“My husband James is changing and I don’t know why.”
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 stark 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 more and more of him every day. 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 retired New York doctor, that she knew too there was nothing I nor anyone could do to bring back my darling James to where he was before. We had entered our life together and 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.

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, I 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

Available on Amazon UK

Published by Seren Books

call the BRACE charity office on 0117 414 4831
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.

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.
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

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.’

Kelly-Ann Page took to her exercise bike to cycle the equivalent of Land’s End to John O’Groats, a whopping 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 for dementia research. BRACE 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!

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.

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.

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.‘

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B R A C E ‘ s  S t a r  F u n d r a i s e r s !

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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 interdisciplinary 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
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_w_r_e_ (2 words)
9 V_t_r_n_r_a_
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_l_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

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

Thank you for your support!

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.

You can find the Autumn 2020’s quiz answers on the previous page.

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

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Thank you for your support!
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!

Choose from over 1300 designs, customise text and use your own photos, send audio or video messages and have them delivered by post, email or text message

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