



PARKINSON'S ASSOCIATION

Parkinson's Association of Ireland
Carmichael Centre
North Brunswick Street
Dublin 7



freephone 1800 359 359
www.parkinsons.ie

MORE THAN MEETS THE EYE

Founded in 1986 in Dublin, the PAI now has branches throughout Ireland. It is a member of the Neurological Alliance of Ireland, the European Parkinson's Disease Association and the World Parkinson's Disease Association.

Why We are Here

- To offer support to those with Parkinson's, their families and carers.
- To help those with Parkinson's become better informed about their condition, and to maximise their quality of life.
- To help advance the progress of scientific research into Parkinson's, financially if possible, or by encouraging its members to participate in appropriate research.
- To help promote awareness of Parkinson's symptoms to the general public, which will hopefully make life a little easier for those with more advanced Parkinson's.
- To fundraise for the purpose of improving the quality of life of people with Parkinson's.
- To lobby for improved services, including the provision of Parkinson's Nurse Specialists.

PARKINSON'S



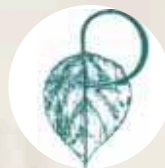
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PARKINSON'S ASSOCIATION OF IRELAND

Our Organisation

Originally we were a Dublin based Association with branches in other parts of the country. Now, after a complete reorganisation, we are what could be termed "A Federation of Branches". Our National Executive Committee consists of two representatives from each of the branches, a truly democratic and representative body. A large proportion of our National Executive Committee are themselves people with Parkinson's.

Our logo is the aspen leaf. The leaf trembles, even on a still day, but the branches and trunk are strong and enduring.



Our Members

There are about 6,000 - 7,000 people with Parkinson's in Ireland. Our membership stands at about 20% of these, but we would like it to be higher. Those of us who are members of the Association have discovered how much benefit membership offers - information, regular meetings, camaraderie, friendship, and above all, the relief that comes from seeing that others in the same situation survive and live well in spite of Parkinson's! The greater our number, the more effective will be our efforts to obtain better services for people with Parkinson's. We offer our support services through our central office in Dublin (1 800 359 359) or through our network of branches (See the map), or PALS, the national branch for those diagnosed before the age of 55.

We also issue a national newsletter three or four times a year. This is full of news about the latest research, information for carers, tips on many aspects of the condition. It is sent to all members of the association, both national and branch members. It is bright, colourful, and emphasizes the positives!

Each new member will receive, upon receipt of their membership form and fee, our lovely enamel brooch/lapel pin depicting our logo.

Patients, carers, children, parents, health professionals, interested others, can access the information we offer, either through our office or through our website www.parkinsons.ie.

More about our Branches

We have branches throughout the country, each providing local support and encouragement. To quote the NPF (National Parkinson Foundation), "the hardest part is walking through the door".

Your local branch is your local support base, and many enduring friendships result from sitting beside someone else at one of the meetings.

Each of our Branches has a Chairman, Vice Chairman, Secretary, Treasurer and sometimes a PRO (Press Release Officer). These officers look after the affairs of the branch. Each of our branches offers meetings, information, and support.

In addition some of the following are offered, depending on the branch:

yoga

reflexology

group physiotherapy

seminars

information about rights and entitlements

Branches would also:

raise awareness of Parkinson's through the media

fundraise both locally and nationally

lobby for better services, both nationally and locally

For the Association, membership of the Neurological Alliance is helping to give us a greater voice when lobbying to improve the availability of services for people, not only those with Parkinson's, but the other neurological disorders.

Outings, Meetings and Other Social Events
Our branches all hold regular meetings, and these are driven largely by what the branch members feel are their priorities. Most hold meetings where they have a guest speaker, e.g. a consultant, or physiotherapist or counsellor. Each branch meeting offers an opportunity to exchange ideas, and often, inspiration! Christmas get togethers have proven the most popular of all of our meetings, and in addition there is a national pilgrimage to Lourdes every second year, or by demand.

Join a Branch

Parkinson's can place a real strain not only on the person with Parkinson's but also on their spouse/carer, and family, and for patient and carer alike, going to branch meetings can provide an opportunity to let off some steam and gather strength - and sometimes, solutions - from others who know and understand.

We also welcome volunteers who can bring energy and commitment with them. If you don't wish to join a branch at the moment, then become a National Member. This entitles you to receive all correspondence sent out to all members, with the option of joining a branch at a later date, if so desired.



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Our Helpline: 1 800 359 359
Email: parkinsonsireland@eircom.net

This is operated by our Administrative Secretary, Marie, and by volunteers.

