



Parkinson's Ireland

www.parkinsons.ie

Autumn 2024

Call to Action



Walk with us



A MESSAGE FROM THE CEO - SHANE O'BRIEN

Dear members,

Welcome to the autumn edition of our magazine. I hope that you enjoyed the summer and are looking forward to resuming classes and regular activities.

There continues to be lots of progress and change in the organisation.

Existing services:

The number for our freephone helpline is 1800 359 359. The service provides information, support and advice from our Parkinson's nurse specialists and dietitians.

We are recommencing our weekly Zoom classes shortly. Please keep an eye on our website for further details. Our weekly nurse zoom clinics are also continuing. These clinics cover various PD related topics. In addition, our online newly diagnosed programmes delivered by our nurses are becoming increasingly popular.

Please liaise with your local branch regarding services in your area and keep an eye on our weekly e-newsletter.

Government Funding

Our Parkinson's nurse helpline service was awarded government funding for 2024. We were thrilled with this outcome.

This followed a high-profile and sustained campaign to highlight the lack of government funding for Parkinson's Ireland. I would like to thank all the members for their support, both this year and over many previous years in advocating for the charity. This is the first time in the history of the charity that the government has funded our nursing services.

Additional nurse:

In the strategic plan, a major area of focus is to grow the services that we offer to meet increasing demand. This will be required over the coming years due to the increase in the number of people being diagnosed with PD.

You may have seen that we are currently in the process of recruiting an additional nurse in the Cork area. This is due to shortage of nurses within the HSE in this area. This is the second nurse role that we have created in the last 12 months following Kathy Foley joining us as a specialist nurse in October 2023. This will be our first time creating a nurse role in the community. This will be a welcome and much needed service. There is a major skills shortage currently in the recruitment market, particularly in healthcare, but we are hopeful that we will be able to fill this role.

I'm determined to continue to increase our services across all areas over the coming years. As a charity that gets most of its income through fundraising, it is important that we grow in a sustainable way.

Flagship Fundraiser

Our first ever flagship fundraiser: 'A Walk in the Park for Parkinson's' is taking place in venues across Ireland on the 21st of September. Further details are contained in this edition. You can register on walkinthepark.ie or on the day of the walk itself. We would encourage you to register in advance.

As I mentioned in the last edition, our main focus this year is on raising awareness, and seeking to grow the fundraiser as it becomes an annual event in the calendar.

I look forward to seeing as many of you as possible on the day.

Care Partner Webinar

We recently held a webinar specifically for care partners. The topics covered by the speakers were entitlements and grants, occupational therapist, ICPOP nurse, long-term care and carer support groups. The recording of the webinar is on our website for anyone who would like to view it.

Assistive Technology Webinar

A webinar in relation to assistive technology will take place on the 11th of September. This is being delivered in conjunction with Enable Ireland. This topic is very relevant, and technology has an important role to play in increasing accessibility for people with Parkinson's.



General Election

We still have no news on the general election date, but we will keep you updated on this and our advocacy plans.

Leave a Lasting Legacy

September is Free Will month. During this period, we will be increasing our focus on Wills. This is an area that I want us to increase our focus on. In a brand-new initiative, we are one of only a few charities that will have a facility to provide a free online Will writing service. You can find out more about this in the 'Ways to Help' section of our website.

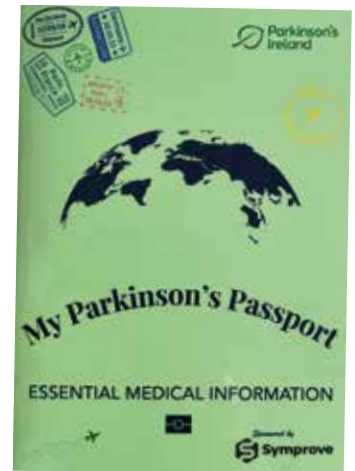
Branch developments:

We hope to hold a public meeting in the autumn to

- try to obtain interest in creating a Monaghan branch.
- This follows our recent new Offaly and Wicklow branches. In addition, we continue to provide
- support to a newly formed Parkinson's support group in Meath.
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- **Leaflets:**
- Our new leaflets and information packs are now ready. I would like to thank my team and the various
- contributors who have assisted us with putting this information together.
- Finally, if you have any ideas or feedback on our work, we would love to hear from you.
-
- Take care,
- **Shane**

PARKINSON'S PASSPORT

Parkinson's Ireland are excited to be involved in the update of the IMSN (Irish Medicines Safety Network) Parkinson's Safety Alert. Our involvement in this project encompasses our key objectives of education to all, people with Parkinson's, care partners and health professionals, and advocacy for our members. It is hoped that this safety alert will raise awareness among medical professionals who might be providing care for a person with Parkinson's disease in their setting, emphasise the significance of managing a person's medication, lessen harm to those who have the disease, prevent instances of medication errors or delays, and prevent the administration of drugs that are not appropriate for a person with Parkinson's disease. We are delighted to have had the opportunity to collaborate with a fantastic working group. We believe the updated safety alert will complement our Parkinson's passport tool very well, increasing awareness and alleviating stress for people with Parkinson's.



SUMMER RAFFLE 2024

The National Office would like to thank all those that contributed to our 2024 Summer Raffle.

A big thank you to all who bought/sold tickets to help this Annual Fundraiser.

Thank you to all who sponsored prizes a sincere thank you.

All Winners have been notified.

Thank you.



A WALK IN THE PARK FOR PARKINSON'S

Parkinson's Ireland is delighted to announce the launch of its new flagship fundraiser, 'A Walk in the Park for Parkinson's.' Sponsored by Home Instead, this annual event will take place in various locations across Ireland on Saturday, September 21st at 11 a.m.

Why Participate?

- **Raise Awareness:** Join us for a positive day of awareness and fundraising for Parkinson's Disease and the essential services provided by Parkinson's Ireland.
- **Community Support:** This annual event promises to be a fun day out for our members, their loved ones, and the public. Come together to support one another!
- **Impact:** By participating, you contribute to raising awareness about Parkinson's as a condition and promoting better care and support for those living with Parkinson's and their families.

Event Details:

- **Date:** Saturday, September 21st
- **Time:** 11 a.m.
- **Locations:** Various locations across Ireland
- **Tickets and Registration:** Available from www.parkinsons.ie

Speaking on the launch, CEO of Parkinson's Ireland Shane O'Brien said: "We are delighted to launch our new annual fundraising event 'A Walk in the Park for Parkinson's.' We are very grateful to Home Instead for their sponsorship and support of this event. In addition to raising much needed funds for the services that Parkinson's Ireland provides, the event will be an opportunity for the Parkinson's community across Ireland to come together in a show of unity and support. We hope that this event will raise awareness of the fact that an estimated 18,000 people in Ireland have Parkinson's and that it's the fastest growing neurological condition."

Danette Connolly, National Clinical Lead at Home Instead Ireland, expressed her enthusiasm about the partnership: "Parkinson's is the second most common neurodegenerative condition after Alzheimer's. By partnering with Parkinson's Ireland on their flagship



Walk in the Park for Parkinson's, we aim to raise awareness and foster a caring society that supports people living with Parkinson's and their families. We encourage all Home Instead staff to participate and urge the public to join us."

About Home Instead:

- Home Instead is Ireland's leading provider of home care services, committed to their mission to enhance the lives of ageing adults and their families.
- Home Instead empowers ageing adults to maintain their independence and dignity within the familiar comforts of home. Their dedicated CAREGivers play an integral role in delivering exceptional care and support to clients and their families.

The walk will take place in various locations throughout the country. We are hoping to raise awareness and fundraise for our charity. Please visit www.parkinsons.ie to register your interest. If you happen to be in Dublin on Saturday 21st September we would love if you would come along to Merrion Square East at 11am and join us after the walk for refreshments.



