DES daughters

Summary

- Diethylstilboestrol (DES) was commonly prescribed as an anti-miscarriage medication between 1946 and 1971 in Australia.
- DES can cause reproductive changes and diseases in both the mothers and their children.
- Everyone who was exposed to DES needs special medical care, even if they don’t have any obvious health problems.
- All DES daughters should have a yearly DES examination.
- All DES daughters over the age of 40 should have an annual mammogram and medical breast check, as well as doing a monthly breast self-examination.
- There is no evidence that the third generation is affected by DES exposure.

Diethylstilboestrol (DES) was a medication commonly prescribed to prevent miscarriage, between 1946 and 1971 in Australia. If your mother took DES while she was pregnant with you, then you are a DES daughter or DES son. We now know that DES exposure in the womb can cause a range of reproductive changes and fertility problems later in life.

Oestrogen is one of the female sex hormones that regulates the menstrual cycle. DES was a synthetic oestrogen medication, sold under many different brand names.

Doctors and obstetricians commonly prescribed DES to women who had fertility problems or who were at risk of miscarriage, usually as a pill. Sometimes, doctors gave the medication along with vitamin supplements and some women may not have realised they were taking any medications.

Anyone who was exposed to DES needs special healthcare, even if they are not having any obvious health problems.

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 DES while pregnant, or your mother took it while she was pregnant with you, it is important to check your medical records. Under the Freedom of Information Act 1982, you have the right to see your records from doctors, hospitals and pharmacists.

If you can’t find out for sure, but suspect you may have been exposed to DES, you should have a DES examination to remove any doubt.

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 (especially if you are aged over 70).

Special healthcare for DES mothers includes:

- monthly breast self-examination (BSE)
- annual breast x-ray (mammogram)
- annual gynaecological check-up including a cervical screening test.

DES sons

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If you are a man whose 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 in DES sons include:

- undescended testicles
- underdeveloped testicles
- cysts on the testicles
- lowered sperm count.

**DES daughters – gynaecological changes**

DES daughters can experience many changes to their reproductive organs – some harmless, others serious. Even if a DES daughter doesn’t have any obvious health problems, she still needs special healthcare. This includes regular physical examinations for life.

It is important to tell any healthcare professional that you have been exposed to DES. If any surgery is recommended on your vagina, cervix, fallopian tubes or uterus, always get a second opinion from a doctor experienced in looking after women who have been exposed to DES. This is because some DES-related changes can be misdiagnosed as other gynaecological conditions.

**Vaginal adenosis in DES daughters**

DES exposure commonly causes adenosis, where a part of the vagina and cervix secretes mucus (becomes ‘glandular’). An increase in vaginal discharge is usually the only symptom and the tissue is otherwise healthy. There is no need for medication or any other treatment. In fact, unnecessary surgery to remove the adenosis might make it difficult for doctors to interpret the findings of future DES examinations.

**Altered shape of the uterus in DES daughters**

DES exposure can change the shape of the uterus, usually with no ill effect. Sometimes, a woman’s fertility can be affected and an operation is needed to correct the shape of her uterus.

**Altered shape of the cervix in DES daughters**

DES exposure can alter the shape of the cervix (the neck of the uterus). To a doctor unfamiliar with DES-related gynaecological changes, these changes can look a lot like cervical polyps, which are common and harmless growths. This misdiagnosis can lead to unnecessary surgery.

**Changes to the cells of the cervix in DES daughters**

Dysplasia, or cervical intraepithelial neoplasia (CIN), is a change in the cells of the cervix or vagina. DES-exposed women have a higher risk of developing cell changes. Sometimes, vaginal adenosis can be misdiagnosed as CIN.

**Cancer and DES daughters**

DES daughters have a higher risk of developing certain cervical and vaginal cancers and pre-cancerous conditions. You should have a special DES check-up every year, along with annual clinical breast examination and mammography, once you have reached 40 years of age.

**Clear-cell cancer and DES daughters**

Clear-cell cancer, or adenocarcinoma, is a rare cancer of the vagina or cervix associated with DES daughters. If this cancer is discovered at an early stage, doctors can treat it successfully. It is important to have regular DES examinations, because a cervical screening test may not pick up the clear-cell cancer.

**Breast cancer and DES daughters**

Research is limited on the risks of developing breast cancer for DES daughters, but a 2006 study indicated that DES daughters may have a slightly increased risk of developing breast cancer after the age of 40 (1.4 times the risk of the general population).
All DES daughters over the age of 40 should have an annual mammogram and medical breast check, as well as doing a monthly breast self-examination.

Having a DES examination

The recommended yearly DES examination includes:

- a careful inspection of the vagina
- cervical screening tests taken from the upper vagina as well as the cervix
- an internal pelvic examination
- a breast examination.

Other procedures for DES daughters

A DES examination might also include:

- a colposcopy – an examination of the cervix using a speculum (as for a cervical screening test) and a kind of microscope called a colposcope
- a biopsy (occasionally required) – a small sample of tissue taken from your vagina or cervix to be examined under a microscope.

DES daughters and reproduction

DES daughters may experience a range of problems relating to fertility, pregnancy and contraception.

Contraceptive limitations for DES daughters

If you are a DES daughter you will need to take your exposure to DES into account when you decide on a method of contraception. Discuss your options with a doctor who understands that you are a DES daughter.

Some of the contraceptive problems DES daughters may experience include:

- natural family planning – heavy vaginal discharge might make it more difficult to interpret your cervical mucus for fertile and infertile days
- intrauterine devices (IUDs) – if you have changes in the shape of your uterus you will need to avoid using an IUD.

DES daughters can choose other contraceptive methods such as:

- the pill – the combined pill contains oestrogen, but there are no reported problems specific to DES
- other hormone treatments such as Depo-Provera injections and the high-hormone-dose ‘morning after pill’ – these may be used if appropriate and necessary
- the ‘mini-pill’ (progestogen only) – there are no problems with DES
- condoms
- diaphragm and spermicide.

Abortion, miscarriage and DES daughters

If you are considering having an abortion, it is vital that you consult with a doctor who understands your DES exposure. It is possible, but not proven, that having an abortion could increase your risk of cervical incompetence (where the cervix can’t remain properly closed during pregnancy) and miscarriage in future pregnancies.

DES daughters and infertility

DES daughters have a slightly increased risk of infertility. However, it’s important to remember that women who weren’t exposed to DES sometimes have fertility problems too.

If you are having trouble conceiving, it might be caused by reasons other than your exposure to DES. Treatment for infertility depends on the cause. In vitro fertilisation (IVF) and other infertility treatments are available to DES daughters and work as well for them as for other women.

Risks in pregnancy for DES daughters
DES daughters have a slightly higher risk of certain pregnancy complications, including:

- ectopic pregnancy – a serious condition where the fertilised egg lodges in a fallopian tube instead of in the uterine wall
- miscarriage – an incompetent (weak) cervix can cause a miscarriage in both the first and second trimesters (the first or second three months of pregnancy)
- premature labour – caused by an incompetent cervix
- delivery problems.

As DES exposure ceased in 1971, issues around pregnancy are becoming rare.

Children of DES sons and daughters

Most children of DES daughters and sons (the DES third generation) are just beginning to reach the age when any relevant health problems (such as reproductive tract problems) can be studied.

There is no reason to believe that children born from DES daughters or sons will be affected. Animal studies don’t conclusively show any DES-related problems by the third generation.

Where to get help

- Your GP
- DES Follow-up Clinic, Royal Women’s Hospital Tel. (03) 9344 5077

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

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