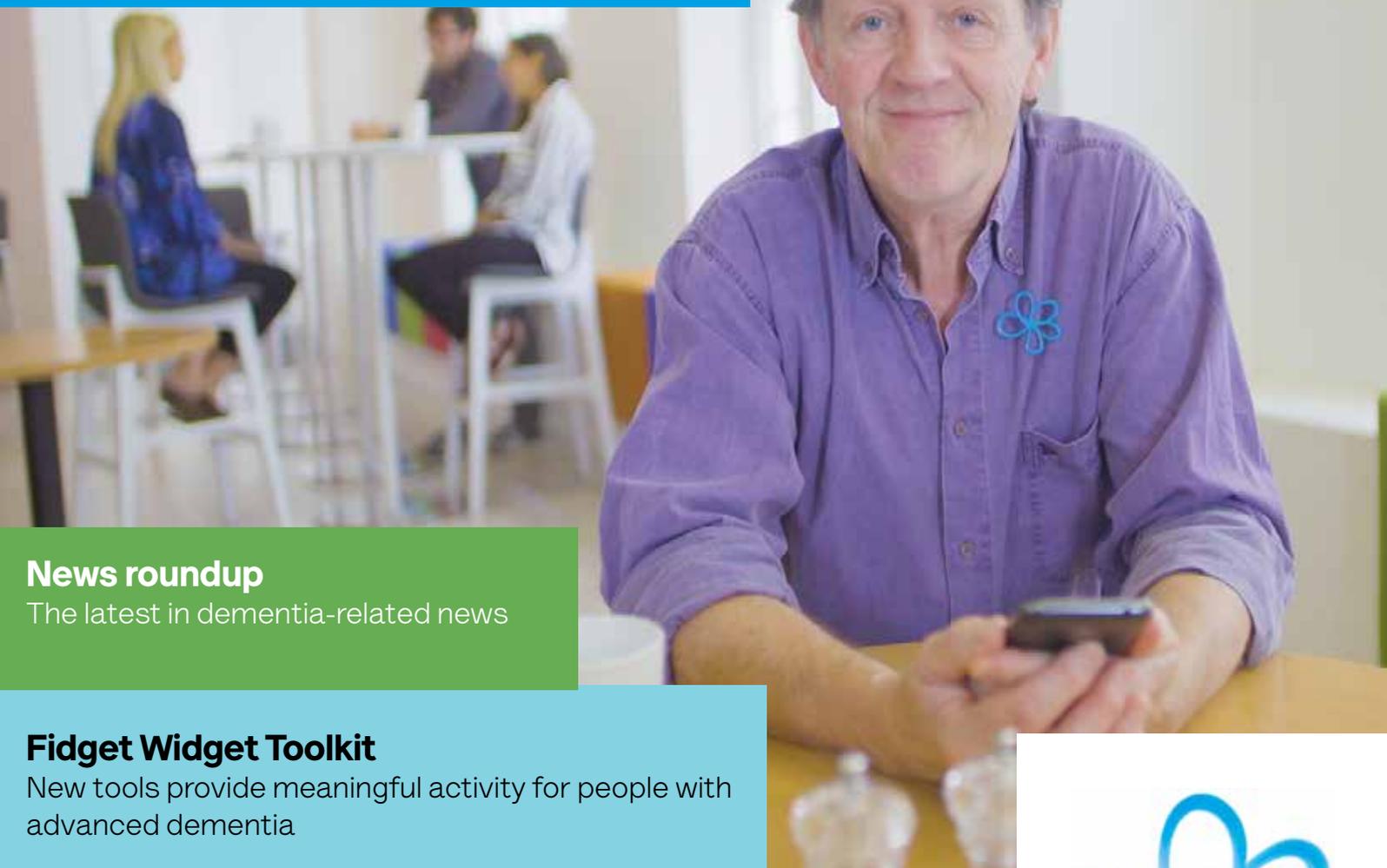


Care and cure

The Alzheimer's Society research magazine

Become a GameChanger

Find out how you can use your smartphone to help dementia research



News roundup

The latest in dementia-related news

Fidget Widget Toolkit

New tools provide meaningful activity for people with advanced dementia

The arts and dementia

Researchers are providing evidence of the benefits of the arts in dementia care along with a good dose of joy





Dr Aoife Kiely
Editor

Welcome to Care and cure magazine

In this issue of Care and cure, we learn about the science behind the new dementia research app GameChanger. This Society-supported research is set to revolutionise how future technology is used to diagnose dementia (Page 6).

