

Cambridge Branch Newsletter – July-August 2021

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BRANCH MEETINGS

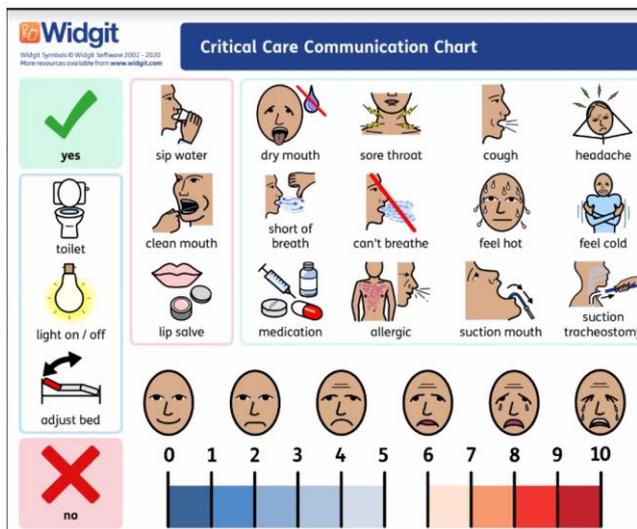
CARDS TO HELP PATIENTS COMMUNICATE

COVID has made the wearing of full-scale PPE (Personal Protective Equipment) vital to minimise the risks of infection to healthcare staff. But it has a drawback: it makes communication with hospital patients significantly more difficult.

This is especially true in intensive care, and with people whose first language is not English. Which is why the speakers at our most recent Cuppa & Cake meeting, on June 25, decided to form a group to tackle this precise problem.

founder of the CardMedic communication tool, Rachael Grimaldi, an anaesthetist.

In fact, the aim of the meeting was not only to tell us about the project, but also for them to get feedback from us. And members were very helpful, making a series of perceptive comments, some encouraging, others critical. But overall, our Secretary Keith was impressed. "I think this could transform the relationship between some of the people and staff in the care home where I work as a volunteer," he said. For more, see the website www.cardmedic.com, or contact Michèle at michelegasper@cardmedic.com



They are part of the CardMedic Foundation, and have recruited several people, some of them professional speech and language therapists. Their aim is to create a tool featuring graphics-based messages to make communication easier and more effective for patients and staff – not just non-English speakers, but also those who have communication problems for other reasons like dementia, or stroke victims.

Michèle Gasper was the presenter, joined at our meeting by two other partners in the project, Alix Lewer and Nadia Iftikhar. They are working with the

PAINTING HELPS ALLAN WITH TREMOR

An inspiring story of dealing with the onset of Parkinson's was told by Allan Brown at our May 14 meeting. Previously, Allan had been a keen guitar player and photographer, but the worsening of his tremor began to rule out these hobbies. So what did he do? Took up sketching instead!

He started with water colours and pencil drawings, and found that it actually helped with the tremor. "I wasn't very good at the start, but found I improved



quite quickly," he says. Something his paintings now prove beyond doubt. Like many People with Parkinson's (PwP), Allan has problems sleeping, and one of the less

obvious advantages of painting is that he can do it in the middle of the night without making any noise. He was soon painting one picture every day, and the results are clear to see.

Now, Allan has been invited to join the Open Studios in Cambridge, where his work will be on display at the Pitt Building on Trumpington Street over the weekend of July 3-4, from 11am to 6pm. All are welcome, and his pictures will be for sale, with all money raised going to Parkinson's UK. He even closed a few deals at our meeting, raising £160 in the process.

Allan is completely self-taught but he has had great encouragement from his wife Lorraine, who is an accomplished artist herself. He uses acrylic, gouache, watercolour and ink, producing a variety of work, and his latest passion is painting birds.

"I wouldn't say I have a favourite subject – I find it all such fun. But I am still a beginner, keen to learn new techniques and trying to be more adventurous and hopefully creative." For Allan's gallery go to [Home \(artweb.com\)](http://Home.artweb.com), and to watch the meeting, see <https://www.youtube.com/watch?v=5z-LNnKusCuY>.

BBC TECHNOLOGY REPORTER HELPS DEVELOP ARTIFICIAL INTELLIGENCE MONITORING

Our speaker on June 6 attracted an excellent audience, probably 30+, and it seemed he was familiar to all of us – being the BBC's TV technology correspondent, Rory Cellan-Jones.



