

# Drug treatments for Parkinson's

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



Treatments and therapies

Lisa and Sheila

**While there is no cure yet for Parkinson's, there are many different drugs that can help manage the symptoms. This booklet is for people with Parkinson's and their families, and it provides information about the drugs most commonly used to help manage the condition.**

The booklet starts with some practical points about taking Parkinson's drugs and it moves on to give further details about each individual drug, including:

- its name
- how it works
- how it's used
- advantages
- disadvantages

There is a section that explains more about clinical trials to develop new drug treatments, and a glossary to explain the meaning of unfamiliar medical words.

Living with Parkinson's is not always easy and there are many people who can help you with practical support, information, advice or just a listening ear when you need it. The booklet has a section explaining the many ways that Parkinson's UK can help.

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## Disclaimer

We've made every effort to make sure the information in this booklet is correct at the time of printing.

Parkinson's UK, however, cannot take responsibility for the correctness, sufficiency or completeness of this information or any recommendation.

Please remember that information about drugs can change. This booklet does not list all the uses

and side effects of these drugs. For full details, please see the drug information leaflet that comes with your medication.

Your GP, specialist or Parkinson's nurse (if you have one) will look at your medical condition and make you aware of any information or side effects that could affect you. You should speak to a medical professional about your individual healthcare needs.



# PARKINSON'S DRUGS – AN OVERVIEW

Researchers are still looking for a way to cure Parkinson's. Today, no treatment can offer a cure. But there are many drugs that can help manage symptoms such as tremor, or problems with co-ordination, balance and movement. These drugs are improving all the time, too.

## Individual treatment

Every person with Parkinson's has a different experience of the condition. Some symptoms may trouble you more, or less, than they do another person. Your GP, specialist or Parkinson's nurse will aim to find the treatment that is best for you as an individual.

Finding the best medicine, dose and timing may need some changes along the way. Because the symptoms of Parkinson's change over time, your medication will sometimes have to change, too. For some people this process can happen more quickly than it does for others.

“No two people with Parkinson's have the same symptoms, so at first, it's a case of trial and error. But once the right combination is found for your symptoms, the drug treatment for Parkinson's is very good.”

## Steve, diagnosed in 1999

### Getting it right

In newly diagnosed people, carefully introducing the right Parkinson's drugs can often improve the symptoms. When you are diagnosed you will have a consultation with your specialist to discuss whether you need to start treatment immediately. This is because Parkinson's drugs can become less effective, or you might develop side effects after taking them for a while.

For these reasons, drugs for Parkinson's are often started gradually, stepping up the dose until symptom control is good. Anyone with Parkinson's can aim for a healthier lifestyle by focusing on exercise, relaxation and diet, reducing stress and alcohol intake, and stopping smoking. For more information visit the website [www.nhs.uk/livewell](http://www.nhs.uk/livewell)

No booklet is a substitute for advice from your GP, specialist or Parkinson's nurse. Choosing the right medication is always a decision that you make with them. With this in mind, you can show this booklet to your GP, specialist or Parkinson's nurse and ask them questions about the information here. You may find it a useful starting point when you are talking about next steps in your treatment.

## How the drugs work

The symptoms of Parkinson's happen when levels of a chemical messenger in your brain, called dopamine, become too low. This is because many of the brain cells that produce the dopamine have died.

Without enough dopamine, you will find that your movement slows down. It will take you longer to do things. Lack of co-ordination can also be a problem. Parkinson's may cause your hands or body to shake. This is known as tremor and can make everyday activities difficult or frustrating.

You may find it hard to move freely, and your muscles might become stiff. Some people with Parkinson's freeze suddenly and this leaves them unable to move. This is a Parkinson's symptom, but can also be a sign that medication is 'wearing off'.

Most drug treatments for Parkinson's aim to ease the movement symptoms by:

- increasing the amount of dopamine in the brain, or
- stimulating the parts of the brain where dopamine works, or
- blocking the action of other factors (enzymes) that break down dopamine

## Managing other symptoms

People with Parkinson's can also have non-motor symptoms – symptoms that aren't connected to movement problems. These include anxiety and depression, pain and constipation.

Parkinson's drugs are not used to treat the symptoms of Parkinson's that are not related to movement. These types of symptoms will be treated separately depending on the problems you experience. Constipation and depression, for example, may be treated with drugs designed to treat those symptoms.

There are too many different treatment options to include all

of the drugs for other symptoms in this booklet. Also, people with Parkinson's will often receive the same or similar treatment for other symptoms, such as sleeping problems, as people without Parkinson's would (as long as any medication given is compatible with their Parkinson's medication and other factors of the condition).

Always tell your GP, specialist or Parkinson's nurse about any other symptoms you have. This can be easily done by giving them a copy of our non-motor questionnaire that you've filled in. The questionnaire is available to download from our website at **[parkinsons.org.uk/publications](https://parkinsons.org.uk/publications)**



Dennis



# PRACTICAL POINTS

Whatever treatment you and your specialist or Parkinson's nurse decide on, you may find it helpful to bear these tips in mind.

## DO:

- Ask questions or have your doctor, nurse or pharmacist explain something again if you don't understand. They won't mind! You can also ask for written information.
- Keep a brief diary or chart when you start a new drug, or if your GP, specialist or Parkinson's nurse changes your dose. Record the dose and time you took the drug and what happened to your symptoms. This information can help the medical professional who is adjusting your medication.
- Keep your medication out of the reach of children or other people who might be confused and take it by mistake. Store it as you're told to on the packet.
- Tell your GP, specialist or Parkinson's nurse if you think you could be pregnant.
- Take your Parkinson's drugs as recommended by your GP, specialist or Parkinson's nurse. Make sure you understand what to do if you forget a dose.
- Tell your GP, specialist or Parkinson's nurse straight away if your Parkinson's drugs are causing problems or side effects (but don't stop taking your Parkinson's drugs until they tell you to).
- Tell your GP, specialist or Parkinson's nurse how your treatment is working for you. Making notes before your appointment can help you remember what you want to say.
- Remember that your pharmacist can also be a very good source of advice. They will also help you dispose of your unused Parkinson's drugs if necessary.



