

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

CONTENTS

- News Headlines
- Membership
- Fundraising
- Living Well with Parkinson's
- Events / Activities
- Useful Information

News Headlines

Main updates from your committee:

- Festive greetings
- Visit to our branch from CEO
- Our new website
- Contactless card reader

Festive greetings are sent to all our members ahead of this year's Christmas season from your committee volunteers, we hope that everyone has a safe and enjoyable time with family and friends. For those attending, we hope you all enjoy the Xmas lunch 12th Dec at Minchinhampton GC.

Chief Executive Officer of Parkinson's UK, Caroline Russell will be visiting our branch. A profile of Caroline is included on Page 6 of this edition. She was asked if she wanted to come and meet our branch members and snapped up the opportunity almost immediately. She was offered the choice of attending any one of our events / activities in 2023 and chose to join in with us at the Tai Chi / PD Warrior event from Tim Bird scheduled for **Mon 20th February**. Other branches will be inviting lead volunteers and a Q&A session will be added for anyone to ask her questions and hear what she has in mind for the charity going forward. So, you have plenty time to think up a few.

Our new website has been given the go-ahead by HQ after a legal debate was resolved. This means that Cirencester website firm Athena Web Design can commence work very soon. It is hoped that full access will be available to all members sometime in January. This is a big step forward in being able to communicate current and pertinent information to all of you and to communicate to future perspective members about our branch and activities. The content of this newsletter will be contained and maintained on the website going forward.

We now have a 'Sumup' **Contactless card reader**. This enables a person to pay for goods / services / entrances fees and so on with their debit card and the money goes directly to our charity account with Barclay's. Very useful in these days of a 'cash-less' society.

CIRENCESTER AND STROUD BRANCH NEWSLETTER XMAS 2022

I had the pleasure of visiting 'Cricklade Café' 16th November and was made very welcome by Vincent Mobey who runs a drop-in session for the local Parkinson's community. An occasion very well enjoyed by all 30+ attendees. An open invite is extended to anyone from Cricklade area to our planned events and activities for 2023.

It is also important for the on-going successful running of the branch that we fill the following Committee roles as soon as possible, please contact your committee if you know of anyone who would become a volunteer for the branch:

- Treasurer
- Social / Fundraising Volunteer
- Membership Secretary

Thank you for reading and have a safe enjoyable festive season.

Kevin Young,

Branch Chairman

Membership

We currently have circa 130 members in our branch, we've had 9 new members recently. A warm welcome goes to:

Christine Clark & Pete Stone

Peter and Barbara Handford

Andy Chapman

Paul Holmes

Rodger Threlfall

Mollie and Alan Fisher

However, there are many more people living with Parkinson's in our area who are unaware of the Branch and support activities. A new 'Flier' of the branch details is being created and will be given to all Parkinson's Nurses and consultant surgeries as well as medical practices, chemists, and other organisations for distribution to newly diagnosed or affected people. Our new website will also help with communication when fully up and running.

Fundraising

The December Committee meeting will include a review of the financial year, a decision on how much we send to research and how much of our funds we need to support 2023 activities. A report on these aspects will be included in the next newsletter and on our new website.

One of next years fundraising events is **Clubbing Together**. This is a Parkinson's Golf Day held at Cirencester Golf Club on Friday 19th May 2023. Arrangements for this event are well underway. This will be the 9th year the event has been held, having raised well over £50,000 to date.

Events / Activities

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554)

This section is an update on some of our recent events and activities, and a summary of the remaining planned events for the rest of the year and a look ahead at what's being planned. If you want to attend any activity, please contact your committee at cirenstroudpuk@yahoo.com.

