

BRACE MAGAZINE



Together We Will Defeat Dementia





The Longest Farewell...

Nula Suchet is an author and dementia campaigner. She spoke at BRACE's online annual conference 'Together 4 Dementia' on 3rd November 2020 about her unique experience of losing a loved one to dementia.

My husband James is changing and I don't know why. He's not himself. I'm doing my best to adapt to his strange moods and the odd things he does. I find myself brushing the starker facts under the carpet: he's stressed, there's too much on his plate, he's getting scatty in his old age.

But the thing is that James isn't very old: he's only fifty-seven. Surely he shouldn't be losing his keys quite so often, or leaving his favourite jacket and valuable wristwatch on a film shoot, or his passport on a plane? And why is he forgetting to return important work calls? It's not like him at all. Normally he lives and breathes work, often compulsively writing his screenplays and documentary scripts late into the night about subjects closest to his heart.

It's hard to tell when the first signs of Pick's Disease (now known as fronto-

temporal dementia), a particularly brutal form of dementia which affects the frontal lobes of the brain, started to show in James.

But this was the beginning of what was to be the most terrifying and painful journey of both our lives. It's a condition that affects both men and women in their prime, like James, and there is no cure. Patients and carers usually find themselves fobbed off by the medical profession — 'sorry there is nothing we can do for you' — and cast adrift on an increasingly turbulent sea. That's how it was for me for eleven soul-destroying and utterly frightening years.

All those metaphors about denial are true for me. The elephant in the room. The swan so sedate on the surface, whilst under the water the webbed feet are going frantically. I didn't want to face up to what

was going on. At the time I was running a thriving interior design practice with all that that entails - travelling, meeting architects, dealing with clients whose lives bore no resemblance to mine. I was constantly busy paying the bills, keeping us afloat. So I hid my head in the sand and life went on in its old rickety way.

Dementia, like some strange alien, had entered our lives, which were beginning to spiral out of control. James was retreating further and further into himself and I was losing more and more of him every day.

After several trips to three doctors in which none mentioned dementia, it was only when visiting a friend, a retired New York doctor, that she recognised something was wrong. She suggested I take James to see a specialist as soon as possible.

This time the neurologist examined James and asked him many questions - subtract seven from ninety-three, spell 'world' backwards etc. - and did a brain scan and tests. The diagnosis after several hours was conclusive - Pick's Disease. Furthermore I was told there was no cure and no further treatment was possible. A total hammer blow.

I knew too there was nothing I nor anyone could do to bring back my darling James to where he was before. We had a shared map of our past together. The idea of losing him and navigating a future without him was beyond unbearable.

My witty, funny, brilliantly bright James, who had the most wonderful mind and most beautiful soul, was travelling further and further away from me. Both of us were in our fifties, death was in the far distant future. The bastard dementia had gatecrashed our life together and was taking away every wonderful thing we had. We had not asked for this and had done nothing to deserve it.

Dementia, dementia. What is it? All I know is it's a bloody cruel, sadistic disease, that has now demolished my hopes, plans and dreams. As for James, dementia has launched a missile attack on his brain, robbing first his memory, then his ability to speak, then progressively taking over all other functions as it encroaches further into his brain, leading him into a wilderness alone until every last vestige of his dignity has disappeared.

So that's it. There's something so very final about dementia, so it's no wonder there is a stigma attached to it. There were no further appointments. You're on your own now. For the next five years I became James's sole carer, nurse, and mother. I became embroiled in a battle with dementia to try to hold on to every second of our life together, a battle that was destined to last for eleven years, and which I knew from day one I would lose.

What I could never have foreseen was that, as I was saying farewell to one life, another entirely new one would

beckon. A man whose wife Bonnie was in the same care home as James — just two doors away — became first, someone to talk to, then someone to share the horrendous journey with. Then finally, after we had both reached the end of our dementia journey and bade farewell to James and Bonnie, we joined our lives together as husband and wife.

I am now ambassador to Alzheimer's UK and work with Rare Dementia Support Group. I have involved myself in campaigning for better recognition and more public awareness of the disease that took James, and more meaningful support for families and carers.

