



# PARKINSON'S

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A GUIDE FOR THE  
NEWLY DIAGNOSED

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## A GUIDE FOR THE NEWLY DIAGNOSED

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

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

*Dr Barry Snow, Neurologist, Lorraine Macdonald, Movement Disorders Nurse,  
Auckland Hospital March 2018*

## ABOUT THE AUTHORS

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Dr Barry Snow is a neurologist and Medical Director of the Adult Healthcare Service Group, Auckland District Health Board. He established, and still leads, the Auckland Movement Disorders Clinic.

Lorraine Macdonald is Movement Disorders Nurse Specialist, Neurology Department, Auckland City Hospital.

## CONTENTS

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Introduction .....	3
Parkinson's .....	3
The Main Symptoms Of Parkinson's .....	5
What Causes Parkinson's? .....	8
How Does Parkinson's Develop? .....	9
Treatment Of Parkinson's .....	10
Medications For The Treatment Of Parkinson's .....	12
The Future .....	16
Parkinson's New Zealand .....	19
Other Services .....	21
Additional Publications and Resources .....	22

# INTRODUCTION

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The diagnosis of Parkinson's is often unpleasant news. Usually the affected person and family 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 it can be treated and what the outlook is. 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 of this booklet.
2. Your family doctor or specialist is the best person to help you make decisions about the medications that you should be taking to treat your Parkinson's. If you have any questions about any medications including those for Parkinson's, please talk to your family doctor or specialist.
3. Remember, Parkinson's is a highly variable condition, and everyone has a different version of the disorder. Remember this when you see others with the condition or hear about others' stories. You will not necessarily have the same symptoms, experiences or outlook.

## 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 one and two 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 minor 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 (shaking), 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. Others develop a stooped posture or a reduction in arm-swing when they are walking. Sometimes the first development is a sense of increased fatigue,

making tasks take longer and seem more of an effort. These changes are often noticed by a family member. However, because Parkinson's develops so slowly, people who see the person every day, or on a regular basis, can miss small changes so it may be a new doctor or locum for the family doctor who first notices.

Approximately 80% of people with the physical symptoms of Parkinsonism have Parkinson's. There are a number of other conditions that can resemble Parkinson's. These conditions include medication induced Parkinsonism, Lewy Body disease, Multiple System Atrophy (MSA) (previously known as Shy Drager syndrome) and Progressive Supranuclear Palsy (PSP). These conditions are less common than Parkinson's, and 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 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

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## 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 tremor is usually more on one side, at least at first. A 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; although like all things about Parkinson's, this is not always the case. Because the tremor usually disappears with movement, it is frequently not 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, combing hair or shaving. 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. Some people can develop a problem of 'freezing' in which the feet seem to stick to the floor during walking. The person comes to a temporary stop before getting going again.

## OTHER SYMPTOMS

The four main symptoms of tremor, stiffness, slowness and loss of balance are characteristic of what is known as Parkinsonism.

We are becoming increasingly aware of non-specific symptoms, some of which can occur many years before the diagnosis. 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 may be electric or tingling sensations of the limbs. They are often more prominent at night. Some 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. Shoulder pain is very common, and people often have a frozen shoulder in the year preceding the diagnosis of Parkinson's. Back and neck pain can occur as a consequence of muscle stiffness and may improve when the Parkinson's is treated.

## Constipation

Constipation is very common in Parkinson's and can precede the diagnosis by years. Parkinson's constipation 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 along. 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.

## Apathy

A closely related symptom is a lack of motivation or apathy. Apathy is a reduction in motivation related to not caring enough about things, either because we can't feel strongly enough about something to act, or because we don't think that it is important enough. This can be particularly frustrating for family members. So it is important to understand that apathy is a characteristic of Parkinson's - not the person being lazy or difficult. It is also sometimes mistaken for depression.

## Depression

Approximately one third of people develop depression at some time during their Parkinson's. Depression can sometimes precede the diagnosis of Parkinson's.

