

PARKINSON'S^{UK}

Carlisle Branch

Newsletter Spring 2017

Parkinson's Awareness Week

April 10-16th has been chosen as Parkinson's Awareness Week 2017. The national campaign by Parkinson's UK will focus on the search for new treatments. It is now 200 years since an English doctor, James Parkinson, published "An Essay on the Shaking Palsy" in 1817. Later, the condition was named after him. The first medication for it, levodopa, was identified more than 50 years ago, and it is still the main treatment available. No wonder that there is pressure to find new ones.

However, there are other Parkinson's issues to be aware of, too. Staying active, work and family life, social contacts and interests – these are as important to people affected by Parkinson's as they are to anyone else. Many are actively involved in the work of Parkinson's UK. The message here is that people with Parkinson's are well able to enjoy a long, full life. At times they will need support, sometimes a lot, sometimes not very much, but of the right kind.

That is what Carlisle Branch and all its local activities are here for. Why not drop in on one of our activities in Parkinson's Awareness Week, or talk to someone you know who is living with Parkinson's, and find out more about us.

Making Contact

- ❖ For personal support and advice, contact Lorraine Nicholson, Local Adviser, tel: 0344 225 3657. Email: lnicholson@parkinsons.org.uk
- ❖ Information about Carlisle Branch: parkinsonsukcarlisle@btinternet.com or go to facebook.com/parkinsonsukcarlisle.
- ❖ To find out about an activity, contact the person named in the information about that activity.
- ❖ Parkinson's UK web site: parkinsons.org.uk



Carlisle Branch Annual General Meeting

Members met on Tuesday 21st February for a talk by Dr Ailish O'Callaghan, Parkinson's specialist at the Cumberland Infirmary, followed by reports, and finally the election of the Committee for the coming year.

Dr O'Callaghan outlined the range of medication for Parkinson's Disease. Levodopa, which replaces the dopamine lacking in people with Parkinson's, is still the main treatment to reduce the disabling symptoms. After a time, usually years, it may become less effective, and symptoms are relieved for a shorter period of time before returning. Users can experience "wrigginess" as the levodopa starts to take effect, and shaking as it wears off.

Other drugs are used in various ways to make the levodopa more effective or to ease some of the many side effects. Most are taken by mouth, and one is given as a skin patch. For the most severe symptoms, some can be delivered by a small pump which feeds directly into the digestive system. An alternative is DBS – deep brain stimulation – in which electrical impulses are passed into the brain, following an operation to place electrodes there. This is effective to control shaking in those patients for whom it is suitable.

Research, often funded by Parkinson's UK, is currently seeking new drug treatments. A recent example is safinamide, which is similar to some other drugs but works in a slightly different way and has a steadying effect. Researchers hope to find completely new kinds of treatment.

There were many questions from the audience, who spoke frankly about their own experience. Dr O'Callaghan's helpful answers reminded us how much we depend on medical support, and how important it is for a complex condition like Parkinson's to have specialist services in our local area.

We also welcomed Parkinson's UK staff: Lorraine Nicholson, Local Adviser, who spoke about the planned self-management course (see page 6) and Linny Rubra, Volunteer Coordinator, who conducted the election.

After a much-appreciated break for tea and cakes, provided by Committee members and volunteers, we turned to Branch business. It was reported that the Branch now has more members and more activities, and is beginning to strengthen its finances (details were

given in the meeting papers). With this background, and a strong turnout which more than fulfilled the quorum, the following Committee members were elected:

David Gray	david.gray049@btinternet.com	01228 593147
David Little (Chair)	dwl2412@aol.com	07710 413235
Margaret Lowes (Programme Secretary)	margaret.lowes@hotmail.co.uk	01697 473247
Ian Russell	russellig@icloud.com	016977 42646
Henry Thompson	henrythompson55@btinternet.com	01228 533201
Agnes Twedde (Social Secretary)	agnestwedde8@gmail.com	01228 538158
Simon White (Treasurer)	s_p_white@btinternet.com	01228 527707
Irene Wilson		01228 402158

We hope to fill the role of Secretary in the near future.

Branching Out.

What is a “branch”? The clue is in the name. Once a year members gather for our Annual General Meeting – general, because it brings together a wider range of members to talk about what we do.

We do a variety of things in different places, but we are still all one Branch. A Branch spreads out, but it joins together too. That is its strength.

