THINK RESEARCH.

WE’RE ANOTHER STEP CLOSER TO A CURE FOR DEMENTIA.

INSIDE:

04: All about the new Alzheimer’s drug donanemab.
08: Trekking the Sahara for research.
12: “Big things are happening!” in drug discovery.

Autumn issue 2023
Welcome to think research.

This is a very special issue of think research.

And, to my mind, it brings together everything that makes our cause so unique.

There are the people who turn their experiences of this heartbreaking condition into something life-changingly positive for others. There are the scientists who make unprecedented headway in our laboratories. And there are the thrilling landmark moments – in this case, the development of the new Alzheimer’s drug donanemab – which prove that research is gaining on a cure for dementia.

This winning combination of support, progress and breakthroughs is how we’ll put an end to dementia, once and for all. I’m so grateful that you’re with us, making all of this possible. And I really hope you enjoy the issue.

Hilary Evans

Hilary Evans, Chief Executive, Alzheimer’s Research UK.
INSIDE YOUR THINK RESEARCH NEWSLETTER.

04 A new Alzheimer’s drug succeeds in clinical trials.

06 When will people benefit from new drugs and treatments?

08 “It’s one of the best things we’ve ever done.” – a life-changing trek across the Sahara.

11 Are you ready for a new challenge?

12 Meet Prof Fiona Ducotterd, Chief Scientist at our Drug Discovery Institute in London.

15 Eat your way to better brain health.

16 Finding peace of mind by planning for the future.

18 Dementia Research Infoline.

20 Tea-time teaser.

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A NEW ALZHEIMER’S DRUG SUCCEEDS IN CLINICAL TRIALS.

The Alzheimer’s drug donanemab has successfully slowed memory and thinking decline in a rigorous phase 3 trial, making it the second ever drug to show positive results in advanced clinical testing.

Donanemab was trialled with almost 1,800 people who have early-stage Alzheimer’s disease. And results show that participants who took donanemab had a slower rate of decline in their memory and thinking skills, compared to people who didn’t receive it.

Although donanemab’s benefits were modest, and it caused serious side effects for some participants, it proves that the first life-changing dementia treatments are here.

Newer, better drugs are certain to follow. And this progress will lead to a cure.

Donanemab is a ‘monoclonal antibody’ drug, developed by Eli Lilly and Company in the US.

It contains antibodies that bind to a protein called amyloid, which builds up in the brain in the early stages of Alzheimer’s disease, helping the body to break it down. This is also how the other Alzheimer’s drug, lecanemab, is designed to work.

Donanemab is delivered via infusion, which has required the participants in the trial to spend several hours in a clinic every month.
“With lecanemab and now donanemab, we’re on the cusp of a first generation of treatments for Alzheimer’s disease. It’s something that many thought impossible only a decade ago.

Of course, much more work needs to be done. But you should feel really encouraged by this news. It’s more proof that research leads to life-changing breakthroughs. And it will result in new ways to treat, diagnose, prevent – and ultimately cure – dementia.”

Dr Susan Kohlhaas, Executive Director of Research & Partnerships.
WHEN WILL PEOPLE BENEFIT FROM NEW TREATMENTS?

Since 2021 three drugs for Alzheimer’s disease have passed clinical trials. But will they be approved in the UK, and when will this happen?

**LECANEMAB.**

In July 2023, the FDA granted full approval for lecanemab’s use in the US, where it is marketed as Leqembi. This will enable more people to access the drug through the US health insurance plan, Medicare, which now covers older people with limited income and resources.

Lecanemab was submitted for approval by the UK’s Medicines and Healthcare products Regulatory Agency (MHRA) in May 2023 and we expect an answer in early 2024. If the MHRA approves the drug, it will also need to be assessed by the National Institute for Health and Care Excellence (NICE) in England and Wales, and the Scottish Medicines Consortium, to decide whether it’s cost-effective for NHS use.

We have written to the MHRA urging them to complete their review as a matter of urgency, without compromising on quality, so people with Alzheimer’s in the UK aren’t left waiting.

**ADUCANUMAB.**

In June 2021, the US regulator, the Food and Drug Administration (FDA) approved aducanumab for use in the US, under the brand name Aduhelm.

In December 2021 the European Medicines Agency refused a similar approval, citing concerns about the drug’s efficacy and safety and a need for further development. As such, aducanumab remains unavailable in both the UK and Europe.
Donanemab.