Our guest author Josie Clarkson, a dementia adviser in south London who is also an excellent science communicator, fills us in on the latest research into how star-shaped support cells in the brain could be dysfunctional in Alzheimer's (Page 4).

We get a sneak peek at the brand new Fidget Widget Toolkit—an activity set for people with advanced dementia. Designed to promote connection and interaction, it eases the agitation of fidgeting by providing purposeful activity (Page 11).

We hear the latest news from TAnDem, a doctoral training centre focusing on the arts and dementia with a report from their third annual conference (Page 10). Their researchers tell us how they are providing evidence to show the benefits of arts interventions for people affected by dementia.

If you'd like to order additional copies of this magazine please contact me at aoife.kiely@alzheimers.org.uk

Thank you for picking up this issue of our research magazine – I hope you enjoy it!

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About us

Since 1990, Alzheimer's Society has funded £50 million of cutting-edge dementia research. Over the next decade we plan to invest £10 million per year in research and raise £50 million to support the UK Dementia Research Institute. This research helps to improve the quality of life of people with dementia by investigating prevention, improving practice in care and pursuing a cure.

[alzheimers.org.uk/research](https://www.alzheimers.org.uk/research)



Sex and intimacy: Lift the Lid

A new Alzheimer's Society resource will help care home staff address taboos.

Imagine that you've moved into a care home. It's likely that – as much as possible – you'd want to continue with every aspect of your life as you had before. As well as being able to choose how to dress and what to eat, you may want to hold hands or cuddle with a loved one, to share a bed and maintain your sex life with a partner, or to seek a new partner. These are things many of us take for granted, but the sex and intimacy needs of people with dementia in residential care may be viewed as inherently problematic.

Last year, Alzheimer's Society began a new project to tackle sex and intimacy taboos in care homes. We involved 10 homes run by Bupa, Four Season and St John's Trust to better understand the situation and explore potential solutions. Some care home staff told us that they had never considered residents' sex and intimacy needs at all. Others said they didn't know how to broach the topic, were concerned about issues of consent or lacked clear guidance.

The evidence suggests that care home staff want to get this right but don't know where to start. We worked with care homes to create Lift the Lid – a 'workshop in a box' for care home staff that challenges their perceptions and behaviours through three creative activities. This helps them to develop a sex and intimacy policy so that staff can feel confident about providing all-round person-centred care, in line with guidance from regulators such as the Care Quality Commission.

Dr James Pickett, Head of Research at Alzheimer's Society, said, 'Sex and intimacy in the context of a care home raises countless questions that many people don't know how to answer or don't even want to think about. When you consider that 70% of people in care homes are living with dementia, the conversation gets even more complicated.'

'It can be a really taboo topic, but we believe care home staff are best placed to tackle this challenge and make a real difference. We're all different, so there is no "one size fits all" solution. Lift the Lid is a flexible tool to help care home staff talk through the issues in a creative and constructive way.'

'Dementia research isn't only about finding a cure. We're also investing in vital care research like Lift the Lid, because we owe it to the 850,000 people in the UK currently living with dementia to understand the condition better so that they can live better.'

You can read more about Lift the Lid and what it's like to try out the workshop in the December/January issue of Dementia together magazine – see alzheimers.org.uk/magazine or call **0330 333 0804** (local rate).

Care homes can order a Lift the Lid workshop toolkit by calling **0300 124 0900** (local rate) or at shop.alzheimers.org.uk



Lift the Lid, the 'workshop in a box' for care home staff.



Failing stars - by Josie Clarkson, a dementia adviser in south London

Finding out more about star-shaped cells in the brain.

You may be familiar with astrocytes from the article 'Stars of the show' in our autumn 2018 issue. They are star-shaped cells in the brain that help to clear away waste products, helping neighbouring brain cells to work properly. Recent research suggests that how acidic these astrocytes are could make a difference to their role in the development of Alzheimer's disease.

Clusters of a protein called amyloid are found in the brains of people with Alzheimer's. Amyloid disrupts the communication between brain cells. As brain cells die, this causes gradual and progressive decline in the person's memory and thinking skills.

In healthy brains, astrocytes 'mop up' amyloid before it can do any damage. However, if astrocytes are too acidic or alkaline, then astrocytes can't take hold of the amyloid and so it doesn't get cleared up. That means the amyloid can build up in the brain.

