



## Newly Diagnosed With Parkinson's Disease

If you have just been diagnosed with Parkinson's disease you will probably feel anxious about the future and have many questions. This leaflet provides some guidance on what you need to know or do just after being diagnosed. Always try to keep in mind that although living with Parkinson's can be difficult, many people with Parkinson's continue to lead active, fulfilling lives.

### Who Should Manage Treatment of My Parkinson's Disease?

If possible diagnosis and care of your Parkinson's should be by a Consultant Neurologist or Geriatrician in conjunction with your GP. Ideally the Consultant should have a special interest in Parkinson's and have access to a Parkinson's Disease Nurse Specialist (PDNS), Physiotherapist, Occupational Therapist and Speech and Language Therapist.

### When Should Treatment Be Started and What Drugs Should be Used Initially?

When you are first diagnosed with Parkinson's, your GP or Consultant will discuss your particular symptoms and your needs with you before recommending possible treatment options. It is important to recognise that each person with Parkinson's is unique and each recommendation of when to start treatment and what treatment to use is therefore going to be unique. There is no point in comparing what has been recommended for you with what has been recommended for other patients. Please be assured that starting treatment early does not mean that you have more severe symptoms than someone else.

If after your initial consultation you need further information from your doctor regarding the treatment recommended, write your questions down and make another appointment to see your doctor.

### When you first get your medicines read the Patient Information Leaflet provided inside the box

This has been prepared to provide to people with Parkinson's information they should know about the medicine. If the text on the leaflet is too small for you to read you can ask your pharmacist to get you a leaflet with the text in a larger print size.

Once you do start treatment, let your doctor know if you experience unwanted effects from your treatment. If you are not sure if your treatment is causing an unwanted effect, look in Section 4 of the Patient Information Leaflet provided with your medicines. This lists possible unwanted effects that can occur with the treatment. It is worth mentioning any unwanted effects as your doctor may be able to prescribe something else to make the effect tolerable or change your treatment to another drug.

### Will I Have to Pay for Treatment?

If you are not eligible for a Medical Card you can get free medicines, medical and surgical appliances for the treatment of Parkinson's under the Long Term Illness Scheme. You will still have to pay for medicines prescribed to treat other conditions (e.g. antibiotics for an infection). In order to apply for the Long Term Illness Scheme you need to fill in the application form which is available from your Local Health Office. Your GP or Consultant will sign the form to confirm your condition and list your medicines or medical and surgical appliances. You will also need to specify the pharmacy where you want your medicines dispensed. If your doctor or occupational therapist prescribes a medical or surgical appliance, it will be supplied to you from your Local Health Office.

Even if you are not entitled to a medical card you may be eligible for GP Visit Cards which can allow individuals and families in Ireland to visit their family doctor for free. Only the cost of visits to your family doctor is free.

If you are not entitled to a medical card you should also apply for a Drugs Payment Scheme Card if you don't already have one, since other medicines not related to Parkinson's have to be paid for in the normal way but they will be covered by the Drugs Payment Scheme. This scheme ensures no individual or family has to pay more than a government determined maximum amount each month for medicines. The maximum amount is subject to government review from time to time.

Please see the following HSE website for information regarding current available medical entitlements for patients [http://www.hse.ie/eng/services/Find\\_a\\_Service](http://www.hse.ie/eng/services/Find_a_Service)

## What Financial Help or Benefits are Available?

Make sure that you find out what financial support is available to you. Information regarding benefits which may be available to you and your family can be obtained from the Citizen's Information website (<http://www.citizensinformation.ie>), your local Citizen's Information Centre, the government's website providing information on public services (<http://www.oasis.gov.ie>) and the social welfare information website (<http://www.welfare.ie>).

## What Impact Will Parkinson's Disease Have on My Life?

Diagnosis of any illness which progresses will require you and your family to adapt over time. Although the diagnosis of Parkinson's may be upsetting, it is important to try and maintain a positive outlook, have a healthy diet, exercise and focus on doing things you enjoy. Additionally, remember that although you have Parkinson's your family will be significantly affected by your condition. Try to look after family relationships and understand how Parkinson's affects you and your family and learn how to work around it. Keep in mind that you may need to be more realistic about what you can achieve, and work around times when your medication is working well. You may also need to change some of the roles within the family over time.

## Who Should I Tell?

When to tell others about your diagnosis is an individual decision for you. Some people find it easy to tell family and friends about their diagnosis while others need time to adjust before telling others. There are however, some notifications you will need to consider. For example, if you are driving and feel able to continue to do so you must inform your car insurer of your diagnosis. They will require medical reports to support your claim that you can continue to drive. Similarly, 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 illnesses.

If you are still working, discussing your diagnosis with your employer is a decision that only you can make. You need to take into account whether your employment contract requires you to notify them of your Parkinson's and whether your Parkinson's 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. Many people with Parkinson's find that letting their employer and colleagues know about their Parkinson's leads to better support and assistance. Your local Citizen's Information Centre will be able to provide advice on specific issues or questions relating to employment with a disability. There is also useful information on the Citizen's Information website (<http://www.citizensinformation.ie>) regarding employment rights for people with disabilities. If you need legal services FLAC, an organisation that provides some basic free legal services, may be of help (<http://www.flac.ie>).

If you have children or grandchildren you should ideally tell them after your diagnosis. You may need to remind them of the symptoms on several occasions. Remember that children are incredibly perceptive and may already have noticed your symptoms and be worried about them. When describing Parkinson's, tell them as much as you think they want to know. Make it simple and appropriate to their age and maturity and do not overload them. Tell them that they can talk to you about Parkinson's at any time. It is also important to remind them that although you may not be able to do everything you used to do, you still love them just the same. Remember, too, that how you cope with Parkinson's will be a powerful influence on how the children in your family cope.

There are several publications available to assist patients in explaining Parkinson's to children which you might find useful. These are listed at the end of this Information Sheet.

## How Can I Find Out More About Parkinson's Disease?

The Parkinson's Association of Ireland run an Information Helpline to support people with Parkinson's and their families. If you want to learn more about Parkinson's or speak to others about Parkinson's, particularly others with Parkinson's, then call the helpline and the Association will be able to help. The Association also holds educational meetings around the country and publishes leaflets on different aspects of Parkinson's which you might find helpful. There are also regional branches of the association and a national branch for patients diagnosed below the age of 55 (PALS). These branches meet regularly providing information and support to their members.

## Relevant Websites

Parkinson's UK (<http://www.parkinsons.org.uk>)

The American Parkinson Disease Association (APDA) (<http://www.apdaparkinson.org>)

Parkinson's Disease Foundation (PDF) (<http://www.pdf.org>)

National Parkinson Foundation (<http://www.parkinson.org>)

European Parkinson's Disease Association (EPDA) (<http://www.epda.eu.com>)

Michael J Fox Foundation for Parkinson's Research (<http://www.michaeljfox.org>)

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DISCLAIMER – The information on these pages is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

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