MEDICINE INFORMATION

Diethylstilbestrol

Understand diethylstilbestrol: how to take or receive treatment, monitoring, side effects and everyday care.

At a glance

Diethylstilbestrol is a medicine used in specialist cancer care. The practical instructions depend on the exact prescription and product supplied.

Your prescription and the instructions for your own product take priority over a general guide. Keep the medicine leaflet as well as your treatment plan, especially if the brand or formulation changes.

You do not need to remember every possible side effect. Start with the administration instructions and the section on urgent help. Most people experience only some of the effects described here. Tell your team about difficulties early: supportive treatment, a planned pause or a different medicine may make treatment easier to continue.

How it works

Diethylstilbestrol, sometimes shortened to DES or called stilboestrol, is a synthetic oestrogen used in selected specialist cancer-treatment plans. It can suppress androgen stimulation, but its significant clotting and cardiovascular risks make careful patient selection essential.

Is this treatment suitable for me?

This is an older option for castration-resistant prostate cancer when other treatments are unsuitable. The UK product must not be used with a history of blood clots, heart or brain blood-vessel disease, moderate or severe high blood pressure, or active or severe liver disease. Porphyria and certain blood disorders are also exclusions that the specialist must check. It is not an ordinary hormone supplement.

Your oncologist considers the biology of the cancer, treatments already received, other illnesses and your preferences. The aim may be to reduce the chance of cancer returning, control cancer that is present, or relieve symptoms. Ask which aim applies to you and how benefit will be assessed. The same medicine can be used for different lengths of time in different treatment plans.

A brand name alone does not tell you whether a medicine is suitable. The dose, formulation and other medicines in the plan also matter. Discuss the possible benefits and risks with your care team.

Before treatment

Discuss previous clots or stroke, heart disease, blood pressure, diabetes, migraines, liver or kidney disease and planned surgery. The team should explain clot-prevention measures and any plan to reduce breast symptoms. Tell them if you take aspirin or an anticoagulant already.

Bring an up-to-date list of prescription medicines, pharmacy medicines, supplements and traditional or herbal remedies. Include medicines used only occasionally, creams containing

hormones, and anything recently stopped. Mention previous allergies and describe what happened, rather than only naming the drug. Your pharmacist can check the whole list together.

Tell the team about any planned operation, dental procedure, travel or difficulty attending appointments. Discuss costs and supply before the first dose if obtaining regular refills may be difficult. Agree who will arrange repeat prescriptions and tests. Keep your own hospital's daytime and out-of-hours contact details where you and a caregiver can find them quickly.

How to take or receive treatment

A commonly labelled oncology dose is 1 to 3 mg daily, but take only the dose prescribed for you. Swallow tablets with water at the agreed time. There is no standard fasting requirement; follow the supplied product instructions.

If a dose is forgotten, follow your pharmacist's advice for that day's schedule and do not double the next dose. If an entire day has passed, resume as prescribed without taking an extra day’s tablets. Do not automatically repeat a vomited dose. Discuss recurrent nausea because it may affect adherence.

Swallow the medicine as directed for your product. Do not crush, open, dissolve or divide it unless the oncology pharmacist has confirmed a safe method for that exact formulation. Some products have a specific dispersion method; this is different from crushing tablets yourself. Tell the team before starting if swallowing is difficult or you use a feeding tube.

After vomiting a dose, do not automatically take a replacement because some medicine may already have been absorbed. Follow the drug-specific instructions in this section and call the team if vomiting persists. A missed dose and a vomited dose are different situations, so use the relevant rule.

Store tablets or capsules in their labelled packaging, out of children's sight and reach, away from heat and moisture, within the temperature limits on the pack. Keep any drying container supplied in the bottle. Ask before transferring anticancer medicines into an organiser. A caregiver should avoid direct contact with damaged tablets or powder and follow the pharmacy's handling advice; pregnant caregivers should not handle damaged anticancer tablets. Wash hands after handling. Return unwanted doses to a pharmacy rather than putting them into household waste or a drain.

Use a calendar or a phone reminder that records what was actually taken or given. A tick made after a dose is more useful than one made in advance. If someone helps with medicines, agree who records each dose so it is not accidentally repeated. Keep the drug name, strength and current instructions together; an old prescription may no longer describe your current dose.