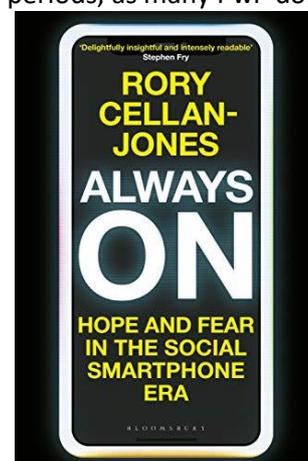
Rory took us briefly through his career, having started on a three-month contract with the BBC in Leeds. From there he progressed to Newsnight, subsequently becoming a business reporter at the time of the dot.com boom. Then in 2007, he was made technology correspondent.

It was in 2018 that his wife told him he was dragging his foot. Then, following a live broadcast he did from the Channel Islands, a viewer wrote to him saying they had noticed a tremor. "So I wasn't totally surprised when told I had the symptoms of Parkinson's," he said. This was in January 2019.

For a time he kept this private, telling only a few close colleagues and friends. But after being told his tremor was becoming more obvious, he decided it was right to go public. On the train to Birmingham, he posted a message on social media.

"That was when I was at Birmingham International," he said. "Five minutes later, my phone was going ballistic, with virtually all the messages being positive and helpful – it was the really good side of social media."

Rory started taking Sinemet (a version of L-dopa well known to many of us), which does help. But he says he doesn't experience 'off' periods, as many PwP do. Appropriately, given his job, Rory has become involved in developing technology to help with Parkinson's. He has just taken part in a trial run by Imperial College, London, aimed at using artificial intelligence (AI) techniques to monitor and diagnose symptoms. This involved wearing sensors while performing movements on the instruction of a researcher for 20 minutes a day for 10 days. The range of the movements was sent by Bluetooth to a computer.



He's also pledged to leave his brain to science after a visit last year to a brain bank that's working on drug developments. And he has participated in a study into the genetics of Parkinson's. But doctors don't think genes played a part in Rory's diagnosis, even though his father, James Cellan Jones, director of the huge 1960s TV hit the Forsyte Saga, developed the condition in his late 70s. He died in 2019 aged 88.

Meanwhile, another potential treatment option for him is deep brain stimulation (DBS), and the hospital he first attended, St Mary's Paddington, is potentially a UK centre for focused ultrasound (FUS). It is developing a system using FUS combined with an MRI scanner, creating a much less intrusive way of delivering DBS.

Not everything in Rory's life is concerned with Parkinson's. He has written a book, just published, with the self-explanatory title of "Always on: Hope and Fear in the Social Smartphone Era". And he is a

baker – as he demonstrated in his talk to us, which was interrupted by occasional visits to the oven and the production of a loaf at the end!

DOGGED DETECTIVES SNIFF OUT DISEASES

Our meeting on May 28 was surely one of the most remarkable and memorable of the last few years. It featured the charity Medical Detection Dogs (MDD), and its story was told by Volunteer Manager, Claire Baker.

The origins of the charity go back some 30 years and involved another Claire (Guest), who is now the Chief Executive and Chief Scientific Officer. A friend of hers, Gillian, had a dog that started to behave strangely, constantly licking and sniffing a small freckle on her leg. Eventually, she saw her doctor and discovered that the tiny freckle was a malignant melanoma. Gillian was only 19 at the time, so this was highly unusual.

Fast forward to 2003, and Claire was listening to a Dr. John Church on the radio, a man who believes that maggots can be invaluable in removing infected wounds, often better than conventional treatment such as large doses of antibiotics or surgery. Church, an orthopaedic surgeon, set up the International Biotherapy Society in 1995. In the broadcast, he also said he believed dogs could smell cancer. Claire contacted him, found he was only 20 minutes away, and immediately went to see him. MDD was born.

Dogs' remarkable ability is slightly less amazing when you consider the sensory 'apparatus' they possess that is devoted to smell. The average human has about 5m smell receptors. A typical dog – but especially breeds such as labradors and spaniels – has around 300m. Claire gave a powerful example of what this means in terms of smell sensitivity.

"If you put one serving of sugar in a cup of coffee, some people can just about detect it through smell," she said. "A dog could find the same amount of sugar when it was diluted in two Olympic size swimming pools!"

"Because the dogs are so cute, it's easy to think that what we do is all a bit pink and fluffy, but it isn't at all," she said. "Everything we do is underpinned by science, and the first academic paper we published was in the British Medical Journal back in 2004. We are using dogs' noses to save human lives."

