

# PARKINSON'S<sup>UK</sup>

## CHANGE ATTITUDES. FIND A CURE. JOIN US.

News and Information Letter for Cornwall & the Isles of Scilly

*February/March '21*

***Coronavirus restrictions have led to the suspension of all our group activities.  
Please turn to Page 7 of this issue for more information.***

## Editorial Thoughts

Despite still being so restricted in our strange world once again we have a packed Newsletter.

There will be no AGMs this year so relevant documents are included in your mailing.

There is another quiz for the pen and pencil brigade together with a new selection of courses for you to consider online. In the Medicine Chest there is an article about a new programme for the newly diagnosed, Living well with Parkinson's. If you are not confident with online working this initiative is also available on a DVD that you can take your time with at home.

We have lighter mornings and evenings now, perhaps soon there will be some spring flowers to cheer us further, in the meantime Happy Reading!

# Points West

## West Cornwall & Isles of Scilly Branch – AGM

You will be very disappointed to learn that we are unable to have our Annual Cream Tea (oops, we mean General Meeting!) in person this year. However, we are still required to present you with Reports and an update of the Branch's status. With this Newsletter you have the Chairperson's Report for 2020, the Treasurer's Report for 2020, the Minutes of the 2020 AGM, and the proposed Management Committee for 2021.



LINDA ASHMORE (FORMERLY TIMMS) IS STEPPING DOWN AS WEST CORNWALL BRANCH SECRETARY – WE WISH TO **THANK HER VERY MUCH** FOR FULFILLING THIS ROLE MOST EFFICIENTLY FOR THE PAST YEAR. FORTUNATELY, LINDA WILL REMAIN ON THE COMMITTEE AS MINUTES & SOCIAL SECRETARY!

### VACANCIES:

**Secretary** –duties in “normal times” include: attend committee meetings (approx. every 6/8 weeks), collating & submitting newsletter inclusions (every 2 months), booking class venues & tutors (mostly ongoing), receiving occasional telephone enquiries, helping to arrange events (Education Day, Annual Lunch, Fish n Chip outings etc), liaison with Mary Jane (PUK Network Support). Computer skills essential.

The committee Constitutionally cannot operate without a Secretary – so please step up (or ask Family members or Friends if they could spare a few hours each month...)!

**General Committee Members** – attend meetings (approx. every 6 weeks), ideas & help for fundraising & events & improving our “services” for local people with Parkinson's & their carers.

Please contact

Helen (admin) 01736 762048 [helenandy20@hotmail.com](mailto:helenandy20@hotmail.com)

Linda (outgoing secretary) 01736 711293 [generaltimms@gmail.com](mailto:generaltimms@gmail.com)

or Mary Jane Hunter 0344 225 3695 [mjhunter@parkinsons.org.uk](mailto:mjhunter@parkinsons.org.uk)

## **Non Committee Vacancy:**

Help is required to help run the Ludgvan (2<sup>nd</sup> Tuesday 1.30pm-4pm) & Helston (3<sup>rd</sup> Friday 12.30pm-3pm) Support Groups ongoing on a monthly basis when these groups return post-Covid. Please contact Linda to discuss further.

## **“NEW” Year Quiz**

### **“Where in the World” anagrams:**

1. Weasel Owns Hut (3,5,5)
2. Reefs Town (3,6)
3. Twenty-one shillings, freshly minted : GENUINE HW (3,6)
4. Wales has one and so does the Isles of Wight : WORN PET (7)
5. Dog with webbed feet : LADEN DOWN FUN (12)
6. Chief monk found on race course here : BOAT BENT NOW (6,5)
7. End of the line from Par : QUENWAY (7)
8. Sounds like an English County in British country but across the Pond : SHEEP WARN HIM (3,9)
9. Mardi Gras and all that jazz : ANSWER NOEL (3,7)
- 10 You'll find magpies here in St James Park : SWEET CLAN (9)

