

INFORMATION & SUPPORT

Sports and Brain Health

**Learning from research with
family carers of former sports
persons affected by dementia**



Head Injury, Sport, and Dementia

Learning from conversations with family carers

Living with head injuries and/or dementia can bring significant changes to a person's life. These changes may include cognitive decline, personality shifts, communication difficulties, loss of independence, altered family dynamics and increased dependency on others for daily care.

Adapting to changes in roles and relationships can often be challenging for family carers who may experience emotional stress, physical exhaustion and social isolation whilst balancing caregiving with work and other personal responsibilities.

Support is readily available for those seeking guidance, whether it involves talking through concerns, obtaining a diagnosis, or managing daily life.

As dementia progresses, families face decisions that can feel overwhelming. **In this booklet, we provide insights shared by family carers from our research, along with resources and contacts to help you navigate this journey.**



For those with loved ones who are former sports players, concerns may arise about the impact of repeated head injuries sustained during their time spent playing sport. These concerns might relate to Chronic Traumatic Encephalopathy (CTE), a brain disorder linked to repetitive head injuries.

Information and support are available for all sports participants – whether recreational, amateur, or professional – as well as their families.



Figure 1 (front cover): Memories of sporting success.

Figure 2: Family life combined with a sporting career.

Dementia

Dementia is a general term for symptoms affecting memory, thinking, and daily functioning caused by brain cell damage. The condition typically progresses over time, making everyday tasks increasingly difficult and potentially leading to the need for support at home or in a care setting.

It is estimated that one person in three will experience dementia before the end of their life. This number is increasing because people are living longer. There are several types of dementia, and it is possible to have more than one type.



Figure 3: A former sportsperson and their partner contribute to research.

Former sports persons, especially footballers, rugby players and boxers, face higher risks of early-onset dementia compared to non-sports persons.

Common causes of Dementia

Alzheimer's Disease:

Characterised by memory loss, confusion, and difficulties with language.

Vascular Dementia:

Often connected to strokes relating to reduced blood flow to the brain.

Dementia with Lewy bodies:

Can affect memory, movement and thinking. People can experience visual hallucinations or delusions and sleep and mobility problems.

Frontotemporal Dementia:

Leads to changes in memory, mood, behaviour, personality, and language abilities.

Chronic Traumatic Encephalopathy (CTE):

A neurodegenerative condition associated with repetitive brain trauma, frequently observed in former sports persons.



Chronic Traumatic Encephalopathy (CTE)

Chronic traumatic encephalopathy is brain damage caused by repeated head injuries, often linked to contact sports. This neurodegenerative condition can lead to dementia and changes to memory, movement, behaviour, increases in depression and aggression and progressive cognitive decline that affect daily functioning.

CTE can develop years after retiring from sports and, at present, can only be definitively diagnosed after death, though specialist medical professionals can diagnose probable CTE by identifying symptoms of neurodegenerative disease in living individuals.

Former sports persons, especially footballers, rugby players and boxers, face higher risks of early-onset dementia and CTE compared to non-sports persons.

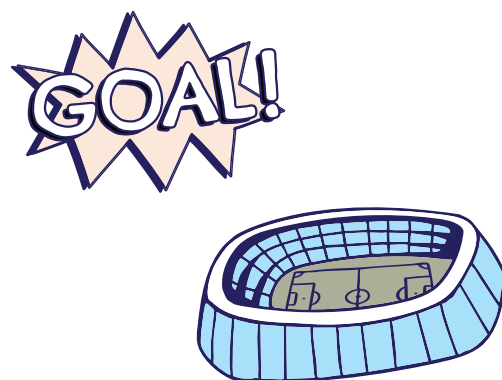
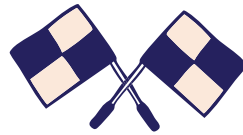


Figure 4: Sporting memories and symbols of current activities, brushing the garden and collecting sticks were mentioned as repetitive tasks people became focused on.



Family carers told us about these dementia symptoms

Confusion:

Becoming easily disoriented about time, place, and identity of people.

Repetition:

Repeating questions or stories multiple times.

Difficulty with daily tasks:

Struggling with familiar tasks such as cooking, cleaning, or personal hygiene.

Language problems:

Trouble finding the right words or following conversations.

Personality changes:

Becoming withdrawn, suspicious, or displaying uncharacteristic mood swings.

Poor judgment:

Making decisions that are out of character and potentially harmful.

Increased apathy:

Showing decreased interest in previously enjoyed activities and social interactions.

Walking:

People may walk in different directions; with a purpose they cannot communicate.

Changes in sleep patterns:

Experiencing disrupted sleep or changes in sleep habits.

Increased anxiety and agitation:

Displaying restlessness, irritability, or distress, particularly in unfamiliar environments.

Difficulty with complex thinking:

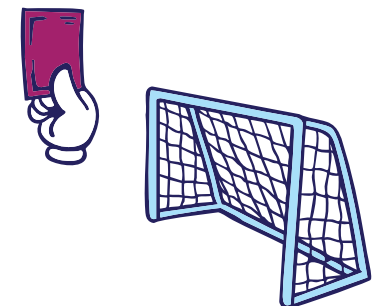
Struggling with tasks that require planning, organization, or problem-solving.

