

ORGANIZING A DES SUPPORT GROUP

Groups of DES mothers, daughters, and sons may want to organize separately because they will want to focus on different issues. A group of 4-10 women (or men, in the case of a DES son's group) could get together to talk about their experiences with DES. The group could be organized by contacting people who have been in touch with DES Action for information. Those organizing the group could also put up notices in community centres, libraries, and/or churches, or advertise in their community newspaper.

POINTS TO BE COVERED IN THE FIRST MEETING

1. When, where and for how long to meet? (Can be in someone's home or in a room at a community centre, library or church.)
2. What do women want from the group?
 - . Opportunity to share feelings and experience; support?
 - . Information?
 - sharing knowledge that women in the group have
 - doing research and discussing findings at the group (Libraries often have outdated books but may have recent articles. Women's centres will have more recent articles and information.)
 - inviting a speaker
 - getting a film or slide show.
 - . Discussion of topics of interest?
3. Deciding the agenda for the next meeting will help women to come prepared. The group may decide on a particular piece of reading to be done by everyone by the next meeting. Sometimes it is useful for one woman to take responsibility for organizing the next meeting. This may mean going to the library to look for reading material, preparing an informal presentation on a particular topic and/or acting as a "chair" at a meeting. This responsibility can be rotated at each meeting. Planning ahead for each meeting is usually a good idea.
4. It helps to agree on how informal or how structured women want the meetings to be. A group of friends may be most comfortable in an informal situation, but if women don't know each other (and sometimes even if they do), some agreed upon structure of format will help the meetings to move along smoothly. These are some suggestions for a format which many women have found useful:
 - . start with a round of names (until women know each other) and a brief statement of how each woman is feeling
 - . when discussing a topic, go around the room so that each woman gets a chance to talk (although it is okay for a woman to "pass" and not feel pressured to talk) before having a general conversation
 - . end with appreciations (letting someone know that you appreciate a piece of work she has done for the group, or something special she shared with the group, or whatever). This ends the meeting on a pleasing and positive note.

5. It is very important to make an agreement that any personal information shared in the group will be kept strictly confidential.

●SESSION 1

Some possible topics to get discussion started:

DES Mothers

How did we discover we took DES?
How did we tell our children about their DES exposure?
How did DES affect our relationship with our children?
What are our feelings about our DES exposure?
Have we found ways to cope with our children's exposure to DES?
Have our children been able to cope with their DES exposure?
Have our children experienced health problems because of their DES exposure?
How has our approach to health care and doctors changed because of DES?

DES Daughters or Sons

How did we learn about our DES exposure?
How did our DES exposure affect our relationships with our mothers?
What are our feelings about our DES exposure?
Have we experienced health problems because of DES?
Have we been able to discuss our DES exposure with friends/family/co-workers?
How has our DES exposure affected our sense of ourselves and our lives?

DES Daughters

What were our feelings during our first DES exam? Have we been able to discuss our feelings with health workers?

●SESSION 2

The health effects of DES:
- effects on fertility and pregnancy
- links to cancer in daughters, mothers, and sons.
The history of DES.

●SESSION 3

How to take care of ourselves:

DES Mothers

Avoidance of synthetic hormones such as estrogen replacement therapy for menopause.
Breast self-exam.

DES Daughters

The DES exam.
Avoidance of synthetic hormones, such as the birth control pill of estrogen replacement therapy.
Maintaining fertility.

DES Sons

Testicular self-exam.
Maintaining fertility.

● SESSION 4

Other health care issues:

- Doctor-Patient relationships
- Drug Testing
- Drugs in Pregnancy
- The Drug Industry.

DES Mothers

Menopause
Breast lumps

DES Daughters

Pap tests
Cervical self-exam
Contraception
Infertility
Pregnancy problems

● SESSION 5

Evaluation of what has happened so far: what has been learned? how useful has it been?

Where next? Does group want to keep meeting? For support? For further discussion and study of problems and concerns, health-related issues? How can group members share what they have learned with other women? By starting new groups?

GUIDELINES FOR GROUPS

The purpose of the group is to create a safe, non-threatening, non-judgmental environment where women can learn from each other and feel free to speak about feelings, whatever they are, without fear or embarrassment. Some guidelines are:

1. Every woman should have a chance to speak without being interrupted.
2. No advice-giving (unless asked for).
3. Give positive feedback freely. Honest support and validation for feelings, struggles, attempts to change and successes strengthen us for further changes. Be sure that positive comments are given only when meant sincerely; people can usually detect insincerity, and it weakens the ability of the group to give support if there is not a feeling of trust that people will be honest with each other. The group can be a place to celebrate our successes.

4. A common problem in leaderless groups is that one or two people can tend to dominate the discussion. Some ways to deal with this problem are:
- . when you have chosen a topic for discussion, do a "round". This means to go around the group and give each woman a chance to talk before there is a general discussion. Women can "pass" if they have nothing to say; no-one should feel pressured to talk. These rounds can be time-limited, with each woman having, for instance, 5 minutes (or whatever time the group decides) to talk about her feelings and opinions about the topic.
 - . in a general discussion, if you notice that one or two women are not saying much, check with them to see if there is something they would like to say. Many women hold back out of shyness or not wanting to interrupt when their contribution would be valuable to the group.
5. There should be respect for each woman's right to make her own choices about her life. The group is an opportunity to learn from each other and gain information to help make those choices.

RESOURCE FOR GROUPS

Helping Ourselves: A Handbook for Women Starting Groups is available by mail order for \$5 from the Women's Counselling Referral and Education Centre, 348 College Street, Toronto, Ontario, M5T 1S4.