



# DES Exposure: Questions and Answers

## What is DES?

DES (diethylstilbestrol) is a man-made (synthetic) form of estrogen, a female hormone. Doctors prescribed it from 1938 until 1971 to help some pregnant women who had had miscarriages or premature deliveries. At that time it was believed that these problems might have been caused by low levels of estrogen in the woman's body. DES was used to correct this problem. It was given to millions of women in the United States during this time.

DES was used less in the 1960s, after studies showed that it might not help women carry pregnancies to full term. Later, it was learned that infants whose mothers took DES during the first 5 months of pregnancy were more likely to have problems in their reproductive systems.

In 1971, the US Food and Drug Administration (FDA) advised doctors to stop prescribing it during pregnancy. A campaign was also started to tell the public about the problems DES could cause, and doctors were urged to tell patients who may have taken the drug. But there was no good way to tell every person who was exposed to DES. Many people who were exposed to DES as a fetus still don't know it.

Estrogens are still prescribed for some medical reasons, including to help treat some cancers, but they are no longer used during pregnancy. Other than in a rare clinical trial, DES is no longer available in the United States for use in humans.

## Who was exposed to DES?

About 5 to 10 million people are thought have been exposed to DES during pregnancy:

- **DES mothers:** Women who took DES while pregnant

- **DES daughters:** Women whose mothers took DES while pregnant with them. This exposed them to DES while they were growing in the womb
- **DES sons:** Men whose mothers took DES while pregnant with them. This exposed them to DES while they were growing in the womb

Only those children who were in the womb at the time their mothers took DES were exposed to it. Brothers or sisters from pregnancies during which DES was not taken were not exposed.

## How do you know if you (or your mother) took DES during pregnancy?

Many women do not know if they got DES while they were pregnant. Any woman who was pregnant between 1938 and 1971 and had problems during the current or a previous pregnancy may have been given DES or another estrogen-like drug. Women who did not have problems are less likely to have been given DES. Women who were not under a doctor's care while pregnant most likely did not take DES either, because you could only get it with a doctor's prescription. DES was given in pills, injections, and vaginal suppositories (sometimes called pessaries).

### Checking medical records

If you think you (or your mother) took a hormone like DES during pregnancy, you should try to contact the doctor who managed the pregnancy or the hospital where you were born to ask if there is any record that you (or your mother) were given DES. Mothers and children have a right to see any of their remaining medical records.

Unfortunately, finding medical records after such a long period of time may not be possible in many cases. Most hospitals and doctors' offices do not keep medical charts or records beyond a few years. If the doctor has moved, retired, or died, another doctor might have taken over the practice as well as the records. The county medical society or health department may be able to tell you where the records are, if they still exist. A few pharmacies keep prescription records for a long time, but many chain drugstores only keep them up to 10 years. If you know where the prescription was filled, you might want to ask there.

If you are able to get records, it may help to know that DES was sold under many different names. You can find a list of DES brand names here <https://desaction.org/brand-names/><sup>1</sup>. Two of the most commonly used names were stilbestrol and DESPlex, but there are dozens more.

It's important to keep any records you have about DES exposure. Write down and save anything you find out about dates the drug was taken, and other details.

In many cases, it may not be possible to find out if DES was used. And there are no medical tests that can tell you if you were exposed to DES.

## **What health problems might women who took DES during pregnancy have?**

### **Breast cancer**

Women who took DES appear to have an increased risk of [breast cancer](#)<sup>2</sup>. Most research suggests that the risk of breast cancer in DES-exposed mothers is about 30% higher than the risk of women who have not been exposed to this drug. When looking at breast cancer risk during a woman's lifetime, this means about 1 out of 6 women who took DES during pregnancy will get breast cancer, as opposed to about 1 out of 8 women who were not exposed to DES. Of course, many other factors affect breast cancer risk as well.

There are no other known health effects of DES exposure in pregnant women who took this drug.

## **What should women who took DES while they were pregnant do?**

A woman who took DES while pregnant (or suspects she may have been given it) should tell her doctor. If possible, she should try to find out the dose, when the medicine was started, and how it was used.

She also should tell her children who were exposed in the womb. They need to tell their doctors, so that this information can be included in their medical records.

DES-exposed mothers should follow a regular schedule for early breast cancer detection, as is recommended for all women. (For American Cancer Society recommendations on breast cancer screening, see [Breast Cancer: Early Detection](#)<sup>3</sup>.) Women should report any new breast lumps or other breast changes to a doctor right away. They should also have regular medical check-ups.

## **What health problems could DES-exposed daughters have?**

## Clear cell adenocarcinoma

DES is linked to a rare cancer called **clear cell adenocarcinoma** (CCA) in a very small number of daughters of women who used DES during pregnancy. This cancer of the vagina and cervix usually occurs in DES-exposed daughters in their late teens or early 20s. But it has been reported as early as age 8, and the upper age limit, if any, is not known. DES-exposed daughters are now older than 40, but their risk may still be higher than in women who were not exposed.

