

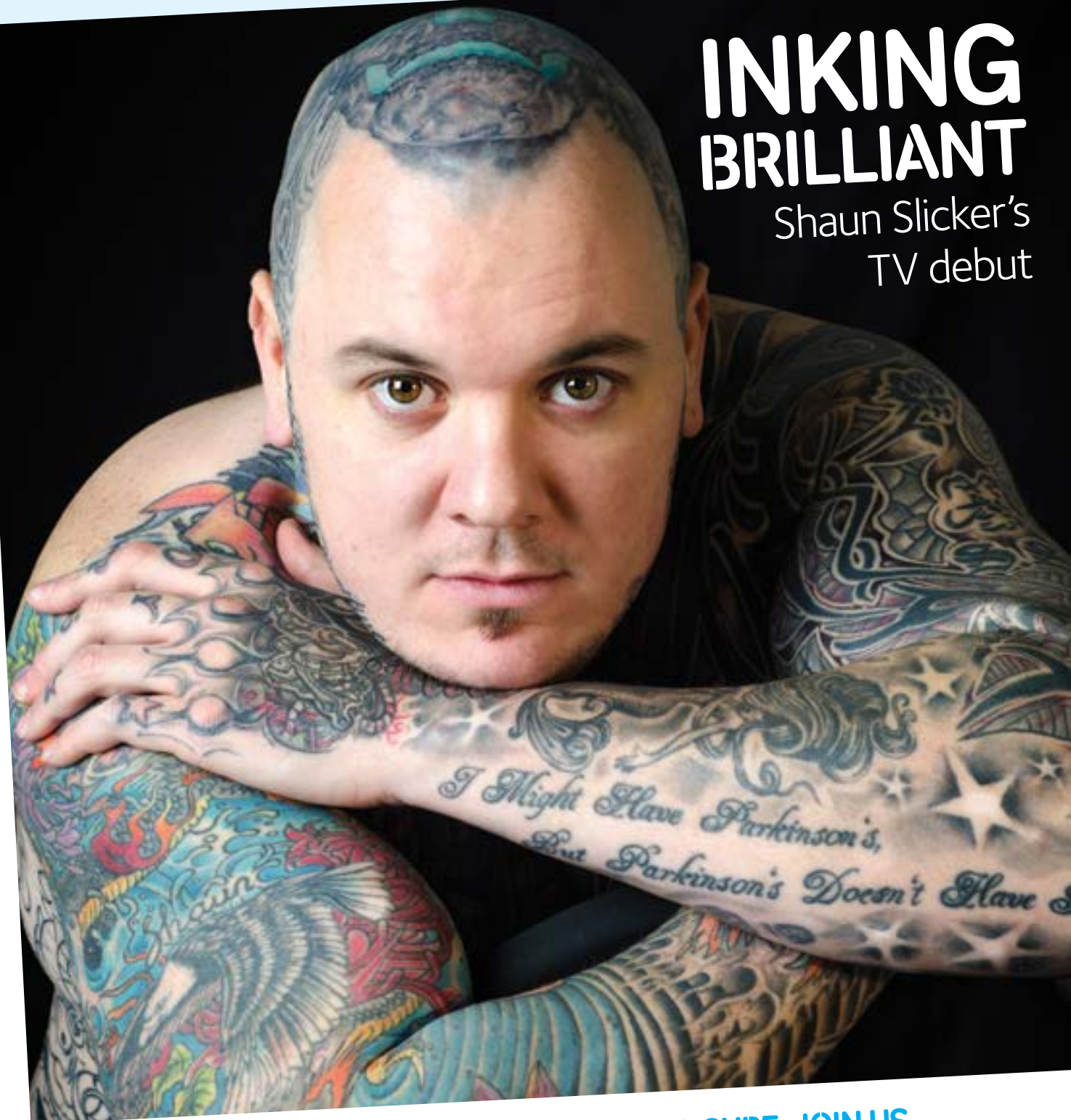
NETWORK NEWS

THEME:
Communication
matters

OCTOBER 2016 | ISSUE 55

INKING BRILLIANT

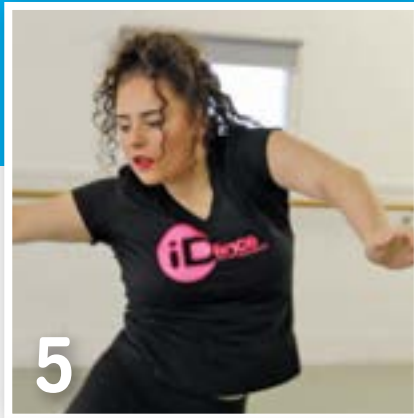
Shaun Slicker's
TV debut



PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

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Send your stories to localnetworks@parkinsons.org.uk
Any questions? Call 020 7963 3929.



Hello

I'm delighted to introduce your new-look *Network News* and hope you love it as much as we do.

Check out page 4 on why we've refreshed the design and content – but the biggest change is each alternate issue will be themed. This month, it's all about communication and how powerful it is in engaging different audiences.

The mag is crammed with features – from how we involve

people with Parkinson's in everything we do on page 8 to the launch of our When I Dance competition on page 5.

Page 10 explores how important it is for our frontline employees to have fantastic communication skills – and two different stories show how this saved the day.

Our striking cover star Shaun Slicker was featured on Channel 5's *Tattoo Disasters* along with Oldham Branch members. Read more on page 9 – where you'll also find results of the 'what matters most survey'.

Meet our new Director of Digital Transformation and Communication Julie Dodd on page 11.

Finally, we've launched the UK Parkinson's Excellence Network Awards and you've got a week to nominate the service that's made a difference to you – so get in quick.

Enjoy – and do let us know what you think.

Best wishes

Tyna Brych
Head of Local Networks

Awarding excellence

Our Excellence Network Awards have now launched – to shine a light on the professionals doing fantastic work driving up standards of care for people living with Parkinson's.

The Excellence Network's Clinical Director David Burn says: "We know great examples of health and social care are already happening. This awards scheme will give us the opportunity as a community to celebrate these examples and look at how we can establish these practices more widely, so more people can benefit."

