



**PARKINSON'S**  
...planning your journey



*“I often say now I don’t have any choice whether or not I have Parkinson’s, but surrounding that non-choice is a million other choices that I can make.”*

Michael J. Fox

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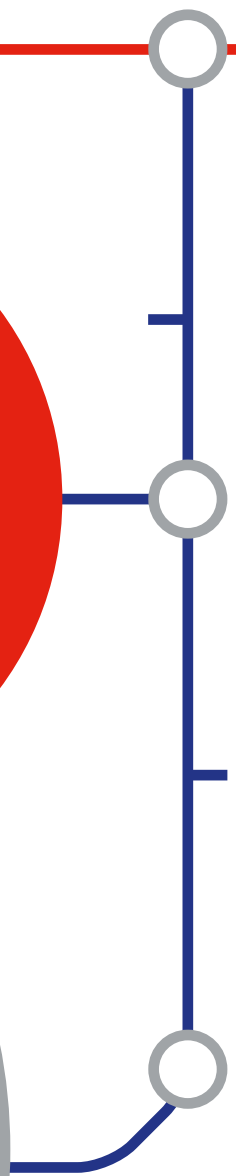




### *What is Parkinsonism?*

Parkinsonism describes a range of conditions that feature the main symptoms of Parkinson's (tremor, rigidity and slowness of movement).

Most people with Parkinsonism (about 85%) have Parkinson's disease but others have rarer conditions including Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Drug Induced Parkinson's, and Parkinsonism secondary to other medical issues such as a stroke.



# ABOUT PARKINSON'S DISEASE

## WHAT IS PARKINSON'S DISEASE?

Parkinson's disease, commonly referred to by its shorter name Parkinson's, is a progressive neurological disorder. It primarily affects movement, though there are both motor (movement-related) and non-motor (non-movement related) symptoms.

The progression of Parkinson's varies from one person to the next; it can progress more slowly in some people and the symptoms may be effectively controlled with medication for many years.

Parkinson's is sometimes called a 'designer disease' as the symptoms and progression of Parkinson's is so individual.

## WHAT CAUSES PARKINSON'S?

We all have a chemical called *dopamine* in our body – it helps in the transmission of signals in the brain and other vital areas and is also responsible for movement.

As we age, we all lose some of this chemical. But people with Parkinson's have lost this chemical at a faster rate than others as some nerve cells in the brain that make it have died. Signs and symptoms do not appear until 70%-80% of dopamine cells are lost.

Researchers don't know exactly why people get Parkinson's but it is thought that a combination of genetic and environmental factors lead to dopamine-producing nerve cells dying.

## HOW COMMON IS PARKINSON'S?

Parkinson's is the second most common neurodegenerative condition after Alzheimer's. The incidence is 1 to 2 cases per 1,000 of the general population and 1 case per 100 in people aged over 80. It's estimated that there are around 9,000 people living with Parkinson's in Ireland.

## AT WHAT AGE DOES PARKINSON'S OCCUR?

It is most commonly diagnosed in people aged over 60 but it can also affect younger people:

**EARLY ONSET PARKINSON'S:**  
age 40 to 60

**YOUNG ONSET PARKINSON'S:**  
age 21 to 40

**JUVENILE PARKINSONISM:**  
age before age 20

# SIGNS AND SYMPTOMS

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Parkinson's can be a difficult condition to diagnose as it can present itself in many ways and in the early stages signs and symptoms can be subtle. In addition, not everyone with Parkinson's displays the same symptoms and they don't happen in a particular order. Everyone's Parkinson's is different and symptoms can change from day to day as well as over a longer period.

Diagnosis is usually made by a neurologist in a clinical setting, it is a complex condition and there is no simple diagnostic test such as a scan or blood test that can confirm the presence of Parkinson's.

However, there are signs and symptoms connected with Parkinson's that you or your doctor would have noticed prior to getting a diagnosis. Some of these symptoms may or may not appear as your Parkinson's progresses.

**Remember that you can talk to your healthcare team to get help with any concerns and the Parkinson's Association of Ireland have more information on symptoms and support available.**

Signs and symptoms can be broken into two groups – motor and non-motor.

**Motor symptoms** are connected with movement while **non-motor symptoms** aren't related to movement. Sometimes people with Parkinson's aren't aware that non-motor symptoms are connected to their condition and therefore they are not as easily identified or treated.

