

# SPORTING MEMORIES

A practical guide to  
living with dementia  
for people who have  
received a diagnosis  
and for their  
relatives/carers



# THE PFA & SPORTING MEMORIES



The PFA is and always has been committed to a duty of care for all past, current and future members and has lobbied the football authorities to join with us on all aspects of health and safety in the game.

The regulations in place for concussion and heart screening are testimony to this. Neurological problems in later life – which may be connected to concussion, head injuries and heading the ball – have been on our agenda for the last 20 years.

Following previous inconclusive research findings, we are now working with the support of the FA to establish a robust, comprehensive research strategy that will help determine whether the incidence of degenerative neurocognitive disease is more common in former professional footballers than in the general population.

We have jointly commissioned an independent study led by Dr William Stewart of Glasgow University, titled 'Football's Influence on Lifelong Health and Dementia Risk' (FIELD). The research begins in January 2018 and will compare data from around 15,000 former professional footballers with information about the general population.

Dr Stewart said: "In the past decade there have been growing concerns around perceived

increased risk of dementia through participation in contact sports. However, research data to support and quantify this risk have been lacking.

"Through the FIELD study we hope to be able to provide some understanding of the long-term health impact of football within the next two to three years."

In the meantime we will continue to offer help to all members and their families in a variety of ways. If any members or their loved ones are looking for support, please call the PFA on 0161 236 0575.

This guide has been produced to help members who have received a diagnosis of dementia – either of a family member or themselves. It has been designed to give some useful information on the disease, practical first steps and tips on living day to day with dementia.

Produced in association with the Sporting Memories Foundation, it has been found that recalling sporting events and sports people and looking back through photo albums and memorabilia can stimulate memory, keeping people connected and promoting conversation.

Reminiscing enables people to relive and recall events, people and places from their past in a way that can be beneficial to their inner self and their interpersonal skills. It is a process that focuses on the personal way people experience and recall these memories, rather than on chronological or historical accuracy.

If you haven't already, then putting together albums or scrapbooks of your life can provide an interesting activity and create a helpful resource to prompt conversations.

The Sporting Memories Foundation, which has received funding and support from the Professional Footballers' Association, uses sport to help people enjoy reminiscing with family, friends and other sports fans.

It has developed a free app (Replay Sporting Memories) to use on your phone or a digital tablet (such as an iPad) that has thousands of images, videos and audio recordings that can help stimulate memories of watching or playing sport. It can also be used to record your memories, should you wish to add to the archive.

Sporting Memories groups meet at local venues including some football grounds. They are available free of charge and are open to anyone over the age of 50. Many who attend are older men who have dementia or memory problems. The groups are fun and friendly and offer the opportunity to share stories, meet people facing similar challenges and also to enjoy trying out some gentle exercise and sports.

Find out more about using Sporting Memories and where your nearest group is by visiting the website at [www.sportingmemoriesnetwork.com](http://www.sportingmemoriesnetwork.com).

**Gordon Taylor OBE**  
PFA Chief Executive



# WHAT IS DEMENTIA AND WHAT A DIAGNOSIS MEANS

Dementia is a term that describes the symptoms associated with a range of progressive neurological conditions, these symptoms include memory problems, loss of concentration, mood and behaviour changes and difficulties with reasoning and communication.

While dementia is a progressive condition that gradually gets worse over time, earlier diagnosis means that people now often live for many years with their diagnosis. There are some common symptoms that many people experience, but how people react and how dementia progresses will be different for each person.

Having a diagnosis does not mean you have to stop doing the things you enjoy. This guide will help you to think about how you can live well with a diagnosis of dementia.

There are over 100 different diseases that come under the umbrella of dementia. However, the most common types are Alzheimer's disease, Vascular dementia, dementia with Lewy Bodies and Frontotemporal dementia.

All types of dementia stop the cells in the brain, called neurons, from working properly and eventually to die. Neurons send messages between each other and then down the spinal cord to activate all bodily actions, such as speech and movement. If they don't work properly it can take longer for the messages to get around the brain, or they may be confused or not get there at all. This leads to the symptoms of dementia.

## **ALZHEIMER'S DISEASE**

This is caused by the build up of two proteins in the brain Amyloid and Tau. These proteins block the connections in the brain and cause the brain cells to die. This usually occurs throughout the brain so the symptoms people may have can be quite broad and there is usually a gradual decline in functioning.

