LIVING WITH PARKINSON'S: SYMPTOMS, CAUSES AND TREATMENT



CAUSES OF PARKINSON'S DISEASE

The most common cause of Parkinson's disease is a loss of nerve cells in the part of the brain responsible for producing a chemical called dopamine. Dopamine helps control and co-ordinate body movements. It is not known why the loss of nerve cells associated with Parkinson's disease occurs.

Currently, it is believed that a combination of genetic changes and environmental factors may be responsible for the condition. One gene associated with Parkinson's is called the LRRK2 gene and this is more common in certain populations including Ashkenazi Jews.

There are other less common types of Parkinsonism caused by medication, progressive brain conditions and strokes.

SYMPTOMS OF PARKINSON'S DISEASE

There are many different symptoms associated with Parkinson's disease, but the order in which these develop and their severity is different for each individual with the condition. The symptoms of Parkinson's disease usually develop gradually and are mild at first.

Some of the most common symptoms are described below, although it is unlikely that a person with Parkinson's disease would experience all of these. The three main symptoms of Parkinson's disease that affect physical movement are:

- Tremor uncontrollable shaking, which usually begins in the hand or arm and is more likely to occur when the limb is at rest
- Slowness of movement (bradykinesia) where physical movements are much slower than normal, which can make everyday tasks difficult and can result in a distinctive slow, shuffling walk with very small steps
- Muscle stiffness (rigidity) stiffness and tension in the muscles, which can make it difficult to move around and make facial expressions and can result in painful muscle cramps (dystonia).

Parkinson's disease can also cause a range of other physical and mental symptoms.

OTHER PHYSICAL SYMPTOMS THAT ARE CAUSED BY PARKINSON'S

- balance problems
- loss of sense of smell (anosmia)
- problems with urination
- constipation
- sexual dysfunction
- dizziness, blurred vision or fainting
- swallowing difficulties (dysphagia)
- excessive production of saliva (drooling)

OTHER MENTAL SYMPTOMS THAT ARE CAUSED BY PARKINSON'S

- depression and anxiety
- insomnia
- •mild cognitive impairment
- dementia

WHEN TO SEEK MEDICAL ADVICE

You should book an appointment to see your GP if you are concerned that you may have symptoms of Parkinson's disease.

Your GP will ask about your symptoms and your medical history to help them decide whether it's necessary to refer you to a specialist for further tests. If they suspect Parkinson's they will refer you to a neurologist or a geriatrician. If you are diagnosed with Parkinson's, as well as talking to your family and care team, support and information is available, details of organisations who can help you can be found at the end of this document.

TREATING PARKINSON'S DISEASE

There is currently no cure for Parkinson's disease, but treatments are available to help relieve the symptoms and maintain your quality of life. You may not need any treatment during the early stages of Parkinson's disease as symptoms are usually mild.

- Medication most people with Parkinson's disease are treated with medication to improve the main symptoms of the disease, such as tremors (uncontrollable shaking) and movement problems. Everybody's medication will be unique to them. It is vital that medication is taken at the times it is prescribed, if it is not, the person's symptoms may become very much worse.
- Physiotherapy to relieve muscle stiffness, joint pain and fitness through movement and exercise
- Occupational therapy to help you to find practical solutions so you remain as independent as possible
- ■Speech and language therapy to help you with swallowing and speech difficulties
- Dietitian making dietary changes can help improve some symptoms, such as constipation, low blood pressure and weight loss
- Deep Brain Stimulation a type of surgery called deep brain stimulation is used in some cases. This involves surgical implants in the chest wall and brain. A tiny electric current stimulates the part of your brain affected by Parkinson's disease. Although surgery does not cure Parkinson's disease, it can ease the symptoms for some people for some time.

Everyone with Parkinson's disease should be entitled to be under the care of a neurologist or geriatrician and a Parkinson's nurse.

■Other sources of support – you may also find it helpful to talk to a trained counsellor or psychologist, or to someone at a specialist helpline like Parkinson's UK or at a local Parkinson's UK group. The contact details for Parkinson's UK national, local groups and for Jewish Care's Helpline are at the end of this leaflet. Jewish Care's Helpline can provide information and support about a range of issues including local groups for you and for your carers, benefits advice and other practical questions.

ADVANCED PARKINSON'S DISEASE

Parkinson's is a progressive disease. The disease advances differently for different people.

As Parkinson's disease progresses, you should be invited to discuss with your healthcare team the care you want as you near the end of your life. Palliative care tries to make the end of a person's life as comfortable as possible by attempting to relieve pain and other distressing symptoms while providing psychological, social and spiritual support for you and your family. Palliative care can be provided at home, in a hospice, in a residential home or in a hospital.

You may want to consider talking to your family and care team in advance about where you would like to be treated and what care you wish to receive. It is ideal to have these conversations before you become too unwell. Jewish Care's Social Work team can support you, contact Jewish Care's Helpline to find out about this service.

NEED MORE INFORMATION, SUPPORT OR ADVICE?

JEWISH CARE'S HELPLINE

A free confidential helpline that can provide advice and information about support on offer either from Jewish Care or other local service providers.

Telephone: 020 8922 2222 Email: helpline@jcare.org Website: www.jewishcare.org

PARKINSON'S UK

Specialist advice, information and support through the charities helpline and website. Can also provide information about support groups.

Parkinson's UK, 215 Vauxhall Bridge Road, London SWIV IEI

Telephone: 0808 800 0303

(Monday-Friday: 9am-8pm, Saturday: 10am-2pm)

Text Relay: 18001 0808 800 0303 (for textphone users only)

Email: hello@parkinsons.org.uk Website: www.parkinsons.org.uk

RICA

Consumer research and guidance on products for older and disabled people.

G03, The Wenlock, 50-52 Wharf Road, London NI 7EU

Telephone: 020 7427 2460 Email: mail@rica.org.uk Website: www.rica.org.uk

DISABLED LIVING FOUNDATION

National charity providing impartial advice and information about products to help with independent living.

4th Floor, Jessica House, Red Lion Square, 191 Wandsworth High

Street, London SW18 4LS Telephone: 020 7289 6111 Email: info@dlf.org.uk Helpline: 0300 999 0004

Contact: helpline@dlf.org.uk

Website:www.dlf.org.uk

HEALTH TALK ONLINE

Free, reliable information about health issues by sharing people's real-life experiences. You can watch people sharing their stories about living with a range of health conditions and disabilities including Parkinson's.

Email: info@healthtalk.org Website: www.healthtalk.org

NHS CHOICES

Website: www.nhs.uk

GENES AND PARKINSON'S - THE LRRK2 STUDY

Dr Mie Rizig (Clinical Research Fellow to Profs Nick Wood and Huw Morris), Neurogenetics Department, Institute of Neurology, Queens Square, London WCIN 3BG

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Studying people with the LRRK2 gene (which is more common in certain populations, including Ashkenazi Jews) who have Parkinson's and their unaffected relatives. The research hopes to provide early diagnosis and enable early treatment and to develop new drug treatments. Dr Rizig would like to hear from anyone interested in this area of research.

Please contact 020 8922 2450 if you require this information in larger print or an alternative format.

