



Parkinson's
Victoria Inc.

Parkinson's Victoria
20 Kingston Road
Cheltenham 3192

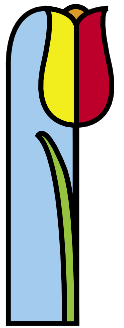
tel: 03 9551 1122
freecall: 1800 644 189

website: www.parkinsons-vic.org.au
email: info@parkinsons-vic.org.au
fax: 03 9551 1310
ABN 68 038 728 034

Office Hours 9am – 5pm
Monday to Friday

Whilst we are able to provide information about various aspects of Parkinson's, Parkinson's Victoria cannot provide individuals with medical advice, this can only be provided by your health practitioner.

*So...
I've got
Parkinson's...
What's that?*



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Parkinson's What's that?

So you've just been diagnosed with Parkinson's...

You probably have thousands of questions running through your mind...

"What is it?"

"What will happen to me?"

"What can I do about it?"

"Where can I get help?"

This booklet is designed to introduce you to Parkinson's and answer any of these initial questions you might be having.

Parkinson's affects each person differently – no two people will have exactly the same experiences.

With good advice and support, **Parkinson's is a manageable condition**. We encourage you to share your experiences and concerns with others so they can best help support you.

***Parkinson's does not
need to decrease your
quality of life!***

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Parkinson's What is it?

Parkinson's is a progressive disorder of the brain resulting from the degeneration of nerve cells in the Substantia Nigra, a part of the brain which helps regulate and control smooth movement throughout the body.

The nerve cells in the Substantia Nigra produce a substance called dopamine. Dopamine is like a carrier pigeon for the brain. It takes messages from one part of the brain to another, telling it how to control movements in the body.

If there are fewer nerve cells in the Substantia Nigra, less dopamine will be produced. This means that the brain will receive fewer messages on how to control movements in the body. This is what causes the classic tremor, stiffness and slowness of movement characteristic of Parkinson's.

Although there is no cure for Parkinson's, symptoms can be somewhat controlled by medication, which aims at replacing the lost dopamine in the brain. This will enable people living with Parkinson's to live independently for a number of years in spite of the challenges that the condition may present.

Parkinson's affects each person differently!

In Summary...

Parkinson's is a condition of the brain that affects body movements. The three main symptoms associated with Parkinson's are:

- Tremors
- Stiffness in the muscles
- Slowness of movement

And remember –
Parkinson's affects each person differently.

"Think of your body as being like a motor car.

***Look after it, feed it, exercise it,
attend to its general maintenance and
get sufficient knowledge about what you
may expect to happen in the future.***

***However, don't delve into all of the details
in great depth because you may not be
affected by all of them"***

Tremors

A tremor is a continuous, involuntary shaking of part of the body. Most often, tremors seen with Parkinson's are "*resting tremors*" This means they occur when the limb is not in use. A small percentage of people may experience "*action tremors*". These occur when the person begins some form of activity for example, when the person walks, their hands may begin to shake.

So what *might* this mean for me?

- Usually tremor is worst at rest, improves during voluntary movement and disappears during sleep.
- Your tremors may become worse when you feel anxious or are in a stressful situation.
- You may experience 'restless legs'. This is when your legs appear to move or feel as if they are moving constantly, especially at night. You might find that you have trouble sitting still, and have to relieve this discomfort by walking around.

In most cases, tremors can be successfully managed by medication.

◆ *For tips on managing the symptoms, turn to page 8*

Stiff Muscles (Rigidity)

Stiff muscles, or 'rigidity' is where the muscles seem unable to relax and are tight, even at rest. You might feel that your muscles will not do what you want them to do. Rigidity may be experienced through the entire range of movement of a joint (called 'lead pipe rigidity') or just in parts (called 'cog-wheel rigidity').

So what *might* this mean for me?

