

DES daughters - gynaecological changes

Between 1946 and 1971 in Australia, the synthetic hormone diethylstilboestrol (DES) was commonly prescribed to pregnant women in the belief that it helped prevent miscarriage. We now know that DES exposure can cause health problems both for the women who took the drug and their children in later life.

If your mother took DES while she was pregnant with you, you are a DES daughter. DES daughters can experience many changes to their reproductive organs and need careful monitoring.

Special health care for reproductive changes

Even if a DES daughter doesn't have any obvious health problems, she still needs special health care. This includes regular physical examinations for life. DES daughters can experience a range of reproductive changes, both harmless and serious.

It is important to tell any health care practitioners 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 DES-exposed patients. This is because some DES-related changes can be misdiagnosed as other gynaecological conditions.

Vaginal adenosis

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

Altered shape of the uterus

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 the uterus.

Altered shape of the cervix

DES exposure can alter the shape of the cervix. 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

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

Clear-cell cancer

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

Increased risk of breast cancer

Women who took DES during their pregnancy (DES mothers) have an increased risk of breast cancer in their later years – especially if they are over the age of 70. A recent report (2006) has indicated that women exposed to DES in utero (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).

It is recommended that all DES daughters over the age of 40, and all DES mothers, have an annual mammogram and medical breast check as well as doing a monthly breast self-examination.

The DES examination

The recommended yearly DES examination includes:

- A careful inspection of the vagina
- Pap smears taken from the upper vagina as well as the cervix
- An internal pelvic examination
- A breast examination.

Other procedures

A DES examination might also include:

- **A colposcopy** – an examination of the cervix using a speculum (as for a Pap smear) 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.

Where to get help

- Your doctor
- The 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 in DES daughters and may increase the risk of a DES daughter developing breast cancer after the age of 40.
- A yearly DES examination and an annual mammogram and medical breast check are recommended for all DES daughters, even if they don't have any obvious health problems.

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

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