New research by Professor Hari Prasad and Dr Rajini Rao found that the astrocytes of people with Alzheimer's disease are more acidic than those of other people's. In people with Alzheimer's, the researchers also discovered faults in genes that control the acidity of their astrocytes.

Not satisfied with simply understanding astrocyte acidity, the researchers also wanted to fix it. They treated mice, which had been bred to develop Alzheimer's, to change the genes that control astrocyte acidity.

They also treated them with an antibiotic, which they also expected to reduce the acidity of their astrocytes. Both of these treatments made the astrocytes less acidic, and this allowed them to clear the amyloid. This, in turn, boosted the mice's thinking and memory skills.

Professor Prasad and Dr Rao have brought astrocyte acidity into the spotlight. In the future, research could investigate whether astrocytes hold the key for potential treatments.

Every other woman

The importance of raising awareness of how lifestyle can reduce risk, particularly among women.

A third of men and one in two women over the age of 45 are likely to develop dementia or Parkinson's or to have a stroke, according to recent research highlighting the impact of lifestyle changes.

Many of us understand that risk of cancer can be reduced by avoiding smoking, regular exercise and healthy eating. Yet less people are aware that these lifestyle changes can also help to reduce your risk of dementia, Parkinson's and stroke.

The Dutch study involved over 12,000 people aged at least 45 and followed their health over 26 years. They found that men were more likely to have a stroke at a younger age than women. Yet women were twice as likely to be diagnosed with both dementia and stroke during their lifetime.



Encouragingly, the study reaffirmed that lifestyle changes can reduce the risk of developing these conditions. People who made healthy changes at age 45 reduced their lifetime risk by 20%, and this rose to over 50% for people aged over 85.

This underlines not only how lifestyle changes can reduce dementia, Parkinson's and stroke risk, but also that it is never too late to start.

Exercise, bottled?

Could medication mimic the effects of exercise?

Most of us understand that exercise is good for us. It can make us feel good and keep fit, and large studies have supported the idea that it reduces our risk of developing dementia. However, we still have a lot to learn about how physical exercise affects the brain.

Researchers at Massachusetts General Hospital, led by Dr Rudy Tanzi, are investigating whether they can bottle the benefits of exercise to boost our brains. They gave mice that had been bred to develop Alzheimer's a combination of drug and gene therapy to see how this affected their memory.

Mice that were treated showed increased levels of chemicals that nurture the cells in their brains. Their minds were as sharp as those of mice who had spent hours running on a wheel, even if they hadn't moved a muscle all day.

Don't throw away your running shoes just yet, however – more research is needed and there are many other benefits of exercise that the treatment couldn't deliver.

The mice in this study did not show any reduction in the toxic proteins that build up in the brains of people with Alzheimer's. The type of gene therapy used isn't suitable for humans, and it will be some time before we can find out if the drug treatment may benefit people.

Exercise also has plenty of other positive effects, for people with dementia as well as those hoping to reduce their risk of developing it. This includes opportunities for social contact, a sense of achievement and chances to enjoy nature.

News in brief

Young blood

A small study at Stanford University suggested that blood transfusions from younger people to people living with dementia might ease day-to-day symptoms of the condition. However, this didn't confirm any long-term benefits or show any improvements in the progressive brain damage involved in dementia.

Waist away

Alzheimer's Society researchers at Cardiff University have found that if your waist is larger than your hips you may have weaker connections between cells in brain regions linked to processing memory and emotion. Their work continues to investigate whether greater body fat and associated inflammation could increase risk of dementia.

Intellectual disability and dementia

Dr Karen Watchman presented her Society-funded research at the Alzheimer Europe Conference. Her work focuses on the experiences and perspectives of people living with an intellectual disability as well as with dementia, reinforcing that they also need the best dementia care.



Become a GameChanger



Sign up to play games on your phone for five minutes a day and help to improve the future diagnosis of dementia.

We know that a timely and accurate diagnosis is a key step for a person with dementia and those around them to live as well as possible with the condition. But a third of people with dementia still don't get a diagnosis. For those who do, it's too often a slow process they have to fight for.

A new research project is looking for people who don't have dementia to play games on a smartphone app to help improve how the condition is diagnosed, researched and treated.

Need for diagnosis

There is no single, reliable test that can diagnose dementia quickly and easily. Instead, doctors rely on a combination of written tests, brain scans and observations.