## MOTOR SYMPTOMS

### TREMOR

A tremor can present itself in Parkinson's disease when the hand or leg is relaxed and not in use. This is called a rest tremor and it usually begins in one hand or arm, causing some people's hands or bodies to shake.

Anxiety can cause the tremor to get worse so people with Parkinson's can notice that in times of stress, the tremor can become more noticeable. It is a symptom that many people associate with Parkinson's but not everyone with the condition has a tremor.

### RIGIDITY/STIFFNESS

Rigidity or stiffness can happen as a result of the muscles being unable to stretch or relax and this can make it more difficult to do everyday things. It can also make movement more painful.

Some people find that their posture can become stooped because of stiff muscles and they may also find it harder to make facial expressions.

### SLOWNESS OF MOVEMENT

It can become harder to make movements and it may take longer to complete actions such as getting dressed or putting items away. The technical term for this is *bradykinesia* and it's most clear when carrying out actions that require a few successive steps. Slowness in movement can show itself through a whole range of things including walking (short shuffled steps), speech and gestures.

## Getting Help

It's important that help is sought as early as possible in the progression of Parkinson's – therefore it's vital that there is awareness of the condition's signs and symptoms.

Communication with your doctor and nurse is key to the management of Parkinson's and your well-being.



## IMPAIRED BALANCE/POSTURE

Balance and posture can deteriorate as Parkinson's progresses – this can lead to problems walking, turning around and moving out of a chair or bed. It can sometimes also lead to falls as slowness of movement means it is difficult to correct an overbalance to one side.

## FREEZING

Many people with Parkinson's will experience freezing at some point – it is the experience of stopping suddenly when walking or starting to walk. The feet are unable to move forward and it feels like they are stuck to the ground.

Freezing does not happen to everyone with Parkinson's but as the condition progresses, it is likely to happen more often. There are techniques you can use to get moving again when freezing happens.



## NON-MOTOR SYMPTOMS

You may not experience all of these non-motor symptoms but they include:

- Dry mouth
- Speech and language problems
- Problems with swallowing and/or drooling
- Low blood pressure
- Bladder and bowel problems (including constipation)
- Pain
- Sleep problems
- Fatigue
- Mood changes
- Hallucinations
- Loss of sense of smell

Some of these additional symptoms may actually be side effects of the treatment of Parkinson's rather than the underlying illness.

## PROBLEMS WITH SWALLOWING AND/OR DROOLING

Many people with Parkinson's experience difficulty with swallowing (known as *dysphagia*) at some point and it can have a big impact upon quality of life.

Both swallowing difficulties and drooling arise due to bradykinesia affecting the swallowing muscles which makes swallowing less effective and reduces the frequency of swallowing, causing saliva to build up and spill out of the mouth.



## SLEEP PROBLEMS

You may experience problems sleeping at night-time and therefore feel tired during the day time.

Sleep problems can be caused by pain, adjusting to a medication, muscle spasms, mood changes, rapid eye movement sleep disorder (loss of the ability to paralyse oneself while sleeping and therefore acting out dreams) and *Restless Leg Syndrome* amongst other causes.

## MOOD CHANGES

These are some of the most common non-motor symptoms of Parkinson's and may pre-date motor symptoms by several years. They include **depression, anxiety, apathy** and **impulse control disorders**.

- **Depression** can be connected to low mood, trouble concentrating, lack of sleep or oversleeping, lack of appetite and a lack of energy.
- **Anxiety** can be connected with panic attacks or feelings of social anxiety.
- **Apathy** is when you don't feel motivated to do very much and may feel disconnected from what is going on around you.
- **Impulse control disorders** can occur as a side effect of some Parkinson's medications and are characterised by an inability to resist an impulse. They can include behaviours such as compulsive gambling, binge eating, hypersexuality and compulsive buying.





### *Educating yourself*

Research shows that people who educate themselves about their illness and learn how to manage it do better and have a better quality of life over time. You have a key role in making sure your Parkinson's is well managed.

# — UNDERSTANDING YOUR CONDITION —

## **BUILD A GOOD RELATIONSHIP WITH YOUR HEALTHCARE TEAM**

The best management of Parkinson's is based on shared decision making between the person living with the condition and their doctor.