Members meeting 21st November

St. Lawrences Church Hall, Cirencester

We had 2 activities:

- **Dr Tina Smith PGCE(PCET), FHEA** a Senior Lecturer in Biomechanics from Wolverhampton University Health & Wellbeing Faculty gave us a very interesting talk on her newly funded research project on 'monitoring symptoms of Parkinson's disease to improve quality of life'. She is looking for direct involvement in a Patient and Public Involvement (PPIE) session. She will 'tailor' requirements suited to the individual person to monitor motion and from there will use the data to analyse how mobility is affected by Parkinson's aimed at designing suitable living aids. Here is a summary of the project from Dr Smith: -

Monitoring Symptoms of Parkinson's Disease Project

It was with great pleasure that I attended the groups meeting in November to give a talk about my current project on monitoring symptoms of Parkinson's disease. The project aims to work with people with Parkinson's disease, their carer's and family, and medical professionals specialising in Parkinson's disease (nurses, clinicians, therapists etc.), to co-design a device that will effectively monitor symptoms of the disease at home.

The project has received funding from a prestigious awarding body, and we already have a prototype that collects accurate data during a movement task. Over the course of the project, we aim to identify the problems people with Parkinson's disease have that home monitoring could help with, and design a final product driven by their suggestions. Input from people with Parkinson's disease is key to the success of this project and we will be asking for volunteers to either help guide the activities we use during the project or participate in co-design sessions.

The response from the group and questions I was asked after my talk demonstrated enthusiasm for the idea. That was good news for us, indicating we are on the right track! Hopefully we can co-design a meaningful product that makes a significant change to managing the disease and improving quality of life for people with Parkinson's disease.

Thank you, from Dr Tina Smith, University of Wolverhampton (Tina.Smith@wlv.ac.uk)

This work is supported by the UKRI Industrial Strategy Challenge Fund, Healthy Ageing Challenge, Catalyst Awards [grant number ES/X006557/1]



- **Phil Collins and his Ukulele Workshop** was a very amusing event.



A couple of images of us all having some fun

A Night at The Museum has been arranged for 1st Dec – a chance for those going to have a drink, some nibbles, and a tour of Corinium Museum in Cirencester.

Xmas Lunch 12th December at Minchinhampton Golf Club will be well attended this year, 38 members have signed up at time of writing, an update will appear in the next newsletter (or on our new website).

New Drop-in 'Cuppa-Chat'

Please come along to our new drop-in session last Wednesday of each month 10:30 – 12:00 at Cirencester Baptist Church, Chesterton Lane, Cirencester with free parking. You can have a lovely catch up over a bottomless cuppa.

WALKING GROUP

The next walking event will be January 22nd organised by Mark & Shirley Jee who have arranged for a walk around Duntisbourne Abbots, here's the route:

A circular route around the Duntisbournes of about 2.5 miles on quiet tarmac lanes. No stiles, but quite steep in places. There's a shorter flatter route option if anyone would prefer that.

The walk will start at Duntisbourne Abbots village hall, where car parking and toilets are available. We'll set off walking at 10:00 am, aiming to be back around 11:00 to 11:30 for coffee and cakes.

Duntisbourne Abbots is about 6 miles north-east of Cirencester, just off the A417 dual carriageway. The postcode for the start point is GL7 7JN. Here's a link to a sketch map which might help:

<https://e-voice.org.uk/theduntisbournes/village-hall/>

- **Steven Moore from Gloucestershire Carers Hub** will be at *Cirencester Library* on **Friday 2nd December between 9:30 and 12:30**, go along and find out about what they do and how they can support you.

CAN & DURSLEY ACTIVITIES (from Diane Shelley)

November proved to be a quiet month. The Dogs and Cats Charity due on the 15th unfortunately never made it as the vehicle broke down on its journey, so we were left to a quiz. These usually end in lots of laughter and cheating, and this was no different.

The last meeting for the year is Thursday 1st December when we are holding a mince pie and coffee morning including a Tombola stall. Open to everyone.

Details for the 2023 program are almost complete, here's the confirmed bookings

CIRENCESTER AND STROUD BRANCH NEWSLETTER XMAS 2022

January 16th – a talk from Louise Wilson about the benefits of utilising Longfield’s Health & Wellbeing Centre (all services offered are free of charge)

February 20th – Tim Bird a talk and demonstrations around PD Warrior / Tai Chi / boxing / wellness & physical activities – **Also a Q&A session with P-UK CEO Caroline Russell**

March 20th – Branch AGM plus Mary Burton – a talk / demonstration on benefits of physio and exercise