- You may have difficulty performing automatic movements. For example, swinging your arms when you walk or rolling over in bed.
- Your stiffness may be accompanied by an aching pain in the affected limb. This may be improved with Parkinson's medications.
- You may feel that your muscles are so tight that they won't move. This is very common, and is called 'freezing'. This usually occurs at the commencement of movement, such as when you try to stand up or walk.
- You may lack facial expression.

Live each day as it comes. Enjoy what you can do, don't focus on what you can't.

Slow Movements (bradykinesia)

Slow movements, or 'bradykinesia' occur because the brain is not able to control smooth and delicate movements.

So what *might* this mean for me?

- You might be hesitant when starting new movements, or stopping an ongoing movement.
- You might get tired more readily than usual.
- You may have trouble doing delicate work with your hands such as doing up buttons, putting on make-up, shaving, or writing.
- The muscles of speech and/or swallowing may be affected. This may decrease the volume and/or tone of your voice, alter the speed, distort the articulation and make it difficult to chew or swallow.
- You may find that you think a little more slowly and following conversation in a social setting maybe more difficult. You may also find it difficult at times to initiate speech and swallowing. You may have a dry mouth or experience excessive saliva.

But remember, each day is different, and your symptoms may vary from day to day.

Other Symptoms

The three main symptoms just explained can sometimes lead to other types of movement problems. It is usually at the much later stages of the disease that these symptoms will present.

Poor Balance

You may feel that you have poor balance, or are not steady when you are standing. It may be particularly noticeable when you are changing from lying down to sitting / standing, or trying to stand up from sitting.

Walking Difficulties

You may begin to walk with short, shuffling steps (referred to as 'festinating gait'), have trouble starting to walk or come to an involuntary stop. Some people have described gait disturbance as feeling as though they are walking through thick mud.

Falls

Factors such as poor balance, walking difficulties and muscle weakness as well as some medications can increase the likelihood of falls. There are many ways to reduce the risk of falls. Telephone Parkinson's Victoria for more information.

For more information on symptoms call Parkinson's Victoria on 03 9551 1122

Medication

When should I start medication?

Your Doctor with a special interest in Parkinson's should discuss this with you. Much depends on your life style, your symptoms and to some extent your age. The best time to start is probably when your symptoms are affecting your ability to FUNCTION whether that be at work or home. From diagnosis onwards, all treatment should be aimed at maintaining function and safety. At present, cure is not available.

What are the medications and what do they do?

Levodopa for most is the first line treatment and will remain the mainstay of treatment for life. Other medications may be introduced later but they are all extra to your Levodopa and helping it and you to get maximum benefit. Levodopa comes as Sinemet and Madopar. In some people the first treatment may be a Dopamine agonist and this is a choice for you and your Neurologist to make.

Levodopa is like the petrol in your car. It is important to take your medication absolutely correctly to avoid:

- running out of petrol between doses
- side effects
- taking more than necessary to treat symptoms
- under treating symptoms.

It is very important that you discuss your medication with your neurologist or a Parkinson's Nurse to make sure you fully understand your medication, how to take it and what it does.

Tips for Daily Living

Tremors

To reduce tremors try these three tricks:

- Hold you limb in a variety of positions.
- Hold onto something to stabilize your limb.
- Press your upper arm against your body.

Shuffling

If you feel you are beginning to shuffle:

- Stop...** Don't try to go faster to catch your balance.
- Relax...** Then begin to walk again. Make sure you place your heels firmly on the ground and walk with a wide stance.
- Concentrate...** Lift your head – look straight ahead. Lift your feet and count with each step.
- Exercise...** Walking is one of the best things you can do to help you maintain your mobility and independence and keep you fit and feeling good.

Keep yourself mobile – walk, walk, walk, a lot!

Remember

- Concentrate on walking only.
- Take big steps.
- Swing your arms.
- Pay extra attention when walking on uneven surfaces as your balance may be affected.
- Wear supportive shoes.

