



GENERAL INFORMATION

This insert highlights some common symptoms associated with Parkinson's disease and how they might affect you. It also discusses options for treatment as well as explaining the "Wearing-Off" effect.

Parkinson's disease (PD) is now recognised as one of the most common neurological disorders affecting people over the age of 55. It usually begins somewhere between the ages of 40 and 70 and men are affected more frequently than women. The incidence is roughly the same in all countries around the world. It is a slowly progressive disorder which is life altering, but with good medical care patients usually live a normal life span. The more positive you are, the better your long-term outcome is likely to be.

Parkinson's is a disease where cells in a small part of the brain (called the substantia nigra) die prematurely. This area of the brain is rich in cells that produce a substance called dopamine. Dopamine is a chemical used by the brain to relay signals. When there is a loss of dopamine the brain is not able to generate or send the proper signals to control movement.

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COMMON SYMPTOMS

It is important to remember that Parkinson's affects everyone differently. Do not assume that you will experience the same symptoms as someone else. Some symptoms will be the result of Parkinson's itself and others may be due to the medication. It is very important that you are aware of all of your symptoms and report any changes to your doctor.

Shakiness or trembling in the hands, arms, legs, jaw and face (often referred to as "**tremor**"). This is the earliest symptom to appear in about 70% of patients. This is worse at rest and gets better when the arms are being used. Because of this the tremor experienced does not tend to be physically disabling.

Muscles that become tight and stiff (often referred to as "**rigidity**").

NOTE

Some frequently used terms and their meanings are included in this pack on page 8.

Slowness of movement or difficulty starting movements, such as getting up from a chair. Your doctor may refer to this as "bradykinesia". This symptom responds well to treatment. It can manifest in different ways:

- *It is often hard to begin a movement (e.g. getting up from a chair)*
- *Fine movements become clumsy (e.g. doing up buttons and writing)*
- *Movements may be more restricted and less spontaneous*
- *Movements may suddenly stop (i.e. freezing, especially when turning corners or going through doorways)*

Problems with balance and coordination - walking and turning are unsteady.

Other symptoms unrelated to movement can also occur. These are referred to as **non-motor symptoms**. These may include: anxiety, depression, pain, constipation, depression and fatigue.



MANAGEMENT

In 1888 the eminent physician Gowers recommended that for people with Parkinson's:
"Life should be quiet and regular, freed, as far as may be from care and work".

Thankfully the management of Parkinson's has moved on in the last century, as a result of ongoing research into drug therapies and surgical procedures.

TREATING PARKINSON'S

Because the number of specialised nerve cells that produce dopamine are reduced, most of the drugs used to control the symptoms of Parkinson's work in one of the following ways:

To replace the missing dopamine by giving levodopa (e.g. Stalevo, Sinemet, Madopar)

To support the dopamine produced by the remaining nerves (e.g. Eldepryl, Azilect)

To provide an agent that mimics the action of natural dopamine (e.g. Requip, Mirapexin)



Your doctor may recommend a treatment based on your specific symptoms. Not everyone will receive the same medications or even the same dose and in the early stages of the disease you may not need any medication at all. A list of most of the available drugs used for the management of Parkinson's is included in this pack.

The outlook for people with Parkinson's improved markedly with the introduction of levodopa therapy in the early 70's (levodopa is a dopamine replacing drug). Levodopa is still the mainstay of treatment for

Parkinson's and is the best drug available for the management of the symptoms. Almost anyone can tolerate levodopa and almost everyone with Parkinson's will eventually be treated with it, although there is debate on when to start treatment with this drug.

Levodopa is normally very effective when it is first used to treat the symptoms but as the disease progresses the duration of response you get from levodopa will change. This change in response is known as "Wearing-Off".



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Wearing-off happens when a dose of levodopa that previously used to help your symptoms does not last as long and your next dose is needed sooner.

Symptoms of wearing-off include changes in:

movement and mobility
(motor symptoms)

and

thoughts, feelings, sensations and your sense of well being
(non-motor symptoms)

TIP

It is very important to keep as active and as fit as possible. Maintain as normal a routine as you can.





SURGERY

In special cases, when symptoms become more problematic, surgery may be considered. The most common procedure to be carried out now is Deep Brain Stimulation (DBS). A “pacemaker” is inserted into an area of the brain known as the globus pallidus, or other structures, and stimulates the area electronically at a very fast rate. This alleviates some of the symptoms of Parkinson’s. DBS is currently not available in the Republic of Ireland so patients are sent abroad for the procedure.

There are other health professionals who can help significantly with the management of your Parkinson’s and ultimately improve your quality of life. A list of these specialists is included in this section of the pack. If you feel that any of your symptoms could be helped by seeing one of these specialists, you can discuss this with your doctor.

It has been estimated that nearly half of Parkinson’s patients will feel the effects of their levodopa “wearing-off” within two years of starting to take the drug. Despite this, levodopa is still an effective treatment for managing symptoms. As a result, newer drugs are often used to extend its benefits.



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ALWAYS REMEMBER

There are many things you can do for yourself and your participation in the management of your Parkinson's can greatly effect how you will be in years to come. So here are some useful tips for staying positive.

Understand Parkinson's disease, its cause and its treatment

Read all you can about the disease. Become a member of the Parkinson's Association of Ireland (phone 1800 359359). Visit the Parkinson's Association website at www.parkinsons.ie

Find a good doctor you can trust and talk to

If you have problems don't be afraid to ask for advice. Simple measures such as adjusting your tablets, exercise or counselling may help.

Take control of your future

Focus on the improvements you get, whether they are small or large and make the most of them. Report the effects of treatment, good and bad, to your GP/Hospital doctor - make notes in advance of your appointment.

