Understanding Parkinson’s

THIS FACT SHEET explains what Parkinson’s is, who develops it and what we know about its cause. It describes diagnosis, symptoms, effects of the condition over time, treatments and therapies.

What is Parkinson’s?
Parkinson’s is a neurological condition that affects the control of body movements. People with Parkinson’s experience trembling, rigidity, slowness of movement and changes in posture. The condition is neither fatal nor contagious, but it is degenerative, which means the symptoms become worse over time.

What Causes Parkinson’s?
At present, we do not know the cause of Parkinson’s. We do know that there is a loss of nerve cells (neurones) in the substantia nigra (a pigmented area in the base of the brain), which is part of the basal ganglia (the area that controls and coordinates body movements).

Neurones produce a chemical called dopamine that enables nerve impulses (messengers to and from the brain) to move between one nerve cell and the next. With fewer neurones in the substantia nigra, there is less dopamine, which interferes with the transmission of messages within the basal ganglia. As a result, some parts of the brain which control body movement become overactive, while other parts become underactive.

The first signs of Parkinson’s are usually noticed when approximately 60% to 70% of these dopamine-producing neurones are lost. Why these cells die remains a mystery to researchers.

Who Develops Parkinson’s?
Parkinson’s is the second most common degenerative neurological condition after dementia. More than 80,000 people in Australia are living with it and about 4000 new cases are diagnosed each year. Parkinson’s affects men and women and is more prevalent in people aged between 50 and 75 years. Approximately 10% of those diagnosed are 40 years and younger.

Diagnosis
Parkinson’s is highly individual and complex in nature and diagnosis is based on clinical assessment and patient history. It also appears similar to a number of other neurological conditions. Many patients therefore undergo a range of blood tests and scans (MRI and CT) to eliminate the possibility of other conditions. (See Fact Sheet 3: Tests and Technology).

There is no definitive test to prove a person has Parkinson’s but a good indication of correct diagnosis is if they respond well to levodopa therapy (see Medication).

Accepting a diagnosis of Parkinson’s can be difficult for the person diagnosed and their family. It needs to be addressed sensitively to allow people time and space to come to terms with the condition. Do seek further information and advice as you need it. Just ask us for help.

Symptoms
Each person with Parkinson’s has a different pattern of symptoms that varies enormously both throughout the day and over time. It is important to keep a diary that notes any changes in symptoms for discussion with your neurologist.
Many people notice that stress, anxiety and fatigue greatly increase the severity of their symptoms. Fluctuation of symptoms can also occur as the illness progresses.

**Tremor:** Tremor usually begins in a finger or hand, although sometimes the legs, lips and head also shake. The tremor is slow and mostly present when limbs are resting. It decreases when the person uses the limb and it disappears during sleep. About 70% of people with Parkinson’s will exhibit this symptom.

**Rigidity:** This is the resistance you feel when you move the limb of a person with Parkinson’s. If the resistance feels stiff and jerky, it is known as “cog-wheel rigidity”. If it is smooth and consistent, it is “lead-pipe rigidity”. It may affect some limbs more than others and can affect the muscles of the face and neck (often present as cramping). People with Parkinson’s sometimes experience “freezing” or the inability to start certain movements.

**Slowness:** Parkinson’s causes movements to become slow and restricted (bradykinesia). Spontaneous movements, such as swinging the arms while walking, facial expressions and gestures, become difficult. Bradykinesia usually begins with fine movements, such as doing up buttons or writing. Some people begin to shuffle as they walk, taking smaller steps and leaning forward with hunched shoulders, which can lead to poor balance and falls.

**Depression:** People with Parkinson’s are more vulnerable to depression due to the chemical changes happening in their brains. Some people find the challenges of Parkinson’s too much, which can also lead to depression. It is important to determine the cause of depression and to get it treated.

**Speech and swallowing difficulties:** About half of those with Parkinson’s develop some difficulty with their speech or swallowing as the condition progresses. Speech may become soft or slurred and speed control becomes difficult – the person may start to talk at normal speed but get faster and softer and more difficult to understand. Slow, stiff and uncoordinated mouth movements affect eating and swallowing.

**Loss of animation:** Parkinson’s can cloak a person’s personality and emotional responses. Communication through facial expression can become restricted and the voice may become flat, with less expression, which might be mistaken for lack of interest or perhaps, dementia.

**Cognitive problems:** Some people have difficulty with short-term memory and with organising a sequence of tasks.

**Treatments**

The main treatments are individual management through medication or surgery.

**Medication:** A person with Parkinson’s requires a highly specific drug regime that suits his or her particular needs. This often involves a ‘cocktail’ of different drugs. Responses to the drugs vary with the passage of time, the progression of the condition, the dosage of the drug and the length of time the person has been taking it. As a result, the drug combination must be reviewed and modified. For some people, that means periodic stays in hospital of two to four weeks to monitor the effects of the drugs and to work out the most effective new regime. It also means having regular appointments with a specialist.

Five main groups of drugs are used:

- Dopaminergic
- COMT inhibitors
- Dopamine agonist
- MAO inhibitors
- Anticholinergics

**Dopaminergic:** These drugs restore levels of dopamine in the brain. Levodopa is the most effective treatment for reversing the symptoms. It is absorbed into the brain and converted into dopamine. Some common therapies are levodopa with carbidopa (brand name: Sinemet or Kinson) and levodopa with benserazide (brand name: Madopar).
Levodopa treatment has some long-term side effects - dystonias (twisting postures) and dyskinesias (involuntary movements).