We provide:

information pages on various aspects of Parkinson's and living with it - or living well despite it

a listening ear - sometimes the most popular item

other assistance - if we can't help, we will try to refer you on, perhaps to our website at www.parkinsons.ie .

We are preparing information pages on such topics as:

Rights and entitlements

Parkinson's

The various therapies

Home help and respite care

Bathroom conversions

Our helpline is open between 8.30am and 3.30pm from Monday to Friday.

At times, you may get a taped message. If this is your first time calling us, PLEASE LEAVE A MESSAGE - we know how hard it is to make that first call, but you have, and if you leave your name and telephone number, **we WILL phone you back."**

The Multidisciplinary Care Team and Parkinson's

Ideally, each person will be in the capable hands of a team of health professionals that will cooperate in an integrated individualised treatment program. Here in Ireland, a multidisciplinary care team in the field of Parkinson's offering all the options (neurologist, nurse specialist, counsellor, speech therapist, physiotherapist, occupational therapist) may be hard to find, but in some locations we are seeing their emergence. In some countries they are becoming more commonplace and more accessible. Reports suggest that they contribute immensely to a patient's quality of life. A multidisciplinary clinic is a newer idea emerging where the patient or caregiver can drop in on certain days and schedule treatment e.g. physiotherapy. It may even be possible to have the treatment on the same day!

Ireland is a signatory of the Global Declaration on Parkinson's, the Parkinson's Patient Charter, which states that a person with Parkinson's is entitled to:

be referred to a doctor with a special interest in Parkinson's

receive an accurate diagnosis

have access to support services

receive continuous care

take part in the management of their own condition.

"Effective and appropriate management of strategies could improve the quality of life for those with Parkinson's and reduce cost and effect on the global economy".

Global declaration on Parkinson's

Counselling

We do not offer this as yet, but some of our branches are investigating the possibility of funding a counsellor. It is not a very well developed field in this country, but we would encourage all those who feel in need of the assistance of a counsellor, to ask their GP or consultant to be referred on to one - in this way you are safeguarding your wellbeing.

Parkinsonsireland

Our revamped newsletter is a marvellous way of keeping everyone up to date with the latest in research - giving people hope. We try to approach topics in a positive fashion, and so far feedback has been very good.



Funding

We are in receipt of NO statutory funding, and therefore are extremely dependent on fundraising. The Evening Herald/Flora Ladies Mini Marathon is our biggest source of funding for the main/national office. So we encourage anyone that might be able to enter, to do so. We are always very grateful for any donations made. Our branches do their own fundraising, but once each year we hold a national event in which all branches participate.

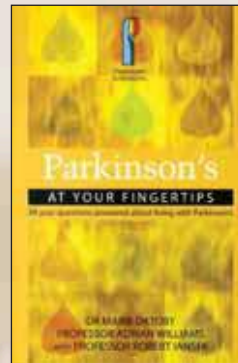
We offer t-shirts and hats along with sponsorship cards for anyone running or walking for PAI in a marathon - phone 1 800 359 359 and tell us what you need.



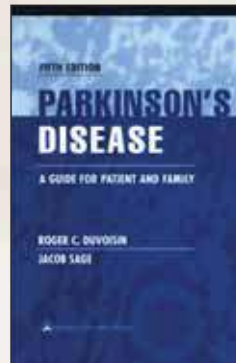
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Publications

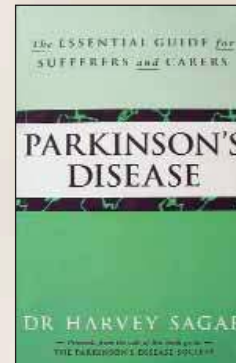
The office has a selection of books about Parkinson's, as well as newsletters from other support organisations around the world. The following are worth purchasing for reading and for later reference, as they are easy to follow, and look at the positives.



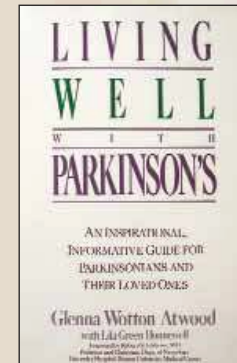
Parkinson's at your Fingertips
Dr. Marie Oxtoby and Prof. Adrian Williams; Class Publishing, London. *In question and answer format, this book is quite comprehensive.*



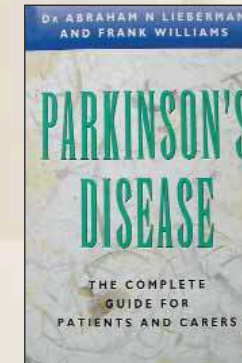
Parkinson's Disease - A guide for Patient and Family
Robert C. Duvoisin, M.D., & Jacob Sage, M. D. Lippincott-Raven Publishers, Philadelphia/New York *A real find, easy to read and understand;*



Parkinson's Disease
Dr. Harvey Sagar; Vermillion, London *Businesslike, informative.*



Living Well with Parkinson's
Glenna Wotton Atwood John Wiley and Sons *Excellent, personal, plenty of advice.*



Parkinson's Disease - the Complete Guide for Patients and Carers
Dr. Abraham Lieberman and Frank Williams; Thorsons. *Comprehensive again, positive tone.*

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Branches

Here is a list of our nationwide network of contacts and support groups.