Dorothy

## DON'T:

- Assume that you will have serious side effects. Many people don't. However, if you think you are having side effects or if you have any other worries about your Parkinson's drugs, talk to your GP, specialist, Parkinson's nurse or pharmacist right away.
  - Assume that your treatment, dose or the timing of your medication should be the same as other people with Parkinson's. Everyone is different.
  - Change the dose on your own. Your GP, specialist or Parkinson's nurse should be asked for guidance about any changes to your medication.
  - Forget to tell the doctors and nurses you are taking Parkinson's drugs, if you go to hospital. You should make sure staff understand that you need your medication on time.
- Some hospitals will allow you to look after your own medication, so that you can self-medicate outside of the usual drugs round.
- Forget to wear a medical alert bracelet or necklace if you want to make health professionals aware of your condition and the drugs you are taking in the event of an emergency. These are items of jewellery that can be inscribed with important medical information and are widely available. You can also order our Medication Card, on which you can write down the drugs you are taking.
  - Stop taking your Parkinson's medication unless your GP, specialist or Parkinson's nurse tells you to. It can be dangerous to stop taking Parkinson's drugs suddenly or without guidance. They are generally stopped gradually with medical supervision.

## Taking special care with Parkinson's drugs

- You must tell your GP, specialist or Parkinson's nurse about any other medical conditions you have and any other medications you are taking.
- If you are pregnant, breastfeeding, or suspect you may be pregnant, tell your GP, specialist or Parkinson's nurse.
- Some Parkinson's drugs can make you very sleepy. Sometimes this happens suddenly and without warning. Make sure you understand what safety precautions you need to take, for example whether you can drive. Sometimes it can be hard to know whether your sleep problems are part of the condition or whether they are a side effect of your Parkinson's medication.

**Find out more:** see our booklet *Driving and Parkinson's* and our information sheet *Sleep and night-time problems in Parkinson's*.

- Some Parkinson's drugs can make your blood pressure fall very quickly, causing you to feel dizzy or faint. Again, find out what safety precautions you should take in case this happens.

- With some Parkinson's drugs, particularly dopamine agonists and in a small number of cases levodopa, some people have problems controlling impulsive or compulsive behaviour. Examples of these are gambling, becoming a 'shopaholic', binge eating and thinking about sex so much that it gets in the way of everyday life. This can have a huge impact on people's lives, so if you think this is happening to you or the person you are caring for, tell your GP, specialist or Parkinson's nurse right away so they can help.

**Find out more:** see our information sheet *Impulsive and compulsive behaviour in Parkinson's*.

- If you think you are experiencing any side effects (you can find examples of these in each section of this booklet), tell your GP, specialist or Parkinson's nurse right away, but do not stop taking your Parkinson's drugs until they tell you to.
- If you are taking a drug for Parkinson's, never stop taking it suddenly. This can be dangerous. Generally, these drugs should be stopped gradually with the help and guidance of your GP, specialist or Parkinson's nurse.

## If you have other conditions or take other medication

If you have other medical conditions, this may have an effect on your Parkinson's symptoms and how effective the drugs are. Some medications for other conditions can make Parkinson's symptoms worse.

Also, if you have a problem like constipation (which is often experienced by people with Parkinson's) or problems with your digestive system that may affect how well the drug reaches your bloodstream, this may reduce how well your Parkinson's medication works.

Parkinson's drugs can interact with a lot of drugs for other conditions. The different drugs can make each other weaker or stronger. This can be dangerous. Herbal or complementary treatments may also affect your Parkinson's drugs.

Do make sure that every healthcare professional treating you knows that you are taking drugs for Parkinson's, and which ones. If you want to take a non-prescription medicine, check with your pharmacist first that it is safe.

## Drugs to avoid

Some drugs can bring on Parkinson's-like symptoms and should be avoided unless they're recommended by a specialist.

These are some (but not all) of the drugs to avoid:

- chlorpromazine (Largactil®)
- fluphenazine (Modecate®)
- fluphenazine with nortriptyline (Motival®)
- perphenazine (Fentazin®/Triptafen®)
- trifluoperazine (Stelazine®)
- flupenthixol (Fluanxol®/Depixol®)
- haloperidol (Serenace®/Haldol®)
- metoclopramide (Maxalon®)
- prochlorperazine (Stemetil®)

Domperidone (Motilium®) is the anti-sickness drug of choice to prevent and treat nausea and vomiting caused by levodopa. Other anti-sickness drugs that are generally considered useful include cyclizine (Valoid®) and 5-HT<sub>3</sub> receptor antagonists like ondansetron. If you have any queries about medication, contact your GP, specialist or Parkinson's nurse.



# TYPES OF PARKINSON'S DRUGS

There are many different drug treatments for Parkinson's. The table on the following pages gives you a summary of the main types, their names, how they are used, and where to find more details in this booklet.

## What's in a name?

Sometimes, the same drug goes by a number of different names – even if the ingredients are the same and they do the same job.

## Class

Each drug belongs to a class – a wider group of drugs that work in the same way.

## Common (generic) name

All types of drug have a common, or generic, name. Every drug that has the same active ingredient will have this name, no matter who it is made by.

Though the active ingredient of the generic drug is the same as the branded version, some people may find they respond a bit differently to different versions. You should discuss any concerns with your GP, specialist or Parkinson's nurse.

## Brand name

In addition to its common name, some drugs will also have a brand name, decided by the company who makes it.



Mike

# LEVODOPA

These are the different types of levodopa that can be prescribed. This section explains what levodopa is and how it works, and looks at other considerations, including possible side effects.