NEWLY DIAGNOSED PROGRAMME

Since its pilot launch in May 2023, our Newly Diagnosed Programme for people with Parkinson’s and their families has surpassed all expectations. Originally planned to run four sessions annually, the overwhelming demand has led us to conduct seven sessions over 15 months, with two more scheduled for September. This innovative four-week programme, held virtually and facilitated by Lisa Wynne and Kathy Foley, is designed to empower participants by providing crucial information on Parkinson’s disease, including insights on medication, the importance of exercise, and available support systems. **“Self-management is an important component of care for PD” WHO**

Developed in response to the needs identified through our support line, the programme aims to offer comprehensive education and foster a supportive community for those newly diagnosed with Parkinson’s. Recognising the challenges that come with a new diagnosis, we have also incorporated a follow-up Zoom session, adding an extra layer of support to ensure that participants feel informed and connected. The success of the programme highlights the vital role of education and community in managing Parkinson’s, and we are committed to continuing this important work. Engaging and informing participants are central to person-centred care, which is why our Newly Diagnosed Programme emphasises self-management and self-advocacy. By prioritising medication adherence and health behaviour change, the programme integrates the core principles of the Sláintecare model of care. Through this approach, we empower individuals to actively manage their Parkinson’s, promoting both immediate well-being and long-term health.



This method ensures that participants are not only supported in the present but are also prepared to navigate their future with confidence. Below are just some of the comments from participants.

If you are interested in attending the next Newly Diagnosed please keep an eye on our website www.parkinsons.ie or contact 1800 359 359. All upcoming dates will be released shortly with zoom registration required.

References:

- WHO A Public Health Approach, Technical Brief 2022
- National Framework for the Integrated Prevention and Management of Chronic Disease in Ireland 2020-2025. Integrated Care Programme for the Prevention and Management of Chronic Disease

ENTITLEMENT AND SUPPORTS AVAILABLE

Whether you are a person with Parkinson's, or a care partner; it's important that you are claiming all entitlements that you are eligible for, and availing of all supports available to you.

- **Long-Term Illness Scheme (LTIS).**

Upon diagnosis, the first thing that many people will have to consider is treatment for their Parkinson's.

Parkinson's is one of the conditions covered under the LTIS. The LTIS is one of the most important schemes to avail of, as the entitlements are automatic rather than means tested. Under the LTIS, some drugs, medicines and medical appliances are free.

Further details on the LTIS, including details on how to apply, are on our website www.parkinsons.ie

- **Medical Cards & GP Visit Cards**

Certain people may qualify for a medical card. A medical card provides the entitlement to obtain certain health services for free.

There is no automatic entitlement to a medical card. You may qualify in one of three ways:

- Means tested based on your income.
- A discretionary medical card based on an assessment to determine: 'if your circumstances would result in financial hardship without one'.
- Other circumstances: e.g. people with a EU entitlement.

Further details on medical cards, including how to apply, are on our website www.parkinsons.ie

If you do not qualify for a medical card, then you may qualify for a GP visit card, or you may have coverage under private health insurance.

- **Housing Adaptation Grant for People with a Disability**

This grant provides funding to improve how you enter and move around your home, in order to

make it more accessible.

This can include, for example:

- Extending your home to create more space, for example, adding a downstairs bedroom.
- Adding accessible bathroom facilities.
- Installing a stair lift.
- Installing grab rails.

Further details on the grant amounts, eligibility, and how to apply are on our website www.parkinsons.ie

- **Mobility Aids Grant Scheme**

The Mobility Aids Grant Scheme provides grants for minor works, designed to address mobility problems in the home. For example, the grant can be used for the purchase and installation of a level access shower.

Further details on this grant can be found on our website www.parkinsons.ie

- **Seniors Alert Scheme**

The Seniors Alert Scheme provides a grant support for the supply of equipment, to enable older people without sufficient means to continue to live securely in their homes. The grant is towards the purchase and installation of monitored personal alarms.

Further details on this grant can be found on our website www.parkinsons.ie

- **Free Travel Scheme**

Some people with Parkinson's and/or their care partners will qualify for the Free Travel Scheme.

The Free Travel Scheme allows free of charge travel on public transport owned by the State, such as Irish Rail.

Everyone aged 66 and over, living permanently in Ireland, qualifies for the Free Travel Scheme.

People with disabilities and their care partners aged under 66 may also qualify for free travel.

This additional entitlement was introduced in July 2024. You will qualify if you:

- Have never been able to drive due to a



disability; or

- Have a driving licence and are medically certified as 'not fit to drive' for at least 12 months.

Further details on this scheme can be found on our website www.parkinsons.ie

• Nursing Home Support (“Fair Deal Scheme”)

This is a scheme which provides financial support for people in need of long-term nursing home care. Under the scheme, a contribution to the cost of the care is required by the person in need of care. This contribution will be based on their means.

Further details on the scheme are available on our website www.parkinsons.ie

• Social Protection Payments, Grants and Benefits

A person with Parkinson’s and/or their care partner, may be entitled to some social protection payments depending on their particular circumstances. These include:

- Carer’s Allowance
- Carer’s Benefit
- Carer’s Leave
- Carer’s Support Grant
- Household Benefits Package
- Disability Allowance
- Illness Benefit
- Invalidity Pension
- Supplementary Welfare Allowance
- Partial Capacity Benefit

• Tax Credits and Reliefs

A person with Parkinson’s or someone affected by the condition, may qualify for certain tax credits and reliefs depending on their circumstances.

- Tax relief on medical expenses
- Home Carer Tax Credit
- Dependent Relative Tax Credit
- Tax Relief for Employing a Carer

* The aim of this page is to provide a high-level summary of the main entitlements and supports available, and to signpost the reader to more detailed information. Please consult the relevant organisations mentioned above for more detailed information.

FREE TRAVEL SCHEME



From 29th July, the Free Travel Scheme is being extended to:

- People who have never been medically fit to drive due to a disability
- To drivers who have a licence and are medically certified as not fit to drive for a period of 12 months or longer.

Please visit: <https://www.gov.ie/en/service/9bba61-free-travel-scheme/> to apply

PRE-BUDGET SUBMISSION 2025

Ask 1

Provide increased state funding for Parkinson's Ireland nurse specialists and other services, such as speech therapy



Parkinson's Ireland (PI) is calling on the government to address the increasing rate of Parkinson's Disease (PD), by increasing the funding it provides to PI, and by investing further in neurological care services within the HSE.

PI provides vital services within the community for people with PD and those affected by PD. These services such as providing access to PD nurse specialists, speech and language therapy, and physiotherapy are crucial in preventing hospitalisations and aiding in long-term rehabilitation after a hospital stay.

PD is the second most common neurodegenerative disease. It currently affects approximately 1% of people over the age of 60. The rate of PD is projected to double by 2040. The need for further services will increase rapidly over the coming years.

PI received less than 10% of its income from the state in 2023. PI generates the remaining 90% of its income from fundraising and voluntary donations. This is not sustainable, as the number of people that are newly diagnosed with PD continues to increase.

PI also recognises the inequality in care experienced by people with PD across Ireland. This is highlighted

Ask 2

Provide equal access to a Community Neurorehabilitation Team across the country



Ask 3

Increase the number of consultant neurologists in Ireland, starting with providing access to consultant neurologists in 5 regional hospitals



https://www.ucc.ie/en/media/research/centreforgerontologyandrehabilitation/2014newsarticles/NationalauditofmovementdisorderservicesREPORT_April2024.pdf

by the UCC audit report on the quality of care received by people with PD e.g. lack of access to nurse specialists in some areas and the need to have equal access to a Community Neurorehabilitation Team across the country.

Ask 1: Provide increased state funding for PI nurse specialists and other services, such as speech therapy



The main service that PI provides is its specialist nurse services which includes its free-phone helpline and weekly zoom workshops.

PD nurses are quite limited and are located mainly in Dublin. For example, there are currently no PD nurses in Cork and Kerry.

Staggeringly, just 57% of patients in this audit had documentation of accessing a PD nurse specialist. In the UK, the findings of their 2022 audit found that 95% of patients have such access. The NICE Standards state that all adults with Parkinson's should have a point of contact with specialist nurses. The UK are largely meeting this standard, but Ireland is falling way short.

Currently there are 12 PD nurses within the HSE, for the whole country. Ireland should have upwards of 35 according to NICE guidance.

The recent UCC audit report also found that multidisciplinary input is generally poor for people with PD, especially dietetics and social work input. For example, only 8% of people with PD have access to a dietitian and only 9% have access to counselling.

PI currently provides an array of services in these areas but needs sustainable government funding to sustain and expand these services to meet growing demand.

Ask 2: Provide equal access to a Community Neurorehabilitation Team across the country

PI supports the ask of the Neurological Alliance of Ireland for funding for community neurorehabilitation teams in each of the nine CHOs around the country. These teams will provide short-term intensive rehabilitation for people with PD to support their recovery.

