



## Living With Parkinson's Disease

Once you and your family have had some time to adjust to the diagnosis of Parkinson's Disease you then need to get on with your lives as best as possible. There is no doubt that Parkinson's will have an effect on many aspects of your lives since Parkinson's is with you 24 hours a day, seven days a week. It can take over if you let it. It is important not to be defined by your Parkinson's. Remember that how you cope will have a powerful influence on how your family and friends also cope with your illness. An optimistic outlook, maintaining your social life and being willing to adapt all make for a better outcome.

This Information Sheet provides an overview of how you can help yourself and your family cope with Parkinson's. It may not always be easy, but how you manage your illness will have an impact on the quality of your life and that of your family. Keep in mind that many people with Parkinson's continue to lead active fulfilling lives despite their illness.

### Stay healthy

Having Parkinson's doesn't make you immune from developing other illnesses such as diabetes, heart disease, arthritis, etc., so please remember not every ailment is due to Parkinson's. Therefore tell your doctor about all symptoms you experience. Try not to ignore problems. They rarely go away and can get worse.

### Watch your diet

Try to eat a balanced diet to avoid excessive weight gain or weight loss. In particular, you need to be mindful of the effects of food on the medication you are taking. Protein in the diet can interfere with absorption of levodopa medication (Sinemet, Madopar and Stalevo), resulting in less benefit from it. In general it is best to take levodopa medication 30 to 45 minutes before eating a meal or one and a half hours after the meal. The Parkinson's Association have an Information Sheet "Diet in Parkinson's" which you may find helpful.

Some of the medicines used to treat Parkinson's can sometimes cause nausea. Be sure to discuss any potential treatment for nausea or vomiting with your doctor since some of these treatments (e.g. prochlorperazine (Stemetil), and metoclopramide (Maxalon)) can actually cause Parkinson's symptoms to worsen. Domperidone (Motilium) is the treatment of choice to prevent or treat nausea in Parkinson's.

Look after your mental health. If you suffer from depression, anxiety or panic attacks ask for treatment for these. If you require treatment with medication, ensure your treating doctor is aware of all the medications you take for Parkinson's, or discuss this with your Parkinson's specialist. Some of these psychiatric medications may also cause Parkinson's symptoms to worsen, and so should be avoided in patients with Parkinson's.

Keep your brain active. Making the effort to keep your mind active and healthy through regular stimulation can have definite benefits for your mental abilities. Studies have found that engaging in quick calculations and appropriately designed brain fitness workouts can help keep our minds sharp and several existing studies cite challenging, interactive games as one effective method to keeping the brain challenged and agile. Actively participating in appropriately designed brain fitness workouts can defer the onset of dementia and other signs of aging in the brain.

Try to challenge your brain by involving yourself in a new hobby or interest, returning to education, doing stimulating puzzles (such as crosswords and Sudoku), playing games that require you to think (such as Scrabble or chess), reading books and using brain-training programs.

Watch out for potential side effects of treatment which affect your mind such as hallucinations, vivid dreams and less commonly compulsive disorders (gambling, increased spending, binge eating, hypersexuality and other risk taking behaviours). Modifications can be made to your medication to eliminate these.

Recent research has suggested that the chance of people with Parkinson's being diagnosed with melanoma is estimated to be twice that of people without Parkinson's. Melanoma is fairly rare in the general population, so while people with Parkinson's may be at slightly increased risk they are still very unlikely to develop skin cancer. By far and away the most common risk factor for developing melanoma is exposure to the sun - all of us should be cautious about our skin and aware of the dangers. Talk to your doctor about your specific risk, and what skin symptoms you need to watch for. You may need to have regular skin exams.

If you feel overwhelmed by Parkinson's and getting through each day then talk to someone about this. If you cannot talk to family, friends or others with Parkinson's, then feel free to call the Parkinson's Association free phone helpline 1800 359 359, or you can ask your doctor to refer you to a counsellor.

## Keep fit

Try to exercise regularly doing something you enjoy. It is never too late to start exercising. Exercise can be especially beneficial for people with Parkinson's in managing symptoms and easing any discomfort. It may also promote your level of wellbeing and quality of life. It is also known that physical exercise is essential for maintaining good blood flow to the brain as well as encouraging new brain cells.

