

## Information Statement

### The Silent Struggle: Share your CTE story

#### 1. What is this initiative about?

We are collecting stories from people who are living with CTE (either diagnosed or suspected) about the reality of life with this condition.

Taking part in this storytelling is voluntary. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

#### 2. Who is collecting the stories?

The stories are being collected by [ConneCTErS Australia](#).

ConneCTErS Australia Ltd is a not-for-profit charitable organisation which exists specifically to support individuals with Chronic traumatic encephalopathy (CTE) and their loved ones.

Our mission is to [promote CTE awareness, prevention and clinical research; and support individuals and their families living with CTE in achieving better health and life outcomes.](#)

#### 3. Who can take part in the story telling?

Participation is open to people who -

- Have been diagnosed with CTE by a medical professional,
- Are under the care of a medical professional with no diagnosis yet,
- Have concerns about their health in relation to possible CTE.

You can tell us your story if you are the person with probable or suspected CTE, or if you are their partner or a family member or friend.

#### 4. What will the storytelling involve?

You are being asked to tell us -

- Your name.  
We will not use your name unless you authorise us to do so.
- Your relationship to the person in the story,

- Where the person in the story lives (postcode only). This is to help us ascertain the geographical areas where further support services may be required.
- The diagnostic status of the person in the story.
- The story in your own words about your, or your loved ones, journey with CTE.

## 5. Can we withdraw once started?

Contributing to this storytelling is completely voluntary and you do not have to take part.

Any decision will not affect current or future relationships with the ConneCTErS Australia.

If you decide to withdraw before completing the storytelling form any information collected will not be used.

## 6. Are there any risks or costs?

It will not cost you anything to take part in this storytelling apart from your time.

The only risk we foresee is if you become upset telling us about your experiences. If you do become upset during or after telling us your story, you can contact Lifeline on 13 11 14. Lifeline has trained people who can listen and give you support.

## 7. Are there any benefits to taking part in this initiative?

When individuals share their stories, they do more than recount events; they connect with others on a deeply human level. For those living with probable CTE, speaking out can be a powerful tool for change. It can:

- **Educate the Public:** Many people are unaware of CTE's existence or its symptoms. Personal stories can illuminate the reality of living with CTE, fostering greater understanding and empathy.
- **Encourage Early Detection:** By sharing the signs and progression of their condition, individuals can help others recognise the symptoms early, leading to prompt medical attention and support.
- **Promote Research and Support:** Personal accounts can highlight the need for more research and better support systems, potentially influencing policymakers and healthcare providers to allocate more resources to this cause.

- Reduce Stigma: Mental health and neurological disorders often carry a stigma. Openly discussing the challenges of CTE can help break down misconceptions and promote a more supportive environment.

## 8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you and your loved one's experience with CTE for the purposes of storytelling. Any information provided to us will be stored securely and we will only disclose it with your permission unless we are required by law to release information.

In the form we will ask for your permission to use your words in publicly available information. Publicly available information may include short summaries, quotes, stories, journal articles, conference presentations, policy briefs and factsheets. These may be located on social media, on the ConneCTers Australia or other websites, or sent out via email.

We may use your story to explore similarities between yours and other people's stories and report on these similarities. These similarities are known as themes.

We may also use the information from this storytelling for other research projects. You will be asked permission in the survey for us to do this.

## 9. What if I would like further information?

You can contact Kayleen Doyle to ask questions, raise concerns, provide feedback or talk about this initiative at [kayleen.doyle@connecters.org.au](mailto:kayleen.doyle@connecters.org.au)

*This information sheet is for you to keep.*