The frequency of depression in Parkinson's is greater than would be expected in people with other chronic condition. 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.

Depression in people with Parkinson's has traps for both patients and doctors. Many of the symptoms of Parkinson's: namely the slow movement, poor energy and disrupted 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. The important point is to recognise the possibility of depression and bring it to the attention of your doctor.

## Anxiety

Anxiety is thought to affect up to 40% of people with Parkinson's to some degree, ranging from mild to severe. Anxiety is often present at the same time as depression although one can be present without the other.

## Sleep disturbance

Most people develop some form of sleep disturbance. This can include interruption of sleep by tremor, pain or difficulty rolling in bed. A very common pattern is marked tiredness in the evening and falling asleep soon after going to bed. This is followed by waking around midnight and frequent awakenings through the rest of the night. This pattern is often associated with sleepiness in the early afternoon. It is reminiscent of jetlag, and in fact it may be due to disturbances of the biological clock.

Other people develop a more distinctive sleep disturbance. The most striking of these is Rapid Eye Movement (REM) sleep behaviour disorder. In this situation, the person talks or acts out vivid dreams. They may run, punch or kick as they dream about fighting a wild animal or other assailant. The spouse sometimes bears the brunt of the attack.

Curiously, REM sleep behaviour disorder is another symptom that can occur years before the onset of more recognisable features of Parkinson's. REM sleep behaviour disorder is worth discussing with your doctor as it can be treated with low doses of the medication clonazepam or melatonin.

## Melanoma

Melanoma is not a symptom of Parkinson's, but it is more common in people with the condition; possibly because Parkinson's is more common in pale skinned people. People with Parkinson's should examine their skin regularly and report any new or growing pigmented lesions to their doctor.

# WHAT CAUSES PARKINSON'S?

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The tremor and movement symptoms of 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 loss of smell, sleep disturbance, pain and changes in thinking and memory.

At present we do not know what causes the degeneration of the substantia nigra and other brain nerve cells. 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.

We are becoming increasingly aware of a genetic contribution to the development of Parkinson's. There are a number of genes that seem to increase the risk of developing Parkinson's and there is a slight increase in risk of development in people who have family members with Parkinson's. However this risk is low. Young onset Parkinson's is more likely to be due to a genetic disorder, but this is usually recessive inheritance (i.e. requiring one gene from each parent). This means there is little risk of passing it on to their 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 like Parkinson's. This experience raised 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 something in the environment that might cause Parkinson's. As yet, however, no particular factor has been identified for certain. In fact, there are some environmental factors that seem to partly protect against Parkinson's. The most curious of these are smoking and coffee. We don't recommend that you take up smoking, however!

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 after which Parkinson's symptoms become obvious for the first time. 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 Parkinson's. While stress tends to exacerbate the symptoms of Parkinson's, there is no evidence that it causes it or makes it progress faster. A person with Parkinson's should not think of him or herself as fragile.

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



# HOW DOES PARKINSON'S DEVELOP?

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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. In retrospect, the person may have had a loss of smell or wild fighting dreams for years. 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 brain nerves. For this reason early medical treatment is not always necessary, and drugs and other treatments are generally reserved for when the person becomes slowed or disabled by the condition. If the person is having falls or at risk of losing a job, this is an important reason for starting treatment. Other people become self-conscious about the tremor or feel that the fatigue is becoming troubling. These are also good reasons for starting treatment. If you are uncertain, a good rule of thumb is that you should start treatment if you are taking twice as long to get ready in the morning. Pain, such as in the shoulder, can respond to treatment and this is another good reason to start.

It is very important to realise that people don't become immune to the treatment, and it does not stop working after a number of years.

Once the decision is made to start treatment, a number of medications are available. These will be described in detail below. 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 near normal daily function. Most people still have signs of Parkinson's but are able to continue on at work and do the things they want. People can lead otherwise normal and productive lives during this period.

As the years go by, other nerves are affected in the Parkinson's process. These nerves may be those responsible for memory or control of other body functions such as blood pressure or the bladder. These new developments do not respond to the standard Parkinson's treatments, and they need to be treated separately.

