

# Information about Parkinson's

Although life with Parkinson's may be difficult sometimes, you can lead an active, fulfilling life and there is lots of help available.

## About Parkinson's

Around 1 in every 500 people has Parkinson's. It occurs most commonly in people aged 60 or above, but it can also affect people below the age of 40. Parkinson's is a progressive neurological condition, and although we do not fully understand what causes it, there are a range of medicines and treatments that can help manage the symptoms.

The symptoms most commonly associated with Parkinson's are stiffness, slowness and tremor. These are known as 'motor' symptoms.

People may also experience 'non-motor' symptoms which are not connected to movement problems. These may include problems with anxiety, depression, pain, constipation, sleep disturbances, speech/swallowing, memory, sexual dysfunction and others. Everyone's experience of Parkinson's is different and unique. The particular symptoms one person may experience and the way they develop, could be very different to another person and the management will vary accordingly.

The underlying changes in the brain are complex, but one of the characteristics of Parkinson's is that people with the condition lose the ability to make a substance called dopamine, a chemical which delivers messages in the brain. Treatment focuses on reducing the symptoms that result from this, and aims to help people lead a normal, active life. While medication is usually necessary, maintaining a healthy lifestyle by staying physically active and eating a balanced diet can contribute to your overall health and wellbeing.

## Exercise and lifestyle

Research has shown that exercise is particularly beneficial for symptom management and may slow down the progression of the condition. Regular exercise also has many immediate benefits including relieving muscle tension, improving wellbeing, keeping bones strong, increasing muscle strength, helping to maintain balance, reducing the risk of falls and lifting mood.

Many people with Parkinson's take part in active sports like tennis, badminton, swimming and dancing. There are also low-impact exercise options to keep

you flexible and active, such as yoga, tai chi, walking, gardening, and daily stretches. There is no clear evidence on what exercise is most beneficial, but generally it is best to choose the exercise that suits your ability, general health and circumstances. If something is fun, you're more likely to stick with it and enjoy the benefits. This also applies to maintaining hobbies and social activities with friends and family.

Joining an exercise group may also help as it offers you the opportunity to meet new people and maintain social contact.

## **Diet**

People with Parkinson's may find they experience constipation. This can be helped by drinking more fluids, exercising and eating more fibre-rich foods. Eating well is important and excessive weight gain or loss should be avoided.

## **Bone health**

Osteoporosis is a condition which affects the bones in the body, causing them to become weak and fragile. It is often diagnosed with Parkinson's. Current recommendations suggest that people with Parkinson's should take a vitamin D supplement daily to help maintain good bone health. This can be bought from your local chemist.

## **Driving**

Having Parkinson's doesn't mean your driving licence will be taken away, but you may need to have a medical or driving assessment. If you experience sleepiness, which can be a side effect of some anti-Parkinson's medications, you should not drive until this has settled.

However, it is a legal requirement to inform the driving and vehicle licensing agency (DVLA) if you are diagnosed with Parkinson's. You can contact them by:

- visiting the DVLA website: [www.gov.uk/contact-the-dvla](http://www.gov.uk/contact-the-dvla)
- calling the DVLA driver medical enquiries line: 0300 790 6806

You should also inform your motor insurance provider, as your policy may be invalid if you do not. It is an offence to make a false statement or to withhold information to get motor insurance.

## **Treatment**

Treatment is guided by the latest UK clinical guidelines from the National Institute for Health and Care Excellence (NICE) and tailored to the individual.

## Medicines

There are a range of medicines available to help manage the symptoms of Parkinson's, and these can be adjusted to match your own symptoms, circumstances, needs and preferences.

No medication is currently known to change or cure the underlying disease process, but medication can effectively improve the symptoms. There is also some evidence that the early treatment of Parkinson's is beneficial in the long term.

It can take some time to find the best medicine, dose and timing, but your specialist will work with you to find the best treatment for you. You will usually see your consultant/specialist every six to eight months, although this can be flexible depending on specific needs.

Because your symptoms can change, your medication may need to be changed as well. It is important not to make any changes to your medication without discussing this with your doctor or Parkinson's nurse beforehand. Any withdrawal from Parkinson's drugs must be done gradually.

Below are the drugs used to manage Parkinson's symptoms and some of the side effects that can occur.

