





Concussion and CTE Coalition 2024-25 Pre-budget submission

Concussion and CTE Coalition members

 <p>Dementia Australia®</p> <p>Dementia Australia https://www.dementia.org.au/</p>	 <p>Brain Foundation</p> <p>The Brain Foundation https://brainfoundation.org.au/</p>
 <p>Connecters AUSTRALIA</p> <p>ConneCTers Australia https://connecters.org.au/</p>	 <p>THE UNIVERSITY OF QUEENSLAND AUSTRALIA</p> <p>Associate Professor Fatima Nasrallah, Queensland Brain Institute, University of Queensland https://qbi.uq.edu.au/</p>
<p>Dr Rowena Mobbs Mater Hospital Sydney</p>	

Introduction

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. Research has identified an increasingly strong causal link between repeated TBI and chronic traumatic encephalopathy (CTE).

CTE is a type of preventable 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'. 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. People living with CTE may be unaware or only partially aware of their symptoms. There are several different populations at risk of CTE, including contact and collision sports participants, domestic and family violence survivors, and military personnel. It is unknown how many people are currently living with probable CTE, but the need for support and for prevention initiatives is clear.

Our joint pre-budget submission outlines two proposals to:

- Pilot a national program of support for people living with CTE, their families and carers.
- Develop a community awareness and education campaign about concussion and CTE – and to prevent CTE.

Total investment over 3 years: \$17,639,550

Support for people living with CTE and carers

At-risk populations for CTE are primarily, although not exclusively, younger people who will have different services and support needs due to the specific symptoms (including unique behavioural changes along the anger spectrum) and life stage. Specific knowledge and education are required to appropriately meet their support needs.

We propose the development of a national program of support specifically for people living with CTE and their carers. Dementia Australia will pilot a national program, based on the Concussion Connect support group model. An outcome and impact evaluation will be conducted by the Queensland Brain Institute (QBI).

Dr Rowena Mobbs founded the Concussion Connect support group in 2020 and qualitative feedback has been positive. Regular face to face meetings with people living with probable CTE and family are held and can offer immediate broad neurological or neuropsychological advice, validate concerns of patients and families, enable social connection, and facilitate access to services of dementia support such as Dementia Australia, occupational therapy or the National Disability Insurance Scheme (NDIS).

Programs will be delivered in a mix of metropolitan and regional areas across Australia. Suitable participants will be screened and selected from neurology services nationwide as well as via the National Dementia Helpline.

Alternating groups will meet quarterly at each site, with people living with probable CTE and their carers/family members seen in separate rooms to allow for tailored support. The program will be facilitated by Dementia Australia Dementia Support Specialists, with clinical advice and support provided by neurologists and neuropsychologists.

Investment: \$839,550 over 3 years

Community awareness and education campaign in schools

In the final report of the Senate Inquiry into Concussions and repeated head trauma in contact sports (September 2023), it was recommended that the Department of Health and Aged Care consider how best to improve community awareness and education regarding concussion and repeated head trauma.

In response to this recommendation, we propose to develop an evidence-based, national public health awareness and education program to protect the brains of Australian school children.

Brain health in contact sport has come under increasing scrutiny with concussion and its potential long-term outcomes a major concern for participation and safety.

Governments around the country for many years have committed to impactful, comprehensive and established mental health and well-being programs in schools. Just as many schools have vegetable gardens to encourage healthy eating habits, and programs such as Munch and Move in NSW encourage health, nutrition and physical activity information, establishing a national brain health program and culture in schools is important to ensure healthy brain development with a focus on concussion prevention, detection and management.

The program will educate and raise awareness among teachers, parents and school children about the importance of protecting their brains while participating in sports. Good brain health is essential to help all Australians to thrive and perform in all aspects of life.

The program will aim to ensure they are able to recognise the acute signs and symptoms of concussion, as well as the inherent risk of subconcussion; appropriately respond to and manage such injuries; and understand the short- and long-term risks of repeated head trauma.

