

Additional Notes

To read this leaflet in a different language, please visit our website:
www.uhd.nhs.uk/visit/patient-information-leaflets and use the language
 and accessibility function available along the top of the site.

To ask for this leaflet in larger print, please contact the patient experience team
 on **0300 019 8499** or email uhd.patientexperienceteam@nhs.net.

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Some of our hospital services are moving.
 Visit www.uhd.nhs.uk/future to find out more.

Starting Levodopa

(co-beneldopa or co-careldopa)



Scan me for more information

www.uhd.nhs.uk/services/parkinsons

**This information is to help you
 understand your new medication**

You should always read the manufacturer's patient information
 leaflet and speak to your doctor or Parkinson's specialist practitioner
 if you have any concerns before starting the medication.

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What is Parkinson's?

- Parkinson's is a condition that affects the brain. It gets worse over time.
- People with Parkinson's have less of a chemical called dopamine. This happens because some brain cells that make it stop working.
- Everyone is different, so symptoms can vary.

What symptoms may I have?

You may experience the following physical, or **motor**, symptoms. A motor symptom is one that affects **movement**:

- stiff or rigid muscles
- slow movement (called bradykinesia)
- shaking in parts of the body (tremor)

You may also experience **non-motor symptoms**. A non-motor symptom is a symptom that **does not involve movement**.

Symptoms may include:

- balance problems or falls
- nerve pain
- constipation
- memory problems
- trouble swallowing or speaking
- mood changes like anxiety or low mood
- sleep problems

Friends and Family Test

Please tell us how the Parkinson's Service are doing through the friends and family test. Tell us what is working and what we can do better. Your comments will help us plan improvements to the care we provide.

To complete the form online visit **www.uhd.nhs.uk** search Friends and Family test

ON	you feel at your most able and that the drugs are working
OFF	you feel unable to move or function as normal and feel that the medication isn't working
Rapid Eye Movement (REM)	sleep disorder- acting out of dreams that may be vivid, intense or violent
Restless leg syndrome (RLS)	uncomfortable or unpleasant sensations in your legs and an irresistible urge to move them
Sialorrhea	drooling or excessive salivation
Tremor	an involuntary quivering movement, mostly at rest.
Wearing off	your medication has less effect and your symptoms worsen before your next dose

Why am I taking Levodopa?

Levodopa is a medicine taken as a tablet. It helps to increase dopamine levels in the brain.

It helps improve movement and makes life easier.

It does not cure Parkinson's, and you may need to take it long term.

Do not stop it suddenly unless your doctor or Parkinson's team tells you to.

Types of Levodopa

Levodopa is given with another medicine to help it work better.

You might hear it called by its generic name or its brand name, such as:

- **Co-beneldopa** (Madopar)
- **Co-careldopa** (Sinemet)

Levodopa can be used on its own or together with other Parkinson's medicines.

How can I take it?

Both co-careldopa (tablet) and co-beneldopa (capsule) work in a similar way. You will normally be started on a standard release tablet.

The following table shows the different types (preparations) of levodopa medicines and how they work in the body.

Preparation	Unbranded/ branded name	Time to work	What it does	How to take it	Tablet/capsule strengths
Standard release	Co-careldopa Sinemet Co-beneldopa Madopar	30 to 40 minutes	Starts working at a normal speed	Swallow whole	12.5mg/50mg (62.5mg) 25mg/100mg (125mg) Can be called Sinemet Plus - yellow oval tablets 12.5mg/50mg (62.5mg) 25mg/100mg (125mg) 50mg/200mg (250mg)
Slow release (CR)	Co-careldopa Half Sinemet CR Sinemet CR Lecado Co-beneldopa Madopar CR	45 to 60 minutes	Work slowly for a longer time	Swallow whole (do not crush or chew)	25mg/100mg (125mg) Half CR and CR 25mg/100mg (125mg) CR
Dispersible	Co-beneldopa Madopar	20 to 30 minutes	Helps quickly or if swallowing is difficult	Mix with water to make a drink	12.5mg/50mg (62.5mg) 25mg/100mg (125mg)

Commonly used medical terms in Parkinson's:

Akinesia	loss of ability to move muscles voluntarily
Bradykinesia	slowing of voluntary movements
Cognitive processes	mental processes involving thinking and memory
Dyskinesia	involuntary movement
Dysphagia	swallowing difficulties
Freezing	suddenly temporarily unable to move
Gait	a manner of walking
Hallucinations	when a person sees, hears, feels or tastes something that doesn't exist
Hypomimia	lack of facial expression
Hypophonia	quiet speech
Impulsive Control Disorder	behaviour resulting from an uncontrollable need to perform a particular action

Social Services

If you need help with domestic tasks or any social issues and benefits, please contact the Social Services specific to your local area:

- Poole - **01202 633902**
- Bournemouth - **01202 454979** (Care Direct)
- Christchurch - **01202 474106**
- Ferndown - **01202 877445**
- Purbeck - **01929 553456**

For all out of hours emergencies call:
Social Services - 01202 657279

Pendant Alarms -

provide an emergency contact system for people living at home.

- Poole Lifeline - **01202 733255**
- Bournemouth Care-line - **01202 452795**
- ASTER (rest of Dorset) - **0845 6014322**

Carer's Support

Caring for someone in the Bournemouth, Christchurch or Poole (BCP) council area please contact:

BCP Carer Support

Email: **carersupport@bcpcouncil.gov.uk**

Telephone: **01202 128 787**

Caring for someone in the Dorset council area please contact:

Carer Support Dorset

Email: **admin@carersupportdorset.co.uk**

Telephone: **0800 368 8349**

How is Levodopa taken?

You will start on a low dose and increase it slowly over several weeks. This helps your body get used to it.