**Tell your doctor or Parkinson's nurse about the symptoms that are concerning you, even if you are not sure that they are related to Parkinson's. It might be useful to write them down in advance of your meeting.**

To get the most out of your time with the healthcare team try some of these tips:

### **BE PREPARED**

Make a list of what you want to discuss, you could give it to your doctor at the start of your appointment to make sure you discuss each concern

### **TRY TO BE OPEN AND HONEST**

Tell your doctor the real story about how you are and don't take extra medication before your appointment, he or she can only give you the best possible treatment if they know what is going on.

### **TELL YOUR DOCTOR HOW YOU ARE DOING**

- Share all your symptoms, even if you don't think they are related to Parkinson's

- Perhaps bring a diary of symptoms
- Bring the medication you're currently on if you are taking lots of medicines
- Tell the doctor about any appointments you have had with other doctors or specialists

### **ASK QUESTIONS IF ANYTHING IS UNCLEAR**

If the doctor says something that you don't understand, ask them to explain it to you. Make sure you understand any changes in medications, why you are taking it and how and when to take it.

Make notes to help you remember. It can also help to include a family member or care partner during clinic visits, four ears are better than two!

### **TAKE YOUR MEDICATIONS AS DIRECTED**

The more predictably and reliably you are taking your medications, the more predictable and reliable your Parkinson's will be. Perhaps set an alarm if you need to.

### **KEEP A DIARY**

Keeping track of your medications and when you need to take them (along with your food, exercise and symptoms) can help you feel involved in your treatment.

Bring it along to help jog your memory for your visit to your neurologist if they ask about how your medication is working for you.

## STAY INFORMED ABOUT PARKINSON'S

The **Parkinson's Association of Ireland** has a wealth of information available through its website at: [www.parkinsons.ie](http://www.parkinsons.ie) and via its freephone helpline on **1800 359 359**, open 9am to 7pm Monday to Thursday and 9am to 5pm, Friday.

Another organisation working in the Parkinson's community is **Move4Parkinson's**. For more information visit their website at: [www.move4parkinsons.com](http://www.move4parkinsons.com) or telephone **01 295 0060**.

## MEET OTHERS IN A SIMILAR SITUATION

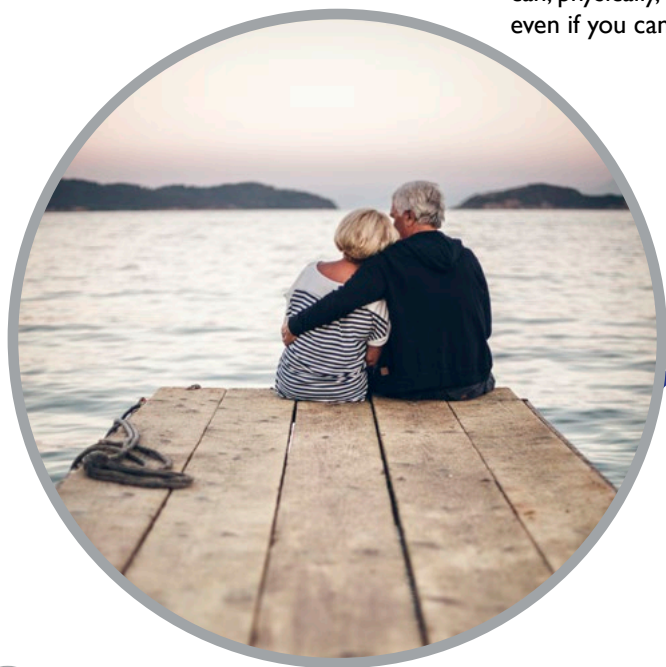
Being able to talk to other people who are going through similar things can help you to feel like you're not alone with the condition.

Contact the **Parkinson's Association of Ireland** to find out about local support groups.

## DO WHAT YOU CAN, WHEN YOU CAN

There may be times when you need to rest and can't take part in social activities. Don't be too hard on yourself when this happens – sometimes you need to be realistic in setting goals and accepting your limitations.

Maintain as normal a routine as you can, physically, emotionally and socially, even if you can't go far from home.





# MEDICATIONS FOR PARKINSON'S DISEASE

In this section we take a look at some of the most common medications used for Parkinson's disease. Bear in mind that **each person with Parkinson's will have an individualised medication regimen**, based on his or her age, physical state, level of disease and so on, so **no two patients' medication regimens will be the same** and the following information is a **generalised guide to treatments**.

## LEVODOPA

Levodopa is converted to dopamine in the brain, making it the next best thing to replacing the missing chemical. It has been the main treatment for Parkinson's for the past 40 years and is delivered in different ways, depending on symptoms. In its oral tablet form it is combined with either carbidopa or benserazide and carbidopa/entacapone so that more of it reaches the brain.

