

# PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

News and Information Letter for Cornwall & the Isles of Scilly

*December '21/January '22*

## Christmas Greetings



### Editorial Thoughts

My first issue as Editor was December 2018 and this is my last issue. How could we have ever imagined then what might be happening in our world today? Importantly the Coronavirus restrictions “black box” continues to be absent from this page and slowly our meetings are beginning to start again.

The distribution list of this Newsletter is around 430 copies, a great achievement for the two Cornwall Branches of Parkinson’s UK. Thankyou to all the regular contributors, and of course thankyou to all the readers.

My last task at this time of year is to remind you all to transfer any appointments that you might have into your new diaries. Merry Christmas and a Happy New Year to you all, and as always Happy Reading!

*Kay Maycock*



# Points West

## **A VERY MERRY CHRISTMAS to you all**

It has been so good to start our monthly get-togethers (only just started!) and we must say a huge THANK YOU to Kelsey for continuing to run “Sing for Fun” via Zoom – which has been enjoyed by so many and brings us together in these difficult times. A huge THANK YOU also to Becky for running the PDAActive sessions, again via Zoom. These two supporting “meetings” have meant that those taking part have continued to keep in touch – which has been and continues to be so important. And another huge THANK YOU to Caroline who has resumed “in person” our “exercise to music” sessions at St Piran’s Hall, Goldsithney on Monday mornings, as well as at our monthly meetings.

We are looking forward to getting back to our monthly meetings which will be held at St Piran’s Hall, Goldsithney, on the third Friday of each month – meeting up at 1.30 pm and finishing by 4.00 pm

We have lost some very dear members – and we miss them.

## **TO CHEER US UP and make us smile**

We are quoting some “Did I read that sign right”:-

IN A LONDON DEPARTMENT STORE : “Bargain Basement Upstairs”

IN AN OFFICE : “Would the person who took the step ladder yesterday please bring it back or further steps will be taken”

OUTSIDE A SECOND-HAND SHOP : “We exchange anything – bicycles, washing machines, etc. Why not bring your wife along and get a wonderful bargain?”

NOTICE IN HEALTH FOOD SHOP WINDOW : “Closed due to illness”

SEEN DURING A CONFERENCE : “For anyone who has children and doesn’t know it, there is a Day Care on the 1st Floor”

NOTICE IN A FARMER’S FIELD : “The farmer allows walkers to cross the field for free, but the bull charges”

MESSAGE ON A LEAFLET : “If you cannot read, this leaflet will tell you how to get lessons”

ON A REPAIR SHOP DOOR : “We can repair anything. Please knock hard on the door – the bell doesn’t work”

IN AN OFFICE : “After tea break, staff should empty the teapot and stand upside-down on the draining board”

SPOTTED IN A SAFARI PARK : “Elephants, please stay in your car”

PANDA MATING FAILS. VETERINARIAN TAKES OVER : (Well, he must be quite something!)



### **Christmas Meeting**

Our Christmas meeting is on the 17<sup>th</sup> December at St Piran’s Hall, Goldsithney, from 1.30pm. Join in games and carol singing. No exercises (please don’t bring raffle prizes this time). Family and friends welcome! Refreshments will be provided.

### **You are invited to the West Cornwall & Isles of Scilly Branch Parkinson’s UK Annual Lunch**

West Cornwall Golf Club, Lelant

(between Lelant & Carbis Bay, turn right into Church Lane. Golf Club is then approx 1 mile down here on your left)

Sunday 30<sup>th</sup> January 2022 from 12 noon – for 12.30pm dining

Cost of £26 or discounted to £20 for anyone with Parkinson’s

Please find enclosed with this Newsletter the booking form and menu pre-order (additional copies available at our Christmas “get together” on the 17<sup>th</sup> December, or call Emily 01736 365267).

Reply soon to guarantee your place – closing date 8<sup>th</sup> January 2022.

## **Advance Notice re AGM**

Our AGM is due to take place in March and will be held at St Piran's Hall – all being well, and with no further lock-downs occurring! We will give the date in the next Newsletter. Please let us know if you are interested in joining the Committee.



## **Looking Ahead**

### **Mid Cornwall Branch's February Feast**

Given the uncertain nature of meeting in the Winter months, the Christmas meal we had hoped to share in December has been converted to a FEBRUARY FEAST.