DES-exposed daughters are about 40 times more likely to develop CCA than women not exposed to DES in the womb. But because this cancer is so rare, this means that about 1 of every 1,000 DES-exposed daughters might develop CCA.

Treatment for CCA depends on the location and stage (extent) of the cancer. For more information on the treatment of clear cell adenocarcinoma, see [Vaginal Cancer](#)<sup>4</sup> or [Cervical Cancer](#)<sup>5</sup>.

## Abnormal cells in the cervix and vagina

DES exposure before birth has been linked to a higher risk of having abnormal cells in the cervix and vagina. Daughters who know they were exposed to DES typically have more frequent exams to look for these types of changes, but it's not clear exactly how much the risk is increased.

Doctors use a number of terms to describe these abnormal cells, including:

- *Atypical glandular cells*
- *Dysplasia*
- *Cervical intraepithelial neoplasia* (CIN)
- *Squamous intraepithelial lesions* (SILs)

These abnormal cells look like cancer cells. But they do not spread into nearby healthy tissues like cancer cells do and so are often called **pre-cancers**. This condition is not cancer, but it might develop into cancer if it's not treated.

## Structural changes in the female reproductive tract

DES-exposed daughters may have a vagina, uterus, or cervix with an unusual shape or form (structure). Most of these changes do not threaten the woman's life or health. But some can cause problems for women who want to get pregnant or cause other reproductive health problems.

## Problems getting pregnant

DES-exposed daughters are more likely to have fertility problems than women who weren't exposed to DES. Still, most don't have problems becoming pregnant. The largest study of fertility found that 28% of women who had been exposed to DES didn't get pregnant after trying for at least 12 months, compared with 16% in women who were not exposed to DES.

At least part of this difference seems to be caused by changes in the shape of the uterus. DES-exposed daughters may also be more likely to have irregular menstrual periods, which could add to fertility problems.

## Problems during pregnancy

DES-exposed daughters may also have a higher risk of certain problems during pregnancy. These include:

- **Premature birth:** Among DES-exposed daughters, about 64% have delivered a full-term baby in their first pregnancy, compared with 85% in women who were not exposed to DES.
- **Tubal (ectopic) pregnancy:** The risk of an ectopic pregnancy (where the egg implants in an area other than the uterus and poses a danger to the mother) is about 3 to 5 times higher in DES-exposed daughters.
- **Miscarriage:** Almost 20% of DES-exposed daughters miscarry their first pregnancy, compared with about 10% among women not exposed to DES.
- **Preeclampsia:** DES-exposed daughters have a slightly higher risk of preeclampsia during pregnancy. Preeclampsia (sometimes called toxic pregnancy or toxemia) is a condition in which high blood pressure and protein in the urine develop in the late 2nd or 3rd trimester of pregnancy. It can be dangerous and may require delivering the baby early.

## Breast cancer

According to the largest study to date, DES-exposed daughters have a slightly increased risk for [breast cancer](#)<sup>6</sup>. This increased risk was not seen in some other studies. So far, the total overall increase in risk appears to be only about 2% (in this study, the group of women without DES exposure had about a 2% risk of breast cancer, while the group of women with DES exposure had about a 4% risk). But it's important to note that the women in this study (and many DES-exposed daughters in general) are

still younger than the average age at which breast cancer usually occurs. The increased risk of breast cancer may become larger as these women get older. This issue is still being studied.

The risk of other cancers does not seem to be increased, but research continues in this area as well.

### **Other possible health problems**

A recent study suggested that DES-exposed daughters might have a higher risk of depression than women who had not been exposed to the drug, although other studies have not found this.

Some studies have found that DES daughters are likely to be younger at menopause.

### **What should DES-exposed daughters do?**

If you were born between 1938 and 1971, and you think that your mother may have been given DES, try to learn how long and at what point in her pregnancy she took the drug. Or you can try to find records from her obstetrician's office. (See the section, How do you know if you [or your mother] took DES during pregnancy?)

Women who believe they may have been exposed to DES before birth should be aware of the possible health effects of DES and tell their doctors about their exposure. Some problems, such as clear cell adenocarcinoma, are usually found only when the doctor is looking for them. This is why it's important that your doctor know about the possible problems linked to DES exposure and to keep records of your exposure, if you have them.

### **Getting recommended screening exams and tests**

DES-exposed daughters should get regular gynecologic exams throughout their lifetimes. Discuss with your doctor which tests are appropriate for you and when you should have them.

Many doctors recommend these women have regular, thorough exams every year. These exams may include the following:

#### ***Pelvic exam***

This is a physical exam of the reproductive organs. As part of a pelvic exam, the doctor feels the vagina, uterus, cervix, and ovaries for any lumps. This is also known as a bimanual exam. An exam of the rectal area may be included as well. Sometimes, feeling for lumps is the only way to find an abnormal growth.

### ***Pap test***

A routine Pap test is not enough for DES-exposed daughters. The cervical Pap test must be done along with a special Pap test of the vagina called a **four-quadrant Pap test**, in which cell samples are taken from all sides of the vagina.