Generic name	Brand names	Forms available
Levodopa is always given combined with either benserazide or carbidopa. These help the levodopa get into the brain where it's needed.		
Co-beneldopa (benserazide plus levodopa)	Madopar	Capsules, dispersible tablets
	Madopar CR	Controlled release (CR) capsules (see page 19)
Co-careldopa (carbidopa plus levodopa, available in generic form)	Caramet CR	Controlled release tablets
	Duodopa	Intestinal gel
	Sinemet	Tablets
	Sinemet CR	Controlled release tablets
	Half Sinemet CR	Controlled release tablets
Co-careldopa plus entacapone (see page 35 for information about entacapone)	Stalevo	Tablets

## How levodopa works

Dopamine is a chemical messenger made in the brain. The symptoms of Parkinson's are caused by a decrease in the levels of dopamine, due to the death of the nerve cells in the brain that make it.

Unfortunately, taking dopamine as a drug would not help you, because it could not cross into your brain where it's needed. Doctors can get around this by using levodopa.

Levodopa is a chemical building-block that your body converts into dopamine. Levodopa already occurs naturally in your body, and taking it as a drug treatment boosts the supply. The nerve cells in your brain will then have more of this ingredient and can then make more dopamine. Levodopa is given with benserazide or carbidopa, as this makes sure it can enter the brain more efficiently.

### Taking special care with levodopa

If you are prescribed this drug for Parkinson's, please make sure you read the important safety advice that comes with it, and the general information on pages 12 and 13.

## How levodopa is used

Levodopa has been used to treat Parkinson's since the 1960s. Later, it was found that adding benserazide or carbidopa could allow more levodopa to get into the brain and make it work better.

Levodopa can be used at all stages of Parkinson's. However, it can have side effects that build up over time. One side effect of levodopa are 'off' periods, where your body becomes so stiff and slow that you are unable to move.

Although levodopa may be taken at any stage of the condition, based on current scientific evidence, there is no particular time to start taking it that is right for everyone. You and your specialist or Parkinson's nurse will need to talk it over, and agree what is the best choice for you at this time.

Treatment will usually start with a low dose and this is gradually increased until you and your specialist or Parkinson's nurse agree that your symptoms are under control.

If you have problems with swallowing, this may determine the form of drug you will take.

There may be a suitable option that is easier to swallow, if you can't easily take tablets. Also, there are some options that allow you to take fewer tablets in a day. However, these will not be suitable for everyone who takes levodopa.

Several different forms are available:

### Tablets

These come in different strengths, depending on the dose your GP, specialist or Parkinson's nurse thinks you need.

### Controlled release (CR) or prolonged release capsules or tablets

These let the levodopa enter your body slowly instead of all at once. Involuntary movements (dyskinesia) can be a side effect of taking high doses of levodopa. Controlled release options can sometimes reduce the number of times that this happens. They can also be taken before going to bed to reduce stiffness during the night.

### Dispersible tablets

This form can be mixed with water to make a drink. It takes effect more quickly than capsules because it doesn't need to be broken down in your stomach to release the

active ingredient. It can also be used if you have trouble swallowing tablets or capsules. If you are prescribed non-dispersible tablets or capsules, these should not be crushed and put into water.

### Intestinal gel

This option is only suitable for a very small number of people, whose symptoms can't be controlled with the more common forms of treatment. The drug is pumped continuously through a tube that is surgically inserted in the intestine. If you are prescribed this option you are less likely to experience involuntary movements. You might also have fewer 'off' periods. It may also help to control your symptoms at night.



## Advantages of levodopa

Levodopa is seen as the most effective treatment for Parkinson's symptoms. When taking it, you may experience a big improvement in your symptoms, especially in stiffness and slowness of movement.

## Disadvantages of levodopa

### Becomes less effective over time

After a while, you may have a less predictable response to levodopa. You may get 'off' periods when you are weak and can't move well. The effect of the dose wears off more quickly, maybe even before your next one is due or has begun to work. When this happens,

sometimes your GP, specialist or Parkinson's nurse will change your dose, the form of drug or how often you take it. Taking other Parkinson's drugs with levodopa will also help it to be more effective in treating the symptoms of your Parkinson's.

### Movement problems

One of the main problems with levodopa is a side effect called dyskinesia. These are spasms or muscle movements that happen when you don't want them to. Dyskinesia can increase over time when you are taking levodopa, although not everyone will have this side effect.



Kris



Claire

## Levodopa and diet

Taking levodopa with food can sometimes help to reduce feelings of sickness. However, for some people, protein (which is found mainly in meat, fish, eggs, cheese and beans) seems to interfere with how well levodopa medication works, by stopping how well the drug is absorbed by the body.

Some people may benefit from taking their medication at least 30 minutes before they eat. Your GP, specialist or Parkinson's nurse can advise you on timing your doses and this should be discussed with them when you are first prescribed the drug. They can also help you get advice from a dietitian.

**Find out more:** see our booklet *Diet and Parkinson's*.

## Sleepiness and fainting

Levodopa drug treatment can make you feel very sleepy. Sometimes this happens quite suddenly and without warning. Levodopa can also make you faint or feel dizzy.

## Other side effects

This booklet can't list all the possible side effects of all Parkinson's drugs. However, some of the most common side effects that can happen with levodopa include: nausea and vomiting, loss of appetite, psychological problems, hallucinations (seeing, hearing, feeling and smelling things that aren't there), and sleep problems.

## Levodopa and impulsive and compulsive behaviour

A small number of people taking levodopa have problems with impulsive or compulsive behaviour. This can also be called impulse control disorder. It affects a much smaller percentage of people taking levodopa than those taking dopamine agonists, but it is still a possible side effect.

Impulsive behaviour is when a person can't resist the temptation to carry out activities that could lead them to harm themselves or others. In many cases, this behaviour is out of character.

Compulsive behaviour is when a person has an overwhelming drive or urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from that urge. Both of these can have a devastating impact on the person with Parkinson's and those around them.

Some examples are gambling, becoming a 'shopaholic', binge eating, and thinking about sex so much that it gets in the way of everyday life. Other behaviour may include punding, which is repetitive collecting and sorting of objects.

Another potential problem is dopamine dysregulation syndrome, where someone with Parkinson's might be tempted to take more of their Parkinson's medication than they are supposed to.

If you think this is happening to you or the person you are caring for, tell your GP, specialist or Parkinson's nurse right away.

