

CTE HELP PACK



CONNECTERS
AUSTRALIA

Chronic Traumatic Encephalopathy (CTE)

What is CTE?

CTE is a type of dementia (degenerative brain disease) involving many repeated injuries to a person's head. It is thought that brain vibration, inflammation, or a person's genetic profile may play a role in the development of CTE dementia.

Those at high risk of developing CTE are people who have experienced repeated concussive and head impacts/knocks over a period of time. CTE is a preventable condition through the avoidance or minimisation of head injury. Good concussion management is likely to be an important aspect of preventative care.



What else do we know about CTE?

- People are diagnosed with probable CTE or identified to be experiencing suspected CTE by a specialist medical practitioner as CTE cannot be diagnosed clinically until after death (research is ongoing and advancing).
- You're unlikely to develop CTE from only one or a few knocks to the head.
- Repeated knocks to your head damage your brain over time.
- CTE is often seen in people who have played contact sports or sports with risk of head knocks, experienced assaults or been involved in violence, have been in active war zones or exposed to explosions, and have experienced multiple falls or accidents with head knocks.
- If a person is suspected to have developed CTE, avoiding alcohol, smoking and illicit substances is important to minimise the worsening of symptoms and progression of the disease.
- There are probable risks associated with people sustaining repeated head knocks and injuries, and drinking alcohol or using illicit substances.

Signs & Symptoms of CTE

Thinking

- Memory loss
- Cognitive difficulties and changes
- Learning difficulties
- Poor concentration
- Confusion
- Loss of sense of direction
- Brain fog
- Headache or head pressure
- Increased disorientation
- Struggling to remember names of people and things
- Unexplained stopping mid-conversation

Mood

- Anxiety and panic attacks
- Unexplained worrying and sadness
- Depression
- Suicidal thinking
- Impulsivity
- Loss of empathy
- Rollercoaster emotions and difficulties regulating mood
- Reduction in desire to socialise

Behaviour

- Rage and unexplained anger
- Agitation
- Loss of motivation
- Reduced social activity
- Wandering
- Slowness or Parkinson's-like changes
- Noticeable changes to personality and out of character behaviour
- Difficulties coping
- Repeating stories and being stuck on topics that cause increased emotions

Function

- Noticeable decreases in some body functions (ie. walking steady, swallowing, coordination)
- Experiencing difficulties with talking and finding words
- Difficulties with cooking
- Difficulties with driving
- Changes in ability doing jobs or tasks that were previously easy or routine



Diagnosis and Clinical Intervention



Appointment with General Practitioner

It is critical for a patient to discuss with their GP

- history of head impacts, head injuries and/or concussions OR history of repeated activities involving high impact to head, in conjunction with
- symptoms
- a referral to specialist - neurologist or neuropsychiatrist
- there is no one test for dementia. Your doctor may consider the need for testing may include MRI brain or neuropsychological testing.



Initial appointment with Specialist

It is critical for a patient to discuss with their specialist

- history of head impacts, head injuries and/or concussions OR history of repeated activities involving high impact to head, in conjunction with
- symptoms
- if testing has not been commenced through your GP, a specialist may consider the need for testing may include MRI brain or neuropsychological testing.



Ongoing coordinated care

Once diagnosed with probable CTE (or relevant conditions), it is critical for a patient to have a coordinated care approach from their:

- Specialist medical officer
- GP
- Clinical professionals
- Support services/agencies

Living with probable or suspected CTE

If you have been diagnosed with probable CTE, taking care of yourself is more important than ever as you adjust to your new normal and maintain quality of life.

The symptoms of CTE are wide-ranging including problems with mood, changes in behaviour and function, and difficulties with thinking and memory.

Many symptoms are manageable with medication support, lifestyle adjustments and strategies to prioritise optimum health. Looking after yourself is crucial for your mental and physical health during this time and living with the disease.

Early and effective intervention and treatment optimises someone living with CTE to continue independently and meaningfully participating in everyday activities (ie. work, driving, socialising, parenting, etc)

Sleep

Prioritise consistent and quality sleep. Your body needs a full night rest to function optimally. Some people with suspected or probable CTE also need small naps during the day to top up their cognitive function and memory. Sleep disorders like sleep apnoea can cause mental fogginess, headaches, and poor emotional regulation. Be disciplined with your sleep habits and going to sleep habits. Seek professional help if needed.