The multidisciplinary services include physiotherapy, speech and language therapy and occupational therapy.

These teams need to be fully funded in every area and recruitment needs to take place as soon as possible.

Ask 3: Increase the number of consultant neurologists in Ireland, starting with providing access to consultant neurologists in 5 regional hospitals

PI supports the Neurological Alliance of Ireland ask for funding for Consultant Neurologists in 5 regional hospitals: Bantry, Letterkenny, Mayo, Portlaoise and Wexford.

In addition, the number of neurologists overall needs to increase. The recent UCC audit report also shows that 60% of people were diagnosed privately, with very long waiting lists in the public system. This needs to be addressed urgently as the rate of PD increases.

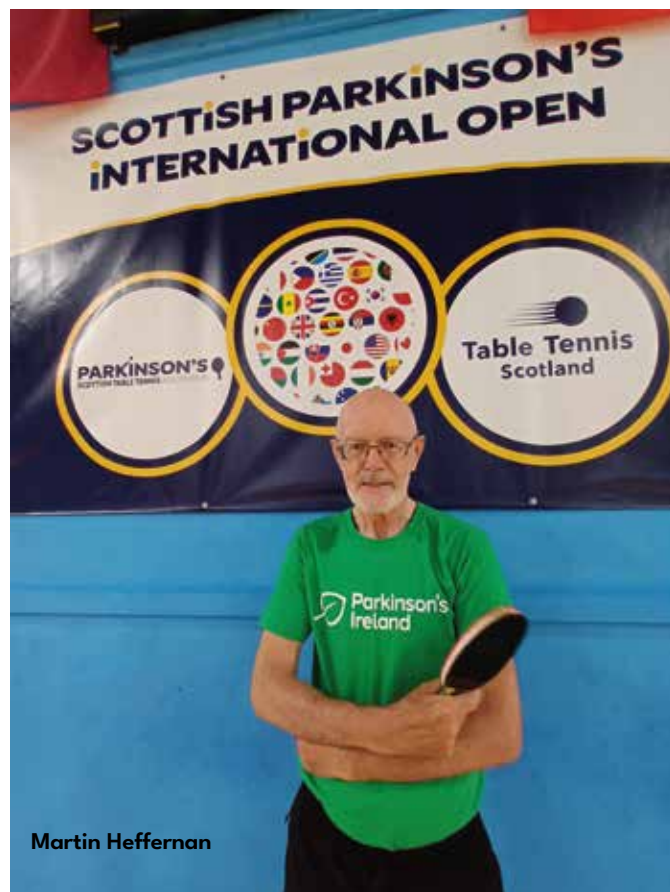
ANYONE FOR TABLE TENNIS

I'm Martin Heffernan from Cashel, Co Tipperary and was diagnosed with Parkinson's in August 2022. I had thought and hoped for about 3 years previously that I had an Essential Tremor in my right hand.

I was always fairly fit and enjoyed cycling and walking. I read about the benefits of table tennis and from March, as part of staying fit I started playing table tennis up to three times weekly. The game improves hand-eye coordination, stimulates mental alertness and concentration which are all impacted by Parkinson's. Table tennis requires one to move fast over short distances which help to improve both large and small muscle movements while it's easy on the joints. It's also a great way to help maintain leg, arm and core strength, which is important as Parkinson's impacts the range and amplitude of movement. It's also just a great way of burning calories while having fun and having social interaction which benefits mental health. A study by Fukuoka University School of Medicine, Japan found that people with Parkinson's who participated in a Table Tennis exercise program once a week for six months showed improvement in their Parkinson's symptoms.

Last month I took part in Scotland's second Parkinson's International Open Table Tennis competition in Inverclyde National Sports Complex in Largs. Sixteen countries competed with approx. 90 competitors which was double the entrants versus 2023. There was 3 different classes depending on your stage of Parkinson's disease and playing ability. Some countries had coaches with them. I was one of 22 entries in my Class 2 event and I finished second in my group. The winner of my group went on to win a silver medal. It was a fantastic experience and the venue was first class with all facilities including accommodation and meals provided on site. I certainly enjoyed meeting new fellow Parky's and the camaraderie of so many people with Parkinson's doing their best to forget about the obvious thing that links them and replacing it with the fun of table tennis. So many people remarked that they forget about Parkinson's when their playing. It amazed me that in so many countries people with Parkinson's

are playing table tennis for its benefits for years. In some countries table tennis clubs have specific 'Bat and Chat' Parkinson's groups that meet weekly. Others like myself play with the local club. Some play in both groups. Believe me choose some form of exercise



several times a week to enjoy life as best as one can and slow down the progression of Parkinson's.

The annual Parkinson's World Championships take place in Metz, France in October and it's likely once again I may be the sole Irish entrant. Wouldn't it be great for next year's events if I was joined by a few others in singles, doubles and mixed doubles !

I would like to thank Eoin Kelly, Munster Table Tennis Secretary and coaches Ben Haughton and Gary Mahoney at Beech Hill and Leaside Table Tennis Club in Cork who have been amazing in terms of their coaching and support.

For anyone interested in finding out more, please email mheffernan1990@gmail.com



ZOOM CLASSES RETURN

MINDFULNESS:

Dee Daly will resume her mindfulness classes on Monday, the 9th of September.

SING ALONG WITH DARA:

Dara will resume her sessions on Tuesday, the 10th of September.

CHAIR YOGA:

Classes will resume on Wednesday, the 11th of September.

CHAIR EXERCISE:

Classes will resume Friday, the 13th of September.

Please visit our website www.parkinsons.ie for full details of zoom classes.



Wellness sessions will resume on Tuesday evenings (from September 10th). The first block will be for care partners only.

UPDATED INFORMATION LEAFLETS



Parkinson's Ireland is delighted to announce that our updated information leaflets are now available.

Our Parkinson's Disease (PD) Nurse Specialists Lisa Wynne and Kathy Foley worked extremely hard to re-write each leaflet to provide important information across 24 topics. These include both motor and non-motor symptoms of PD.

Along with the updated leaflets, our PD nurse specialists also developed new topics, which include fatigue, depression & apathy and cognition in PD.

We would also like to thank the following people for their important contribution: Professor Iracema Leroi for reviewing a selection of the leaflets.

Leanne Ahern, Physiotherapist, PhD researcher HSE, for developing 'The role of physiotherapist in PD'.

Maggie Garvey, Clinical Specialist SLT, Mater Misericordiae University Hospital, and Aislinn Casey for developing our 'Eating & Drinking In PD'.

Aoife Carolan, Senior SLT, HSE CHO 10, for developing our 'Communication & PD' leaflet s2.



Mairead Campbell (Clinical Specialist Occupational Therapist, HSE) and Claire Dolan (Clinical Specialist Occupational Therapist, St James's Hospital) MDT 2 'The role of Occupational therapist in PD'. You can download each leaflet from our website or call our freephone number 1800 359 359 and we can post physical copies to you.

PEOPLE WITH PARKINSON'S EXPERIENCES WITH PROFESSIONAL PSYCHOLOGICAL SUPPORT

Mental health problems

Psychological symptoms, including depression and anxiety, affect around 50% of all people with Parkinson's and are often rated as the most challenging symptoms. Yet research shows that these symptoms are often underdiagnosed and inadequately treated.

What we did:

We interviewed 28 people with Parkinson's to find out about their experiences with mental health support, to help us understand how we can improve services.

What we found:

There are several **barriers that prevent people from accessing mental health support**

- There are long waiting times for NHS support and people struggle to attend in person sessions.
- Private health care is very expensive.
- People are unsure of where to go for help or what type of support is available or most suitable.
- Health care professionals prioritise motor symptoms and do not often ask about mental health.

"I can't blanket all neurologist, but my experience they are marvellous on the drugs and the motor skills and gadgets to keep you walking and all that lot, great. But they don't enquire about the mental health, they enquire about sleep, but they don't seem to take that on. So, you feel it's not important, you're making it [mental health problems] up." (Grace)

Mental health **support does not meet the needs of people with Parkinson's**

- Support is often too generic and is not tailored for people with Parkinson's.
- Mental health practitioners do not always understand the condition, symptoms or needs of someone with Parkinson's.
- NHS support is too rigid and short.



