











Parkinson's News and Information




From Sudbury Independent Parkinson's Group






Resource	Links
 <p>West Suffolk Community Parkinson's Service</p> <p><i>This service covers all those individuals registered with a West Suffolk GP, and those registered with an East Suffolk GP, but are receiving their Neurology service from West Suffolk Hospital.</i></p> <p><i>There are three Parkinson's Nurse Specialists (PNS) working closely with the Neurologists, as well as with all the therapy services you may encounter, voluntary agencies and wider health and social care providers.</i></p>	<p>TRACEY IS RETIRING IN MAY AND THE SERVICE IS EXPANDING – WATCH THIS SPACE!</p> <p>Tracey Ward PNS Phone: 01284 748840 Email: tracey.ward@wsh.nhs.uk</p> <p>Emily Skyrme PNS Phone: 01284 713718 Email: Emily.skyrme@wsh.nhs.uk</p> <p>Sarah-Jayne Moore PNS, Advanced Practitioner Phone: 01284713718 Email: Sarah-Jayne.Moore@wsh.nhs.uk</p>
 <p>NHS New Medicines Service (via your pharmacist)</p> <p><i>If you're prescribed a medicine to treat a long-term condition for the first time, you may be able to get extra help and advice about your medicine from your local pharmacist through a free scheme called the New Medicine Service (NMS).</i></p> <p><i>People often have problems when they start a new medicine. As part of the scheme, the pharmacist will support you over several weeks to use the medicine safely and to best effect.</i></p> <p><i>The service is only available to people using certain medicines. In some cases where there's a problem and a solution cannot be found between you and the pharmacist, you'll be referred back to your doctor.</i></p>	<p>For more information visit the link below: https://www.nhs.uk/nhs-services/prescriptions-and-pharmacies/pharmacies/new-medicine-service-nms/</p> <p>Alternatively, search "NHS New Medicines Service" on Google</p>

Resource	Links
 <p>Suffolk Family Carers Living Fuller Lives</p> <p>Suffolk Family Carers</p> <p><i>Suffolk Family Carers can offer advice and guidance, workshops and courses, a listening ear, support in hospitals and helping you find time for yourself.</i></p> <ul style="list-style-type: none">• <i>Supplying you with information, advice and guidance relevant to your caring role</i>• <i>Offering you the chance to join FREE workshops and courses</i>• <i>1:1 support through our emotional and wellbeing service</i>• <i>Telephone befriending service for those who need someone to talk to</i>• <i>Signposting and referrals to other services</i>	<p>Visit their website: https://suffolkfamilycarers.org/</p>
 <p>Suffolk County Council</p>	<p>Help to stay at home information hub How to live independently at home, including equipment and adaptations, meals, personal assistants, money and debt advice, and returning home from hospital. For more information, visit: https://www.suffolk.gov.uk/care-and-support-for-adults/help-to-stay-at-home</p> <p>Disabled Facilities Grant You could get a grant from your council if you're disabled and need to make changes to your home. For more information, visit: https://www.gov.uk/disabled-facilities-grants</p>
 <p>Parkinson's Care and Support UK</p> <p><i>Parkinson's Care and Support UK (PCSUK) is a UK based charity that focuses on improving the lives of those affected by Parkinson's, whilst they are alive.</i></p>	<p>Visit their website: https://parkinsonscare.org.uk/</p>