Although we can't yet slow down or stop dementia, a diagnosis puts a name to changes that may have been a source of worry for some time. It also enables people to get the support they need, and existing treatments could help to manage someone's symptoms, which may have a big impact on quality of life.

If we can diagnose people at the very early stages of the condition's development, then we can invite them to take part in clinical trials.

New treatments are also likely to be most effective when the diseases that cause dementia are first developing.

For all of these reasons, the earlier that people with dementia receive an accurate diagnosis, the better.

Little and often

Doctors and researchers currently use written tests every few months or even annually to monitor how a person's memory and thinking changes over time. This provides a patchy and inconsistent picture, and can't take day-to-day variations in symptoms into account.



Technology can help us to monitor changes in thinking and memory using a ‘little and often’ approach. More frequent, quick tests allow doctors to get a more accurate view of how memory and thinking is changing over time.

To know what these changes mean, we need to understand how healthy ageing affects thinking and memory.

GameChanger

GameChanger is a research project led by the University of Oxford and supported by Alzheimer’s Society that aims to do just that. Led by Dr Chris Hinds, the team at Oxford has developed a series of games on a smartphone app. These are designed to test specific aspects of memory and thinking that are believed to be affected in the earliest stages of Alzheimer’s disease.

Smartphones can collect an amazing amount of information. Dr Hinds explains, ‘People using the app are just playing games but their phones are collecting data we can use to learn about the brain, to help us understand what is a natural part of ageing and what’s a warning sign.

‘From how we interact with a touch screen and how we move the phone around, to changes in our speech – the sensors in our phone can paint a rich picture of how brain performance changes over time.’

‘Researchers will be able to compare age-related changes in healthy brains, which we will see through GameChanger, with the changes we see in people who have early stage Alzheimer’s disease.’

Dr Claire Lancaster, another Oxford team member, adds, ‘GameChanger will shed light on the changes in thinking and memory that are caused by the very earliest stages of dementia.

‘Researchers will be able to compare age-related changes in healthy brains, which we will see through GameChanger, with the changes we see in people who have early stage Alzheimer’s disease.

‘GameChanger is a simple and fun way to support dementia research. You don’t even have to get out of bed to play your part! All it takes to play is five minutes every day for a month.’

The actor Kevin Whately, whose mother lived with Alzheimer’s disease for nearly 10 years, is joining our call for thousands of people to sign up to play.

He says, ‘I’m supporting GameChanger because it is going to be a really important innovation for dementia researchers and it will drive forward research.’

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The data collected by GameChanger will help us to improve dementia diagnosis in the future, but you can’t diagnose dementia by playing the game at this stage. So if you find the games tricky, it’s nothing to worry about!



How do I sign up?

Anyone over the age of 18 who does not have dementia can take part – simply:

- Sign up at alzheimers.org.uk/gamechanger
- Download the app.
- Start playing brain games today.

All data will be stored securely at the University of Oxford. Data will be shared with the research community only after it is made anonymous.

Sharing what we know

Our Research Network has led the way in ‘patient and public involvement’. We’re sharing our experiences and knowledge so that research into all health conditions can benefit.

Thanks to our Research Network, Alzheimer’s Society has pioneered making sure that the experiences of people affected by dementia are placed front and centre when deciding what research is done and how it is conducted. The unique perspectives of people who are ‘experts by experience’ have had a massive impact on dementia research because of this.



Join the Research Network

Our Research Network, established in 1999, has grown to involve over 270 people with dementia, carers and former carers. With training and support, these volunteers apply their personal knowledge of dementia to improve our research.

Research Network volunteers are involved in all stages of our research – advising on what we should fund, designing studies, monitoring how research is going, and making sure that any discoveries are shared widely.

Visit alzheimers.org.uk/researchnetwork to find out more and get involved.



This way of involving people has become known as patient and public involvement (PPI). Rather than only recruiting people affected by a condition to take part in clinical trials, it means including them in all stages of research.

Despite this, little has been published about the importance of PPI in dementia research. So in November 2018, we produced a special guest edition of the academic journal *Dementia: The International Journal of Social Research and Practice*. This coincided with the annual UK Dementia Congress and recent standards to support PPI in research from the National Institute for Health Research.

The special edition highlights the importance and benefits of PPI to the rest of the research world. A selection of articles written by our researchers and Research Network volunteers share experiences so that others can gain from their insights and be inspired to use this learning in their own fields.