## **VASCULAR DEMENTIA**

Vascular dementia is caused by damage to the blood flow to the brain. Post-stroke dementia and multi-infarct dementia occur after a stroke or series of small strokes. Subcortical vascular dementia or small vessel disease, is caused by

changes in the very small blood vessels in the brain. In both cases this leads to reduced blood flow to the brain and eventually to death of brain cells. Damage may be local to one brain area and so people may notice symptoms in some areas of functioning but not others.

### **DEMENTIA WITH LEWY BODIES**

This type of dementia is caused by a build of a protein called alpha-synuclein inside the nerve cells in the brain. These are called Lewy bodies. They stop the cells from working properly and eventually cause cell death. This type of dementia also includes symptoms similar to that of Parkinson's disease, such as slow movements, muscle stiffness and unsteadiness.

### **FRONTOTEMPORAL DEMENTIA**

Usually associated with younger people aged 45-64, this mainly affects the front parts of the brain and leads to changes in personality, behaviour, movement and to a lack of personal and social awareness and impulsive behaviours. It is caused by a build of three proteins in the brain that clump together, causing the death of brain cells.



# PLANNING FOR YOUR FUTURE AND ADVANCED CARE WISHES

The progression of dementia is different for every person and a diagnosis can bring about many challenges, such as driving and thinking about future living arrangements. Conversations about these issues may not be easy to have, but by planning for your future, you can ensure that your family and professionals meet your wishes.

Many people living with dementia have other illnesses and conditions, which may affect their quality of life. There are a number of ways you can make your wishes known about future care and treatment.

## **ADVANCE DECISION (LIVING WILL)**

This ensures your wishes about care and treatment are taken into account in the future. It allows you

to decide what treatments you do not want in the future if you are not able to make a decision at the time. It is legally binding providing it is:

- Valid – made when the person had capacity
- Applicable – wording has to be specific and relevant to the medical circumstances
- Written down, signed and witnessed

## **ADVANCE STATEMENT**

This is more general and allows you to make statements about wishes and views for the future. It is often known as a 'statement of wishes and care preferences' and can relate to where you wish to live and the type of care and support you wish to have, through to the type of food you'd like to eat. It can also include religious or spiritual beliefs.

# FINANCIAL PLANNING/ LASTING POWER ATTORNEY

Lasting Power of Attorney (LPA) allows another person (your spouse/carer or another family member) to make decisions on your behalf if you no longer have capacity to make the decision for yourself. An application for LPA must be made while you are deemed to have capacity. There are two types of LPA and you can choose to make either and to have the same or different people for each:

- PA for finance – allows someone to manage property and financial matters for you
- LPA for health and personal welfare – lets another person decide on your care and treatment. This includes refusing medical treatment if you have specified this.

Within the LPA documentation you can put limits on what the LPA can do and what decisions they can make under each area. An appointed attorney under the LPA legislation can overrule any advance decisions/care wishes made about life-sustaining treatment.

To be valid, LPAs have to be registered at the Office of the Public Guardian. Contact them on 0300 4560 300 or visit [gov.uk/power-of-attorney](https://www.gov.uk/power-of-attorney)



# BENEFITS ADVICE: ALLOWANCES

There are various benefits that a person with dementia, a family member or a carer may claim if they are of pension age or of working age. These include the disability benefits Attendance Allowance [AA] and Personal Independence Payment [PIP]. The earnings replacement benefits Employment and Support Allowance [ESA] and Universal Credit [UC] [currently being rolled out nationally]. The main carers benefit Carer's Allowance [CA] and a Council Tax Discount on the basis of severe mental impairment.

Claiming benefits can be a complex process and it may be helpful to ask for advice.

## **DISABILITY BENEFITS: ATTENDANCE ALLOWANCE [AA] AND PERSONAL INDEPENDENCE PAYMENT [PIP]**

The above benefits can apply to those whose dementia means that they have a need for some help or supervision with personal care and/or mobility. They are tax-free, do not require any national insurance contributions to have been paid and are not means tested in any way.

AA is the appropriate benefit when a claim is made for the first time after the age of 65. It only concerns the help someone might need with personal care. It is paid at two rates dependent on the level of need: either £55.65pw or £83.10pw.