The details and menu will be sent out with the newsletter, early in 2022. However, all things being equal we shall be meeting in the dining room of the Cheesewring Hotel, Minions, at lunch time on the 24<sup>th</sup> of February.

Booking in advance will be essential, so keep your eyes peeled.

We have chosen the Minions area especially to enable Launceston, Torpoint, Saltash and Liskeard members to come along, but of course members anywhere within Cornwall will be welcome.

*Sue Whipps*





## **Poets Corner**

Here is a poem that Nicky Wilhemsen concocted and Patrick asked me to get it in this newsletter if possible.

### **Patrick**

Have you met our dear friend Patrick? He really is unique,  
he's got this thing about his age and of this he will not speak.

He likes to talk to people where ever he may go,  
you will always see him smiling and he'll always say "Hello."

He likes a good old sing-along and we always get a treat,  
for the words that he'd be singing are not what's on our sheet!  
And when we've finished singing, just before we're out the door,  
you will always hear him saying, "Let's sing it --- Just once more!"

*Nick Wilder*

### **Why be a Volunteer?**

It's not for money, it's not for fame,  
It's not for any personal gain.  
It's just to give a helping hand,  
It's just to give a little of oneself  
That's something you can't buy with wealth.  
It's not medals worn with pride,  
It's for that feeling deep inside.  
It's your reward down in your heart.  
It's feeling that you've been a part  
Of helping others far and near.  
That's what makes one want to  
BE A PARKINSON'S VOLUNTEER

*Jan Wilder*



# ***EXPERT PATIENT PROGRAMME*** **Self care after Covid**

## **Small steps to better health FREE SELF MANAGEMENT COURSE FOR PEOPLE LIVING WITH POST COVID**

Would you like

- To improve your quality of life
- Learn new skills to manage your health condition
- Meet others and share experiences
- Communicate better with family, friends and professionals
- Feel confident and more in control of your condition

The Expert Patient Programme is being run by CFT **online via Teams** for anyone living with post covid. The course is delivered over seven weeks for 2.5 hours, led by volunteer Trainers with lived experience of a long term health condition. Course sessions will cover:

- Relaxation techniques
- Dealing with difficult emotions
- Introduction to physical activity
- Making healthy food choices
- Coping with depression
- Fatigue and getting a good night's sleep
- Pain management
- Planning for the future

We offer 1 to 1 support to enable everyone to access Teams

To register for our online course places now available  
Tuesday 18<sup>th</sup> January to 1<sup>st</sup> March 2022 11 until 1.30pm  
please contact: Elaine Curno EPP Manager Tel: 07824598626 or Tel:  
01579 373500 (please leave a message on Liskeard Hospital  
Reception desk) or e-mail [elaine.curno@nhs.net](mailto:elaine.curno@nhs.net)



# ***EXPERT PATIENT PROGRAMME***

## **Small steps to better health**

### **FREE SELF MANAGEMENT COURSE FOR PEOPLE LIVING WITH LONG TERM HEALTH CONDITIONS**

Would you like

- To improve your quality of life
- Learn new skills to manage your health condition
- Meet others and share experiences
- Communicate better with family, friends and professionals
- Feel confident and more in control of your condition

The Expert Patient Programme is being run by CFT **online via Teams** for anyone living with a long term health condition. The course is delivered over seven weeks for no more than 2.5 hours, led by volunteer Trainers with lived experience. Course sessions will cover:

- Relaxation techniques
- Dealing with difficult emotions
- Exercise
- Eating healthily
- Coping with depression
- Pain and Fatigue management
- Planning for the future

To register for our online course places now available  
Wednesday 19<sup>th</sup> January to 2<sup>nd</sup> March 2022 11 until 1.30pm  
please contact: Elaine Curno EPP Manager Tel: 07824598626 or Tel:  
01579 373500 (please leave a message on Liskeard Hospital  
Reception desk) or e-mail [elaine.curno@nhs.net](mailto:elaine.curno@nhs.net)

## **LOCAL CONTACTS AND SOURCES OF INFORMATION**

### **Parkinson's Nurse Service**

Parkinson's Nurse Service

**01209 318048**

[Pdnurses.cornwall@nhs.net](mailto:Pdnurses.cornwall@nhs.net)

