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SUPPLEMENT TO THE FERTILITY AND PREGNANCY GUIDE

We have included this guide in your packet because we think it provides excellent information on the problems in conceiving or maintaining a pregnancy which you may experience if you are DES exposed. Information on how to recognize the symptoms of an ectopic pregnancy, miscarriage or premature labour are crucially important for a woman to know if she knows she is at "high risk" for these problems. It is also important to have information on standard medical diagnosis and treatment clearly outlined, with some discussion of the pros and cons of each treatment.

The guide emphasizes that it is important to be informed to make decisions about one's own health care, and to consult with doctors experienced with DES-related problems. We would like to add that even an informed doctor may be willing to take risks you may not want to take with your body or your child's body, and that it is up to you and you alone to decide what treatment to accept or refuse.

A woman who has been exposed to DES and is having pregnancy problems as a result may be in the cruelly ironic position of being offered a drug whose effects on the unborn fetus are unknown and possibly harmful. Having had to cope with the effects on her own life of a drug her mother was given in pregnancy, she is now in a position of deciding whether to take a drug which may cause harm to her unborn child. The more information a woman has on known harmful effects of a drug, effectiveness, and other options, the easier and better her decision will be.

Throughout the booklet, alternative treatments not usually used by conventional medicine are not discussed. The main focus of doctors' training is to learn to diagnose and cure diseases, usually using drugs or surgery. They do not learn as much about how to improve a person's general health to prevent disease, or how to help the body to function as well as it possibly can. This approach is reflected in the conventional medical response to infertility and pregnancy problems.

In some cases alternative therapies may be directed towards improving general health so that a woman has the best possible chance of conceiving or maintaining her pregnancy within the constraints imposed by her DES exposure. In other cases, an alternative therapy may work to help a specific body process. For example, a woman's diet may be changed so that she has more of the fats and other building blocks from which her body produces hormones.

Some alternative therapies, like some standard medical practices, may be

harmful to you or your unborn child. For instance herbal teas are sometimes recommended as remedies for specific problems. Some are safe for use in pregnancy and do not have potentially harmful drug-like effects. Others should definitely be avoided during pregnancy. Certain vitamins, like vitamin C, should not be taken in high doses when you are pregnant although they are safe at other times. It is important to do background reading to be sure that alternative treatments you are trying are not likely to be harmful for the same reasons that it is important to check out standard medical treatments.

In the section of the fertility and pregnancy guide on infertility in DES daughters (p. 9-11) the drugs Clomid, Pergonal and Parlodel are discussed in relation to failure to ovulate, progesterone supplements are discussed as a treatment for endometriosis. We would like to add some information on the potential harmful effects of these drugs.

INFERTILITY IN DES DAUGHTERS

Failure to Ovulate

Clomid:

Clomid (clomiphene citrate) is a drug which causes the ovaries to be stimulated to ovulate by tricking the body to believe that estrogen levels are low, so that the pituitary gland releases the hormones which cause the ovary to build up towards ovulation. It has been called an "antiestrogen" because it binds to estrogen receptors in certain cells.[1] However, it can also act in other cells like a long-acting estrogen.[2]

Animal studies of Clomid have shown it to cause birth defects although in studies of women who've taken Clomid the number of birth defects has not been found to be higher than usual. One study of rats given Clomid is especially worrisome for DES daughters. In this study, changes in the surface cells of the vagina and cervix of both the mother rats and their female young occurred after pregnant rats were injected with Clomid on day 5 of their pregnancy. The cell changes were similar to the changes which occur in adenosis in DES daughters.[2]

In this study rats were given Clomid during pregnancy in a single injection. The doses given to the rats were half, per kilogram of body weight, what a woman of 50 kg (120 lbs) would receive in a normal 5-day dose of Clomid pills. Although women do not take Clomid during pregnancy, the drug is excreted from the body very slowly. After 5 days, only half is gone from the body, and traces of the drug are found in the feces of women given it as long as 6 weeks after the drug was taken. Therefore, although Clomid is not given during pregnancy, a woman retains some of the drug in her body during the first few weeks of pregnancy after having taken it to become pregnant. If a woman is given the drug 2 or 3 months in a row, she will receive a larger total dose, and the likelihood of drug effects on her own body may be greater. The effect of Clomid on DES daughters, or on adenosis in DES daughters, has not been studied.

If you have ovarian cysts, you should not take Clomid, as it can cause cysts to become larger. Occasionally, treatment with Clomid results in cysts in a woman who did not previously have them. Cataracts and liver disease are other rare effects of the drug.[5]

Just over a third (35%) of the women who take Clomid because they are not ovulating will start ovulating after treatment with Clomid.[1] It's important to know what the chances of success are if you're contemplating taking this drug.