**Find out more:** see our [information sheet \*Impulsive and compulsive behaviour in Parkinson's\*](#).

# DOPAMINE AGONISTS

These are the different types of dopamine agonists that can be prescribed. This section explains what dopamine agonists are and how they work, and looks at other considerations, including possible side effects.

Generic name	Brand names	Forms available
Bromocriptine (available in generic form)	Parlodel	Tablets, capsules
Cabergoline (available in generic form)	Cabaser	Tablets
Pergolide (available in generic form)	Celance	Tablets
Pramipexole (available in generic form)	Mirapexin	Tablets
	Mirapexin prolonged release	Prolonged release tablets
Ropinirole (available in generic form)	Requip	Tablets
	Requip XL	Prolonged release tablets
Rotigotine	Neupro	Skin patch
Apomorphine (available in generic form)	APO-go PEN	Pre-filled pen for intermittent injection
	APO-go PFS	Pre-filled syringe for infusion. Can be used with a continuous infusion pump

## How dopamine agonists work

Dopamine is a chemical messenger made in the brain. The symptoms of Parkinson's are caused by a decrease in the levels of dopamine, due to the death of the nerve cells in the brain that make it.

One option is to use levodopa, which is converted into dopamine in the brain. Another possible approach is to use dopamine agonist drugs, which act like dopamine to stimulate your nerve cells.

## How dopamine agonists are used

Dopamine agonists are used at all stages of Parkinson's. You might take them alone when treatment is being started, or alongside levodopa to help the levodopa work better.

Treatment with dopamine agonists has to be started carefully, with the dose gradually being increased until you and your specialist or Parkinson's nurse are happy that your symptoms are under control.

Some dopamine agonists are now being made as 'one a day' tablets. These can be a better option



**Lisa and Judith**

for the body and may help both movement and other symptoms of Parkinson's.

### Taking special care with dopamine agonists

If you are prescribed these drugs for Parkinson's, please make sure you read the important safety advice that comes with them, and the general information on pages 12 and 13.

## Several different forms are available:

### Tablets and capsules

These come in different strengths, depending on the dose your GP, specialist or Parkinson's nurse thinks you need.

### Prolonged release tablets

These can be taken less frequently and they work longer in the body, compared to normal capsules and tablets.

### Skin patch

The patch may be good if you have trouble swallowing tablets, as well as for those who have problems with drooling and gastritis. It might also reduce stomach upsets. The patch must be placed on a different part of your body every day and you may have to wear up to two depending on the dosage you are prescribed. The patches should be stored in a refrigerator. If you notice anything strange about how your patches look (such as if the drug starts to crystallise), show them to your pharmacist. You may get a skin rash from the patches, so they are not suitable for everyone.



Ian and Cathy

## Injection or infusion

Apomorphine is a dopamine agonist that is given by injection or infusion pump. It is the strongest known dopamine agonist. It is saved for more advanced Parkinson's that does not respond as well to oral drug treatments. If you continue to have sudden and unpredictable changes in your symptoms that aren't controlled by other Parkinson's medications, these may be helped by apomorphine.

You may need to have injections of apomorphine between doses of your usual tablets, or you may need apomorphine more often. In this case, you can use a portable, battery-driven pump, which gives the drug through a needle under the skin. However, this is not commonly used, and is only suitable in certain cases.

Ideally, apomorphine will be started in hospital, under the guidance of a Parkinson's specialist. Once you are settled on this treatment, and you and your carers have been trained in how to use it, apomorphine can be continued at home.

Apomorphine can cause severe short-term nausea and sickness, so an anti-sickness drug called

domperidone (Motilium) will also be given for at least two weeks when it is started.

Injections of apomorphine are taken in a similar way to insulin for diabetes. There is a ready-to-use injection pen that works within 10 minutes and is often used as a 'rescue' measure. This is very useful if you have a sudden 'off' period.

Soreness can develop at the place where the needle goes into your skin. If this happens, make sure to get advice from your GP, specialist or Parkinson's nurse.

There are two types of apomorphine for infusion (APO-go and a generic form), which means there are two types of infusion pump that look very similar, but the settings on each are very different. Each must be used with the right type of apomorphine. Also, the syringes for the pumps look the same, but they will only fit correctly on their matching model. It can cause great harm if the correct pump, syringe and drug aren't used together.

**Find out more:** see our [information sheet \*Apomorphine\*](#).

## Advantages of dopamine agonists

### Delaying levodopa treatment

Scientific studies suggest that dopamine agonists can be effective treatments for several years when used alone. However, this will not be the case for everyone.

### Fewer movement problems

Your symptoms may be controlled during the day for longer than is usually the case with levodopa. Where this happens, you may be less prone to long-term side effects such as the 'on/off' effect and dyskinesia (movements that you can't control).

### Helping levodopa work better

Dopamine agonists can also be taken with levodopa, at all stages

of Parkinson's. They can help when the effect of levodopa wears off or doesn't always work so well. Dopamine agonists may help to smooth out the 'on/off' effect that you may have with levodopa.

### Fewer tablets to take (in some cases)

There are now some once-daily preparations that could make a big difference by reducing the number of tablets you take. But this option may not suit everyone.

### Positive effects on non-movement symptoms

Dopamine agonists have recently been shown to have a good effect on the symptoms of Parkinson's not related to movement, including sleep problems, pain and mood.



Rob and Surinder

## Disadvantages of dopamine agonists

### Heart problems

Some of the older dopamine agonists increase the risk of heart problems. As a group, these are known as the 'ergot' types and they include: bromocriptine, pergolide and cabergoline. Because of this risk, these Parkinson's drugs are only used when other dopamine agonists do not work well. All newer dopamine agonists are non-ergot in type.

Apomorphine and the newer dopamine agonists – pramipexole, ropinirole and rotigotine – have not been associated with an increased risk of heart damage. As a group, these are called the 'non-ergot' types. Doctors prefer to use these if possible.

### Sleepiness and fainting

Dopamine agonist drugs can make you feel very sleepy. This is most likely to happen when you start taking the drugs. Once a stable dose is reached, this effect often wears off. In a few people, sleepiness happens quite suddenly and without warning. Dopamine agonists can also make you faint or feel dizzy.