Dogs can achieve this because diseases cause volatiles that they can detect in breath, urine or sweat. Each disease has its own unique smell, and the dogs specialise in detecting one particular condition. But a wide range is covered including prostate cancer, neurological (Parkinson's) and bacterial conditions, and malaria.

For Parkinson's, MDD is working with Manchester University and has recently completed a proof of concept study, which is ready to be published. Ultimately, the aim is to detect Parkinson's much earlier than currently possible. The hope is, this will prompt pharmaceutical companies to do more research into treatments for PwP in the early stages – the ideal being a medication that is shown to slow down or possibly even halt the progression.



Some very special dogs.

Detecting COVID is another key area, and working with Durham University and the LSHTM (London School of Hygiene and Tropical Medicine), MDD has demonstrated that dogs can detect COVID with 94% accuracy. Compare that with the lateral flow test accuracy of from 58 to 77%.

Another fascinating project is with the world-renowned MIT (Massachusetts Institute of Technology) in the USA to develop 'electronic noses'. Leading this is an astrophysicist, Andreas Mershin, and the ultimate target is to build the electronic noses into mobile phones, which will be able to detect anything that threatens our health and alert us at a very early stage.

A second part of MDD concerns Medical Alert Assistance dogs, which are trained to give their owners a warning that a potentially life-threatening episode is about to take place – such as might be caused by a drop in blood sugar levels in diabetics. Other alerts could be for severe allergies, or conditions like Addison's disease, a disorder of the adrenal glands. These can cause sudden loss of consciousness, and the dog's warning can help the sufferer take action to avoid collapsing and injuring

themselves. One patient with Addison's was being hospitalised 18 times a month. Now, thanks to her dog, she has not gone once in three years!

Another remarkable patient-dog relationship is Barbara and Frankie. Claire played a short, moving video featuring Barbara, who has Type 1 diabetes. If her blood sugar level goes too low or high, Frankie puts his paw on her – and if she ignores this, he will try to alert someone else! He can even detect problems at night, jumping on Barbara's bed to alert her.

It takes from 18 to 24 months to train a dog, and costs just under £30k. Annual running costs for the MDD are £2.5m, and it relies critically on a team of more than 650 volunteers. It receives very little government funding, relying on donations from the public. To contribute something, go to www.medicaldetectiondogs.org.uk/fundraising.

NEWS, EVENTS & PEOPLE

CATALOGUE OF HELPFUL DEVICES



A new booklet produced by Parkinson's UK is a useful source of information about devices to help with the problems experienced by PwP, which as we know can take many forms. The 40 page booklet features a myriad of different kinds of aids, ranging from a personal

voice amplifier to a two-handled cup, a talking alarm clock or an easy pour kettle. All items can be bought from Parkinson's UK using the order form at the back of the catalogue, by calling 0330-124-3250, or go to www.parkinsons.org.uk/dla.

ANITA FOR PILATES, HANNAH FOR EXERCISE

Members who have been enjoying Hannah's exercise classes for the Peterborough Branch will be pleased to hear that she is returning from maternity leave at the beginning of July. Her classes will be on Thursdays from 2-3pm, on July 8, 15, 22 and 29.



Meanwhile, Anita Barker, who has been involved with the Peterborough Branch for over 20 years, will be holding her usual Pilates class, again from 2-3pm, on Monday, July 5, 12, 19 and 26.

SLEEPWALKERS AT INCREASED RISK

Men who sleepwalk, alone or in combination with another sleep disorder called rapid eye movement sleep behaviour disorder (RBD), are at least four times more likely to develop Parkinson's than those who do not. The finding, based on a study of 25,000 men, suggests sleep impairment may be associated with progressive neuro-degeneration in Parkinson's.

We are all familiar with sleepwalking, and RBD describes a condition in which people almost act out their dreams. Researchers from Pennsylvania State University in the US found that such people were also more likely to experience daytime sleepiness, another sleep problem commonly seen in PwP.

The chances of having Parkinson's was quadrupled for men who sleepwalked, and six times higher in those with RBD. The researchers found that men who had both sleep disorders were more than eight times more likely to have Parkinson's. Further studies are needed, they say, particularly to see whether sleepwalking occurs before the onset of Parkinson's. We also need to find out how many individuals who sleepwalk eventually develop Parkinson's, or other neuro-degenerative diseases.