Rest when tired, know your limits.

Freezing

Freezing is made worse when you are anxious, so if you freeze, the most important thing to do is **Stop** trying to walk and **Relax**. Don't think about trying to move your feet but concentrate on bending your knee or lifting your leg.

Then, try one of these tips to get moving again:

- Visualise a spot on the floor just in front of you and try to step over it.
- Swing your arms backwards and forwards or rock from side to side to get into the rhythm of walking again.
- Whistle a tune or imagine it in your head, and march to the beat with your heels first.
- Count "one, two, one, two..." in your head.

If you freeze in a doorway, you could try:

- Looking through the doorway and not at it.
- Placing a strip of tape under the door frame and try to step over it.

If you try to move and it doesn't work, remember STOP and RELAX before you try again.

Changing Direction

If you need to turn a corner, try walking around in a wider arc rather than turning on the spot. This will help you keep your balance.

Golden Rules for Movements

Stop	If you are having trouble moving
Focus	Relax for a moment before you start again
Start	The movement, using triggers if necessary. eg: visual cues, music, counting, rocking back and forth.

And remember... 'One thing at a time!'

Daily Activities

Are you managing with daily activities?

There are many simple changes that can be made to the home environment and to the way you do things that can make daily living easier. Professionals can offer many suggestions that can help improve your quality of life.

Speech and Swallowing

Having trouble being heard?

Most difficulties with speech and swallowing can be improved with the help of a Speech Therapist.

Nutrition and Diet

Is your medication working for you?

The food you eat may be affecting the way your medication is working. A Dietician might be able to suggest simple changes to your diet that may help your medication be more effective.

Constipation

The bowel muscle is like other muscles in the body and movement is slower in Parkinson's.

Constipation is not pleasant and has serious potential so we need to AVOID it by prevention.

Drink fluids!! Water is the best. Take a BIG glass of water with every dose of tablets you take. For many that will be 4 glasses a day.

Get fibre. Fruit, vegetables, prunes etc.

If in doubt take a fibre supplement available from your supermarket. A small dessertspoon on your cereal every morning (remember it's prevention not treatment) and life is great.

For a referral to an Occupational Therapist, Speech Therapist, Dietitian, Social Worker, Physiotherapist, Neurologist, Registered Nurse or Movement Disorder Program, please contact Parkinson's Victoria on 03 9551 1122.

Who are we?

Parkinson's Victoria is a statewide specialist information and support service providing information, education and support to people with Parkinson's their families, health professionals and the wider community.

What do we do?

- **Information** Provide people with Parkinson's, their carers, family members and service providers with up to date and accessible information which supports self management and choice.
- **Telephone advice** Experienced Client Services Officers provide advice relating to information about Parkinson's including symptoms, management and research.
- **Education Sessions** are provided to health professionals and community groups conveying specific Parkinson's information.
- **Specialist Staff** make regular visits to support groups addressing a range of issues including: newly diagnosed issues, symptoms, medication, safe hospitalization and respite, surgical intervention, home modification, research, movement disorder strategies, adjustment to disability, loss and grief, carer resources.

Why should you contact us?

- **Support Groups** Parkinson's Support Groups are established at over 40 locations in metropolitan and rural Victoria.
- **Seminars, workshops and conferences** with expert speakers, including special seminars for the newly diagnosed.

- **Resource Library** Contains specific information on Parkinson's and many aspects relevant to living with, or caring for someone with Parkinson's. These include books, videos and a variety of fact sheets.
- **Promote** public awareness through community education.

What can we offer?