It is easy to take, has a strong effect throughout all stages of Parkinson's on both stiffness and slowness but over time, the amount taken will probably need to be increased because of disease progression. Levodopa is considered the 'Gold Standard'. However, it has little effect on imbalance.

It is usually divided into three or four daily doses and it is important if you are taking levodopa medication that it is taken at the same time every day, allowing 30 to 40 minutes prior to meals or 90 minutes after meals. This is due to the disruption in absorption caused by

consuming protein along with levodopa medication. You also need to take plenty of fluids to help flush the levodopa down to the jejunum where it is absorbed.

Oral levodopa medications currently available include:

- Levodopa/carbidopa\*
- Levodopa/benserazide\*
- Levodopa/carbidopa/entacapone\*

## DOPAMINE AGONISTS

These have a similar effect to levodopa and trick the brain into thinking it is getting dopamine, but the effect is not as strong. However, they are less likely to cause 'on/off' effects or dyskinesia when taken alone. They are useful in early Parkinson's and as an add-on later.

Oral dopamine agonists currently available include pramipexole\*, ropinirole\* and rotigotine\*.

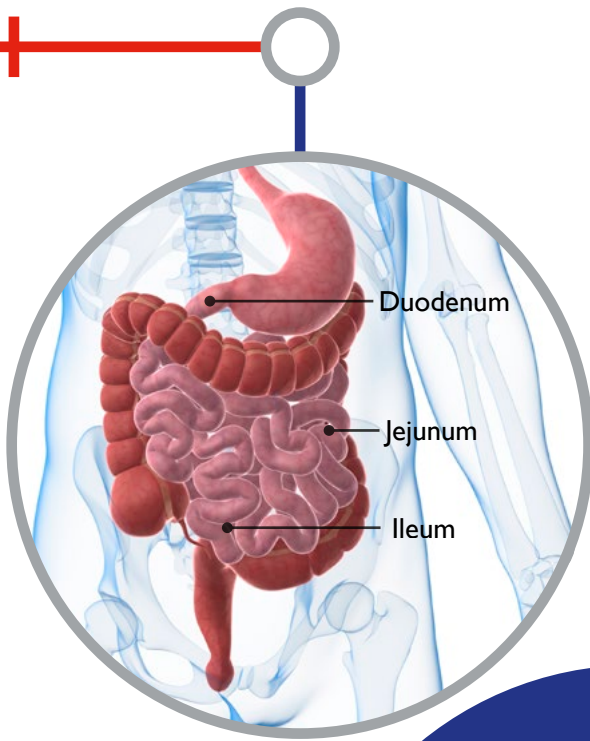
## ENZYME INHIBITORS

These work by preventing the breakdown of levodopa before it gets to the brain or by preventing the breakdown of dopamine in the brain, allowing a longer and smoother supply of dopamine.

Types of enzyme inhibitors include:

- **COMT inhibitors:** Entacapone\* and tolcapone\* (entacapone combined with levodopa is also available as one tablet).
- **MAO-B inhibitors:** Selegiline\* and rasagiline\*.

\* Active ingredients of the medication



### *Significant improvements*

There is currently no cure for Parkinson's but there have been significant improvements in the treatment of Parkinson's symptoms in the last 20 years. Treatments include drug therapy, surgery, physiotherapy, speech and language therapy and occupational therapy.

A lot of research is currently looking at the causes of Parkinson's, to develop new treatments for the condition. The ultimate goal of this work is to slow down the progression or even cure Parkinson's altogether.

Other medications include anticholinergics such as biperiden\* and procyclidine\*. These medications are usually used in the treatment of tremor and dyskinesia.

## ADVANCED THERAPIES

Depending on the progression of your Parkinson's, there may be a point when treatments other than oral medications should be considered as part of your care.

In the following section we will go through options currently available, but all three advanced therapies may not be suitable for everyone.

### APOMORPHINE\*

Apomorphine is a dopamine agonist. It can be administered via a sub-cutaneous (under the skin) pen device, which when injected will bring you out of an 'OFF' phase of Parkinson's in a short amount of time.

Another form of administration is via a small wearable pump, where the Apomorphine is injected under the skin and delivers small amounts constantly during waking hours with the option for an occasional boost if required. This treatment does not require any surgical procedure. Despite its name, apomorphine does not contain any morphine and does not have any addictive properties.