"The Longest Farewell" by Nula Suchet

Published by Seren Books Available on Amazon UK

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BRACE C'ACE BRACE

University of Exeter research team (from front to back): Kevin Fang, Seema Namboori, Dr Akshay Bhinge, Dr Sally Rogers, Dr Steffen Scholpp

New Research Grants awarded to Bristol and Exeter Universities!

After a uniquely challenging year, BRACE ended 2020 on a high note by awarding two new research grants.

Although the charity had done well enough to survive two lockdowns and award a support grant to the South West Dementia Brain Bank, it did not look as if it would be possible to fund new research in the year of the pandemic.

What changed things was the arrival of a major legacy in December, a reminder of the huge contribution that gifts in wills have always made to our research funding. One man, who left a third of his estate to BRACE, made possible two highly promising new lines of dementia research.

One grant was awarded to Professor Jon Hanley at the University of Bristol to fund research by a PhD student over three years. Under the title 'Investigating synaptic dysfunction caused by AMPA receptor trafficking to lysosomes in familial Alzheimer's disease iPSC-derived neurons', it will look at specific problems affecting communication between brain cells.

The other grant was awarded to Professor Steffan Scholpp of the University of Exeter. This is for a one-year pilot project into 'WNT signalling' in Alzheimer's disease. Again, this concerns communication between brain cells and the mechanisms by which connections are created and maintained.

Professor Jon Hanley,

University of Bristol

You can find out more about both projects by visiting the BRACE website. https://www.alzheimers-brace.org/news/grants-

bristol-exeter-universities

We would like to thank supporters whose donations during the year helped protect the charity through the pandemic and also enabled us to continue core support for research in the South West Dementia Brain Bank and Bristol Brain Centre. Being able additionally to fund the applications from Professor Hanley and Professor Scholpp was an enormous boost to all concerned and shows our commitment to helping revive dementia research after the setbacks caused by COVID.

Covid-19 & the Impact on Dementia Research

Join us for an Online Webinar

Wednesday 14th April at 11am - 12.30pm As the Covid-19 crisis continues, the impact on dementia research grows. The strict social distancing measures mean that many of our researchers have been locked out of the laboratories. Others who work directly with patients are not able to continue their clinical research. Many clinical researchers who work to improve care for people with dementia are also clinicians or nurses. With the NHS under great strain many have had to join the fight against the virus.

BRACE, along with other charities, has been hit hard by the crisis with a 60 per cent drop in income. We are increasingly having to turn down good research for lack of funds.

To understand the real impact Covid-19 is having on dementia research please join our panel of experts from across the dementia disciplines.









Professor Bridget Lumb

Professor Antony Bayer

Professor Roy Jones











Four eminent dementia scientists from across the disciplines are joining together for a BRACE webinar, chaired by BRACE Trustee and chair of the Scientific Advisory Committee, Professor Bridget Lumb, to discuss the impact the pandemic has had on their work and their hopes for a better future.

Professor Clive Ballard, Pro-Vice Chancellor and Executive Dean of the University of Exeter was driven to study dementia after witnessing the poor conditions in which people with dementia were cared for. He has co-authored well over 600 research papers and has led more dementia and cognitive health trials than anyone else in Europe over the last decade.

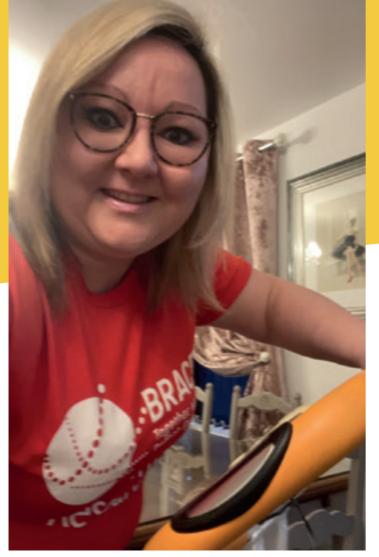
Professor Antony Bayer, chair of the School of Medicine at Cardiff University. His clinical and research interest focuses on epidemiology, assessment and clinical management of cognitive disorders and neurodegenerative disease, especially Alzheimer's disease with particular interest in clinical trials of new pharmacological and nonpharmacological treatments for dementia.