University of Reading

"Having Parkinson's is basically rubbish, so what can I do to make myself feel better. That just didn't get addressed because it was always like the giant elephant in the room." (Andy)

Professional psychological support helps people to **deal with difficult feelings**

- People with Parkinson's need to express their difficult emotions in a safe environment with a non-judgmental practitioner who understands their condition.
- Support needs to reassure individuals that difficult emotions are normal and nothing to feel ashamed about.

"It's just having that sort of validation that you're still, still a functioning human being, still a functioning woman." (Carol)

Mental health support helps people to **deal with unhelpful thoughts and gain new perspectives**

- Identifying and challenging unhelpful thoughts helps individuals to think rationally and consider alternative viewpoints.
- It is important to recognise the positives and focus on the good aspects of life.
- People with Parkinson's need to focus on the present rather than worrying about the future or reminiscing about the past.

"He kind of guided me to look towards the positive rather than the negative. It is a rubbish disease, but there is always reason to be positive." (Stephen)





Psychological support needs to encourage **adaptation and personal growth**

- Therapy helps to build self-awareness and understanding of mental health symptoms.
- This empowers individuals, allowing them to see their strengths and ability to cope.
- Support helps people with Parkinson's to find the words and confidence to open up to loved ones about difficulties and their diagnosis.
- Finding a sense of purpose and meaning after diagnosis helps people with Parkinson's to live well with the condition.

"This is not a big up that I've got Parkinson's and I'm okay because no one's whose got Parkinson's is okay. It's just what part of your life you choose to let it rule. You know, I've got a lovely home, and I've got a lovely wife and kids and family, and you know that's important to me." (Paul)

What next?

The psychological symptoms of Parkinson's are not

- treated with the same level of importance as the motor symptoms and support is often inadequate.
- This study highlights the helpful and unhelpful aspects of psychological support and can be used to guide the development of new programmes that are specially tailored for Parkinson's.
- **We have developed a new group programme for people with Parkinson's that aims to improve quality of life and engagement with meaningful activities.**
- This online programme will help individuals to identify their values and support them to make positive changes. It will provide people with tools to deal with unhelpful thoughts and feelings and aid relaxation.
- The 8-week program consists of 1-1 and group sessions.
- If you would be interested in taking part in this research or want to find out more, please scan the QR code below or email Becca Hunsdon - r.i.hunsdon@pgr.reading.ac.uk

WEBINAR ON DIGITAL ASSISTIVE TECHNOLOGY

DIGITAL ASSISTIVE TECHNOLOGY WEBINAR

11th September @ 7pm

Register at www.parkinsons.ie

Please visit www.parkinsons.ie to register in advance

Parkinson's Ireland will host a webinar on digital assistive technology, provided by Enable Ireland. This will take place via Zoom on Wednesday, September 11th at 7pm and will last approximately one hour.

Training will be presented by Juliann Bergin and Mary Relihan of Enable Ireland.

During the webinar, they will focus on the following tools:

- * What is Digital Assistive Technology?
- * Relevant accessibility features inbuilt into smartphones, tablets and laptops i.e. Easy mode, touch accommodations, filter keys
- * Software/hardware accessories for mouse use
- * Free & cost effective apps for daily living including reminders, organisers etc.
- * Virtual assistants- Amazon Alexa/Google Nest/Apple HomePod - for scheduling, monitoring etc
- * Smarthome technologies - mainstream options.



NURSING HOME SUPPORT SCHEME (FAIR DEAL SCHEME)

Deciding to access long-term nursing home care can be a daunting decision for any individual and their family. Not least of the worries at this time is how the care can be funded.

You can apply for financial support to help pay for the cost of care in a nursing home through the Nursing Homes Support Scheme, also known as the Fair Deal scheme. The Fair Deal scheme is managed by the Health Service Executive (HSE).

Under Fair Deal, you pay a certain amount towards the cost of your care and the HSE pays the rest. Fair Deal covers approved private & voluntary nursing homes and public nursing homes run by the HSE.

Who is Eligible to Apply for Fair Deal?

Anyone who is ordinarily resident in Ireland, or who is an Irish citizen living abroad who intends to return to Ireland permanently, and is in need of long-term nursing home care is eligible to apply for the scheme. You need to be approved for the Fair Deal scheme before you can get funding for nursing home care. Approval is based on an application made to the HSE.

How the Scheme Works

When you apply for the Fair Deal Scheme, your care needs are assessed by the HSE to confirm that long-term nursing home care is the most appropriate option for you.

The HSE also assesses your financial situation to see how much you can afford to pay towards your nursing home care. The HSE then pays the balance between what you can pay for your care and what the nursing home charges for providing that care. Your assets, such as savings and property, are taken into account when assessing

- your financial situation.
- The scheme covers long-term nursing home care only and cannot be used to fund short-term, respite or convalescent care in a nursing home.

The Fair Deal covers:

- You can apply for the Nursing Home Loan if you have assets including land or property.

- With a nursing home loan, you can postpone paying for your care until after your death,

- using your assets to secure the loan.

- Accommodation and food
- Nursing and personal care
- Laundry service
- Basic aids and appliances needed to support you with everyday living

- Other goods and services may be available under other schemes such as the GMS or Drug Payments Scheme.

- The Fair Deal scheme does not cover:

- Short-term care such as respite, convalescent or day-care
- Extra fees charged by the nursing home for services not covered under the Fair Deal Scheme like hairdressing, therapies, activities etc.

How to Apply for the Fair Deal Scheme

1. Complete the Nursing Home Support Scheme application form to apply for Fair Deal.

(https://assets.hse.ie/media/documents/HSE_Nursing_Homes_Support_Scheme_Application_form_and_support_information.pdf)

- The form should be completed and signed by the person applying for nursing home care. If they are unable to apply due to a lack of capacity, a specified person can apply on their behalf. See 'How to apply for someone else as a specified person' below.

- On the form, there is a list of

- documents you need to send with your application form, including proof of your income and assets. After you gather all the documents, send the completed form and documents to your local NHSS Support Office. The HSE will let you know when they have received your application.

- If you need help with your application, you should contact the HSE directly and they will assist you with the application.

- When you submit the application form, you are applying for a Care Needs Assessment and financial support.

2. The **Care Needs Assessment** will check if you can be supported to continue living at home or if long-term nursing home care is more appropriate.

- The HSE will contact you to complete the Care Needs Assessment.

- Healthcare professionals appointed by the HSE such as a public health nurse or doctor will carry out the assessment.

- The assessment may:

- Take place in a hospital or a community setting like your home
- Involve a physical examination

- The Care Needs Assessment will look at:

- Your ability to do daily activities like bathing, shopping, dressing and moving around
- How you currently use any health and personal services such as a home-care
- The family and community support available to you
- Your wishes and preferences

- You may be asked for more information to complete the Care Needs Assessment, such as a referral from your GP. You should provide this as soon as possible to complete your application.



When the Care Needs Assessment is complete

After the Care Needs Assessment, the healthcare professional writes a report. Based on the report, the HSE decides if long-term nursing home care is the best option for you. After they decide, the HSE will write to you within 10 working days. You get a copy of the report and the reasons for the decision.

The HSE may use the Care Needs Assessment to identify other health or personal social service needs. However, there is no legal requirement for them to provide the services they identify.

You must be assessed as needing nursing home care to be eligible for either State support or the Nursing Home Loan.

If you do not qualify for long-term nursing home care

If you do not qualify for long-term nursing home care, you must wait 6 months before you can apply again. If there is a change in your health or circumstances, you can apply before the 6-month waiting period ends.

3. The **Financial Assessment** works out how much you can pay towards your nursing home care. The HSE will pay the remaining balance of the weekly cost of your care.

For example, if the total weekly cost of your care is €1,000 and your weekly contribution is €300, the HSE will pay €700. This payment by the HSE is called State support.

The Financial Assessment looks at all of your income and assets.

If you are part of a couple, the assessment will be based on half of your combined income and assets.

A couple is either:

- A married couple living together
- An opposite or same-sex couple living together as life partners for at least three years. It does not include relatives who live together, or two adults living together but not as life partners.

Income and assets

Income includes any:

- Earnings
- Pension
- Social welfare benefits or allowances
- Income from holding an office or directorship
- Income from fees, commissions, dividends or interest
- Transferred income (any income you transferred to someone else within 5 years of your first application)
- Rental income from any properties which are not your home

An asset is any material property or wealth, including property or wealth outside Ireland. Assets are divided into 2 categories, cash assets and non-cash assets.

