



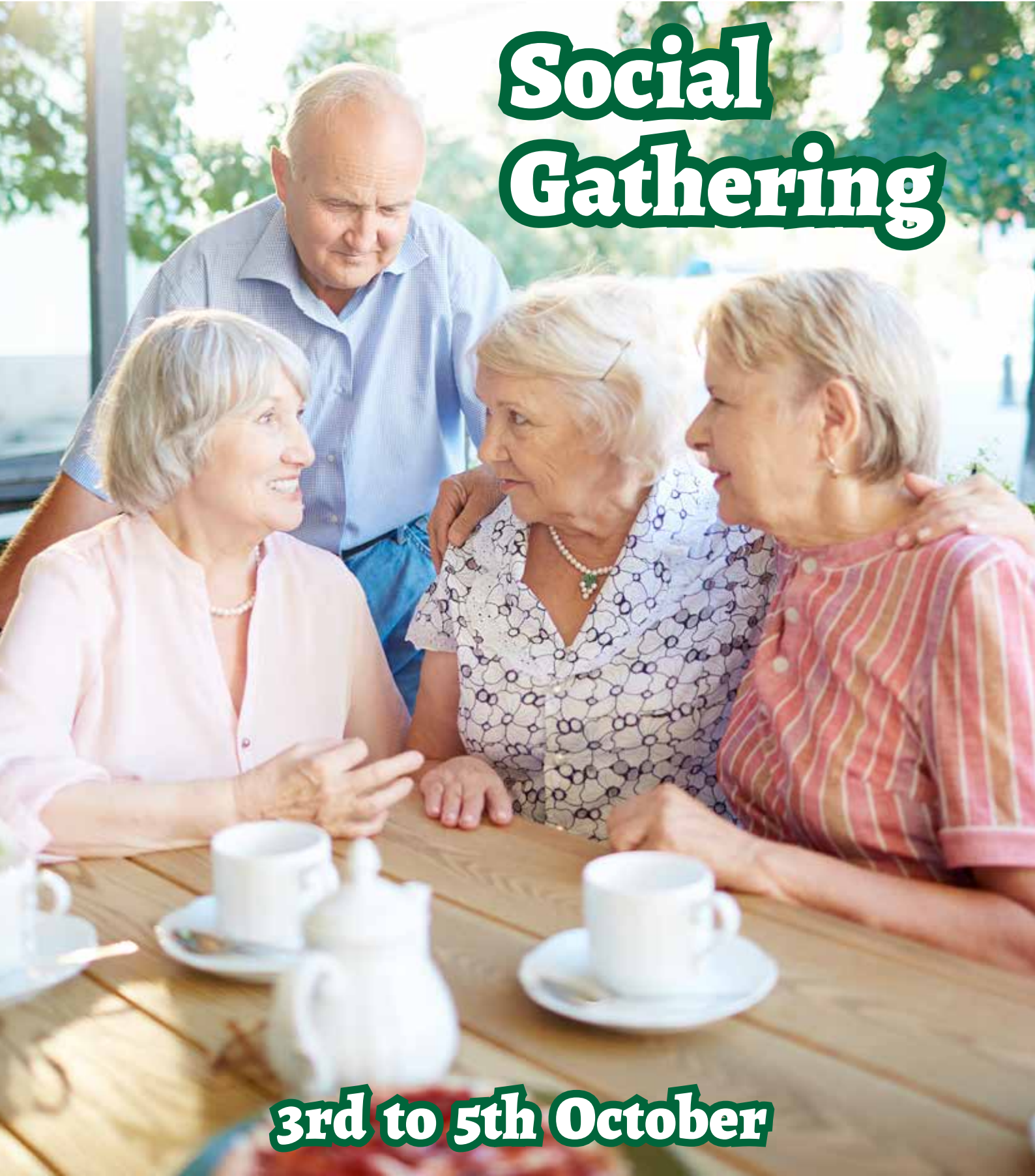
# Parkinson's

## Association of Ireland

[www.parkinsons.ie](http://www.parkinsons.ie)

Summer 2022

# Social Gathering



**3rd to 5th October**



## A MESSAGE FROM THE CEO - PAULA GILMORE

### DEAR MEMBERS

Greetings to all our members, your families and all the Parkinson's community. We feel it's important to acknowledge the challenges we have all faced and to think about some of the things we must celebrate. In this edition we will highlight some of the positive things that have happened over the past number of months.

If you are looking for information, support, or advice our Parkinson's National Helpline is open on 1800 359 359 where you can talk to Pauline, the support line manager. You can arrange a call back from Lisa our PD nurse or Richelle our

- dietitian. You can also log on to any of our weekly
- zoom classes and enjoy some mindfulness, yoga
- or join the weekly 'ask the nurse's clinic. Your local
- branch has also got several things planned so
- make sure you contact them.
- If you don't receive the weekly newsletter with up-
- to-date information, you can email fundraising@
- Parkinson's, and Sabrina will make sure you are on
- the mailing list.
- I hope you found the Parkinson's Awareness week
- programme helpful and informative. The videos
- from the speakers are now online and you can
- listen back to them at your leisure.
- Thank you for your support and PAI deeply
- appreciate the generosity that has been shown by
- those who have chosen to support us throughout
- the past year. From donations to organising
- fundraisers, we greatly appreciate your support.
- We have now completed our strategic planning
- process. We sought input from various stakeholders
- to help shape and guide our organisation in the
- coming years. We used this information and data
- to create a new strategic plan which we plan to
- launch soon.
- Our vision for the next five years is ambitious with
- key priority areas and actions in place to direct
- this work. Our work has been steered by people
- living with Parkinson's, family carers / supporters,
- colleagues, branch members and you, our
- members. We would like to thank you all for your
- incredibly meaningful and insightful feedback in
- its many forms over the last few months
- We are almost at the end of our website re-design.
- The web designers have shared the preview of the
- new website with us. We have a few tweaks to do
- on the site and it will be ready for testing. We will
- be looking for official testers on the system - in
- particular, some people living with Parkinson's.
- The Research Advocacy sub-committee is now in
- place, and we are delighted that Emma O'Shea
- from UCC will chair this committee with Lisa PD
- nurse, two board members', Una and Ann and
- Dublin branch secretary Theresa. We will be
- accepting new members moving forward.

## CONTENTS

A word from our CEO .....	2
Summer Raffle .....	3
Social Gathering .....	4
PD Services and Needs .....	5
Long Term Illness Survey .....	8
Travel - Planning your trip .....	9
Meet the Directors .....	10
PD Nurse Survey 2022 .....	12
Living Well .....	14
Branch News .....	16
Mindfulness and Meditation .....	23
Meds on Time .....	24





The quarterly board/ branch meetings are on-going and your branch committees are representing you on those calls.

All PAI Policies have been reviewed and there is a new GDPR policy. The board has been working on this over the past couple of months to ensure we comply with all charity requirements. You will be able to find these documents on the website.

