



BRACE
Dementia Research

SPRING 2024
MAGAZINE



“One in two of us will be affected by dementia. We need to change that, and that can only be done through more research.”

Stephanie Beacham

Together We Will Defeat Dementia

CHARITY NUMBER: 297965

www.alzheimers-brace.org



Sleep is crucial for overall wellbeing and brain health. Whether living with or without dementia, having enough quality sleep really is a key part of brain health.

BRACE funded researcher, Chloe Tulip, shares her expertise on sleep.

Sleep and brain health

As a sleep scientist, I'm excited to see sleep grabbing headlines these days. Given how much of our lives we spend sleeping, it's great to see that it's getting the attention it deserves. However, the flood of information can sometimes be overwhelming, especially when it highlights the negative health impacts of poor sleep. It's one thing to understand the importance of good sleep, it's another to find yourself staring at the ceiling at 2am worrying about it. I've been there! Here are some straightforward tips to help you achieve a better night's sleep.

Wake Up at the Same Time Every Day (Yes, Even on Weekends)

Our bodies thrive on routine. Waking up at the same time daily, even on weekends, helps regulate your body clock so that you feel sleepy at the same time each evening. This consistency pays off in better sleep quality and even for heart health and blood pressure!

Be Cautious with Napping

Napping can interfere with your night-time sleep by reducing the sleep pressure needed to fall asleep easily in the evening. If you must nap, keep it short (around 20 minutes) to avoid entering deep sleep, which could disrupt your sleep cycle later.

Quality Over Quantity

The myth of needing 8 hours of sleep can add unnecessary stress. Most people do fine with about 7 hours, and it's normal for sleep duration to vary. Focus on sleep quality rather than obsessing over the number of hours.

Listen to Your Body's Sleep Signals

It's tempting to go to bed when we're tired in the hopes of falling asleep quickly, especially when we're trying to stick to schedule. However, trying to force sleep when we're not sleepy rarely works and can lead to frustration and anxiety. It's common to confuse feeling tired with feeling sleepy. Tiredness means physical fatigue, your body needs rest. Sleepiness is drowsiness, it's your brain signalling it's ready for sleep. When you feel sleepy, ride the wave of sleepiness to bed!



Enjoy Your Evenings

If falling asleep is difficult, don't despair. Use the time for relaxing activities that you enjoy but find slightly mundane. Whether it's reading, drawing or doing puzzles view this time as 'me time' rather than something stressful.

Managing Stress

Anxiety and stress are common culprits behind sleep issues. Identifying the source of your stress and finding ways to manage it, such as through a worry journal or designated worry time, can be effective strategies for improving sleep.

Support your Rhythm!

Getting enough natural light, especially in the morning/early afternoon, helps regulate your sleep/wake cycle. Regular exercise, including a gentle walk, also strengthens this cycle. Both will make falling asleep and waking up easier.

When to Seek Help

If sleep problems persist, consider seeing your GP or exploring cognitive-behavioural therapy for insomnia (CBT-I), which has proven effective for many people. Online CBT-I is now available - <https://re-sleep.com/> (sleepio).

Remember, sleep is a natural process and just like breathing, our bodies know how to do it instinctively. Although we may sometimes worry about it, sleep will never go away. If we keep to a consistent sleep routine, are flexible in our expectations of sleep and reduce the stress we place on ourselves to achieve perfect sleep, our bodies will naturally settle back into a sleep rhythm. Be patient when making changes to sleep, but trust in your body to do what it is designed to do, and your sleep will thank you for it.

Chloe Tulip, BSc (hons), MSc, PhD in Psychology Candidate, Swansea University (BRACE funded).

Can you help with a small act of kindness?

If you would like to help support dementia research with a small act of kindness, please read on...

We are looking for people like you to share our new collection pots in local communities.

Are you a regular at your local café or pub? Do you attend a church meeting or play in a sports group?

Could you approach your group and ask if they would like a pot?

If your local business or group would like to support dementia research, we can send you a collection pot to pass on to them. All donations, both big and small, add up to make a big difference

If you're interested in finding out more, please contact Jeanne on jeanne@alzheimers-brace.org

Thank you for your support.



Remembering Wendy Mitchell

In February, we were saddened to hear of the death of Wendy Mitchell, dementia campaigner and bestselling author, at 68 years old.