The Director of RICE, Professor Roy Jones BSc MB FRCP, is an Honorary Consultant Geriatrician in Bath and an Honorary Professor at both the University of Bath and the University of Bristol. He is also the Dementia Specialty Lead for the NHS West of England Clinical Research Network.

Dr Byron Creese, University of Exeter, a research psychologist whose work focuses on understanding the biology, clinical consequences, and treatment of neuropsychiatric symptoms (hallucinations, suspicious thoughts, depression) occurring in later life and dementia.

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BRACE'S



Kelly-Ann Page took to her exercise bike to cycle the equivalent of Land's End to John O'Groats, a whooping 877.35 miles in just 45 days! Kelly's stellar cycling efforts managed to raise over £2000 for dementia research and we really can't thank her enough.

BRACE is so lucky to have

many wonderful supporters

doing their bit to fundraise

has had runners, walkers,

pizza makers, swimmers

and cyclists all going the

extra mile to fundraise, in a

socially distanced way, over

the past few months. If you would like to be a dementia fighting- fundraiser, please

get in touch!

for dementia research. BRACE

Here are a few words from Kelly:

'I have chosen to fundraise for BRACE as dementia is a condition that is extremely close to my heart. I know first-hand how dementia affects a person and their friends and family. Sadly, my grandparents both had dementia and when they passed away last year, I really wanted to do something to support dementia research in the hope that this may lessen the effects of dementia for others or contribute to eliminating it forever. I have chosen BRACE as it is a local charity that covers the South West region. BRACE gives me hope that others may not have to suffer the terrible impact of dementia in the future. I was absolutely blown away by the support of the charity when I notified them of my fundraiser; their kindness and compassion for my circumstances shone through, which was really appreciated and definitely motivated me to pedal on.'

Nikki ran the Virtual London Marathon for BRACE in October 2020.



BRACE 11247

Keira Edwards ran the Virtual London Marathon for BRACE and ran 26.2 miles, in an incredibly quick 3.47 hours, in wet and windy conditions. Keira was due to take part in the marathon in April 2020, undeterred by the event being postponed, Keira committed herself to completing the event one way or another! She managed to raise over £5,000 for BRACE, thank you for being a star fundraiser Keira and thank you to your sponsors.

Here's why Keira chose to fundraise for BRACE:

'When I found out that I'd been lucky enough to secure a ballot place for the London Marathon on my first attempt (a feat unheard of!) I knew that I wanted to use it to raise money for a small dementia research charity. Two of my Grandparents had spent the last few years of their life suffering from dementia and running (or attempting to run!) my first ever marathon for a charity that works toward treating & curing dementia - seemed like a great way to honour them.

I stumbled across the BRACE website, and not only did BRACE tick all of my original boxes - it ticked more - I had chosen to make Bristol my home, and both my Grandparents lived in South Wales - so BRACE being a Southwest Regional Charity seemed like fate! Thank you BRACE for all the incredible work you do - it truly inspired me to keep going both on the day, and through the (unexpectedly!) long months of training.'



William Cartwright generously donated pizzas from his business 'Bill's Pizzas' to raise funds for dementia research. William's takeaway pizzas were a huge sell-out success, which isn't surprising when looking at the delicious pizzas. The tasty sales generated over £550 for BRACE. A big thank you to William and all of his customers. If you would like to know more about 'Bill's Pizza's' you can find them on Facebook and Instagram @billspizzasuk



Emily Smith, set herself a unique challenge to remember her much loved Grandma.

The 12th February 2021 marked one year to the day, since her Grandma sadly passed away with dementia, aged 85 years old.

Wanting to remember her Grandma positively, Emily set herself the challenge of running 8.5km every day for a week to help raise funds for dementia research.

Star fundraiser Emily, successfully completed her running challenge and raised an amazing £650.