Dyskinesia may affect the face, tongue, upper body, arms and legs. The movements are jerky, sudden contractions followed by stretching and writhing motions. Newer drugs can be used to extend the benefits of levodopa to prevent this.

There may be a tendency for the benefits of each dose of levodopa to wear off before the next one is due. Many factors, such as stress and diet, affect how long a dose of levodopa lasts.

**COMT Inhibitors:** These agents are taken at the same time as levodopa. The addition of a COMT inhibitor provides a longer and smoother availability of levodopa to the brain. Entacapone (brand name: Comtan) is a commonly used COMT inhibitor.

**Dopamine agonist:** Rather than replacing dopamine as levodopa does, these drugs copy the action of natural dopamine. They are taken in conjunction with levodopa to reduce the amount of levodopa being taken and to reduce the wearing-off effect that can occur.

**Three drugs available are:** bromocriptine (brand name: Parlodel), cabergoline (brand name: Cabaser) and pergolide (brand name: Permax). These are taken orally and each tablet works longer than levodopa.

Dopamine agonist drugs have side effects, particularly in the elderly. They can create confusion, hallucinations and the lowering of blood pressure when standing up.

A fourth dopamine agonist is available by injection - apomorphine. This is a very potent, “rescue” drug that works within 5 to 10 minutes and gives relief of symptoms for about an hour. It may also be used for people whose fluctuating symptoms cannot be controlled by oral medications.

**MAO Inhibitors:** These are used in conjunction with levodopa to reduce symptoms. Dopamine is broken down in the brain by an enzyme called monoamine oxidase B (MAO B). Research for a drug that would inhibit MAO B exclusively, thereby allowing a lower dose of levodopa to be more effective, led to the development of a drug called selegeline (brand name: Eldepryl).

**Anticholinergics:** In a healthy brain, there is a balance between dopamine and acetylcholine. In a brain affected by Parkinson’s, acetylcholine is more active due to the loss of dopamine. Anticholinergics can help maintain and balance dopamine and acetylcholine levels.

**Anticholinergics available include:** benzhexol (brand name: Artane), biperiden (brand name: Akineton), procyclidine (brand name: Kemadrin) and benztropine (brand name: Cogentin). They are typically used to control tremor that cannot be controlled by other means.

Side effects can include dryness of mouth, blurring of vision, nausea, palpitations and difficulty urinating or incontinence (loss of control over bladder or bowel movements).

**Other:** Amantadine (brand name: Symmetrel) has been around for a while, but in recent years it has been used as an effective treatment for drug-induced dyskinesias. It can produce similar side effects to the anticholinergics.

**Surgery:** Surgery does not cure Parkinson’s but it provides another option if medication becomes less effective. About 5% of all patients are candidates. It can be used to treat specific symptoms and to reduce dyskinesias. The two main procedures are called stereotaxic surgery and deep brain stimulation. Surgery involves considerable risks however, and must be discussed carefully with a neurologist.

**Managing Parkinson’s**

While there is no cure for Parkinson’s, there are plenty of ways to reduce some symptoms and the condition can be managed well with a combination of therapies, regular activity and a healthy diet. It is possible to achieve quality of life, independence, confidence and mobility. The sooner you begin working on these areas after diagnosis, the better.
Rehabilitation: Once established, an alert rehabilitation team can step in to prevent problems before they occur and can assist carers in caring for the person at home for as long as possible.

As the condition progresses, some people may require intensive "top-up" bursts of therapy in a rehabilitation centre. Others may need long-term day or outpatient therapy, perhaps on a weekly basis. A combination of the two may be needed.

Physiotherapy: Physiotherapy improves coordination, balance and movement. Parkinson’s affects a person’s ability to perform many small movements that were once automatic. A physiotherapist can help you re-learn how to consciously make these movements. Good mobility also depends on your will to keep as active and fit as possible.

Speech pathologist: A speech therapist may help with swallowing difficulties or improving your ability to speak loudly and clearly, for example.

Dietician: A dietician can devise a nutrition program that deals directly with any complications or deficits that may be caused by drug treatments or the ongoing effects of Parkinson’s.

Occupational therapy: Occupational therapists can assess potential safety issues around the home that may arise due to tremor or memory difficulties, for example. An occupational therapist can also demonstrate how to break tasks up into small, manageable steps.

Self-help programs

There are also more than 100 Parkinson’s support groups around Australia, with more than 40 in Victoria. These are terrific places to meet other people and talk through any difficulties. Contact the Parkinson’s Association in your state for details.

Developing a good exercise regime is invaluable and can help to reduce rigidity. Tai Chi has proven to be fantastic for many people with balancing problems. Relaxation and meditation are extremely helpful methods of stress management. (See Fact Sheet 5: Assessing Alternative Therapies).

Contact

Parkinson’s Victoria Inc.
20 Kingston Road, Cheltenham, 3192

telephone: (03) 9551 1122
free call: 1800 644 189
fax: (03) 9551 1310

email: info@parkinsonsvic.org.au
website: www.parkinsonsvic.org.au

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