

## WEB EXCLUSIVES

# DES Exposure: Questions and Answers

BY THE AMERICAN CANCER SOCIETY

## 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 in the past. At that time it was believed that these difficulties might have been caused by low levels of estrogen in the woman's body. DES was thought to correct this problem. It was given to about 4 million women in the United States during this time.

The use of DES declined in the 1960s after studies showed that it might not prevent pregnancy complications. Later studies found that when given during the first five months of a pregnancy, DES could interfere with the development of the reproductive system in a fetus. In 1971, the Food and Drug Administration advised doctors to stop prescribing it during pregnancy. A national effort was undertaken to identify all mothers and children who had been exposed to DES up to that time, but not everyone who had been exposed to DES could be found.

DES and other estrogens may still be prescribed for some medical problems including some cancers, but they are no longer used during pregnancy.

## Who Was Exposed to DES?

An estimated 5 to 10 million people were exposed to DES during pregnancy. Three groups of people were exposed:

- > DES mothers: women who took DES while pregnant
- > DES daughters: women whose mothers took DES when pregnant with them, and who were therefore exposed to it while they were in the womb
- > DES sons: men whose mothers took DES when pregnant with them, and who were therefore exposed to it while they were in the womb

Only children who were in the womb at the time their mother took DES are

thought to have been exposed. Brothers or sisters from pregnancies in which DES was not taken were not exposed.

### How Do You Know If You (or Your Mother) Was Given DES During Pregnancy?

Many people are not aware that they were exposed to DES. Many women do not remember if they received DES while they were pregnant. A woman who was pregnant between 1938 and 1971 and had problems during a current or previous pregnancy may have been given DES or a similar estrogen-like drug. Women who did not have such problems were less likely to have been given DES. Women who were not under a doctor's care while pregnant probably did not receive DES because you could only get it with a doctor's prescription. DES was given in pills, injections, and suppositories.

If you think you (or your mother) used a hormone such as 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 of you (or your mother) receiving DES. If you remember taking any pills during pregnancy, check your obstetrical records to find out the name of the drug. Mothers and children have a right to this information.

DES was sold under a number of different names. The Centers for Disease Control and Prevention (CDC) has a list of DES brand names on their [Web site](#). Two of the most commonly used names were stilbestrol and DESPlex.

Finding medical records after a long period of time may be hard to do. If the doctor has moved, retired, or died, another doctor may 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. Some pharmacies keep records for a long time, and if you know where the prescription was filled, you may be able to get the information there. Military medical records are kept for 25 years. In many cases, however, it may be impossible to be sure whether DES was used.

Unfortunately, there are no medical tests that can determine if you were exposed to DES. This is why it is important to keep any records you may already have about DES exposure. Write down and save anything you are able to find out about dates the drug was taken, and other details.

If you cannot find this information and you are unsure of your exposure, you will find additional information about DES and the [CDC's DES Update Self-Assessment Guide](#) to help you determine the likelihood of your exposure. Print versions of this resource can be ordered online or by calling the CDC toll-free number found at the end of this document.

### What Health Problems Might Women Who Were Given DES While Pregnant Have?

#### **Breast cancer**

Women who were given DES appear to have a slightly increased risk of breast cancer. 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 considering breast cancer risk during a woman's lifetime, this means about 1 out of 6 women who were given 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 among pregnant women.

### What Should Women Who Were Given DES While Pregnant Do?

A woman who was given DES while pregnant (or suspects she may have been given it) should tell her doctor. If possible, she should try to learn the dosage, when the medicine was started, and how it was used. She also should tell her children who were exposed before birth so that they will know, and so that this information can be included in their medical records.

The National Cancer Institute (NCI) recommends that DES-exposed mothers follow a regular schedule for early breast cancer detection recommended for all women, including mammograms and clinical breast exams. They should report any new breast lumps or other breast changes to their doctor as soon as possible. In addition, women should have regular medical check-ups.

### What Health Problems Might DES-Exposed Daughters Have?

#### **Clear Cell Adenocarcinoma**

In 1971, DES was first 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 or cervix usually occurs in DES-exposed daughters in their late teens or early 20s. However, it has been reported as early as age 8, and the upper age limit, if any, is not known. Some cases have been reported in women in their 30s and 40s. Now that DES-exposed daughters are more than 30 years old, the number of reported DES-related cases of clear cell adenocarcinoma has declined.

