

Information for people with Parkinson's

Information for patients

Although life with Parkinson's may be difficult sometimes, you can lead an active, fulfilling life with Parkinson's 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 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. Some experts suggest that people with Parkinson's should take calcium and vitamin D daily to help maintain good bone health.

Driving

Having the condition doesn't mean your driving license 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
- 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

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
Levodopa 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 symptoms while taking levodopa.</p> <p>For those patients who do, symptoms can include:</p> <ul style="list-style-type: none">• nausea (feeling sick) or vomiting – this usually goes away after a couple of weeks• low blood pressure and sleepiness <p>Levodopa may cause urine to turn reddish-brown. This is harmless.</p> <p>Behavioural changes: Some people experience behavioural changes and find it difficult to control compulsive and impulsive behaviours such</p>

		<p>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>Dopamine agonists</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>Rotigotine is given as a skin patch – this may be useful if swallowing tablets is a problem.</p> <p>Apomorphine is a strong dopamine agonist and is given by injection or infusion pump. It is used for more complex motor problems.</p>	<p>As with levodopa some people may experience side effects while taking dopamine agonist drugs. These may include:</p> <ul style="list-style-type: none"> • sleepiness, which in a few people can happen quite suddenly • nausea • low blood pressure • hallucinations (seeing, hearing, feeling and smelling things that are not there). <p>Behavioural changes: Some people experience behavioural changes, finding it difficult to control compulsive and impulsive behaviours such as gambling, shopping, binge-eating, 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>MAO-B inhibitors</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>COMT inhibitors</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>Glutamate agonists</p> <p>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>

How can therapy help me?

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.

A **speech and language therapist** can help you overcome communication problems such as slurred or unsteady speech. They can also assess swallowing.

Dietitians may be helpful if dietary advice is needed.

Social workers have an important role in providing appropriate support when needed.

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. It may also 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.

Palliative care teams can also support advanced decision making, to ensure health teams know your preferences and wishes.

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.

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.

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 or for an information pack, call 020 7594 9732.

Our patients

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.

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^{UK}
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

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

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>Parkinson's UK www.parkinsons.org.uk</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>Rita Smith</p> <p>Royal Free Hospital Telephone: 020 7317 7578 Email: ritasmith@nhs.net Website: www.royalfree.nhs.uk/services/services-a-z/movement-disorders</p>
<p>Non-medical advice on benefits, local support and a variety of general Parkinson's information</p>	<p>Your Parkinson's UK local adviser is:</p> <p>Catchment area: Barnet, Brent Ruhullah Ebadi Tel: 0344 225 3688 Email: rebadi@parkinsons.org.uk</p> <p>Catchment area: Camden, Islington, Tower Hamlets, Hackney, City Tariq Saleem Tel : 0344 225 9818 Email: tzsaleem@parkinsons.org.uk</p>
<p>Carers support</p>	<p>Visit our website for more information about support available for carers: www.royalfree.nhs.uk/patients-visitors/caring-for-carers</p>

To meet other people with Parkinson's living locally	Contact details for the groups available from Parkinson's UK: www.parkinsons.org.uk/information-and-support/our-support-services
Research opportunities	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: www.royalfree.nhs.uk/services/services-a-z/movement-disorders/research/
Royal Free London Parkinson's service	Visit our website for more information about Parkinson's, our service and research into movement disorders: www.royalfree.nhs.uk/services/services-a-z/movement-disorders

This leaflet was written by Professor A. Schrag and Rita Smith, Parkinson's nurse specialist, with the help of our Parkinson's patients.

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.

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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Service: Parkinson's service

Version number: 2

First approved: September 2017

Approval date: August 2019

Review date: August 2021

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