

## AUTUMN 2023 MAGAZINE

Dementia Research



Together We Will Defeat Dementia



## BRACE Welcomes Care Campaigner as Ambassador

We are incredibly excited to welcome Jayne Connery, Director of Care Campaign for the Vulnerable, as an ambassador to BRACE.

Jayne has dedicated more than 12 years to improving the lives of people living in care homes and supporting families to ensure their loved ones receive the care they need and deserve.

A committed supporter of BRACE, Jayne has generously given her time to the charity for several years. In 2017 she shared her knowledge and expertise at the BRACE Together 4 Dementia conference. Daredevil Jayne has also taken to the skies on three separate occasions to raise an amazing £10,000 for dementia research.

Care Campaign for the Vulnerable was set up soon after Jayne took the decision to bring her mother, who was living with dementia, out of a care home. While in the care sector, she saw an urgent need for greater transparency and safety, particularly in caring for the elderly living with dementia.

You can learn more about Jayne's fantastic work on her website: www.carecampaignforthevulnerable.com

## Worried about a loved one in a care setting?

If you are concerned about the welfare of a loved one in a care setting, or have serious concerns for any other resident, please contact the local adult safeguarding team in that area and the CQC (England) Care Quality Commission, (Wales) Inspectorate Wales, (Northern Ireland) RQIA.

# Eye tracking with a smartphone or tablet for early diagnosis of Alzheimer's Disease

BRACE is thrilled to be funding a new pilot project investigating the link between eye movements and cognitive decline.

This research is led by Dr Wenhao Zhang, Associate Professor of Computer Vision and Machine Learning and Co-Director of the Centre for Machine Vision (CMV) at the University of the West of England, Bristol.



People with Mild Cognitive Impairment, which increases the chances of Alzheimer's Disease, may experience mild problems with thinking, memory, and executive attention. Executive attention is used all day, in everyday life, for tasks such as cooking dinner and organising weekly food shopping. Problems with executive attention are one of the first non-memory related symptoms of Alzheimer's. Small changes in eye movements may indicate changes in attention and cognitive control. Wenhao's research will investigate if measuring eye movement changes can be used to detect early-stage Alzheimer's.

The research will use a low-cost eye-tracking technique with a gaming app on a smartphone/tablet to test higher-level thinking skills. The app will give users various challenges, such as tracking a moving object while

performing a finger-tapping exercise. These tasks alter the mental workload to induce different eye movement patterns. Artificial Intelligence will be used to compare these different eye movement behaviours and to learn from clinical tests to automatically assess cognitive performance - how well the brain is working - based on eye movements.

If successful, this method will allow for earlier detection of cognitive decline in patients in the comfort of their homes. This will assist medical staff in identifying early changes in patients, predicting the risk of dementia, and monitoring interventions.



#### What is Wenhao's hope for his research?

Leveraging his expertise in eye tracking and machine learning, Wenhao aims to develop accessible, convenient, and pervasive eye tracking tests for neurodegeneration and various eye diseases. This project is part of CMV's broader healthcare initiatives that integrate cuttingedge ideas in computer vision and

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machine learning across a diverse range of applications. The outcomes often yield novel and innovative technologies that significantly enhance the quality of life, including for individuals at risk of dementia.

#### What does it mean to have a BRACE-funded pilot?

Thanks to the support from BRACE, a remarkable integration of cross-discipline expertise comes to life, combining the fields of computer vision and machine learning, cognitive science and neuropsychology, as well as biomedical and clinical science. This funding will enable the validation of an exploratory yet potentially highly impactful research idea. It will play a critical role in advancing the clinical readiness of this mobile health technology and will foster engagement with wider stakeholders while forging new partnerships.



## 2023 London Marathon Success

Huge congratulations and thanks to the 10 BRACE runners who took on the 2023 London Marathon for dementia research. It is no mean feat, and we know each and every runner had committed to months and even years of training to get to that point. Our runners battled through the wind and rain throughout the 26-mile course, which added to the challenge. BRACE staff watched from the sidelines of Tower Bridge, loudly cheering on the runners at the halfway point.