April 17th – a talk from Ann Henderson (Glos. Parkinson’s Advisory Service) + Deb Thurman (Parkinson’s Specialist Practitioner)

May 15th – Sue Mills, Parkinson’s UK – a demonstration of the latest Parkinson’s living aids

June to October – yet to be confirmed

November 20th – Mark Cummings from BBC Radio Gloucestershire

December 18th – Xmas Lunch

2023 Program - a few spaces left for bookings aimed at social events and ‘other’ interesting events.

Cirencester and Stroud Branch - Events & Activity Program for 2023

	January	February	March	April	May	June	July	August	September	October	November	December
Committee Meeting	9th The Bear Inn Ciren 7pm	6th The Bear Inn Ciren 7pm	6th	3rd	tba	5th	3rd	31st July	4th	2nd	6th	4th
Members' Information / Speaker Meetings	16th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00)	20th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Tim Bird - Tai Chi / PD Warrior demo & talk	20th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Mary Burton - benefits of physio & exercise AGM	17th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Ann Henderson Glos. Parkinson's Advisory Service Deb Thurman - Parkinson's Nurse	15th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Living Aids Demonstration Sue Mills PUK	19th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Stephen Moore Carers Hub	17th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) TBA	21st St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) TBA	18th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) TBA	16th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) Cotswold Canal Trust Lisa Mant	20th St. Lawrence's Church Hall, Cirencester (14:00 - 16:00) A Talk from Mark Cummings BBC Radio Gloucestershire	
	19th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00)	23rd Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	23rd Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00)	20th Cam & Dursely Local Group Mtg Cam Parish Council Rooms	18th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00)	22nd Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	20th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	24th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	21st Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	21st Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	19th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA	23rd Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) TBA
Social Events		Proposed - wine tasting & quiz in Stroud		11th World Parkinson's Day	19th Clubbing Together Cirencester Golf Club	Proposed - Stroud Brewery tour and lunch	Sing along with i-sing-choir from Cirencester (TBC)	Marjorie's Tea Party 7th 2pm	Proposed - boat trip with Willow Trust			
Other Events							Gloucester conference					

REGULAR MONTHLY MEETINGS AND GET TOGETHERS

Cirencester Coffee Morning - last Wednesday each month 10:30 - 12:00 at Cirencester Baptist Church

Stroud Longtable Carers Café, Brimscombe - Thursday each month, drop in after 11am

Members Pub Lunches are last Tuesday every month at The Ram, Bussage (12-2pm) - book through Stuart Keay

Other social activities to be arranged are:

- Singing along with I Sing Choir from Cirencester – potentially in July
- Parkinson’s Dance (still looking for a new venue for this)
- Table Tennis group activities (Cheltenham)

Carer drink and a chat night out

- Longfield House wellbeing events are available for all at various times
- Potentially, a tour of Renishaw to understand the technology behind the Deep Brain Stimulation probe
- Dr Fletcher / Parkinson’s Nurse talks – potentially August (awaiting confirmation)
- Future collaborations with the PSP charity and with Jill Lyons from the MSA Trust – Potentially September (awaiting confirmation)

TRANSPORTATION

We have sourced two organisations that could help with transporting members to and from meetings, activities and appointments and continuing to source other organisations to cover much more of our area. The two organisations we found are:

1. **Community Connexions** T: 01242 386275 W: www.cummunityconnexions.org.uk
They can provide –
 - Individual transport at a cost of £24 per annum for registration plus £11 per return journey and they cover the Cotswold area
 - Also provide, if required a minibus for group activities or travel
2. **Cotswold Friends**, they cover the Cirencester and surrounding villages only (not Stroud) T: 01608 697002 W: www.cotswoldfriends.org
Their costs –
 - Membership is £12 per annum to register and then pay the driver in cash on the day of up to 50p per mile – you will be advised the cost during booking

If you wish to register and use these services for meetings, activities / events, appointments, then please ask for a receipt for your journey - the branch will refund you 50% of the costs when used associated with branch activities and appointments.

Living Well with Parkinson's

This section is dedicated to stories, people or organisations that may interest you relating to living well with Parkinson's.