(Recorded message covering the whole county with advice, and explaining the current service)

Appointment changes only (NOT Nurses)

**01209 318050**

### **Neurological Advice Service**

Mary Eason and Bernadette Murray

**01209 318106**

[cpn-tr.NeuroRehab@nhs.net](mailto:cpn-tr.NeuroRehab@nhs.net)

(Answerphone service – please leave a message and one of the advisors will call you back)

### **Living Well with Parkinson's Programme**

Jane Rideout

**07511 592318**

[livingwellwithparkinsons2021@gmail.com](mailto:livingwellwithparkinsons2021@gmail.com)

Website

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

### **Parkinson's UK Representatives**

Local Parkinson's Adviser

**Kirsty Maidment** 0808 800 0303 [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

The whole of Cornwall and Isles of Scilly

Network Support Officer

**Mary Jane Hunter** 0344 225 3695

[mjhunter@parkinsons.org.uk](mailto:mjhunter@parkinsons.org.uk)

## **LOCAL CONTACTS AND SOURCES OF INFORMATION**

### **Contacts for Mid Cornwall, West Cornwall & IoS Branches**

#### **Mid Cornwall**

<u>Chairman</u>	Jan Wilder 01726 61502 <a href="mailto:chairman@parkinsonscornwall.com">chairman@parkinsonscornwall.com</a>
<u>Vice Chairman</u>	Position vacant
<u>Secretary</u>	Sue Whipps 01503 262166 <a href="mailto:secretary@parkinsonscornwall.com">secretary@parkinsonscornwall.com</a>
<u>SE Cornwall Rep</u>	Tom Bevan 01579 321132
<u>Newsletter</u>	Kay Maycock 01208 420432 <a href="mailto:newsletter@parkinsonscornwall.com">newsletter@parkinsonscornwall.com</a>
<u>Membership Sec</u>	Kay Maycock 01208 420432 <a href="mailto:membership@parkinsonscornwall.com">membership@parkinsonscornwall.com</a>
<u>Treasurer</u>	Nick Wilder 01726 61502 <a href="mailto:treasurer@parkinsonscornwall.com">treasurer@parkinsonscornwall.com</a>
<u>YOPs</u>	see Facebook group People with Parkinson's in Cornwall

#### **West Cornwall and Isles of Scilly**

<u>Chairman</u>	Edward Bolitho 07980 826613
<u>Vice Chairman</u>	Helen Hichens 01736 788309
<u>Secretary</u>	Linda Ashmore 01736 711293 <a href="mailto:secretarywest@parkinsonscornwall.com">secretarywest@parkinsonscornwall.com</a>
<u>Treasurer</u>	Rob Burt 01326 221330
<u>Membership Sec</u>	Kay Maycock 01208 420432 <a href="mailto:membership@parkinsonscornwall.com">membership@parkinsonscornwall.com</a>

**Parkinson's UK Helpline 0808 800 0303**

[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)



## Promas Caring for People

**Are you an unpaid carer who needs support?**

### **Face-to-face course for first part of 2022**

Coping Strategies	2 <sup>nd</sup> March Penzance 17 <sup>th</sup> May Bodmin
Making time for Art for Carers	28 <sup>th</sup> April Pool
Managing Mental Illness	6 <sup>th</sup> April Truro
Caring for Dementia Carers	16 <sup>th</sup> -17 <sup>th</sup> February Penzance 11 <sup>th</sup> -12 <sup>th</sup> May Truro
Managing Stress	10 <sup>th</sup> February Liskeard 24 <sup>th</sup> March Bude
Citizens Advice	4 <sup>th</sup> March Penzance 13 <sup>th</sup> May Truro
Mindfulness	21 <sup>st</sup> March Truro
3-day Caring for Carers	26 <sup>th</sup> -28 <sup>th</sup> April Penzance
Creative Writing	19 <sup>th</sup> May Penzance
Caring for Carers	24 <sup>th</sup> May Liskeard
Listen, Talk and Be Heard	17 <sup>th</sup> March Pool

Helpline: 07435 870587 / 01736 339226 / 07775 756454

**For more information or to apply – contact us:**

email on [info@promas.co.uk](mailto:info@promas.co.uk)

Website [www.promas.co.uk](http://www.promas.co.uk)

Or call us on 01736 339226 / 07775 756454

Illustration + Design ©Melanie Chadwick 2021

Supported by  
Public Health Cornwall

# Keep active Keep Moving at home this Winter!

FREE!

