



GYNAECOLOGICAL CHANGES IN DES EXPOSED DAUGHTERS

DES (di-ethyl-stilboestrol or stilboestrol) is a synthetic oestrogen drug. It was prescribed to pregnant women in the belief that it prevented miscarriage and ensured a healthy pregnancy. Eventually though the drug was found to be both ineffective and damaging to the future health of both the women and their babies.

A gynaecologist experienced in DES related problems will check you for the following gynaecological changes that are found in DES exposed women.

Benign changes

Benign changes (such as vaginal adenosis and changes in cervical or uterine shape) are commonly found in DES exposed women. These changes indicate the need for careful medical follow-up by an experienced clinician but do not in themselves require “treatment” of any kind.

Vaginal adenosis is common because DES exposure causes this portion of the vagina to become glandular (mucus secreting) tissue. The only symptom that this is likely to produce is an increase in vaginal discharge. Despite the condition, the portion of vaginal skin affected is healthy.

Heavy vaginal discharge in a DES exposed woman is a possible indication of vaginal adenosis. The discharge is due to the larger area of mucus-secreting glandular tissue on the cervix and vagina. It is important though that you see a doctor to make sure the discharge is not due to infection.

Prescribed medication or other treatment is not necessary for vaginal adenosis.

If it is found that the discharge is normal (i.e. not due to infection) it is essential that no treatment be used. Unnecessary surgery for the removal of adenosis may make future routine examinations more difficult to interpret and can potentially cause problems in future pregnancies – these treatments should only be used when a DES expert recommends them.

Discharge due to adenosis will lessen over time because these changes gradually disappear as women grow older.

Changes in uterine shape

In a proportion of DES exposed women, the shape of the womb may be altered. In some women, these changes may affect future fertility. In most however, the changes are of no significance and do not affect child-bearing. If you experience fertility problems that are caused by the structural changes in your uterus, then it is possible to correct the problem with surgery.

Cervical polyps

Cervical polyps are relatively common, benign growths found on the cervix, and are easily removed.

Variations in cervical shape – which are quite normal in DES exposed women – are often mistaken for polyps and doctors may recommend unnecessary corrective surgery. Again, this highlights the importance of getting a second opinion from a gynaecologist experienced in DES related problems.

Abnormal smear tests

Dysplasia or Cervical Intraepithelial Neoplasia (CIN) are common in the general community but are slightly more common in women exposed to DES. Dysplasia is a premalignant change in the cells of the cervix or vagina. Cervical Intraepithelial Neoplasia or CIN is another name for the same benign condition.

Recent studies show that DES exposed women are at a greater risk than other women for developing CIN. However, DES exposed women are also at risk of being misdiagnosed with CIN. This is because DES related changes will often mimic CIN. With the large area of cell change that occurs in vaginal adenosis, immature cells may be easily mistaken for abnormal ones.

This mistake may be made due to misreading the appearance of tissue patterns during the colposcopic examination or by 'over-reading' the results from the special smear test of the cervix and vagina (interpreting it as abnormal when it really is not).

It is important that the examining doctor or nurse practitioner knows about your DES exposure.

Any diagnosis of abnormal cell change must be taken seriously and an adequate treatment plan followed. Obtain a second opinion from a DES expert before any treatment or if the slightest doubt exists.

Clear-cell cancer

Clear-cell cancer (adenocarcinoma) of the vagina or cervix is associated with DES exposed daughters. It is extremely rare. This cancer can be treated successfully if diagnosed early. A special smear test of the cervix and vagina may not detect clear-cell cancer which is why as a DES exposed woman you are encouraged to have thorough pelvic examinations when you have your smear test. The condition should only be treated by knowledgeable and qualified specialists experienced in gynaecological cancer.

Increased risk of breast cancer

Women who took DES during their pregnancy (DES mothers) have an increased risk of breast cancer in their old age – especially if they are over the age of 70. However, 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, as well as DES mothers, have an annual mammogram and medical breast check as well as doing monthly breast self-examination.

In summary

- Always tell your doctor that you are, or that you may be DES exposed.
- Have a recommended pelvic examination for DES daughters annually.
- Practice monthly breast self-examination. A regular mammogram every two years beginning at age 40.
- Ask for a second opinion from a doctor experienced in caring for DES daughters whenever any surgery on the vagina, cervix, fallopian tubes or uterus is recommended.

Where to get more information

The DES Follow Up Clinic

Suite C, Frances Perry Consulting Suites
2nd Floor, Royal Women's Hospital
Cnr Grattan St & Flemington Rd
Parkville VIC 3052
T: (03) 9344 5077 for an appointment.

All patients of the DES Clinic require a medical referral from a general practitioner and their Medicare card.

Women's Welcome Centre (Victoria only)

The Royal Women's Hospital
T: (03) 8345 3037 or 1800 442 007 (rural callers)
Email: wwcadmin@thewomens.org.au

DES Action, Australia

P.O. Box 282 Camberwell, VIC, 3124
www.desaction.org.au

DES Action is a non-profit, voluntary organisation which operates as a self-help group for DES mothers and daughters. DES Action offers information, support and lobbying for health issues that affect women.

Related fact sheets on the Women's website

- DES exposure
- DES daughters, sons and mothers
- The later years – for women exposed to DES