Each runner had their own personal reason for taking on the marathon, with loved ones affected by dementia in their hearts and minds throughout the race.

Maggie ran in memory of her beloved husband Paul, who passed away with frontotemporal dementia in November 2022. With Paul's photo taking pride of place on Maggie's running top, she raced towards the finish line. Her London Marathon efforts were in support of the vital work at the Brain Bank, where Paul generously donated his brain. Maggie's incredible efforts ensure that Paul's donation can live on in the world through the work that is done by the team in the Brain Bank, who support researchers to take us closer to treatments and a cure for dementia.

To read more about Paul and Maggie's story please go to page 8.

We are incredibly thankful to all our London Marathon participants and are so proud of their achievement! Collectively more than £16,000 was raised for dementia research which is a huge amount and will make a significant difference.



Lucy running for victory.



## Fancy taking on a challenge for BRACE?

Are you looking for a new challenge and keen to support dementia research? We have a range of challenge events on the BRACE website to browse and sign up to! There are even more options on the Run for Charity website, it's as simple as selecting BRACE as your charity when signing up through the website.

Any distance, anywhere in the world and even online, there's something you can do to support dementia research!

Want to join #TeamBRACE?
Send an email to
fundraising@alzheimers-brace.org,
take a look on
alzheimers-brace.org/challengeevents

or **runforcharity.com**Thank you for your support.

## BRACE Lottery Seeks Winners

Play the BRACE lottery for just £1 per week and you could be £25,000 richer! You could be booking a lovely holiday, buying a new car, or treating your loved ones if you win big and all while supporting an important cause...



The lottery helps fund world class dementia research, taking us all one step closer to a cure for dementia.

#### How does the lottery work?

6 numbers between 1 and 49 are randomly selected each week.

If all 6 numbers are matched, you win £25,000 and if you match 5 numbers you will win £1,000. If more than one entry matches 5 or 6 numbers the prize pot will be split equally between each players.

#### How do I sign up?

Signing up can be done in less than 5 minutes. You will need to have your bank details to hand. Simply go to: https://bracelottery.affinitylottery.org.uk/

If you would like to join the lottery and need help to do so, or have further questions, please email: fundraising@alzheimers-brace.org or call the office on: 0117 414 4831. Thank you.

#### How easy is it to win?

There is a 1 in 80 chance of you winning each week.

#### How many prizes are there?

Each week you have the opportunity to win one of 37 cash prizes: 1st Prize: £25,000, 2nd Prize: £1,000 and 35 guaranteed Runner-up Prizes: 5 x £20, 10 x £10 and 20 x £5

#### How often does the draw take place?

Every week on a Friday.

#### How does giving money away support dementia research?

The lottery prizes do not come from the charity's funds. Your ticket is helping to defeat dementia!

Everyone's a winner when you take part in the BRACE Lottery.

Thank you for supporting dementia research.

## 2023 Christmas Cards

#### This year's new designs to choose from are:



Starry Christmas Tree Size: 140 mm x 140 mm Sending warm wishes for Christmas and the New Year 10 cards & envelopes £3.95



Christmas Village Robins Size: 140 mm x 140 mm Sending warm wishes for Christmas and the New Year 10 cards & envelopes £3.95



Twelve Days Icons
Size: 140 mm x 140 mm
With best wishes for
Christmas and the New Year
10 cards & envelopes £3.95

These cards can be ordered using the order form included with this magazine.



Christmas Day Carols
Size: 100 mm x 152 mm
Wishing you Hope, Peace and Love at
Christmas time
10 cards & envelopes £3.95



Santa's Flight
Size: 140 mm x 140 mm
Sending warm wishes for Christmas
and the New Year
10 cards & envelopes £3.95

The Christmas cards and envelopes are manufactured in the U.K. from materials carrying the FSC® (FSC-C003675) Chain of Custody certification. The Forest Stewardship Council® (FSC) is an independent, non-governmental, not-for-profit organisation established to promote the responsible management of the world's forests.