VIEWPOINT

The development of extremely effective vaccines against COVID is a remarkable scientific/medical success story. It shows what can be achieved if the world's science community sees a target as a critical priority.

It therefore raises a question: if we were to devote the same vast, worldwide efforts to tackling Parkinson's, could we hope for the same result?

Unfortunately, the answer is probably not, for at least two reasons. The first is that Parkinson's is not a single condition. As we learn more about it, we are discovering that it is two, or possibly even several. It has reached the point at which naming these conditions with the single term 'Parkinson's' is becoming increasingly misleading.

For example, it looks as though one form stems from the gut, while another doesn't (see 'Not one but two', page 6 of the 2020 Nov-Dec newsletter). Admittedly, we know that Parkinson's happens because of things going wrong in the brain: notably, the depletion of dopamine-producing cells in the substantia nigra, and the accumulation of alpha-synuclein. But we still don't know what causes these events to happen. That is why the term 'idiopathic' is used to describe the great majority of cases.

So unlike COVID, it is not clear what the target is that we should aim at, in order to cure Parkinson's. With a specific virus identified, as COVID was very quickly, scientists knew precisely what the enemy was, and could devote their efforts accordingly. Similarly, if we knew exactly what was causing the faults in the Parkinson's brain, we could be well on the way to doing something about it.

Another reason relates to the speed of progression in Parkinson's. This can vary hugely: with so-called 'benign tremulous Parkinson's', people can experience little more than a tremor for many years, a decade or more. With others, serious problems such as movement difficulties and postural instability develop within a few years.

If we could find a drug that had a major impact on the speed of progression, we might not have found a cure, but we would have enormously improved the whole outlook for PwP (see the Viewpoint column in the March-April 2019 issue). This is probably a more realistic target than finding a complete 'cure'.

PARKINSON'S AFFECTS OUR EXPERIENCE AND VALUATION OF ART

Parkinson's can alter how we experience and value art, according to a study at Pennsylvania University in the US. It aims to show that cognitive neuroscience can provide clues about what our neural systems are doing when we view art, and how this affects our valuation of what we are looking at.

For instance, one study shows that viewing art activates motor areas, both in terms of the clear representations of movement – think of Adam and Eve in Michelangelo's *Expulsion from Paradise* – and also in implied movement through brush strokes, such as in Franz Kline's gestural paintings (pictured).



Adam and Eve in Michelangelo's *Expulsion from Paradise* & Franz Kline's *Black Reflection*.

Researchers found that people with damage to the motor areas in the brain had less experience of motion in abstract art, and enhanced preferences for 'high-motion art'. The subjects in the trial made motion and aesthetic judgements about 10 Jackson Pollock and 10 Piet Mondrian paintings. They rated them according to nine categories such as Liking, Beauty, Motion and Complexity.

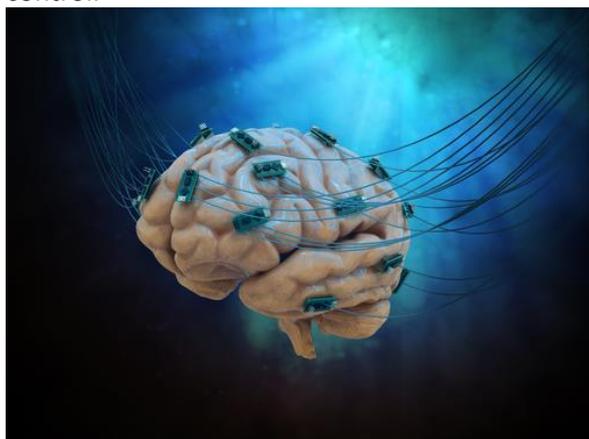
PwP demonstrated consistent preferences for abstract art, but their perception of movement in the paintings was diminished compared with controls. This suggests that the brain's motor system is involved in translating non-representational information from static visual cues in the image into representations of movement.

Patients participated while on their usual medication, which raises another question: what effect, if any, does typical Parkinson's medication have on aesthetic experiences? It is particularly relevant because dopamine plays a significant role in the normal functioning of the brain's reward system, which is consequently disturbed in Parkinson's.

SCIENCE & RESEARCH

DBS BENEFITS SUSTAINED FOR YEARS

More evidence has been found showing how effective DBS is for treating Parkinson's. A new study by the University of California in San Francisco shows that it lessens impairments of motor function and reduces the need for medication for up to 10 years. This applies to both brain regions that are typically stimulated: the subthalamic nucleus (STN) or the globus pallidus interna (GPI), both involved in motor control.



