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DES Exposure: Questions and Answers

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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'd 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.

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](#)³.) 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](#)⁴ or [Cervical Cancer](#)⁵.

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:

- 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

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

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

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](#)⁸, 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](#)⁹, 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 generationdconlo 0 g peo

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