

• PARKINSON'S DISEASE FACTSHEET

What is Parkinson's disease?

Parkinson's is a disorder of the central nervous system, resulting from the loss of brain cells in various parts of the brain, which in turn starve the brain of the chemical dopamine. Dopamine is a chemical messenger responsible for transmitting signals within the brain that allow for co-ordination of movement. Loss of dopamine causes neurons to fire without normal control, leaving patients less able to direct or control their movement.

The onset of Parkinson's is often in the 60's, though people have been diagnosed as young as 18.

Symptoms of Parkinson's disease

The symptoms of Parkinson's disease vary from person to person and many people with Parkinson's experience some symptoms but not others.

The symptoms are grouped into motor and non-motor symptoms.

1. Motor (cardinal) symptoms: these are the symptoms that most people associate with Parkinson's as they are visible to the onlooker. They often start at one side of the body and migrate to the other. They include:

- Tremor (shaking)
- Slowness of movement
- Balance problems
- Body rigidity
- Reduced facial expression

2. Non-motor (dopamine-non-responsive) symptoms:

- Cognitive impairment (memory loss / confusion)
- Mood disorders (e.g. depression or anxiety)
- Sleep disorder
- Loss of sense of smell
- Constipation
- Speech / swallowing difficulty
- Unexplained pain
- Drooling
- Sweating
- Low blood pressure when standing

Symptoms tend to worsen over time but again each case is different and the speed of deterioration varies on an individual basis.

Cause

The exact cause of Parkinson's disease is unknown, though research points to a combination of genetic and environmental factors. If a continuum existed, with exclusively genetic causes at one end and exclusively environmental causes at the other, different patients would fall at many different places along that continuum.

In the past ten years, researchers have identified a number of rare instances where Parkinson's disease appears to be caused by a single genetic mutation. Here, the mutated gene is passed from generation to generation, resulting in a great number of Parkinson's cases within an extended family. On the opposite of end of the continuum, in the early 1980s, a group of heroin users in the US took drugs from a batch contaminated with a substance called MPTP. After ingesting this chemical, the drug users were stricken with a form of Parkinson's disease that was primarily, if not exclusively, "environmental" in origin.

For most people with Parkinson's, the cause lies somewhere in between. Whilst many people with Parkinson's have relatives with the disease, it is not always possible to identify the 'offending' gene. Similarly, whilst some suspect exposure to a certain chemical or environmental toxin is the cause, it is difficult to prove.

Scientists believe that, in the majority of cases, genetic and environmental factors interact to cause Parkinson's disease. Research into this subject continues but for now, it is generally impossible to determine what specifically caused a person's case of Parkinson's disease.

Diagnosis

There is no widely accessible definitive test for Parkinson's whilst a person is alive. Rather it is diagnosed by a doctor examining the person's medical history and seeking to eliminate alternative medical conditions that could be causing the symptoms. In addition to this, Parkinson's medication can be used and the patient's response to this medication will be observed.

Due to the unscientific nature of the assessment, an estimated 20% of cases are misdiagnosed. A more definitive test is available in a post-mortem by examining the brain under a microscope.

Cure

At present, no cure has been found for Parkinson's disease, though significant levels of research for a cure continue.

Living with Parkinson's

Whilst the search for a cure for Parkinson's continues, the treatment is focussed upon controlling the symptoms of the disease. This treatment is through a combination of medication and therapy, though surgical treatment can also be used in certain cases.

Medication

Drug treatment is the main method used to control the symptoms of Parkinson's. Drug treatments aim to increase the level of dopamine that reaches the brain and stimulate the parts of the brain where dopamine works.

There are many different drugs prescribed for Parkinson's but none of them are perfect. Every person with Parkinson's has a different experience of the condition. The main drugs, along with their pros and cons are:

1. Dopamine Replacement Therapies (Levodopa)

In the 1970s, Levodopa was the first drug approved specifically for Parkinson's. Levodopa is converted by enzymes in the brain to produce dopamine, thereby supplementing function that has been lost as dopamine-producing neurons die.

Brand names are:

- Madopar®,
- Madopar® CR (co-beneldopa)
- Sinemet®,
- Sinemet® CR,
- Half Sinemet® CR (co-careldopa)

Pros

- In most patients, Levodopa significantly improves mobility and allows them to function relatively normally, at least in the early stages of the disease. Because Parkinson's worsens over time, increased doses must be taken to manage symptoms as they progress.
- Levodopa is widely recognized as the most effective treatment for motor symptoms of the disease.