Professional Engagement Programme Manager Suma Surendranath adds: "In sharing their models of care, knowledge, skills and expertise, we can create the collaboration that's needed to improve care UK wide."



OVER TO YOU

Help us by telling everyone about the awards and encouraging people with Parkinson's to nominate the services that made a difference to them. The nominations deadline is Friday 30 September. Nominated services will be contacted to submit a formal entry into the Awards. Find out more at parkinsons.org.uk/excellenceawards or email excellenceawards@parkinsons.org.uk

Help our partnership flourish

Our partnership with the National Gardens Scheme (NGS) has raised **£622,000** over the past few years.



We want to maintain this high profile, as NGS trustees always consider how hard the partner charities are working when deciding how much their annual donation will be.

OVER TO YOU

That's where you come in. We'd like every group to feature an article in their newsletter to spread the word further. We can provide you with text and images.

The article will explain how the partnership works and what we'd like members to do. That's spending an afternoon visiting a local garden – as an individual or in a group – and letting us know about your experience.

Email corporate@parkinsons.org.uk to request the article text and image. For more on the partnership, visit parkinsons.org.uk/ngs and www.ngs.org.uk

Shining a light on research

At this year's Florence Pite Memorial Lecture, we'll be sharing an update from our groundbreaking GDNF trial.

Currently, the best Parkinson's drugs can do is mask the condition – they can't stop, slow down or reverse it. But we believe we're at a tipping point and the next generation of treatments are within our reach.

GDNF is one of the most promising therapies being investigated for Parkinson's, so come along and find

out more at the event. We'll also be sharing more about our work to ensure the discoveries being made in the lab translate into treatments in years, rather than decades.



Venue: Royal College of Surgeons
Date: Wednesday 23 November 2016

OVER TO YOU

Book your free place at parkinsons.org.uk/RCSlecture

Network News gets a refresh

Network News has been given a fresh new makeover – from the way it’s designed to the stories it features.

