

PARKINSON'S

A GUIDE FOR THE NEW PATIENT



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INTRODUCTION

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This booklet has been produced for New Zealanders who have just been given a diagnosis of Parkinson's disease. The content of the booklet is based on the discussions and questions that have arisen in the Movement Disorders clinic when we have told our patients about Parkinson's.

This is the fourth edition of the book with changes to reflect new developments.

Dr Barry Snow, Neurologist, Lorraine Macdonald, Movement Disorder Nurse, Auckland Hospital. April 2008.

The diagnosis of Parkinson's is often unpleasant news. Usually a patient leaves the doctor's clinic remembering only a few points - the diagnosis and perhaps one or two other facts that may not even be particularly relevant. After the news has sunk in, most people want to know more about Parkinson's, how can it be treated and what is the outlook. This booklet is designed to provide you with this information. The first part of the booklet describes Parkinson's. The middle part describes non-medical treatment, and the final part describes medical treatments for Parkinson's.

1. If you have any questions about any of the information in this booklet, please refer to your family doctor or specialist, or contact Parkinson's New Zealand at the address on the back cover of this book.
2. Your doctor or specialist is the person who is in the best position to make decisions about the medications that best suit your particular condition. If you have any questions about any medications including those for Parkinson's, please talk to your doctor or specialist.





PARKINSON'S

Parkinson's has probably always affected humans. We have some accounts from Roman times that could do for descriptions of Parkinson's. The first authoritative, medical description was by Dr James Parkinson in 1817 in a paper describing many features of the condition. Since that time many doctors and scientists have taken an intense interest in Parkinson's, and we now know more about it than any other degenerative condition of the brain.

Parkinson's is quite common. Over the whole population between 1-2 people in a thousand have the condition. It becomes more common with older age groups however, and perhaps 1% of people above the age of 60 have Parkinson's. Nowadays, with good medical treatment, Parkinson's generally has only a small effect on life expectancy. However, it can be disabling. With a positive outlook, good medical care and good support from other resources, most people with Parkinson's can lead a productive life for many years.

The condition develops very slowly, and it may be a while before the diagnosis can be made with certainty. Some people initially develop a tremor, which becomes obvious and often leads them to the doctor. Other people notice mild clumsiness of a limb. Sometimes

this can interfere with handwriting, which becomes small. Other people develop a stooped posture or a reduction in arm-swing when they are walking. Other people develop a sense of increased fatigue, making tasks take longer and seem more of an effort. Often these changes are noticed by a family member or, sometimes, by a new doctor or locum for the family doctor. This is because Parkinson's develops so slowly that people who see the person every day may miss these small changes.

Approximately 80% of people with the symptoms of Parkinsonism have Parkinson's. There are a number of other conditions that can resemble Parkinson's. These conditions include medication-induced Parkinsonism, Multiple System Atrophy (MSA) (previously known as Shy-Drager syndrome) and Progressive Supranuclear Palsy (PSP). These conditions are less common than Parkinson's, and sometimes they can be difficult to distinguish in the early phases. For this reason, in a number of people the diagnosis of Parkinson's may be revised after a few years. Fortunately however, the initial treatments of these different conditions is usually the same, and therefore time is not lost if the diagnosis must be changed.



THE MAIN SYMPTOMS OF PARKINSON'S

Tremor

About three quarters of people develop a tremor at the onset of their illness. However, a number of people never develop tremor throughout the course of their Parkinson's. The important feature of the tremor is that it tends to occur when the limb is relaxed. The tremor tends to disappear while performing tasks such as writing or drinking from a cup. For this reason the tremor is frequently not particularly disabling, although it can be embarrassing.

Stiffness

Stiffness or rigidity is often detected by the examining doctor. These symptoms can contribute to deep aching sensations felt in the limbs.

Slowness of movement

This is also known as bradykinesia. It can affect various parts of the body. One of the early signs of Parkinson's is a flat or expressionless face. This can sometimes give the person the appearance

of lacking emotion, not being interested in other people, or looking serious and not smiling. When the bradykinesia affects body movements the person has difficulty rolling over in bed or sometimes getting out of a chair. Bradykinesia in the limbs affects rapid movements. This is particularly noticeable with alternating movements such as cleaning teeth or combing hair. People with bradykinesia of the hands develop a distinctive change in handwriting where the letters get progressively smaller and less legible as the writing proceeds across the page.