Caroline Russell, Chief Executive

"I feel very lucky to have joined Parkinson's UK. It's clear from everyone I've met and everything I've seen already, that at the heart of the charity is a collective of people with a passion to make a real and lasting difference to people living with Parkinson's, their families, and friends. That drive is invaluable to both a Chief Executive and the Parkinson's community."

"Putting people affected by the condition at the heart of my work is something I've always strived to do."

"I have worked for a number of years both in local government and more recently in the NHS where I was the CEO for a health system pushing to provide opportunities for people to live well. Most recently I worked for the charity Versus Arthritis overseeing a strategic review of their services."



"I have, over the last few years completed the couch to 5km programme and become an avid park runner and wellbeing advocate. I also recently returned to piano playing and am proud to say that there was a 40-year gap between passing grade 1 and grade 2!"

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554)

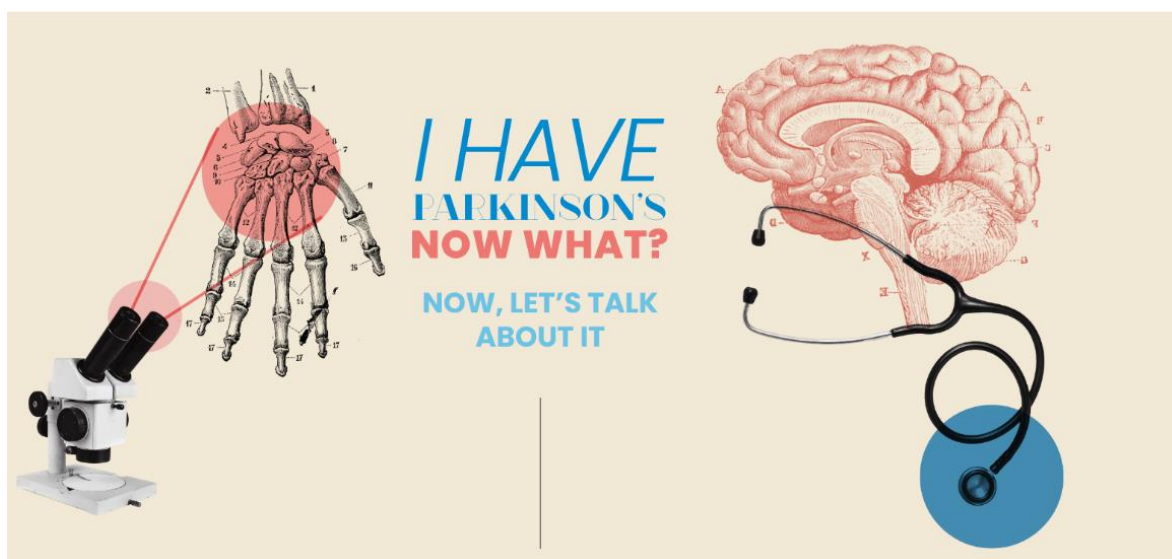
On her appointment, 1st Sept 2021 Caroline said:

"I believe that the charity is already going in the right direction with their pioneering plans and I'm looking forward to working with the staff, researchers, healthcare professionals, members, volunteers and the wider Parkinson's community to make sure that the future continues in the same vein. Putting people affected by the condition at the heart of the ground-breaking and vitally important work. This is something that I've always strived to do in my work, and I'm excited to be taking it forward when I join later this year."

So, please prepare your questions for Caroline's meeting with us on Monday 20th February at St.

Lawrences Hall, Cirencester.

LET'S TALK ABOUT PARKINSON'S



Not so much about the disease - there are doctors, nurses, medical leaflets, papers, and news for that, but everything else that exists beyond it: the stories that the word Parkinson's, by itself, doesn't tell us. From patients to caregivers, from breakthroughs to gadgets, from benefits to exercises, from famous to anonymous. "Now what?" you ask. Now, let's talk about all of them. And how a disease - this disease doesn't have to be an end, but rather a beginning.

A useful read at this link:

<https://bial-keepiton.co.uk/keep-on-inspiring/i-have-parkinsons-now-what/>

TRY BOXING

Here's news about a new partnership with Parkinson's UK which will help subsidise training costs for participants in the UK.