Services are re-opening again after COVID. Some smaller branches were nervous about re-opening and Lisa (our nurse) is happy to visit to help with the re-opening.

A special thank you to the treasurers of each branch for the financial information as the national audit is now taking place and a date for the AGM will be circulated in the coming weeks.

We hope you enjoy reading this issue. If you have any feedback or have suggestions on what you might like to see in future editions, please contact the nationaloffice@parkinsons.ie

I hope you all have a lovely summer and I look forward to seeing you at the members social gathering in the Hudson Bay hotel in Athlone on the 3-5th October if not before.

Kind regards

Paula

## Parkinson's Virtual Conference

To view the full conference go to <https://parkinsons.eventxlive.com/>

abbvie



# Summer Raffle 2022

## Our Annual Summer Raffle Has returned

Every ticket you buy gives you a chance to win one of our super prizes. Did you know?

1 ticket (€5) would help pay the cost of sending out an information pack to a newly diagnosed person with Parkinson's.

A book of 5 tickets (€20) would help pay for providing our Parkinson's helpline and nurse support for 1 hour.

Every ticket you buy or sell will make a positive difference to the lives of people with Parkinson's

Draw takes place on 12th August 2022.

Amazing prizes, including

€500 Cash Prize

€200 Cash Prize

€100 Cash Prize

Overnight in the Hodson Bay Hotel with dinner

2 tickets for Riverdance

**Parkinsons.ie**  
RCN 20028237  
CHY REVENUE NO 10816

**ANNUAL NATIONAL DRAW 2022**

Name \_\_\_\_\_  
Address \_\_\_\_\_  
Phone No. \_\_\_\_\_  
Email \_\_\_\_\_  
Sold by \_\_\_\_\_  
Ticket No. \_\_\_\_\_

**ANNUAL NATIONAL DRAW 2022**

Top Prizes include:  
**€500 Cash Prize**  
**€200 Cash Prize**  
**€100 Cash Prize**  
**Overnight in the Hodson Bay Hotel with dinner**  
**2 tickets for Riverdance**  
**And many more prizes**

€5 EACH OR €20 FOR A BOOK OF 5

Draw will take place on 12/08/2022 @ 12 Noon in Carmichael Centre, North Brunswick Street, Dublin 7.  
 Permission Granted - RCN 20028237 and CHY Revenue no 10816.

Parkinson's Association of Ireland, Carmichael House, North Brunswick Street, Dublin 7 Tel: 01 872 2234 Email: info@parkinsons.ie Web: www.parkinsons.ie Freephone Helpline: 1800 359 359

Company registered in Ireland No. 123532, CHY No. 10816 Registered address as above



We make every effort to be as accurate as possible, and in the event of a mistake being made, it is our policy to acknowledge it in the following quarter's publication.

The material herein is for your information only, and does not represent advice. No changes to your treatment regime should be made without the prior agreement of your consultant or GP.

# SOCIAL GATHERING 2022

Monday 3rd Oct- Wednesday 5th Oct  
Hodson Bay Hotel Athlone

The Parkinson's Association of Ireland are delighted to announce our Social Gathering will take place from Monday 3rd Oct-Wednesday 5th Oct 2022.

**Please join us for this gathering in the beautiful surroundings of the Hodson Bay Hotel.**

## THE OFFER INCLUDES

- Two Nights B&B
- Lunch
- Two nights Gala Dinner and entertainment both evenings.
- Full Day Conference to include
- An exciting line up of speakers including Parkinson's Nurse Specialist Lisa Wynne, set dancing, yoga,

Nurses clinic to name some of the activities we hope to include.

Price includes all of the above

€209 per person sharing

Or

€300 per single room.



**BOOK NOW TO AVOID DISAPPOINTMENT**

**CONTACT THE HOTEL DIRECTLY ON 090-644 2005 TO BOOK.  
EARLY BOOKING IS ADVISED TO AVOID DISAPPOINTMENT.**



# PD SERVICES AND NEEDS FOR PARKINSON'S NURSING (UPDATE)



## MAPPING PARKINSON'S DISEASE: POLICY BRIEF ON ACCESS TO HEALTH & SOCIAL CARE PROFESSIONALS

Principal Investigator: Professor Suzanne Timmons

University College Cork

Health Research Board Funded

### 1. BACKGROUND

The prevalence of Parkinson's disease (PD) will double between 2015 and 2040. There has not been enough investment in PD healthcare services in Ireland. Under-staffing is a problem across all disciplines (NAI, 2021). A key problem is the poor levels of access to health and social care professionals, but especially those with expertise in the assessment and management of PD.

These professions include Physiotherapy, Occupational Therapy, Speech & Language Therapy, Dietician, Psychology, Social Work, etc.

### 2. METHODS

We have data on clinical therapy access, and patient experiences of same through:

1. National Survey of people with PD (N=1504)
2. PD Service Mapping (N=14)
3. Interviews with people with PD (N=25)

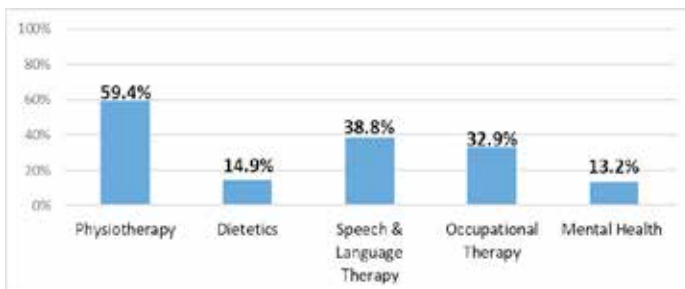
### 3. KEY FINDINGS

#### Service Mapping:

There are just 14 specialist PD outpatient clinics nationally, for a population of approximately 12,000 people with PD.

Just 21% of people with PD reported having had any access to a PD nurse specialist since diagnosis, contrary to NICE Guidance. PD nurses play a key role in coordinating patient care, including facilitating access to the range of clinical therapies.

As can be seen in the figure below, patient-reported (N=1504) access to the range of clinical therapies is universally poor, but especially so in relation to **dietetics** and **mental health services**.



### 4. ACTIONS REQUIRED

Specialist PD services are under-provided, and where they are provided, are under-resourced.

All specialist clinics should be resourced to provide timely access to the range of clinical therapy disciplines, as appropriate to PD patients' needs.

**Increased provision of all clinical therapies is urgently needed.**

**Pathways to dietetics and mental health services are needed urgently.**

### CONTACT

0860354526

Twitter: @ParkinsonsProj1

Emma.oshea@ucc.ie

<https://www.ucc.ie/en/cgr/rp/>



# MAPPING PARKINSON'S DISEASE: POLICY BRIEF ON NURSE SPECIALISTS

Principal Investigator: Professor Suzanne Timmons

University College Cork

Health Research Board Funded

## 1. BACKGROUND

The prevalence of Parkinson's disease (PD) will double between 2015 and 2040. There has not been enough investment in PD healthcare services in Ireland. Under-staffing is a problem across all disciplines in these services (NAI, 2021). The role that is lacking most is the PD nurse specialist. PD nurses improve patient outcomes and save money for the health system, e.g., avoided hospital admissions.