Loss of balance

This tends to occur later in Parkinson's. Sometimes there is some difficulty getting out of a deep chair or a low car seat. As the condition progresses, the person becomes less able to compensate for a mild loss of balance when walking on rough ground and may tend to fall forwards. Sometimes to compensate for this the feet move forward quickly to produce a peculiar running walk.

Other symptoms

The four main symptoms described on page 3 are characteristic of what is known as Parkinsonism. People with Parkinson's often suffer other symptoms however. These often go unrecognised despite the fact that they can be more annoying than the main symptoms. Some symptoms are curious such as the loss of sense of smell that can occur many years before the onset of other symptoms of Parkinson's. Other symptoms can include the following.

Skin sensations and pain

Many people develop unusual skin sensations. These are often electric or tingling sensations of the limbs. They are often more prominent at night. Some people develop unusual aches and pains. Sometimes these can be particularly severe. Some of the pains occur in the morning and relate to a lack of medication overnight. Other pains develop when the medication is at its peak. Often these pains are misdiagnosed as arthritis.

Constipation

Constipation is very common in Parkinson's. This is caused by a reduction in the ability of the bowel to contract. While eating bran to increase the bulk of the bowel motion is important for most causes

of constipation, in Parkinson's this must be done cautiously as the bowel may not have the strength to move the extra bulk. Often people need to treat themselves with exercise and extra fluid along with stimulating agents such as fruit extracts. Sometimes a special laxative such as lactulose is necessary.

Tiredness

Fatigue, daytime sleepiness and a loss of motivation can be common symptoms for people with Parkinson's. Some find the tiredness can be improved with regular exercise and rest. When tiredness is prominent, people often have to be careful not to take on too many responsibilities or tasks that they cannot complete.

Depression

Approximately one third of people with Parkinson's develop depression at some time during their illness. Depression can sometimes precede the diagnosis of Parkinson's. The depression can also be associated with anxiety, which occasionally is severe.

The frequency of depression in Parkinson's is greater than would be expected in people with other chronic illness. For example, there is much less depression in people with heart disease. The increase in depression in Parkinson's is probably related to chemical changes in the brain, similar to the chemical changes that produce the Parkinson's itself.



The depression of Parkinson's has traps for both patients and doctors. Many of the symptoms of Parkinson's: namely the slow movement, the poor energy and disruptive sleep, are very similar to those of depression and can mask the true diagnosis of depression. Often people think that the symptoms of depression are caused by under treatment, and this can lead to inappropriate increases in the dose of the anti-Parkinsonian pills.

A number of symptoms can point to the development of depression. These include a disturbance of sleep, a lack of energy, a feeling of hopelessness or lack of optimism, poor concentration and forgetfulness, a change in appetite and feelings of sadness.

The depression associated with Parkinson's responds to standard anti-depressant treatment and usually requires medication.

The important point is to recognise the possibility of depression and bring it to the attention of your doctor.

Sleep disturbance

Most people develop some form of sleep disturbance. This can include interruption of sleep by tremor, pain or difficulty rolling in bed.

Other people develop a more distinctive sleep disturbance. The most striking of these is rapid eye movement (REM) sleep behaviour disorder. In this condition, the person acts out vivid dreams. They may run, punch or kick as they dream about fighting a wild animal or other assailant. The spouse often bears the brunt of the attack! REM sleep behaviour disorder is worth discussing with your doctor as it can be treated with low doses of the medication clonazepam.



WHAT CAUSES PARKINSON'S?

Parkinson's is caused by the degeneration of a group of nerves in an area of the brain called the substantia nigra, which is located in the base of the brain. These nerves produce a chemical called dopamine. The lack of dopamine produces the symptoms of Parkinson's. There are also changes in other parts of the brain. These may cause symptoms such as sleep disturbance, pain and changes in thinking.

At present we do not know what causes the degeneration of the substantia nigra. There are many theories, and a large amount of research is going on around the world into the cause of Parkinson's, but there are no clear answers yet. A person with Parkinson's has a slightly increased chance of another family member having the condition.