# TREATMENT OF PARKINSON'S

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

## EXERCISE

Exercise is very important for people with Parkinson's. As well as improving general health and well-being, it seems to improve the response of the body to dopamine and may even protect nerve cells from degeneration.

Everybody with Parkinson's should attempt to get at least 20-30 minutes of exercise each day. Possibilities include walking or exercise classes. Most Parkinson's New Zealand divisions offer exercise classes. If possible, it is a good idea to join a gym.

Many people ask what is the best exercise, and how much? The answer is we do not really know. A good approach is to do the exercise you enjoy and therefore are more likely to continue. As to how much, it is the amount you can do again tomorrow without getting progressively exhausted.

## 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.

Many people have disrupted sleep despite taking these steps. If this is the case, sometimes medication can be helpful. In general, 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. 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. Watch out for increased difficulty passing urine if you have prostate problems. Amitriptyline can also make constipation worse and cause a dry mouth.

## NON-MEDICATION MANAGEMENT

We are very fortunate in New Zealand to have a coordinated health system; and people with Parkinson's can access a wide range of therapy and support. The key point is that this support is best organised by your Parkinson's New Zealand Community Educator. Everyone should join Parkinson's New Zealand and keep in contact with their Parkinson's Community Educator. You will find more information on PAGE 19.

### Physiotherapy

Physiotherapy can help with local problems such as shoulder pain and more general health including exercise programmes. There are physiotherapy programmes that work on movement patterns to help coordination and balance for people with Parkinson's.

### Occupational therapy

An occupational therapist can assist in maintaining independence both at work and at home by modifying the environment and providing aids for mobility and other adaptive equipment.

### Speech language therapy

Some people with Parkinson's have difficulty projecting their voice or develop a stuttering speech. A speech language therapist can provide advice and specific strategies to improve communication. Your Parkinson's Community Educator can help organise a review by a speech language therapist.

### Dietician

Usually people with Parkinson's need a standard, balanced diet. They may need specific help from a dietician if they are losing weight.

## THINGS THAT ARE NOT NECESSARY

You will get plenty of well-meaning advice on how to manage your 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. For some time we had high hopes that antioxidants like coenzyme Q10 might help, but good studies have shown that coenzyme Q10 does not help Parkinson's. Stem cell therapy has promise in research, but there is no evidence that the currently commercially available stem cell therapy is helpful.

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

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The main symptoms of Parkinson's are caused by a lack of dopamine in the brain. Eventually, almost every person 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 that don't respond to dopamine.

## LEVODOPA

The standard treatment for Parkinson's is a drug called levodopa which comes in the form of a pill. 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®, Sindopa, Kinson and Madopar®. You will see on the package 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.

It is quite common for people to believe that levodopa only works for a few years. This is wrong. It is a mistake to hold off taking levodopa in the hope that it can be saved up for when the condition gets worse. In fact, there is some evidence that leaving medication too late may mean that you cannot catch up to where you would have been if you started the medication earlier.

If levodopa is given in a full dose immediately it usually causes nausea. For that reason we recommend starting the medication slowly at approximately 50mg per day. The dose is then increased gradually towards 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 1000mg per day divided into three or four doses.

Levodopa only lasts a short time in the bloodstream. In early Parkinson's levodopa is taken from the blood and stored in the brain then is released slowly so that the person 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 person tends to notice the effect of the medication coming and going with each dose. 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 is to 'kick start' you in the morning, and the slow formulation for control during the day. If you need to go onto levodopa therapy, your family doctor or specialist will be able to select the correct combination for your particular condition.

## Side effects of levodopa

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. Many anti-nausea drugs can make the Parkinsonism worse, but domperidone blocks the nausea effect of levodopa and other Parkinson's medication without worsening Parkinson's symptoms. Domperidone should ideally be taken half an hour before the dose of levodopa.