Cash assets include:

- Savings and deposits
- Stocks, shares, securities and other financial instruments
- Approved retirement funds (value of fund at date of application)
- Money loaned by you to another person
- Cash assets transferred to another person in the last 5 years

Non-cash assets include:

- Your home (if you own or part-own it)
- Any property or land you own
- Businesses
- Overseas land and property

In the case of assets, the net value of the asset is assessed. The net value is the value minus any borrowings for the purchase or improvement of the

asset.

Assets Transferred within the Previous 5 Years

The assessment will look at assets that you have transferred since applying for State support or in the 5 years before the application. For example, any land, money or property you have given to another person. These assets will be included in the Financial Assessment.

Deductions for your Financial Assessment

You can subtract the following deductions from your financial assessment:

- Income tax, PAYE, Universal Social Charge and PRSI
- Levies you must pay by law such as property tax
- Interest on loans for the purchase, repair or improvement of your home (if you own it)
- Rental payments from renting your home (primary residence), while you are in nursing home care (details and application form below)
- Rental payments from your partner, your child, or your partner's child (aged under 21) who live in your property
- Health expenses such as GP visits, prescription charges, medicines and medical expenses after tax refund, (not including contributions paid under Fair Deal)
- Maintenance payments for a child, spouse or former spouse made under a separation agreement or a court order
- A dependent child in full-time education.
- Any redress you received under a qualifying redress scheme

Financial Safeguards

As part of the Financial Assessment, the following safeguards are in place:

- You will not pay more than the actual cost of care
- You keep a personal allowance of 20% of your income or 20% of the maximum rate of the State Pension (Non-Contributory), whichever is

more

- If you have a spouse or partner remaining at home, they will be left with 50% of the couple's income or the maximum rate of the State Pension (Non-Contributory), whichever is more

Your Payment for care is calculated as follows

After assessing your income and assets, the Financial Assessment will work out how much you pay towards your care.

You pay:

- 80% of your income (less the deductions above),
and
- 7.5% of the value of your assets per year

The first €36,000 of your assets, or €72,000 for a couple, are not counted in the Financial Assessment.

If you are part of a couple, you will contribute half of the amounts above, that is, 40% of your income and 3.75% of the value of your assets per year.

If your assets include land or property, the 7.5% contribution based on these assets may be deferred and paid after your death. You can defer paying the 7.5% contribution by applying for an optional Nursing Home Loan from the HSE.

Rental Income

Since 1st February 2024, if you own your home and are renting it out to a tenant while you are in a nursing home, you can apply to keep 100% of this rental income, instead of having to pay some of it towards your nursing home care. This means you can keep all of the rental income from renting your own home. Your home is your principal private residence.

If the property you are renting is not your own home, you must pay 80% of the rental income to nursing home care. In other words, this income will be included in your Financial Assessment above.

Value of Some Assets Capped for 3 Years

Some assets are only included in the Financial Assessment for the first 3



years you are in care. This is known as the '3 Year Cap'. It means that you pay a 7.5% contribution based on the value of certain assets for up to 3 years.

These assets can include:

- Your home (Principal Private Residence)
- The proceeds of the sale of your home
- Your farm or business

After 3 years, you will not give any further payment based on these assets, even if you are still getting long-term nursing home care. The '3-year cap' applies whether you choose to get the Nursing Home Loan or not.

All other assets will be taken into account for as long as you are in care and the payment of 7.5% of the value of these assets will continue to be expected to be paid each year that you are in nursing home care.

If you have already been in a nursing home for 3 years when you apply for the scheme, then you do not pay the 7.5% on your home.

If you are part of a couple, you will pay a 3.75% contribution based on your home for a maximum of 3 years. Your total contribution over the 3 years is capped at 11.25% of the property's value.

If both partners are in care, the total contribution is capped at 22.5%.

If you get the Nursing Home Loan for your home, your partner can also apply to have the repayment of the loan deferred for their lifetime.

Principal Private Residence (Your Home)

Your home will be removed from your Financial Assessment after you have been in care for

3 years. You do not need to do anything.

If you sell your home while you are in care, the net proceeds of sale will also qualify for the 3-year cap. You need to contact your Local NHSS Support Scheme Office if you sell your home.

Family Farms & Businesses

Family-owned farms and businesses can be included in the '3-year cap' if they meet some conditions.

These include:

- You must apply to the HSE to appoint a family successor who will commit to running the farm or business for at least 6 years.
- Your farm or business must have been actively run by you, your partner or your proposed successor for 3 of the previous 5 years.
- A charge in favour of the HSE will be placed on the chargeable property of a business or farm.

On Completion of the Assessments What will Happen?

When the Care Needs and Financial Assessments have been completed, the HSE will write to you about:

- What you need to pay as your contribution to care
- Whether you qualify for State support and the Nursing Home Loan
- What nursing homes are part of the scheme

You may choose any nursing home that is part of Fair Deal as long as:

- The home has a place for you.
- The home can cater for your needs. The nursing home will have to carry out an assessment to decide if it can meet your needs.

Your payment under the Fair Deal Scheme will be the same regardless of which nursing home you choose or whether it is a voluntary, private or a public nursing home.

You can request another financial review 12 months after your first assessment or your last review. However, the HSE may review a financial assessment at any stage.

State Support Payment



The HSE will start paying the State support and the nursing home loan (if applicable) from either of the following (depending on which date is later):

- The date that the application is approved
- Date you are admitted to the nursing home

Waiting list

There is a set level of funding for the scheme each year, so your name may go onto a waiting list until funding becomes available. If this is the case, the HSE will let you know when it writes to tell you if you are eligible for State support. While you may be on a waiting list, the HSE will confirm you have been approved for financial support under the scheme.

Payment of Your Contribution

Normally your contribution to the cost of your care will be paid directly to the nursing home. Most nursing homes will invoice residents on a monthly basis and expect payments to be made on a monthly basis.

Nursing Home Loan (Optional)

The Nursing Home Loan is an optional element of the Fair Deal scheme. It is an option if the person in nursing home care has assets including land and property but may not have the cash reserves to pay their contribution to the cost of care.

If you are approved for the Nursing Home Loan, the contribution based on your assets (land or property) can be postponed. This means the HSE will pay the money to the nursing home for you, and it will be collected after your death or after the sale of all or part of your asset or assets.

How to Apply for the Nursing Home Loan

If you want to apply for the Nursing Home Loan, see Part 5 of the Fair Deal application form (pdf) for information and application details. You can apply for the Nursing Home Loan when you first apply for Fair Deal or at any stage while resident in the nursing home.

To apply for the Nursing Home Loan, you must provide written consent to having a Charging Order registered against your asset. If you are part

- of a couple, your spouse or partner must also provide written consent.
- The Charging Order is a simple type of mortgage which secures the money loaned by the HSE.

After you consent, the HSE is responsible for making the Charging Order, registering it against your asset and making Nursing Home Loan payments on your behalf. You will not need to do anything (although the HSE may need to check with you about the information in your application).

If a person does not have the capacity to consent to the Nursing Home Loan and the Charging Order, only one of the following can apply for them:

- A care representative (a person appointed by Circuit Court)
- A Ward of Court (a person appointed by Office of Ward of Courts)
- A holder of a registered enduring power of attorney (chosen to act on behalf of another person)

How to Apply for Fair Deal for Someone Else as a Specified Person

The fair deal application form (pdf) should be completed and signed by the person applying for nursing home care. However, in certain cases, another person may apply on their behalf as explained below. There is no charge to apply for Fair Deal.

Who is a Specified Person?

If you are helping someone with reduced decision-making capacity to apply for Fair Deal, you need to be a specified person. A specified person may apply on behalf of a person needing care if they are unable to apply themselves.

A specified person is:

First priority

- A. Your Decision-Making Representative (a person appointed by the Circuit Court)
- B. A person appointed under an Enduring Power of Attorney who is not restricted from applying for the scheme
- C. Your Committee, if you are a Ward of Court

Lesser priority

- D. Your spouse or partner
- E. A child of yours who is 18 or over
- F. A registered medical practitioner, nurse or social worker

If you had a care representative, they are now called a decision-making representative (DMR). They can still act on your behalf.