### ***Iodine staining of the cervix and vagina***

An iodine solution is used to briefly stain the linings of the cervix and vagina. This helps the doctor find **adenosis** (an abnormal growth of glandular tissue that is not cancer) or other abnormal tissue.

### ***Colposcopy***

For this exam, the doctor uses a magnifier to look closely for abnormal tissue in the vagina and cervix. Some doctors do not do this for everyone, but this is commonly done if the Pap test result is not normal.

### ***Biopsy***

Small samples of any parts of the cervix or vagina that look abnormal on other tests are removed and looked at under a microscope to see if cancer cells are present.

### ***Breast exams and screening tests***

DES-exposed daughters should follow current breast cancer screening recommendations. (For American Cancer Society recommendations on breast cancer screening, see [Breast Cancer: Early Detection](#)<sup>7</sup>.) Women should report any new breast lumps or other breast changes to a doctor right away.

### ***Reducing risks during pregnancy***

Because of the problems that may show up during pregnancy, DES-exposed daughters need to tell their doctors about their DES exposure. It's best if they do this before they become pregnant. This way they can work with their doctors to watch for signs of

problems and deal with them as soon as possible. Their pregnancies will probably be treated as high-risk, meaning these women will be closely watched by their doctors throughout the pregnancy.

Again, it's important to note that most DES-exposed daughters do not have problems getting pregnant or carrying a baby to full term. All women should have good prenatal care, but it's even more important for DES-exposed daughters.

### **Is it safe to use oral contraceptives (birth control pills) or hormone replacement therapy?**

Each woman should talk about this with her doctor. Studies have not shown that birth control pills or hormone replacement therapy is unsafe for DES-exposed daughters, but some doctors believe DES-exposed daughters should avoid them because of the estrogen in them. Structural changes in the vagina or cervix do not usually cause problems with the use of other forms of contraception, such as diaphragms, female condoms, or spermicides.

## **What health problems could DES-exposed sons have?**

### **Epididymal cysts**

DES-exposed sons have an increased risk for epididymal cysts, which are non-cancerous growths on the testicles. Some studies have found that as many as 1 out of 5 DES-exposed sons may develop these.

### **Other health problems**

Whether DES-exposed sons are at higher risk for other genital changes is not known. Some studies have found that DES-exposed sons might have a higher risk of undescended testicles or hypospadias (a birth defect in which the urethra opens along the bottom of the penis rather than at its tip). But other studies have not found these risks.

The possible relationship of DES exposure to increased risk of testicular or prostate cancer is not clear at this time. Some studies have suggested a possible link, but others have not.

DES-exposed sons don't seem to have more fertility problems than other men.



## What should DES-exposed sons do?

There are no special screenings or tests recommended for DES-exposed sons, but they should tell their doctors about their exposure and get regular exams .

Even though DES-exposed sons have not been found to have a higher risk of developing cancer, males with undescended testicles or unusually small testicles have a higher risk of testicular cancer, whether they were exposed to DES or not. DES-exposed sons may want to talk to their doctors about whether they should examine their testicles regularly.

## What about children of DES-exposed sons and daughters (DES third generation children)?

It is not yet clear if children born to DES-exposed daughters and sons have any greater health risks than other children. These children were not directly exposed to DES, so they would not be expected to have the same risks as their parents, but research in this area continues.

Some studies have suggested that the risk of hypospadias may be higher in boys whose mothers were exposed to DES. Most other studies so far have not found higher risks of birth defects or cancer in these children, but some health problems might not show up until they're older. Researchers are following these children to look for possible health effects.

## DES research

Several groups of researchers around the world continue to follow people who may have been exposed to DES (and their children) to look for possible health effects.

Some people known to have been exposed to DES are being watched in the [National Cancer Institute's DES Combined Cohort Follow-up Study](#)<sup>8</sup>, which was started in 1992. Researchers are following up with more than 20,000 people to look for possible effects of DES, such as higher risks of breast and [testicular cancers](#)<sup>9</sup>, as well as other health issues that might not be as easily linked to DES exposure. This research is still going on, and study results continue to be published.

The Follow-up Study also includes the children of the daughters and sons who were exposed to DES — the third generation of DES-exposed families. The third generation will continue to be studied, along with the mothers who were first exposed to DES and

their children.

## Hyperlinks

1. [desaction.org/brand-names/](http://desaction.org/brand-names/)
2. [www.cancer.org/cancer/breast-cancer.html](http://www.cancer.org/cancer/breast-cancer.html)
3. [www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection.html](http://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection.html)
4. [www.cancer.org/cancer/vaginal-cancer.html](http://www.cancer.org/cancer/vaginal-cancer.html)
5. [www.cancer.org/cancer/cervical-cancer.html](http://www.cancer.org/cancer/cervical-cancer.html)
6. [www.cancer.org/cancer/breast-cancer.html](http://www.cancer.org/cancer/breast-cancer.html)
7. [www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection.html](http://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection.html)
8. [www.desfollowupstudy.org/index.asp](http://www.desfollowupstudy.org/index.asp)
9. [www.cancer.org/cancer/testicular-cancer.html](http://www.cancer.org/cancer/testicular-cancer.html)

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