The risk of multiple pregnancies after taking Clomid or an alternative such as Pergonal is discussed in The Fertility and Pregnancy Guide. Any woman who carries twins or triplets risks having a premature delivery. For a DES daughter, this risk is added on to the possibility that she may have a premature delivery because she is DES exposed.

Pergonal:

This drug is produced from the pituitary hormones in the urine of women who are past menopause. It is taken together with HCG (human chorionic gonadotrophic hormone which the embryo releases in early pregnancy) to cause a woman to ovulate. There is no reason to consider Pergonal a safer alternative to Clomid. In fact, as the guide mentions, most doctors will try Clomid first because it is cheaper, easier to administer, and safer as far as immediate health effects are concerned. Pergonal can cause the ovaries to become overstimulated, sometimes to the extreme that a woman must be hospitalized (0.4% of the women who take the drug).[1] Birth defects have not been reported as a result of this drug's use at any higher than average rates, although the rate of miscarriage is higher than normal. A woman is more likely to have twins, triplets, or more with Pergonal than with Clomid.[1]

Parlodel:

This drug is only helpful for women with higher than normal prolactin levels. Prolactin is a hormone which is produced by the pituitary and is involved in breast development and milk production. It will only lower prolactin levels during the time that it is taken daily. Therefore, if a woman is using it to become pregnant she must continue taking it from the day of conception until she knows she is pregnant. If a woman is taking Parlodel it is important for her to insist on having an early blood pregnancy test (10 days after conception) and not wait until a urine test is positive (4 weeks after conception) so she can stop taking the drug as soon as possible in her pregnancy. Parlodel's safety for use during pregnancy hasn't been established. One concern with taking the drug is that a woman's prolactin levels may be higher because she has a small undiscovered tumour in her pituitary gland. When a woman is pregnant, tumours of the pituitary gland grow much faster than they otherwise would. It's therefore extremely important to know that you don't have a pituitary tumour before taking Parlodel.

These three drug therapies for failure to ovulate have a basic similarity in that they are based on the assumption that a woman is not ovulating because of hormonal imbalances. However, there is no attempt to treat a woman so that her own hormones are able to regain the balance which will allow her to ovulate. Instead, she is temporarily treated with hormonal stimulants which will only cause her to ovulate while she is under drug therapy, and not in the following months. An alternative approach would be to try to find out why a woman is not ovulating, and try to directly help her body to regain the ability to ovulate.

Some women who are extremely thin do not ovulate or have menstrual periods. It is much safer for a woman to gain more body weight and make sure her diet is nutritionally sound so that she begins to ovulate than to take a drug such as Clomid or Parlodel. For a woman with the eating disorder anorexia, it may mean going through a process of emotional therapy to be able to allow herself to gain

some weight. In Vancouver, there is a support group called ANAD for women with anorexia.

Luteal Phase Defect

Progesterone supplements:

If a woman takes progesterone because her luteal phase is too short, she must take progesterone during the second half of her cycle, after ovulation, and therefore after she has conceived. There is concern about the effect of this hormone on the developing embryo.

A woman who is given progesterone supplements may be given natural progesterone or synthetic progestogens. Natural progesterone is made from sources such as yams or soybeans. Progestogens are chemicals which act like progesterone but have a different chemical structure. It is generally assumed that natural progesterone is safer than progestogens, but natural progesterone is not known to be safe. Birth defects have occurred in babies exposed to progestogens. It is not known whether the specific chemical action of progestogen causes birth defects in ways which are different from natural progesterone, or whether the birth defects happen because these chemicals act like progesterone and the foetus is growing in an environment where there is more progesterone than usual.

These birth defects have been linked to progestogens: masculinization of female foetuses, male feminization, abnormal shortening of the arms and legs in male babies, and in a large study of 50,282 pregnancies double the risk of heart and circulatory system defects.[3]

At this point, with what we know about the effect of synthetic progestogens and our lack of knowledge of the effects of natural progesterone on the foetus, one should probably avoid taking any progesterone while pregnant. If a woman does decide that she has no other options, she should take as low a dose as possible (no more than the amount a woman's body normally produces) of natural progesterone.

Various other approaches have been used to treat luteal phase defect. Naturopaths often presceibe glandular extracts from the ovaries of cows to women with short luteal phases. The hormones in these glandular extracts are broken down by the digestive system, so a woman is not directly taking hormones, but she is providing her body with the nutrients needed to provide more of her own hormones.

Some women have used light therapy to lengthen their luteal phases.[4] Light therapy is based on observation that women in tribal situations often tended to menstruate around the new moon, which would make ovulation happen around the time of the full moon. This involves sleeping in a totally darkened room, with blankets over the window and absolutely no light coming in, every day of your cycle except 3 days at mid-cycle. On these 3 days, a nightlight in the bedroom or a 60 watt bulb in an adjoining room with the door open is left on. This technique can stimulate a woman to ovulate during the time she is sleeping with a light on. By stimulating her body to ovulate earlier in her cycle than she otherwise would, she can also cause her luteal phase to lengthen.