It’s all part of a plan to make sure each issue contains content that’s not just interesting but useful in helping you lead your local group. You’ll spot it’s now in colour – that doesn’t mean it’s an expensive choice.

Topical themes

Naudette Harvey, from the Local Networks team, explains: “We wanted to develop *Network News* into a handy resource, so we’ve changed our approach. Now, you’ll receive your copy every other month – and

they’ll be themed. Each issue will feature hints and tips on a particular topic, and action you can take, as well as signposting to different resources.

“We’ve decided to print *Network News* in colour so that it’s in line with the quality of our other publications. Every other month, we’ll be producing bite-sized issues so you won’t miss out on essential news.”

This issue is all about the importance of communication – and how that’s threaded through everything we do. Every story will have an ‘over to you’ icon, highlighting what you can do.



Naudette adds: “We’ve some interesting themes ahead like research, raising awareness of Parkinson’s and the charity, and sharing things your group’s been up to that make you proud.”

OVER TO YOU

We’re really interested in what you think of the new-look *Network News*, as well as stories or themes you’d like covered. Let us know by emailing localnetworks@parkinsons.org.uk



EXPRESSING EMOTION WITHOUT WORDS

Do you love to dance? Enter our exciting new dance competition to reveal how moving your body to music makes you feel.

Dance is a shared experience – it connects people and everyone can enjoy it. It can also relieve symptoms for people with Parkinson’s.

The English National Ballet recently completed a groundbreaking piece of research spanning three years.

This demonstrated how dance can positively affect wellbeing, physical movement and social integration for those living with the condition. It also examines the subject from a physiological, social, emotional and artistic perspective.

The When I Dance competition has been created to raise awareness of Parkinson’s and the benefits of dance for people with the condition.

Tania Diggory, Marketing Project Manager, explains: “For people living with Parkinson’s, dance allows you to take control by staying in shape and spending time with friends without needing fancy clothing or equipment.”

Make your moves count for something

When I Dance is open to anyone who loves to dance. Show us how dance makes you feel and be in with a chance to win fantastic prizes.

There are three competition categories:

- solo
- groups
- Parkinson’s dance groups

Whether you love ballet, salsa, Zumba, hip-hop, African, Bollywood or another dance form, all styles are welcome.

Help us by getting involved, spreading the word or encouraging family and friends to take part. You can get started on preparing your entry now by making a video of you or your group dancing. You’ll be able to enter the competition on our website from 9 to 30 November 2016.

We’d like to give a special thanks to our all partners. Find out more at www.whenidance.uk

OVER TO YOU

Encourage your members to watch the When I Dance competition video, and find out more about the entry and judging processes. For any enquiries, contact:
Email: dance@parkinsons.org.uk
Twitter: [@parkinsonsuk](https://twitter.com/parkinsonsuk)
#whenidance

Shoot the best snap



A picture is worth a thousand words – and a great way of illustrating your *Network News* stories and group newsletter. Here are some tips for getting the best shot.

Move in closer Let your subject fill the frame. Details are often more interesting than an overall view.

Keep distractions out of the picture Watch your borders. If anything hangs into

your picture, like unattractive telephone wire, a distracting sign, your finger, or a camera strap, try again.

Keep focused Get to know the way your camera focuses. If it’s a point-and-shoot, you’ll likely indicate a focus point if you:

1. Aim so the object is in the middle of the viewfinder.
2. Press the shutter button down halfway and hold it.
3. Move your camera until you have the composition you like best.
4. Press the button down the rest of the way to take the picture.

Let there be light Which way

are the shadows falling? Unless you want a silhouette effect, it’s generally best to shoot with the sun behind you.

Accessorise If you get one accessory, make it a tripod. This can help with ‘camera shake’ – common if you’re taking pictures in low light.

What format? Please send original, high-resolution JPEG files of at least 1MB. Avoid photos pasted into a Word document or PDF files. Don’t forget to ask permission from those in your photos.