In May 2023, pharmaceutical company Eli Lilly announced top line results from its phase 3 clinical trial, which showed donanemab was able to slow cognitive decline by 35% in people with early Alzheimer’s disease. The full results were published in July 2023, which confirmed the promising results.

The company is set to apply for FDA accelerated approval in the coming months. Here in the UK we’re pushing for collaborative, constructive dialogue between people affected by Alzheimer’s disease, NHS England, drug manufacturers, the MHRA, NICE and more to ensure that treatments can be licensed without delay.
“IT’S ONE OF THE BEST THINGS WE’VE EVER DONE.”

There are many amazing ways to support dementia research, and waking up every morning to a Saharan sunrise takes some beating. Yet even remarkable experiences like this can come with a few niggles.

“The blisters!” exclaims James Aston, one of the ten walkers taking part in this year’s Saharan Trek for dementia research. “Even my well-worn boots aren’t helping. I’m grateful for every plaster I’m given. I’m also more than happy for my feet to pay the price. Especially as I get to experience something so awe-inspiring.”

It’s just one of the 23 fundraising challenges he’s taken on in 2023 after being spurred into action by his father, David. “Dad was diagnosed with frontotemporal dementia five years ago. It’s been heartbreaking to see his decline, and I knew I had to do everything I could to raise money for research into a cure.”

“I’m very glad to be helping. This is one of the best things I’ve ever done, to be honest. And the desert is such a stunning place. Much more beautiful than I could have ever imagined.”

The Sahara Trek team.
It was in the Moroccan desert that James met Prof James Rowe, a dementia researcher from the University of Cambridge and Chair of Alzheimer’s Research UK’s Scientific Advisory Board. Prof Rowe was inspired to join the other trekkers to build awareness of dementia research and to raise much-needed funding for our cause.

“You didn’t need to be called James to take part, even if it may seem that way”, says Prof Rowe. “In fact, the only requirements seem to be that you’re a lovely person and committed to finding a cure. Everyone has been brilliant and so willing to share their experiences of the condition. That’s a really useful thing for a medical researcher like me because we always need to keep families in mind when we’re working. It keeps us focused on the ‘why’ of research, and it proves beyond doubt that our studies matter.”

“It’s been really encouraging for me too,” says James Aston. “Learning about Prof Rowe’s work gives me a lot of hope. Dad’s already in the later stages of dementia, losing his language and his ability to recognise people and the world around him. In the future, research is going to really help people like my dad. And supporting that progress makes me feel very useful. Even when I get blisters, or when I’m struggling to walk up a sand dune in 30-degree heat. 

James with his dad, David.
“He’s right,” laughs Prof Rowe. “Those dunes are not easy! But like James, I’m relishing the opportunity to take on such a unique challenge.”

“We get up at about six every morning,” he explains. “Heading out before the heat rises properly. And what a privilege it is. It’s such a beautiful time of day to be out and about and there’s so much to take in. I’ve really loved spotting the different wildlife as we walk over the red dunes and coloured rocks. We’ve seen desert hares, all kinds of bright and colourful insects, lizards and eagles.”

James Aston agrees. “Even the sand doesn’t stay the same. It turns from yellow to black to orange as you walk or as the sun rises and sets. It’s even been purple! It’s just another reason that this trek has been so rewarding. I’m so happy to have taken part. What an experience.”

A life-changing experience.
“It’s been an incredible way to support research”, says Prof Rowe (who is pictured on the cover of this issue).
ARE YOU READY FOR A NEW CHALLENGE?

Since 2021, over 13,000 of you have taken part in a Facebook challenge for Alzheimer’s Research UK raising an astonishing £1.3 million. And it’s thanks to every walker, runner, swimmer, baker and knitter that we’ve been able to support hundreds of vital new studies.

We’re getting closer to a cure for dementia. But you could get us closer still. If you fancy ending 2023 on a high, why not take part in one of our upcoming Facebook challenges?

- **55 Miles in October** – walk, jog, run or roll your way through October, completing 55 miles for the 55 million people living with dementia worldwide. Find out more at alzres.uk/think-miles.

- **Knit, Sew or Crochet in November** – get crafty throughout November and aim to raise £100 for dementia research. You could sell your creations at the end of the challenge or gift them to loved ones this Christmas. Find out more at alzres.uk/think-knit.
“This is a pivotal moment for dementia research. And it’s really, really exciting.”