Take an active role in your symptom management

The more information you can provide, the more options will be available for managing your changing symptoms effectively and quickly. Find out whether physiotherapy, occupational therapy and/or speech therapy can help you adapt to, and improve, certain aspects of your disability.

Remember your successes

Keep a brief diary when starting a new drug or adjusting the dosing.

Pace yourself - know and accept your limitations

You should continue to do as much as possible for yourself, even if it takes longer.

Accept help when you need it

Don't be afraid to ask questions.

Keep doing the things you enjoy

Eat well

Try not to ignore any problems

Some symptoms may be related to the treatment rather than the disease itself, so always discuss new symptoms with your doctor.

Remember - you are not alone!

It's a long road to a cure for Parkinson's but much of it has been travelled already. Every year greater advances are being made in researching the disease, discovering more effective drug therapies, researching more innovative surgical therapies and ultimately improving the outlook for people with Parkinson's.

TIP

Learn the terms your doctor uses - "dyskinesias", "on", "off", etc so that you can be as well informed as possible

YOUR SUPPORT TEAM

A support team is essential when treating Parkinson's. Family and friends can be as important as healthcare professionals. Here we list some members of that team.

YOU and your family - most importantly, try to consider yourself and your family as a central part of this specialist team - this is your condition.

Your family doctor - is usually your first point of contact and is the healthcare professional you will probably see the most over the years. They will look after your general health and keep all of your medical records. They will also help to co-ordinate the care you receive from other healthcare professionals involved in your treatment.

Specialist doctor - this is a consultant, usually a neurologist or a geriatrician, who has specialist knowledge of Parkinson's disease. You may only see the specialist occasionally and referral is normally via your doctor - ask to be referred if you feel you would benefit from speaking to a specialist.

The pharmacist - is another important part of your team. Try to make sure that you use the same pharmacy all the time and that it has a record of all your medication. The pharmacist can give you advice about your drug treatment and ensure that over-the-counter medication and vitamin supplements do not adversely interact with your prescription drugs.

Additional team members that may be available

The Nurse - Parkinson's disease nurse specialists can provide specialist advice and information on coping with the day-to-day challenges of Parkinson's. There are an increasing number of these specialist nurses in Ireland.

Physiotherapist - because Parkinson's is a motor disease and affects your movement control, exercise plays an important role in helping people with Parkinson's maintain a healthy lifestyle. Physiotherapists can assess problems you are having with mobility, balance and posture. They can also advise on exercise routines, and provide advice on overcoming symptoms and minimising its impact on your daily routine.

Occupational therapist - having Parkinson's does not necessarily mean that you have to give up your job if you are still working. An occupational therapist can help you plan your day, and balance work, relaxation and leisure activities.

Speech and language therapist - speaking can be affected in the later stages of Parkinson's disease. Speech therapists can help improve

speech quality and help you to minimise such problems as speaking too softly and lack of clarity. They can also help you cope with any swallowing problems that you may eventually encounter.

Dietician/Nutritionist - These can advise you on how to plan a healthy diet and maintain the right weight. If you have problems with weight loss (or gain) or constipation, your doctor may refer you to a dietician. Dietary advice may also benefit your treatment, because diet (even including when you eat) can affect how well the drugs used to treat Parkinson's work.

Counsellor - the difficulties encountered with Parkinson's can often be accompanied by feelings of sadness and depression. It can often help to talk to a professional about these feelings. A counsellor can provide individual or family counselling to help you adjust to the changes Parkinson's is making in your life.

Psychiatrist - this is an expert on mental health problems. They can help with problems that may occur, such as depression, anxiety and disturbances in thinking and perception, which may require specialised treatment.

GLOSSARY OF TERMS

COMT

Catechol-O-Methyl Transferase, is an agent that reduces the breakdown of levodopa in the bloodstream.

DDC

Dopa-DeCarboxylase is an agent that reduces the breakdown of levodopa in the gut.

Delayed on

Delayed on is when you take your medication but it does not seem to work, or takes an extra long time to kick in.

Dyskinesia

Abnormal involuntary movement.

Dystonia

Abnormal involuntary movement causing a prolonged, often twisted posture of the affected part of the body.

Freezing episodes

Not to be confused with being 'off', freezing is literally becoming stuck to the floor. It quite often

happens when approaching a doorway, or in restricted areas like between a sofa and coffee table.

Honeymoon period

The length of time during which you are able to function perfectly while taking medication. This is the period of time during which you get all the benefits of the medication without any of the potential drawbacks.

Motor fluctuations

These occur after the "Honeymoon period". You become aware of the effect of your medication i.e. the effect of your medication does not last as long and your symptoms start to reappear before the next dose of medication is due. Motor fluctuations include wearing-off and dyskinesias.

Non-motor fluctuations

Dips in between doses that affect things other than your ability to move. They include slowness of thought, feeling down, sweating, and are relieved when your next dose kicks in.

Off-time

The time when your medication has worn off between doses and movements are more difficult.

On-time

The time when your medication (Sinemet/Madopar/Stalevo) is working well and your movements are easier. You may also have dyskinesia for a while in the middle of this time.

Rigidity

Abnormal increased stiffness.

Tremor

The typical shake of Parkinson's. Tremor is a rhythmic trembling movement of an arm or a leg that mainly occurs when you are not doing anything, and is one of the primary signs of Parkinson's.

Wearing-off

This happens when a dose that previously used to help your symptoms does not last as long and your next dose is needed sooner. Symptoms of wearing-off include changes in movement and mobility, thoughts and feelings, sensations and sense of well being.

Contact Information

Parkinson's Association of Ireland
Carmichael Centre,
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Dublin 7

freephone 1800 359 359
www.parkinsons.ie

PALS Support Group (Young Onset Branch)
Phone 01 851 0040

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