under-reporting of brain injuries. This is especially so for subconcussion in the absence of monitoring technology to detect these subclinical events. The current protocols and practices for managing head injuries in a range of Australian sporting codes across all age groups and amateur and professional levels are not always guided by, or consistent with, current evidence-based findings. Research on TES and CTE is often restricted to male athletes in traditionally male-dominated sports, to the exclusion of female athletes, despite their higher risk of more severe and prolonged concussion.

Given the circumstances under which survivors of family violence and war veterans sustain head injuries, symptoms and consequences are also likely to be significantly under-reported in these 'hidden' cohorts. It has been estimated that the number of women who have experienced head injury due to intimate partner violence (IPV) and

domestic violence is eleven to twelve times greater than the number of injuries experienced by military personnel and athletes combined.[vii] A lack of research investigating TES and CTE in these populations and limited clinical awareness of the signs and symptoms are also contributing factors to delayed diagnosis and misdiagnosis.

Single or low number mild traumatic brain injuries are unlikely to be associated with neurodegenerative disease. Where possible, steps should be taken to minimise the risk of sustaining repeated and prolonged mild traumatic brain injury in the community. For those who have a history of repeated and prolonged mild traumatic brain injury, often over years, clinical monitoring for cognitive decline should be considered. Ancillary neuroimaging and cognitive assessment tools in the diagnosis of dementia may be considered as discussed in the **Clinical practice guidelines and principles of care for people with dementia: recommendations.**

CTE has been diagnosed in people as young as seventeen but is typically observed some years after head injuries are sustained, in people from their thirties onwards. Affected individuals are a predominantly younger cohort and their treatment, care and needs can be distinct from those living with other neurodegenerative conditions or other forms of dementia. Services and support for people with TES need to be adjusted accordingly.

Our position

The Concussion and CTE Coalition make the following recommendations to improve community understanding of TES and CTE and risk reduction measures, and advocate for appropriate services, supports and research initiatives:

Recommendation 1: Education to improve awareness and promote risk-reduction measures in relation to TES and CTE[viii]

TES and CTE are *preventable* conditions and can be avoided or minimised by preventing head injuries and/or managing a head injury or concussion effectively by following evidence-based, best practice guidelines. There is an urgent need to improve awareness about the risks of head injuries and promote the importance of risk reduction measures in the broader community, the health sector, and organisations and institutions supporting groups and individuals at higher risk of developing TES and CTE.

Education measures could include:

- Public health campaigns addressing the importance of good brain health *over the life course* including clear messaging around ways to prevent the cumulative risks of both concussive and subconcussive events.
- Tailored campaigns/information and resources for First Nations, culturally and linguistically diverse (CALD), veteran, survivors of family violence and other diverse and at-risk communities.
- Education programs and initiatives around brain health from pre- and primary school level through to older ages; for the latter, self-monitoring of brain health and brain injury could be encouraged by the use of apps (Dementia Australia's **BrainTrack app** for example) and other tools and resources that assess and track brain health.

- Education on TBI, TES and CTE for health professionals including specialists, GPs, nurses (including nurse practitioners), and allied health professionals (particularly social workers and psychologists).
- Targeted education on TBI, TES and CTE for sporting bodies and associations, services supporting survivors of family violence and the veteran community, and other relevant organisations and services.

Recommendation 2: National guidelines for contact sports[ix]

Leading Australian researchers and clinicians working in the field of TBI, TES and CTE in contact sports have called for national guidelines to be developed in Australia. These guidelines could include specifying the age at which participation could safely commence, and head injury management protocols including mandatory time away from the sport after head injury. The guidelines should encompass subconcussive risk, TES and CTE. These guidelines would ideally be applied consistently across all contact and other sports under a revised and regulatory framework. Detailed and meaningful engagement and consultation with sporting clubs at all levels, from amateur (non-elite) to professional (elite), would be critical in the development and implementation of these national guidelines. Regular, transparent, and independent reviews will help to ensure that modifications to guidelines are realistic and effective in mitigating and managing head injuries for participants in Australian contact and other sports.

Recommendation 3: Tailored services and support for people living with TES

At-risk populations for TES and CTE are primarily, although not exclusively, younger individuals. Given the singular circumstances in which each at-risk population experiences brain injury and develops TES, these populations will have different services and support needs. Given the complex, long term physical and psychosocial impacts associated with neurodegenerative conditions including TES and CTE, we support a concerted focus on research, policy and planning to determine how best to provide services and support for each of these

at-risk populations. People living with TES, and their family members and carers, must be involved in co-designing the planning of services and supports to ensure these meet their needs.