Young onset Parkinson's may be due to a genetic disorder, but this is usually recessive inheritance. This means there is little risk in passing it on to children.

In the 1920s there were epidemics of a form of flu called encephalitis. Some of the people who recovered from this developed a disease that looked very much like Parkinson's. This experience raises the possibility that Parkinson's could be caused by an infection. Parkinson's is not passed from person to person however, so an infectious cause seems unlikely.

Some scientists think that there may be some substance in the environment that might cause Parkinson's. As yet, however, no particular substance has been identified.

Many people have a theory for the cause of Parkinson's based on their own experience. This may be an injury, an operation or another cause of unusual stress. Stress tends to exacerbate the symptoms of Parkinson's. If the diagnosis has not yet been made the symptoms may become obvious for the first time, which may lead to the erroneous conclusion that the stress has caused the Parkinson's.





HOW DOES PARKINSON'S DEVELOP?

There is no evidence that any of these factors actually cause Parkinson's however. While stress may make the symptoms more noticeable during the time of stress, there is no evidence that it makes the Parkinson's progress further. It's important for the person with Parkinson's not to think of him or herself as fragile.

The important point to remember is that Parkinson's is not anyone's fault. It has nothing to do with a bad diet, smoking or other behaviour. It is also important to remember that there is not enough risk of inheritance for family members to worry about developing the Parkinson's. It is also not infectious - you do not have to worry about being in contact with someone who has Parkinson's.

A person does not suddenly develop Parkinson's. The nerves in the substantia nigra degenerate or die out slowly and so the condition comes on gradually. The first observation is sometimes a tremor or slowness of movement. Gradually Parkinson's becomes more obvious and usually after six months or a year the diagnosis of Parkinson's is made. A few patients who are initially given a diagnosis of Parkinson's go on to develop additional symptoms, and their diagnosis is changed to another Parkinsonism condition such as PSP or MSA. The initial treatment of these conditions is the same as for Parkinson's, so it is not critical to differentiate the conditions at an early stage.

At the time of diagnosis the symptoms may be obvious but are usually not disabling. No treatment currently stops the degeneration of the nerves in the substantia nigra. For this reason early medical treatment is not necessary, and drugs and other treatments are generally reserved for when the patient becomes slowed or disabled by the condition.



TREATMENT OF PARKINSON'S

If the person is falling down or at risk of losing a job, this is an important reason for starting treatment. Other people become embarrassed by the tremor or feel that the fatigue is becoming troubling. These are also good reasons for starting treatment.

Once the decision is made to start treatment, a number of medications are available. These will be described in detail from page 10. After an initial settling in period, most people respond very well to the treatment for years.

This period of good responsiveness to medication is sometimes called the 'honeymoon period'. It is characterised by long smooth response to medication and a return to normal daily function. Most people still have signs of Parkinson's but most are able to continue on at work and do the things they want. People can lead otherwise normal and productive lives during this period.

There are a number of important approaches to the treatment of Parkinson's that do not involve medication.

Exercise

Exercise is very important for Parkinson's. As well as improving general health and well being, it seems to improve the response of the body to dopamine. Everybody with Parkinson's should attempt to get at least 20-30 minutes of aerobic exercise each day. Possibilities include walking and exercise classes. Most Parkinson's New Zealand divisions offer exercise classes.

If possible, it is a good idea to join a gym.

Sleep

The brain recharges its dopamine overnight. Most people with Parkinson's feel they have good mornings and tend to deteriorate throughout the day. Most people also find that a good night's sleep leads to a good day with Parkinson's.

Regular exercise improves sleep. Avoiding coffee and other caffeine-containing drinks in the afternoon can also be helpful. It is important not to spend too much time in bed. People should go to bed relatively late and get up relatively early in order to compress their sleep and prevent waking overnight.

Sometimes people have disrupted sleep despite taking these steps. If this is the case, sometimes medication can be helpful. By and large, it is best to try to avoid taking standard sleeping pills as they tend to lose their effectiveness after a time. People often respond to low dose tricyclic anti-depressants, such as amitriptyline, which are also very good at modulating sleep. These can be prescribed by your doctor. An advantage of these drugs is they tend to relax the bladder slightly. This can prevent the need to wake up and go to the toilet repeatedly during the night.