### Other side effects

This booklet can't list all the possible side effects of all Parkinson's drugs. However, some of the most common side effects that can happen with dopamine agonists include: nausea, constipation, low blood pressure, headaches, psychological problems, hallucinations (seeing, hearing, feeling and smelling things that aren't there), movement problems, swollen limbs, a stuffy nose and a dry mouth. Sight problems can include blurred vision, so it's important to have regular eye checks.

## Dopamine agonists and Impulsive and compulsive behaviour

Some people taking dopamine agonists have problems controlling compulsive or impulsive behaviour. It can also affect people taking levodopa, but it more frequently affects people taking dopamine agonists.

Impulsive behaviour is when a person can't resist the temptation to carry out certain activities that could lead them to harm themselves or others. In many cases, this behaviour is out of character.

Compulsive behaviour is when a person has an overwhelming drive or urge to act in a certain way, often repetitively, to reduce the worry or tension that they get from their drive or urge.

Both of these can have a devastating impact on the person with Parkinson's and those around them.

Some examples are gambling, becoming a 'shopaholic', binge eating, and thinking about sex so much that it gets in the way of everyday life. Other behaviour may include punding, which is repetitive collecting and sorting of objects.

If you think this is happening to you or the person you are caring for, tell your GP, specialist or Parkinson's nurse right away so they can help.

**Find out more:** see our [information sheet \*Impulsive and compulsive behaviour in Parkinson's\*](#).



Karen

# MAO-B INHIBITORS

These are the different types of MAO-B inhibitors that can be prescribed. This section explains what MAO-B inhibitors are and how they work, and looks at other considerations, including possible side effects.

Generic name	Brand names	Forms available
Rasagiline	Azilect	Tablets
Selegiline (available in generic form)	Eldepryl	Tablets, liquid
	Zelapar	Tablets that dissolve on the tongue

## How MAO-B inhibitors work

Dopamine is a chemical messenger made in the brain. The symptoms of Parkinson's are caused by a decrease in the levels of dopamine, due to the death of the nerve cells in the brain that make it.

Unfortunately, taking dopamine as a drug treatment for Parkinson's would not help you, because it could not cross into your brain where it's needed. However, you can boost the supply in your brain by taking levodopa, a drug that acts as a chemical building-block to help your body produce more dopamine.

MAO-B inhibitors can help your nerve cells to make better use of the dopamine that it does have. They do this by blocking an enzyme called monoamine oxidase type B (MAO-B), which breaks down dopamine in your brain.

## How MAO-B inhibitors are used

A MAO-B inhibitor can be used on its own in early Parkinson's, or in combination with other drugs at all stages of Parkinson's. These drugs are mainly available as tablets. There is also a form that dissolves on the tongue. This may help if you have trouble swallowing.

## Advantages of MAO-B inhibitors

### Improving Parkinson's symptoms

On its own, a MAO-B inhibitor can help with some Parkinson's symptoms, but it can become less effective over time.

### Not all have to be stepped up gradually

Many drug treatments for Parkinson's have to be started gradually, with the dose slowly being increased over time. Rasagiline can be started on the full dose, although selegiline can't.

### Delaying levodopa treatment

By taking a MAO-B inhibitor at an early stage of Parkinson's, you might be able to start levodopa later when your symptoms are harder to manage.

### Taking special care with MAO-B inhibitors

If you are prescribed these drugs for Parkinson's, please make sure you read the important safety advice that comes with them, and the general information on pages 12 and 13.



### Helping levodopa work better

When taken with levodopa, these drugs can help it work better. When you have been taking levodopa for a while, you may find that its effects wear off too quickly.

A MAO-B inhibitor can help with this. Taking a MAO-B inhibitor may also reduce the dose of levodopa you need and lengthen the time between your doses of levodopa.

## Disadvantages of MAO-B inhibitors

### Combination with antidepressants

If you're taking some types of antidepressant, you might not be able to take MAO-B inhibitors, as these drugs can interact with each other to raise blood pressure to a dangerous level.

### Worse levodopa side effects

Because MAO-B inhibitors strengthen levodopa, the side effects of levodopa, including unwanted movements and sickness, can get worse, too. If this happens, your GP, specialist or Parkinson's nurse can help you reduce the dose of levodopa.

## Dietary precautions

Your GP, specialist or Parkinson's nurse may advise you to avoid certain foods, such as cheese, broad beans, Bovril, yeast extracts or fermented soya bean (tofu).

## Other side effects

This booklet can't list all of the possible side effects of all Parkinson's drugs. However, some of the most common side effects that can happen with MAO-B inhibitors include headache, aching joints, indigestion, flu-like symptoms and depression.



Jamita and Jason



# COMT INHIBITORS

These are the different types of COMT inhibitors that can be prescribed. This section explains what COMT inhibitors are and how they work, and looks at other considerations, including possible side effects.

Generic name	Brand names	Forms available
Entacapone	Comtess	Tablets
Tolcapone	Tasmar	Tablets

## How COMT inhibitors work

Dopamine is a chemical messenger made in the brain. The symptoms of Parkinson's are caused by a decrease in the levels of dopamine, due to the death of the nerve cells in the brain that make it.

Unfortunately, taking dopamine as a drug treatment for Parkinson's would not help you, because it could not cross into your brain where it's needed. However, you can boost the supply in your brain by taking levodopa, a drug that acts as a chemical building-block to help your body produce more dopamine.

COMT inhibitors can block an enzyme that breaks down levodopa.

## How COMT inhibitors are used

These drugs are used alongside levodopa, to help it work more smoothly. They can be tried if your dose of levodopa is not working for long enough (end-of-dose deterioration).

COMT inhibitors do not help Parkinson's on their own – they have to be used with levodopa.

COMT inhibitors come as tablets. There is also a three-in-one tablet that includes levodopa, carbidopa (one of the 'helper' drugs that are always given alongside levodopa) and the COMT inhibitor entacapone.