MOTIVATING!

Get Your NEW 12 week  
programme of Physical  
Postcards

FREE!



To receive yours through the post  
sign-up today!



Phone us 10am-6pm Mon-Fri  
07936 648347 or  
07730 586306



Email us  
[physicalpostcards@dancecentred.co.uk](mailto:physicalpostcards@dancecentred.co.uk)

The closing date for signing up is 11.12.21

[www.dancecentred.co.uk](http://www.dancecentred.co.uk)





# Medicine Chest

## **Parkinson's Nurses Royal Cornwall Hospital NHS Trust**

Emma Worden and Angela Hart are the new Parkinson's Nurses working within the Acute Hospitals Trust in Cornwall. They have recently been joined by Pharmacist, Stephen Chan, who has a specialist interest in Parkinson's. We aim to support people with Parkinson's who may need to come into the Acute Hospitals, whether as a planned or an emergency admission.

If you do need to come into hospital, please remember to bring your medications (in their original packets if possible) and a copy of your most recent prescription. This will help to avoid delays and ensure that you get your medications on time.

The team's priorities include providing education to staff to ensure that people with Parkinson's feel understood and supported and confident that your needs will be met. We will continue to prioritise medication management and promote the need for people with Parkinson's to 'get it on time, every time'.

## **An update from the Parkinson's Service from Cornwall Partnership Foundation Trust.**

Hello All, Time seems to have flown by so quickly and hopefully this year we will all have a better Christmas. It has been some time since my last update as the Parkinson's service has been so busy trying to return to a new normal!

A new Parkinson's Nurse has been recruited to the community Parkinson's team. She is called Stephanie and is currently going through an induction process and will be mainly working in the west but also covering some of mid Cornwall. We are continuing to work closely with the new Parkinson's Nurses at the Royal Cornwall Hospital, and I

know they are providing tremendous support with the Parkinson's admissions that have taken place in recent months.

The Physical self-management group continues to run for people who are newly diagnosed with PD and has recently taken place face to face in the St Austell area. If you have been diagnosed within the last year and have not been offered a place, please contact the Parkinson's service to request this. This group focuses on the importance of physical exercise and the role exercise plays in Parkinson's management.

Other project work that has taken place throughout the year has included the development of a Clozapine pathway for people with Parkinson's who occasionally require specific medication for hallucination / delusions. We have worked with our mental health colleagues in Cornwall to set up this service.

We are also working hard to ensure people receive their medication on time within our community hospitals through additional pharmacist support. We also have an online educational session planned for care home staff in December, which will also focus on the importance of medication being taken on time.

Going forwards please continue to contact the Parkinson's Nurse Specialist Service when required. We continue to provide a responsive telephone service to people with Parkinson's and from this can determine the best route of review for you. Sometimes your query can be dealt with straight away but if not then a video consultation or face to face appointment if required, can be arranged. Reduced clinics are taking place over the county including Penzance, Camborne Redruth Community Hospital, Falmouth, St Austell, Bodmin and Liskeard.

If we have not heard from you for twelve months you will receive a letter asking that you make contact to provide us with an update.

The secure NHS Video platform called Attend Anywhere is working well. It is a great way to have a face to face discussion without the need to travel or park. The information below outlines a couple of key steps for this to happen and you are welcome to try it out at any point:

To attend your appointment, you need to click on the link below, or copy the link into your Google Chrome or Safari web browser:

1. Click on the link to access our Video Appointments  
<https://www.cornwallft.nhs.uk/video-appointments>
2. At the bottom of the page click on the Adult Community Services Waiting Room link
3. Click on the **Join your video appointment** button to begin

If you have not informed the service about your email address please let us know, as it provides us with an alternative way to communicate with you going forwards.

If you have concerns about your Parkinson's symptoms, please contact the Parkinson's Nurse Specialist Service on 01209 318 048 or via email on [Pdnurses.cornwall@nhs.net](mailto:Pdnurses.cornwall@nhs.net)

Wishing you all a restful Christmas and New Year.