Things that are not necessary

You will get plenty of advice on how to treat Parkinson's. While some may be helpful, much will have no basis in fact. No special diet is necessary beyond a good balanced intake of a wide variety of foods. There is no evidence that special vitamin supplements make any difference. There are a number of so-called energy supplements available in health food stores. There is no evidence that these make any difference. The one exception may be coenzyme Q10. One small study suggested that it may help Parkinson's but only at high doses. We currently do not recommend coenzyme Q10, however.

Don't make any hasty decisions about your life. Parkinson's progresses slowly, and there is no urgency to make decisions about work and whether you should move house. The need for any change like this will become clear with time. In addition, no particular activity should be avoided. Driving is permissible in the early stages of Parkinson's. Many people continue with their sporting activities such as tennis. There is no reason to avoid sexual activity.



MEDICATIONS FOR THE TREATMENT OF PARKINSON'S

The symptoms of Parkinson's are caused by a lack of dopamine in the brain. Eventually, almost every patient with Parkinson's will need to take medication in order to replace the missing dopamine. The following is a list of treatments for motor symptoms of Parkinson's. Other medications may be used to treat non motor symptoms.

Levodopa

The standard treatment for Parkinson's is with a drug called levodopa. Levodopa is taken up from the stomach, absorbed into the brain and converted to dopamine, which is the brain chemical missing in Parkinson's. The standard levodopa treatments are Sinemet® and Madopar®. You will see on the package containing Sinemet or Madopar that the dose is written such as 25/100 or 125. The 100 refers to the amount of levodopa in the tablet and the 25 refers to an extra medication in the tablet designed to prevent conversion to dopamine in the blood before it gets to the brain.

Side effects of levodopa

If levodopa is given in a full dose immediately it virtually always causes nausea. For that reason we recommend starting the medication slowly at approximately 50mgs per day. The dose is then increased gradually until the patient is taking approximately 50-100mg three times per day. The effect of the medication is reassessed and then the doses adjusted accordingly. As the Parkinson's progresses, people require progressively higher doses. Most people manage on a total of less than 1000mgs per day in three or four doses.

Levodopa only lasts a short time in the bloodstream. In early Parkinson's levodopa is stored in the brain and is released slowly so that the patient has a smooth steady response to the medication. As Parkinson's advances however, the brain loses some of that storage capacity. At that time the patient tends to notice the effect of the medication coming and going. When this occurs sometimes medication may need to be given more frequently. Both Sinemet and Madopar are also available in

slow release formulations which are more suitable for some patients. In others a combination of slow and fast release formulations are used, the fast one to 'kick start' the Parkinsonism in the morning, and the slow formulation for control during the day. If you need to go onto levodopa therapy, your doctor or specialist will be able to work with you to select the correct combination for your particular condition.

The most common side effect of levodopa is nausea. This usually goes away after a time. The best way to prevent nausea is to start the medication at low doses and increase it gradually. Initially the medication should be taken with food. Usually this approach is sufficient to prevent nausea.

If the nausea does not go away, the medication domperidone may be added. Domperidone blocks the nausea effect of Parkinson's without making the Parkinsonism worse as do some other anti-nausea drugs. Domperidone should be taken half an hour before the dose of Sinemet or Madopar.

Nightmares and hallucinations

Older people can develop nightmares when taking levodopa. Sometimes people see a flash of light in the edge of their vision. They may interpret this as a cat or rat running across the edge of the room. Sometimes they experience a strong feeling that there

is somebody else in the house. These hallucinations are usually not troubling or frightening. The doctor should be told about them however as they are a reason to avoid increasing the dose of levodopa.

Other medications

Dopamine agonists

The dopamine agonists are a family of drugs that help bolster the effect of levodopa. Some neurologists choose to introduce these drugs at the beginning of Parkinson's, and then add levodopa when that is necessary. Other neurologists start with levodopa first and add a dopamine agonist later on.

There are four dopamine agonists currently available in New Zealand. They are bromocriptine (Parlodel), pergolide (Permax), lisuride (Dopergin) and ropinirole (Requip). These medications have very similar effects. The side effects are also generally similar to those seen with levodopa.