Application Forms for Fair Deal

You can download an application form (pdf). Forms are also available from any healthcare setting in your area, including your local Health Centre and hospital. Send the completed form with the documents listed on the application form to your Local NHSS Support Office.

Appeals

When the HSE writes to you about the outcome of your Care Needs and Financial Assessments, it will outline the appeals process and give you details of your local Appeals Office.

For example, if your Care Needs Assessment finds that you do not need long-term nursing home care, you can appeal the decision to your local Appeals Office.

Reviews

Any Care Needs Assessment can be reviewed six months after a previous assessment or earlier if one of the following apply:

- The HSE believes there has been a material (significant) change in your health or circumstances
- A registered medical practitioner states that there has been a material change in your health or circumstances since your most recent care needs assessment

Your Local NHSS Support Office carries out the review. Contact them if you want to have your Care Needs or Financial Assessment reviewed.

After the HSE decides, they will write to you with the decision and the reasons for it within 10 working days.

Author: Liam Harvey, Member Business Support, Nursing Homes Ireland

BRANCH NEWS

EASTMIDLANDS BRANCH

East Midlands Branch will hold our annual outing from Sunday 1st of September to Tuesday 3rd. We will spend two nights in the lovely Riverside Park Hotel in Enniscorthy with a full itinerary for the three days. We hope to have photos for the next Magazine.

Our Yoga and Movement to Music classes will return in September. For further information on the classes please contact Marian on 085 2112973 in relation to the Yoga class on Tuesdays in the Parish Centre Newbridge and John on 087 2712448 for the Movement to Music classes in the Parish Centre Portlaoise on Thursday's.

East Midlands Branch will hold our walk on Saturday 21st September in Colt GAA grounds Raheen Co.Laois at 11am.

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For further information please contact John on 087 2712448.

CORK BRANCH

Day trip to Kinsale 18th July by Jackie O'Reilly

At 11am the PI Cork branch arrived to a very foggy Kinsale – but

once we saw what awaited us the weather seemed immaterial. We received the warmest welcome accompanied with a fantastic selection of cakes, plenty of chat and the opportunity to get to know one another. We would like to thank Fred, Irena and everyone else in the Kinsale group for a fantastic morning and all their hard work. It was then time to work off some of the calories from our tasty treats and two groups took part in a Dance for Parkinson's class with Marissa Carroll, dance instructor. This was great fun and enjoyed by all.

After all that fun it was on the road again for the Lusitania Visitor Centre where we were treated to a guided tour by Shannon (historian) who was very informative and enjoyed by all. We then had a beautiful rendition of Home from the Sea by Jerome Maume and joined by the group. This is the lifeboat song by Phil Coulter and was a salute to the brave lifeboat men and women who saved so many over the years, very fitting place and enjoyed by all. Then, it was time to end the day the way it started....with cake. We were

drawn to the lovely Café where apple strudel, cookies and an array of tempting delights awaited us – what could we do – only indulge, again!! Then, in true Irish fashion the sun came out just as we were packing up to go home but we didn't care about the weather after such a great day.

Jerome (087) 3614572

DUBLIN BRANCH

It's going to be a busy autumn. All our weekly exercise classes will be back in the first week of September. Details of times and each venue will be in the Dublin Branch Newsletter.

Table Quiz

On Thursday 12th September at 8pm there will be a quiz in aid of the Dublin Branch

It's taking place at Portmarnock Sports and Leisure Club, Blackwood Lane, Portmarnock, Co. Dublin. The cost is €40 per table for a team of up to four people.

To book your table or make an inquiry, contact Tony Brady 087 7953302

Go along, enjoy the fun and help the branch at the same time.





WALK IN THE PARK FOR PARKINSON'S

The Dublin walk of Parkinson's Ireland's new flagship fundraiser, 'A Walk in the Park for Parkinson's', sponsored by Home Instead will take place in Merrion Square at 11am on Saturday, 21st September. Half of all proceeds from the Dublin walk will come to the Dublin Branch so we are urging all our members to register for it. If everyone gets one family member or friend to do it with them it will make a huge difference and, if you can't do the walk in person there is the option to donate on the fundraiser page. To register for the walk go to: <https://www.parkinsons.ie/walk-park-parkinsons-ireland-home-instead> or go to www.parkinsons.ie and click on Walk in the Park for Parkinson's: it's half way down the home page. Make sure you choose Dublin as your location. Registration costs €20 per person, €5 for a child and €35 for a family. Everyone there on the day will receive a T-shirt and there will be refreshments afterwards as well.

It's a great chance to meet and mix with other people in the Parkinson's community while raising much needed funding to help support those living with Parkinson's. Do try to join us for what we hope will be an uplifting day and show your support for Parkinson's Ireland.

Dublin Branch Autumn Meeting

Our autumn meeting takes place at 3pm on Saturday 12th October. The venue is the Maldron Hotel in Tallaght, Whitestown Way, D24 XC9W

Our guest speakers will be Marion Slattery, Occupational Therapist, Personal Health Rathmines who has specialist qualifications in Parkinson's Disease and years of experience with people living with the condition. The Parkinson's Ireland CEO, Shane O'Brien, has also kindly agreed to speak about the services Parkinson's Ireland offers and the work national office is undertaking in various areas from research to advocacy to awareness raising. Tea/coffee and refreshments will also be served. The Maldron Hotel Tallaght is just off the M50, close to a Luas and

bus stops and has ample parking under the hotel and in the adjacent shopping centre car park.

Mary (087) 2434990

WEXFORD BRANCH

Hi Everyone, we hope you had a great summer in spite of the weather

Our Chair Yoga and Singing Classes took a break for the summer but will be back up and running in September

We would like to thank Mr Brendan Corcoran and family for the amazing donation of €14052 which was raised by doing the Wexford Half Marathon in memory





of Nuala Corcoran who was such a great lady and lots of fun. We would also like to thank Mr Paddy Buckley and the Caim Vintage Club for their kind donation of €850 and Oylegate Vintage Club for their absolutely great donation of €2575 this is the 2nd year Oylegate have given us a donation from their road run and we cannot thank them enough

Our AGM went very well, and a new committee has been elected we would like to wish them all the best and thank them for coming on board to help us continue to help the people of Wexford

We are looking forward to the Flagship Fundraising event "A Walk In The Park for Parkinsons" which will be held on Saturday 21st of September our local one will be held in The Orchard Peace Park, Enniscorthy Y21 X889 at 11am with refreshments afterwards in the Presentation Arts Centre we hope you will join us on the day You can register on www.Parkinsons.ie Please contact us if you have any questions

Contact: Chairman – Pat Lacey 087-2585992

Treasurer – Breda Kennedy 087-0958984



Parkinson's Disease Patient Conference

Date: Saturday 14 September, 2024

Errigal Country House Hotel, Coothill, Co. Cavan H16 KX07

Time	Title	Speaker
10-11am	Medical and Surgical Management in PD	Professor Richard Walsh (Consultant Neurologist) Tallaght University Hospital and Mater Hospital
11-11.45am	Impulsive Disorders in PD	Lisa Wynne - Nurse Specialist PI
11.45-Noon	Questions and Answers	
12.00-12.45	The Role of the OT in the management of Parkinson's Disease	Elaine Martin (Senior Occupational Therapist) HSE Cavan
12.45-1.15	Chair Yoga	Catherine Sheridan (Yoga Instructor) Cavan
1.30-3.00	2 Course Dinner	Booking Essential

Booking is essential. To book your place and a family member please contact Katie: 087 408 2143 (Monaghan), Michelle: 087 941 5593 (Cavan) before Monday, 2 September, 2024

CAVAN BRANCH

Chair Yoga classes continue every Friday morning from 11am-12noon in Castlemanor Nursing Home led by Catherine Sheridan.

Contact Paddy 086-1500871

GALWAY BRANCH

Classes: Physiotherapy

Classes: The classes in our six venues Connacht Hotel, The Hub in Barna, Raheenwoods Athenry, St Vincent De Paul in Tuam, Midlands Cancer Support Centre in Ballinasloe and Station House Hotel in Clifden.

Speech Classes: We are delighted to be working with Rebecca and Roisin Speech Therapist from HSE in Doughiska for Speech Therapy on a monthly basis.