## Nightmares and hallucinations

Older people can develop nightmares when taking levodopa. Sometimes people see flashes of light or movement in the edge of their vision. They may interpret this someone besides them or 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 as higher doses could cause the hallucinations to become more severe.

## 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 five dopamine agonists currently available in New Zealand. They are bromocriptine (Apo-bromocriptine), pergolide (Permax), lisuride (Dopergin), ropinirole (Requip, Ropin) and pramipexole. These medications have very similar effects. The side effects are also generally similar to those seen with levodopa; although the side effects tend to be more common and more severe.

There is also an injectable dopamine agonist, known as apomorphine. Apomorphine can be given under the skin either as single doses or as an infusion from a pump. This treatment is for people with more advanced Parkinson's who are struggling to get consistent results from medication.

Dopamine agonists can cause sleepiness. This can be a general fatigue, but there is a more dangerous phenomenon known as sleep attacks. If you are suddenly getting sleepy shortly after taking your Parkinson's medication, you should stop driving and discuss the sleepiness with your doctor.

## Pathological Impulsiveness

*Dopamine agonists can cause a bizarre side effect of impulse control disorder where people compulsively gamble, shop, eat or engage in inappropriate sexual activity. This is potentially a very severe complication, and it is important to be aware of the possibility and report any change in behaviour to your doctor. This can be a very destructive side effect. As well as the person taking the dopamine agonist, your family should also know about this side effect and look out for it.*

## Amantadine and anticholinergics

Amantadine (also known as Symmetrel) and a number of anticholinergics (e.g. benztropine) 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, nightmares and memory loss. In elderly people these medications can also cause confusion.

## COMT inhibitors

After taking the standard levodopa treatment, 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 in a small number of people 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 definite evidence that starting treatment early will alter the long-term course of Parkinson's. For that reason we often reserve medication for when the Parkinsonism becomes troublesome. There is also no evidence that any medication will make the underlying condition 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 of effectiveness is caused by the Parkinson's progressing.

More detailed information about medications is available in the Parkinson's New Zealand booklet *The Medication Treatment of Parkinson's: a guide to people with Parkinson's and those who care for them*.

## 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 (DBS).

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

## MANAGING OTHER SYMPTOMS

While we tend to think mostly about the symptoms caused by a lack of dopamine, people with Parkinson's often need help with a range of other symptoms that do not respond to dopamine replacement. These include poor sleep, pain, constipation, frequent urination, excess saliva, mood and memory changes. Each requires a specific management plan, and you should discuss these symptoms with your doctor.

# THE FUTURE

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Sixty 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.



# CONTACT SHEET

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☐ Please have a Parkinson's New Zealand Community Educator contact me

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Best time to call: \_\_\_\_\_

I would like more information on Parkinson's and Parkinson's New Zealand.

## *Please send me*

☐ Contact details for my local Parkinson's New Zealand division

☐ More information about Parkinson's Community Educators

## *Additional publications*

☐ Keep moving: an introduction to Parkinson's and exercise

☐ The Drug Treatment of Parkinson's: a guide for people with Parkinson's and those who care for them

*To return this form to Parkinson's New Zealand please remove, fold in half and secure on all sides before posting. Or contact us at PO Box 11067, Manners Street, Wellington 6142.*

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# 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.

There are over 30 Parkinson's Community Educators across the country. Each region has one or more professional Parkinson's Community Educators to provide services in their local area.

## PARKINSON'S COMMUNITY EDUCATORS

Parkinson's Community Educators are available to support you through your journey with Parkinson's. They can offer you the following services:



**Home visits.** These can provide reassurance, advice and practical help on living with Parkinson's, evidence-based information about Parkinson's and support for the person with Parkinson's, their family, and/or carers.



**Support groups for People with Parkinson's.** Need to talk to others about how you're feeling or get advice from someone who's coping with a similar situation to yours? Support groups are co-ordinated by educators and include speakers, fellowship and information.