An incredible legacy has been left by Wendy, through her tireless campaign work, her daily blogs - 'Which me am I today,' and her books which explore the many ways that Alzheimer's and dementia affects the person living with the illness, while offering advice.

BRACE was lucky enough to have Wendy as a guest speaker at our annual conferences in 2018 and 2022, where she shared many words of wisdom.

To quote Wendy Mitchell in 2018:

"Talking is the most powerful thing you can do when you get the dementia diagnosis.

Simply don't think of it as the end. Think of it as the start of a different life, a life of adapting, and if you think about it like this, it makes it a much easier journey to be on.

Take part in any research you can, because research is the one thing that gives us hope for the future."

A truly inspirational woman who will be missed by so many. Thank you, Wendy, for sharing your world and creating such positive change while navigating and adapting to the challenges of Alzheimer's.

'What is it like

BRACE is based in the Bristol Brain Centre, at Southmead Hospital in Bristol. The centre is unique in that it offers the patients attending appointments with neurologists, doctors and nurses the chance to take part in research.

Julie Clayton supports many research projects, some of which are at the Brain Centre. She shares what it is like volunteering for research and the important role volunteers play.

There are hundreds of research projects taking place across the South West, many of which are dementia research. We regularly invite people to get involved in research if they have dementia or mild cognitive impairment (early changes in thinking and memory, which in some people may progress to dementia). And we are also keen to invite family members and others who are in a caring role.



volunteering for research?

Julie Clayton is a Patient/Public Involvement and Engagement lead at Bristol Brain Centre, (Southmead Hospital, North Bristol NHS Trust), and also in the Centre for Academic Primary Care (Clifton Down)

Volunteering for research can be very rewarding. Many of our volunteers say they just want to do something that will help others in future. Without them, we could not make progress in developing better ways to diagnose and treat dementia.

What do we mean by volunteering?

Being a research volunteer could mean advising on the design of a study, or it could mean taking part in a study.

Volunteer advisor

Being a volunteer advisor can be as simple as chatting to us over a cup of tea and biscuits and telling us your views about what it's like to have dementia. It may be sharing your experience of the challenges of caring for someone with dementia. This is an important part of research, especially at the very beginning of a project, when we are exploring new ideas for research, and we need patients and family members to tell us if they are worthwhile or not. We don't mind people telling us our ideas are rubbish!

At the design stage, we ask volunteers to advise on how we can attract and support people to take part once a study begins. This design phase can involve one or several meetings over three to six months. We discuss where to advertise, and how to get a wide range of people from all backgrounds to take part. We ask the volunteers for feedback on how we advertise the study, and the tasks the study involves. Once the study is underway, we ask volunteers to help us make sense of the results and decide next steps.

Research study participant

The other option is to take part in studies - as a study participant. This could involve doing interviews over the phone or in the comfort of your own home, to help us understand people's experiences better, and improve healthcare in future. Or it could involve visits to our research clinic at the Bristol Brain Centre, at Southmead Hospital, to undergo tests such as thinking and memory skills, and it may include a blood test or a brain scan. The kind of tests depends on the study.

Your rights as a volunteer

Very importantly, we make sure that when we invite volunteers to get involved, that everything is clear, and they understand what we are asking them to do. We give people written information and allow time for people to decide for themselves if they wish to volunteer or not. Even if people first say yes out of enthusiasm, they can change their minds at any time.

We are very strictly governed by University of Bristol and NHS ethics committees, who scrutinise our plans with a fine-tooth comb to make sure that everything is done properly. We fully respect people's rights to privacy and to make their own decisions. And we have clear divisions between research and the routine NHS care that patients receive. So taking part in research, or declining an invitation, does not affect the care that patients receive.

If you are interested in volunteering in dementia research, in and around Bristol, please get in touch! You can email me at Julie.clayton@bristol.ac.uk

Stephanie Beacham joins BRACE to defeat dementia!

Beloved actress Stephanie Beacham, supports BRACE and dementia research with her new film, "Grey Matter." We are thrilled to have been chosen for this new partnership with W4 Films and Stephanie.

In the film Stephanie plays Peg, who is living with Alzheimer's, and her teenager granddaughter, Chloe, becomes a carer to her Nan overnight. Together they write a list of things Peg wants to do before she forgets everything, so that Chloe can try and make her summer unforgettable. Grey Matter shows, with sensitivity, the challenges and triumphs of living with the disease and caring for a loved one living with Alzheimer's.