Cons

- Levodopa has not been shown to slow disease progression. Additionally, the drug has significant side effects for some patients, including dyskinesia (involuntary movements and tics), hallucinations and illusions.
- Over time, symptoms may begin to come back before it is time for another dose of Levodopa.
- As "wearing-off" becomes more noticeable, the duration of good response to Levodopa shortens, while the duration of poor response may lengthen.

- High protein-diets may inhibit Levodopa absorption in some people, thus impacting drug effectiveness.
- Not effective at treating all symptoms of Parkinson's. Posture, depression and cognitive problems are not responsive to Levodopa.

2. Dopamine Agonists

Dopamine agonists are drugs that do not convert to dopamine in the brain, but instead mimic the effect of dopamine on the brain. Dopamine agonists supplement function that has been lost as dopamine-producing neurons die.

Brand names are:

- pramipexole dihydrochloride (Mirapexin®, Mirapexin® prolonged release)
- ropinirole hydrochloride (ReQuip®, ReQuip® XL)
- pergolide mesilate (Celance®)
- bromocriptine mesylate (Parlodel®)
- cabergoline (Cabaser®)
- rotigotine (Neupro®)
- apomorphine hydrochloride (APO-go®, APO-go® PEN, APO-go® PFS)

While some dopamine agonists have been around for years, new dopamine agonists have been developed that attempt to better manage side effects.

Dopamine agonists can be used alone or in combination with Levodopa.

Pros

- Dopamine agonists cause motor fluctuations including dyskinesias less frequently than Levodopa.
- No protein effects as seen with Levodopa.
- Agonists offer potential for alternate forms of delivery (such as a skin patch) that may offer certain advantages over oral administration.

Cons

- Dopamine agonists have not been shown to slow the progression of the disease.
- Dopamine agonists are not as effective as Levodopa for the treatment of motor symptoms.
- They may also cause other side effects including daytime sleepiness, sudden unanticipated sleep ("sleep attacks"), hallucinations and risk-taking behaviour-such as gambling and sexual obsessions.
- Not effective at treating all symptoms of PD. Posture, depression and cognitive problems are not responsive to dopamine agonists.

3. MAO-inhibitors

MAO-inhibitors inhibit an enzyme that breaks down Levodopa, thus extending its action.

Brand names are:

- Selegiline (Eldepryl®, Zelapar®)
- Rasagiline (Azilect®)

Used alone or in combination with Levodopa.

Pros

- Can prolong the action of Levodopa.
- May have a mild antidepressant effect
- Research is ongoing, but these drugs may offer some neuro-protection.

Cons

- Small symptomatic benefits.
- The drugs may have interactions with other medications and foods:
- Blood pressure issues must be monitored carefully.
- Both have potential interactions with antidepressants.
- Selegiline has more problems in the elderly (especially hallucinations).

4. COMT-inhibitors (Examples: Entacapone, Tolcapone)

Catechol O-methyltransferase (COMT) inhibitors allow a larger amount of Levodopa to reach the brain, thus raising dopamine levels there. They help provide a more stable, constant supply of Levodopa, which makes its beneficial effects last longer and manage off times better.

5. Used in conjunction with Levodopa

Pros

- Can prolong the action of Levodopa.

Cons

- By increasing the amount of Levodopa that reaches the brain, a COMT inhibitor also may increase some of the side effects associated with Levodopa use, including dyskinesia and hallucinations.
- Tolcapone has had some liver issues in some patients.

Surgery

Surgery is generally only used to treat people who have had Parkinson's for a long time and are not responding well to medication. It may also be used for people who are experiencing very troublesome dyskinesias (involuntary movements).

The risks of surgery may be increased in very elderly people and those with other conditions that might cause complications. As such many surgeons will not operate on anyone who is experiencing confusion or psychosis, has experienced a stroke or has dementia or severe depression.

The main forms of surgery are:

Deep brain surgery

This can help to alleviate slowness of movement, stiffness and tremor for some people.

Deep brain stimulation involves the implantation of a wire, with 4 electrodes at its tip, into one of 3 target sites in the brain:

- the thalamus (this procedure is known as thalamic stimulation)
- the globus pallidus (this procedure is pallidal stimulation)
- the subthalamic nucleus (this procedure is subthalamic stimulation)

The implantation procedure is usually performed under local anaesthetic with the person awake.

The target site is then stimulated with a small electric current and the person's response monitored to confirm accurate target localisation. The wire is then connected to a small unit called an Implantable Pulse Generator (IPG). This is implanted - under general anaesthetic - under the skin in the chest, similar to a pacemaker.

The wire goes from the top of the scalp, underneath the skin, and down the side of the neck to the IPG, generally by the collarbone or sometimes in the abdomen.