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 <p>Parkinson's UK</p> <p><i>Parkinson's UK is the largest charity funder of research into Parkinson's in the UK. It funds research aimed at finding better treatments and improving the understanding of Parkinson's and its causes. It raises money through donations, legacies, community fundraising, events and corporate partnerships. The charity offers support and information to people affected by Parkinson's, their families and carers through a network of 350 local groups.</i></p>	<p>Visit their website: www.parkinsons.org.uk</p> <p>Call their Confidential Helpline: 0808 8000303</p> <p>Email them: hello@parkinsons.org.uk</p> <p>Find them on Facebook https://www.facebook.com/parkinsonsuk/</p> <p>Parkinson's UK offers an online session for newly diagnosed people to outline the support offered by Parkinson's UK. It's also an opportunity to talk to others who are newly diagnosed. Numbers will be small (12 or so) to ensure interaction. Where: Online via Zoom Booking: See their webpage to book in to the latest session and for future session dates Cost: Free Any questions, please feel free to contact Linny Rubra at lrubra@parkinsons.org.uk</p> <p>Your Parkinson's Diagnosis - what you wish you had asked webinar When: TBC Where: Online via Zoom What: Since your diagnosis, there may be things you wish you had asked. Now is your chance! How to join: Book your place on Eventbrite. Contact: newlydiagnosed@parkinsons.org.uk</p>
 <p>Movers and Shakers: A podcast about life with Parkinson's</p> <p><i>Rory Cellan-Jones, Mark Mardell, Nick Moysten, Jeremy Paxman, Gillian Lacey-Solymar and Paul</i></p>	<p>Click here to listen on your computer</p> <p>or</p> <p>Listen on your phone by searching 'Movers and Shakers' on your favourite podcast app.</p> <p>You can also find it online searching "Movers and Shakers Podcast" on Google.</p> <p>You can also join their Facebook Group</p>

Resource	Links
<p><i>Mayhew-Archer discuss their lives with Parkinson's.</i></p> <p><i>They generally discuss a new subject every week (eg. diet, voice, sleep).</i></p> <p><i>Summaries of some of the podcasts can now be downloaded as a pdf fact sheet from their Facebook pages.</i></p>	<p>They also now have a website: www.moversandshakerspodcast.com</p>
 <p>Parkinson's at Kings - Centre of Excellence in Parkinson's and Movement Disorders</p> <p><i>The group focuses on high quality clinical and translational work addressing non motor aspects of Parkinson's disease (PD) regarded and listed as a key unmet need by NICE.</i></p>	<p>Visit their website: https://parkinsons-london.co.uk/</p>
 <p>Cure Parkinson's UK</p> <p><i>Cure Parkinson's has funded millions of pounds of research, made scientific discoveries and opened new avenues of research.</i></p> <p><i>They have made enormous strides in involving people with Parkinson's in research and given hope to many who are living with the disease. Their innovative approach – which has led to collaborations with the world's leading researchers and their inspirational work, combined with the active support of thousands of people living with Parkinson's around the world – is bringing us closer to a cure for Parkinson's.</i></p>	<p>Visit their website: https://cureparkinsons.org.uk/</p> <p>Find them on Facebook: https://www.facebook.com/cureparkinsons</p>
 <p>John van Geest Centre for Brain Repair, Department of Clinical Neurosciences, University of Cambridge</p>	<p>Visit their website: www.thebarkerwilliamsgraylab.co.uk</p> <p>Join them on Facebook: The Barker/Williams-Grey Lab</p>

Resource	Links
<p><i>Leading research under Professor Roger Barker and Dr Caroline Williams-Grey. They are focusing on the role of the immune system in Parkinson's. They have also started the STEM-PD transplant trial and future cell therapy trials are planned in 2024. Some of our members went to hear Roger Barker talk about his research back in November.</i></p>	
 <p>The Michael J Fox Foundation for Parkinson's Research</p> <p><i>The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.</i></p>	<p>Visit their website: https://www.michaeljfox.org/</p>
 <p>Alexander Technique Works with Andrea Walsh MSTAT</p> <p><i>Find out details of our course with Andrea on our Alexander Technique dedicated page.</i></p>	<p>Visit Andrea's Website: www.alexandertechniqueworks.co.uk</p> <p>Email Andrea: andrea@alexandertechniqueworks.co.uk</p> <p>Call Andrea: 07949083629</p>
 <p>Charco Neurotech</p> <p><i>A non-invasive device for Parkinson's</i> <i>The CUE1 utilises pulsed cueing and high-frequency focused vibrotactile stimulation to alleviate symptoms including slowness, stiffness, rigidity, freezing of gait, and more.</i></p> <p><i>Developed by a team of designers, engineers, and clinicians, the CUE1 offers a novel, non-invasive approach to improving quality of life for people with Parkinson's, with the simple push of a button.</i></p>	<p>Visit their website: https://charconeurotech.com/</p>