## Advantages of COMT inhibitors

### Helping levodopa work more smoothly

COMT inhibitors can help when levodopa is not working long enough and starts to wear off between your doses. It can help to reduce the 'off' time when you have more trouble with your Parkinson's symptoms and it can increase the amount of 'on' time when your symptoms are better controlled.

### Taking less levodopa

In many cases, levodopa can be taken less often and at a lower dose.

### Improving Parkinson's symptoms

Sometimes, adding a COMT inhibitor to your medication regime can help your Parkinson's symptoms.

### Taking special care with COMT inhibitors

If you are prescribed these drugs for Parkinson's, please make sure you read the important safety advice that comes with them, and the general information on pages 12 and 13.



## Disadvantages of COMT inhibitors

### Liver damage

With tolcapone, there is a risk of liver damage that can be fatal. It is rare, but for this reason, it is a second choice, only used if you can't take another COMT inhibitor. If you take this drug, you will need regular blood tests to check the health of your liver. This risk has not been seen with the other available COMT inhibitor, entacapone.

### Worse levodopa side effects

Because COMT inhibitors strengthen levodopa, the side effects of levodopa, including

unwanted movements and sickness, can get worse, too. If this happens, your GP, specialist or Parkinson's nurse can help you reduce the dose of levodopa.

### Other side effects

This booklet can't list all the possible side effects of all Parkinson's drugs. However, some of the most common side

effects that can happen with COMT inhibitors include: sleeping problems, loss of appetite, diarrhoea, dizziness, fainting, falls, hallucinations (seeing, hearing, feeling and smelling things that aren't there), headache, confusion, dry mouth, chest pain, sleepiness and getting flu or having flu-like symptoms. These drugs can also discolour your urine.





# GLUTAMATE ANTAGONIST

There is only one glutamate antagonist that can be prescribed. This section explains what a glutamate antagonist is and how it works, and looks at other considerations, including possible side effects.

Generic name	Brand name	Forms available
Amantadine	Symmetrel	Capsules, syrup

## How a glutamate antagonist works

Exactly how this drug works for Parkinson's isn't known yet. It may modify levels of certain chemicals in the brain.

## How a glutamate antagonist is used

Amantadine can be used to treat tremor and stiff muscles. It isn't used very often and it is unlikely to be prescribed alone. It is usually given with other drug treatments for Parkinson's. It can be used at all stages of Parkinson's.

It is started at a lower dose and the amount is stepped up gradually. Amantadine is available as capsules and syrup.

## Advantages of a glutamate antagonist

### Fewer movement side effects

Guidelines for the NHS say there is not enough scientific evidence to support it as a first choice in early Parkinson's. But in some people, amantadine may reduce dyskinesia (involuntary movements) caused by your other Parkinson's drugs, without making your Parkinson's symptoms worse.

## Disadvantages of glutamate antagonist

### Limited effects on Parkinson's

Amantadine is not a first choice for the treatment of Parkinson's and it may have only a mild effect. Over time, amantadine can become less effective.

### Blurred vision, fainting, confusion or dizziness

If you have these side effects, it is not safe to drive or use machinery.

### Other side effects

This booklet can't list all the possible side effects of all Parkinson's drugs. However, some of the most common side effects that can happen with glutamate

antagonist include: feeling nervous, anxious or overexcited, poor concentration, headache, hallucinations (seeing, hearing, feeling and smelling things that aren't there), movement problems, sleep problems such as insomnia, fast or irregular heartbeat, loss of appetite, nausea and vomiting, constipation and sweating.

## Taking special care with glutamate antagonist

If you are prescribed this drug for Parkinson's, please make sure you read the important safety advice that comes with it, and the general information on pages 12 and 13.



# ANTICHOLINERGICS

These are the different types of anticholinergics that can be prescribed. This section explains what anticholinergics are and how they work, and looks at other considerations, including possible side effects.

Generic name	Brand names	Forms available
Orphenadrine (available in generic form)	Biorphen	Liquid
	Disipal	Tablets
Procyclidine (available in generic form)	Arpicolin	Syrup
	Kemadrin	Tablets
Trihexyphenidyl (benzhexol) (available in generic form)	Broflex	Syrup

## How anticholinergics work

These drugs block the action of acetylcholine, a chemical messenger that is found in your body. Acetylcholine helps to send messages from your nerves to your muscles.

## How anticholinergics are used

These drugs are older and are not used very often for Parkinson's

today. Sometimes they are prescribed for reducing tremor and muscle stiffness. They can be used on their own, especially in the early stages of your Parkinson's, before levodopa is prescribed.

Anticholinergics can also be used with levodopa or a glutamate antagonist. They are taken as tablets or as a liquid.

## Advantages of anticholinergics

### Possible effect on mild movement symptoms

Older medical studies found some benefit with Parkinson's symptoms. Anticholinergics can be effective for younger people in the early stages of Parkinson's when symptoms are mild.

### Possible effect on other Parkinson's symptoms

Anticholinergics may also be used to reduce saliva production if you have a problem with drooling.

Oxybutynin is an anticholinergic that is used in people without Parkinson's to reduce bladder contractions that can cause a strong, frequent urge to urinate. It is only used very cautiously in people with Parkinson's.

## Taking special care with anticholinergics

If you are prescribed these drugs for Parkinson's, please make sure you read the important safety advice that comes with them, and the general information on pages 12 and 13.

## Disadvantages of anticholinergics

### Limited effect on movement symptoms

These drugs are not recommended in guidelines for the NHS in Scotland. The authors of these guidelines say the benefits do not outweigh the disadvantages.

### Memory problems

Anticholinergics are not very often given to people with Parkinson's because they can cause memory problems or make them worse. If you're taking anticholinergics, your GP, specialist or Parkinson's nurse must closely monitor your situation.

### Side effects

Another reason these drugs are not seen as a first choice is their side effects. This booklet can't list all the possible side effects of all Parkinson's drugs. However, some of the most common side effects that can happen with anticholinergics include: dry mouth, blurred vision, upset stomach, constipation, dizziness and trouble urinating. Confusion, hallucinations (seeing, hearing, feeling and smelling things that aren't there), forgetfulness and psychological problems are less common, but they can also happen with these drugs.