OVER TO YOU

Share this with anyone in your group who takes photos. Send snaps to localnetworks@parkinsons.org.uk



USING VIDEO TO SHARE INFORMATION AND EXPERIENCES

Video is a hugely popular and easy way to get across information and share experiences with others. Here, we look at the video resources Parkinson's UK has on offer that you can use and share with others, and how you can get involved making your own videos.

Support for people who are newly diagnosed

We worked closely with a group of newly diagnosed people to create *New to Parkinson's?* – a film for people who have found out that they have the condition.

It features a wide range of people living with the condition talking about their journeys coming to terms with their diagnosis, and how they've

started to take control of life with Parkinson's. Please share this resource with anyone you come into contact with who has been recently diagnosed.

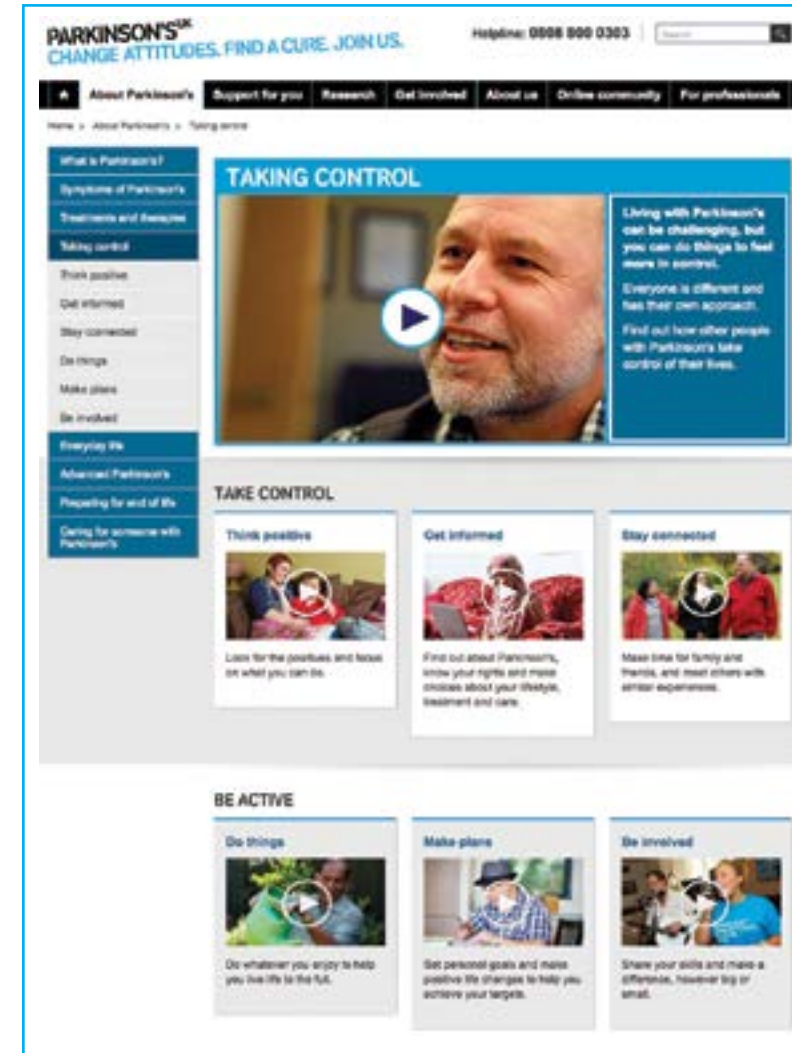
Watch online at parkinsons.org.uk/newtoparkinsons

Or order the DVD free from CDL using code V012 (or V012S for a subtitled version).

Inspiration and ideas about feeling more in control

The 'Taking control' area of our website has videos and ideas from other people with Parkinson's about the things they do to feel more in control of life with the condition.

Please share the page with anyone living with Parkinson's who wants to hear more about how others manage their life with



the condition. Visit parkinsons.org.uk/takingcontrol

A brand new video every week

Our YouTube channel is the best place to stay up to date with all our latest videos. Each week, we add new videos about cutting-edge research or stories from people affected by Parkinson's.