Thank you Emily for going above and beyond for dementia research, and a big thank you to your sponsors.

What's it like to be a BRACE PhD student?

Over the past 20 years, BRACE has funded more than 30 PhD students to ensure there will always be dementia researchers both now and, in the future, to fight dementia.

You may be wondering, what's it like to be a BRACE PhD student? What does studying dementia research at PhD level look like?

We would like to introduce you to one of BRACE's newest PhD students, Chloe Tulip.

Chloe began her BRACE PhD position at the start of 2020, studying 'sleep and dementia' at Swansea University. Chloe has kindly taken the time to give us more insight into her work and what it is really like to be a PhD student right now!

Why did you decide to study dementia research?

Before my PhD, I worked with people with Traumatic Brain Injuries (TBIs) for several years and got to know how common and how difficult it can be to live with a neurological condition. I was really fortunate to work on a project that was recently published and looked at improving wellbeing for people living with TBI. The results were incredible and many of the participants said that the wellbeing course changed their lives.

It was such a rewarding experience to be able to directly help people through research. I knew then that I wanted to work in an area of research that can offer a real-life benefit. Dementia affects so many people and so deeply. I am glad to be part of the global effort towards bringing us closer to new treatments, diagnostic markers and hopefully someday - a cure!





What steps have you taken to study at PhD level?

I completed an MSc in Clinical Psychology and a BSc in Psychology, both at Swansea University. Each degree has helped to steadily build my research skills, along with broadening my understanding of psychology and how research ultimately translates into real-life change.

Why is charity PhD funding important to you?

Firstly, I think BRACE is a great charity! I feel fortunate to have a fully funded studentship (this is the name of PhD funding), as the skills I learn along my journey will lay the foundation for (what I hope will be) a lifelong career in dementia research.

The inter-disciplinary work that BRACE funds is so diverse, and it is really inspiring to see all this great work as an early-career researcher. The funding is so helpful because not only does it allow me to work full-time on my research, it also provides scope for high-quality research. I am fortunate to be able to use some of the funding on training workshops which will give me the skills to work with complex equipment, like neuroimaging devices and polysomnography technology.

Equally, it's also really helpful to be able to use some of the funding towards recruiting research participants. Often with sleep studies, participants will be asked to spend considerable time in the sleep lab and finding people willing to devote so much of their time can be tricky. That use of funding is really helpful and allows me to complete more projects within my studentship.

Do you work with volunteers on your research?

Yes I do! Currently, due to COVID-19, I am mostly working online with young adults from Swansea University but I am planning to run a number of studies in my final year which will aim to recruit people with vascular and mixed dementia.

Who else is working on your project?

My supervisors for my PhD are Professor Andrea Tales and Professor Mark Blagrove. I feel very lucky because Professor Andrea Tales specialises in dementia research and has spent many years working closely with BRACE. Professor Mark Blagrove also specialises in sleep research and has spent many years examining all things sleep. I am lucky to be working with them at the same time, because I can approach them for advice on sleep and dementia, respectively. They're great supervisors, really friendly, approachable and highly knowledgeable. I hope that I can work in-person with them soon!

How have you found the pandemic and lockdowns?

In terms of my work, I've found that I've needed to change a lot of my plans for study designs, data collection and training. I had hoped to attend some conferences and training workshops, but unfortunately, most have been cancelled. Where most of my current research would have been conducted in person, in the sleep lab, I have now moved studies online meaning that I can conduct studies remotely, which is really good but a different way of doing the research. After speaking with lots of other people completing PhD's, it seems that we're all in a similar boat in feeling that we're all a bit behind. I'm hoping, I think like everyone else in the world, that the vaccines will mean that things start to return to normal. I'm really looking forward to doing some in-person research and volunteering for the Swansea Carers Centre.

On a personal level, I think I've had a few wobbles, but have mostly remained optimistic and feel like I'm just used to it all now- which I guess is a good thing!

What do you do when you're not studying and working?