Stephanie has a strong connection to the subject matter as her late father died of Alzheimer's disease.

"Having witnessed my father's descent into Alzheimer's, this film is very personal to me."

"One in two of us will be affected by dementia, and last year it was the leading fatal disease in the UK over anything else. We need to change that, and that can only be done through more research. Please support BRACE Dementia Research, visit their website, sign up to their emails and watch the film. Together we can defeat dementia."

Stephanie Beacham, actress



"Partnering with BRACE Dementia Research was a natural fit for the film, as we recognize the urgency of supporting research initiatives that can make a tangible impact on individuals and families affected by dementia."

Arabella Burfitt-Dons, Director of Grey Matter

How can I help defeat dementia?

Watch the film to defeat dementia

Grey Matter played in cinemas across the country in the first few months of 2024, from London to Nottingham, to Bristol, to Liverpool and more.

BRACE also hosted a one-off screening at the Bristol IMAX cinema that took place in April. All proceeds from this event went straight to dementia research! A big thank you to everyone who joined us.

The film will be exclusively available in cinemas until the end of May. Look out for the BRACE logo in the credits!

Share your story to defeat dementia

By sharing your story, you will help to raise awareness of the reality of life with dementia and bring comfort to families also affected by it. You can find out more, and share your story by going to: www.alzheimers-brace.org/my-story-brace, emailing contactus@alzheimers-brace.org or calling the office on **0117 414 4831**

Play the BRACE lottery to defeat dementia

The BRACE lottery is a fun and easy way to support vital dementia research. Play from just £1 per week to be in with a chance of winning up to £25,000!

To join online please go to <https://bracelottery.affinitylottery.org.uk>

If you need help to do so, please call the office on **0117 414 4831**.

Sign up to our emailing list to defeat dementia

Stay up-to-date with the latest dementia research news, events and ways that you can help defeat dementia. Simply visit www.alzheimers-brace.org to sign up in 2 minutes.

Donate to defeat dementia

Research gives us hope for a dementia free world. Use the form to the right or visit the BRACE website to set up a regular or one-off gift and help fast-track a dementia free future for all.

Donation form

Yes, I will donate to defeat dementia!

I would like to give a donation of:

My choice of £_____

I would like to make this donation

monthly annually once only

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year.

Yes - I am a UK taxpayer and would like to Gift Aid my donations now and in future.

I understand I must pay enough income tax and/or capital gains tax each tax year to cover the amount of Gift Aid that all charities and community amateur sports clubs claim on my donations in that tax year, and I am responsible for paying any difference. Please remember to let us know if your tax status, name or address change or if you wish to cancel your Gift Aid declaration.

www.alzheimers-brace.org/privacy-policy

Registered charity 297965

NAME (BLOCK CAPITALS PLEASE):

ADDRESS:

POST CODE:

I would like to pay by (please tick)

CHARITY VOUCHER

CHEQUE/CASH

VISA MASTERCARD

AMEX

MAESTRO

CAF CARD

NAME AS ON CARD

CARD NUMBER

MAESTRO

VALID FROM

EXPIRY DATE

ISSUE NO

CVC NO

SIGNATURE

DATE

Please send me an acknowledgement by email* in the post not at all



*EMAIL ADDRESS

Please keep me informed with news, research updates, events and more via your

E-newsletter (please supply email address)

Bi-annual magazine

If your details are incorrect or have changed, please let us know by emailing fundraising@alzheimers-brace.org or calling **0117 414 4831**.

Thank you so much for your support



Storm Force 10. Photo © Tom Rogers

80th Birthday bash for BRACE

It's not every day you turn 80 and supporter Jean Watson was keen to make a difference with her birthday celebration.

Being part of the Claverham Ladies Guild who had donated to BRACE earlier in the year, she felt that she would like to do more for dementia research.



Jean is a keen lover of traditional jazz, alongside many of her friends, and an evening of music was decided upon instead of going out for a meal.

The Dart Valley Stompers with their traditional New Orleans jazz and award-winning reed player Jeremy Huggett were booked for the night.

Invites to family, friends, old school friends, jazzers from her monthly club and more were sent out far and wide. Tickets were sold for the event with all proceeds going to BRACE.

Close to ninety people joined in the birthday celebration, which had everyone grooving away to the jazz band, till late, in Claverham Village Hall.