Please subscribe to the channel – you'll get an email letting you know the moment a new video is available. You can also help others find useful content by sharing the videos with your friends.

Social media

We also regularly share films on Facebook and Twitter – keep

an eye out for these, and please share them with others to educate, inspire and support. Follow us at www.facebook.com/parkinsonsuk and www.twitter.com/parkinsonsuk

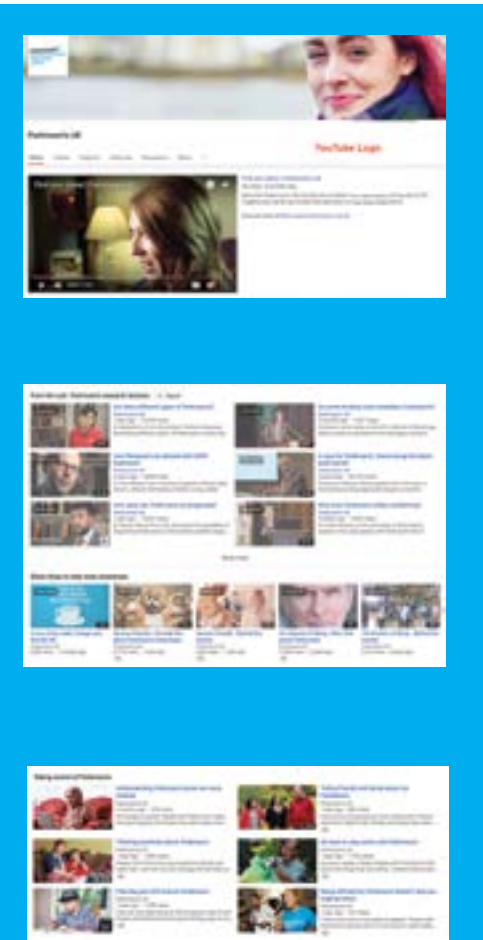
OVER TO YOU

Get creative

It doesn't need to cost a lot to make a video – you only need a phone with a camera, a video camera or laptop to start getting creative and filming your own.

Share with us

All our videos are inspired by stories from people like you, so we want you to help us continue our video journey. We've started to see more short films created by local groups and individuals –



and we would love to see what you're up to for inspiration and to potentially share with a wider audience.

We want to hear about your experiences. How does Parkinson's affect you? How do your local group and activities support you?

To share your videos with us, please upload them to a video-sharing site (such as YouTube) and email the link to videos@parkinsons.org.uk ^{NN}

If you get stuck uploading your video, just search 'how to upload your YouTube video'.



The experiences of people living with Parkinson's are at the heart of everything we do as a charity – and our Involvement and Inclusion team plays a big part in this.

INVOLVING YOU IN OUR WORK

One of the team's key activities is capturing input and comment from those who use our services, and making sure our work reflects their needs and views.

Head of Involvement and Inclusion Luis Perpetuo explains more about our commitment to listening to these:

Your views count

"We are here to ensure people with Parkinson's are involved. We review the feedback we receive every month, and make changes where needed. It's an ongoing process of improvement.

Local experts needed

"But the feedback process is just the tip of the iceberg. There are plenty of other ways people affected by Parkinson's can get involved. We currently have opportunities for people to apply for community-based 'local expert' roles within Local Development teams and also opportunities coming up within

the Excellence Network.

"These roles are crucial to our work – getting the views of those with the condition on what support and activities are needed in their area or how healthcare services can be improved. All this requires input from those with lived experience of the condition.

Channelling creativity

"For many people affected by Parkinson's, creative writing is a popular pastime and a way to take control. In recent years, we've been receiving lots of questions from people asking how we can better support and promote this creativity.

"This got us thinking and we've started to develop a toolkit. This is happening in collaboration with people affected by Parkinson's, who write and have a wealth of experience to share.