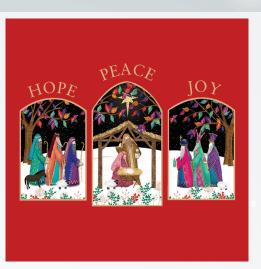
The cards have been independently certified as coming from forests that meet the internationally recognised

FSC Principles and Criteria of Forest Stewardship.

All cards are printed on FSC certificated board, by an FSC certificated printer. The cards are then packed with envelopes manufactured from FSC certificated paper.



## now on sale!



Hope, Peace and Joy Size: 140 mm x 140 mm Wishing you Hope, Peace and Joy at Christmas time 10 cards & envelopes £3.95



Christmas Eve Skating
Size: 152 mm x 100 mm
With best wishes for Christmas and
the New Year
10 cards & envelopes £3.95

Buying cards really makes a big difference to dementia research.

Christmas cards raise more than £10,000 for research each year.

Thank you for your support.



Midnight Four Candles
Size: 126 mm x 126 mm
Sending warm wishes for
Christmas and the New Year
10 cards & envelopes £3.95



Let it Snow Penguin
Size: 126 mm x 126 mm
Sending warm wishes for Christmas
and the New Year
10 cards & envelopes £3.95



Moonlit Forest Deer
Size: 126 mm x 126 mm
Sending warm wishes for Christmas
and the New Year
10 cards & envelopes £3.95

#### As well as using the order form enclosed, our 2023 cards are available from the following sources:

Melanie's Kitchen 2 Downend Road Downend Bristol BS16 5UJ 0117 957 2662 Tourist Information Office The Clock Tower High Street Chipping Sodbury Bristol BS37 6AH 01454 326336 Wilmslow Library South Drive Wilmslow SK9 1NW

#### And our full range is available from:

www.alzheimers-brace.org/Pages/Shop

www.christmas-cards.org.uk/bracealzheimers

www.ebay.co.uk/sch/the-bracecharity-shop



## Paul and Maggie

Paul was the life and soul of any party, the first to get up to dance and the last to leave, with Maggie, his wife of 14 years, by his side. They were the best of friends throughout their 29-year relationship which was filled with non-stop talking.

However, at just 50 years old Paul started having issues with his vocabulary and communicating. Conversations were different to how they'd always been. Maggie knew there was a problem. Seeking answers, she went to Google to find a reason for his symptoms. After coming across dementia as a possible cause, she just knew that was what Paul had and they sought medical advice. Two years after Paul's language issues began. and following several trips to different doctors, he received a diagnosis of Frontotemporal Dementia (FTD) at the age of just 52.

Paul had led an active and full life with Maggie, his two daughters from a previous marriage, three grandchildren and another on the way. He was lucky enough to walk both daughters down the aisle before dementia took away his mobility. When the girls were young, the family enjoyed special holidays and visited Disney Florida and Paris amongst others. Later Maggie and

Paul travelled the world to far flung places like Australia, India and China, living life to the fullest. They even witnessed the Northern Lights while on an Arctic cruise.

Paul held various jobs over the years, not least as sous chef to Maggie on Sunday mornings before lunch. He was a qualified carpenter and twice a pub landlord, which really suited his sociable nature. He was a huge lover of sport, with football being his favourite. He captained Wales at school football level a few times and continued to play and manage at a local level until his health declined. There were few places Maggie and Paul could go without someone knowing him from either work or sport.

Wanting to turn a difficult diagnosis and illness into a positive, Maggie and Paul felt they would like to support dementia research. They had lots of open conversations about what that may look like. A decision was made to generously donate Paul's brain to the South West Dementia Brain Bank. A chance for Paul's legacy to live on and to support vital research, that one day could mean a cure for dementia.

Paul and Maggie also fundraised for the Brain Bank in various ways during Paul's lifetime, even walking up the highest mountain in Wales together.