### **“NEW” Trivia**

1. Which magazine do the initials NME stand for
2. Who partnered John Newcombe to win the Mens' Doubles at Wimbledon
3. What song was made famous by the New Seekers and Coca Cola
4. What comes next in the New Testament, Mark, John, Luke and .....
5. Who played the role of Purdy in The New Avengers
6. Who wrote The Emperor's New Clothes
7. What is the meaning of “Neolithic”
8. What can be Smooth, Great Crested or Palmate
9. Paul Newman played which famous film role with Robert Redford
10. Which phrase containing the word “new” means “to start behaving in a better way”

### **General Knowledge** (nothing “new” here except for question 2!)

1. What Nursery rhyme character was rich on Monday and buried on Sunday
2. Who performed the first successful heart transplant
3. What was the backing group for Gerry Marsden
4. What was the name of the Scottish Prison Officer in Porridge

5. How old is a town celebrating its “sesquicentennial”
6. What year did man first land on the moon
7. What was Pearl Carr’s and Teddy Johnson’s Eurovision song
8. What novel did Daphne du Maurier write about Cornish ship wreckers
9. What British poet has his own national day
10. What Hebrew word means “so be it”

Thanks to Linda & Emily for their sterling efforts, answers on page 10.

### **Exercise to Music**

Dear Dancers,

It feels like a very long time since we have been able to dance together. I have bumped in to some of you over the last few months and it’s been lovely to catch up. Penzance Prom seems to be a good place to see people. It’s now looking fantastic after it’s facelift and great to see it being enjoyed by humans and dogs alike.

When I had to suspend my Sundance classes (weekly dance and fitness classes for people over 50) I created a set of 7 postcards for the group to encourage them to keep moving. The first three cards are Stamina, Stretch and Stillness. If you would like these, or the full set of cards, please contact me and I can email you copies.

Very best wishes to all of you,

*Caroline*

07773 669667 / [caroline.schanche@icloud.com](mailto:caroline.schanche@icloud.com)



## Helpful Hints

It's not always easy to **keep track of when medications need to be re-ordered**. I find that keeping a record on a separate calendar is a great help.

Get a calendar which has space to write in for each day. When I get a new lot of tablets, I fill in the calendar for each day that these will last me. I use an initial letter for each medication, eg M for Madopar, D for Dispersible etc. Always write the medications in the same order. I have six different tablets, so I write M N D O A S for each day I have the tablets for. You could use different coloured pens for each tablet. It is then easy to see at a glance when a tablet is going to run out.

**Problems with liquids going down the wrong way** – the swallowing mechanism does not work well with head tilted back. Tilt to imbibe but return to level to actually swallow.

**Solids and liquids falling off utensil** on the way to your mouth. When you lift spoon/fork it gets tilted on the way to your mouth because the upper arm/shoulder is not doing its full lifting movement. Only using the lower arm results in odd angles for a spoon, resulting in spillage. I find I have to constantly remind myself to lift my elbow as I lift a spoon.

We wouldn't be without our **chair-leg risers**, which simply fit on the legs of chairs to make them taller. This can make them more comfortable and much easier to get up from, and not just for those with Parkinson's! We now sit at a more comfortable height at the dining table too. The ones we have are called "Leg-X Chair Raisers", which we find don't mark the carpet either.

### From the Parkinson's UK Online Magazine:

[www.parkinsons.org.uk/information-and-support/your-magazine](http://www.parkinsons.org.uk/information-and-support/your-magazine)

**Exercise** is good for people with Parkinson's, especially if you experience fatigue.

Fatigue can often trigger a cycle in which you become less and less active. This can happen if your daily activities make you feel tired. But the less you do the weaker your muscles become and the more fatigued you'll feel.

Exercise can help you manage your fatigue, boost your mood and help you sleep well. The more you can do the more benefits you'll get. So find something that suits you at the right level and go for it. This could be as simple as chair-based exercise or a brisk walk that gets your heart rate up.

Having calendars, clocks, noticeboards and notices around your home may help **jog your memory** and provide helpful reminders. You may find it helps to keep a list of things to do. You can see what you have achieved as you tick off each task.