Exercise

Don't underestimate the benefits of regular exercise. Exercise can relieve stress, alleviate pain, and improve overall well-being. Remember, what's good for your heart is also beneficial for the vascular system supporting your brain health and function.

Avoid exercising in the heat of the day and stay well hydrated as people with probable or suspected CTE can be impacted by exercising in hotter temperatures. . Consult a doctor before beginning any new exercise.





Nutrition

Maintaining a balanced diet is beneficial for everyone, but it's especially important for those living with CTE. A nutritious diet can improve your energy levels and help you feel better overall.

Studies show there are certain foods that assist with brain health and function:

- Green leafy vegetables
- Fatty fish
- Berries
- Nuts & seeds
- Avocado
- Eggs
- Turmeric
- Dark chocolate
- Tea and coffee (within moderation for someone with CTE or symptoms of CTE)

Consider consulting a dietitian before making significant dietary changes.



Environment and outings

Depending on what stage of CTE, busy and overstimulating environments can have a significant impact on a person with probable CTE. From a busy home to a loud and crowded street or shopping center; it is important for a person living with or caring for someone with CTE to be aware of the need to minimise loud, busy, crowded and/or overstimulating settings and interactions.

Support from an Occupational Therapist will assist with determining suitable activities to reduce risk of overstimulation.



Monitoring Health and Medication:

Many individuals with CTE may benefit from medications to manage mood, anxiety, memory, sleep disturbances, or a range of other symptoms.

An overall approach to managing health is important as people with CTE also have other conditions which need to be managed holistically.

Regular check-up's with healthcare providers can help adjust medications and manage side effects.

Cognitive, Speech and Physical Therapy:

Cognitive therapy can aid in slowing cognitive decline. Activities like memory games, reading, puzzles, etc. can be beneficial. An occupational therapist will be able to assess and assist with cognition.

For individuals in the later stages of CTE or with comorbidities, physical therapy may help maintain mobility and reduce the risk of falls, as CTE can impair balance and coordination. A physiotherapist will be able to assist with assessments and recommendations.

An assessment and recommended interventions from a speech therapist is often required when someone is experiencing difficulties with swallowing, and/or with words and speaking.

Helpful Communication

Depending on the stage of CTE, it is important for clear and concise communication to ensure a person can understand the content of the conversation and anything being asked or tasked.

- Do not assume a person nodding or responding is always understanding the content of the conversation.
- Approach communication with patience, as processing and responding can be slow.
- Use clear and concise language and avoid overwhelming them with too much information at once.
- Emotional outbursts or mood swings can be challenging. Stay calm, provide reassurance and sensitive redirection, and avoid confrontations.

Other Helpful Tips:

- Establish routines - regular schedules can help with memory and reduce confusion. Structure daily activities to include rest, as fatigue can exacerbate symptoms.
- Keep the environment calm - reducing noise and distractions can help lessen stimulation, agitation and confusion.
- Safety adaptations - as the disease progresses, people with CTE need home and lifestyle modifications to ensure their environment is safe. Please consult with professional for a review and plan.



Caring for someone living with probable or suspected CTE

Caring for someone with CTE requires patience, understanding and a supportive environment, as symptoms can profoundly affect both the individual and their family.

Caring for someone with CTE can be difficult. In the early stages, caregivers may not even realise they are, and have been, caring for someone with CTE as the disease is often "invisible."

Caregivers may experience feelings of grief and loss, fear, resentment, helplessness, isolation and a range of varying emotions common for carers.

As a CTE caregiver, you are not alone.

Self care

Personal Support

Professional Support



Remain connected

**Informal and formal
respite**

Ask for help

Help is available for carers

ConneCTers Australia - provides both group and confidential individual support for individuals and their carers living with CTE. support@connecters.org.au

Carers Gateway - provides support to carers through a national helpline or an online portal Monday to Friday between 8am and 6pm. 1800 422 737

Lifeline - provides 24/7 crisis support and suicide prevention services.