Parkinson's UK has awarded a physical activity grant to **Rock Steady Boxing** for a new boxing training programme for coaches in the UK.

Rock Steady Boxing already supports affiliates in Widnes and Glasgow, and this grant funding will subsidize training courses for up to ten new approved boxing coaches, allowing them to reach more people living with Parkinson's in the UK.

The Rock Steady Boxing courses are designed for physiotherapists, boxing coaches, personal trainers, fitness coaches and medical professionals who work with, or want to support, clients with Parkinson's. Courses involve a mix of 10 hours online learning and a two-day coaching session at Rock Steady Boxing in Widnes, which will take place in March 2023.

This partnership is part of Parkinson's UK's physical activity grants programme, which is supporting more than 80 new projects across the UK. The grants will enable people with Parkinson's to try sports such as table tennis, boxing, walking, football, and Boccia, helping them to stay active, manage their symptoms, and "feel good inside and out".

Tim Morton, Physical Activity Programme Manager for Parkinson's UK, said:

"We are delighted to be in partnership with Rock Steady Boxing. They offer the absolute gold standard in equipping providers to become excellent boxing coaches, equipped with an understanding of Parkinson's, and helping people with the condition understand the benefits of being physically active. We hope that this great offer will help set up new Rock Steady centres all over the UK, and ultimately help thousands of people to live well with the condition."

Ryan Cotton, Chief Executive Officer at Rock Steady Boxing, said:

"Rock Steady Boxing is excited to be collaborating with Parkinson's UK and to bring our training to more people across the country. Current evidence from the Parkinson's community supports regular, vigorous activity to help manage symptoms and Rock Steady Boxing is a great way to deliver this life-changing physical activity. We hope that with training across the UK, we can develop more locations, so the entire Parkinson's community has a local Rock Steady Boxing class available to them."

To register as a Rock Steady Boxing affiliate or for more information about joining a training course, contact info@rocksteadyboxing.org.

A link to Live Well with Parkinson's

Web pages full of information on booking onto online sessions of different speaker sessions: -

<https://www.livewellwithparkinsons.uk/>

CIRENCESTER AND STROUD BRANCH NEWSLETTER XMAS 2022

CHRISTMAS 2022 Xmas Cards

Christmas cards for sale, available for order from the PUK shop – click on this link [Christmas cards](#)



It costs just £1 to play and each ticket you buy will help improve the lives of people living with Parkinson's.

Buy your tickets today ➡ <https://prksn.uk/3ekDlcC>

Useful Information (keep for your reference)

This final section is for your own reference relating to contact details of people and organisation that you may wish to use for help, support, activities, or information. We will keep adding to this list as information becomes known and keep up to date when things change.

Branch Contacts

Branch email - cirenstroudpuk@yahoo.com

Chair – Kevin Young cirenstroudpuk@yahoo.com

Treasurer – **POSITION AVAILABLE** - please contact Branch Chair if anyone can help

Secretary – Karen Young cirenstroudpuk@yahoo.com

Local Group Coordinator (Cam) – Diane Shelley dianeshelley@btinternet.com

Membership Secretary – **POSITION AVAILABLE** – please contact Branch Chair if anyone can help

Social / Fundraising Secretary – **POSITION AVAILABLE** – please contact Branch Chair if anyone can help

Committee Volunteers – Steven Goldblatt, Karen Brookes, Angie Fenton

Cirencester and Stroud Branch Website – this could be ready after Xmas 2022, we aim to have one similar to this one at Parkinson's Newbury – check theirs at this address www.newburyparkinsons.org.uk please feedback any comments to your committee.

