# **Dienogest** **Patient Information Sheet**

## Dienogest use within the endometriosis service

This information leaflet should be read in conjunction with the Patient Information Leaflet (PIL) inside the packaging of dienogest.

## What is dienogest?

Dienogest is a synthetic form of progesterone - a hormone made by the ovaries. It is used as a treatment for:

* Endometriosis (implants of endometrium-like tissue outside of the uterus).
* Endometriomas (ovarian cysts containing endometriosis).
* Adenomyosis (implants of endometrium-like tissue inside the muscle of the uterus).

For ease of reading, this information sheet will use the word ‘endometriosis’ to represent endometriosis, endometriomas and adenomyosis.

## Why have I been prescribed dienogest?

You have been prescribed dienogest to help improve your pelvic pain and bleeding symptoms, or to reduce the chance of your endometriosis coming back.

## How does dienogest work?

Dienogest works by:

* Suppression: Suppressing the growth of existing endometriosis implants.
* Stopping your periods: This reduces periods over time and in some women periods may eventually remain absent
* Reducing inflammation: Inflammation can cause pelvic organs to become stuck to each other, leading to pain.

## How do I take dienogest?

Each tablet contains 2mg dienogest. The dose is one tablet once daily, ideally taken at the same time every day. It can be started anytime during the menstrual cycle. When a pack is finished, the next one should be started without a break. Tablets should also be taken on days of menstrual bleeding. Unless advised by your clinician, any hormonal contraception (tablet/hormonal coil/patch/ring) should be stopped before starting dienogest.

## Before starting treatment:

If any of these apply to you, please inform us before starting treatment:

* Hypersensitivity to the active substance or to any of its excipients (this can be found on [product SmPC](https://www.medicines.org.uk/emc/search?q=dienogest) or Patient Information Leaflet inside the dienogest box)
* You have unexplained vaginal bleeding.
* You are pregnant or think you might be pregnant
* You are breast-feeding
* You have a blood clot in your veins or have a history of this
* You have or have ever had arterial disease such as a heart attack, stroke or heart disease
* You have diabetes mellitus
* You suffer or have ever suffered from severe liver disease
* You have ever had a liver tumour, or malignant sex-hormone dependent tumour

## Side effects

As with any new medication, you may get side effects. Please refer to the Patient Information Leaflet (PIL) inside your box of the dienogest medication for full list of side effects.

After starting dienogest, please let your hospital clinician know if you experience:

* Severe depression or anxiety.
* Unexplained itching
* Unexplained calf pain / swelling / redness or any other signs of a blood clots (e.g. sudden breathlessness and sharp chest pain)

## How will dienogest affect my bleeding pattern?

When you first start taking dienogest, you may experience changes to your bleeding pattern:

* In the first 3 months of use, around 1 in 3 women experience irregular or prolonged periods.
* As dienogest begins to supress the growth of endometrium, bleeding becomes lighter and less frequent.
* By the end of the third month of treatment, periods have stopped for 6 in 10 women.
* By the end of the sixth month of treatment, periods have stopped for 9 in 10 women.
* Occasionally, dienogest can cause heavier bleeding, or bleeding that does not settle down over time. If this happens, then please let your clinician know.

## Can I become pregnant when taking dienogest?

Although the likelihood of falling pregnant while on dienogest is reduced, it is not licensed as a contraceptive and as such a barrier method of contraception, e.g. condoms or non-hormonal methods, is recommended.

If you become pregnant when taking dienogest, there is a slightly higher chance of having an ectopic pregnancy (a pregnancy outside the womb). If you have ever had an ectopic pregnancy or treatment to your fallopian tubes, tell your doctor before you start taking dienogest.

## How long can I take dienogest for?

Women can take dienogest for up to several years, however as your circumstances or needs may change over time, the endometriosis team will review at intervals of 24 months once established on dienogest. Once treatment is stopped, your periods will return to normal in around 2 months.

## Can my GP prescribe dienogest for me?

Your dienogest treatment will be started by your hospital clinician, who will monitor your progress for the first 3 months, making sure that dienogest is managing your endometriosis symptoms well and any side effects well controlled.

After this, your GP will be asked to take over the dienogest prescribing, with the hospital clinician retaining overall responsibility for treatment. This is called a ‘shared care agreement’.

Under the shared care agreement, your GP will issue your prescriptions for dienogest and carry out a medication review at least once per year. Your hospital clinician will continue to monitor your progress, and will review you at least once every two years:

* They will carry out a bone density risk assessment; and, if required, order a DEXA scan to check your bone health.
* They may order other tests and investigations, such as a blood test to check your liver function.

Should you require to be seen sooner by your hospital clinician, this can be arranged through Patient Initiated Follow Up (PIFU) appointment. Details of which will be provided by your hospital clinician.

## What should I do if I want to stop taking dienogest?

There can be many reasons why someone may wish to stop taking dienogest; for example, to become pregnant. If you would like to stop, then please make an appointment with your hospital clinician, so that they can help you to make a new plan, going forward.

## Contact us

[Each organisation to insert contact details here]

## Document History

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