Dementia Australia - provides a range of supports for people living with dementia. The National Dementia Helpline is a free and confidential service. 1800 100 500

Carers Advisory Service - provides information and advice to carers and their families about carer supports and services. 1800 242 636

In an emergency, call 000 or present to your closest hospital for urgent assistance.

www.connecters.org.au

ACCESSING NDIS

Under 65 years

It is important to register with the NDIS once diagnosis confirmed.

Treating Professionals Information

Clear diagnosis is required representing degenerative brain disease and/or dementia + comorbidities.



A diagnosis often seen with people with probable CTE is Traumatic Encephalopathy Syndrome (TES)

Treating Professionals Information

Capturing the functions impacted is important in all professional reports.



Capturing any risks to a person due to functional decline is important for NDIS documentation so the required funding package is obtained.

An occupational therapist will be responsible for assessing and recording function and support need.

Early Intervention Support Needs



Clear and specific details of support for someone requiring early intervention to remain empowered to be safely independent and active.

Increased Supports Needs



Providing additional professional reports and supporting evidence of impacted functions, risks and reduced capabilities is important when more support is needed

APPLYING FOR THE NDIS



Contact your local NDIS Office or local NDIS partner or call 1800 800 110 and ask for an NDIS Access Request Form (PDF 1MB) to be mailed or emailed to you.

Download and complete the NDIS Access Request Form (PDF 1MB) on your computer and email it to enquiries@ndis.gov.au with supporting information.

Download the NDIS Access Request Form (PDF 1MB) on your computer, print it out, and mail it to PO Box 700, Canberra, ACT 2601 with supporting information.

Phone the NDIS on 1800 800 110 to be supported to apply to the NDIS.

Change In Circumstances



You do not need to wait for a plan to expire to apply for more/different funding. With a degenerative illness, needs can change suddenly.

You can submit a Change In Circumstances with more supporting evidence.

Reviewable Decision



Worried about yourself or your loved one's NDIS plan? You can appeal. complete the Request for a review of a decision form and sent it to NDIS

- send an email with supporting evidence to enquiries@ndis.gov.au
- call us on 1800 800 110
- visit an NDIS or partner office.

<https://www.ndis.gov.au/applying-access-ndis>

ACCESSING MYAGEDCARE

65 years or older (50 years or older for Aboriginal or Torres Strait Islander people)

1 Diagnosis Confirmed



2 Aged Care Support

1. Confirm eligibility for a MyAgedCare assessment:
<https://www.myagedcare.gov.au/am-i-eligible>
2. Apply for an assessment:
<https://www.myagedcare.gov.au/assessment/apply-online>

3 Support services required

- Getting out of bed or chairs
- Walking
- Going to the toilet, wipe and re-dress
- Taking a bath or shower
- Getting dressed
- Eating a meal
- Preparing a meal
- Taking medication
- Basic housework
- Driving or taking public transport
- Shopping
- Managing money and paying bills



4 Assessment

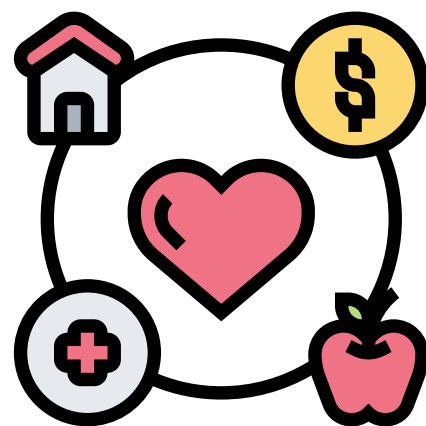
An assessment will be conducted in-home based on information, reports and both person and home environment assessments.

Assessments cannot be conducted while in hospital unless the person requires a Residential Aged Care Facility.

5 Package & Management of Services

Once a package is granted, engaging dementia specific services and professions will ensure appropriate service support for person living with CTE.

Accessing respite, if assessed as required, is a great service to ensure both the person with CTE and their carer is supported and not at risk of burnout.



You can call My Aged Care on **1800 200 422**. They are open:

- Monday to Friday: 8am to 8pm
- Saturdays: 10am to 2pm

www.myagedcare.gov.au