



## ***Facts about...***

### **Living with Parkinson's**

#### **What is Parkinson's disease?**

The NHS defines Parkinson's disease as a condition in which parts of the brain become progressively damaged over many years. Clinically, Parkinson's disease is primarily described as a movement disorder and is characterised by its variety of motor symptoms.

#### **How Many People Are Affected?**

Parkinson's is the second most common neurodegenerative disorder affecting 1-2% of the population aged over 65 years and 3-5% of those aged 85 years and older. Parkinson's is more common in men than women in age groups 60 years and above.

#### **What Happens to the Brain When Someone Has Parkinson's?**

The symptoms of Parkinson's appear because certain nerve cells in the brain begin to die. Many of the symptoms are due to a loss of neurons called dopamine. Dopamine is a chemical messenger in your brain. When this decreases, it causes abnormal brain activity triggering the symptoms of Parkinson's.

#### **Is Parkinson's disease Curable?**

Parkinson's and its symptoms cannot be cured. However, the symptoms can be managed, both through therapies and with medication.

#### **Main Symptoms of Parkinson's disease Include:**

- ❖ Tremor (involuntary trembling or shaking movements)
- ❖ Bradykinesia (Slowness of movement)
- ❖ Rigidity
- ❖ Balance problems, problems with posture (particularly tendency to stoop forwards)
- ❖ Sleeping Problems
- ❖ Speech difficulty

There are many different symptoms for Parkinson's however the symptoms will not be the same for everyone with the disease. Generally the symptoms do get worse over time but the speed of this varies depending on the person.

## Tremor: What Can Help?

Tremor is when you are unable to control shaking in part of your body.

- If you are experiencing tremor in your hand, rolling or squeezing a ball or a similar object may help to suppress the tremor.
- Your GP may refer you to an occupational therapist who will be able to give you more advice on overcoming the day-to-day obstacles surrounding the symptoms of Parkinson's.
- A weighted armband [available in any sports shop] may help to steady your hand when tremor affects writing.
- Tremor can spread to other parts of the body e.g. mouth, neck, and internally. It usually starts in the foot and then spreads up towards the leg then the arm.
- Medication may help to control tremor.
- Visiting a physiotherapist can also help to keep muscles active.

## Slowness of Movement (Bradykinesia)

- This is where physical movement is slower than normal. People with Parkinson's may end up walking with a shuffle, taking very small steps. Ultimately this can make everyday tasks more difficult.
- Physiotherapy helps to improve symptoms as they can recommend techniques and exercises to help with mobility.
- Medications can also help improve movement and reduce slowness.

## Muscle Stiffness (rigidity)

- Muscle stiffness can make it difficult to move around and make facial expressions. It can also result in dystonia (painful muscle cramps).
- To manage this symptom, regular stretching and exercise can help to strengthen muscles. Trying to move throughout the day can reduce symptoms. Speech and language therapy may help with exercises to keep facial muscles flexible.
- Taking a magnesium supplement has been helpful to some in reducing rigidity.
- For this symptom, again Physiotherapy may help with muscle cramps.
- Exercises such as yoga and weight lifting have also been shown to help. The more intense the exercise is, the more beneficial it is at alleviating symptoms.

## Speech: What Can Help?

- When you have Parkinson's, some people notice changes in their voice. Your voice may sound quieter, monotone, slurred or just unsteady.
- These problems can make everyday activities more difficult.
- To help with speech difficulties you can try blowing through brass tubes regularly to improve the loudness of your voice.
- Singing can also help strengthen a quiet voice.
- If your voice is quiet speaking low and deep may also help.
- It is worth visiting a speech and communications therapist to help with speech difficulty.

## Sleeping Do's & Don'ts

Resting and getting as much sleep as possible matters.

- ✓ Make a list of things that disturb your sleep, as there are usually things that can help.
- ✓ Find ways to help you relax
- ✓ Sleep in a cool quiet room
  
- X Avoid stimulants at night
- X Do not watch TV, eat or use the computer 2-3 hours before bedtime.

## Eating right with Parkinson's

Parkinson's disease medication is more likely to work better when eating a nutritious, well balanced diet.