## 2. METHODS

We have data on PD nurse availability and access, and patient experiences of same through:

1. National Survey of people with PD (N=1504)
2. PD Service Mapping (N=14)
3. Interviews with people with PD (N=25)

## 3. KEY FINDINGS

### Service Mapping:

There are just 14 specialist PD outpatient clinics nationally, for a population of approximately 12,000 people with PD.

There are 480 specialist PD clinic sessions per year in Ireland. For each patient to be seen twice annually at a specialist PD clinic (as per NICE guidance), each clinic would have to see **50** patients per clinic session. Clinics can only see 8-25 (mean=15) patients per session, indicating the vast level of under-provision.

Only half (7/14) of the *specialist* PD services have either a PD nurse specialist or an advanced nurse practitioner attached to them.

Just 21% of people with PD reported having had any access to a PD nurse specialist since diagnosis.

*"We have nowhere near enough PD nurses, and considerably less than what they have in other countries".*

Nurse specialists, where available, provide hugely valuable services:

- Medication review/adherence
- Care coordination
- Emotional Support/Counselling
- Treating non-motor symptoms
- Domiciliary visits
- Self-management support

## 4. ACTIONS REQUIRED

Specialist PD services are under-provided.

All patients should have, at a minimum, access to yearly clinic visits.

All specialist clinics should have at least one PD nurse specialist.

All patients should have access to a PD nurse specialist.

**A minimum of 30 PD nurses** is required, to cater to the current population of people living with PD.

## CONTACT

☎ 0860354526

💬 Twitter: @ParkinsonsProj1

✉ [Emma.oshea@ucc.ie](mailto:Emma.oshea@ucc.ie)

🌐 <https://www.ucc.ie/en/cgr/rp/>

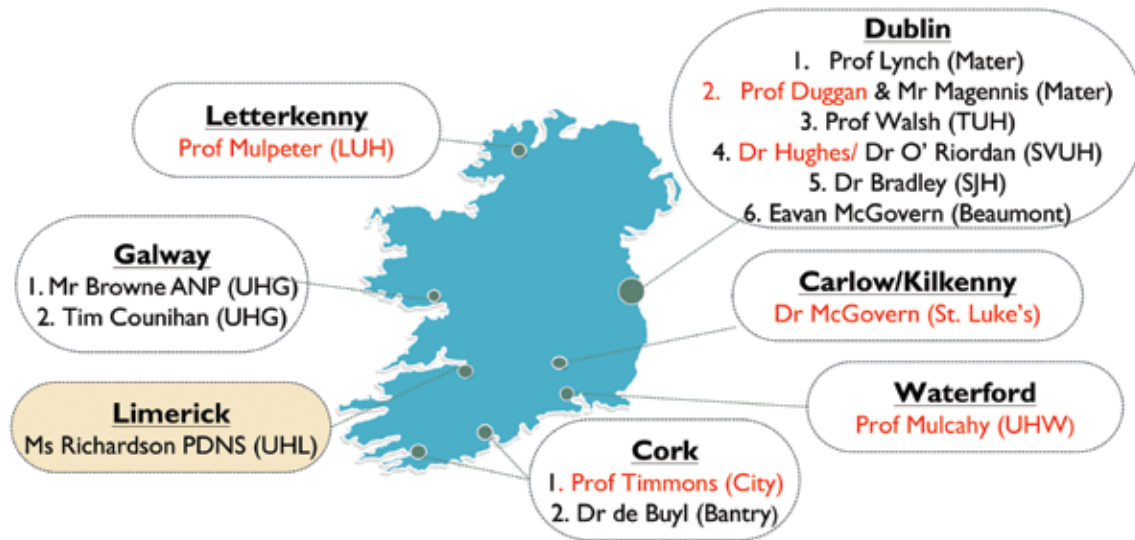






# PARKINSON'S UPDATE

## MAPPING OF SPECIALIST PD SERVICES (N=14)



The Parkinson's Association of Ireland (PAI) appointed a full-time PD nurse Lisa Wynne in October 2021 to replace Nicola Kavanagh, the part-time PD nurse. The board has approved funding to appoint a second nurse to assist Lisa and the PAI branch network. We have experienced an increase in the calls to the support line and branch visits. The board want to re-assure members that the new post will enable branches to have more access to the nursing service we offer.

Following the very successful 'Patient's Deserve Better' campaign meeting organised by the Neurological Alliance of Ireland (NAI) with Oireachtas members on June 15th, we will continue to work with NAI to campaign for more PD nurses. This campaign is a nationwide campaign calling for more nurse specialists in neurology services. The PAI is a member of the NAI and are supporting this campaign and working with NAI to call for more nurse specialists.

### NEUROLOGY CLINIC PROGRAMME

The CEO Paula Gilmore and Professor Suzanne Timmins UCC, the lead on the Mapping Parkinson's Research have requested a meeting with Professor

Orla Hardiman, National Clinical lead, Neurology at the HSE to discuss the estimates and present research findings. The aim is to highlight the need for more Parkinson's nurses in advance of Professor Hardiman's budget submission. The PAI and its members are the PPI lead in the Mapping Parkinsons research.

The HSE budget estimates are being prepared in July and the meeting will summarise the findings and see if some data from the project might support a specific ask in the budget for extra PD nurses nationally that are requested through the 'Patient's Deserve Better' campaign).

The CEO and the board of PAI also had meetings with Minister Anne Rabbitte (Disability) and Minister Joe O'Brien (Charities) requesting stable core funding for the PAI. We are also in the process of submitting a section 39 funding proposal for core funding to enable us to grow the nurse specialist and the branch network in advance of the budget.

The Strategic plan is nearly completed and the first draft will be presented to the board at the July board meeting.

We will also be launching a GP and Hospital awareness campaign in September.

We will be launching the new website in the coming weeks.

We will keep you updated on progress.







# TRAVEL

## Planning holidays and trips abroad?

Lisa Wynne, Parkinson's Disease Nurse Specialist



Now society is starting to open up across the globe people may start to get back to planning holidays and trips abroad. The process of planning, booking and transiting can be a stressful time. Some of us have had a hiatus from both in-Ireland and international travel. You may find some of these tips beneficial.