Jean's friends helped with tea, coffee, and cheese rolls which added more to the the donations buckets throughout the night

The night raised almost £1,000 for dementia research. A huge thank you to Jean for including BRACE in her birthday celebrations, and to her generous guests.

Sea shanty band raises £3000 for BRACE!

A Bristol sea shanty band, Storm Force 10, spent 2023 fundraising for BRACE during their gigs throughout the year. The popular band keep the tales of Old Bristol's great sea-faring tradition alive, creating new songs and revitalising the old.

In lieu of charging a fee to their gigs, Storm Force 10 generously asked attendees to donate to dementia research. Their gigs took them to venues such as a Somerset Cider Farm, festivals in Devon, Cornwall, Weston Super Mare and more.

Over the course of the year they raised a staggering £3,000 for BRACE and we really can't thank them enough for their support.



BRACE Gala 2024 – you're invited!

We would like to invite you to the **BRACE 2024 Gala** on Thursday 5th September 2024, 7pm until late at the Bristol Harbour Hotel, 53-55 Corn Street, in central Bristol.

The Gala will take place in the hotel's Sansovino Hall, which has magnificent skylights and detailed ceilings. The grand setting will offer you all the glitz and glamour for this fabulous, black-tie event.

It will be a night to remember with fine dining, live music, and an auction.

Much loved journalist Ali Vowles will be supporting the event as Master of Ceremonies.

Tickets are available to buy individually for £70, or as a table of ten for £650. All tickets include a welcome drink, a three-course dinner with wine, plus live entertainment.

Proceeds from the Gala will go towards vital dementia research. Your night out can really make a difference!

To book your tickets please go to
www.alzheimers-brace.org/events/brace-charity-gala/

Email events@alzheimers-brace.org

or call the office on 0117 414 4831

We hope to see you there.

Event Sponsors

CCFTV is generously sponsoring the event

CCFTV stands as an independent, national, not-for-profit organisation dedicated to safety in dementia care.



Wards solicitors are joining BRACE as generous silver sponsors.

WARDS

S O L I C I T O R S

Interested in sponsoring this event?

Please contact liberty@alzheimers-brace.org for an informal chat and to learn more about sponsorship packages.



Dementia diagnoses – why are they important?

At the end of 2023, a report by the Dementia Commission found that for every 5 people living with dementia in England, 3 people have a diagnosis and 2 people do not. While no one wants to receive the news ‘you have dementia,’ it gives an individual and their loved ones, the chance to prepare for the next phase of life.

A diagnosis offers choices about how to approach and manage dementia. Would the person living with dementia like to take medication, volunteer for dementia research, or join support groups?

Research shows that lifestyle choices can protect the brain for longer, even once a dementia diagnosis is given. Quitting smoking or changing diet may become more of a priority to help protect brain health.

With new Alzheimer’s drugs being developed, that are showing positive signs of being able to slow down the disease, a diagnosis is more important than ever.

Research into the drugs also suggest they may be most effective in the earliest stages of the disease. The sooner the diagnosis, the better!

Diagnosing dementia

Current NHS dementia tests:

- Memory tests
- Lumbar punctures
- PET/MRI scans

Each method has pros and cons. Memory tests are the most common way to diagnosis dementia, they are relatively quick and do not require any complex tools. However, this method has limitations and test results can be influenced by many factors. If you think back to your school days, having exam nerves could cause lower results. The same can be said for memory tests.

Lumbar punctures involve spinal fluid being taken from the back to test for proteins that indicate Alzheimer’s and dementia. This test is considered a very reliable way of diagnosing dementia. The procedure is, however, invasive, can be uncomfortable and compared to memory tests it is expensive.

PET or MRI scans of the brain can give clear results of dementia, but not in all cases, they are also expensive, need very specialist equipment and have long waiting lists.

Both lumbar punctures and PET/MRI scans are considered the ‘gold standard’ for diagnosis, but only 2% of people have access to them.



Worried about dementia?

If you think you may have dementia, the first step is to book an appointment with your GP to discuss your concerns.

Common early dementia symptoms can include memory loss, difficulty concentrating, impaired daily tasks, language problems, disorientation, and mood changes.

It is important to remember that symptoms that may look like dementia, such as memory loss, are not always dementia. Your GP will ask you questions about any ongoing health conditions you have, review any medication, and ask about your lifestyle.

New dementia tests

As you can see, the demand for dementia testing is high and many people are not diagnosed due to lack of awareness about the early signs of dementia, being unable to access the right type of medical support at the right time, or long waiting lists.