Good for a Branch:

- ❖ light – information, knowledge, advice.
- ❖ air – fresh ideas, openness, confidence.
- ❖ warmth – a welcome, reassurance, sharing.
- ❖ roots – people affected by Parkinson's, the local community, health and care services, Parkinson's UK .



Not good for a Branch.

Carlisle Branch Programme 2017

We welcome anyone affected by Parkinson's to Carlisle Branch meetings and activities, including partners, carers and companions. There is no need to join the Branch or to be a member. However, we encourage everyone affected by Parkinson's to join Parkinson's UK.

Some activities are for people with Parkinson's. If there is room, family or friends accompanying them may be able to take part, or may prefer to wait nearby. These activities are subsidised and there will usually be just a small charge for them.

Monthly Meetings

If you haven't met us yet, you could turn up at our friendly monthly get-together. You do not have to let us know you are coming and there is no charge. The meeting usually starts with a talk or slideshow on a topic of general interest, followed by refreshments and time to meet and mix with other people affected by Parkinson's.

The meeting is from 2.30 until about 4.00. The venue is St James Parish Centre, St James Road, Carlisle, CA2 5PD. Tel: 01228 810616. There is disc parking outside the venue.

21st March: Barber Shop Singers. Live vocal music.

18th April: The English Solway – An illustrated talk on the Solway plain through the ages, with local historian Richard Speirs.

16th May: Cumbrian Folklore - Canon Brian Dawson.

20th June: Blood Bikes – a talk on the volunteers who deliver emergency medical supplies and blood.

18th July: Afternoon Tea. See page 5 for information.

15th August: Wiltshire Farm Foods.

19th September: Watchtree Nature Reserve – slideshow on local wildlife conservation by a speaker from Watchtree.

17th October: Carlisle Canal – An illustrated talk by local historian and writer David Ramshaw.

21st November: Mike Angelo Photography – a slideshow with stunning images of Cumbria and the Lakes.

December: Christmas Lunch – date and cost to be announced.

Exercise Class and Coffee

Our weekly exercise class has moved to a larger venue. It still takes place each Wednesday morning but now at St James Parish Centre, St James Road, Carlisle CA2 5PD, from 10.15 to 11.15.

The contribution for each session varies, depending on how many people attend. It has been £3-4, and recently £2.50 – the class is growing! (max £5). There is a side room where companions can wait. If you want to join please contact the class trainer Mike Salkeld – (info@northlakesphysio.com or 07947 918063).

We have coffee/tea after the class on the first Wednesday of each month, from 11.15 – 12.00 approx. Also every week, for companions who are waiting in the side room, or for anyone affected by Parkinson's who just wants to drop in and meet us at 11.15 – 12.00.

The new venue is easy to find and there is disk parking outside. There are staff in the office just inside the front door. They will show you where we are, if you are not sure. Please go LEFT after passing the offices. All rooms on the right are reserved for other users.

Around our local area

In Brampton, afternoon drop-in sessions will continue at Church Cottage, St Martin's Church, Front Street. For information, contact Ian Russell, 016977 742646, russellig@icloud.com. Drop in on the fourth Friday of each month 3 – 5 pm (except 28th April – why not join us at Rheged that day? See page 8).

In Wetheral, the Tai Chi class continues most Wednesdays at 5-6 p.m. at Wetheral Village Community Hall. New members please contact the teacher, Lesley Relph: townandvillagetaichi@gmail.com, 01228 710898. Routine queries, contact Dave Little by email or phone (dwl2412@aol.com or 07710 413235).

- ❖ If you have been advised to be careful with physical activity, consult your medical professional before starting any new form of exercise.

Summer Tea, 18th July

This year, we are holding our Summer afternoon tea at our usual monthly meeting venue, St James Parish Centre, as a buffet meal provided by a professional caterer. If you would like to come, contact Henry Thompson 01228 533201 henrythompson55@btinternet.com . Give your details so that you can be contacted if necessary. The contribution to the cost of the tea is £3.50, payable by 30th June.

Blackpool Week

The Blackpool holiday in early October at the Savoy Hotel, North Shore, Blackpool (right on the sea front) is specially for people living with Parkinson's. Rooms are allocated to suit your mobility needs. The cost includes 6 nights with dinner bed and breakfast, entertainment at nights, a selection of talks and advice sessions, beauty treatments and massages – in fact everything except transport to/from Blackpool and lunch which you can buy in the hotel. Last year the hotel underwent a major refurbishment costing well over £1,000,000.