Read this special edition of the journal *Dementia: The International Journal of Social Research and Practice* at journals.sagepub.com/toc/dema/17/8



What is your gut telling you?



Dr Luke Whiley talks about his research.

Who are you?

My name is Luke Whiley and I'm a postdoctoral researcher at the UK Dementia Research Institute at Imperial College London. I am researching how and why people get dementia.

Before I started this work at Imperial, I did my PhD at King's College London. This involved investigating how certain fats – lipids – in the brain are different in people who have Alzheimer's.

What are you researching now?

My research involves looking at processes in our body that make us who we are, and which have an impact on our health and disease. Some of these things can be controlled by lifestyle factors such as what we eat and whether we smoke. However, other factors – including the genes we inherit from our parents – are beyond our control.

In particular, I'm looking at the gut and how the combination of bacteria that normally live there can influence our health. We believe there are more bacterial cells in our gut than there are of our own cells in our entire body, so it is understandable that they could play a big role in our health.

Many of the effects that these bacteria have on our bodies are believed to be good for us, but some could make us ill. Some bacteria even release chemicals that create signals provoking a response in our brains. My work focuses on these chemicals to see if they could affect the processes that lead to dementia.

Why is this research important?

This research is important for two main reasons. First, if I discover that gut bacteria influence our brain health, this could help to explain why some people develop dementia while others have healthy brains until old age.

Secondly, if we identify which bacteria are protecting or hurting our brain health, then we can develop treatments to control the 'bad' bacteria and encourage the 'good', helping to keep our brains healthy throughout life.

'If we identify which bacteria are protecting or hurting our brain health, then we can develop treatments to control the "bad" bacteria and encourage the "good", helping to keep our brains healthy throughout life.'

What is next for you and your research?

Now that the UK Dementia Research Institute is up and running, this is a really exciting time for our field. I'm surrounded by team members from lots of different backgrounds, and we're all linking up and working together to tackle dementia. For example, our research now involves analytical scientists, microbiologists, statisticians, geneticists and epidemiologists. We're bringing all of this together to help us get an overall picture of health and dementia.

As for me personally, I'm expanding my research skills, ideas and networks of other researchers. Long term, I want to lead my own research group to help further uncover the causes of dementia.

Luke has also signed up to run the 2019 Virgin Money London Marathon for Dementia Revolution to raise funds for the UK Dementia Research Institute.

Join the Dementia Revolution

Dementia Revolution is a year-long partnership between Alzheimer's Society and Alzheimer's Research UK to power groundbreaking dementia research, overthrow old attitudes and lead the change towards a cure.

You don't have to run a marathon to support researchers like Luke—to find out what you can do, visit:

dementiarevolution.org

TAnDem: The arts and dementia

Researchers at an arts-focused doctoral training centre in the Midlands are boosting knowledge along with a good dose of joy.

TAnDem is a training centre for PhD researchers that focuses on the arts and dementia. Supported by Alzheimer's Society and the universities of Nottingham and Worcester, TAnDem enables students to explore how interventions using arts could benefit people affected by dementia. An arts invention can involve anything from writing poetry and painting to singing and dancing.

While we don't yet have a way to stop or slow down the progression of diseases that cause dementia, there is growing evidence that arts activities may improve the quality of life of people affected by the condition.

The work of TAnDem researchers will support the choices of people with dementia and their families, so they can be confident about which arts activities are right for them. Funding commissioners can also use this evidence to justify spending money on arts interventions.

Unique challenges

In September, TAnDem students held their third annual conference to showcase their work. They shared how they are tackling the unique challenges of studying the effectiveness of arts interventions.

Emily Cousins asked how we classify an arts intervention and Karen Gray looked at how we measure whether it is improving a person's quality of life. Emma Broome explored how we put arts interventions into practice and make sure they are delivered properly, while Amy Veale asked which type of invention is most suitable at what time.



A scene from the play 'Silva Lining's Care Plan'

Research impact

Professor Justine Schneider, from the University of Nottingham, co-directs TAnDem with Professor Dawn Brooker from the University of Worcester. Professor Schneider told us that, 'The research of the students is being fast-tracked into practice.'