"The toolkit will be full of resources on how to generate

ideas and structure stories, along with other useful tips on creative writing, which we will make available by the end of the year.

Bringing your views together

"We also invite people to come together for focus groups. For example, our Marketing team recently organised focus groups on issues of real importance for people affected by Parkinson's in everyday life, such as problems with online banking and airport travel."

OVER TO YOU

If you have a great idea, want to find out more about involvement opportunities or aren't happy about any aspect of what we do, get involved with us. We'd really value your input.

Share your views at:
feedback@parkinsons.org.uk
 020 7963 3901
parkinsons.org.uk/feedback

Making his mark

Shaun Slicker attributes his 100-plus tattoos to helping him deal with his condition. He took his story to Channel 5's *Tattoo Disasters* – arranging for Oldham local group members to feature too.

In a unique opportunity to raise awareness of the condition, Shaun, 30, was filmed showing off his tattoos at a branch meeting. One supporter was even wearing a Parkinson's UK T-shirt.

A model tattoo

Diagnosed when he was just 23, Shaun is one of the youngest people with the condition in the UK. He had his first tattoo done at 14 and has since added some Parkinson's-related inkings, including "I Might Have Parkinson's, But Parkinson's Doesn't Have Me".

Shaun models his tattoos, donating 50% of the money he earns to the charity. He was also keen to unveil his newest additions to a group of Parkinson's UK supporters on *Tattoo Disasters*. And we have our



Parkinson's Local Adviser Danny Mills and Volunteer Co-ordinator Sue Newsham to thank for that.

Despite only receiving the request three days before filming was scheduled, the pair delivered the goods. They asked Alan Dale, Social Secretary of the Oldham Branch, if he could get four or five people along. Alan proved the hero of the hour, producing a group of more than 10 people!

Watch the show at www.my5.tv

What matters most?

Earlier this year, we conducted our 'What matters most?' survey to find out what people with Parkinson's think we should be campaigning on. Your answers have helped us understand what really matters to people living with the condition.

Laura Cockram, Policy and Campaigns Programme Manager, says: "The results have identified key issues we'll focus our campaigning efforts on."

We will campaign to improve the benefits system so it works better for people with Parkinson's and defend support such as Attendance Allowance from cuts. We'll also campaign for free prescriptions in England.

We will campaign to improve access to and the quality of health and care services UK wide, including improving access to therapies and respite care. We'll grow and empower local campaigners to call for more specialist staff so everyone has the same access to support, wherever they live.

We will develop new and better treatments and ensure there's the funding. We will fight to protect research funding, making sure there is investment and support for our work around drug repurposing.

We will improve public awareness. We'll do that by speaking to decision makers in parliament, local government



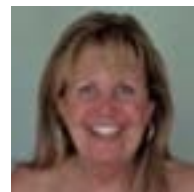
and health and social care professionals about the full range of symptoms. We will continue to improve understanding in hospitals and care homes about getting medication on time. We'll also encourage local councils, retailers and public service providers to deliver our Parkinson's awareness sessions.

OVER TO YOU

Arrange a visit from the Campaigns team to find out more about how you can improve services in your area. Contact us at campaigns@parkinsons.org.uk or on 020 7963 9349.

IT'S GOOD TO TALK

Fantastic communication is a crucial part of the make-up of our helpline advisers and Parkinson's local advisers. *Network News* explores how this simple skill made the biggest difference to two clients.



Susan's story: Communicating the full picture

Nurse Co-ordinator Susan Ashley vividly recounts how communication saved the day for an elderly caller.

"The caller's on/off fluctuations had recently become more difficult to live with. On this particular day, she could hold her phone but nothing else. She could talk but was otherwise completely immobile.

"No one was due to visit that day as she only had one visit a week from a private care agency. She couldn't alert her neighbours by banging on the wall because she couldn't move. She couldn't remember her GP's or neighbours' names or phone numbers.

"The situation became more fraught – the longer she went without her medication, the more debilitated she became. I managed to get her to give me her address and phone number. I asked permission to contact her Parkinson's local adviser.