“Big things are happening,” says Prof Fiona Ducotterd from her office at University College London (UCL). “And like every scientist involved in dementia research, I’m very excited to be a part of them.”

After specialising in neuroscience for two decades, Prof Ducotterd now works as the Chief Scientific Officer at our Drug Discovery Institute (DDI), which is part of UCL’s world famous Queen’s Square Institute of Neurology in London.

This is part of our Drug Discovery Alliance (DDA), which ensures that discoveries in the lab are translated into potential treatments as quickly as possible.

“It’s an amazing place,” says Prof Ducotterd. “We have cutting-edge research and clinical facilities at our disposal. We even have access to a ‘brain bank’ – an archive of brains and tissue donated to research by people with neurodegenerative diseases. These resources, combined with our biotech capabilities, are helping us to better understand the causes and consequences of dementia. And they’re leading to new ways to prevent and treat it.”

Prof Ducotterd returned to the UK for this role in 2022 after increasingly senior research roles in Japan, China and the US, where she was “part of everything from preparing cells for study to forging partnerships between companies and universities worldwide.”
Prof Fiona Ducotterd
At the UCL Drug Discovery Institute, July 2023.
And when asked to describe herself, Prof Ducotterd opts for ‘Neuroscientist, Drug Discovery Professional and Mum’. “I’m very lucky to spend my working days involved in incredible, life-changing research, then come home to dinner and bedtime stories with Isla, who’s two.”

“It’s good to have the balanced perspectives. And it’s because of my family that I’m here in the first place. My grandmother Elsie lived with dementia. I know how much it hurts to see someone you love disappear, as she did. I want to prevent my daughter’s generation from experiencing that heartbreak.”

“It’s a challenge. Brains are dynamic and no two are the same. We are literally all wired differently. So it’s taken an immense amount of work to get here and it’s going to take even more work to get where we need to be. In research, successes and failures both tell us important information that helps move projects forward. You develop a theory, you apply it and when it doesn’t work, you learn from it and go again. With the brain you have to do that a lot.”

Yet Prof Ducotterd says every supporter of dementia research has very good reason to feel optimistic about the future.

“She’s the inspiration for my career.”
Fiona as a baby with her grandmother, Mary Elspeth ‘Elsie’ McAllister.

“Until recently we couldn’t distinguish between different types of dementia in living patients, but the accuracy of diagnosis is evolving fast. And we’re seeing a pipeline of promising Alzheimer’s drugs that go beyond treating symptoms and can slow cognitive decline. In the US they’re already being approved by regulators. It’s genuinely amazing. It proves that if we keep at it, we’re going to find better ways to treat and even cure this condition, as long as we can keep our research moving forward.”
EAT YOUR WAY TO BETTER BRAIN HEALTH.

Think Brain Health celebrates our incredible brains and the simple things we can do to protect them – which includes eating a healthy, balanced diet. In this issue, we share a recipe from Healthy Brain, Healthy Life – a project you’ve helped to fund in Bournemouth, which promotes brain health through creative and culturally-tailored approaches.

Rainbow prawn skewers (makes 10).
2 peppers (the more colourful, the better!)
1 aubergine.
2 courgettes.
20 tiger prawns.
10-12 wooden or metal skewers.
100ml vegetable oil.
10g chilli powder.
15g mixed herbs and spices.
10g ground coriander.
3 garlic cloves (peeled and grated).
30g ginger (peeled and grated).
An equal pinch of salt, pepper and sugar.

Method.
• Clean the prawns, removing any shells or veins, and wash and cube the vegetables.
• Mix everything together with the seasoning and leave to marinate (ideally for one hour).
• Add vegetables and two prawns to each skewer, then cook under a hot grill (or griddle) for about 10 minutes, turning occasionally.
• Serve with brown rice, a green salad or whatever healthy option takes your fancy!

Prawns are rich in proteins, iron, iodine, selenium and zinc which are important in immune function and brain development.

Aubergines are especially rich in anthocyanin pigments, which have beneficial antioxidant effects.

Peppers are a great source of vitamin C, beta carotene, vitamins E and K, antioxidants, folate, and potassium which contribute to a healthy heart.
IS IT TIME YOU MADE OR UPDATED YOUR WILL?

PERHAPS YOU’RE WORRIED ABOUT INHERITANCE TAX OR PAYING FOR CARE?