PIP applies to people claiming under the age of 65 [it has replaced Disability Living Allowance [DLA] for new claimants]. This benefit includes a daily

living element similar to AA, and with the same rates of pay, but also a mobility element. The maximum payment of PIP is currently £141.10pw. Once awarded this benefit can continue to be paid after age 65 and the mobility element can be retained.

Unfortunately, the claim forms for both AA and PIP are long, detailed and quite daunting. It is important to get professional advice on completion, as it is easy to overlook or under appreciate the extent of care /mobility needs and therefore fail to provide sufficient information to facilitate an award. This is particularly the case for those with dementia where everyday care needs can be taken for granted and consequently omitted from the claim form.

If a person with dementia subsequently goes into care and is responsible for their own funding then both AA and PIP can remain in pay to assist with the funding. For someone who is receiving local authority support with fees the mobility element of PIP [or DLA] can remain in pay.

It remains important to be aware that someone who is in care as a result of their dementia may require a need for medical care at some point as the disease progresses. At such a point they can become entitled to fully-funded care from the NHS. Families need to be aware of this possibility and the need to request their GP, care home manager or social worker to refer the resident for the necessary assessment.

## **EMPLOYMENT AND SUPPORT ALLOWANCE [ESA]**

ESA is relevant to those people who are diagnosed with dementia while still of working age and who are no longer capable of work. This is quite a complicated benefit having various elements and requirements.

There are two types – contribution based ESA is based on national insurance contributions and would generally apply to people who have recently ceased work. Income related ESA is means tested and available to those without the necessary national insurance contributions and with no other, or very little other, income.

Income related ESA can be paid on its own but also on top of contribution based ESA, dependent on circumstances, as it can include extra premiums based on receipt of other qualifying benefits and can help with mortgage interest payments as well as certain other housing costs.

NB. Universal Credit is currently replacing the income related element of ESA in a national roll out. The date at which someone starts claiming Universal Credit depends on various factors, including where they live. Entitlement to contribution based ESA is not affected but is known as new-style ESA in UC areas. The Department for Work and Pensions [DWP], which administers benefits, provides information on this on the gov.uk website.

## **CARER'S ALLOWANCE [CA]**

CA can be paid to carers who spend at least 35 hours per week caring for someone getting either AA, the daily living element of PIP or the middle or high rates of DLA care component.

CA is taxable but not dependent on national insurance contributions. Carers are not eligible for CA if they earn more than a limited amount each week [currently £116pw] after the deduction of allowable expenses [such as Income tax and pension contributions].

CA is known as an 'overlapping benefit' so, for example, would not be paid to someone receiving a state pension higher than the CA rate, currently £62.70pw. Receipt of CA can affect the benefits of the person being cared for but can increase receipt of other benefits the carer receives. Advice should therefore be sought prior to claiming CA.

## **COUNCIL TAX DISCOUNT**

Certain residents in a dwelling can be 'disregarded' when counting the residents. This would normally include someone with dementia who is receiving either AA or the daily living element of PIP [middle or high rate care of DLA]. This is commonly referred to as an SMI discount, as it is based on a resident having a severe impairment of intelligence. So for example, if there is a couple and one has dementia and receives the qualifying benefit the council tax bill will be reduced by 25%. A discount can be backdated to the date it should have first applied, normally subject to a limitation of 6 years.

# PRACTICAL ADVICE ON DAY-TO-DAY LIVING

## DIET

People living with dementia sometimes become less interested in eating regularly. This can be because foods that once tasted pleasant to them no longer do, their sense of smell may have changed, or there may be some confusion around whether they have already eaten. Medications being taken can also affect the appetite and desire to eat.

For people who may have impairments with their vision, placing food on plates that are different colours to the food can help with identifying what is and isn't food.

If using a knife and fork becomes tricky, consider finger foods that are easier to eat.

## EXERCISE

Exercise is thought to assist with preventing falls for people living with dementia, as it improves balance and muscle strength. However, exercise also has positive effects on the mood of individuals, as well as reducing wandering and improving night-time sleep.

