



DES EXPOSURE

You have recently been informed that you may have been exposed to DES (di-ethyl-stilboestrol or stilboestrol); that is, your mother was prescribed DES when she was pregnant with you.

Most women will experience a range of emotions when they are given this news. You might be feeling confused or frightened. You may also feel angry or powerless which is totally understandable.

DES exposure is an issue the community is still coming to terms with. It has received very little publicity and there are still only a limited number of health professionals who can provide up-to-date information.

Over the years a great deal has been revealed about DES exposure however there is still the possibility that long-term effects will emerge in years to come.

This means DES daughters require ongoing monitoring for the rest of their lives.

Nobody likes to be at risk, but with up-to-date information and adequate support you can put these risks into perspective and not let them dominate your life.

Many DES daughters have found that being informed and taking an active role in their health care lessens their sense of powerlessness. Some women cope by talking with other women while others feel more comfortable with a professional counsellor.

What medical treatment will I require?

You will need to have regular examinations throughout your life. As this is a specialised area it is important that follow-up examinations are done by professionals who are experienced in the management of DES exposed women.

Never accept any medical intervention, no matter how minor, without being sure that it's absolutely necessary. If in doubt get a second opinion.

What does the DES examination involve?

The recommended annual pelvic examination for DES daughters involves the following:

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

The examination may also include:

A Colposcopy

This is an examination that uses a special optical device called a colposcope to magnify the view of the cervix. This examination is non-invasive, as no part of the colposcope will touch you. Staining the vagina and cervix with an iodine solution (brown liquid) may occasionally be necessary.

A Biopsy

If, on examination, it is found that changes have occurred in the vagina or the cervix and your doctor believes that further examination is required, a biopsy will be taken from the affected area. This involves taking a sample of tissue from the cervix or the vaginal wall. The procedure may be slightly uncomfortable and there may be some slight bleeding afterwards.

Mammograms

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.

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 daughters, sons and mothers
- Gynaecological changes in DES exposed daughters
- The later years – for women exposed to DES