New tests that make diagnosis easier and faster could help tens of thousands of people and save the NHS money.

Blood tests and dementia diagnosis

In April 2024, the NHS began a large research project into blood tests to diagnose dementia. If successful, dementia blood tests could be rolled out by the NHS in as little as 5 years time. The research is being led by teams at the University of Oxford, and the University College London.

The test works by detecting the same proteins in blood that are found in Alzheimer's, and other types of dementia, in a low cost and quick way.

Future diagnosis could involve a combination of memory tests and blood tests, with each test offering medics different insight into a person's brain health.

Fastball and dementia diagnosis

A BRACE funded early Alzheimer's test called Fastball is also being investigated by the NHS, thanks to NIHR funding. The EEG test is lightweight, quick, and easy to use. Results so far suggest the test may be able to diagnose Alzheimer's up to five years before noticeable symptoms.

Earlier diagnosis offers researchers new opportunities to understand how dementia develops. Alzheimer's starts 10 - 20 years before noticeable symptoms, this means that researchers have been trying to tackle the disease too late. Fastball may be able to change that.

Dr George Stothart, the project co-lead at the University of Bath says:

"Quicker, more accurate ways to diagnose dementia are greatly needed so that patients can get treatments earlier and families can plan better for the future, which is why we are so excited for the potential of Fastball EEG and the development of our work."

You can find out more about Fastball and the NHS work: www.alzheimers-brace.org/testreceives-1-5m-nhs-use

Smartphones and dementia diagnosis

BRACE is also funding work at the University of the West of England (UWE) into early Alzheimer's diagnosis.

The research led by Dr Wenhao Zhang, will investigate if measuring eye movement changes can be used to detect early-stage Alzheimer's. A low-cost eye tracking technique with a gaming app on a smartphone/tablet will be used to test higher-level thinking skills. Changes in eye movement may indicate the early stages of Alzheimer's.

If successful, this method will allow for earlier detection of cognitive decline in patients in the comfort of their homes.

In as little as five years, the way dementia is diagnosed and treated could look very different from today.

Thank you for supporting research and helping in the fight against dementia.



**FREE
Tickets!**

**Sat 18 May
10.30 - 16.30**



A one stop event to learn more about dementia.

**Watershed, 1 Canon's Rd
Bristol BS1 5TX**



Let's Talk Dementia!

We invite you to join us at Let's Talk Dementia, a free public information event on Saturday 18th May, 10.30am - 16.30pm, at the Watershed, 1 Canon's Road, Bristol, BS1 5TX.

The event is brought to you by BRACE, Bristol Dementia Action Alliance and Alive Activities, charities specialising in dementia, research, and improving the lives and care, of older people.

A one stop event to learn more about dementia.

Whether you are living with dementia, caring for a loved one, or keen to learn more about a condition that affects one in two people, this event will have something for you.

There will be dementia specialists giving short talks and workshops, exhibitors and interactive sessions for people living with dementia.

Meet the experts, have your pressing questions answered in a friendly setting and spend time with families like yours.

You will leave Let's Talk Dementia armed with knowledge and new ideas about how best to support your loved ones, and yourself.

The Watershed is a fully accessible venue, which includes hearing loops that can be used during talks, lifts and accessible toilets

This event is taking place in Dementia Action Week, which is happening May 13th - 19th, a chance for people from all walks of life to learn more about dementia, research and the support available.

BRACE Dementia Research funds world-class clinical and laboratory research into dementia to find better treatments, achieve earlier diagnosis and hopefully, one day, a cure. Together, we will defeat dementia.

Bristol Dementia Action Alliance educates the communities of Bristol about dementia and supports those living with dementia and their loved ones through activity groups. BDAA provides free dementia awareness sessions for businesses, organisations and groups and recognizes those who are striving to make Bristol a dementia aware city through its annual BDAA Awards.

Alive Activities is the UK's leading charity enriching the lives of older people in care and training their carers.

Alive:

- Engage older people creatively through meaningful activity sessions
- Train staff to deliver outstanding care at every opportunity
- Connect older people to their local communities
- Speak up for the rights of older people in care



To book free tickets please go to: www.alzheimers-brace.org/events/lets-talk-dementia-2024

Email events@alzheimers-brace.org

or call the office Monday - Thursday on: 0117 414 4831

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