It will empower target audiences with knowledge and lifelong skills to make informed decisions regarding brain safety, reducing the risk of sports-related brain injuries, and promoting overall brain health.

Stage 1: Consultation and strategy development

A strategy will be developed after a 6-month consultation with teachers, parents, students, researchers, sports organisations and other relevant sector stakeholders and in partnership with the Departments of Health and Aged Care; Sport; and Education. This will include an embedded Diversity and Inclusion strategy as well as engagement with regional, rural and remote schools.

Stage 2: Program design, development and implementation

While the final program developed will be based on the consultations, a proposed strategy and program for an awareness raising campaign and education initiatives, activities and engagement strategies to promote brain health in schools to assist in understanding what could be achieved.

Awareness raising

We propose an awareness raising campaign for the launch and ongoing across three years to include developing a website, media campaigns, social media activity, EDMs (electronic direct mail) and sharing through stakeholder networks and channels. This will include paid campaign activity. The campaign will include establishing an annual calendar day/week of brain health for focus.

The program will include digital and downloadable templates and resources and we will encourage all schools to develop their own Brain Health Action Plan using a supplied template.

The Action Plan template will have suggestions and recommendations on key messages, policies and protocols, links to resources and research updates, activities, audience engagement, utilising resources, developing a school's individual objectives and timelines.

Schools will be able to develop an Action Plan tailored to their local capacity. The sharing of Action Plans will encourage school-to-school learning and sharing of outcomes. Schools will log their Action Plans with the program to assist with ongoing program measurement of impact and evaluation.

We will develop resources accessible via a website to enable teachers, volunteer parents and students to deliver workshops, organise assemblies and presentations. We will also deliver comprehensive digital dissemination strategies to ensure program reaches all schools, including regional, rural, remote areas.

Promotional brain health packs could be shared with schools that log their Action Plan to include posters, banners, badges, stickers and materials highlighting the importance of brain safety with all ages in mind - including digital branding to enable them to highlight on their school website, at entrances and on noticeboards that they are a brain health school.

We would develop Concussion Community Advocates and high-profile Concussion Champions (locals and celebrities who kids look up to) group of volunteers to champion the program. They could record video messages and be the 'Face of' the program online and at in-person events.

While the focus of the program would be on sports, all audiences would be exposed to brain health messaging to empower and inspire a lifelong approach to brain health.

Education

This involves educating schools, parents and teachers about head trauma, concussion and the risk of CTE.

Similar successful Australian school health initiatives would be reviewed such as Asthma Friendly Schools in Victoria, the Munch and Move program in New South Wales, and the Food Allergy Aware School program in Queensland to develop a grassroots schools-based program to educate teachers, students and parents about concussion, brain injury and CTE.

To reach as many primary and secondary schools as possible partnerships with key stakeholders including government agencies, health and sports organisations, and education bodies will develop and implement a program aligned with national and state-wide initiatives and with the support of key decision-makers.

We will provide training and resources for schools which could include online modules, fact sheets, and enable delivery of face-to-face workshops and toolkits. We will develop incentives for schools to participate, such as awards or a brain health challenge. We will develop a stakeholder engagement strategy to sustain engagement with and action by leaders in the Australian education sector and community.

Student Concussion Champions could include school nominated students trained to serve as peer educators to inspire and motivate students to prioritise brain safety. We will provide them with resources and online training modules to conduct small group discussions, presentations, and awareness activities. Resources will be provided to enable these Concussion Champions to organise engaging events at school, such as brain health days, where students can learn about brain safety through interactive exhibits and games.

The program will be evaluated to assess its effectiveness and to ensure ongoing continuous improvement through surveys, focus groups, and potentially tracking the incidence of sports-related brain injuries in participating schools. Data and other information will also be sourced from the Action Plans.

Investment: \$16,800,000 over 3 years

Stage 1: Consultation and strategy development - \$300,000, one off cost

Stage 2: Program design, development and implementation - \$16,500,000