### LEVODOPA/CARBIDOPA\* INTESTINAL GEL

Levodopa/carbidopa\* intestinal gel contains a combination of levodopa and carbidopa monohydrate. Unlike the oral forms of levodopa, the levodopa/carbidopa\* intestinal gel ensures a small dose of the drug is delivered continuously during the day-time through a portable pump.

Treatment involves a procedure of passing a small tube through your abdomen into a selected part of your small intestine. The tube is then connected to a portable pump that you wear during the day that gives levodopa/carbidopa\* directly into your small intestine. You will disconnect the pump when you go to bed but you will have tablets available to manage troublesome night-time symptoms if you need them.

### SURGERY – DEEP BRAIN STIMULATION

This is brain surgery where electrode wires are positioned in the brain and connected to a stimulator which delivers pre-programmed steady pulses of low voltage current that seems to restore normal movement – to varying degrees.

This option can be discussed with your neurologist and if in agreement with your consultant that it may be a suitable option, a referral can be sent to The National Deep Brain Stimulation Service Ireland.

\* Active ingredients of the medication



The most common effects of the medications used to treat Parkinson's include nausea, vomiting, dizziness and sleepiness.

Less common side effects include orthostatic hypotension (light-headedness after standing up), dyskinesia (involuntary movements) and confusion.

However, most are transient side effects and those that remain can, for the most part, be controlled effectively with due care and careful manipulation of medication by your medical team.

**Contact your doctor if any of these side effects are persistent.**



## **What is On/Off in Parkinson's?**

If you have Parkinson's, you will be aware of the On/Off cycle. When people with the condition start to take medication for it, they usually notice that their symptoms go away for a few hours at a time (On times) but that the symptoms can later return (Off times).

It is an adjustment to learning to live with the On/Off cycle. It can be useful to try and time your day's activities around your On/Off rhythms and in consultation with your doctor, be able to adjust your medications so that they are effective when you most need them to be.



# LIVING WITH PARKINSON'S DISEASE

Receiving a diagnosis of Parkinson's disease takes time for both you and your loved ones to come to terms with as there's no doubt that the condition will have an effect on many areas of your lives.

However, it is a case of living with Parkinson's rather than letting Parkinson's define you or your life. The way that you approach the condition will have a huge impact on how it affects your life both now and in the future, and your friends, family and colleagues will take the lead from how you deal with your condition.

Life with Parkinson's is not always easy but focusing on it one day at a time and trying to have a healthy lifestyle and positive outlook will help you to manage the lifelong condition. Read on for more about exercise, diet, alternative therapies and daily life with Parkinson's.

## EXERCISE

Keeping active is good for your physical well-being and your mental health too. Moving regularly is important for people with Parkinson's in managing symptoms and keeping muscles moving.

At times, it may take a little more effort for you to exercise – especially if you feel muscle stiffness or feel tired. It is worth making the effort though because otherwise, you may fall into a vicious circle of not exercising and this can lead to further mobility problems as muscles and joints become stiffer and weaker.

It is important to find an activity or exercise that you enjoy and which you can fit easily into your day – whether that's walking with your dog, cycling, playing a team sport, swimming, spending time in the gym or countless other activities.

**An activity such as Nordic walking may be worth investigating – as it gives a great cardiovascular workout but uses poles that aid posture and balance.**

Yoga can be beneficial in working on flexibility, muscle strength and posture – in light of some of the symptoms that accompany Parkinson's. It can also help increase body awareness and is a relaxing activity.

If you are thinking of taking up yoga, make sure you find a teacher that matches your needs and understands that you may need to modify some poses due to your condition.

There are many benefits to taking regular exercise. It works wonders for the whole body – all of the organs, muscles and bones benefit from regular activity and it also helps your posture, flexibility and your central nervous system.

Keeping active can also help you to counteract stress in your life and help you sleep better at night. Getting involved in a team activity such as bowling, tennis or sailing can help you to form new social circles.

If you feel your movement is not good enough to take exercise or you are starting a new exercise regime, talk to your doctor or ask to be referred to a physiotherapist to help you work on improving your mobility.

### ***It all counts!***

Remember that activities like gardening, dancing and housework also contribute to your fitness level.

There may be some days when you feel tired or not up to exercising but don't let that get to you – just make sure that you make the most of the days when you are feeling good and try to make exercise a regular part of your week.