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 <p>The BeechBand</p> <p><i>The BeechBand, designed by Parkinsons sufferer Carl Beech, is a wearable device in development, showing promising signs of being able to manage symptoms including speech issues, anxiety and gait.</i></p>	<p>Visit their website: https://www.beechband.com/</p>
 <p>Careium UK Limited</p> <p><i>Personal alarms with 24/7 support</i></p> <p><i>These may be available free through Suffolk CC if you meet the needs outlined in the Care Act – see Suffolk CC link above with savings of less than £23,250</i></p>	<p>Visit their website: https://www.careium.co.uk</p>
 <p>The Parkinson's Centre for Integrated Therapy</p> <p><i>Based at the University of Kent, in Canterbury, the Parkinson's Centre for Integrated Therapy provides a range of evidence-based non-pharmacological treatments and wellness resources, so that multiple Parkinson's symptoms can be managed on one site.</i></p>	<p>Visit their website: https://www.kent.ac.uk/parkinsons/about-us</p> <p>John has been to visit and can tell you more – ask him about it!</p>
 <p>Parkinson Society Canada</p> <p><i>A useful set of relatively gentle exercises</i></p>	<p>View the PDF below: https://www.parkinsons.va.gov/NorthWest/Documents/Pt_ed_handouts/Exercise_for_PD_1-20-12.pdf</p>
 <p>Poets with Parkinson's</p>	<p>Visit their website: www.poetswall.com</p>

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<p><i>The Wall was built in December 2022 as a new and safe home for poets from all over the world who are living with Parkinson's Disease.</i></p>	
<p>“Paxman – Putting Up with Parkinson’s” Documentary</p> <p><i>Investigative journalist Jeremy Paxman reveals the real impact of his Parkinson's disease and investigates the myths surrounding the illness.</i></p>	<p>Available on ITVX via your smart TV</p> <p>or</p> <p>Watch here online</p>
<p>“Still: A Michael J. Fox Movie”</p> <p><i>A 2023 American documentary film directed by Davis Guggenheim about the life of actor Michael J. Fox and his struggle with Parkinson's disease.</i></p>	<p>Available on Apple+ TV (Subscription required)</p>
<p>“Barbara Thompson – Playing Against Time”</p> <p><i>A moving and powerful exploration of Parkinson’s Disease seen through the prism of music, featuring the virtuoso UK jazz saxophonist/composer Barbara Thompson and her husband, drummer John Hiseman.</i></p>	<p>Watch on YouTube: https://www.youtube.com/watch?v=WIVKYkvhUXg</p> <p>or</p> <p>Search “Barbara Thompson Playing Against Time” in the search field on YouTube</p>
<p>BBC Sounds</p> <p>Radio4 The Art of Now – The Walking Dance</p> <p><i>A story, told in dance steps, of people with Parkinson’s finding balance in the movements and rhythms of the Argentine tango. Four couples living with Parkinson’s disease attend a dance class for people with balance issues.</i></p> <p><i>The dance becomes entwined with their stories as they master the basic walking steps of the Argentine tango and work towards a choreographed performance for a group of people newly diagnosed with Parkinson’s. Along the way, they reflect on how dancing is helping them to confront their diagnosis and what it means to them.</i></p>	<p>Listen on BBC Sounds: https://www.bbc.co.uk/programmes/m000c4pp</p>
<p>Other news and information</p>	<p>We have a copy of the Which magazine review from March 2024 on Rollators. If you are interested in seeing this please ask John.</p>

<https://www.parkinsonsudbury.org.uk/>

Other useful websites include:

- [Parkinson's Europe](#)
- [MovementDisorders.org](#)
- [PSP Association](#)
- [Interactions between Levodopa and Food – What to Avoid](#)