DONEGAL/SLIGO
Northwestern Branch
Tel: 071 9852377

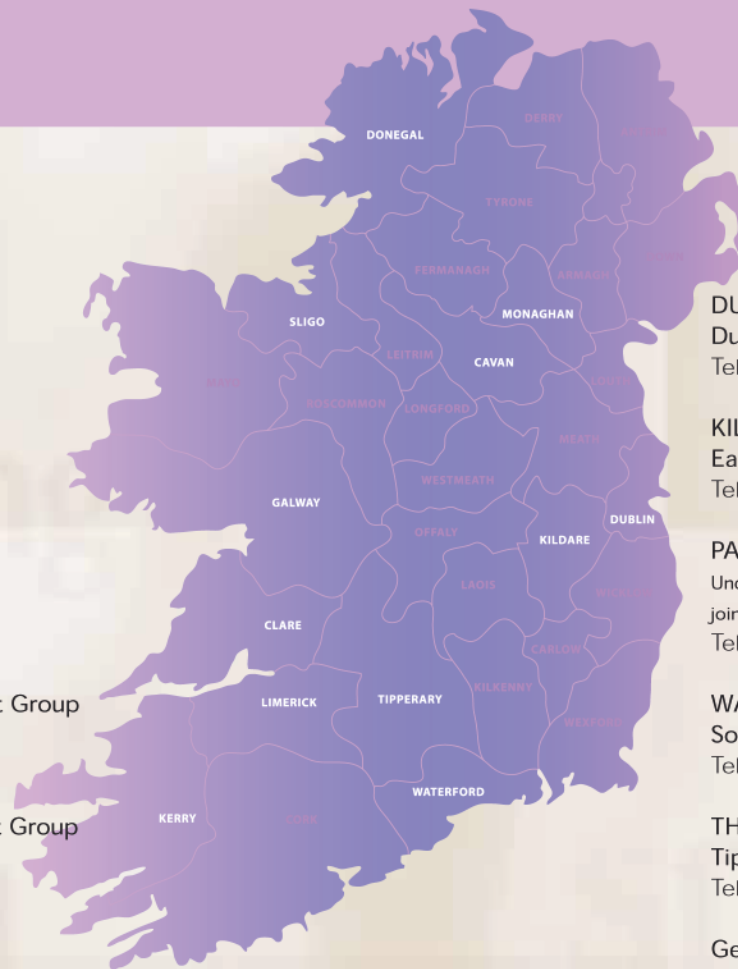
GALWAY
Galway Parkinson's Association
Tel: 091 569400

LIMERICK/CLARE
Midwest Branch
Tel: 061 228316

NORTH KERRY
North Kerry Parkinson's Support Group
Tel: 068 21927

SOUTH KERRY
South Kerry Parkinson's Support Group
Tel: 066 9762335

CAVAN/MONAGHAN
Cavan/Monaghan Branch
Tel: 049 4332821



DUBLIN
Dublin Branch
Tel: 01 2852902

KILDARE
East Midlands Branch
Tel: 045 435024

PALS Support Group (Young Onset)
Under 55 at diagnosis -
join alone or along with your local branch
Tel: 01 8510040

WATERFORD
Southeastern Branch
Tel: 051 895506

THURLES
Tipperary Branch
Tel: 086 2430215

General Membership
Tel: 01 800 359 359

Contact Information

Parkinson's Association of Ireland
Carmichael House,
North Brunswick Street
Dublin 7

freephone 1800 359 359

www.parkinsons.ie

Our website is well stocked with articles that cover many topics.

If there is anything you would like to see covered that you cannot find there, email us at parkinsonsireland@eircom.net and we will try and assist.

PALS Support Group (Young Onset Branch)

Phone 01 851 0040

06MTMTEPP03

Date of Preparation: April 2006

Please join the Parkinson's Association today!

Fill in the application form enclosed in this pack and send it in.

There is strength in numbers!"

UNRESTRICTED
GRANT FROM
ORION
PHARMA

MORE THAN MEETS THE EYE ◀

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