Previous studies have reported the effectiveness of DBS after three years, but longer-term studies were lacking, especially comparing the effectiveness of stimulating the STN versus the GPI. The study featured 155 patients who had DBS to one region and were assessed according to the Unified Parkinson's Disease Rating Scale (UPDRS) while off medication and on stimulation. The specific effects of DBS that were examined included those on tremor, bradykinesia, behaviour and mood, daily living, and complications linked with therapy.

Significant improvements were seen for all the periods tested, for both brain areas stimulated, although there was a trend favouring STN-DBS. Tremor scores showed the greatest reduction, followed by rigidity. Also, the amount of medication needed was reduced significantly over the periods, with no differences between the brain regions.

Overall, these findings show that "DBS therapy had a significant and stable effect on motor function, regardless of target, over 10 years," the researchers wrote. "This is remarkable, given that Parkinson's is a progressive neurodegenerative disease," they added.

VAGUS NERVE STIMULATION HELPS WITH WALKING AND MOTOR ABILITIES

A trial has shown that stimulating the vagus nerve using a hand-held device can improve walking and motor abilities in PwP. The motor benefits were accompanied by a reduction in pro-inflammatory molecules and a rise in antioxidant and nerve cell survival molecules.

The trial was conducted at the Institute of Neurosciences in Kolkata, India, working with Newcastle University, and the stimulation consisted of gentle electric pulses to the vagus nerve, which is an important highway of communication between the brain and the body (especially the gut), passing through the neck and thorax in reaching the abdomen.



This type of treatment, delivered through a surgically implanted device, has been an approved therapy for epilepsy for more than 20 years, and also shown to be effective in treating depression and headaches. More recently, hand-held vagus nerve stimulation (VNS) devices requiring no surgical implantation have been approved

ElectroCore's VNS device (pictured), called gammaCore Sapphire, is approved in the US and

Europe for treating migraines and headaches. Designed as a portable and easy-to-use technology, gammaCore can be self-administered by patients by placing the device over the vagus nerve in their neck.



Previous studies in a rat model of Parkinson's and in PwP suggested VNS could be effective

at treating walking difficulties, helping patients to walk faster and with improved rhythm. Increasing evidence also suggests that VNS can reduce pro-inflammatory molecules and oxidative stress, both involved in Parkinson's. These findings provide the

first evidence VNS could have disease-modifying effects in Parkinson's, the researchers say. There were no significant adverse effects of the treatment.

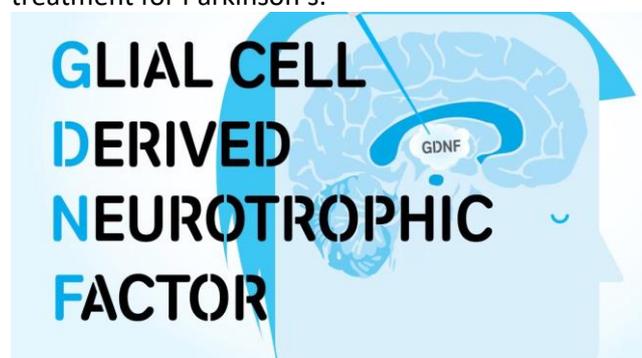
PHARMACEUTICAL COMPANIES LOOK TO DELIVER GDNF THROUGH THE NOSE

Two pharmaceutical companies, Herantis and Nanoform, are to collaborate on developing a nasal delivery system of a drug treatment for Parkinson's. The treatment uses CDNF, a protective protein closely related to GDNF, the molecule that featured in a BBC documentary back in 2019 (see the May-June 2019 newsletter). (GDNF stands for Glial cell Derived Neurotrophic Factor, CDNF for Cerebral Dopamine Neurotrophic Factor).

Protective proteins are renowned for being large, preventing them from crossing the blood-brain barrier. This has meant that so far, surgical techniques have been used to directly infuse the protective molecules into the specific region of the brain affected in Parkinson's.

But there could be an alternative way to get CDNF into the brain, which has the huge advantage of being non-invasive: through the nose. Nanoform has developed technology to encapsulate the necessary molecules into nanoparticles – ultra-small packages 80,000 times smaller than the width of a hair. This not only enables the CDNF to get into the brain, it also means it is protected from the body breaking it down. The researchers are exploring and fine-tuning this potential delivery method in the lab.