## **DIET**

Eating a healthy well balanced diet is important for everyone, including people who have Parkinson's disease.

For most people with Parkinson's, there is no special diet to follow but you should follow the general advice given for healthy eating. Some people living with Parkinson's may have an issue with protein (see overleaf).

Make sure that you eat a wide variety of foods each day and eat regularly (try to have three main meals a day with small snacks in between or six smaller meals throughout the day).

## **FOOD GROUPS**

A balanced diet means choosing appropriately from the different food groups each day:

- **Starchy foods:** Each of your meals and snacks should have starchy food (high in carbohydrates) such as bread, potatoes, rice, pasta, oats, crackers and cereals.
- **Fruit and vegetables:** Aim to have five a day from this group – whether they're fresh, frozen, canned or dried.
- **Dairy products:** Try to have three to five servings of dairy foods each day – a serving is a third of a pint of milk, one small pot of yoghurt or a small matchbox portion of cheese.
- **Meat, fish and alternatives:** Aim for two to three servings each day from this group. Choose from red or white meat, white or oily fish, eggs or pulses (beans, chickpeas, peas etc.) and nuts.
- **Fatty and sugary foods:** These foods should be eaten in moderation – they include soft drinks, cakes, biscuits, chocolate, crisps, sweets and fast foods.
- **Fluids:** It is important to drink plenty of fluids – aim for 8 to 10 cups of fluids every day. Fluids can include water, fruit juice, squash, milk, tea and coffee. Keep tea and coffee to a maximum of four to five cups per day as the caffeine in these can lead to dehydration.



## HAVING A HEALTHY WEIGHT

It is important to have a healthy weight for your height and build – being overweight or, more commonly in Parkinson's, underweight, can have effects on your health.

Weight loss can occur due to the extra movements associated with Parkinson's. These extra movements can be tremor or dyskinesia (involuntary and/or uncontrollable movements), both of which can burn up extra calories. If you are prone to extra movements, you may need to increase your calorie intake to avoid weight loss. Equally, it can be easy to gain weight if you become less active due to your Parkinson's and are eating the same amount of food as previously.

**If you need advice on weight management, talk to your doctor or ask to see a registered dietitian.**

## PROTEIN IN YOUR DIET

Some people find that protein (which is found mainly in meat, fish, eggs, dairy products, nuts and pulses) can stop their Levodopa medication from working as well as it should.

This is because Levodopa is an amino acid and will have to compete for absorption with the amino acid produced from dietary protein.

For this reason, most people benefit from taking their Levodopa 45 minutes before meals or 90 minutes after meals (though you should check if this advice applies to you with your doctor or Parkinson's nurse).

## VITAMINS AND MINERALS

There is no evidence that taking extra vitamins, minerals or antioxidants will improve your Parkinson's symptoms or slow down the progression of the condition.

It is always better to try and get your vitamins and minerals directly from a well-balanced diet. However, if you feel you are lacking in a vitamin or mineral, talk to your doctor about possible supplementation. Some vitamins, when taken in large doses, can cause side effects.

People with Parkinson's are more likely to get *osteoporosis* (a thinning of the bones) and so an adequate intake of **calcium** and **Vitamin D** is vital to keep bones strong and healthy.

**Calcium** is mostly found in dairy foods such as milk, cheese and yoghurts along with some vegetables, tinned fish and fortified cereals and juices.

**Vitamin D** is mainly sourced from the sun via the skin. However, we do not get a lot of sun in Ireland so you should look to get Vitamin D through food sources such as eggs, oily fish, margarine, fortified milks and cereals.

### **DRINKING ALCOHOL**

Unless you have been advised by your doctor not to drink alcohol, moderate drinking is not harmful.

The Department of Health and Children advises that the recommended maximum limits are 11 standard drinks a week for women and 17 standard drinks a week for men.

A standard drink is:

- Half a pint of lager/beer/cider
- 100mls of wine
- One pub measure of spirits

### **Remember...**

Always talk to your doctor before taking herbal medicines as these can interact with medications that you're taking for your Parkinson's.

## **ALTERNATIVE THERAPIES**

Alternative therapies are often based on ancient systems and many people use them alongside western medicine treatments. They will not provide a cure and should not be used instead of medication or other treatments prescribed by your doctor.

People with long-term conditions like Parkinson's can find they get some relief from symptoms and an increased sense of well being from alternative therapies though it can vary from one person to the next.