Treatment for CCA will vary depending on the location and stage of the cancer. For more information on the treatment of clear cell adenocarcinoma, please see our documents, [Vaginal Cancer](#) or [Endometrial Cancer](#).

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

#### **Abnormal Cervical/Vaginal Cells**

Some scientists have found a link between DES exposure before birth and an increased risk of developing abnormal cells in the tissue of the cervix and vagina. Doctors use a number of terms to describe these abnormal cells including dysplasia, cervical intraepithelial neoplasia (CIN), and squamous intraepithelial

lesions (SILs). These abnormal cells look like cancer cells. However, they do not invade nearby healthy tissues as cancer cells do.

These cellular changes usually occur when women are between 25 and 35 but may appear at other ages as well. Although this condition is not cancer, it may develop into cancer if left untreated. The National Cancer Institute recommends that DES-exposed daughters have a yearly Pap test and pelvic exam to check for dysplasia, or abnormal cells. American Cancer Society guidelines also recommend yearly Pap tests for these women, even after age 30.

### **Structural Changes in the Reproductive Tract**

DES-exposed daughters may have structural changes in the vagina, uterus, or cervix. Most of these structural changes do not cause medical problems. Some, however, may interfere with a woman's ability to become pregnant or cause other reproductive health problems.

### **Problems Getting Pregnant**

While early studies of fertility rates among DES-exposed daughters did not produce clear results, the most recent study did find that DES-exposed daughters are more likely to have fertility problems. The study found an infertility rate (inability to become pregnant after trying for at least 12 months) of 28% among women exposed to DES, compared with 16% in women who were not exposed to DES. The DES-exposed daughters who never became pregnant were exposed during the first 9 weeks in the uterus.

At least part of this difference appears to be due to changes in the shape of the uterus. DES-exposed daughters may also be more likely to have irregular menstruation, which could contribute to fertility problems.

It's important to note that while DES-exposed daughters are at higher risk for fertility problems, most do not have problems becoming pregnant.

### **Problems During Pregnancy**

DES-exposed daughters may also have an increased risk of certain problems during pregnancy. According to a recent study these problems include:

#### **Premature Birth**

Among DES-exposed daughters, about 64% delivered a full-term baby in their first pregnancy, compared with 85% in unexposed women.

#### **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) appeared to be 3 to 5 times higher in DES-exposed daughters.

#### **Miscarriage**

Almost 20% of DES-exposed daughters had a miscarriage during their first pregnancy, compared with about 10% among unexposed women.

Because of these potential problems, DES-exposed daughters need to tell their doctors about their DES exposure, preferably even before they become pregnant,

so that any potential problems can be identified and addressed. For instance, some may want to talk with their doctors about the early symptoms of ectopic pregnancy, so that if it happens, it can be treated quickly. Their pregnancies will probably be classified 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 have no problems becoming pregnant or carrying a baby to full term. Although all women should have good prenatal care, this is especially important for DES-exposed daughters.

At this time, there is no evidence that the risk of birth defects, other abnormalities, or cancer is any greater for children born of DES-exposed daughters and sons than for other children.

### **Other Potential Problems**

A recent study seems to lend credibility to the link between DES-exposure to daughters and a slightly increased risk for breast cancer. The risk seems higher in women older than 40. The risk of other cancers does not seem to be increased, but research is continuing in this area.

### **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 was given the drug. Or, you can try to find records from her obstetrician's office (see 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 inform their doctors of their exposure. It is important that your doctor be familiar with possible problems linked to DES exposure, because some problems, such as clear cell adenocarcinoma, are usually found only when the doctor is looking for them.

DES-exposed daughters should keep records about their exposure, and continue to receive regular gynecological exams throughout their lifetimes. The American Cancer Society recommends that DES-exposed daughters get annual Pap tests, even if they have had a hysterectomy. The National Cancer Institute (NCI) recommends these women have regular, thorough exams that may include the following:

#### **Pelvic Exam**

A physical exam of the reproductive organs. An exam of the rectal area also should be done.

#### **Palpation**

As part of a pelvic exam, the doctor feels the vagina, uterus, cervix, and ovaries for any lumps. Often palpation provides the only evidence that an abnormal growth is present.

#### **Pap Test**

A routine cervical Pap test is not adequate for DES-exposed daughters. The

cervical Pap test must be supplemented 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**

Iodine staining of the cervix and vagina: An iodine solution is used to temporarily stain the linings of the cervix and vagina to detect adenosis (a non-cancerous but abnormal growth of glandular tissue) or other abnormal tissue.