Dance Movement: Everyone is enjoying our chair based Dance Movement Classes with Pat O Dea. The classes are free and take place in the Connacht Hotel on a Tuesday at 11am and Tuam Stars Hall at 2pm. This gives everyone an opportunity to get involved If you have not yet taken part feel free to contact us and come along



with a friend or family member.

Chair Yoga via Zoom:

Everyone is enjoying our chair based Yoga Classes with Jimmy every Tuesday 12 to 1pm on Zoom. Everyone is welcome, family, friends and carers.

Choir Classes: Our choir have been busy practising and recently they sang in the Cathedral Church. We got lots of great feed back from their performance. We practice in the Clayton Hotel once a month.

1. Honda 50

Run A big Thank You to Gerry Fahy and all involved in organising the Honda 50 Run on the 28th July 2024 at 12 o clock. This will be a wonderful day out and all funds raised will go towards our classes.

2. Walk the Prom We had our annual Walk the Prom on 11th August 2024 at 1pm and the Prom was a see of Green. We enjoyed a cuppa and chat after in the Galway Bay Hotel with

our members, their families and friends and we were entertained by our wonderful Choir.

3. Cycle Paris2Nice A big Thank You to Conor Power, son of Hillary Power who has organised a fundraiser for us Cycle Paris2Nice. This will take place in September. The funds raised will go towards our classes.

4. Card Drive A big Thank You to Hubert Geoghegan who has organised a Card Drive for Parkinson's Ireland Galway and Alzheimer's Ireland on Sunday 10th November 2024 at 8pm in Temperance Hall Loughrea, Galway. We will have more details nearer the time.

Thank You for Recent Fundraising: Coffee Morning

A big Thank You to Bridie McClean and her daughter Sharon who held a Coffee Morning in their home recently. There was great support

from the community and lovely to meet up with lots of Bridie's family, neighbours and friends.

Golf Classic in Loughrea A big Thank You to Pat Loughnane and John Reddin who organised a great weekend of Golf in Loughrea Golf Club on the May Bank Holiday Weekend. We were blessed with lots of sun shine all weekend and every one that took part enjoyed.

Ellen Hardiman A big Thank You to Ellen Hardiman who took part in the Belfast Marathon on the 5th of May to raise funds for us. Ellen's mum Joan is a member of our group and attends our classes,.

Niamh Colleran A big Thank You to Niamh Colleran who took part in Half Marathon in Portumna on the 8th of June 2024 to raise funds for us. Niamh father Michael is a member of our group and attends our classes.

Karen Molloy A big Thank You to Karen Molloy and her fellow swimmers who completed the



North Channel relay on the 15th June 2024. Karen is aware of the services we provide to people with Parkinson's and her late dad was a member of our group.

Marie Cahill (087) 7783825

OFFALY BRANCH

The Summer outing of the Offaly Branch took place on the 14th of August to Dun na Si. Amenity and Heritage Park, Moate. This included a very enjoyable guided heritage walk and talk, ranging from historical to folklore, with outdoor art displays to view and afterwards tea and snacks in the tearoom. Good memories of childhood were shared by the members and made the day very special.

Our monthly gathering took place in the Charleville Centre with guest speaker Ken Fitzpatrick, Boxercise, This is an exercise program which is said to be very helpful for people with Parkinson's.

Jean (086) 8069855

ROSCOMMON BRANCH

We had a great day at our Annual Walk at Oran GAA Pitch in April. The sun came out while we did our walk and then the rain came but this did not damper our day. What a great community spirit in Oran and this was evident on the day. A big thank you to Alan, Rose and all at Oran GAA for your kindness. We were delighted to confirm that the wonderful sum of €10,000.00

was raised on the day. Great to have a presentation to Oran GAA at our meeting at Hannons Hotel recently.

Our Physiotherapy classes continue ever Tuesday in Hannons Hotel with James Diskin. The benefit of the classes are huge and the members are enjoying same.

Avril holds Chair Yoga classes on a Wednesday in Hannons Hotel. These are very relaxing and all that attend love to chill out for an hour.

We are organising a break away with our members in October to Portlaoise and this is a great way for every one to relax and enjoy time with members.

Caroline Rushe 086 2566655





NORTH WEST BRANCH

A special word of thanks to Annie Walker, aunt of Evelyn Kearns, who donated €1,000 to our branch in memory of Evelyn who passed away recently. Evelyn was a long standing member of the branch and participated in all our events. She will be greatly missed by all who knew her. May her gentle soul rest in peace. We would also like to thank Margaret and Clare Fox for their donation of €500 recently. Both ladies celebrated significant birthdays this year and kindly chose to make the donation to our branch. The Innisfree Wheelers cycling Club have made our branch the beneficiary of their Women's Sportif Cycle at the end of August. We are very grateful that they have chosen us and thank them most sincerely. We wish them success with the event. There was a large attendance at our branch meeting on 18th August in Dorrians Hotel with some new members in attendance also. A discussion took place on the possibility of increasing services and organising new ones for our members. We will keep you all updated. The National Flagship Fundraiser, "A Walk in the Park for Parkinson's" will take place in Bernard McGlinchey Park, Letterkenny, on Saturday 21st September at 11am. The aim of this event is to raise awareness and to fundraise for Parkinson's Disease and essential services for people living with Parkinson's Disease. We look forward to seeing you there.

CHRISTMAS IDEAS FROM PARKINSON'S IRELAND

With Christmas fast approaching we have our Christmas cards now in stock.

These cards bright cheerful cards include the Parkinson's Logo logo and are on offer for €10.00 per pack of 15 cards.

We have teamed up with Newbridge Silverware to produce these beautiful Newbridge pieces showcasing the Parkinson's logo.

Newbridge Pendant €35.00 Plus P&P

Newbridge Pins €20.00

Parkinson's Lapel plus P&P



Please place your order early to avoid disappointment by calling the Freephone 1800 359 359



Many thanks for your support

JOHN O'LEARY: "THE MAKING OF A CITY IN FLAMES"

John O'Leary spoke to Parkinson's Ireland about the work behind the CD and documentary made to honour the men and women of Cork who fought in the War of Independence.

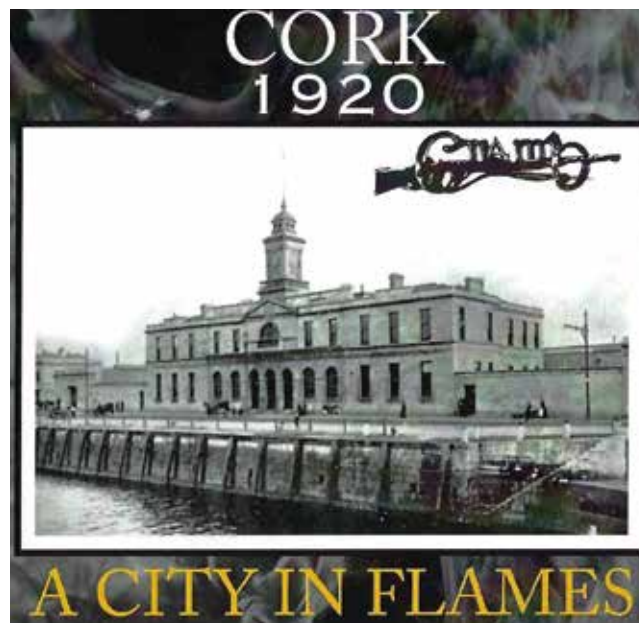
Called 'Cork 1920: A City in Flames', the CD was conceived by John O'Leary and was launched at St Peter's Vision Centre in Cork City in 2021.

John O'Leary approached his neighbour, songwriter John Murphy, about the CD, who was more than happy to apply his talents to the project to bring it to life. The CD features 10 original songs, written by John, and one each by Tim O'Riordan and Cliff Wedgbury. The CD even includes the first song ever written and recorded by Tomas Mac Curtain, which John O'Leary describes as "a work of art".

John Murphy then approached John O'Leary about making a documentary behind the making of the CD. John O'Leary explained that the pair were neighbours for over thirty years before coming together for this project: "We never had a conversation before, we said hello and goodbye as we passed each other – but now we're best of friends."

John Murphy said the reason he wanted to make a documentary was because of John O'Leary's Parkinson's. John was diagnosed with Parkinson's in 2016 after his children and wife noticed some changes in his behaviour: "These included disengaging at family gatherings or in groups and in general just slowing down with daily tasks. One thing I found difficult was getting the key into the front door lock."