If you forget a dose:

- take it when you remember
- if it is nearly time for the next dose, skip it
- do not take two doses together

You be given a plan that shows you how to start and slowly increase the dose. This may be as follows:

Number of times to take medication each day

Week	Breakfast	Lunch	Dinner
1	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa		
2	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa	
3	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa
4	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa
5	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa	12.5mg/50mg x1 tablet Co-beneldopa or Co-careldopa
6	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa	12.5mg/50mg x2 tablets Co-beneldopa or Co-careldopa

What unwanted effects of Levodopa may I experience?

All medicines can have side effects. It is important to read the patient information leaflet that comes with your medicine.

Most side effects are mild and often improve after 1 to 2 weeks. Some side effects happen more often than others. The words very common, common, and rare help us understand how likely a side effect is to happen.

Frequency	How often it happens
Very common	About 1 in every 10 people
Common	About 1 in every 100 people
Uncommon	About 1 in every 1000 people
Rare	About 1 in every 10 000 people
Very rare	About 1 in every 100 000 people

Useful contacts:

Parkinson's UK

Email: hello@parkinsons.org.uk

Helpline: **0800 800 0303**

Monday to Friday, 9am until 6pm

Saturday, 10am until 1pm

www.parkinsons.org.uk

The Cure Parkinson's Trust

Email: info@cureparkinsons.org.uk

Telephone: **0207 487 3892**

www.cureparkinsons.org.uk

Local Parkinson UK groups

There are local branches for East Dorset, Christchurch, and Poole districts. Details of local meetings and exercise classes or activities can be found on the Parkinson's UK website.

Mental wellbeing

You do not need to be referred by your GP or other health professional - you can refer yourself to these services.

- **Connection**- a 24/7 helpline open to all ages. Dorset residents or people visiting Dorset can call **0800 6520190** or NHS **111** for free.
- Our local **NHS Talking Therapies service** is: www.steps2wellbeing.co.uk or call **0800 484 0500**
- **'Help and Care'** is an organisation that focusses on supporting people with long term conditions and their carers/families: www.helpandcare.org.uk or call **0300 111 3303**

How do I contact the Parkinson's Service?

You can contact the Parkinson Service on:

Telephone: **0300 019 8012**

8.30am to 4.30pm, Monday to Friday

Email: **uhd.parkinsons.service@nhs.net**

Please leave your name, date of birth, hospital number, and a short message explaining why you are calling.

The table below shows some of the side effects that may happen when taking Levodopa. It also shows how often these side effects happen.

Side effects	How common?	What should I do?
Nausea (feel sick)	Very common	Take medication with food
Dizziness/light-headedness especially when standing	Very common	Do not drive or operate machinery, contact your Parkinson's team
Loss of appetite	Common	Eat small, frequent meals
Fatigue or daytime sleepiness	Common	Do not drive or operate machinery, contact your Parkinson's team
Headache	Common	Contact your Parkinson's team
Sleep problems -difficulty sleeping or vivid dreams	Common	Contact your Parkinson's team
Confusion	Common	Contact your Parkinson's team
Hallucinations- seeing or hearing things that are not there	Common	Contact your Parkinson's team
Dark urine, saliva or tears	Common	Harmless. No treatment needed
Sudden sleep episodes	Uncommon	Do not drive or operate machinery, contact your Parkinson's team
Changes in behaviour	Uncommon	Contact your Parkinson's team
Allergic reaction or fever	Common	Seek urgent medical attention if there is swelling of the face, lips or throat or breathing difficulties
Skin reaction such as rash or blistering	Common	Seek urgent medical attention immediately
Changes to blood tests	Common	Please advise that you are taking co-beneldopa or co-careldopa

Nausea and vomiting

When you first start taking Levodopa, you may feel sick (nausea) or be sick (vomit). This can often be helped by taking your medicine with food or a small snack while your body adjusts.

After the first few weeks, if you are feeling well, you should try taking your levodopa 30 minutes before a meal or one hour after a meal. This may help the medicine work better. If you still feel sick, you can take it with a light snack, such as a cracker or biscuit.

Long-term effects

After some time, you may notice:

- **Wearing off:**
This is when the medicine does not work as well as it used to.

This means your Parkinson's symptoms may come back before your next dose is due, or as the previous dose is wearing off.
- **Involuntary movements (dyskinesia):**
These are movements you cannot control. They may include:
 - twitches
 - jerky movements
 - twisting or writhing movements
- **Impulsive and compulsive behaviours:**
Some people may feel urges to do things more often than usual or feel like they cannot stop doing certain things (like shopping, gambling, binge eating, hypersexuality).
- **What to do if this happens**
If any of these symptoms start to affect your daily life, you should speak to your Parkinson's team. They may change your medication to help.

Not everyone gets these side effects. Most people do not.

Serious side effects are often linked to the dose and can sometimes be reduced by using the lowest dose that still works well.

Levodopa and protein

Protein (like meat, fish, eggs, cheese, and beans) can affect how the medicine works.

Some people do better if they eat most protein in the evening.

If my Parkinson's is well controlled, can I stop taking Levodopa?

No. Stopping Levodopa suddenly can make symptoms worse.

Do not change your dose without advice.

When should I contact the Parkinson's Service?

Sudden changes in your symptoms are not usually expected. You should contact the Parkinson's service if your:

- symptoms get worse. Only after the GP has checked and ruled out other causes like infection, constipation, or dehydration
- the Parkinson's medicine stops working well
- side effects are a problem

The Parkinson's Service email and telephone line is not an urgent care service. If you need urgent medical help, contact your GP, NHS 111, a walk-in centre, or go to the Emergency Department if you are very unwell.