Sometimes it's good to go offline after a period of work and I quite like doing anything creative. At the moment, I'm teaching myself how to silversmith. I've always really enjoyed making things and I really like working with silver and fire. I can now successfully make fabricated jewellery, although I'm still a ways to go!

I also really like running, cycling and roller skating. Shortly before the first lockdown, I was training to run a half-marathon for BRACE, but unfortunately, it was cancelled so I'll be keen to start training again! I find it important to exercise as it really helps to clear my mind. I try to incorporate at least one positive activity into my day, and I think that's really been a help over lockdown.

Thank you, Chloe, for sharing with us what it is like to be a BRACE PhD student in 2021. If you would like to learn more about past BRACE PhD students please visit: www.alzheimers-brace.org/Pages/Category/the-future-of-dementia-research

Bath Half 2021

Sunday 5th September 11 am - 3pm

Keen runners wanted!

Apply for your **FREE race place** on the BRACE website

Use your running shoes to help Defeat Dementia this Autumn.



Nailsea Rotary Club Fundraiser

Help raise funds for BRACE by walking, running or cycling.

Take part on Sunday 13th June or choose a date and time that suits you!



* * * SAVE THE DATE * * *

Wednesday
13th October 2021

Lunch with BBC's
Emma Britton

At the Double Tree, Hilton

Competition Time

KEY WORKERS

Fill in the missing letters to find the names of some of our amazing key workers

1 D_c_o_	
2 V _ c _ r	
3 P_l_c_ o_f_c_r	(2 words)
4 J_u_n_l_s_	
5 A _ b _ l _ n _ e d _ i _ e _	(2 words)
6 N _ r _ e	
7 R_f_s_ c_l_e_t_r	(2 words)
8 P_s_a_ w_r_e_	(2 words)
9	
10 F _ r _ f _ g _ t _ r	
11 T _ a _ h _ r	
12 C _ r _ w _ r _ e _	(2 words)
13 A _ m _ d F _ r _ e _	(2 words)
14 F _ o _ r _ t _ i _ e _	(2 words)
15 P _ r _ m _ d _ c	
16 B _ o _ d _ a _ t _ r	
17 S _ c _ a _ w _ r _ e _	(2 words)
18 C _ e _ n _ r	
19 D _ l _ v _ r _ d _ i _ e _	(2 words)
20 S _ r _ e _ c _ e _ n _ r	(2 words)

Entry is £5.00 - closing date Monday 31 May 2021

Please send your answers together with a cheque for £5.00 payable to BRACE to The BRACE Charity Office, The Brain Centre, Southmead Hospital, Bristol BS10 5NB.

The winner will be contacted within 2 weeks of the competition closing and the winner's details will be announced in the next magazine. The answers will also be published.

The winning entry will receive a £30 gift voucher of their choice. The editor's decision is final.

Thank you for your support!

ADDRESS:
POST CODE:
CONTACT NUMBER(S):

Autumn 2020's quiz answers

- 1. Walking 2. Knitting 3. Learn a language 4. Running 5. Studying
- 6. Listening to music 7. Writing letters 8. Quizzes 9. Painting
- 10. Watching films 11. Cooking 12. Online shopping 13. Reading
- 14. Swimming 15. Playing an instrument 16. Watching television
- 17. Crochet 18. Helping others 19. Exercise 20. Social media
- 21. Baking 22. Housework 23. Phoning friends 24. Gardening
- 25. Home improvements 26. Learning to Zoom

The last competition winner was from Bristol, winning £30 in gardening vouchers.

If you receive this Magazine by post or email, it is because we have you on record as having opted in to our mailing list. If you do not wish to receive our mailings in future, just send us an email or a letter and we will ensure that you do not receive further mailings.

List of Events

Please visit

www.alzheimers-brace.org/events

for more information and

to sign up to challenge events.