In the early stages of dementia, there are several things to think about:

- It is important to establish an exercise routine or adapt an existing routine if one exists
- Focus on exercise of low to moderate intensity that is easy to do. Activities such as walking, swimming, gardening and dancing can be fun
- Focus on maintaining balance and muscle strength

In the later stages of dementia, there may be some challenges that you need to consider:

- Fine and gross motor skills may deteriorate, so your exercise routine may need to be adjusted to be easier to follow
- Remember to include simple exercise such as walking and balance training. Both of these help reduce the likelihood of falls
- Short bursts of activity throughout the day may be easier than one longer session
- Think about seated exercise, focusing on what you enjoy doing and can do without causing yourself any pain

## **MAINTAINING INTERESTS: THINGS THAT CAN HELP CARERS**

The following measures can help you to support a person with dementia you may be caring for. They can help to keep a person as independent as possible as well as helping to support their wellbeing and confidence.

- Focus on what the person can do, not on mistakes or things they can't do
- Be patient and try not to criticise
- Break tasks down into smaller parts
- Keep instructions simple (avoid multiple components)
- Speak more slowly and take time to listen/wait for a response
- Use non-verbal prompts (gestures, demonstrations) alongside verbal
- Avoid asking lots of questions
- Do things together, and include the person
- Try and see/understand the world or task through their eyes
- Try to introduce new things the person might enjoy doing



## LIST OF USEFUL ORGANISATIONS

### INFORMATION ABOUT DEMENTIA:

#### **Alzheimer's Society**

[www.alzheimers.org.uk/info/20000/about\\_dementia](http://www.alzheimers.org.uk/info/20000/about_dementia)

#### **Alzheimer's Research UK**

[www.alzheimersresearchuk.org/about-dementia/](http://www.alzheimersresearchuk.org/about-dementia/)

#### **Brain Tour**

[www.alzheimers.org.uk/info/20073/how\\_dementia\\_progresses/112/dementia\\_brain\\_tour](http://www.alzheimers.org.uk/info/20073/how_dementia_progresses/112/dementia_brain_tour)

Find out more about how the brain works and how having different types of dementia affects the brain.

### PRACTICAL ADVICE FOR PEOPLE WITH DEMENTIA OR THEIR CARERS:

#### **Carers UK**

[www.carersuk.org/help-and-advice](http://www.carersuk.org/help-and-advice)

#### **Dementia UK**

[www.dementiauk.org/get-support/admiral-nursing-direct-dementia-helpline/](http://www.dementiauk.org/get-support/admiral-nursing-direct-dementia-helpline/)

#### **The Sporting Memories Foundation**

[www.sportingmemoriesnetwork.com](http://www.sportingmemoriesnetwork.com)  
Information on sports reminiscence and local groups.

### FINANCIAL AND LEGAL INFORMATION AND ADVICE:

#### **Advance Decision (living will) Living will pack**

<http://compassionindying.org.uk/library/advance-decision-pack/>

<http://www.ageuk.org.uk/money-matters/legal-issues/living-wills/about/>

#### **Age UK**

[www.ageuk.org.uk/money-matters/](http://www.ageuk.org.uk/money-matters/)

#### **Lasting Power of Attorney**

[www.gov.uk/power-of-attorney/overview](http://www.gov.uk/power-of-attorney/overview)

#### **Citizens Advice Bureau (CAB)**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk)

Your local CAB can provide advice and information in confidence or point you in the right direction to further sources of support. Trained CAB advisers can offer information on benefits in a way that is easy to understand. To find your nearest CAB, look in the phone book, ask at your local library or visit the website.

#### **Department for Work and Pension**

[www.gov.uk](http://www.gov.uk)

The government department responsible for employment and

social security. The gov.uk website gives details of the various benefits and how to claim them, as well as information on pensions and pension credits. Claim forms are available to download.

#### **Attendance Allowance**

(also for DLA claimants who are 65+)  
Telephone: 0345 605 6055  
Textphone: 0345 604 5312

#### **Disability Living Allowance**

Telephone: 0345 712 3456  
Textphone: 0345 722 4433

#### **Personal Independence Payment**

Telephone: 0345 850 3322  
Textphone: 0345 601 6677

#### **Personal Independence Payment (New claims only)**

Telephone: 0800 917 2222  
Textphone: 0800 917 7777

#### **The PFA**

Members of The Professional Footballers' Association and former members and their families can access specialist benefit advice and support [including assistance with forms completion and representation at Social Security tribunals] directly from the association.

■ [www.thepfa.com](http://www.thepfa.com)

■ 0161 236 0575

■ Email: [info@thepfa.co.uk](mailto:info@thepfa.co.uk)