

WORKING WITH YOUR HEALTH CARE PROVIDER

How to Work Effectively with Your Health Care Provider

To stay informed about DES and protect your health, you should communicate regularly with your health care provider (for instance, your physician, physician's assistant, nurse, or nurse practitioner). Talking with your health care provider is not always easy; some patients hesitate to ask questions during regular office visits or check-ups because it is difficult for them to ask about complex issues such as DES. Others may be reluctant to contact their health care provider between office visits unless it is an emergency. But your health care provider needs to know your questions and concerns. Addressing your questions and concerns is the best way your health care provider can work with you to protect your health. You must take the initiative and help your health care provider give you the most effective care – the care that is right for you.

This section of CDC's DES Update addresses some of the most common questions and concerns that patients ask about how to work with a health care provider.

My health care provider has never talked with me about DES exposure.

If your health care provider has not talked with you about DES exposure, you can initiate the conversation. Most health care providers only have a few patients who have been exposed to DES, so they rarely have patients ask about the topic. Although CDC's DES Update is designed to give health care providers current information and resources for working with patients, if you do not mention your DES exposure, your health care provider will likely remain unaware.

I know (or have strong reason to suspect) that I was exposed to DES. What should I expect my health care provider to do?

Once your health care provider knows or suspects you were exposed to DES, certain screenings to check for DES health effects may be recommended. You and your health care provider can work together to set up a screening schedule that may minimize your risk of health problems. For a list of recommended screenings, see the section of CDC's DES Update titled [WHAT YOU CAN DO ABOUT DES: Protecting Your Health and the Health of Your Family](#).

Are there materials I can take to my health care provider to help us talk about DES?

The following are some DES resources that you can take to your health care provider.

- CDC's DES Update summary card titled [WHAT YOU CAN DO ABOUT DES: CDC'S DES Update in Brief](#).
- Downloadable materials from CDC's DES Update Web site at www.cdc.gov/DES.
- Recent DES research summarized in the section of CDC's DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#).

What can I do if I want or need to change health care providers?

If you do not have a health care provider, or if your health care provider does not meet your needs, ask for recommendations from family, friends, or other health care providers. Be sure to check with your health care plan about any network or referral requirements.

You can also contact the consumer advocacy group, DES Action USA. DES Action has compiled a National Physician Referral List that includes physicians who have experience working with DES-exposed patients. This referral list can be obtained free of charge. Other health care providers in your area also may know about DES, but this referral list is a good place to start. Contact DES Action by telephone (1-800-DES-9288) or by e-mail (desaction@earthlink.net).

My gynecologist knows about my DES exposure. Do I need to tell my other health care providers?

Yes. Your DES exposure is a part of your health history, and all of your health care providers should know about it. The more your health care providers know about your health history, the more you can work together to protect your health.

In addition, you should keep copies of your medical records, especially if you see more than one physician. To help you keep track of your DES health history, including DES-related health problems, refer to the section of CDC's DES Update titled [WHAT YOU CAN DO ABOUT DES: DES Health Information Record](#).

The American College of Obstetricians and Gynecologists is a resource for names of obstetricians, gynecologists, and maternal-fetal medicine specialists. Contact the Resource Center at The American College of Obstetricians and Gynecologists at 202-863-2518, P. O. Box 96920, Washington, D.C., 20090-6920, or www.acog.org.

I am a DES Son. Who should be aware of my DES exposure?

DES Sons should tell their primary care provider about their DES exposure. If you already have a urologist, be sure he or she is aware of your DES exposure. If you do not have a urologist, your primary health care provider can refer you to one, if necessary.

What is CDC doing to help educate health care providers?

CDC's DES Update is working with health care providers around the country to increase awareness about recent DES research and to give them current information and resources for working with patients. You can also help with this effort. When you visit your health care provider, bring along the summary card in the section of CDC's DES Update titled [WHAT YOU CAN DO ABOUT DES: CDC'S DES Update in Brief](#).