### Documentation:

- ▲ Ensure passport within date, for some it has been a long time since we have needed them!
- ▲ letter from your GP or physician in case any health issues arise
- ▲ list of medications/copy of current prescription
- ▲ Travel insurance (if required)/ European Health Insurance Card (E111)
- ▲ Health Insurance policy number

### Medications:

- ▲ Pack medications in your hand luggage
- ▲ A copy of your prescription
- ▲ Ensure you have a sufficient supply of medications for length of stay including an emergency supply in case of delays
- ▲ Ensure sufficient supply/ back up pump/ chargers if on advanced therapy for Parkinson's disease (apomorphine, levodopa/ carbidopa gel system/ Deep Brain stimulation)

### Planning:

- ▲ Good planning and research prior to your trip may be beneficial; knowing what provisions are in place in accommodation, if required
- ▲ Assessing what tourist attractions may present a challenge or if there is suitable access
- ▲ Purchase advance tickets for events/tourist attractions avoid queues
- ▲ Find out local hospital locations/ local emergency numbers

- ▲ Arrive early at airport/port if possible, to avoid any unnecessary time restraints and stress.
- ▲ Take into consideration time difference/time zones. Adjust medication timing as necessary. Avoid missing doses.
- ▲ Stay hydrated. Air travel can contribute to dehydration. If traveling to a hot climate be aware you may need to increase fluid intake.

### Assistance:

#### **If you require assistance in the airport it is suggested:**

- ▲ Make contact and notify your airline, travel agent or tour operator with details of your assistance requirements at least 48 hours in advance of the departure of your flight.
- ▲ If you require assistance in the airport, it is suggested you contact OCS services (Dublin, Cork, Belfast) Telephone: (01) 704 7700 Email: [prm@ocsireland.com](mailto:prm@ocsireland.com)
- ▲ If traveling by boat/ ferry it is suggested you contact company at least 48 hours prior to departure

When booking tickets, it may be beneficial to mention at time of booking if assistance or priority services required. Alleviate some of the stress.

### Covid- 19

- Ensure you check most up to date travel requirements & government guidelines applicable to destination
- [gov.ie](http://gov.ie) - International travel ([www.gov.ie](http://www.gov.ie))

● **Note: Not all of these will apply to everyone**

# MEET THE DIRECTORS



## PARKINSON'S ASSOCIATION OF IRELAND



**ANN FOX**  
**CHAIRPERSON**

Ann was instrumental in setting up the North-West branch over 20 years ago and is the current serving secretary of the North-West branch. She has over 20 years' experience with PAI and is well-versed in compliance.



**PÁDRAIG BARRY**  
**VICE CHAIRPERSON**

Pádraig is from Limerick, is a member of the Midwest branch and continues to work fulltime

with Saint-Gobain Construction products in Ireland. Pádraig has worked in general manager roles for more than 25 years, has a general interest in most sports, particularly hurling, rugby and golf. A keen runner and cyclist, Pádraig is living with Parkinson's.



**UNA ANDERSON RYAN**  
**TREASURER**

Una is a founding member of the original board for PAI. Has worked with the Midwest Branch for over 30 years, implementing and developing their vision for a Parkinson's Disease nurse service in the Midwest.



**DAVE POWER**  
**DIRECTOR**

Dave joined the Board of the Association in October 21. Dave has been working in IT all his life. He has worked in numerous roles such as developer, solution architect, lead consultant and manager. Currently Dave works with Microsoft as a senior Technology Specialist.

Dave became involved with the Parkinson's Association of Ireland through a project we worked on in early 2021.

Dave is from Dublin and spends his spare time tending to his city centre garden, cooking and taking long walks in the country.



**BECCY CAMERON**  
**DIRECTOR**

Beccy Cameron joined the Board in November 2021. Beccy has over thirty years' experience working within the human resource management sector acquired through a wide range of organisations such as financial services, retail, IT, telecommunications, media, accountancy and the public sector in Ireland, the UK and across Europe. Beccy is the Founder/ Director of Robin HR Consultancy, a Fellow of the Chartered Institute of Personnel Management (CIPD) and a Member of the Irish Institute of Training & Development (IITD). Living in Enniskerry, Co Wicklow, Beccy is an Iyengar Yoga teacher, daily sea swimmer, avid reader and gardener.



**PAULA GILMORE**  
**CEO**

Paula is the CEO of the Parkinson's Association of Ireland since 2014. Paula was elected to the BOD of the European Parkinson's Disease Association (EPDA) in 2019 and has worked in the healthcare field since 2000, working with and providing support services for people living with HIV and AIDS up until 2014. She holds a Masters in Management, M.A.(Hons) Pastoral & Voluntary Services at DCU.



**SINEAD COLLERAN**  
**DIRECTOR**

Sinead Colleran joined the Board in March 2022. Sinead lived for 10 years in France where she set up her own translation and education services company.

Upon returning to Ireland she commenced work with Community Games where she is now the Operations Manager. Sinead holds a postgraduate certificate in Leadership and Management from NUIG, a postgraduate diploma in Digital Marketing from the Digital Marketing Institute, and a Bachelor of Arts in Community Development from TUS. She recently completed the Accelerate course in Management with Sport Ireland. She is a member of the Association of Data Protection Officers of Ireland as a certified Practitioner. Sinead volunteers with her local community in Ballinasloe by designing and maintaining their website and enjoys going to concerts, travelling, and cooking!



**ROBERT YOUNG**  
**SECRETARY**

Robert joined the Board of PAI in August 2021. He has worked in the domestic and cross-border insurance and pensions sector for 33 years. Robert is a fellow of the Association of Chartered Certified Accountants (ACCA). He has held senior roles in Finance, Risk and Compliance.



# PD NURSE SURVEY 2022

Lisa Wynne, Parkinson's Disease Nurse Specialist

This survey was created to assist the Parkinson's nurse specialist in prioritising the needs of those members living with Parkinson's or caring for those with Parkinson's disease. It was to serve as a way of highlighting the availability of nurse services provided by PAI. A possible activity that would identify issues relating to Parkinson's disease that one may not have been aware of or had previously addressed.

1

## General Information

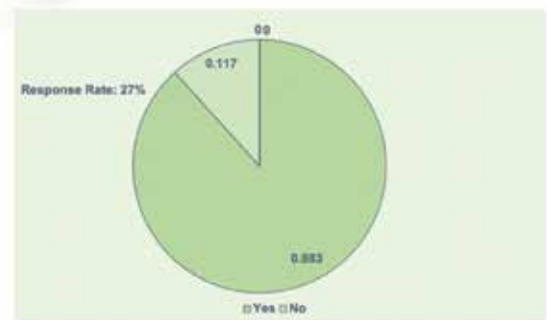
39.2% response rate



\* Compulsory question

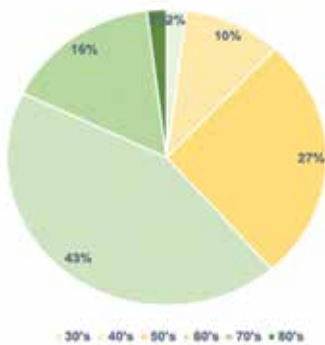
4

Would you be interested in participating in a New Diagnosed Support Programme?



2

## Age at Diagnosis



Average age at diagnosis: 60.6 years

Diagnosed 2020-2022: 27%

\* Compulsory question

3

Average Rating: 2.67/5

2.7

How would you rate your experience of being told of your PD diagnosis?