# PILL TIMERS

If you have Parkinson's, it is important to take your Parkinson's medication at the right time, as this will help you to manage your symptoms. A pill timer is a box that you can store your Parkinson's drugs in to remind you when to take each dose. They are useful if you have to take lots of different tablets, or if you have trouble remembering to take your medication.

There are many different types and sizes of pill timer. Some have sections for different times of day, so you can store all of your Parkinson's drugs for one day. Others are big enough to hold your tablets for a whole week, with sections for each day. Some weekly pill timers are also split into times of day.

When you choose a pill timer, make sure it has enough space for the number and size of the tablets you have to take.

Some pill timers have labels on each section that show days or times. Others have a timer or a digital clock face with an alarm to remind you to take your Parkinson's drugs.

Pill timers vary in cost, depending on the type and who it is made by. An occupational therapist can help you to choose the right option.

The Disabled Living Foundation, an organisation that provides information on a range of equipment for disabled and older people, can advise you on the options available. Contact them at:

## Disabled Living Foundation

380–384 Harrow Road  
London W9 2HU

Helpline: **0845 130 9177**  
(textphone **020 7432 8009**)  
(10am to 4pm Mondays to Fridays)

Web: **[www.dlf.org.uk](http://www.dlf.org.uk)**

Email: **[helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)**

# IMPROVING DRUG TREATMENTS

As yet, there is no cure or perfect drug for the treatment of Parkinson's. Research into better treatments is vital.

This is why some people with Parkinson's agree to take part in research to test new Parkinson's drugs or other aspects of the condition and its treatment. You may be invited to join a study (often called a clinical trial). This should only happen through your GP, specialist or Parkinson's nurse. You might be able to ask your doctor if you can be in a trial.

Details of some clinical trials are posted on the Parkinson's UK website, with details of who to contact for further information.

Clinical trials are often sponsored by the manufacturer of a drug. Sometimes they are funded by public organisations such as the NHS or a government research council. Before they go ahead, clinical trials have to be approved

for safety and ethics by an independent committee of experts.

Parkinson's UK also sponsors some clinical trials that examine the best use of existing drugs, and others on the non-movement symptoms of Parkinson's.

Before you start treatment in a trial, you should always ask for written information about it. You should also have time to talk about the pros and cons with your GP, specialist or Parkinson's nurse and your family before you decide whether to take part.

You should never feel under any pressure to take part or to continue in a clinical trial. Saying no or leaving the trial will not affect the way you are treated – it is your right to do this and your GP, specialist or Parkinson's nurse will continue to do their very best for your care.

Clinical trials for drugs generally go through four phases:

Phase 1	Phase 2	Phase 3	Phase 4
Healthy volunteers take the drug. In some cases, people with the condition may take part in this stage of the trial.	People with the condition volunteer to take the drug.	A larger number of people with the condition volunteer to take the drug – some may get a ‘dummy’ treatment.	Once the drug is approved for doctors to prescribe, people with the condition volunteer for follow-up studies.
Assesses the safe dose, side effects, how it works in the body.	Studies how well the drug works, safe and effective dose and side effects.	Studies safety, effectiveness and side effects over a longer period and compares the new drug to other treatments.	Continues to study safety and effectiveness over a longer period.

# MORE INFORMATION AND SUPPORT

If you have more questions about your drug treatment, talk to your GP, specialist or pharmacist. If your area has a Parkinson's nurse, they can provide further help and advice on Parkinson's drugs. These nurses are specially trained in all aspects of Parkinson's and you can get a referral from your GP.

If you need more general information, support or to talk through general queries about your Parkinson's medication, call the Parkinson's UK helpline and speak to a nurse adviser:

Free\* confidential helpline  
**0808 800 0303** (Monday to Friday 9am–8pm, Saturday 10am–2pm). Interpreting available.  
Text Relay  
**18001 0808 800 0303**  
(for textphone users only)  
**hello@parkinsons.org.uk**  
**parkinsons.org.uk**

\*Calls are free from UK landlines and most mobile networks.

The Medicines and Healthcare products Regulatory Authority (MHRA) is the government body that makes sure that drugs work and are safe. It is keen to receive feedback about medication side effects.

To report a side effect, you should complete a Yellow Card form, available from your pharmacist, GP, specialist or via the Yellow Card hotline (**0808 100 3352**). You can also complete this form online, or download and print it out from **yellowcard.gov.uk**

## Further resources

Further information and advice on Parkinson's and related topics are available from Parkinson's UK. We produce a wide range of booklets, information sheets and cards about living with Parkinson's. They're available from our distributor (see below) and many are available on our website at **parkinsons.org.uk/publications**

Resources include:

### [‘Get it on time’ materials](#)

Resources to help you stay in control of your Parkinson’s drugs when you are in hospital.

### [Parkinson’s medication record](#)

A booklet you can use to record information about your drugs, the times you take them, and contact details for the healthcare professionals involved in your care.

### [Parkinson’s medication card](#)

A card you can write your drug treatment and doctor’s details on, to carry with you in case of emergencies.

### [Parkinson’s alert card](#)

A card you can carry with you to tell people you have Parkinson’s. It’s useful in case of emergencies, or when you’re having problems with movement or communication.

### [Diet and Parkinson’s booklet](#)

This booklet includes information on diet and Parkinson’s medication.

### [Driving and Parkinson’s booklet](#)

Includes useful information on driving, such as how you need to inform the DVLA and your car insurer when you are diagnosed with Parkinson’s.

### [Impulsive and compulsive behaviour in Parkinson’s information sheet](#)

This resource offers more information about the side effect some people with Parkinson’s get from taking some Parkinson’s drugs.