This card also includes a list of the resources available for health care providers. In addition, CDC's DES Update Web site (www.cdc.gov/DES) has information and resources specifically designed for health care providers, along with information and resources for people who were exposed to DES.

What else can I do to more effectively work with my health care provider?

The following are some actions you can take to work more effectively with your health care provider.

- **Keep track of your health history.** Keeping a record of your health care visits, writing down any test results, and keeping track of future screening appointments will help you work effectively with your health care provider. To assist you in organizing this information, refer to the section of CDC's DES Update titled [WHAT YOU CAN DO ABOUT DES: DES Health Information Record](#).
- **Prepare for your office visit with your health care provider.** Refer to the list of suggested questions provided in the next section. Prepare the questions you would like to ask and take the list with you to your appointment.
- **Do not wait to ask questions that are on your mind right now.** Call your health care provider's office with specific questions. If your health care provider is not available, ask to have your call returned or talk with a nurse or physician's assistant.

WORKING WITH YOUR HEALTH CARE PROVIDER

Questions To Ask Your Health Care Provider About DES

The following are questions everyone should ask their health care provider.

- Have you treated women/men who were exposed to DES?
- I was/may have been exposed to DES. What would you recommend I do to protect my health?
- Do you know about CDC's DES Update?
- Do new DES research findings mean I should be doing anything different to protect my health?

The following are questions to ask your health care provider if you were prescribed DES while pregnant.

- I was prescribed DES while pregnant. DES research shows that women like me have about a 30% increased risk of developing breast cancer over their lifetime. How will we plan my mammogram schedule and other physical exams to manage my increased risk?
- I know that monthly breast self-exams may help protect my health. Will you show me how to do a breast self-exam correctly? Does it matter what time of the month I perform breast self-exams?
- I was prescribed DES while pregnant with my daughter/son. What health risks should I be discussing with her/him?
- Do new DES research findings mean I should be doing anything different to protect my health?

The following are questions to ask your health care provider if you are a woman who was exposed to DES before birth (in the womb), known as a DES Daughter.

- My mother was prescribed DES while pregnant with me. Current DES research shows that DES Daughters continue to be at a higher risk for clear cell adenocarcinoma (CCA) of the vagina and cervix into their late 40s. I understand I should be monitored for CCA throughout my lifetime. What types of screenings and exams should I receive to manage my increased risk?
- Have you worked with any DES Daughters who were able to become pregnant?
- Do you work with high-risk pregnancies? If not, could you refer me to a health care provider who does?
- Research shows that DES Daughters have an increased risk for structural changes of the uterus and cervix (such as a T-shaped uterus, cockscomb on the cervix, and hooded cervix). Do I need to be examined for any of these differences? If so, when?
- DES research shows that DES Daughters have an increased risk of tubal pregnancies, miscarriages, and premature deliveries. What additional screenings or tests should we think about to protect my health during pregnancy?

- Preliminary results of DES research indicate that DES Daughters older than 40 are at higher risk for breast cancer. I know that monthly breast self-exams may help protect my health. Will you show me how to do a breast self-exam correctly? Does it matter what time of the month I perform breast self-exams?
- What health risks does my mother have because she was prescribed DES while she was pregnant with me?
- (If applicable) What health risks does my brother have because he was exposed to DES before birth (in the womb)?
- Do new DES research findings mean I should be doing anything different to protect my health?

The following are questions to ask your health care provider if you are a man who was exposed to DES before birth (in the womb), known as a DES Son.

- My mother was prescribed DES while pregnant with me. Researchers are exploring whether DES exposure is linked to testicular cancer. I know that testicular self-exams may help protect my health. Will you show me how to do a testicular self-exam correctly? How often should I do self-exams and what should I look for?
- What health risks does my mother have because she was prescribed DES while she was pregnant with me?
- (If applicable) What health risks does my sister have because she was exposed to DES before birth (in the womb)?
- Do new DES research findings mean I should be doing anything different to protect my health?