**Support groups for Carers.** Meet and talk to other carers of people with Parkinson's.



**Referrals.** An educator can give advice about referrals to other community health professionals as appropriate such as physiotherapists, speech therapists, counsellors, occupational therapists and specialist geriatricians.



**Advice on monitoring of medication.** Parkinson's medications routines are unique to each individual and an educator can help with information about managing side effects, 'on and off' periods, sleep problems and depression.



**General advice.** Need a hand rail installed and don't know how to go about it? Or want to know about home help or welfare benefits? Ask your educator where to start.



**Advocacy.** Need someone to speak up for you? Educators can talk to hospitals and specialists on your behalf if you are having difficulty.



**Social activities.** Social activities may be available in your area, these can include group lunches or dinners, coffee mornings, walking groups, and bus trips.



**Exercise and other therapies.** Your educator can let you know what programmes for people with Parkinson's are available in your area such as exercise, physiotherapy, hydrotherapy and art therapy sessions. Research has shown that exercise is a vital component in the overall management of Parkinson's.



**Educational seminars.** Your educator can inform you of upcoming Parkinson's educational seminars which provide access to a variety of speakers including neurologists, Parkinson's researchers, pharmacists and other health professionals.



**Facilitate family meetings.** Educators are available to meet with your family/whanau to discuss how they can best support their family member. They can also provide information about Parkinson's to give family/whanau a better understanding of this condition.



**Work alongside GPs, specialists and other health professionals.** Educators work as part of a multi-disciplinary team and provide education and information to health professionals such as physiotherapists, occupational therapists and speech therapists.

# OTHER SERVICES

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## Parkinson's New Zealand also offers:



Further information on Parkinson's and other Parkinson's-like conditions including MSA and PSP



Regular up-to-date information through our national magazine, website and local newsletters



Responsible reporting of recent research



UPBEAT – a special interest group for people with early onset Parkinson's



Books and audio-visual material

*For more information about Parkinson's and how we can help you or services in your local area please contact us.*

# ADDITIONAL PUBLICATIONS AND RESOURCES

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Parkinson's New Zealand has a range of publications and resources available on Parkinson's and its management.

Printed publications are available from your Parkinson's Community Educator or by calling 0800 473 4636. Our publications also can be found on our website [www.parkinsons.org.nz](http://www.parkinsons.org.nz)

## The Medication Treatment of Parkinson's: a guide for people with Parkinson's and those who care for them

Provides general information about the medication treatment of Parkinson's (both medications for Parkinson's and others commonly used) and detailed information about each medication.

## Introduction to Parkinson's

Provides a brief introduction to Parkinson's and may be useful to give to family and friends to explain the condition. In addition to English it is available in Te Reo Maori; Samoan, Tongan; Simplified and Traditional Chinese; Korean; Hindi; Spanish and Arabic.

Brief introductions to other Parkinson's-like conditions (Progressive Supranuclear Palsy (PSP) and Multiple System Atrophy (MSA) are also available.

## Factsheets

A number of two-page factsheets on specific aspects of Parkinson's (e.g. Parkinson's and Depression) and living with Parkinson's (e.g. Telling people you have Parkinson's). A full list is available on the website.

## Parkinson's Website

On the Parkinson's New Zealand website [www.parkinsons.org.nz](http://www.parkinsons.org.nz) you will also find:

- Copies of the quarterly magazine *The Parkinsonian*
- Details about services in your local area
- Links to our social media (e.g. Facebook)

## This image shows a single page of white paper with horizontal blue lines, resembling notebook paper. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.



## WHERE TO FIND FURTHER HELP

*Parkinson's New Zealand recommends that if you have any questions about your diagnosis you discuss them in full with your doctor.*

If you need more general information, advice or support, our contact details are:



Parkinson's New Zealand  
PO Box 11 067  
Manners Street  
Wellington 6142



Freephone: 0800 473 4636  
Phone: 04 801 8850



[info@parkinsons.org.nz](mailto:info@parkinsons.org.nz)



[www.parkinsons.org.nz](http://www.parkinsons.org.nz)

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