

WHAT A SUPPORT GROUP DOES

Cry a Little, Laugh a Lot, and Heal

 by Roberta Wright

A Support Group for parents of FAS/FAE children has been meeting twice a month since June, 1991 in north Seattle. These parents have become such an important part of my life, it seems that I have to have known them for much longer than that.

What do we do at our meetings? We talk, and we listen, and we cry a little, and we laugh a lot, and we heal. Believe me, we heal...

Living with an FAS/FAE child is at times (especially when they become adolescents) like living under siege. We often stumble along, doing the best we can, being told by professionals that things will certainly get better if we just become better parents. We try — we try every approach we read about or are told about — and things get worse.

In our Support Group, we discover that none of us is alone. We all share similar experiences. We can laugh at experiences that other people would find sick.

We can share our grief when our child continues to take two steps backward for every small step forward. We can share our happiness when those forward steps are taken.

We know that through our group and groups like ours, we can begin to work toward a solution to the problem. We already know that part of the solution is the sharing of our experience, strength, and hope.

An important part of what we do in our group is to become advocates. We are actively involved in informing and educating the people who hold power within the system. They will make changes that will

provide appropriate care for our FAS/FAE children. We spend a lot of time speaking out at conferences and meetings. We testify at Senate and House Committee hearings. We speak wherever we are asked.

We support each other in this kind of involvement. Many of our group members have professional back-grounds and we have formed an efficient and up-to-date network that knows what is (and isn't) available in Washington. We share with other families how to access these services.

So you can see there are three themes in what our Support Group does. It offers a safe place to share our feelings, and connect with other parents who really understand. It provides direction and support for political action to bring about necessary changes. It enriches our store of practical information on how to deal with FAS/FAE issues. Just three little things. Exactly the things we need.

Roberta Wright is a birth mother of an 18 year old boy diagnosed as FAE and works as a Research Advocate helping high risk infants and mothers through the Birth to Three Project at the University of Washington. She also acts as secretary for the north Seattle Support Group, and writes a monthly news letter for group members.

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CHALLENGES AND JOYS

How to Start a FAS/FAE Support Group *by Diane Davis*

A parent support group offers parents and caretakers a caring, understanding, supportive place to talk openly about the challenges and joys of raising children with fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE).

In June, 1991, Marceil Vadheim and I started a FAS/FAE support group in North Seattle. We were elated so many parents joined us the first night; since that time, we have watched that core group grow and touch the lives of many others. Several parents have asked how to start a support group. I offer the following suggestions.

1. First Steps

Decide on a meeting place.

Possible meeting places could be someone's home or office, a school, a church meeting room, a community center, the local library, or a social service agency meeting room. Often, there is no charge for the use of these facilities, especially when people know the purpose of your meeting.

Get the Word Out

There are a variety of ways to advertise your meetings:

- Announce it in a PTA, church, community center or social service agency newsletter.
- Distribute fliers in places where parents will see them.
- Place an ad in a local newspaper.
- Utilize radio and television stations that air public service announcements.
- Contact leaders of other parent support groups and ask them to announce it to their members.
- Organize a telephone "grapevine" to inform people of the upcoming meeting.

Once the group meets for the first time, the word will spread. It only takes a few people coming together to start a group that will grow and reach many others.

2. Establish Ground Rules

It is important to take time at the first meeting to establish a group format or "ground rules". This insures safety and consistency, and is primary in building trust and rapport among group members. Some things you might want to decide upon are:

- Does the group want one appointed leader or will the leadership be rotated?
- Will the group be open to whoever wants to come, whenever they want to, or will it have a maximum number of members and be "closed"?
- How often will the group want to meet?

- Will there be any fees? (Especially if there is a room rental cost or any mailing expenses.)
- Does the group want to become socially and politically active? Who will represent the group?
- Will you invite guests and/or guest speakers to the meetings.
- Will you produce a newsletter or minutes of the meetings so that others who can't attend can still be part of the network?
- If the group grows, you may want to break into sub-groups and meeting at different locations to accommodate members who come from different areas in the community. The sub-groups may want to meet periodically as a larger group.

3. Group Interaction

It is important to establish how members will interact with each other during the meetings. Some basic rules that help make the group successful are:

Confidentiality

What is shared in the group remains in the group. Members should not tell others outside the group what someone else has said or repeat the names of members without their permission.

No interruptions

If someone is talking, it is their turn to speak and others should wait until that person is finished. You may also want to set a limit as to how long a person can talk.

Just listen

Sometimes the person speaking just needs to talk and be listened to. No "crosstalk" or giving advice to someone during group time unless it is asked for.

Honor feelings

Let others express their feelings. Don't put down or discount what someone says. Don't "help" unless asked.

Respect meeting times

Start and end group meetings on time.

As the group begins to meet regularly and grows, adjustments may be necessary simply because the group members know more about the group process and the needs of one another. I wish all of you who do begin a FAS/FAE support group the best of luck! Some very positive, exciting results can come from the meetings for you and the people you will get to know.

Diane Davis is a trainer, consultant and school counselor. She focuses on children and family issues around FAS and can be reached at: P.O. Box 22871, Seattle, WA, 98122-0871.

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