Sometimes the wire can get tight so it's important to keep moving your neck after the operation.

The IPG contains the battery and electronics to generate the electrical signals for the stimulation.

The batteries in the Implantable Pulse Generator have a relatively long life. They only need to be changed every 3 to 5 years.

The IPG is programmed by the clinician using a computer. On a day-to-day basis, the stimulation can be switched on and off by the person with Parkinson's using a hand-held programmer or a magnet.

Lesioning techniques

Lesioning techniques involve making selective damage (a lesion) to certain cells within specific areas of the brain

These lesions are known to have a beneficial effect on some Parkinson's symptoms.

Pallidotomy: the most common form of lesioning technique used. Here the target site is located in the part of the brain known as the globus pallidus. Pallidotomy is most important for its effect on rigidity and akinesia (slowness of movement), and reductions in the sudden, involuntary movements (dyskinesia) that can result from drug therapy.

Stereotactic thalamotomy: recommended mainly for patients with a severe or drug resistant tremor, especially when one side of the body is afflicted more than the other. Thalamotomy is used mainly to treat tremor.

Subthalamotomy: has been performed by neurosurgeons at a few hospitals. This procedure involves making a destructive lesion in the subthalamic nucleus rather than implanting an electrode as is the case with subthalamic stimulation. Subthalamotomy is still experimental. It has not gained popularity because of the perceived high risk and the uncertainty about its long term effects in a progressive condition.

The risks of surgery

Each form of surgery for Parkinson's carries its own risks. These should be discussed with your consultant.

Some of the general risks associated with these techniques include:

- increased risk of a stroke leading to paralysis
- cognitive changes
- speech problems
- death (very rarely)

Therapies and Parkinson's management

There are a number of therapies that can help people with Parkinson's. Therapists can provide practical help and advice on a whole range of issues.

- Physiotherapy: advice on posture, walking and exercises.
- Occupational therapy: advice on such things as home adaptations which may ease many tasks.
- Speech and language therapy: if difficulties with speech, swallowing or saliva occur.
- Psycho therapy: support with depression.
- The advice of a dietician and other therapists may be needed for some people.

For carers, they can also advise or train them in safe and appropriate ways to help you with mobility concerns, and suggest ways to prevent falls.

Exercise

A regular exercise regime can help in maintaining physical abilities, strengthening muscles, increasing mobility in joints and building up general fitness and health. Making exercise part of your regular routine provides a sense of achievement. It can also reduce feelings of stress, anxiety and depression.

Complementary therapies and Parkinson's

Complementary therapies are treatments that may be used in addition to or alongside conventional medicine. Many people with Parkinson's find complementary therapy to be a very positive experience. Some people find relief from Parkinson's symptoms and find that treatments can be relaxing.

Complementary therapies do not replace orthodox medicine. They should always be used in addition to, not instead of, usual treatments.

Some complementary therapies do have side effects, can clash with prescribed medicines or can be harmful if provided by untrained practitioners.

Always check with your GP, specialist or Parkinson's nurse before you try any complementary therapy.

Care

Early on, Parkinson's disease may not greatly disrupt people's lives. But for most people, the disease becomes more disabling over time. Home care can help people adjust as the disease progresses and help them stay independent for as long as possible. The quality of life may depend, in part, on one's ability to continue working, take care of a home, care for their family and remain independent. People may need adaptive devices such as canes or zimmer frames as the disease progresses.

Aspects of home care that are important for a person with Parkinson's disease include:

- Modifying activities and the home, such as simplifying daily activities and changing the location of furniture so that things can be held onto to ease moving around the house.
- Eating healthy foods, including plenty of fruits, vegetables, grains, cereals, poultry, fish, lean meats, and low-fat dairy products.
- Exercising and doing physical therapy that has benefits in both early and advanced stages of the disease.
- Dealing with tremor, which may include putting a little weight on the hand to help reduce tremor and restore control.
- Improving speech quality by working with a speech therapist.
- Reducing problems with eating and drooling by changing how and what is eaten.

- Dealing with "freezing" by various means, such as stepping towards a specific target on the ground.
- Dealing with sexual function problems – doctors may be able to suggest a change in medication or exercise.
- Dealing with depression - asking friends or family members for help. If the feelings persist, then talking to a doctor.
- Dealing with dementia. Dementia is common late in Parkinson's disease. Symptoms may include confusion and memory loss. If dementia is thought to be present, talk to a doctor. There are medicines that can help dementia in people with Parkinson's disease.

Here to Help

We understand the frustrations that people face in providing care for people with Parkinson's disease. If you would like help or further, please don't hesitate to contact us on 020 8892 9222 or info@curacare.co.uk