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[Home](#) > DES (Diethylstilbestrol)

DES (Diethylstilbestrol) ^[1]

Dear Alice,

Do you know anything about the drug DES, taken by some women to enable them to have children? It seemed to have prevented miscarriages and the doctor recommended this drug in the 1940s. Now women and men are having problems, for instance, cancer, etc. Do you have any more info on it?

Answer

Dear Reader,

You're right on the money with your intel on this drug. Diethylstilbestrol (DES) is a synthetic, lab-made form of the hormone estrogen. When the drug was first introduced, researchers theorized that low levels of estrogen contributed to pregnancy complications such as miscarriage and premature births. From 1938 to 1971, DES was prescribed in the United States to anywhere from five to ten million pregnant people in an effort to prevent miscarriages, premature labor, and other pregnancy complications from occurring. Later, it was found that DES didn't prevent the conditions it was meant to curtail, and, in 1971, researchers sounded the alarm that the drug was linked to serious health issues. Following these findings, the U.S. Food and Drug Administration (FDA) advised all health care professionals to avoid prescribing this medication. Although health care providers were encouraged to also alert the patients they previously prescribed DES about the problems associated with the drug, it's possible that many people who were exposed to DES, both while pregnant and in the womb, may not be aware.

It has also since been revealed that DES disrupts the body's endocrine system, which is responsible for the body's hormones. Substances that interfere with the endocrine system are known to increase the likelihood of cancer and problems during fetal development. With this in mind, a person who used DES during their pregnancy is 30 percent more at risk for developing breast cancer. This equates to a rate of about one in six cases of breast cancer in those who took DES, as opposed to one in eight for those who did not. DES was found to affect the babies of those who took DES as well.

The children assigned female at birth of pregnant people who were given DES may experience or develop the following health concerns:

- Abnormalities of the cervix, uterus shape, and tissue that lines the vagina
- Abnormal cells in the cervix and vagina
- Increased risk of developing an otherwise rare form of cancer of the vagina or cervix, called clear cell adenocarcinoma
- Difficulty becoming pregnant
- Increased risk of miscarriage, pre-term labor, ectopic pregnancy (pregnancy that occurs within the fallopian tube instead of the uterus), and preeclampsia (a condition that results in protein in the pregnant person's urine and high blood pressure, which, in turn, may require early delivery)
- Slightly increased risk of breast cancer

Some studies indicate that the children assigned male at birth of those who took DES may experience or develop abnormal testicles (e.g., non-cancerous cysts on the epididymis or undescended testicles), and may be at increased risk of infection or inflammation of the testicles, and hypospadias (atypical development of the opening of the urethra). However, these risks haven't been found in all studies.

In addition to folks exposed to DES in the womb, the effects of the drug on the third generation (referred to as DES grandchildren) are now being investigated. Current studies aim to determine whether the changes to DNA potentially caused by the drug may be passed down from generation to generation, and whether it may increase the risk of fertility issues, pregnancy concerns, and other health issues among this population. Right now, it's unclear whether the third generation is at greater risk than children whose parents weren't exposed to DES. However, some studies do indicate that the male offspring of those who were impacted by DES in the womb may have a higher risk of developing hypospadias.

Those who have used DES are advised to let their children and health care providers know about their past use, and to seek regular health and breast cancer screenings (as recommended of all those assigned female at birth). However, knowing for sure that they were exposed to DES may be a challenge. The [American Cancer Society](#) [2] has more information to help track down the information needed to verify or determine the likelihood of exposure. It's also recommended that anyone who was potentially exposed to DES in the womb let their health care provider know, and to undergo routine exams. For female offspring, this may include pelvic exams, Pap smears, iodine stainings of the cervix and vagina, colposcopies, biopsies, and breast exams. Although it's recommended for those who've been exposed to DES during fetal development to tell their health care provider before becoming pregnant (to ensure that extra precaution is taken), many are able to have full-term, healthy pregnancies.

Hope this information is helpful! If you have additional questions, consider also checking out the [National Cancer Institute](#) [3] website, which has a handy fact sheet with a number of commonly asked questions about DES exposure.

Alice!

Category:

[Alcohol & Other Drugs](#) [4]

[Prescription & Over-the-Counter-Drugs](#) [5]

[General Health](#) [6]

[Cancer](#) [7]

[Sexual & Reproductive Health](#) [8]

[Reproduction](#) [9]

[Pregnancy](#) [10]

Related questions

[Effects of breast cancer on having children](#) [11]

[Paternal grandmother – Breast cancer link?](#) [12]

[Fertility awareness: The symptothermal method](#) [13]

Resources

[Medical Services \(Morningside\)](#) [14]

[Medical Services \(CUIMC\)](#) [15]

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Footer menu

▼ [Contact Alice!](#)

- [Content Use](#)
- [Media Inquiries](#)
- [Comments & Corrections](#)

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- [Licensing Q&As](#)
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Links

[1] <https://goaskalice.columbia.edu/answered-questions/des-diethylstilbestrol-1>

- [2] <http://www.cancer.org/cancer/cancercauses/othercarcinogens/medicaltreatments/des-exposure>
- [3] <http://www.cancer.gov/about-cancer/causes-prevention/risk/hormones/des-fact-sheet>
- [4] <https://goaskalice.columbia.edu/category/alcohol-other-drugs>
- [5] <https://goaskalice.columbia.edu/category/prescription-over-counter-drugs>
- [6] <https://goaskalice.columbia.edu/category/general-health>
- [7] <https://goaskalice.columbia.edu/category/cancer>
- [8] <https://goaskalice.columbia.edu/category/sexual-reproductive-health>
- [9] <https://goaskalice.columbia.edu/category/reproduction>
- [10] <https://goaskalice.columbia.edu/category/pregnancy>
- [11] <https://goaskalice.columbia.edu/answered-questions/effects-breast-cancer-having-children>
- [12] <https://goaskalice.columbia.edu/answered-questions/paternal-grandmother-%E2%80%93-breast-cancer-link-0>
- [13] <https://goaskalice.columbia.edu/answered-questions/fertility-awareness-symptothermal-method-0>
- [14] <https://goaskalice.columbia.edu/resource/medical-services-morningside>
- [15] <https://goaskalice.columbia.edu/resource/medical-services-cuimc>