

DES daughters - possible problems

If you were pregnant or born between 1946 and 1971, you may have been exposed to the drug diethylstilboestrol (DES). DES was a hormone pill once given to pregnant women in the belief that it helped prevent miscarriage. It was found that the drug didn't work and could cause health problems later in life, for both the pregnant women (DES mothers) and their babies (DES daughters and DES sons).

Everyone who was exposed to DES needs special health care, even if they're not having any obvious health problems.

Diethylstilboestrol (DES) was a synthetic hormone

Oestrogen is one of the female sex hormones that regulates the menstrual cycle. DES was a synthetic oestrogen drug, marketed under scores of different brand names. Doctors and obstetricians commonly prescribed it to women with fertility problems or at risk of miscarriage from 1946 until 1971 in Australia, usually as a pill. Sometimes, it was administered along with vitamin supplements and some women may not have realised they were taking any drugs.

DES mothers

If you were given DES while you were pregnant, you are a DES mother. Exposure to DES has increased your risk of developing certain diseases, such as breast cancer. Special health care for DES mothers includes:

- Monthly breast self-examination (BSE)
- Annual breast x-ray (mammogram)
- Annual gynaecological check-up including a Pap smear test.

DES daughters

If your mother took DES while she was pregnant with you, you are a DES daughter. Exposure to DES has increased your risk of developing certain cervical and vaginal cancers and pre-cancerous conditions. Research is limited on the risks of developing breast cancer for DES daughters, but a 2006 study found a slightly higher risk in DES daughters aged 40 and over. A special DES check-up every year, along with annual clinical breast examination and mammography once you have reached 40 years of age, is recommended.

Many DES daughters have fertility and pregnancy problems, including:

- Ectopic pregnancy (where the fertilised egg lodges in a fallopian tube)
- Miscarriage
- Premature labour
- Delivery problems.

DES sons

If your mother took DES while she was pregnant with you, you are a DES son. Exposure to DES has increased your risk of developing certain reproductive and urinary tract problems and you should examine your testicles for lumps every month. Some common DES-induced problems include:

- Undescended testicles

- Under-developed testicles
- Cysts on the testicles
- Lowered sperm count.

DES third generation

Most children of DES daughters and sons (the DES third generation) are just beginning to reach the age when relevant health problems (such as reproductive tract problems) can be studied. There is no evidence yet that DES exposure has any effect on the third generation but research is ongoing.

How to find out if you were exposed to DES

DES was commonly prescribed to women who had a history of pregnancy problems such as bleeding, miscarriages, premature births, stillbirths or diabetes. Some women didn't know they were being prescribed a hormone pill. If you think you either took the drug while pregnant, or your mother took the drug while she was pregnant with you, it is important to check your medical records. The Freedom of Information Act allows you to access your records from doctors, hospitals and pharmacists.

If you can't find out for sure, but suspect you may have been exposed, it is recommended that you have a DES examination to remove any doubt.

Where to get help

- Your doctor
- DES Follow-up Clinic, Royal Women's Hospital, Victoria Tel. (03) 8345 2594
- DES Action, Australia

Things to remember

- Diethylstilboestrol (DES) was commonly prescribed as an anti-miscarriage drug between 1946 and 1971 in Australia.
- DES can cause reproductive changes and diseases in both the mothers and children.
- Everyone who was exposed to DES needs special medical care, even if they don't have any obvious health problems.

This page has been produced in consultation with, and approved by:

Royal Women's Hospital

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