Before the making of the documentary, John explained that his Parkinson's was private to him: "I wasn't really interested in letting the world know. But John (Murphy) kept on about it and he approached



my wife Mary, and she was all for it, so I had no choice then!"

John touches on his Parkinson's in the documentary, which he found difficult: "To speak about myself on the documentary was one of the hardest things I've ever had to do in my life. I still have no visible signs. I get stiff if I am sitting down for a while and can not move immediately when I stand up, but other than that I do not have any visible signs." John also recalls losing his sense of smell around 2004, which he did not realise was a sign of Parkinson's, until his neurologist asked him about it.

John said that making the documentary helped him to open up about his Parkinson's: "Doing the documentary opened me up to the world and to be continually involved in life in general."

He also discussed the importance of exercise: "It's fantastic. If you can exercise, make sure you do. Every day I do a minimum of forty minutes." John also sings





as much as he can to help his vocal cords: “I sing as loud as I can to exercise my vocal cords because at times, my voice can get weak and sore.”

John explained that the CD and the documentary took two years to complete and launch due to some pandemic setbacks: “We had intended to launch in October 2020 to coincide with the death of Joseph Murphy, but Covid stopped that. We were going to have a concert in the city hall in Cork, but that then became the vaccination centre.”

When the launch eventually took place in St. Peter’s in Cork, John recalls the fantastic reception: “We got a standing ovation from the audience. It was absolutely amazing.”

The documentary was produced by Wombat Media, with the launch held in The Gate Cinema and charged no entry fee: “Myself and John decided this as it was to be made for the people, completely free.” 1,000 people turned up to the launch in the cinema, and John described the response as “a humbling and great experience.”

John always remains positive and discussed the importance of having his family’s support: “Get your family to back you, it’s vital. You have to have your family’s support all the way. Just try and get people comfortable with you, I let them know that I might be a bit slower, but I’ll get there, I will always get there. And always think positive.”

You can watch the documentary ‘The Making of a City in Flames’ on YouTube here: [The Making of A City in Flames documentary \(youtube.com\)](https://www.youtube.com/watch?v=...)

FLU VACCINE - OVERVIEW



The flu is a contagious viral infection that spreads every winter. Getting the flu vaccine is the best way to protect yourself against flu.

The best time to get the flu vaccine is before the flu season starts.

It is available from October to the end of April each year.

Who can get a free flu vaccine

You can get a free flu vaccine if you are:

- **age 65 and older**
- **age 2 to 17**
- a healthcare worker
- **pregnant**
- living in a nursing home or other long-term care facility
- in regular contact with pigs, poultry or waterfowl
- someone with a health condition that puts you at higher risk of flu (age 6 months and older)
- living with someone who has a health condition that puts them at higher risk of flu
- a carer for someone who has a health condition that puts them at higher risk of flu

Please visit [hse.ie](https://www.hse.ie) for further information on the flu vaccine.

REDUCING HARM FROM OMITTED AND DELAYED PARKINSON'S DISEASE MEDICATIONS IN IRISH HOSPITALS

Collaborative publication by the Irish Medication Safety Network & Parkinson's Ireland

This year, the Irish Medication Safety Network (IMSN) & Parkinson's Ireland agreed to work together with a common goal to enhance the safe use of medicines for people with Parkinson's disease, in particular for those admitted to hospital in Ireland.

Established in 2007, the Irish Medication Safety Network (www.imsn.ie) is a voluntary, independent group of hospital pharmacists from public and private Irish hospitals, with aim to improve patient safety with regard to the use of medicines. We promote the exchange of information on medication safety & facilitate and support national and global initiatives to help minimise risks to patients.

In 2018, the IMSN published a one page guidance document for front line healthcare professionals on Reducing harm from omitted and delayed Parkinson's disease medications. The IMSN and Parkinson's Ireland established a collaborative working group to review and update this document, with a people with Parkinson's focus. The working group includes:

- Specialist PD nurses from Parkinson's Ireland
- Pharmacists from Our Lady's Hospital, Navan; Our Lady of Lourdes Hospital, Drogheda; St John's Hospital, Limerick, & St Vincent's University Hospital, Dublin
- Medical review/sign off by a Medical Consultant working with Parkinson's Ireland

The hospital pharmacists involved work in different models of hospital – from smaller, less acute hospitals, to regional, acute hospitals to large, academic teaching hospitals, representing a variety of the different hospital environments people with Parkinson's could be admitted to in Ireland, all with goal of providing high quality and timely care.

How can I best ensure I receive my anti-parkinson's medications on time in hospital?

- 1 Bring in your own supply of regular medications with you.

On occasion, there may be delay sourcing some of the less frequently used medications used to treat Parkinson's disease, so to avoid any interruption to your usual medication

schedule it can be helpful for patients to have your own supply. Discuss same with the healthcare professionals looking after you

- 2 Bring in a list of all your regular medications. Inform us of times you take your Parkinson's medications

For people with Parkinsons attending hospital, it is really helpful to provide a list of up-to-date medications that you are taking, including any over the counter medications or any herbal preparations. This can ensure in hospital we are aware of all the medications you take, and in relation to anti-parkinsons medicines, what times of day you take your medication to best suit you.

You could keep the list in your Parkinson's passport, or the HSE have a My Medicines List template you can fill in available via www.hse.ie/safermeds. It would be helpful if you allow healthcare professional view/ photocopy your medication list, and then return it to you. Keep your Parkinson's passport/medication list with you – so if you move within the hospital environment, your list moves with you.

In Autumn 2024, the Irish Medication Safety Network & Parkinson's Ireland will jointly publish updated guidance aimed at front line healthcare professionals in Irish hospitals on Reducing harm from omitted and delayed Parkinson's Disease medication. We intend to publish further guidance on medications that should be avoided in people with Parkinson's disease later this year.



Niamh O'Hanlon



TIME TO TALK, TOMORROW STARTS TODAY



To die and grieve well wherever the place

ENCOURAGING PEOPLE TO TALK ABOUT DYING AND GRIEVING

Irish Hospice Foundation (IHF) is encouraging people to start having conversations about dying and grieving, with the aim of normalising these difficult topics and acknowledging that they are part of the lifecycle. Our **Time to Talk, Tomorrow Starts Today** campaign aims to help people navigate the conversations surrounding death, advance care planning and grief.

IHF team and campaign supporters Damian and Gabrielle at the Time to Talk campaign launch, July 9, 2024.

Why do we need to talk about dying and grieving?

Death and grief affect us all. It's important that we explore and think about our end-of-life wishes, and that we discuss them with our loved ones. By thinking ahead and communicating our preferences, we can alleviate the burden on our families and ensure our wishes are respected when we die. It's also important that those of us who are grieving are acknowledged and given the space and opportunity to talk about our losses.

Results from an IHF report, **Time to Reflect**, which explored the impact of COVID-19 on the experiences and perceptions of the Irish population in relation to dying, death, and bereavement, highlighted that nearly half of participants (47%) had given more thought to their own end-of-life wishes.

The **National End of Life Survey** by the National Care Experience Programme was the first national survey asking bereaved people about the care provided to their relatives and friends in the last months and days of their life. A key theme from the survey was families knowing what to



expect when a loved one was nearing end of life, demonstrating the importance of communication between healthcare professionals, patients and their families.

For those whose loved one died in a hospital, three quarters of participants (76.3%) stated that a discussion about what to expect when their relative was dying would have been helpful. For families whose loved one died at home, it was 71.5%.

Both these surveys shine a light on the importance of communication, conversations with loved ones, planning in advance and documenting our end-of-life wishes.

How can I start these conversations?

Irish Hospice Foundation understands that discussing what a loved one might want for their end of life, or talking to someone about their grief, can be difficult, but it's important to do so. We have provided practical tips, helpful resources, and FAQs on starting and having these important conversations at: hospicefoundation.ie/time-to-talk/.

How can I record my end-of-life wishes?

If you're ready, we encourage you to record your end-of-life wishes in a Think Ahead Planning Pack. It is a practical tool and customisable guide for advance care planning and end of life. It is a place to record your preferences and choices for your future care through illness, end of life and after death.

Download your free Think Ahead Planning Pack or order a physical copy at thinkahead.ie.

#TimeToTalk #TomorrowStartsToday



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.



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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.