TAnDem students and supervisors have inspired local services, and people living with dementia are eager to attend arts-focused activity sessions and conferences. A recent University of Nottingham ESRC Business Boost fund means the centre can develop a plan for a local, arts-led day centre for people with dementia. This will be informed by the University of Worcester's experience of evaluating and disseminating the MeetingDem model of day care, which originated in the Netherlands.

Professor Sebastian Crutch, a Society-funded researcher at UCL (University College London), shared his research on posterior cortical atrophy. By collaborating with people from a number of disciplines, his team has created online courses to help people understand dementia and how the arts could help – see www.futurelearn.com/courses/dementia-arts

Inspiring projects

TAnDem has been a hub for many inspiring dementia-related creative projects. As fans of Singing for the Brain will tell you, group singing can be a very uplifting and positive experience. Becky Dowson's research investigates whether music therapy principles can be successfully used by someone who doesn't have a music therapy qualification. She works with the Blue Skies singers, a choir of people affected by dementia, and shared how their lives have been improved by the joy of singing together. They then serenaded us and led a wonderful sing-along.

TAnDem team members also gave us a preview of the play 'Silva Lining's Care Plan' that explores the relationship between a person with dementia and her carer. Rumour has it that there's an opera in the works, so watch this space!



The Fidget Widget

A Society-funded project has developed a set of tools designed to provide meaningful activity for people with advanced dementia while also involving carers.



Seeing a lack of suitable activities for people with more advanced dementia, Judith Bower and Jane Souyave decided to do something about it.

Judith, internal trainer and Dementia Adviser at the Society in Lancashire, and Jane, Senior Graphic Design Lecturer at the University of Central Lancashire, had noted how often fidgeting and repetitive movements came up in conversations with carers.

Positive ends

They wanted to dispel the myth that fidgeting is negative or a kind of 'disruptive behaviour'. Instead, they decided to recreate repetitive fidgeting actions such as turning, twisting, rolling, pulling and flicking movements for positive ends.

They applied successfully to innovation funds run by Alzheimer's Society and the University of Central Lancashire to help develop an intervention called Positive Connections. This aimed to raise awareness of how to communicate and connect with people in the later stages of dementia, when words may become difficult. Judith and Jane hoped to provide opportunities for people with dementia to engage in meaningful activities that could also involve carers.

Work began to design and test their ideas, and this resulted in five wooden, handheld tactile tools that come in a handy pack called the Fidget Widget Toolkit.

Testing the tools

The tools are designed to not rely on memory or words, and not to represent a recognisable tool, such as a screwdriver or kitchen utensil. This means that people interact with them creatively, with no right or wrong way to use them.

Over a two-year period, the Fidget Widget Toolkit was tested in people's own homes, day centres and care homes. A range of measures were used to measure its impact, including interviews and audio and video recordings. Care home staff also attended a two-hour Positive Connections awareness session before each test.

Judith and Jane found that men and women engaged with the tools equally. Families, who were supported with techniques to connect and communicate, enjoyed being involved. They particularly appreciated that these were interactions which weren't focused on providing personal care.

Interactions with the Fidget Widget Toolkit enhanced the person's wellbeing by supporting their psychological needs to feel occupied, engaged and included in a meaningful activity of their choice. According to carers, this effect was ongoing and lasting.

One carer said, 'It's the only thing he can do for himself, it gives him that little bit of independence.'

Comments from care staff included that the tools were 'simple but effective' and that 'the experience changed how we engage with people'.

Making them available

We have partnered with Active Minds, a supplier that develops activities for people with dementia, to produce the Fidget Widget Toolkit.

It will be available through the Alzheimer's Society online shop from late December. For the Fidget Widget Toolkit and many other useful products and gifts, visit shop.alzheimers.org.uk





Join us for Carols at Christmas

Come celebrate in song at our flagship event at St Paul's Cathedral, London on Tuesday 18 December 2018.

Alternatively, there are a host of other concerts across the country.

Find your nearest concert and buy your tickets at
alzheimers.org.uk/carolsatchristmas

For further enquiries please contact
carols@alzheimers.org.uk
or call us on **0330 333 0804**.

Carols at Christmas

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Call 0300 222 1122 and ask about Join Dementia Research

Join our Research Network

Involving people with dementia, carers and former carers to influence our research,
alzheimers.org.uk/researchnetwork

General enquiries

enquiries@alzheimers.org.uk

Magazine enquires: Aoife Kiely

Research Communications Officer and Magazine editor
aoife.kiely@alzheimers.org.uk