## Looking Ahead

### **Mid Cornwall Branch of Parkinson's UK AGM**

Due to Covid Restrictions we are not able to hold an AGM this year. You will find the 2020 reports and minutes of the 2019 AGM with this Newsletter. They will be accepted in retrospect at the next AGM. There is also a list of the proposed Management Committee for 2021.

### **PDActive**

Becky Duncan, of Neuro Physio Practice, restarted the PDActive online on Thursday 21<sup>st</sup> January from 12.30pm, for 10 weeks for all existing participants.

If anyone new wishes to join this group on Zoom, they are very welcome and they need to contact Becky on 01326 561012 or email [becky@physiopracticecornwall.co.uk](mailto:becky@physiopracticecornwall.co.uk) so that she can assess them over the phone or video. The cost for the assessment is £38.50. Some of this can be claimed back – please contact the treasurer on 01208 420432 or email [treasurer@parkinsonscornwall.com](mailto:treasurer@parkinsonscornwall.com)

### **For the Trembellows now that 2021 is here**

May I take this opportunity to wish everyone the very best of whatever you want for this NEW YEAR! So here we go into 2021. With the vaccine being promised there should be better news in two months' time, who knows, we may even have something to sing about, here's hoping, keep washing those hands and keep safe.

*Alan*

# Coronavirus

You will all be aware of the current restrictions on travel and social contact. As a result of this we are still unable to produce the normal flyers that accompany the Newsletter.

The calendar entries have all been cancelled until further notice.

However, probably the most important information for you all is the list of local contacts and sources of information.

This list appears over the next two pages of this Newsletter.

If you wish to remove the centrefold you can pin the list to your noticeboard or keep it close to your phone.

*Editor*

## **Vaccine for Carers**

There has been an addition to the priority list for vaccinations. If you are an unpaid carer (do not receive Carer's Allowance) then you are also entitled to be vaccinated at the same time as the person you care for.

To be sure that this happens you should contact your GP and make sure your record is updated to show you as carer.

## **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)

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

Local Parkinson's Adviser

**To be appointed** 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)

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

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

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

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

#### **Mid Cornwall**

Chairman Jan Wilder 01726 61502  
[chairman@parkinsonscornwall.com](mailto:chairman@parkinsonscornwall.com)

Vice Chairman Position vacant

Secretary Nick Wilder 01726 940495  
[secretary@parkinsonscornwall.com](mailto:secretary@parkinsonscornwall.com)

SE Cornwall Rep Tom Bevan 01579 321132

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

Membership Sec John Whipps 01503 262166  
[membership@parkinsonscornwall.com](mailto:membership@parkinsonscornwall.com)

Treasurer Chris Maycock 01208 420432  
[treasurer@parkinsonscornwall.com](mailto:treasurer@parkinsonscornwall.com)

YOPs see Facebook group People with Parkinson's in Cornwall

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

Chairman Edward Bolitho 07980 826613

Vice Chairman Helen Hichens 01736 788309

Secretary Linda Ashmore 01736 711293  
[secretarywest@parkinsonscornwall.com](mailto:secretarywest@parkinsonscornwall.com)

Treasurer Rob Burt 01326 221330

Membership Sec John Whipps 01503 262166  
[membership@parkinsonscornwall.com](mailto:membership@parkinsonscornwall.com)

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

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

# Coronavirus

## Calendar Entries

The Calendar page on the Parkinson's Cornwall Website will show the cancelled events. Obviously this will be the first place that will show when activities re-start.

Perhaps those of you who do not have on-line access can ask a friend (or your local library) to check the site for you?

The website address is <https://parkinsonscornwall.com>

A reminder to all of you who attend drop-ins or other activities, the contact details of the leaders are all listed on the back page of the Newsletter. Please contact them if you need any further information.