Always check with your doctor, specialist or Parkinson's nurse to discuss any benefits or risks of an alternative therapy. It is also important to make sure that you are attending a trained practitioner.

## **WORKING, DRIVING AND TRAVELLING**

One of the biggest concerns that people newly diagnosed with Parkinson's have is how it is going to affect their day to day life. Questions arise over whether it is still possible to work, drive and travel.

Find out as much as you can, particularly with a view to how your condition might progress so that you are equipped to make the right decisions.

### **WORKING**

If you are currently working and have been diagnosed with Parkinson's, it may make you concerned about the future of your job and your livelihood. However, being diagnosed with the condition does not mean you have to stop work and most of the time people with Parkinson's are able to continue a career for many years.

How Parkinson's affects your work and how you deal with telling your employer is a very individual decision. You may need to take into account whether your employment contract requires you to notify your employer about your Parkinson's and whether your condition might impact on health and safety in the workplace.

The *Employment Equality Acts (1998; 2004)* make it illegal for an employer to discriminate on grounds of disability in employment, promotion or training and employers must reasonably accommodate people with disabilities to do their job, where the cost is not disproportionate to the employer.

It is also your decision whether to tell your colleagues about your condition. Many people with Parkinson's find that letting their employer and colleagues know about their condition leads to better support and assistance.

If you have questions relating to employment rights for people with a disability, your local Citizen's Information Centre is a good source of information ([citizensinformation.ie](http://citizensinformation.ie)).

If you need legal services, Free Legal Advice Centres (FLAC), an organisation that provides some basic free legal services may be of help ([www.flac.ie](http://www.flac.ie)).

You may need to make some modifications to your daily working life as your condition progresses. If you do decide to work fewer hours or to retire, it is important to be sure that this is the right decision for you.

## DRIVING

If you are driving and feel able to continue to do so, you must inform your car insurer of your diagnosis. The company will require medical reports to support your claim that you can continue to drive.

Your premium shouldn't increase as a result of you informing the insurance company of your condition.

Parkinson's disease is amongst a list of conditions that need to be reported to the Driving Licensing Authority on application for or renewal of a driver's licence. As part of the process, you will need to get a medical report completed by a registered medical practitioner.

Over time, you may need to make adaptations to your car to take into account your condition – you can speak to an occupational therapist about these changes.

If you do start to develop more symptoms over time that you feel may have an impact on your ability to drive, you should speak to your doctor about whether it is safe to continue to drive.



## TRAVELLING

Having Parkinson's does not have to stop you from travelling; it may be more of a challenge than before but with careful planning travel can be made easier.

Travel companies and airlines can be contacted in advance to arrange help and support. Pack any medication you will need in your hand luggage – it may be a good idea to pack a full day's medication in case of any delays – along with anything you need to take the medication, such as food or water.

It can be useful to have a letter from your doctor detailing the drugs you take, both for customs but also in case you need to seek medical help while away.

If you are travelling to somewhere you have not been before and have mobility needs, it is worth inquiring ahead about what provisions are in place.

If you travel and have travel insurance, be sure to notify your insurer of your diagnosis. You may need to change insurer to a more specialised insurance company that provides travel insurance for people with particular conditions or disabilities.

## PLANNING FOR THE FUTURE

With Parkinson's disease, it is often useful to try and deal with issues as and when they arise. However, that does not mean that you cannot also plan for the future, being able to think ahead and enjoy what life has to bring. Look at what you can do when it comes to medications, organising care and look after your financial planning.

## MEDICATIONS

The best time to look at the next treatment steps is when your medication is working – don't wait until it is no longer working to plan.

It is important for you to discuss any changes to how your medication is working with your doctor or Parkinson's nurse so that adjustments can be made or further treatments considered.

## ORGANISING CARE

It is very important that you retain a sense of independence and as your condition progresses, modifications to your home and/or work space can help you to keep doing things for yourself.

There is a time when you'll need to put plans in place for your care. As your Parkinson's progresses further you may need to have residential care or assistance in your own home, whether it is through a trained professional or through your family or friends providing care for you.

It is a discussion that may be difficult for you and for others but having an early discussion about it can help to eliminate some of the worry about the future.

## FINANCIAL PLANNING

We all tend to put our financial affairs on the long finger but it is important to have a plan in place, particularly if you may have to stop working or need additional care.

You should check out any financial supports you may be entitled to and also make sure your legal affairs are in order.