5

Which of the following services have you availed of?

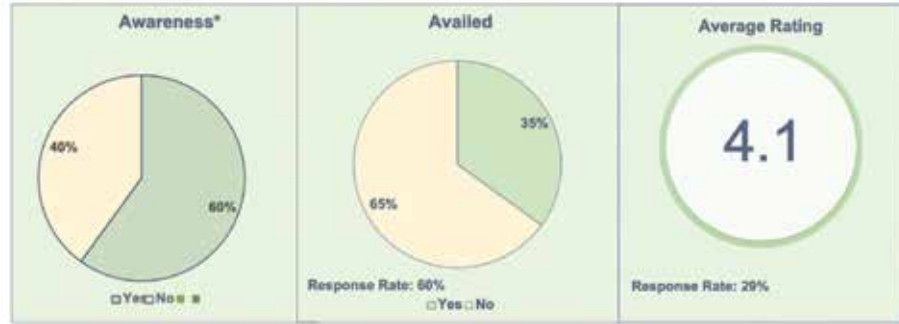


\* Compulsory question



## Nurse Call Back Service?

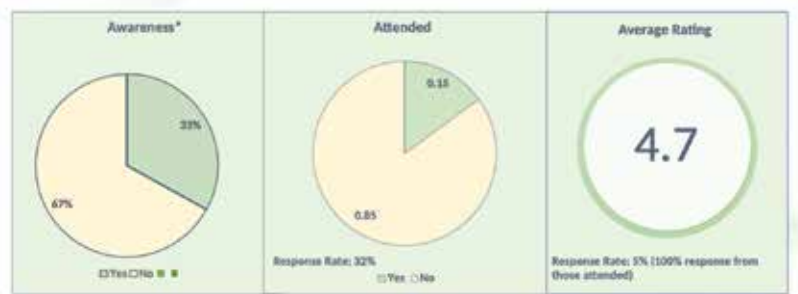
6



\* Compulsory question

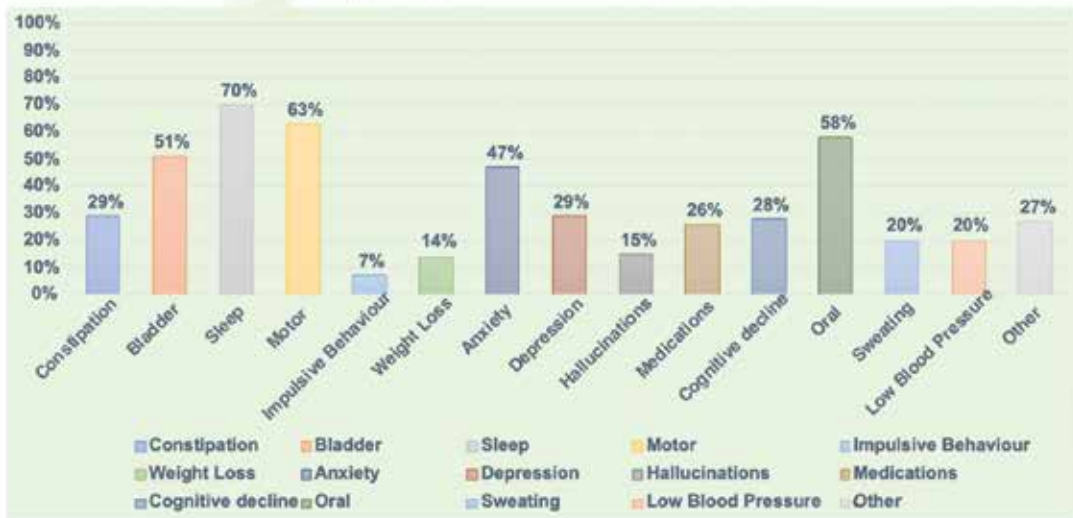
## PAI Nurse Zoom Clinic

7



## Symptoms Experienced

8



9

## Other Comments



Response Rate: 31%

The PAI would like to thank all those who took part in this survey and appreciate the time you took to complete it. Further data will be published over coming months.

Further information can be requested through the PAI support line 1800 359 359.

# LIVING WELL

## A PROGRAMME FOR ADULTS WITH LONG-TERM HEALTH CONDITIONS



### What is the Living Well Programme?

Living Well is a HSE free group self-management programme for adults with long-term health conditions.

A long-term health condition is one, which can be treated and managed but usually not cured. Examples include asthma, COPD, diabetes, stroke, multiple sclerosis, heart conditions, arthritis, inflammatory bowel disease, chronic pain and many more.

Living Well may also be a support for those with 'long-COVID'.

### What is Self-management?

Self-management is what a person with a long-term health condition does every day. This may include recognising and dealing with symptoms; taking medication and managing other treatments; making lifestyle changes and coping with the emotional effects of the health condition.

Good self-management happens in partnership with your healthcare team. It is not about 'going it alone'.



### What does the Living Well Programme involve?

- Living Well is a free group programme, which runs for six weeks. There is one workshop each week, which lasts 2.5 hours.
- During COVID-19, the programme has been delivered online. In-person programmes will return when it is safe to do so. Support to get online is available, if required.
- Two trained leaders run the workshops. At least one of the leaders lives with a long-term health condition.
- People taking part in the workshops may or may not have the same health condition(s).
- The workshops are delivered in a relaxed and friendly way so that all participants can learn from each other.
- Each person who takes part gets a book about self-management.



## What is covered each week?

<b>Week 1</b>	<ul style="list-style-type: none"><li>• Using your mind to manage symptoms</li><li>• Fatigue and getting a good night's sleep</li><li>• Introduction to action plans</li></ul>
<b>Week 2</b>	<ul style="list-style-type: none"><li>• Dealing with difficult emotions</li><li>• Physical activity, exercise, preventing falls</li></ul>
<b>Week 3</b>	<ul style="list-style-type: none"><li>• Decision making</li><li>• Pain management</li><li>• Healthy eating</li></ul>
<b>Week 4</b>	<ul style="list-style-type: none"><li>• Better breathing</li><li>• Reading food labels</li><li>• Communication skills</li></ul>
<b>Week 5</b>	<ul style="list-style-type: none"><li>• Medication management</li><li>• Positive thinking, dealing with low mood and feelings of depression</li></ul>
<b>Week 6</b>	<ul style="list-style-type: none"><li>• Making informed treatment decisions</li><li>• Planning for the future</li></ul>

The Living Well Programme supports you to develop the skills and confidence that will help you to self-manage and to live well with your health condition(s).

These skills include how to:

- set goals to make changes in your life
- make plans to achieve these goals
- problem solve
- manage your medications
- cope with difficult emotions, low mood and feelings of depression
- manage pain, fatigue and sleep problems
- communicate well with your family, friends and healthcare team

**These skills become your toolkit for better health.**



## Who can join the Living Well Programme?

The Living Well Programme is for adults aged 18 years and over. It is suitable for those who are:

- living with one or more long-term health conditions
- caring for someone with a long-term health condition

The programme is not suitable for people with significant memory or learning difficulties.