Contact the treating team if a supply problem or illness is likely to interrupt treatment. Do not stretch the supply by taking smaller doses or lengthening intervals yourself. If you receive too much medicine, seek urgent advice and have the packaging and dose times available. Do not induce vomiting.

Monitoring your treatment

Blood pressure, fluid retention and cardiovascular symptoms need regular review. The team follows treatment response and may check liver function and glucose. A planned operation or prolonged immobility needs a supervised stopping plan because clot risk can rise. If high blood pressure develops, contact the prescriber promptly; the product information advises stopping treatment.

Monitoring has two purposes: checking whether treatment is helping and detecting problems that may be silent at first. Your schedule depends on the medicine, any partner treatment and your general health. Ask which results need to be reviewed before the next prescription or injection, and who will contact you if a result is abnormal.

Record symptoms that affect eating, walking, sleep or daily activities, along with when they began. Bring this record to appointments. A single symptom or blood result rarely explains the whole picture; the team may compare trends, examination findings and scans. Feeling well is welcome, but it does not remove the need for planned monitoring.

Common side effects

Effects to discuss with your team

Breast enlargement and tenderness, nausea, fluid retention and changes in sexual function may occur. Some people are offered preventive treatment for breast symptoms before starting. Rapid swelling or increasing breathlessness should not be treated as a harmless cosmetic change.

Lowering or blocking androgen activity can cause hot flushes, reduced interest in sex, erection difficulties and changes in muscle strength or body composition. These effects can arise from the accompanying testosterone-lowering treatment as well as this medicine. Tell your team what matters most to you; advice about sexual health, exercise and symptom control can be part of routine cancer care.

Long-term treatment that reduces testosterone can affect bone strength, blood sugar and cardiovascular health. Discuss fracture risk, weight, blood pressure and diabetes monitoring. Resistance and balance exercises may help maintain function when adapted to your condition. If you have bone involvement, get advice before lifting heavy weights or beginning strenuous exercise.

If your plan includes a separate testosterone-lowering injection, taking a tablet does not usually replace it. Follow the combination schedule exactly. Some patients have had surgery that permanently lowers testosterone, and some specific regimens differ; your team will explain your own plan. A change in PSA should be interpreted alongside symptoms and other assessments, not used as a reason to change treatment yourself.

Making symptoms easier to manage

Tell the team which symptom is causing the most difficulty. Describe its effect on ordinary tasks: for example, whether pain prevents dressing or tiredness stops you preparing food. This helps the team choose practical support and judge whether treatment needs adjustment. Avoid waiting until the next routine visit if symptoms are worsening.

For mild nausea, try smaller meals and regular sips of fluid, following any food rule for the medicine. Ask about an anti-sickness medicine if needed. Repeated vomiting, inability to keep fluids down or

very little urine needs prompt advice. If you have been told to restrict fluids for another illness, use that plan rather than forcing extra drinks.

Energy and emotional wellbeing

Pace demanding activities and allow rest, but keep some gentle movement in your day if you can. Persistent exhaustion deserves assessment; poor sleep, anaemia, low mood and other illnesses may contribute. Tell the team about persistent anxiety, sadness or loss of interest. If you feel at risk of harming yourself, seek emergency help and ask someone to stay with you.

Important side effects

The effects below are important because they may require tests or a change in treatment. They are not a prediction that you will develop them. New symptoms can also come from the cancer or an unrelated illness. Reporting them promptly allows the team to work out the cause; do not assume that everything is a routine treatment effect.

Thromboembolic complications are an important and potentially serious risk. The UK product information recommends prescribed aspirin prophylaxis, but the choice must account for bleeding risk and other medicines. DES also has carcinogenic and teratogenic potential; it is reserved for selected malignant-disease settings.

When to get urgent help

Sudden breathlessness, chest pain, coughing blood, stroke symptoms or collapse require emergency care. One-sided painful leg swelling needs urgent assessment. New severe headache, visual disturbance, jaundice or rapidly increasing oedema also needs prompt medical attention.

Get emergency help immediately for severe breathing difficulty, swelling of the tongue or throat, collapse, a seizure, severe chest pain, or signs of a stroke such as a drooping face, new arm weakness or difficulty speaking. Do not drive yourself if you are faint, confused or seriously unwell, and do not wait for an oncology callback before seeking emergency care.