But sadly, at the age of just 58, Paul passed away with FTD at the end of 2022. Maggie, who had already started training for the London Marathon, amazingly ran it in April 2023 in memory of Paul, with Paul's photo on Maggie's running top and funds kindly being raised for the Brain Bank. Maggie raised more than £4200 to help support the vital work that takes place there. This is a chance for Paul's legacy to live on and to support vital research that, one day, could mean a cure for dementia.



## Together We Hit the Target

A big thank you to our incredible and generous supporters who helped BRACE to raise more than our £15,000 target in the first half of 2023 for the South West Dementia Brain Bank!

In 2022 alone,

the Brain Bank

sent over 11,000

tissue samples to

researchers all

over the world.

This is an amazing sum that will make a real difference in our fight to defeat dementia. Our work will continue thanks to our supporters' generosity. Thank you so much.

£15,000 will fund more than 390 hours of Dr Laura Palmer's work at the Brain Bank.

This funding will ensure that researchers around the UK, and the world, have tissue samples to conduct vital research.

The South West Dementia Brain Bank does not receive any government funding and is reliant on charities, like BRACE, to fund their work. It is simply down to the generosity of

BRACE supporters that work at the Brain Bank is possible.

In 2022 alone, the Brain Bank sent over 11,000 tissue samples to

researchers all over the world. Tissue samples are vital for breakthrough moments in drug development such as Donanemab and Lecanemab, which are showing promising signs of slowing down Alzheimer's disease.

Every day, thanks to people like you, we are closer to defeating dementia.

We can't wait to see what can be achieved by the Brain Bank thanks to your support.

#### More Research Made Possible!

In 2022, 78p of every pound BRACE received went towards charitable activities.

What does this mean?

Well, it means BRACE is keeping overheads down and research well and truly up.



We would like to say a big thank you to every person, community group, business and trust that donated last year. Be it a big or small donation, it all adds up. Because of these people and organisations, in 2022 BRACE funded:

- 13 PhD students
- Research into the role of sleep and dementia in Lewy Bodies Dementia
- A study into Alzheimer's disease diagnosis tests
- A project investigating new ways to target Alzheimer's with drugs
- Ultrasound research and if it can change Alzheimer's
- A Dementia Research Nurse
- The South West Dementia Brain Bank

None of this would have been possible without the generosity of our supporters. Your donations are making a huge difference. Thank you for making research possible.

#### Together we will defeat dementia.

If you would like to know about 2022's income please visit the Charity Commission website.





#### Volunteer thank you



During Volunteers Week we held a coffee morning to say thanks to our amazing volunteers. This brought together supermarket collectors, event helpers and office volunteers, some of whom had never met before and it gave everyone a chance to meet and catch up over some delicious cake and a cuppa.

#### Supermarket collections

Supermarket collections bring in thousands of pounds each year for BRACE! When Tesco Extra in Quedgeley invited BRACE to collect for the first time, our committed volunteers jumped at the chance to get involved with lovely volunteers travelling a considerable way from home to chat, smile and collect an incredible £400 for dementia research. Thank you to our wonderful collectors.



## Wonderful Supporters

## Friends Groups

We are always grateful to our volunteers who bring skills, expertise, time and passion to the cause and who share our aim of a world free from dementia.

Do you have a group of like-minded friends who'd be interested in forming a Friends Group?



You could represent BRACE at events, help raise awareness of dementia and encourage your local communities to get involved by holding a coffee morning or other fundraising event.

Whether it's few hours a month, or every so often, it all adds up and makes a difference. We currently have three groups based in North Bristol, North Somerset and Weymouth Bay, but would love to expand on this and reach different areas.

If you're passionate about defeating dementia and would be interested in setting up a Friends Group please email jeanne@alzheimers-brace.org or call 0117 414 4831











As a small charity, our wonderful supports and volunteers do so much to make research possible and we truly cannot thank you enough.