To order any of these, or to request a list of all our products, which include publications, DVDs and merchandise, please contact our distributor:

### [Parkinson’s UK Resources](#)

Westerfield Business Centre  
Main Road  
Westerfield, Ipswich  
Suffolk IP6 9AB

Tel: **01473 212 115**

Email: [resources@parkinsons.org.uk](mailto:resources@parkinsons.org.uk)

## Summary of Parkinson's drugs

Generic name	Brand names
<p><b>Levodopa</b> (see page 17)</p> <p>Levodopa is always given combined with either benserazide or carbidopa. It can be used at all stages of Parkinson's.</p>	
Co-beneldopa (benserazide plus levodopa)	Madopar® Madopar® CR
Co-careldopa (carbidopa plus levodopa, available in generic form)	Caramet® CR Duodopa® Sinemet® Sinemet® CR Half Sinemet® CR
Co-careldopa plus entacapone (see opposite)	Stalevo®
<p><b>Dopamine agonists</b> (see page 23)</p> <p>These drugs may be given on their own or prescribed alongside levodopa or other drugs.</p>	
Bromocriptine (available in generic form)	Parlodel®
Cabergoline (available in generic form)	Cabaser®
Pergolide (available in generic form)	Celance®
Pramipexole (available in generic form)	Mirapexin® Mirapexin® prolonged release
Ropinirole (available in generic form)	Requip® Requip® XL

Generic name	Brand names
Rotigotine	Neupro®
Apomorphine (available in generic form)	APO-go® PEN APO-go® PFS

Unlike other dopamine agonists, apomorphine is usually reserved for late Parkinson's when symptoms are severe and levodopa is not working well all the time.

### **Monoamine oxidase type B (MAO-B) inhibitors** (see page 31)

These drugs are sometimes used alone in early Parkinson's, or with levodopa and sometimes other drugs, in late Parkinson's.

Rasagiline	Azilect®
Selegiline (available in generic form)	Eldepryl® Zelapar®

### **Catechol-O-methyltransferase (COMT) inhibitors** (see page 35)

In late Parkinson's, COMT inhibitors are used alongside levodopa to help it work more smoothly.

Entacapone	Comtess®
Tolcapone	Tasmar®

### **Glutamate antagonist** (see page 39)

This is usually used with other Parkinson's medication and has an effect on tremor and stiff muscles.

Amantadine	Symmetrel®
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Generic name	Brand names
<p><b>Anticholinergics</b> (see page 41)</p> <p>These drugs are not used very often for Parkinson's but sometimes they are used for reducing tremor and stiff muscles.</p>	
<p>Orphenadrine (available in generic form)</p>	<p>Biorphen® Disipal®</p>
<p>Procyclidine (available in generic form)</p>	<p>Arpicolin® Kemadrin®</p>
<p>Trihexyphenidyl (benzhexol) (available in generic form)</p>	<p>Broflex®</p>

# GLOSSARY

(meaning of medical terms)

## Acetylcholine

A chemical messenger found in the body that sends messages between nerve cells and muscles. These messages can affect the way muscles work. The anticholinergic drugs work on acetylcholine.

## Dopamine

A chemical messenger made in the brain. It transmits messages from the brain to other parts of the body, mainly to the ones that control movement. In Parkinson's, there is less dopamine because the brain cells that make it die. Parkinson's symptoms are caused by this loss of dopamine.

## Dyskinesia

Involuntary or unusual movements, such as jerking, twitches or spasms. They can affect any part of the body. The strength of dyskinesias can vary from mild to severe. Dyskinesia happens because of the combination of the condition and Parkinson's medication. It is most common in people who have been taking levodopa for many years. The prescription often has to be adjusted to find a balance between

enough medication to control the symptoms, and a dose that does not bring on too much dyskinesia.

## Enzyme

Complex proteins made by living cells, which speed up chemical reactions in the body, such as breaking down drugs. Some Parkinson's drugs work by acting on enzymes in the body.

## 'On/off'

Describes changes in the ability to move, which happens in some people with long-standing Parkinson's who take levodopa. In the 'on' state, the person can move, while in the 'off' state they can stop moving altogether. People can switch from one state to the other in minutes or even seconds.

## 'Wearing-off'

An effect experienced by many people who have been taking Parkinson's drugs for some time. The dose does not work for as long as it used to and the beneficial effects wear off before it is time to take the next dose.

# NOTES

## Drug treatments for Parkinson's

If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to:

### Information Resources

Parkinson's UK

215 Vauxhall Bridge Road

London SW1V 1EJ

Or you can email us at [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thanks!

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

### Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other .....

How useful have you found this booklet?

(1 is not useful, 4 is very useful)  1  2  3  4

Have you found the publication easy to read/use?  Yes  No



Continued over the page

What aspects did you find most helpful? .....

.....

.....

Were you looking for any information that wasn't covered?

.....

.....

Do you have any other comments? .....

.....

.....

If you would like to become a member of Parkinson's UK, or are interested in joining our Information Review Group, please complete the details below and we'll be in touch.

Membership

Information Review Group  
(who give us feedback on new and updated resources)

Name .....

.....

Address .....

.....

Telephone .....

Email .....



**Thank you to everyone who contributed to or reviewed this booklet:**

**Professor K Ray Chaudhuri, Director, National Parkinson Foundation Centre of Excellence, King's College Hospital and Lewisham Hospitals and King's Health Partners, London**

**Shelley Jones, Pharmacy Clinical Team Leader, Neurosciences, Department of Pharmacy, King's College Hospital NHS Foundation Trust, London**

**Thanks also to our information review group and other people affected by Parkinson's who provided feedback.**

We make every effort to make sure that our services provide up-to-date, unbiased and accurate facts. We hope that these will add to any professional advice you receive and will help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

References for this booklet can be found in the Microsoft Word version at **[parkinsons.org.uk/publications](https://parkinsons.org.uk/publications)**

### **How to order our resources**

Call **01473 212115**

Email **[resources@parkinsons.org.uk](mailto:resources@parkinsons.org.uk)**

Visit **[parkinsons.org.uk/publications](https://parkinsons.org.uk/publications)**

### **Can you help?**

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Services team on **020 7932 1303** or visit our website at **[parkinsons.org.uk/support](https://parkinsons.org.uk/support)**. Thank you.

# Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

## Parkinson's UK

Free\* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday 10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

**hello@parkinsons.org.uk**

**parkinsons.org.uk**

\*calls are free from UK landlines and most mobile networks.

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