Contact your oncology team the same day for repeated vomiting, dehydration, new jaundice, a rapidly worsening rash, or a sudden major change in how you feel. Fever with shaking chills or feeling acutely unwell also needs prompt advice, particularly if you receive another treatment that can lower white blood cells. Follow the temperature threshold and emergency instructions given for your complete regimen.

When asking for help, give the medicine name, last dose or injection date, other cancer treatments and main symptoms. Mention any blood thinner or steroid. If you cannot reach the team and the problem is urgent, use your hospital's emergency service rather than waiting for the next appointment.

Stop the tablets and seek urgent assessment if you develop symptoms suggesting a blood clot or severe allergy.

Other medicines and vaccinations

Oestrogens may reduce the effects of diuretics or blood-pressure medicines and alter diabetes control. Ask the pharmacist to review anticoagulants and any proposed aspirin. Do not start aspirin yourself or add it to an existing blood thinner without a clinician's plan.

Ask the oncology pharmacist to check new medicines before you start them, including antibiotics prescribed elsewhere. Do not stop essential treatment for another illness on your own. If an interaction is possible, the prescribers can choose an alternative, adjust a dose or arrange monitoring. Herbal products labelled natural can still alter drug levels or have hormone-like effects.

Vaccination advice depends on your complete treatment plan. Hormone treatment alone does not automatically mean that every vaccine is unsuitable. Ask about influenza, COVID-19 and other recommended vaccines; live vaccines need a specific check if you also receive chemotherapy, an immune-suppressing medicine or certain doses of steroid. Tell the vaccination service all the treatments you receive.

Tell the team before thyroid blood tests: DES can change thyroid-binding proteins and affect interpretation of the results.

Everyday life

Food and movement

Aim for regular meals with enough protein and a varied range of foods that you can tolerate. Tell the team about unplanned weight loss, rapid weight gain or difficulty eating. A dietitian can adapt advice to diabetes, kidney problems, bowel symptoms or a restricted appetite. Do not start a restrictive diet or high-dose supplement as a substitute for treatment.

Choose activity that suits your strength and balance. Short walks or gentle exercises may be easier to sustain than occasional strenuous sessions. If cancer affects your bones, or you have osteoporosis, ask which movements and resistance exercises are safe before starting a new programme. New focal bone pain should be assessed rather than exercised through.

Work and travel

Many people continue some usual activities, but flexibility helps while you learn how treatment affects you. Discuss rest breaks, shorter hours or help with physically demanding work if needed. Avoid driving or operating machinery when dizzy, sleepy, confused or affected by visual symptoms. Follow any additional driving advice after a seizure or loss of consciousness.

Plan travel around prescriptions, injections and tests. Carry an up-to-date medicine list and enough supply for the agreed trip, with advice about storage and time-zone changes. For long journeys, discuss mobility and your individual clot risk. Do not start aspirin or a blood thinner simply because you are travelling.

Relationships and support

Changes in energy, body image or sexual function can affect relationships. You can ask for help privately, with or without a partner present. There may be practical measures or specialist support for discomfort and intimacy. A caregiver can help record symptoms and organise appointments while leaving treatment decisions and personal information under your control.

Fertility, pregnancy and breastfeeding

DES must not be used during pregnancy and has well-established harmful effects on a developing baby. In the oncology setting described here, discuss contraception and fertility with the team rather than relying on reduced testosterone. Pregnant caregivers should avoid handling damaged tablets.

Tell the team before treatment if having children in the future matters to you. Fertility preservation needs discussion before exposure where possible. Reduced fertility is not the same as reliable contraception, and an absence of periods or reduced sexual function does not prove that pregnancy is impossible.

Ask your team which contraception to use and how long to continue it, taking account of every medicine in your regimen. A partner drug may require a longer precaution period than this medicine alone. If pregnancy is suspected in you or a partner during a risk period, contact the treating team promptly for individual advice. Do not make pregnancy or breastfeeding decisions from a generic time interval without checking your own treatment plan.

After treatment

Arrange a stopping plan before surgery. If symptoms suggest a blood clot or severe allergy, stop the tablets and seek urgent medical help; do not wait for a routine oncology appointment. Confirm what happens to any prescribed preventive aspirin when DES ends; do not assume both automatically stop together.

Before a planned stop, confirm which medicines end, which continue, and when the next review is due. Return unused medicine through the pharmacy's recommended route; do not give it to another person. Keep a record of the last dose and any side effects that still need follow-up.