Order your FREE Planning for the Future pack from Alzheimer’s Research UK, which provides information on these and other legal issues, all packaged in a handy folder for you to keep safe and store with your other important documents.

To request your pack:
- Scan the QR code with your smartphone camera
- Visit: alzres.uk/plan-future
- Email: giftsinwills@alzheimersresearchuk.org
- Call: 01223 896 606
The Childhood Friends Who Became Lifelong Sweethearts.

David and Susan Ensor first met as children when they lived next door to each other. But when Susan’s family moved away, the neighbours and best friends were separated. It wasn’t until the 21st birthday of David’s sister Jennifer that fate brought them back together.

And this time romance flourished. David and Susan married in 1969 and settled in Parbold, near Wigan, where they started a loving family and remained inseparable for the next five decades.

It was in 2016 that David first noticed a change with Susan. This began with memory problems and with Susan struggling to do some things she loved, such as cooking or following the words and music at her local choir. But it soon became something more worrying and a diagnosis of Alzheimer’s in 2018 confirmed the family’s fears, after which Susan’s decline accelerated.

It was very painful for David to lose the woman he adored.

Susan passed away in 2021, only a few weeks after moving into a care home. David is determined that others won’t have to experience such heartbreak, or lose the people they love to dementia. So he has pledged to leave a gift in his Will to Alzheimer’s Research UK.

“Leaving a gift to research was something I was determined to do. I desperately want to see a cure for this terrible condition. I know how much it hurts people.” says David. “But I know that tremendous progress is being made into treatments, diagnosis and ways to prevent dementia. A gift in my Will can help this vital work to continue.”

Find out more about supporting dementia research with a gift in your Will at alzres.uk/think-wills.
HOW DEMENTIA DIAGNOSIS AND CLINICAL TRIALS GO HAND IN HAND.

Our Dementia Research Infoline answers your questions about taking part in research, dementia symptoms and much more. We also share trustworthy information in think research and in this issue Information Officer George Mack discusses the current diagnosis methods used in clinical trials, and how we plan to improve them.

People need to be accurately diagnosed to take part in clinical trials. Why is this?

Well-designed clinical trials are essential to understand the benefits and safety of a potential treatment. Scientists must make sure they’re giving the drug to people who are at the right stage of the disease process – and this means making sure they have an accurate diagnosis, which can be tricky.

Diagnosing people with dementia in the UK currently involves a broad range of steps, including cognitive tests, medical history, and brain scans (such as an MRI). More sophisticated techniques like PET scans are less frequently used, due in part to their expense and limited availability. It means diagnosis is usually more of a ‘best fit’ rather than a definitive diagnosis.

What technology can be used to spot diseases like Alzheimer’s?

PET scans detect specific ‘biomarker’ molecules in the brain which act as signs of disease. These include things like an abnormal build-up of the amyloid proteins which can be linked to Alzheimer’s disease. A volunteer will swallow safe dyes which bind to amyloid protein in the brain. The scanner can then detect these dyes, revealing areas where problems are occurring – and allow scientists to monitor new treatments.
Lumbar punctures test samples of cerebrospinal fluid and can also be useful in identifying the presence of faulty proteins found in Alzheimer’s disease, like amyloid and tau. However, both methods are used more commonly in research than diagnosis and can only detect the presence of certain proteins.

**How can we improve diagnosis to boost participation in trials?**

We need more opportunities to detect dementia, in more people. But because of the need for specialist facilities and highly trained staff, the scaling up of PET scans and lumbar punctures is likely to be too expensive for the NHS.

So Alzheimer’s Research UK is determined to find another way to improve diagnosis for people with dementia. With your help we are accelerating our work on the development of affordable blood tests which can spot the same biomarkers, but which could take place in a GP surgery or other community setting.

Not only will this get people the answers they need and deserve, it will also make the screening process for clinical trials much faster and more efficient.
You can volunteer for dementia research studies and play an important role in the search for new treatments.

People with and without dementia can take part in this vital research. When you sign up, you’ll be matched to studies you might be suitable for and can choose which ones you take part in. By doing so, you will be helping scientists to understand more about the diseases that cause dementia – as well as how to diagnose and treat them.

It’s quick and easy to register to Join Dementia Research. Call our friendly team on 0300 111 5 111 (9am-5pm, Mon-Fri), sign up at alzres.uk/think-jdr or scan this QR code.