Parkinson's UK is following this work with interest. It is also still pursuing research into GDNF, as it believes it has the potential to be a life-changing treatment for Parkinson's.



Recently, it launched a new company, Vivifi Biotech, to handle the planning and preparations needed for a new GDNF trial. For this, it is investing up to £800,000 over the next two years. GDNF was discovered in 1991 and experiments quickly

highlighted its potential for protecting or even restoring dopamine-producing brain cells. Since then, the major challenge has been finding a way to deliver GDNF to the right part of the brain at the correct concentration. It is discussing this with regulatory agencies, including the UK's MHRA, because knowing their expectations and requirements is critical if GDNF is ever to become an available therapy.

One other potentially important piece of research suggests that simply injecting the protein into the brain may not be enough. Scientists at Rush University Medical Center in Chicago did post-mortems on the brains of people who had had Parkinson's. They found that many of the remaining dopamine neurons were not producing a protein called Ret, which is required for GDNF signalling. Also, other components of the GDNF signalling pathway were missing.

Most of the neurotrophic factors tested in connection with Parkinson's belong to a branch that requires the RET signalling pathway to be available in order to have their neuroprotective effect. So researchers are now considering the nature of biological signalling pathways involved with neurotrophic factors, and whether they might be affected in Parkinson's.

ROBOTIC PETS HELP PATIENTS & FAMILIES

It may sound slightly odd, but robotic pets are providing significant help to growing numbers of older people, especially those in care homes who have dementia. They improve the quality of life, lessen anxiety, and have other benefits.

We have known for years how real animals help individuals cope with stress, reduce depression, prevent loneliness and improve socialisation. Hence the charity Pets As Therapy. But real animals have drawbacks, because they need care themselves, and exercise etc. Caring for a pet is often just too much for the patient and their family. Also, health risks can make it difficult to have pets in a care home, or mean they must be restricted to brief visits.

None of these drawbacks applies to the robotic versions, such as Joy For All, a golden puppy. This was developed by Ageless Innovation, a spinoff company of the toy maker, Hasbro. Joy For All, which costs around £110, reacts to a touch with puppy-like movements and sounds. It has a realistic

coat, responds to sounds with a bark, and even has a simulated heartbeat. Robotic cats purr, meow, and roll over to ask for a belly rub! One of the first and best known robotic pets was a seal, created by Japan's National Institute of Advanced Industrial Science and Technology. Called PARO (short for personal robot in Japanese), it was tested in Denmark as long ago as 2007.



Plenty of studies have shown the benefits of robotic pets. One was done by US care company, Alacare Home Health & Hospice, with participants including patients suffering anxiety because of advancing dementia, and others who were in danger of social isolation. They were given a robotic dog or cat, and clinical data was collected before, during and afterwards. Carers and family members also took part to discuss how the pet helped them interact with their loved one and how the change affected their relationship.

In most cases, the effect was reduced anxiety, increased communication, and enhanced general

well-being. Some of the patients were suffering from dementia as well as another condition like as Parkinson's. In other instances, they had a single condition such as Alzheimer's.

The data showed reduced agitation and social isolation, fewer expressions of sadness among the participants, and in some cases, less medication. "Patients who were not communicating began interacting with their pet, and then they were willing to speak to others. It has been amazing," said a researcher.

Seeing a loved one who struggles with communication open up toward another person can be monumental for a family member of someone with dementia. And often, communicating with animatronic pets has resulted in better communication with other individuals, such as care-givers and loved ones. This has been seen regularly in people, who remember things and communicate with their family members better after spending time with their life-like, interactive pets.

Although the results of the study were overwhelmingly positive, some challenges remain. For example, one 95-year-old woman with Alzheimer's initially benefited from the pet, but then became worried about her ability to care for it, believing it was a real animal.

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USEFUL CONTACTS

Parkinson's Local Adviser – 08088-000303 email hello@parkinsons.org.uk

Facebook: www.facebook.com/parkinsonsukcambridge/

Twitter: <https://twitter.com/CambBranchPUK>

Help Line 0808-800-0303 (free phone call) Specialist advisers can answer questions on any aspect of Parkinson's

Parkinson's Nurses in our area: for help and information contact the Parkinson's Nurse Team on 0330-726-0077

Addenbrooke's Hospital Parkinson's Nurses 01223-349814

Branch Website: <https://www.parkinsonscambridge.org.uk>

Parkinson's UK 020-7931-8080 enquiries@parkinsons.org.uk www.parkinsons.org.uk