### More Information:

To find out more about the Living Well Programme in Mayo, Galway and Roscommon

Contact: Olga Maguire

E: [omaguire@southmayo.com](mailto:omaguire@southmayo.com)

T: 086 0142688

[www.hse.ie/LivingWell](http://www.hse.ie/LivingWell)

# BRANCH NEWS

## DUBLIN BRANCH

The past few months have been a mixture of re-connecting with members at various venues around the county, welcoming new members and trying new things.

We had our first in-person AGM for three years at the Clayton Hotel in Leopardstown on Saturday afternoon May 21st with some fifty people attending and refreshments afterwards. It was an opportunity to remember, as a community, our deceased members. The PAI's own Nurse Specialist Lisa Wynne gave a very informative presentation as our guest speaker and also answered members' questions afterwards. For most, it was our first opportunity to meet Lisa in person. It was also interesting to hear that the two most common problems Lisa encounters from members are constipation and anxiety. That served as a reminder to never feel alone, no matter what problem Parkinson's throws at you.

The Dublin Branch and YPI had a social meet-up in the Atrium lounge at the Westin Hotel in the city centre on 31st May. Fifteen members came along

- for the chat, coffee/drink. We're going to keep
- these social meet-ups going on the last Tuesday
- evening of the month from 7.30pm. All members
- and their partners/family member are welcome.
- Awareness Week was book-ended by two very
- worthwhile outdoor activities. On Saturday 2nd
- April our Chairperson Mary Butler took part in a
- local WalkWithCharlie event with friends and former
- RTE colleagues around Howth Head to raise
- awareness of neurological conditions. The following
- Saturday our first Nordic Walking Class graduated in
- Cabinteely Park, D18 and were presented
- with their certificates by course leaders Joanne
- and Tony. The Dublin Branch course was also highlighted
- in a feature article in the Examiner in May.
- Our next course starts at the end of June in Albert
- College Park, D11.
- Our sincere thanks to Portmarnock ICA for their
- donation of €1,670 to the branch through our
- member, Tony Brady. Our Chairperson Mary Butler
- raised more than €1,000 by doing her 39th Women's
- Mini Marathon at the start of June. Another
- member of her athletic club whose mother has







Parkinson's also ran the race and raised money for the branch.

Our exercise classes are continuing with at least one class available every day now, Monday to Friday. For details see our most recent bulletin or contact one of us on the committee. We take this opportunity to wish all our members an active and healthy summer.

*Mary Butler 087 2434990, Teresa, Neil, Kieran, Richelle, Sean, Gill and Gerry*

### **CORK BRANCH** **Annual Parkinson's Mass**



*Remembering our dear friends who passed away since we last celebrated our annual Mass.*



*Bishop Fintan with Perpetual Motion choir.*

It was such an honour for us that Bishop Fintan Gavin celebrated our Parkinson's Mass on 27th April. It was a very powerful and moving mass with the celebrants coming down to the congregation for the Healing Anointment ceremony. To remember our fellow CPA friends who have gone to their eternal reward, we lit a candle for each one and remembered them in our prayers. We lit the John Paul II candle to remember all PWP's nationwide who passed away since we last gathered. Special thank you to all those who helped, in particular, Perpetual Motion whose beautiful sound enhanced the experience. In addition to the fantastic attendance in the church we were delighted to see so many people were able to join us online and found the evening very emotional.

### **Spring Party**

It was fantastic to see so many people together in one place after 2 very long years. The Silver Springs Hotel looked after us very well and it was great to see that we had not forgotten how to party! The enthusiasm in the room was infectious and people are very interested in getting the coffee morning up and running again to the level we had before. People are also planning ahead and asking about summer outings and tours. It was also an opportunity to say thank you to our committee members, Mary O'Sullivan, Mags Garvey, Margaret Curtin and Mary Beecher who have stepped down and recognise their many years of service to Cork Parkinson's. We are very grateful to them for their hard work.

Emeritus Chair, Ted Horgan is still an active member of the committee and is about to get involved in a new research project. As many of you know, especially if you are in the choir, Ted is a great fan of the late Shay Healy. Ted was presented with a limited-edition Robert Ballagh print of the cover the 'Travelling home for Christmas'



*Ted Horgan outgoing Chair of CPA receiving his token of appreciation for all the hard work and years of dedication to CPA.*

**Branch News continued on page 118**



Continued from page 17

### Patients Deserve Campaign

On Wednesday, June 15 Tony Wilkinson was one of the keynote speakers at Leinster House with the Patients Deserve Better Campaign pushing to get the 100 specialist neurological nurses Ireland needs right now. Tony spoke about the lack of Parkinson's nurses and demonstrated how that impacts the lives of people living with Parkinson's. The room was full of TDs and Senators from around the country and was the culmination of a number of events organised by NAI (Mags



Colm Burke TD - Cork North-Central, who was instrumental in helping NAI set up this meeting in the AV room in Leinster House, pictured here with Tony Wilkinson of CPA and other speakers.

Rogers) around the country highlighting the woeful shortage of specialist nurses and the immediate need for our politicians to get involved. Tony drew attention to the fact that we had 6 Parkinson's nurses in the country and we are now down to 4. Nobody in the room was in any doubt about the serious nature of this shortfall and the impact it is having on their constituents.

On July 6th, Tony has a separate meeting with TDs and Senators in Leinster house and will be talking solely about Parkinson's and the need to provide proper support and care in the commu-

nity for people with the condition so that they can continue to thrive.

### Parkinson's, Farming and Pesticides

CPA will be working with PDRC's lead researcher, Lucy Collins-Stack and the Irish Farmers Association investigating the potential link between Parkinson's and the use of pesticides in farming. John McNamara a Teagasc Health and Safety Specialist is part of the research team. This project has an international flavour as we will be working with Prof Bas Bloem in the Netherlands who is one of the top Parkinson's researchers.

Ted Horgan, with his close links to the IFA and his standing in the farming community, is the ideal person to drive this forward for CPA. Lucy and the team will be heading for the National Ploughing Championships at Ratheniska, Co Laois in September 20-22 where they will have a stand and will carry out face-to-face interviews. In addition, there will be other events and opportunities around county Cork to gather the information needed to produce a comprehensive report.

Funding research is a key tenet of CPA as we believe no research, no cure.

### PD Rebel runners conquer the Cork City Half-Marathon

On a very wet and miserable Bank Holiday Sunday, the Cork city marathon took place. CPA fielded two teams in the half-marathon. Tony Wilkinson with his running guide Conor O'Mullane and Jerome and Miriam Maume. What a surprise it was to get to the starting line and to meet an intrepid group from the Dublin branch. Those of you who have met Tony will know that walking in a straight line unaided is a tall order so



Paula Gilmore CEO PAI among the attendees with TDs following the very well attended NAI 'Patients Deserve Better' presentation in the AV room.