*Editor*

### Quiz Answers

#### **Where in the World NEW Trivia**

New South Wales

New Forest

New Guinea

Newport

Newfoundland

Newton Abbot

Newquay

New Hampshire

New Orleans

Newcastle

(football team & ground)

New Musical Express

Tony Roche

I'd like to teach the  
world to sing

Acts

Joanna Lumley

Hans Christian Anderson

New Stone Age

Newts

Butch Cassidy

To turn over a new leaf

#### **General Knowledge**

Solomon Grundy

Dr Christian Barnard

The Pacemakers

Mr Mackay

150 years

1969

Sing Little Birdie

Jamaica Inn

Robert Burns

Amen



# **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** for anyone living with a long-term health condition. The course is delivered over six weeks for 2 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 courses being delivered in 2021 please contact: Elaine Curno EPP Manager Tel: 07824598626 or please leave a message on Liskeard Hospital Reception desk 01579 373500 or e-mail [elaine.curno@nhs.net](mailto:elaine.curno@nhs.net)



Cornwall Partnership **NHS**

NHS Foundation Trust

## **EXPERT PATIENT PROGRAMME**

**Small steps to better health**

### **CARING FOR ME AND YOU**

#### **FREE SELF MANAGEMENT ONLINE COURSE FOR CARERS**

Would you like to:

- Manage your caring situation more effectively
- Be realistic about the impact of your caring situation on yourself and your families
- Meet others and share experiences
- Communicate better with family, friends and professionals
- Feel confident and more in control of your own lives

Caring for ME and YOU is being run by CFT **online** for anyone living with a long-term health condition and caring for someone. The course delivered over six weeks for 2.5 hours by volunteer trainers with lived experience. Course sessions will cover:

Relaxation techniques	Dealing with tiredness
Exercise	Eating healthily
Coping with depression	Dealing with triggers
A Healthy you	Finding and Hiring help
Planning for the future	

**We will start the online courses March 2021**

**Please register your interest**

please contact: Elaine Curno EPP Manager Tel: 07824598626 or  
please leave a message on Liskeard Hospital Reception desk 01579  
373500 or e-mail [elaine.curno@nhs.net](mailto:elaine.curno@nhs.net)

### **Fund Raising Greetings Cards**

For several years Sue Williams has made cards and donated the proceeds to Parkinson's UK. Her outlets have been Newquay hotels and a couple of local shops, all of which are now unavailable.

Please contact her if you would like details (postage £3.10 for up to 20 cards) Phone 01637 871169 or 07971164503,  
or email [susie.que@hotmail.co.uk](mailto:susie.que@hotmail.co.uk)

*Editor – Sue sent me some samples but sadly I have no room to include photos! They are lovely big cards, beautifully made.*

# Medicine Chest

## The Living well with Parkinson's Programme

This programme has just launched in Devon and Cornwall.

Prompted by a request from the clinicians for something to offer people newly diagnosed with Parkinson's during the pandemic, a small group of local people affected by Parkinson's got together to design, develop and deliver this new programme of videos and zoom sessions.

The programme includes a video 'What is Parkinson's?', and a number of monthly 60minute information sessions on zoom for people with Parkinson's, their family members and friends.

What sessions are in the programme?

1. Introduction to Living well with Parkinson's – for people newly diagnosed with Parkinson's who would like to find out more about self-managing the condition.
2. For family members and friends of people with Parkinson's – how you can help someone with Parkinson's, and support available to you.
3. "Focus on ....." sessions.

These sessions are for anyone affected by Parkinson's.

Each session goes into more detail on a topic.

Topics include:

Keeping active with Parkinson's

Getting involved with research

How can your Parkinson's nurse help you?

Understanding Parkinson's medications

There are going to be other sessions when the clinical pressures reduce.

You can find out more information about the sessions available:

On the new local website for Devon and Cornwall,

<https://parkinsonslocal.wordpress.com>

Or contact me by email [livingwellwithparkinsons2021@gmail.com](mailto:livingwellwithparkinsons2021@gmail.com)

Or call me on 07511 592318 and leave a message.

Finally, we wanted the help to be available to everyone. We know that many people do not want to use the internet or zoom. To offer them some help we have prepared a DVD that can be played on

their home TV DVD player. The DVD includes some videos of the sessions.

If you know of someone who would benefit from a copy of the DVD, please either email me or call me on the contact details above.

Help is also available for anyone who would like to try zoom for the first time. Please contact me for help with this.