Memory loss:

Frequently forgetting recent events, conversations, or names.

Aggression:

People may become more or unusually aggressive.



Advice from family carers

Concerns about someone's brain health

If you are concerned about any changes in yours or your loved one's memory, mood, personality and behaviour, first seek help from your GP. They may conduct some tests and refer you to your local memory clinic who have expertise in specialist assessment, investigations and diagnosis.

Diagnosis is a process of eliminating other possible causes and this can sometimes take time, **early diagnosis is important so don't hesitate to talk with your GP.**



Figure 5: Planning for future needs because caring is an act of love.

Many family carers told us they felt that symptoms started two or three years before they sought help. An early dementia diagnosis allows for prompt treatment and future planning to manage the disease.

Think about lasting power of attorney (LPA)

Planning for the future and understanding the wishes of the person with dementia may involve some difficult conversations and some family carers told us they regretted not talking about finances and future wishes in terms of health care.

Lasting power of attorney means an individual can appoint someone to make decisions on their behalf and in their best interests.

There are two types of LPA:

1. Property and financial affairs
2. Health and welfare

An LPA must be completed when someone has mental capacity and the best place to start is here: www.gov.uk/government/organisations/office-of-the-public-guardian

Care and support options

Family carers often delay discussing different types of care and support options including day centres, social activities, support groups and respite care, but wish they had started sooner.

The first step is to request a care needs assessment for the person with dementia and a carer's assessment for yourself from your local council.

Whilst respite care might initially feel disruptive, it can often prove essential for preventing carer burnout and allowing carers to rest while ensuring appropriate care and support for their loved one.

Dementia carers can often experience feelings of guilt, isolation, anger, frustration, sadness, grief, and even resentment while dedicating themselves to their loved one's care. It is essential they recognise that maintaining their own physical and emotional wellbeing isn't selfish – it's necessary.

This is to ensure that they can continue to be a source of strength and support for their loved one they are caring for.

Discuss needs openly with family or professionals. After the assessment, explore suitable options based on individual circumstances and support needs.



For funding information, contact your local council, carers organisations, and dementia charities. Consider in-home care, short stay care homes, or day care centres based on the person's needs and preferences.

Former professional footballers and their families can also seek help with funding via the **Football Brain Health Fund (FBHF)** at fbhf@thepfa.com



Figure 7: A family carer shares experiences with a researcher and is always connected to their partner.

Living with Neurodegenerative Disease

There are many organisations who can help, and the following were recommended by family carers and colleagues who support our research.

Please remember the best place to start is with your GP.

For more information on our research at Nottingham Trent University (NTU) and to access the links on the right side of this page, please scan the QR with your smartphone or visit: www.ntu.ac.uk/research/groups-and-centres/projects/caring-for-former-athletes-who-live-with-neurological-disorders



Carers UK: Information and support for family carers. Call [0808 808 7777](tel:08088087777) or visit www.carersuk.org

Dementia UK: Specialist dementia nursing charity. Its nurses, known as Admiral Nurses, provide free, expert support to anyone affected by dementia, including family members. Freephone [0800 888 6678](tel:08008886678) or email helpline@dementiauk.org

Headway: UK-wide charity that works to improve life after brain injury by providing vital support and information. Call [0808 800 2244](tel:08088002244) or visit www.headway.org.uk

The Concussion Legacy Foundation: Information and advice to people concerned about brain health and CTE. Visit www.concussionfoundation.org

Head Safe: Research and information for former footballers concerned about their brain health. Visit www.headsafefootball.org.uk

The Jeff Astle Foundation: In memory of Jeff Astle to raise awareness of brain injury in all forms of sport, offering much needed support to those affected. Visit www.thejeffastlefoundation.co.uk

Rugby Players Association: Representative body and collective voice of elite rugby players in England. Visit www.therpa.co.uk

Rugby League Cares: Assist current and former players experiencing poor health or hardship with practical guidance and financial aid. Visit www.rugbyleaguecares.org

Welsh Rugby Players Association via Second Half: Remove the pressures when a severe illness of injury occurs. Visit www.wrpa.co.uk/2nd-half

The Ringside Charitable Trust: Provide medical help and support for retired boxers. Visit www.theringsidecharitabletrust.com



This leaflet was developed by
Dr Jane Rowley, Charlotte Jackson,
Dr Christopher R. Matthews.

With support from Penny Watson MBE,
Joe Costello, Prof Karen Harrison Denning,
Prof Alison Pilnick, Dr Jack Hardwicke,
Prof Dominic Malcolm, Dr Diane Wren,
Dr Greg Hollin, Dr Reem AlHashmi,
Marit Hiemstra, Prof Tom Denning.

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Addyson Brough: www.gaptoof.co.uk/.
They depict the life and experiences
of family carers and their partners
as they navigated dementia.