



DES DAUGHTERS, SONS & MOTHERS

DES daughters

You are a DES (di-ethyl-stilboestrol or stilboestrol) daughter if your mother took DES while she was pregnant with you.

As a DES daughter you have a higher risk of developing certain types of cancers and pre-cancerous conditions. These conditions are treatable but it is important for you to be monitored. A special smear test of the cervix and vagina annually is recommended.

A very small number of DES daughters (less than 1:1000) develop a rare form of cancer of the vagina/cervix. Early diagnosis provides the best opportunity for successful treatment.

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 DES-related changes to the reproductive system. Most of these changes are not dangerous but you should be monitored on a regular basis.

As a DES daughter you may also experience infertility and pregnancy problems. These include ectopic (tubal) pregnancy, miscarriage and premature labour and delivery problems.

Most DES daughters can have children, but all DES daughters need monitoring and special medical care during pregnancy. You will require early confirmation of your pregnancy to ensure that the pregnancy is not ectopic.

As a DES daughter it is recommended that you have a special DES examination every year.

The DES examination for DES daughters

At your initial visit, there is a consultation with the doctor and a comprehensive medical history is taken.

The recommended annual pelvic examination for DES daughters always includes:

- a careful visual inspection and palpation (feeling) of the entire vagina
- separate special smear tests taken from the cervix and from the surfaces of the upper vagina
- an internal pelvic examination
- a breast examination.

An examination may also include:

- special iodine staining of the vagina and cervix (normal tissue stains brown)
- a colposcopy - an examination using a colposcope (special optical device to magnify the view of the cervix). This examination is non-invasive as no part of the colposcope touches you
- if there are any changes seen that require further assessment, a biopsy may be taken. This involves taking a sample of tissue from the cervix or vaginal wall. The procedure may be slightly uncomfortable and there could be minor bleeding.

DES sons

As a DES son you may have certain reproductive and urinary tract problems: undescended testicles (a known risk factor for testicular cancer), under-developed testicles, cysts on the back of the testicles and a lowered sperm count.

As a DES son you should do monthly testicular examinations (TSE) and report any lumps to your doctor.

If you are concerned, or if problems develop, you should consult a urologist.

DES mothers

DES mothers have a slightly increased risk of developing breast cancer.

As a DES Mother you should perform monthly breast self-examination (BSE) and have an annual clinical breast examination and mammography.

You are also advised to have an annual gynaecological check-up, including a special smear test of the cervix and vagina. Before taking any oestrogen treatment, e.g. HRT, you should discuss the risks and benefits with your doctor.

It is important that you tell your children about your DES exposure, even if your children have not had health problems.

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
- Gynaecological changes in DES exposed daughters
- The later years – for women exposed to DES