*Lynne Osborne Consultant Nurse Parkinson's Service*

## **Pill Timers**



Do you want help to get your medication on time? We have the Tabtime Super 8 pill box reminder available at £5 each (inc postage).

For more information on how to get one phone Rowena on 07813 548767

Please note that this is not a Parkinson's UK product and is not endorsed by Parkinson's UK (company number 00948776).

Parkinson's UK is not responsible for the quality, insurance or upkeep of this product, nor for any loss or damage incurred as a result of its use.



## Peninsula Parkinson's Research Interest Group



To say that the pace of Clinical Trials for Parkinson's is pedestrian is to be polite about a big systemic problem. A group of Parkinson's researchers and people affected by Parkinson's together with funders are adapting and

developing a system used widely in cancer medicine called Multi Arm, Multi Stage or MAMS for short.



Dr Camille Carroll is Co-Lead for the Edmund J Safra Initiative for Accelerated Clinical Trials in Parkinson's Disease (don't blame us for the title). She spoke at length to PenPRIG about how MAMS will enable several Parkinson's therapies to be assessed simultaneously, and those that are promising then taken seamlessly

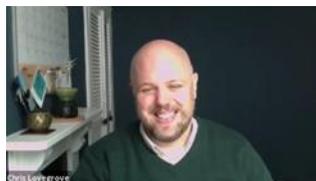
and quickly through the clinical trials system and into therapeutic use.

See the video at <https://youtu.be/7R-ea66pNRQ>

As an excellent pointer to the range of topics we are covering, next up was Chris Lovegrove to explain the project he is leading to develop a non-drug treatment for Anxiety in Parkinson's. The management of anxiety is a significant unmet need for many people with Parkinson's and their care partners. See our 2-part video, Part 1 at

<https://youtu.be/pMoA3lQA5w0> and Part 2 at

[https://youtu.be/TAT\\_dtsY6lc](https://youtu.be/TAT_dtsY6lc)



Next time we will focus on how PenPRIG members are being drawn into close involvement in significant research projects. If you have been inclined to treat involvement in research as a spectator sport, look out for the next issue!



## COUNTY WIDE MEETINGS

We have a number of monthly meetings run by our  
Parkinson's groups and branches, they are:

	Contact nos.
BUDE group on 2 <sup>nd</sup> Sat	01237 441913
LAUNCESTON Drop-In on 1 <sup>st</sup> Tue (NOT YET OPEN)	
TORPOINT Shuffle Club on 1 <sup>st</sup> Thu (NOT YET OPEN)	01752 822870
WADEBRIDGE Drop-In on 4 <sup>th</sup> Mon	01503 262166
GOLDSITHNEY Meeting on 3 <sup>rd</sup> Fri	01736 711293

**These three are generously supported by local Rotary Club members**

EAST TAPHOUSE Drop-In 3 <sup>rd</sup> Wed	01503 262166
ST AUSTELL Drop-In 2 <sup>nd</sup> Wed (NOT YET OPEN)	01726 61502
CARNON DOWNS Drop-In 1 <sup>st</sup> Thu (NOT YET OPEN)	07813 548767

### **ACTIVITY MEETINGS run by the branches**

HELSTON PD Active Thu(term-time) (ZOOM)	01326 561012
SUMMERCOURT PD Active Thu(term-time) (ZOOM)	01326 561012
TOWNSHEND Singing every Wed (ZOOM)	01736 351330
SUMMERCOURT Trembellows every Monday	01726 61502
GOLDSITHNEY Exercise to Music every Monday	07773 669667

Wherever you live in Cornwall and the Isles of Scilly, you are all welcome at  
any of the meetings and events mentioned in this newsletter.

Just follow the instructions to make a booking.

DISCLAIMER. Whilst every effort is made to ensure all details in this News and Information letter are accurate at the time of publication, The Editors, The Mid-Cornwall Branch and the West Cornwall and Isles of Scilly Branch of Parkinson's UK or any Committee Member do not accept any responsibility for the accuracy of information or of any technique, medication or treatment.

This Newsletter is published by Parkinson's UK Cornwall Branches.

[newsletter@parkinsonscornwall.com](mailto:newsletter@parkinsonscornwall.com) 01208 420432

Website <https://parkinsonscornwall.com>

**THE DEADLINE FOR NEXT EDITION IS 15<sup>th</sup> January**