Bromocriptine and pergolide can also cause a persistent cough and redness and swelling of the legs. If these symptoms occur they should be reported to the doctor. In addition, there have been recent reports of scarring of heart valves among people taking pergolide and bromocriptine. This has led to the recommendation that people taking these drugs should have regular echocardiograms.

Recently, dopamine agonists have been associated with a bizarre side effect of impulse control disorder where people impulsively gamble, shop, eat or engage in inappropriate sexual activity. This is a rare complication, but it is important to be aware of the possibility and report any change in behaviour to your doctor.

Amantadine and anticholinergics

Amantadine (also known as Symmetrel) and a number of anticholinergics (e.g. Disipal, Cogentin) have also been used to treat Parkinson's for many years. They have a modest effect on the Parkinson's, but some people find them very useful. Sometimes doctors choose to prescribe these medications initially, then add the more powerful levodopa preparations and dopamine agonists when the Parkinson's becomes worse. Some people can experience side effects of these medications including dry mouth, dizziness, constipation and nightmares. In elderly people these medications can also cause confusion.

COMT inhibitors

After taking the standard levodopa treatment of Sinemet or Madopar, the levodopa in the blood stream is broken down quite rapidly. In early Parkinson's this is not so important, but after a few years the rapid breakdown of the levodopa can cause

a fluctuation in the effectiveness of the medication throughout the day. The main enzyme for breaking down the levodopa in the blood, is called COMT. COMT inhibitors can be very effective for smoothing out the response to levodopa.

Two COMT inhibitors are available in New Zealand. Entacapone (Comtan) is taken with each dose of levodopa. Tolcapone (Tasmar) is taken three times daily. Tolcapone can cause dysfunction of the liver and people taking this drug must have regular blood tests; it is a more powerful medication than entacapone, however.

Which medication is the one for you?

There are many different options for treating Parkinson's and there is some debate as to the best medication for certain situations. Importantly, there is no evidence that starting treatment early will alter the long-term course of Parkinson's. For that reason we tend to reserve medication for when the Parkinsonism becomes troublesome. There is also no evidence that any medication will make the underlying disease worse; so there is no reason to put off treatment when symptoms demand it. It is a myth that the medication loses effectiveness over time; any apparent loss is caused by the disease getting worse.

Surgical management

While a lack of dopamine is the basis of Parkinson's, the symptoms are caused by a complex series of nerve connections. It is possible to interrupt these connections surgically and thus improve some of the symptoms of Parkinson's.

The current surgical management of Parkinson's involves inserting an electrode in the brain and confusing or "stunning" the area with an electrical current that is generated by a small device similar to a heart pacemaker; this is known as deep brain stimulation.

Surgical therapy is only suitable for a few patients with certain types of advanced Parkinson's and is not for the new patient.

Forty years ago, the prospects were very bleak for a person diagnosed with Parkinson's. The only effective treatments were the anti-cholinergic medications, and these are not very powerful. The introduction of levodopa transformed the outlook of people with Parkinson's. Since that time, many new medications and treatments have been released. We also know much more about Parkinson's.

In several countries around the world, scientists are experimenting with transplanting brain tissues, such as stem cells into people with Parkinson's. This tissue is similar to that of the substantia nigra tissue and produces dopamine which can replace or supplement the dopamine medication. There is similar work on inserting genes that alter the way neurons work to make them produce more dopamine.

All of these treatments are being studied intensively, including in New Zealand. None of these treatments are ready for general use, but they offer new hope for people with Parkinson's.



PARKINSON'S NEW ZEALAND

Parkinson's New Zealand is a not for profit organisation that offers support, education and information to people with Parkinsonism conditions, their families, carers and health professionals.

Parkinson's New Zealand has divisions and support groups nationwide.

We can offer:

- ✿ Information on Parkinson's and Parkinsonism conditions including MSA and PSP
- ✿ Regular up-to-date information through our national magazine, website and local newsletters
- ✿ Responsible reporting of recent research
- ✿ Books and audio-visual material
- ✿ Local meetings and education programmes
- ✿ Advice on health and welfare assistance available
- ✿ Support from a professional Field Officer in your area
- ✿ Fellowship and support
- ✿ Links to other services

Parkinson's New Zealand is reliant on funding from grants, bequests and donations.

Your support is welcome!



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