- **A quarterly newsletter** This recently revamped newsletter is distributed quarterly to members. It contains articles on the latest medications and treatments, symptoms and their management, recent research findings, social activities, personal perspectives and information on upcoming events and seminars.
- **Printed material** containing information about Parkinson's and Parkinson's Victoria services.
- **Help and advice** is available from our Client Services Officers who can assist with enquiries and make referrals to other community and specialist services.
- **Information forums** are implemented for a variety of audiences throughout metropolitan and regional Victoria.
- **Education** In-service education sessions are provided to health professionals, including medical students, nurses, personal carers, home support workers, disability workers, allied health staff and many more.
- **Volunteer Program** A volunteer program involving members and their families to utilise their skills to help promote Parkinson's Victoria and to build a community of interest with people living with Parkinson's.

Where to find help

Parkinson's Victoria

Parkinson's Victoria is a great place to start when looking for help or information. They have information and advice specific to people living with Parkinsons, their carers, friends and family. They will have knowledge in what you are experiencing and will be able to give support and point you in the right direction should you require further assistance.

For more information, call
(03) 9551 1122
1800 644 189 (Freecall Australia wide)
<http://www.parkinsons-vic.org.au>

Financial Support

You may be entitled to a disability support pension if you are under pension age and cannot work full-time. Also, if you have someone caring for you, they may be entitled to carer payment or carer allowance.

For more information call
Centrelink on 13 27 17
<http://www.centrelink.gov.au>

Carers Victoria

Are you caring for a relative or friend with Parkinsons? If so, you may wish to contact Carers Victoria. They can provide you with information about carer support groups, counselling support, respite services in your area and much more.

For more information, call
1800 242 636
<http://www.carersvic.org.au>

Commonwealth Carelink Services

Call here to find out about the range of services available to help you live independently at home.

For more information call
1800 052 222
<http://www.commcarelink.health.gov.au>

Movement Disorder Clinics/ Programs

Kingston Centre 03 9265 1411
Peter James Centre 03 9881 1842
Rosebud Rehabilitation Unit
03 5981 2166
Elsternwick Hospital (private)
03 9528 6855

A multi-disciplinary program staffed by a team of specialists in the area of Parkinson's offers people a holistic approach to management of the condition.

Counselling Support

Being newly diagnosed with Parkinson's can be a stressful time for you and your family. You may be experiencing feelings of shock, fear, depression, grief or anger. Talking to someone about how you are feeling can help you to come to terms with the diagnosis in a positive way. There are many confidential services available to help support you. The following list is a starting point for accessing assistance.

Care Ring

13 61 69
Available 24 hours
Provides confidential telephone counselling and referral to face-to-face support.

Lifeline

13 11 14
Available 24 hours
Provides confidential telephone counselling and referral to face-to-face support.

Relationships Australia

03 9835 7570 (Head office)
Centers across Victoria to provide face-to-face couple/family counselling.
www.relationships.com.au

Lifeworks

03 9654 7360
Affordable professional counselling for individuals, couples, families, children and adolescents across Victoria.
lifeworks@lifeworks.com.au

Useful Websites

Parkinsons Victoria:

<http://www.parkinsons-vic.org.au>
Parkinson's Australia
<http://www.parkinsons.org.au>

Parkinson's New South Wales:

<http://www.parkinsonsnsw.org.au>
Parkinson's Queensland:
<http://www.parkinsons-qld.org.au>

Parkinson's Association of Western Australia:

<http://www.quartec.com.au/parkinsons/>

Parkinson's South Australia:

<http://users.senet.com.au/~parkysa>
Parkinson's New Zealand:
<http://www.parkinsons.org.nz>

Parkinson's Disease Foundation, New York & Chicago USA:

<http://www.pdf.org>

American Parkinson's Disease Association:

<http://www.apdaparkinson.com/>

Parkinson's Web:

<http://pdweb.mgh.harvard.edu>

Parkinson's Disease Society of United Kingdom:

<http://www.parkinsons.org.uk>

Parkinson's Disease Index:

<http://pdindex.org>

European Parkinson's Disease Association:

<http://www.shef.ac.uk/misc/groups/epda/cont.htm>

For information in other languages, visit the World **Parkinson's Disease Association:**
<http://www.wpda.org/>