- Foods high in fibre will help with the gut and digestion. These include vegetables, cooked dried peas and beans, whole-grain foods, bran, cereals, pasta, rice, and fresh fruit.
- Choose foods low in saturated fat and cholesterol.
- Try to limit sugars.
- Moderate your use of salt.
- Ask your doctor about drinking alcoholic beverages (alcohol may interfere with some of your medications).
- Parkinson's UK recommends eating less protein during the day and more in the evening if you are taking Levodopa (main drug used to treat Parkinson's).
- Other tips for your diet include staying hydrated and eating slowly and more frequently.

## Equipment and Devices:

<u>Eating and drinking</u>	<u>Getting around</u>
<ul style="list-style-type: none"><li>• Steady Spoon</li><li>• Spoon bowl swivels to keep food stable and level (even when experiencing tremors or weakness.)</li><li>• HandSteady Anti-Spill Cup With rotating handle (no spills when drinking)</li><li>• Other Specially designed cutlery for tremor, stiffness and rigidity can be found at <a href="http://www.essentialaids.com">www.essentialaids.com</a></li></ul>	<ul style="list-style-type: none"><li>• Walking stick</li><li>• Walking frame</li><li>• Wheelchair</li></ul>

<u>Getting out of bed</u>	<u>Personal Care</u>
<ul style="list-style-type: none"> <li>• Bed raiser</li> <li>• Bedside grab rails</li> <li>• Mobile hoist (A mobile hoist can be used to lift you between your bed and wheelchair)</li> </ul>	<ul style="list-style-type: none"> <li>• Raised toilet seat</li> <li>• Converting bath to a wet room or a shower</li> <li>• Commodes (if you need the toilet urgently but can't get up)</li> <li>• Toilet grab rails</li> </ul>
<u>Emergency Device</u>	<u>Medication trackers</u>
<ul style="list-style-type: none"> <li>• Pendant alarms</li> <li>• Global Positioning System (GPS) trackers</li> </ul>	<ul style="list-style-type: none"> <li>• Pill organisers, with timers</li> </ul>

## Tips: Caring for someone with Parkinson's

Everyone with Parkinson's is different so how you support someone with Parkinson's will also be unique. Here are a few tips:

- Stay organised - Keep a record of their symptoms, medications, and doctor visits. This will make appointments more efficient and beneficial.
- Research - Gather information on Parkinson's disease, treatment and care options so you can help better and plan for the future.
- Observe their disease - Share with their doctor symptoms you have observed such as speech issues, mood/anxiety concerns and motor function changes.
- Discuss decisions for the future - Talk about advanced directives, wills and Power of Attorney.

## Support services

You are not alone. Get the support you need today.

- Helplines and local advisers can help with any questions surrounding the topic of Parkinson's.

## Peer Support Service

- Connects you to a trained volunteer who has experience in Parkinson's.
- Contact Parkinson's UK at 0808 800 0303 for **local advisers** and **peer support services** in your area.

## Local Groups

- Search for support groups tailored to you and in your area at Parkinson's UK. [www.parkinsons.org.uk/information-and-support/local-groups](http://www.parkinsons.org.uk/information-and-support/local-groups)
- Guildford Parkinson's Woking Age Group  
0344 225 3668 or by email [adviser8.southeast@parkinsons.org.uk](mailto:adviser8.southeast@parkinsons.org.uk)
- Sutton, Kingston and Epsom Active Parkinson's People  
For further information call 0344 225 9851 or email [vc.south4@parkinsons.org.uk](mailto:vc.south4@parkinsons.org.uk)

## Self-management programs

- Sign up to a Parkinson's self-management programme at [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

## Online communities

Here are a few communities you can join:

- Parkinson's Disease More Than Motion
- Parkinson's UK Forum
- Parkinson's Foundation Forum
- iParkinsons - [www.iparkinsons.com](http://www.iparkinsons.com)

## To contact Share and Care Homeshare:

Tel: 020 3865 3398 or 020 8405 6316

E-mail: [info@shareandcare.co.uk](mailto:info@shareandcare.co.uk)

Website: [www.shareandcare.co.uk](http://www.shareandcare.co.uk)

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This fact sheet should only be used as a guideline and we recommend you seek professional advice.