"The local adviser contacted the local council's adult social care services and found out the lady was known to them and had a named rapid assessment adviser.

"Unable to contact the rapid assessment adviser, she then contacted the local police to visit the home urgently. Later that day, the local adviser rang again to say that the Rapid Response team was going to go in every day that week and then she would be reassessed for a regular increase in care and support.

"The Parkinson's local adviser needed the full picture of the caller's situation, and it was our job to effectively communicate that."



Shona's story: Listening to the client

Watching his local footie team play was just the ticket to relieve the pressure for one carer.

And it was Parkinson's Local Adviser Shona Lawson who made it happen.

"I saw a client who was at the end of his tether. He'd left his job and was caring full time for his father who was showing signs of dementia.

"Through our conversations, I found out he was a football fan and soon realised what would make all the difference to him. For this client, coping was being able to get out and cheer for his local football team on a Saturday. He didn't want a care package four times a day. He just felt that if he could get this 'me time' once a week he could continue to cope.

"I referred the case to a social worker, who made an assessment and put a call out for carers to tender for the sitting service. But boundary issues meant it wasn't seen by care agencies covering the area.

"I identified a local caring organisation whose staff had Parkinson's awareness training and offered a weekend service. They offered an immediate assessment and swiftly put a package in place. I put them in touch with the social worker to arrange it. The client got time out with his friends knowing his dad was looked after by a Parkinson's trained carer.

"Listening to clients is so important. If you're able to appreciate what your client needs, and communicate that to them, you're on your way to a good result." **NN**



Our new Director of Digital Transformation and Communication is looking forward to tapping our potential for technology-led innovation. She tells *Network News* how it isn't just the latest gimmick but essential to meeting the needs of a growing, digital-savvy audience.



JULIE TALKS DIGITAL TRANSFORMATION

Julie Dodd, who joins us as Director of Digital Transformation and Communication, brings infectious enthusiasm and an impressive resume. During her time as a BBC creative director, Julie launched iPlayer, and published a powerful report that made the charity sector stand up and take notice.

Creative thinking

She says: "I started as a designer and researcher, working at the BBC for nine years, where I was involved in a range of innovative projects. It's where I fell in love with technology as a way of solving business challenges.

"I enjoy engaging with people and developing concepts with real emphasis on the end user. I'm obsessed with how you can do things better – in a way that's more audience centred.

"I became really interested in how this approach could have real value for organisations that have a social purpose. I worked for a digital agency on projects for charities from the NSPCC to RSPCA, as well as brands including Coca-Cola and Tesco."

Julie then took time out to publish *The New Reality* – a digital transformation bible for the charity sector. Julie lived and breathed this for three months: "The report is a culmination of research where I spoke to thought leaders, chief executives and digital experts inside the sector as well as commercial organisations Coke and Google. One of my favourite interviews for the report was with our Chief Executive Steve Ford."

The report received a huge response: "It isn't just about improving digital channels like the website but about the possibilities of digital technology to revolutionise our sector."

Parkinson's insight

Julie has a close connection to the charity: "My father-in-law has Parkinson's and my dad is chair of the Horsham Branch. I applied for the role as I was inspired by the charity's five-year strategy and struck by its ambition.

"I'm really interested in health technology and how the market is changing rapidly – putting more power in the hands of patients. We need to respond to this shift

in a really focused way. How can we do things better using technology? And that could be quite basic, like an online form rather than a paper one. We can get even better at understanding our audiences – people with Parkinson's, supporters. Looking at the potential of technology and how it could achieve its purpose.

Accessible technology

"Technology has become much more accessible. My mum, who claimed to have no digital knowledge, now has an iPad and smartphone. Are there better ways of doing things digitally? How can technology help people with Parkinson's take control? How can we learn about their experiences of living with the condition so we can personalise our support and services? The possibilities are endless."

OVER TO YOU

How could digital transformation make a difference to your local group? Let us know at connect@parkinsons.org.uk **NN**





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NIGHT**
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