Conor and Tony with their medals.

the burning question was how did he manage it? Tony walked and jogged the route using Smovey rings, these Smoveys were designed by a person with Parkinson's to help with his Balance and help prevent him from falling over. None of this would have been possible without his guide and coach Conor O'Mullane, a Chartered Physiotherapist. Conor ran alongside Tony pointing out potholes and potential hazards, allowing Tony to concentrate on the mechanics of running and staying upright. The pair were thrilled to cross the finishing line in 2 hours 59 minutes 22 seconds.

For more information on the articles above contact: Tony Wilkinson, Chairman, Cork Parkinson's Association (083 864 3676)

### Wexford Branch

Hope you're all looking forward to the nice weather and we are so happy to be back out and meeting each other again

Our Chair Yoga Classes have finished for the summer but will be back on the 9th of September &



Pat our Chairman presenting a gift to Mrs Betty Sweeney.

our Physio Classes will be back up and running in the Autumn

We are working on meeting up during the summer with some activity days so watch out for our newsletter. We are also working on a trip away any suggestions for places to visit would be greatly appreciated

Attached we have Ruth Donegan presenting us with a cheque for €9000 that she raised doing the 3 Peaks for Parkinson's we would like to thank Ruth for this amazing amount of money which will be put to good use for the people of Wexford

We also have Pat our Chairman presenting Mrs Betty Sweeney with a gift to say thank you for being Secretary of our branch for many years and

Branch News continued on page 20



Ruth Donegan presenting Parkinson's Wexford Branch with a cheque for €9,000.



Continued from page 19

to thank her and her husband Michael (missing from photo) for all their hard work

Please contact us if you have any queries

Chairman: Pat Lacey 087-2585992

Treasurer: Breda Kennedy 087-0958984

Email: [wexfordtreasurer@parkinsons.ie](mailto:wexfordtreasurer@parkinsons.ie)

## NORTHWEST BRANCH



### DONATION TO NORTH WEST BRANCH FROM BRIDIE MELLY

My name is Bridie Melly and I was first diagnosed with Parkinson's Disease in 2009. Since my diagnosis, 13 years ago, I always had a desire to raise money and awareness for the "Parkinson's Association of Ireland", who were so kind and informative especially during the early stages of my diagnosis.

The Parkinson's Association of Ireland is a charity, based in Dublin with branches throughout the country. Its aim is to assist people with Parkinson's, their families and carers, health professionals and other interested people by offering support, a listening ear and information on any aspect of living with Parkinson's.

One evening in early spring the idea of marking my 70th birthday with a fundraiser was discussed and "Bridie's Birthday Bash" was set in motion. During those early discussions, as a family, we also decided to add the Donegal Hospice to our plans as so many of our family, neighbours and friends have benefited greatly from the kind and compassionate service of the hospice.

So many of us were isolated during the pandemic and it was so easy to lose touch with each other,

• coming together for an evening of fun and laughter whilst raising funds for two charities I hold so dear to my heart was just what was needed.

• I would like to take this opportunity to thank everyone who donated so kindly and generously and those who helped on the night. Thank you to all the businesses and friends who donated money, gifts for the raffle and to the charity bingo.

• To DJ Kevin Furey (Highland Radio) for entertaining us on the night.

• I would like to acknowledge and sincerely thank Kevin and Charlotte McCready (The Gweebarra Bar) for the use of the premises and all the support and kindness shown to us in the lead up to the party and on the night itself - nothing was ever a problem.

• We raised €5,000 on the night, which was amazing. The figure far exceeded my expectation.

• To be able to provide €2,500 to each charity is beyond humbling and I thank each and every one of you who made it possible.

• *Contact Ann 086-1605847*

## GALWAY BRANCH

• We were delighted to have our first monthly meeting in the Clayton Hotel since Covid. It was great to meet up with everyone.

• Our Physiotherapy, Speech and Chair Yoga classes are back in full swing and every one is enjoying the classes and more importantly meeting up and having a cuppa and chat after the classes. If you wish to get more information on these classes please call Marie on 087 7783825.

• Mark Coen whose uncles had Parkinson's is organising a fundraiser Parachute Jump on the 1st of July 2022 in Offaly. The funds raised will go toward services for our members. Mark is aware of the benefit the classes have on the members.

• We looking forward to two upcoming Coffee Mornings:

• Monday 27th June 2022 in Shearwater Hotel Balinasloe Co Galway between 10am and 1pm.

• Wednesday 20th July 2022 in Raheenwood Hotel, Athenry Co Galway between 10am to 1pm.

• These are lovely mornings for members to meet up and chat over a cuppa and goodies. There will be lots of great spot prizes also.





Annual Walk the Prom on Sunday the 7th August 2022 starting at 1pm. This is a lovely day out and it great to see the Sea of Green Tshirts going down the Prom in Galway. Members, their families, friends and even their pets come along. We enjoy a cuppa after in the Galway Bay Hotel. We are looking forward to our first annual Weekend away since Covid on the 9th September to 11th September 2022 to the Castlecourt Hotel, Westport. This is a lovely weekend for members to relax meet up with friends and enjoy being pampered. We will arrange a day trip to Glenkeen Farm in Louisburg and then back to Westport for some retail therapy.

Contact Marie 087-7783825

### ROSCOMMON BRANCH

We are delighted to be up and running again here in Roscommon. We are having our first monthly meeting on the 14th of July, 2022 at 7.30pm in Hannon's Hotel, Dublin Road Roscommon.

Donna Kitt and James Diskin from Corrib Physiotherapy will be commencing Physiotherapy Assessments on the 27th of June, 2022 in Hannon's Hotel. If you wish to take part in these classes please contact Marie 087 7783825 and she will arrange for Donna and James to contact you.

Contact: Eddie on 086 1011438

### MIDWEST BRANCH

Greetings from the Midwest.

We would like to encourage all our members to spend as much time as they can pottering in their garden or strolling in the local park.

It is well known that spending time outdoors helps enormously with your mental health. Putting your hands in your garden beds relaxes you and if you are out in your front garden there is always someone to chat to.

The Midwest committee are working together to arrange two information afternoons. One in West Limerick and one in Clare. You will be notified before the end of June. I hope you will all make extra effort to attend the one in your area. You might think you have heard all the tips and tricks living with Parkinson's before now but I can assure you every speaker has something new to tell you and to meet up with other patients living

with the condition can be very encouraging. I would like to thank the Movement to Irish Music group for their outstanding result walking with the Limerick Lions Club and also to say a special thanks to the Lions Club team who matched the amount raised by all.

Margaret O'Sullivan in the Newcastlewest area had her team out at all the Church services collecting for The Midwest Branch. It is great to see some sign of normality when the Church Gate collections start again. Thank you Margaret and Geraldine who covered Askeaton and Foynes areas.

If there are any newly diagnosed patients in your area please give them my number as we can give them various leaflets to get them on their journey.