APRIL 2021 Covid-19 and the Impact on Wednesday 14 April Dementia Research 11am -12.30pm **FREE Online Event** Wednesday 21 April Coping with the Cost of Care 11am - 12 noon FREE Online Event Wednesday 28 April Virtual Superhero Run all day & evening **Hearing Loss and Dementia** Thursday 29 April FREE Online Event with Royal National Institute for 2pm -3pm **Deaf People MAY 2021** Dementia and Learning Disabilities -Thursday 20th May FREE Online Event with the charity 2pm - 3pm MacIntyre

Wednesday 9 June
11am- 12pm

Beth Britton: Dementia and
Life Story Work

Saturday 13 June 31 July

Nailsea Rotary Club Walk and Run
Fundraiser, Scotch Horn Leisure Centre,
Brockway, Nailsea, BS48 1BZ

Wednesday 7 July
2pm - 3pm

Dementia: How You Can Reduce Your
Risk FREE Online Event

SEPTEMBER 2021 Sunday 5 September 11am - 3pm Bath Half Marathon 2021 Sunday 19 September 8am - 2pm Bristol 10K OCTOBER 2021 Sunday 3 October all day London Marathon (both virtual and 'in person') Wednesday 13 Lunch with BBC's Emma Britton

BRACE donation and contact form

October

all day

NOVEMBER 2021

Tuesday 2 November-

Please find	d enclosed a donation of to BRACE.	
•	or your donation. Please tick this box OT want a written acknowledgement	
Please add me to your mailing listPlease send me the magazine by email only		
you or in case of	your contact details below so we can thank of query. If you are eligible to add Gift Aid, a the Gift Aid box.	
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SURNAME		
FULL HOME ADDRES	ss	
POSTCODE	DATE	
If you would like	e us to phone or email you, please supply:	
DAYTIME TEL NO		
AND/OR EMAIL		

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



Together 4 Dementia Conference

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

☐ I want to Gift Aid my donation of £_____ and any donations I make in the future or have made in the past 4 years to BRACE

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Please notify the charity if you:

- want to cancel this declaration
- change your name or home address
- no longer pay sufficient tax on your income and/or capital gains

If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code.

We will keep a record of your donation/enquiry but will not contact you unless you have agreed that we can.

RETURN TO: The BRACE Charity Office, Southmead Hospital, Bristol, BS10 5NB.

Telephone 0117 414 4831

Registered Charity 297965

Dementia and Learning Disabilities

Dementia affects all walks of life. People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia and at a younger age, and many experience a rapid progression of disease. Despite this, they are far less likely to receive a correct or early diagnosis of dementia.



Studies show that 1 in 50 people with Down's syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over.

By comparison, the number of people among the population without a learning disability, aged 60-69 years, who develop dementia is about 1 in 75. It is estimated that 1.5 million people in the UK have a learning disability who are at increased risk of dementia.

This is why BRACE was keen to run a joint event with the charity, MacIntyre. The first event in February attracted so much interest, we are set to run a second event in May. This event also provides valuable training for NHS staff.

The presentation will be by Jane Nickels who is the UK's first Learning Disabilities Admiral Nurse. Jane joined MacIntyre last year with over 30 years' experience in her career supporting adults with learning disabilities and/or autism, both in social care and health care settings. Jane has a keen interest and valuable insight in how the effects of dementia impacts the lives of people with learning disabilities and their wider circles of support.

Jane's role within MacIntyre as an Admiral Nurse is to offer support to people both pre- and post-dementia diagnosis, ensuring they receive a timely diagnosis so that support and environments are tailored to meet individual needs. Another key element of Jane's role is to upskill staff within MacIntyre regarding dementia, sharing

best practice with other professionals and highlighting the needs of people experiencing dementia with a learning disability and/or autism.

Jane also works alongside family members who have loved ones within MacIntyre services offering support and guidance in relation to dementia. Health promotion is also highlighted throughout Jane's work as an important part of dementia prevention and addressing brain health.

Ref: Dementia and people with learning disabilities: making reasonable adjustments - guidance - GOV.UK (www.gov.uk)



"Making A Difference" Cards











Buy your personalised Easter cards or 3D ecards for any occasion and help support dementia research all year round.

Up to 100% of your donation reaches BRACE or 125% if you Gift Aid it!

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https://makingadifference.cards/ supporting/brace-alzheimers-research