There is one condition: you must be able to manage on your own or with the help of the person who goes with you. There are nurses on duty 24/7 but they are for emergencies, not to act as carers

For information about cost, equipment and insurance contact David Gray. David, a Carlisle Branch member who has Parkinson's, organises the holiday privately. 01228 593147, e-mail david.gray049@btinternet.com or by post at 5 Eilbeck Close, Carlisle. Booking begins from April.

What is Self-Management?

"A Path through Parkinson's" is a course designed and run by Parkinson's UK to help you navigate your life with Parkinson's.

The course brings together up to 12 people with a trained leader who is, like them, a person with Parkinson's, partner or carer. They meet for six sessions of discussion about living with Parkinson's. It's free to attend, but you need to book your place in advance.

The aim is to share experiences and discuss the practical and emotional impact of Parkinson's.

The course lasts for a set period of time and sessions are based on a workbook and led by the "facilitator". In this way it differs from the really valuable, more informal, support provided by Parkinson's UK branches and local support groups

"I feel as though I'm more in control, I can see a future" – Pat, whose husband has Parkinson's. Find out more about the programme – <https://www.parkinsons.org.uk/content/self-management-programme-path-through-parkinsons>

The course in the Carlisle area is expected to start after 22nd May.

Tips for living with Parkinson's

Coloured plastic trims make door-keys easy to pick out in a bunch. They make the key easier to grip and turn with your finger-tips. Shoe and key repairers have them – these came from Citadel Row.



Don't try these at home

Or not all of them. Fundraising is “Any event that is held to raise funds, e.g. street collections, raffles, sponsored walks/runs/skydives, exhibitions, games, fireworks displays, auctions of goods, concerts, quiz nights, tea afternoons, cake sales, jumble sales, fêtes, fairs” – Parkinson's UK offers some exciting opportunities.

Fundraising for your local Branch can happen at home, with friends, in your street, or at work. You can use even a small opportunity, such as a coffee morning or car boot sale, as a way to help us.

More adventurous people might make it a personal challenge – maybe a sponsored abseil – or put on an event – a tournament? Do make sure you stay within safe and legal limits.



Carlisle Branch will be grateful for any support. Sponsor forms, advice leaflets, collection boxes (large and small) and some themed stationery are available from the Branch. If you use an online service such as Just Giving for a sponsored event, please make sure you tell them and us well in advance that you want your donation to come to Carlisle Branch.

Any Committee member will be happy to discuss fundraising ideas with you, or you can contact Simon White, Treasurer: email parkinsonsukcarlisle@btinternet.com, phone 01228 527707.

Finding out about us

- ❖ Details of all our activities will be included, if available, in the quarterly Newsletter which is sent to all members. Further details will be given out each month at Branch meetings and sent to members who have email addresses.

Local Development Team information...

... about events which may interest people in the Carlisle area:

- ❖ Self –management course “A Path through Parkinson’s”. A series of six discussions on different topics about living with Parkinson’s will be held in the Carlisle area, expected to start 22nd May. Details and venue to be announced. See page 6.
- ❖ “Research Uncovered” event. Meet researchers, who will sit with small groups in turn, talk about their work and respond to questions. Friday 28 April 2017, 10:30am – 3pm, Rheged Centre, Redhills, Penrith, CA11 0DQ. This event is free to attend and lunch will be provided. Details of the researchers and topics are promised soon. You can book now at <https://www.eventbrite.co.uk/e/parkinsons-research-uncovered-cumbria-registration-32090526629>.
- ❖ “Parkinson’s Together” event. Meet the Local Development Team and be updated on their work. Tuesday 9th May 2017. Penrith Rugby Club Winters Park, Penrith CA11 8RG. The outline time table is: 10.45 registration. 11 am prompt start. Lunch 12.30 to 1.15 pm. Close at 3pm at the latest. There is ample parking at the rugby ground. Full programme, pre work requirements and other details will be out soon.

For enquiries about these events and the Local Development Team, contact Linny Rubra, Volunteer Coordinator - Tel: 0344 225 3604, Email: lrubra@parkinsons.org.uk

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

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