Recommendation 4: Data collection and research

Improved data collection and research is a critical part of improving community awareness about the risks and consequences of TBI, TES and CTE across all vulnerable populations. Funded measures could include:

- The establishment of a centralised national database requiring rigorous and detailed reporting of brain injuries in any context.[x]
- Support for First Nations-led, culturally sensitive initiatives to monitor and report the prevalence and impacts of head injury and concussion in First Nations communities.
- Funding for research to develop risk assessment tools, improved preventative and harm-minimisation strategies, and other resources aimed at preventing and reducing head injury and its consequences for all at-risk populations.[xi]
- Funding of independent and rigorous longitudinal research on people who are at risk of TES and CTE to ensure a better understanding of the long-term impacts of brain injury between the in-life experience and the symptoms and development of CTE-related dementia.[xii]

[i] C. J. Nowinski, et al. Applying the Bradford Hill Criteria for Causation to Repetitive Head Impacts and Chronic Traumatic Encephalopathy. Front. Neurol. 13, (2022), 938163. DOI: **https://doi.org/10.3389/fneur.2022.938163**

[ii] D. I. Katz, et al. National Institute of Neurological Disorders and Stroke Consensus Diagnostic Criteria for Traumatic Encephalopathy Syndrome. Neurology 96, (2021), 848–863. DOI: **https://doi.org/10.1212/WNL.0000000000011850**

[iii] A. R., Changa, R. A.Vietrogoski, & P. W.Carmel. Dr Harrison Martland and the history of punch drunk syndrome. Brain, Volume 141, Issue 1, 2018, 318–321, **https://doi.org/10.1093/brain/awx349**

[iv] Dementia is an umbrella term for multiple neurocognitive disorders and includes Alzheimer's disease, vascular dementia, and many other conditions. Dementia can affect all cognitive domains including thinking, memory, executive function, and emotional and behavioural regulation. The impacts on brain function are often significant enough to interfere with a person's day to day functioning and their ability to socialise and work.

[v] A. C. McKee & M. E. Robinson. Military-related traumatic brain injury and neurodegeneration. Alzheimer's and Dementia, 10, (2014) S242–53. DOI: **https://doi.org/10.1016/j.jalz.2014.04.003**

[vi] Australian Institute of Health and Welfare, Population health impacts of dementia amongst Indigenous Australians. **https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/dementia-in-vulnerable-groups/population-health-impacts-of-dementia-among-indigenous-australians, 2022**

[vii] Lifshitz, J., Crabtree-Nelson, S. & Kozlowski, D. A. Traumatic Brain Injury in Victims of Domestic Violence. Journal of Aggression, Maltreatment & Trauma 28, (2019), 655–659. DOI:10.1080/10926771.2019.1644693

[viii] This recommendation aligns with Recommendation 7 in the report from the Australian Government Senate Inquiry into Concussions and repeated head trauma in contact sports. Australian Government (2023). Community Affairs References Committee Concussions and repeated head trauma in contact sports. **https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000082/toc_pdf/Concussionsandrepeatedheadtraumaincontactsports.pdf**

[ix] This recommendation aligns with Recommendations 10 and 11 in the report from the Australian Government Senate Inquiry into Concussions and repeated head trauma in contact sports. Australian Government (2023). Community Affairs References Committee Concussions and repeated head trauma in contact sports. **https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000082/toc_pdf/Concussionsandrepeatedheadtraumaincontactsports.pdf**

[x] This recommendation aligns with Recommendation 1 in the report from the Australian Government Senate Inquiry into Concussions and repeated head trauma in contact sports. Australian Government (2023). Community Affairs References Committee Concussions and repeated head trauma in contact sports. **https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000082/toc_pdf/Concussionsandrepeatedheadtraumaincontactsports.pdf**

[xi] This recommendation aligns with Recommendations 7 and 8 in the report from the Australian Government Senate Inquiry into Concussions and repeated head trauma in contact sports. Australian Government (2023). Community Affairs References Committee Concussions and repeated head trauma in contact sports. **https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000082/toc_pdf/Concussionsandrepeatedheadtraumaincontactsports.pdf**

[xii] This recommendation aligns with Recommendation 3 in the report from the Australian Government Senate Inquiry into Concussions and repeated head trauma in contact sports. Australian Government (2023). Community Affairs References Committee Concussions and repeated head trauma in contact sports. **https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000082/toc_pdf/Concussionsandrepeatedheadtraumaincontactsports.pdf**