Changes caused by treatment may settle gradually, and some need ongoing support. Report persistent symptoms or new problems after treatment rather than assuming they will disappear on their own. Continue the agreed follow-up and screening plan. If treatment is being changed, ask your team to help you update your treatment schedule so that old and new instructions are not accidentally combined.

Common questions

Is DES the same as ordinary oestrogen replacement?

No. This oncology prescription has a particular purpose and a significant risk profile. It should not be used as a general hormone supplement or exchanged for another oestrogen product. The specialist should explain why it was selected for you.

Should I buy aspirin before starting?

No. Although the UK label recommends aspirin prophylaxis, a clinician must assess bleeding risk and existing medicines and prescribe an appropriate plan. Adding aspirin to a blood thinner without advice can cause harm.

Can breast tenderness be prevented?

Sometimes preventive measures, including breast-bud radiotherapy in selected patients, are discussed before treatment. Ask early if this is a concern. Once symptoms develop, the team can assess their severity and available options.

What if an operation is planned?

Inform the oncology and surgical teams in advance. Surgery and reduced mobility can increase clot risk, and a supervised interruption may be needed. Obtain specific stop and restart instructions rather than stopping according to a general rule.

Is this the same as chemotherapy?

It is a hormonal or hormone-related treatment, with a different way of working from conventional chemotherapy. It still needs careful prescribing and monitoring. If chemotherapy or a targeted medicine is part of your plan as well, read the information for that medicine because the combined treatment may have additional risks.

How will I know whether treatment is helping?

Your team will explain which symptoms, blood tests, examinations or scans are useful in your situation. Improvement may take time, and some treatments aim to prevent future problems rather than produce a change you can feel. Keep review appointments even when you feel well.

Does having few side effects mean the medicine is not working?

No. Side effects are not a reliable measure of benefit. People can respond to treatment without feeling particularly different. Equally, having troublesome effects does not prove that the cancer is responding. Decisions should use your clinical assessments and test results.

Can I take a break when I feel tired?

Do not create your own breaks or change the dose. Contact the team about fatigue and explain how it affects your day. They may look for another cause, offer support or prescribe a planned adjustment. A supervised change can be safer than repeated unrecorded missed doses.

How long will I need this medicine?

The duration depends on the aim of treatment, response and tolerability. Some plans have a proposed end date; others continue while the balance of benefit and side effects remains favourable. Ask when this will be reviewed. Another person taking the same medicine may appropriately have a different schedule.

Can I use herbal or Ayurvedic products alongside treatment?

Show the pharmacist the ingredients and exact product before using it. Products may affect hormone activity, liver function or the way medicines are handled in the body. Different preparations with similar names can contain different ingredients. A claim that a product is natural does not establish that the combination is safe.

Should I stop my usual medicines?

Continue them unless a prescriber tells you otherwise, but arrange a full interaction check. Include occasional painkillers, supplements and any newly prescribed medicine. If an interaction is found, the team can agree a safe change without leaving another illness untreated.

What should I do if I need surgery or dental treatment?

Tell both teams about your cancer medicine well in advance. They may need to consider bleeding, clotting, steroid support, bone-protecting treatment or appointment timing. Do not stop treatment based on a general internet rule. Ask your team when to pause and restart treatment, and keep the instructions handy.

Can someone else manage my medicines for me?

Yes, if you want that support. Agree one shared record of doses and appointments and ask the pharmacist about safe handling. A caregiver should know the urgent symptoms and where to seek help. Do not share this prescription with anyone else, even if their diagnosis sounds similar.

What if I cannot obtain the next supply or attend the clinic?

Contact the treating service before treatment is due where possible. Give the drug name, formulation and date of the last dose. The team can address supply or reschedule safely. Do not substitute another hormone medicine, ration tablets or assume a delayed injection has no consequences.

When should I seek help instead of waiting for my review?

Use emergency care for severe symptoms such as breathing difficulty, collapse, chest pain, stroke symptoms or a seizure. Contact the oncology team promptly for a new or worsening problem that affects normal activities. The urgent-help section gives additional signs especially relevant to this medicine.

Sources and further reading

Information checked against the following sources on 28 September 2026. Product names and instructions can differ between formulations and countries; your treating team should confirm the instructions for your supplied medicine.

- Macmillan Cancer Support - Diethylstilbestrol
- UK product information - diethylstilbestrol