Drug name	What is it?	Side effects
<b>Levodopa</b>  Co-careldopa (levodopa, carbidopa) – brands include Caramet®, Sinemet®, Lecado®  Co-beneldopa (levodopa, benserazide) – brands include Madopar®  Duodopa intestinal gel (levodopa, carbidopa)	<p>Levodopa is the 'gold standard' treatment for Parkinson's and has been used since the 1960s.</p> <p>It can be used at all stages of Parkinson's.</p> <p>Brain cells use levodopa to produce more dopamine which relieves stiffness, tremor, slowness and many other symptoms of Parkinson's.</p>	<p>Not all patients will experience side effects while taking levodopa.</p> <p>For those patients who do, side effects can include:</p> <ul style="list-style-type: none"><li>• Nausea (feeling sick) or vomiting – this usually goes away after a couple of weeks. If you find this is a problem, try taking the medication with a dry cracker or speak to us about anti-sickness medication.</li><li>• Low blood pressure.</li><li>• Sleepiness.</li></ul> <p>Levodopa may cause urine to turn reddish-brown. This is harmless.</p>

		<p><b>Behavioural changes:</b> Some people experience behavioural changes and find it difficult to control compulsive and impulsive behaviours such as gambling, shopping, binge-eating, hyper-sexuality or other unusual behaviours. Often the behaviour is out of character.</p> <p>With long term use, some patients may also experience involuntary movements (dyskinesia) or hallucinations.</p> <p>A small number of people taking levodopa may find having high protein meals affects how well their medication works. If you experience this, you may benefit from taking your medication 30 minutes before meals.</p>
<p><b>Dopamine agonists</b></p> <p>Pramipexole (Mirapexin) Ropinirole (Requip) Rotigotine (Neupro) Apomorphine (ApoGo)</p>	<p>Dopamine agonists can be used at all stages of Parkinson's. They mimic the action of dopamine on receptors.</p> <p>Treatment is started carefully and the dose is gradually increased until optimal symptom control is achieved.</p> <p><b>Rotigotine</b> is given as a skin patch – this may be useful if swallowing tablets is a problem.</p> <p><b>Apomorphine</b> is a strong dopamine agonist and is given by injection or infusion</p>	<p>As with levodopa some people may experience side effects while taking dopamine agonist drugs. Not all people experience side effects but these may include:</p> <ul style="list-style-type: none"> <li>• Sleepiness, which in a few people can happen quite suddenly.</li> <li>• Nausea.</li> <li>• Low blood pressure.</li> <li>• Hallucinations (seeing, hearing, feeling and smelling things that are not there).</li> </ul> <p><b>Behavioural changes:</b> Some people experience behavioural changes, finding it difficult to control compulsive and impulsive behaviours such as gambling, shopping, binge-eating,</p>

	<p>pump. It is used for more complex motor problems.</p>	<p>hyper-sexuality or other unusual behaviours.</p> <p>Often the behaviour is out of character. While they can occur while taking any anti-parkinsonian medication, they are more common in people on dopamine agonists.</p> <p>If any of these side effects occur it is vital to tell your GP, specialist or Parkinson's nurse, as a change in your medication may be necessary.</p>
<p><b>MAO-B inhibitors</b></p> <p>Rasagiline (Azilect) and Selegiline (Zelapar)</p>	<p>These can help your nerve cells make better use of the dopamine it does have.</p>	<p>Side effects are rare but can include abnormal dreams, constipation and a dry mouth.</p>
<p><b>COMT inhibitors</b></p> <p>Entacapone (Comtess) and Tolcapone (Tasmar), Opicapone (Ongentys)</p> <p>Entacapone is available as a single tablet combined with levodopa and carbidopa (entacapone, levodopa, carbidopa) – brands include Stalevo®, Sastravi®, Stanek®.</p>	<p>These drugs are only used alongside levodopa and must be taken at the same time. They help levodopa to work more smoothly and can extend the amount of time the levodopa tablet is effective.</p> <p>Opicapone is a once-a-day medication.</p>	<p>As this medication increases the amount of levodopa in the blood, it can increase its effects. Urine may be reddish-brown, which is harmless.</p>

<p><b>Glutamate agonists</b> Amantadine (Symmetrel)</p>	<p>It isn't known exactly how this type of drug works for Parkinson's, but it is likely to have several actions. It can be particularly useful for helping to manage involuntary movements (dyskinesia). However, not everyone can take this as the risk of having hallucinations is increased.</p>	<p>Side effects can include leg swelling, dizziness, dry mouth, hallucinations, confusion and sleep problems.</p>
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## Therapy

Support from therapy teams, including physiotherapy, speech and language therapy, occupational therapy, dietitians and palliative care can help you to manage your symptoms.

A **physiotherapist** can see how Parkinson's affects your movements. They will then help you manage these problems, prevent future problems and advise you on the right exercises or treatments. We have specialist neuro-physiotherapy available at the Royal Free Hospital.