#### Cuppa for a Cure

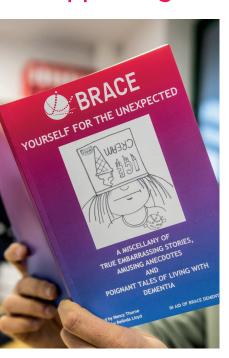
Cardiff BRACE supporter, Nia Honeybun, hosted a Cuppa for a Cure and plant sale at Dynevor Garden Association and raised more than £600 for dementia research. What a superstar!

For the second year in a row BRACE hosted a Cuppa for a Cure at Bristol's dementia friendly allotments, a wonderful site run by our friends at Alive Activities.

## Can you help BRACE?

As you can see, we have a range of community events that take place and a whole lot of ways you can support - whether it's helping at a supermarket collection, hosting a Cuppa for a Cure (at home, work or other venue), helping at an event or in the office, organising collection tins or selling our Christmas cards. If you'd like to get involved please email Jeanne on: jeanne@ alzheimers-brace.org - she'd love to hear from you!

#### Supporting Dementia Research, One Anecdote at a Time



Towards the end of 2022 Nancy Thorne, a supporter from North Somerset, put together a book called BRACE Yourself for the Unexpected to raise funds for dementia research.

The book contains a miscellany of embarrassing true stories and amusing anecdotes as well as poignant tales of living with dementia.

Nancy spent weeks collecting and collating the stories and the book was such a big hit, with sales totalling more than £1,200, that she is currently producing Volume 2 which, this time, will also include puzzles.

Ideal for a stocking filler, you can order the book via the Christmas card order form or from the shop www.alzheimers-brace.org/shop Huge thanks to Nancy for her hard work and dedication to dementia research, and to our wonderful supporters for buying so many books that they've been flying off the shelves.



"My dad and mum both had dementia. It's been very difficult for all of the family. At times you do think you're the only person who has cared, or is caring for a loved one with dementia. I was thinking, 'what can I do to help, however small?' I had this idea of putting together a book as I like funny anecdotes and the rest is history..."

#### The New Alzheimer's Disease Drugs



### There has been a lot of interest and excitement about two new Alzheimer's disease drugs called Donanemab and Lecanemab.

#### But what does this really mean for people living with Alzheimer's?

The new Alzheimer's drugs target amyloid protein in the brain. Not all amyloid is bad, it is a natural protein that is found in everyone's brains and is needed for the healthy functioning of brain cells. People with Alzheimer's, however, have amyloid protein building up in the brain, which causes damage and symptoms such as forgetfulness.

The new drugs, Donanemab and Lecanemab, help the brain to clear the built-up amyloid proteins.

In trials, patients who have taken these drugs have seen improved memory and thinking by up to 30%. These improvements mean the person living with Alzheimer's can spend more time living independently and more time doing the things they love, with the people they love, for longer. The drugs are most effective in the earlier stages of Alzheimer's.

It is a significant breakthrough for treating Alzheimer's, which is the most common form of dementia, as for the first-time ever researchers have developed drugs that may be able to slow down Alzheimer's.

Many people may be aware of the four Alzheimer's drugs that the NHS have been prescribing for the past ten years and wonder, what is the difference?

The 'older' Alzheimer's drugs, available on the NHS, help by boosting the brain cells but they do not stop the progression of Alzheimer's, they do not stop the damage or slow down the disease.

While more research needs to be done and there are more trials taking place, this breakthrough is bringing us closer to a cure for Alzheimer's.

The BRACE office is based in the Bristol Brain Centre which, thanks to BRACE funding, was opened in 2015. Patients with dementia and other neurological conditions attend appointments and take part in dementia research in the centre.

#### Volunteer for Dementia Research

Researchers at the Bristol Brain Centre regularly recruit participants, both with and without dementia, for research projects. They are always looking for volunteers to add to their research volunteer database and their Patient and Public Involvement groups at the Bristol Brain Centre.

If you are interested and would like to offer your time, please contact **Research.Volunteer@nbt.nhs.uk** 

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