Women often have too short a luteal phase when they first come off the pill, when their cycles first start after breastfeeding or childbirth, or after an abortion or miscarriage. In all of these cases, a woman's luteal phase will lengthen

with time as her hormones come back into balance. Most women coming off the pill will experience cycles with short luteal phases for only a few months. However, a few women will find that their cycles are abnormal for as long as 1 or 2 years. If you are in this position, it may be helpful to keep a record of your basal body temperature or your mucus changes to find out whether your luteal phase is gradually getting longer on its own over a period of a few cycles.

Both niacin and vitamin C are needed by the body to produce progesterone.[5] It's important to make sure you are getting enough of both vitamins in your diet if your progesterone levels are low.

Endometriosis

Danazol:

This drug is relatively new, and the long-term effects are simply not known. Danazol causes the lining of the uterus to become inactive, so that the symptoms of endometriosis stop. Usually a woman neither menstruates nor ovulates while she is on Danazol. Treatment usually lasts 3-6 months, and may last 9 months. The cost for the drug is $90-$100 per month. Some women find that their endometriosis comes back when they are no longer taking Danazol.

About half of the women taking Danazol get one or more of the most common side effects. These include acne, bloating and fluid retention, hot flushes, hair growth on the face and body, changes in breast size, weight gain, voice change, etc. Some women will notice definite masculinization while on Danazol, and sometimes these changes continue after a woman is no longer taking the drug.[1]

Alternatives to taking Danazol or other hormones for endometriosis do exist. B vitamin therapy has been used successfully by some women to reduce or eliminate their endometriosis.

SAFEGUARDING FERTILITY

(Additional information for the section in the guide on pages 15-16.)

DES daughters should try to avoid surgery on the cervix such as cryosurgery or cone biopsy, if at all possible. Stenosis, a condition in which the opening to the cervix becomes too narrow, is a complication of surgery on the cervix which is rare for most women (about 1% of women with cryosurgery), but is very common for DES daughters having surgery on the cervix (as many as 74% in one study of 41 women).[6] If the opening to the cervix is too narrow, a woman may not be able to conceive. In extreme cases she may also develop endometriosis because some of her menstrual fluid backs out of her fallopian tubes, since the opening of the cervix is too small to let much out.[7]

Some DES daughters have too few mucus-producing cells inside their cervix. Surgery such as cone biopsy or cryosurgery up the os (the opening to the cervix) will remove some of a woman's mucus producing cells. Therefore, if a woman is "on the edge" and just barely has enough mucus to be fertile, she may find herself infertile after surgery on her cervix.

If you have an abnormal pap smear, be sure to inform yourself of all the possible ways that you can reverse your pap smear without having surgery. Also, be

sure to find out what your pap smear results mean. (See "A Feminist Approach to Pap Tests".) If you decide that surgery is necessary, try to have the least destructive type of surgery possible. Cryosurgery can be done with a colposcope (a microscope used to examine the cervix) so that only the abnormal areas on the cervix are removed. If the os is not affected, care should be taken to make sure it is left intact. Be sure to discuss your concerns about stenosis with the doctor who will be doing the surgery on your cervix before the surgery is done.

CONCLUSION

If a woman is weighing potential unknown hazards of a drug against not having any chance of conceiving, she may be willing to take a drug she would otherwise refuse. If she is weighing nutritional supplements, a stress reduction and exercise program and light therapy to regulate her menstrual cycles against the use of a potentially dangerous drug, the choice she is facing will look quite different. Some women may decide only to use a certain drug as a last resort when other safer therapies have failed, others may decide the risks of a particular drug would always outweigh the benefits.

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Footnotes

1. Facts and Comparisons, Facts and Comparisons, Inc., 111 West Port Plaza, Suite 423, St. Louis, Mo.63141.

2. McCormack, S. and Clark, J.H., "Clomid Administration to Pregnant Rats Causes Abnormalities of the Reproductive Tract in Offspring and Mothers", Science 204: 629-631, 1979.

3. Ruggiero, R., "Progesterone Exposure in Pregnancy", DES Action Voice 5(3):5-6, Winter 1983/84.

4. Lacey, L., "Lunaception", Co Evolution Quarterly, pp.82-90, Winter 1974.

5. Kutsky, R.J., Handbook of Vitamins, Minerals and Hormones, 2nd edition, 1981, Van Nostrand Reinhold Co.

6. Schmidt, G. and Fowler, W.C., "Cervical Stenosis Following Minor Gynecologic Procedures on DES-Exposed Women", Obstetrics and Gynecology 56(3):333-335, 1980.

7. Haney, A.F. and Hammond, M.G., "Infertility in Women Exposed to Diethylstilbestrol in Utero", Journal of Reproductive Medicine 28(12):851-856, 1983.