**Occupational therapists** can assess you in your home and look at any adaptations that may help.

**Speech and language therapists** can help you overcome communication problems such as slurred or unsteady speech and/or a softer voice. They can also assess swallowing.

**Dietitians** may be helpful if nutritional or dietary advice is needed.

**Social workers** are professionals who aim to enhance overall wellbeing and help meet basic and complex needs of individuals. For example, they conduct assessments to see if a person may benefit from having extra support at home. You can contact social services at your local council for social worker support or via your GP.

**Palliative care** is an approach which concentrates on improving the quality of life for people with advanced illness and providing support for them and their families. It aims to identify and address physical, emotional and practical issues, and end of life issues where appropriate.

In someone experiencing the advanced stages of Parkinson's, care needs may be more complex. Palliative care teams can also support advanced decision making, to ensure health teams know your preferences and wishes. It may be helpful to consider options and decisions that may be required in the future, such as a chair lift or wet room, well in advance with family and health and social care professionals. Your GP can refer you to a palliative care service if needed.

### **Complementary therapies**

Some people like to explore complementary therapies or alternative medicines. Please do discuss with us if you wish to take non-prescription medication so we can ensure there are no interactions with your prescription medication.

## **Research**

### **Research at the Royal Free London**

The Royal Free London is committed to on-going research into Parkinson's. This involves looking for new and better treatments, understanding the underlying disease processes and improving quality of life. You can find out more about Parkinson's research at University College London (UCL) and Royal Free London by visiting the UCL website:

[www.ucl.ac.uk/ion/research/research-centres/movement-disorders-centre/research/clinical-studies](http://www.ucl.ac.uk/ion/research/research-centres/movement-disorders-centre/research/clinical-studies)

Do speak to us if you would like to participate in our current research into Parkinson's, which will benefit people with the condition now and into the future.

### **Parkinson's UK Research**

Website: [www.parkinsons.org.uk/research/take-part-research](http://www.parkinsons.org.uk/research/take-part-research)

### **Research at Parkinson's UK**

The Parkinson's UK Brain Bank collects precious tissue from people with and without Parkinson's who have decided to leave their brains to Parkinson's research. The tissue is supplied to researchers around the world who are working towards a cure for Parkinson's. Research using donated brain tissue has already led to important medical breakthroughs in treating Parkinson's. Anyone can become an organ donor, including people who do not have Parkinson's. This enables researchers to compare what happens in a brain affected by Parkinson's and one that is not. If you are considering becoming an organ donor, it is important to discuss with those closest to you to ensure they are aware of your plans.

For more information visit: [www.parkinsons.org.uk/research/parkinsons-uk-brain-bank](http://www.parkinsons.org.uk/research/parkinsons-uk-brain-bank) or for an information pack, call: 020 7594 9732.

## Help from our Parkinson's Nurse

Everyone responds differently to their diagnosis and we are here to help and support you. You can call or email Rita Smith, Parkinson's nurse specialist, with any concerns or worries (contact details below).

## Further information

### Parkinson's UK

Parkinson's UK is a charity which offers information and support to people with the condition. This includes information leaflets for many of the specific questions that you may have in your particular circumstances. They also provide Parkinson's local advisers who can visit you at home and run local support groups where you can meet other people with the condition.

**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES. FIND A CURE. JOIN US.

The charity also run a peer support service where you can arrange to talk to someone with Parkinson's.

Visit the Parkinson's UK website: [www.parkinsons.org.uk](http://www.parkinsons.org.uk)  
Call the Parkinson's UK helpline: 0808 800 0303

### The Cure Parkinson's Trust

Visit The Cure Parkinson's Trust website: [www.cureparkinsons.org.uk](http://www.cureparkinsons.org.uk)  
Call The Cure Parkinson's Trust: 020 7487 3892