We are sad to say goodbye to our Nurse Specialist Elaine. We are sorry to see her go as she made a great impression on our patients who she gave such great time to.

We now have the difficult task of finding a replacement. We have the money in place and the role has been agreed with the HSE so maybe St Anthony will help find one.

If any of you have a little time to spare we would appreciate some new committee members to join our team. I know how busy everyone is but if enough people gave a little time the branch would thrive and it won't fall on just the few. You can give me a ring and I will let you know what is involved.

I would like to wish all our members a great summer. Stay safe and take care.

Contact: Una 087 2511156.

### YPI BRANCH

Join YPI members at the

- Private Whatsapp Group
- Private Facebook Group
- Coffee Morning - Thursdays 10am
- Book Club - Monthly on second Wednesday at 8pm
- Walkers Club - Next walk is on May 8th from Trim Castle
- Golf
- Yoga - Wednesdays at 7pm

Branch News continued on page 22

Continued from page 21

- Breathing & Meditation - Thursdays 7pm
- PD Nurse Support - Thursdays 11am
- Big Boot Camp Waiting List

**WhatsApp**

If you are interested in being contacted by text for reminders and alerts contact YPI and join our private WhatsApp Group. It's not a place for sharing cartoons and jokes, rather it's a way for members to make contact with each other. For instance PAI will not share information about who may be in your area and have PD, but you can personally ask on WhatsApp if someone lives near you and is interested in meeting up for a walk or a coffee.

**Facebook**

We have created a new private Facebook Group for YPI members only. It's a place to ask for and provide support for each other.

**Coffee Morning**

Join our weekly zoom coffee mornings every Thursday at 10am.

**Book Club**

Our Book Club meets on the second Wednesday of each month.

The Book Club have decided to add movies to the topics covered under two categories: cinema releases and Netflix movies.

**Golf**

If you are interested in joining the new PAI Golf Society please send an email to [ypiinfo@parkinsons.ie](mailto:ypiinfo@parkinsons.ie) with "Golf" in the subject line and we will pass it on. The Society have a number of outings in the pipeline already.

**Yoga**

Yoga Class on Wednesday evenings with Theresa Kearney - 0860532432 .

Class time 7pm to 8pm

Recommencing in September

Breathing & Meditation

Thursday Evening's 7pm - Mindfulness and Relaxation with Dee Daly .

Recommencing in September

**PD Nurse Support**

Thursday Mornings at 11am - Parkinson's Specialist Nurse Lisa Wynne will be covering a number of topics via zoom .

Members of the YPI Branch can book a 1 to 1 zoom call with Lisa by sending an email to [nurse@parkinsons.ie](mailto:nurse@parkinsons.ie)

**Big Boot Camp**

Is a zoom exercise class for YPI Members. The first 6 week session is free to new members and subsequent 6 week sessions are partially subsidised by the Branch.

**Monthly Social Meet-ups**

We are planning to meet up on the last Tuesday of each month in a central location for a couple of hours.

If you are thinking of joining us please send an email to [ypiinfo@parkinsons.ie](mailto:ypiinfo@parkinsons.ie) with "Meet-up" in the subject line.

Contact Kieran 083-1059922

# UPDATING OUR RECORDS

As an organisation we are always trying to reach out and connect with our members.

The Parkinson's Association of Ireland currently connect with members using our website: [www.parkinsons.ie](http://www.parkinsons.ie)

Facebook: [Parkinsonsireland](https://www.facebook.com/Parkinsonsireland)

Twitter: [@parkinsonsire](https://twitter.com/parkinsonsire)

Instagram: [Parkinson' Ireland](https://www.instagram.com/Parkinson_Ireland)

We also send out a quarterly printed magazine and a weekly e-zine to keep our members up-to-date on the latest research, surveys etc.

We have noticed that we do not have email addresses for some members on our database.

In order to receive your weekly e-zine please contact the office on 1800 359 359 or email [nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie) and we will update our records





# MINDFULNESS MEDITATION:

## A script to follow for inner peace Article by Gracie M.

'Meditation' a term or idea some people can find themselves overwhelmed at the mention of. What is this magical elixir so many people across the world use? And how can I avail of this mindfulness technique to improve my own quality of thoughts?

Contrary to popular belief meditation is not staring into the abyss, free of any negative thought or mental chatter. To be frank, it's kind of the opposite! Meditation is a practice where you are continuously focussing the mind on one specific thing, be it your breath, an object or a word etc. Noticing yourself becoming distracted by thoughts coming in is in fact being mindful, the awareness you cultivate from a continuous practice helps you draw your eye to what types of thoughts you're thinking, and how your mind or body is feeling at a certain time. Again, these sharp mindfulness benefits of clarity and great awareness come with a long-standing and continued practice!

### So, how can mindfulness aid a person suffering with Parkinson's disease?

'15 minutes of mindfulness can go a long way. By training your mind to be present, you can feel the benefits in your everyday life. It can be particularly helpful when facing the challenges that Parkinson's brings'. - Parkinson's.org.uk

Set up a quiet space for yourself in a comfortable setting, perhaps light a candle for ambiance and below you'll see



a short scripted mindfulness meditation practice you can try at home. If at first you feel you're not settling into the practice or feeling much benefit, try again tomorrow. With an open mind you can achieve anything you want! Good luck.

#### Script:

- Begin by finding a comfortable seat where you can rest for several minutes. Sit upright and lengthen your spine.
- Soften your forehead, jawline and shoulders.
- Notice your inward breath. Notice your outward breath. Continue this for 5 rounds.
- Become aware of your external environment through sounds and temperature around you.
- Become aware of your internal environment by

asking yourself how you are feeling at this moment. Don't attach to whatever feeling comes up.

- Notice your breath once more, this time draw your hands to your belly and feel the rise + fall of your breath for 5 rounds of breathing.
- Return to your regular breathing, let your hands rest and take a scan down through your body noticing where you can soften your muscles or release tension.
- Take a deep inhale to fill up your lungs then take a loud sigh out from your mouth.
- Stay in this silent and peaceful resting of mind and body for as long as you feel like.
- (Continue this practice again tomorrow) Article by Gracie Menezes





# Parkinson's Association of Ireland

## People with Parkinson's need their medication on time, every time

**PLEASE ATTACH THIS FORM TO MY FILE**

**To be handed to your Doctor and used for planned or unplanned admission to hospital.**

I am living with Parkinson's Disease. I may have difficulty speaking or writing clearly. My condition may deteriorate if my medication is not taken at the correct times prescribed for me.

I WILL NEED A FULL GLASS OF WATER PER PD TABLET

Name

Contact Number

Next of Kin  Contact Number

Doctor/Neurologist  Contact Number

Name of PD Medication	Dosage	How Often
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>

Other Medication

**Don't leave it until there is an emergency to fill out this form.**

By asking your Health Care Professional to attach this to your file you will be helping them to manage your condition while you are in hospital.



*If people with PD don't get their meds on time, their condition deteriorates.*