# MEMBERSHIP APPLICATION FORM

## WHY JOIN?

The Parkinson's Association of Ireland aims to help people with Parkinson's, their families and carers, and health professionals, by offering support and information on any aspect of living with Parkinson's. We operate a freephone helpline **1800 359 359** and have a Parkinson's Nurse Specialist on staff. The Association also initiates and funds research into Parkinson's disease, and its causes and effects.

Some of the membership benefits include regular information meetings and social events organised throughout Ireland, quarterly magazines, support through our branch network and free access to information booklets, exercise charts and updates on Parkinson's.

We are becoming stronger each year with the involvement of new members, more branches becoming active, and through greater professional input.

## HOW DO I JOIN?

Membership of the Association includes General Membership or Membership of a local branch. All members receive our magazine and items of national interest as well as notice of national events.

**To join the Parkinson's Association of Ireland, simply complete and return the form overleaf.**

(For existing members, please visit our website [www.parkinsons.ie](http://www.parkinsons.ie) and complete the renewal form).

## MEMBERSHIP FEE

The annual membership fee is currently €25, the membership year runs as per the calendar year, and you can send the form overleaf to our head office or directly to your chosen branch.

Please note that one membership fee covers a person with Parkinson's and a spouse, companion or carer.



## PARKINSON'S ASSOCIATION OF IRELAND MEMBERSHIP APPLICATION FORM

Please complete the following form and return it to us at the address below.  
Alternatively, call us on **1800 359 359**.

<b>Name</b>			
<b>Email</b>			
<b>Date of Birth</b>		<b>Phone Number</b>	
<b>Address</b>			

<b>I am</b>	<b>Patient</b> <input type="checkbox"/>	<b>Carer</b> <input type="checkbox"/>	<b>Health Professional</b> <input type="checkbox"/>	<b>Other</b> <input type="checkbox"/>
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<b>Credit/Debit Card Number</b>																			
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	<b>Exp</b>					<b>Security Code</b>				
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<b>Cheque/Postal Order enclosed?</b>	<b>Yes</b> <input type="checkbox"/>
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Please make cheque/postal order for €25.00 payable to "Parkinson's Association of Ireland".

Membership of the association includes general membership or membership of a local branch, or the branch Young Parkinson's Ireland for those diagnosed before the age of 60. Once you have completed the membership application form, please send it along with cheque/postal order/card details to:

**The Parkinson's Association of Ireland, North Brunswick St., Dublin 7.**

The PAI will contact you with details of your branch options.

# USEFUL RESOURCES

## ORGANISATIONS

Organisation Name	Phone number	Website address
Alzheimer National Helpline	1800 341 341	<a href="http://www.alzheimer.ie">www.alzheimer.ie</a>
Aware	1890 303 302	<a href="http://www.aware.ie">www.aware.ie</a>
Family Carers Ireland	1800 240 724	<a href="http://www.carersireland.com">www.carersireland.com</a>
Caring for Carers	065 686 6515	<a href="http://www.caringforcarers.ie">www.caringforcarers.ie</a>
Citizens Information Board	0761 074 000	<a href="http://www.citizensinformation.ie">www.citizensinformation.ie</a>
Disabled Drivers Association	094 936 4054	<a href="http://www.ddai.ie">www.ddai.ie</a>
European Parkinson's Disease Association		<a href="http://www.epda.eu.com/en/parkinsons/">www.epda.eu.com/en/parkinsons/</a>
Irish Hospice Foundation	01 679 3188	<a href="http://www.hospicefoundation.ie">www.hospicefoundation.ie</a>
Move4Parkinson's	01 295 0060	<a href="http://www.move4parkinsons.com">www.move4parkinsons.com</a>
Multiple Systems Atrophy		<a href="http://www.msatrust.org.uk">www.msatrust.org.uk</a>
Multiple Sclerosis	1850 233 233	<a href="http://www.ms-society.ie">www.ms-society.ie</a>
Parkinson's Association of Ireland	1800 359 359	<a href="http://www.parkinsons.ie">www.parkinsons.ie</a>
PSPA Ireland	01 838 3606	<a href="http://www.pspaireland.ie">www.pspaireland.ie</a>
Think Ahead Campaign	01 679 3188	<a href="http://www.thinkahead.ie">www.thinkahead.ie</a>



The Parkinson's Association of Ireland would like to thank  
Dr Richard Walsh, Consultant Neurologist, for endorsing this booklet.