## Helpful contacts for people with Parkinson's, families and carers

<p>General help and advice</p>	<p><b>Parkinson's UK</b>  <a href="http://www.parkinsons.org.uk">www.parkinsons.org.uk</a></p> <p>Parkinson's UK helpline: 0808 800 0303</p> <p>Information about Parkinson's, description of symptoms and information on types of medication and caring for someone with Parkinson's.</p> <p>They also provide information about support local to you.</p>
<p>Parkinson's nurse specialist</p>	<p><b>Rita Smith</b></p> <p>Royal Free Hospital          Telephone: 020 7317 7578          Email: <a href="mailto:ritasmith@nhs.net">ritasmith@nhs.net</a>          Website: <a href="http://www.royalfree.nhs.uk/services/services-a-z/movement-disorders">www.royalfree.nhs.uk/services/services-a-z/movement-disorders</a></p>
<p>Non-medical advice on benefits, local support and a variety of general Parkinson's information</p>	<p>Your <b>Parkinson's UK local adviser</b> is:</p> <p>Catchment area: Barnet, Brent  <b>Ruhullah Ebadi</b>          Telephone: 0344 225 3688          Email: <a href="mailto:rebadi@parkinsons.org.uk">rebadi@parkinsons.org.uk</a></p> <p>Catchment area: Camden, Islington, Tower Hamlets, Hackney, City  <b>Tariq Saleem</b>          Telephone: 0344 225 9818          Email: <a href="mailto:tzsaleem@parkinsons.org.uk">tzsaleem@parkinsons.org.uk</a></p>
<p>Carers' support</p>	<p>Visit our website for more information about support available for carers: <a href="http://www.royalfree.nhs.uk/patients-visitors/caring-for-carers">www.royalfree.nhs.uk/patients-visitors/caring-for-carers</a></p>
<p>To meet other people with Parkinson's living locally</p>	<p>Contact details for the groups available from Parkinson's UK:  <a href="http://www.parkinsons.org.uk/information-and-support/our-support-services">www.parkinsons.org.uk/information-and-support/our-support-services</a></p>

<p>Research opportunities</p>	<p>If you are interested in finding out more about our current research opportunities contact Rita Smith, Parkinson's nurse specialist. Alternatively, you can visit our website: <a href="http://www.royalfree.nhs.uk/services/services-a-z/movement-disorders/research/">www.royalfree.nhs.uk/services/services-a-z/movement-disorders/research/</a></p>
<p>Royal Free London Parkinson's service</p>	<p>Visit our website for more information about Parkinson's, our service and research into movement disorders: <a href="http://www.royalfree.nhs.uk/services/services-a-z/movement-disorders">www.royalfree.nhs.uk/services/services-a-z/movement-disorders</a></p>
<p>For further practical support: adult social care services</p>	<p>Provided by your local council:</p> <p><b>Camden</b> Telephone: 020 79744 000 Email: <a href="mailto:access.services@islington.gov.uk">access.services@islington.gov.uk</a></p> <p><b>Islington</b> Telephone: 020 75272299 Email: <a href="mailto:access.services@islington.gov.uk">access.services@islington.gov.uk</a></p> <p><b>Barnet</b> Telephone: 020 8359 5000 Email: <a href="mailto:socialcaredirect@barnet.gov.uk">socialcaredirect@barnet.gov.uk</a></p> <p><b>Brent</b> Telephone: 020 8937 4300</p>
<p>For mental health support, for example for depression or anxiety</p>	<p>You can self-refer to local NHS mental health services:</p> <p><b>Camden</b> Telephone: 020 3317 6670 Website: <a href="http://www.icope.nhs.uk">www.icope.nhs.uk</a> Email: <a href="mailto:cpts@candi.nhs.uk">cpts@candi.nhs.uk</a></p> <p><b>Islington</b> Telephone: 020 3317 7252 Website: <a href="http://www.icope.nhs.uk">www.icope.nhs.uk</a> Email: <a href="mailto:icope.referrals@candi.nhs.uk">icope.referrals@candi.nhs.uk</a></p> <p><b>Barnet</b> Telephone: 020 8702 5309 Website: <a href="http://www.lets-talk-iapt.nhs.uk">www.lets-talk-iapt.nhs.uk</a> Email: <a href="mailto:lets-talk-barnet@nhs.net">lets-talk-barnet@nhs.net</a></p>

	<b>Brent</b>
	Telephone: 020 8206 3924
	Website: <a href="http://www.cnwl.nhs.uk/services/mental-health-services/adult-and-older-adult/brent-talking-therapies">www.cnwl.nhs.uk/services/mental-health-services/adult-and-older-adult/brent-talking-therapies</a>
	Email: <a href="mailto:cnw-tr.brent.iapt@nhs.net">cnw-tr.brent.iapt@nhs.net</a>

### **More information**

For more information about the Parkinson's service at the Royal Free London, please visit our website: <https://www.royalfree.nhs.uk/services/services-a-z/movement-disorders/parkinsons/>

### **Your feedback**

If you have any feedback on this leaflet or for a list of references for it, please email: [rf.communications@nhs.net](mailto:rf.communications@nhs.net).

### **Alternative formats**

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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[www.royalfree.nhs.uk](http://www.royalfree.nhs.uk)