Branch Meetings (at the moment)

Committee meetings – 4th Monday each month (Frampton Mansell Village Hall)

Member's meetings – 3rd Monday each month (St. Lawrences, Cirencester)

Pub Lunch @ The Ram, Bussage – 4th Tuesday each month (contact Stuart Keay)

Cam Coffee Mornings – 4th Thursday each month (Cam Parish Council Rooms 4 Noel Lee Way Cam GL11 5PS)

Parkinson's Charity Contacts

Parkinson's UK Southwest Region - Jane Henderson 0344 225 3694
(jhenderson@parkinsons.org.uk)

Parkinson's Fundraising: Aaron Coleman (acoleman@parkinsons.org.uk)

Parkinson's UK Website: <http://www.parkinsons.org.uk>

Parkinson's UK Helpline: (phone free) 0808 800 0303 or email (hello@parkinsons.org.uk)

Parkinson's Local Advisor Service: contact our helpline on 0808 800 0303 or email hello@parkinsons.org.uk to be put in touch with a local adviser

Parkinson's Nurse Specialist Service: 0300 422 6610 or (gkn-tr.parkinsonsteam@nhs.net)

Cheltenham Branch: www.cheltenhamparkinsons.org.uk/

CIRENCESTER AND STROUD BRANCH NEWSLETTER XMAS 2022

Organisations and activities that may be what you are looking for in our area

- **Everyone Active** – An excellent opportunity to join Cirencester Leisure Centre free of charge for anyone with Parkinson's, follow this link:
<https://www.parkinsons.org.uk/news/everyone-active-offers-free-membership-people-parkinsons-and-their-carers>
- **Parkinson's Living Aids** – offering: *a chance to purchase quality everyday living aid products to make life just that little bit easier for people with Parkinson's* can be contacted here – www.parkinsons.org.uk/dla (this is the catalogue ordering page, Sue Mills, PUK Trading Manager will be booked to give a talk to us in 2023)
- **Longfield's Well-being Centre** – offering: *a very wide range of activities and therapies from 'just diagnosed' onwards and are all completely free of charge* can be contacted here - Burleigh Lane, Minchinhampton GL5 2PQ, 01453 886868 www.longfield.org.uk
- **Carers Hub** – offering: *support for carers to meet others in a safe place* can be contacted here – Bond Mills, Stonehouse GL10 3RF Tel: 0300 111 9000 www.gloucestershirecarershub.co.uk
- **Charcot Therapy Centre** – offering *guidance, support, information and therapies to anyone living with or supporting someone who has a neurological or long term condition* can be contacted here - 71-75 Frampton Road Gloucester GL1 5QB 01452 419 246 www.thecharcot.org.uk
- **The Churn Project** – offering: *people of the Cirencester community free (or at very low cost) support and wellbeing through difficult times when needed including Friendship Café; Family Matters; Memory Club (for anyone with memory problems)* can be contacted here – 14-16 The Waterloo, Cirencester GL7 2PY Tel: 01285 380038 www.churnproject.org.uk
- **Cotswold Friends** – offering: *support to people who do not have access to transport, helping with journey's for medical, social and practical need* can be contacted here – High Street Moreton-on-Marsh, GL56 0AZ Tel: 01608 651115 for transport bookings www.cotswoldfriends.org
- **Megan Baker House** – offering: *sessional services for adults and children with neurological motor disorders using methods of conductive education* can be contacted here - Orchard Lane, Ledbury, Herefordshire HR8 1BY 01531 633840 www.meganbakerhouse.org.uk
- **Walking Football** – offering: *a chance to play football at a slower, safer pace in a fun way regardless of age, proven to improve confidence, coordination and mobility and to make friends* can be contacted here – Abbeydale Sports and Community Centre GL4 4BL Tel: 0777 989 5832 Email: stuartlangworthy@thewfa.co.uk
- **National Trust - Discounted and free entry**
<https://www.nationaltrust.org.uk/features/access-for-everyone>
- **Essential Companion card** - The Essential Companion card makes it simple to bring one or two carers or companions with you, free of charge. Just show the card when you arrive, and your carer(s) or companion(s) won't need to pay an entry fee. It's in your name so you can bring whomever you like, but even if you don't have an Essential Companion card, you can still bring carers or companions free – the card just makes it quicker and simpler for you. If you're not a National Trust member, you will still need to pay for your own entry.
- **The Young Ones** – offering: *an informal network of working age people living with Parkinson's, playing sports, walking, socialising, 1:1 support when needed* contact Alison Anderson on 07775 525 053 to join WhatsApp group
- **Helping Old Friends** – offering: *personal assistants and companionship services tailored for you* contact number 01793 550895 www.helpingoldfriends.co.uk