*Jane Rideout*

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

By the time you read this article the evenings should be lengthening out slightly and we can start to look forwards to the spring. Hopefully many of you would have been offered the covid vaccination, which I hope you will have.

Kerry our new Parkinson's Nurse started with the team in November and is helping to return phone calls to the service. Therefore you may get the opportunity to speak to her at some point if you have not done so already.

As I write this update, we have just gone into another Covid lockdown and as such, this may affect any virtual or face to face appointment you may have either the Parkinson's Nurse Specialists or Medical Consultants, due to work pressures this may bring. It is therefore important that you contact the service with any arising Parkinson's issues. All messages to the service are prioritised and returned quickly. Following the Parkinson's Nurse Contact, we are then able to book you into a virtual clinic slot for either a video consultation or telephone review. This is working well enabling us to provide a responsive service to people with Parkinson's. We have started sending out letters to everyone on our caseload providing an update on the Covid situation and outlining that routine appointments are not being offered by the Parkinson's Nurse Specialist Service. The letter reiterates the requirement for you to contact the service.

For some time now we have been sending out three questionnaires via post prior to your virtual clinic taking place. These request information around your motor symptoms, your non motor symptoms and general wellbeing. Many thanks for completing and sending these back to the service, as they are very useful to form the basis for discussion and for other team members such as Medical

Consultant and Therapists to be kept up to date with your Parkinson's journey.

If you have not been reviewed by a Parkinson's Nurse Specialist or Medical Consultant for a year, you will receive a different letter from us. This will ask that you contact the service with any arising problems and is a mechanism for ensuring we have an update about your Parkinson's symptoms.

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) . We are collecting messages frequently throughout the day.

It is appreciated that not all people locally receive this newsletter, so if you are able to share the key messages below across the Parkinson's community until individual letters can be sent out, we would be very grateful.

### **Key Messages**

- Routine follow up appointments with the Parkinson's Nurse Team are not taking place
- If your Parkinson's symptoms have deteriorated please contact the Parkinson's service
- A letter informing you of the service changes will be gradually mailed out to you
- You will receive a letter if you have not been reviewed by a Parkinson's Nurse or Medical Consultant in a year

Many thanks *Lynne Osborne Consultant Nurse Parkinson's Service*

### **Pill Timers - FREE**

The Tabtime Super 8 pill box reminder is now available FREE (while stocks last).

Two Compact pill box reminders are also available FREE for assessment. If you like it, tell us and keep it.

The stock of Pill Timers is held by Rowena Wilson. Telephone her on 01326 376710 to make an arrangement for collection or posting. If you have any difficulty using them, our Drop-In Group Leaders will (soon) be familiar with them, so may be able to help.



## COUNTY WIDE MEETINGS

We now have ten monthly meetings run by our  
Parkinson's groups and branches, they are:

	Contact nos.
BUDE group on 2nd Saturdays	01237 441913
LAUNCESTON group on 1st Tuesdays	01208 420432
TORPOINT Shuffle Club on 1st Thursdays	01752 822870
WADEBRIDGE group on 4th Mondays	01503 262166
HELSTON Meeting on 3rd Fridays	01736 711293
LUDGVAN Meeting on 2nd Tuesdays	01736 788309

### **These four are generously supported by local Rotary Club members**

EAST TAPHOUSE Drop-In on 3rd Wednesdays	01503 262166
ST AUSTELL Drop-In on 2nd Wednesdays	01726 61502
CARNON DOWNS Drop-In on 1st Thursdays	01326 376710
NEWQUAY Coffee morning on 3rd Thursdays	01503 262166

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

HELSTON PD Active every Thursday	01326 561012
SUMMERCOURT PD Active every Thursday	01326 561012
TOWNSHEND Singing every Wednesday fortnight	01736 351330
SUMMERCOURT Trembellows sing every Monday	01726 815054
GOLDSITHNEY Exercise to Music every Monday	07773 669667

Many of the above have exceptions during the year especially summer and Christmas. Please see the calendar flyers for full details.

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 and flyers. 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.

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Website <https://parkinsonscornwall.com>

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