### Exercise:

- Maintains flexibility;
- Improves balance;
- Improves muscle strength;
- Improves general functioning;
- Improves fitness and stamina;
- Provides a sense of achievement and empowerment;
- Reduces stress and anxiety;
- And most importantly, it can be enjoyable.

There is also emerging data to suggest that playing sports games on computer consoles may offer a fun and motivational way of maintaining beneficial exercise regimes at home.

If you feel your movement is not good enough to take any form of exercise ask to be referred to a physiotherapist who will be able to work with you to improve your mobility.

## Continue to be socially active

It is important to try and continue to socialise with your friends and family and get out of the house. Take advantage of events, activities and support that may be available to you locally.

Consider joining a branch of the Parkinson's Association and meeting others who truly understand what you are going through. The various information meetings and social events held by the branches are held for people like you and all are welcome at these events. Call the help line for the contact details of your local branch.

Try not to worry about how you think you look to others. This is not important to true friends. If the reaction of others to your illness makes you uncomfortable, explain your symptoms. You will generally find this makes people more understanding and helpful. It also helps to improve the general public's awareness of Parkinson's.

You may have to plan for social activities more than you would have in the past e.g. checking out facilities available, having medication with you, dealing with crowds, dealing with the impact of a meal out on your medication. Others with Parkinson's may be able to share tips and ideas for overcoming particular problems with socialising.

## Learn the skills needed to manage your Parkinson's Disease

Studies have shown 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. The best management of Parkinson's is based on shared decision making between the individual with Parkinson's and their doctor. Find a doctor you like, preferably a neurologist or a geriatrician with an interest in Parkinson's. Take advantage of the resources available to you from the Parkinson's Association of Ireland and similar organisations worldwide.

Over the years tips and tricks have been identified which help people in their daily lives. Many of these are simple but can be considered a kind of magic. Examples of these include tips to overcome freezing and initiate movement, tips on modifications to consider making in your bathroom, tips for dressing. Useful tips are regularly published in the Parkinson's Association Quarterly Magazine and on our website ([www.parkinsons.ie](http://www.parkinsons.ie)). The European Parkinson's Disease Association has a section on their website detailing coping tips developed by people with Parkinson's, their carers and healthcare professionals over many users ([www.epda.eu.com/copingstrategies](http://www.epda.eu.com/copingstrategies)). Tips are also available from the American Parkinson's Disease Association ([www.apdaparkinson.org](http://www.apdaparkinson.org)).

Keep a sense of perspective and try to maintain a sense of humour. Laughter is not only good for the soul but it is also good for your health and overall sense of wellbeing.

Adapt your activities to fit around times when you get the most benefit from your medicines. Focus on doing the things that are important to you and your family. Be realistic in setting goals and objectives, know and accept your limitations.

Rest when you need to, particularly before a challenging activity. In general try to get as much sleep as you can.

Ask for help when you need it but try to maintain as much independence as possible.

Over time you may need to organise adaptations to your home or your car. An Occupational Therapist

will be able to advise you on the most appropriate adaptations for your specific needs.

You may find keeping a diary of your condition helpful for both you and your doctor.

### **Can complementary therapies help?**

You may also find complementary therapies beneficial although they will not provide a cure and should not be used instead of medication prescribed by your doctor. People can find relief from symptoms and an increased sense of wellbeing. Some treatments can be quite relaxing and help lift your mood.

It is however important to remember that just because a therapy is described as 'natural' does not automatically mean it is safe. Some complementary therapies have side effects, or can be harmful if provided by untrained practitioners. Sometimes they can clash with your prescribed medicines or treatment. Your usual medicines have been tested in clinical studies. Before a medicine is available for doctors to prescribe, it must meet scientific standards to prove it is effective, safe and high quality. There is not nearly as much evidence for complementary therapies. There are fewer studies and they do not always have the same scientific strength. Some therapies have been tested more than others.

Always check with your GP, specialist or Parkinson's Disease Nurse Specialist before you try any complementary therapy. That way you can discuss any benefits and risks. They may even be able to recommend a good therapist. Bringing up the subject of complementary therapy may also alert your doctor or nurse to problems they did not know about. If they can adjust your medical treatment to improve your symptoms or quality of life, all the better.

### Other relevant information sheets:

G1.1: What is Parkinson's Disease?

G1.2: Newly Diagnosed with Parkinson's Disease

G4: Medications in Parkinson's Disease

G8: Diet in Parkinson's Disease

EX1: Exercise in Parkinson's Disease

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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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