### **Colposcopy**

A magnifying instrument is used to look at the vagina and cervix. Some doctors do not do this routinely, but if the Pap test result is not normal, it is very important to check for abnormal tissue.

### **Biopsy**

Small samples of any tissue that appear abnormal on other tests are removed and looked at under a microscope to see whether cancer cells are present.

### **Breast Exams**

While it is not known for sure if DES-exposed daughters are at higher risk for breast cancer, they should continue to follow current screening recommendations, such as those established by the American Cancer Society.

### **Is It Safe for DES-Exposed Daughters to Use Oral Contraceptives (Birth Control Pills) or Hormone Replacement Therapy?**

Each woman should discuss this important question with her doctor. Although studies have not shown that the use of birth control pills or hormone replacement therapy is unsafe for DES-exposed daughters, 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 or spermicides.

### **What Health Problems Might DES-Exposed Sons Have?**

**Epididymal cysts:** DES-exposed sons appear to 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 problems:** Whether DES-exposed sons are at higher risk for other genital abnormalities is not certain. Some studies have found that DES-exposed sons may have an increased risk of testicular problems such as undescended testicles or abnormally small testicles. However, 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.

DES-exposed sons do not appear to be at increased risk for infertility.

## What Should DES-Exposed Sons Do?

Although there are no special screenings or tests for DES-exposed sons, they should tell their doctor of their exposure and be examined periodically. Even though DES-exposed sons have not been found to be at increased risk of developing cancer, males with undescended testicles or unusually small testicles have a higher risk of testicular cancer, whether or not they were exposed to DES. DES-exposed sons may want to consider examining their testicles regularly.

## DES Research

People known to have been exposed to DES continue to be followed in the NCI's DES Combined Cohort Follow-up Study, which was started in 1992. At that time, an education campaign for doctors and for the public was also begun. Researchers are monitoring about 15,000 people to look for other possible effects of DES such as increased risks of breast and testicular cancers, as well as other health issues that might not be as easily linked to DES exposure. This research is ongoing, 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. At this time, there are no data to clearly support that DES is adversely affecting the third generation with cancer or other health problems. One small study in The Netherlands suggested that the sons of DES daughters had a fairly high risk of a birth defect called hypospadias. (In this defect, the opening of the urethra is along the shaft of the penis rather than at its tip.) A later study suggested that the risk of hypospadias was much smaller than it was first thought to be. The third generation will continue to be studied, along with the mothers who were first exposed to DES and their children.

## Additional Resources\*

Centers for Disease Control and Prevention (CDC) DES Update  
Telephone: 1-800-232-4636  
Internet Address: [www.cdc.gov/des](http://www.cdc.gov/des)

Centers for Disease Control and Prevention (CDC)  
National Breast and Cervical Cancer Early Detection Program (NBCCEDP)  
Telephone: 1-800-CDC-INF or 1-800-232-4636  
Internet Address: [www.cdc.gov/cancer/nbccedp/index.htm](http://www.cdc.gov/cancer/nbccedp/index.htm)

Centers for Medicaid and Medicare Services (CMS)  
Preventive Services  
Cervical and Vaginal Screening (Pap test and pelvic exam)  
Telephone: 1-800-MEDICARE OR 1-800-633-4227

DES Action USA  
Telephone: 1-800-DES-9288 or 1-800-337-9288

Internet Address: [www.desaction.org](http://www.desaction.org)

DES Cancer Network

Internet Address: [www.descancer.org](http://www.descancer.org)

DES Daughters (DES-L) Online Support Center

Internet Address: [www.surrogacy.com/online\\_support/des](http://www.surrogacy.com/online_support/des)

DES Sons Network

Telephone: 609-795-1658

Mailing Address: 104 Sleepy Hollow Place

Cherry Hill, NJ 08003

National Cancer Institute

Telephone: 1-800-4-CANCER (1-800-422-6237)

Internet Address: [www.cancer.gov](http://www.cancer.gov)

Registry for Research on Hormonal Transplacental Carcinogenesis

(Clear Cell Cancer Registry)

Telephone: 1-773-702-6671 (collect calls accepted)

Internet Address: <http://obgyn.bsd.uchicago.edu/registry.html>

\*Inclusion on this list does not imply endorsement by the American Cancer Society.

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