

LEADING SELF-HELP GROUPS:
REPORT ON WORKSHOP FOR LEADERS OF
CHILDHOOD CANCER SUPPORT GROUPS

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May 13-14, 1987

San Francisco, California

By

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For the Candlelighters Childhood Cancer Foundation

SPONSORS:

Candlelighters Childhood Cancer Foundation
American Cancer Society, California Division
Parents Action For Children's Cancer Treatment

EXECUTIVE SUMMARY
Report on Group Development Workshop
San Francisco, California
May 13-14, 1987.

PURPOSE OF THE WORKSHOP:

In June, 1986, the National Board of the Candlelighters Childhood Cancer Foundation made a decision to sponsor and initiate planning for a series of Leadership and Group Development Workshops for local leaders of self-help groups. The thrust of this program was to improve the skills of local group leadership, hopefully to increase parents' ability to lead local groups, collaborate with local medical and agency personnel, and meet some of the needs of parents and families.

The May, 1987 Workshop in California grew out of this agenda, with local initiative from Parents Acting for Childhood Cancer Together (a San Francisco-based self-help group) and the California Division of the American Cancer Society. It had the added concerns of establishing dialogue and interaction among leaders of California groups and between these groups and the ACS.

General issues addressed within the Workshop included:

- What are common needs of families of children with cancer?
- What kind(s) of self-help groups and group activities do these needs suggest?
- How does one lead a group?
- What organizational structures seem to work?
- How can one facilitate parent group-professional collaboration?
- How may groups reach out to resources available in their community?
- How can we help each other?

DESCRIPTION OF THE WORKSHOP:

21 parent leaders (from 10 existing groups and 5 prospective groups), two California ACS staff and 3 facilitators attended the two-day workshop. During the workshop, the primary emphasis was upon participatory learning through large and small-group discussions and leadership practice exercises. Group members were encouraged to share their own experiences as leaders and parents, and the lessons they had learned from this experience in running a self-help group. Within certain portions of the workshop, the facilitators provided lectures and demonstrations for participants.

One of the principal design features of the workshop was the creation of a support group atmosphere among these self-help group leaders, thus modelling principles which could be applied to their own groups as well as providing an environment maximally conducive to learning, growth and sharing at multiple levels.

Specific sections covered: information about major needs of families of children with cancer; information about the activities of groups; programming on the basis of the needs, interests and potential contributions of parents; facilitating group meetings and discussions; solving problems related to medical care and relations with medical staff; maintaining groups over time, especially with leadership changes; talking with families; involving others (networking, group coalitions, agencies, advocacy).

EVALUATION OF THE WORKSHOP:

At the end of the workshop, participants were asked to complete a reaction form, providing evaluative feedback. This questionnaire included both open-ended items about the strengths and weaknesses of the workshop and objective rating scales.

Six specific features of the workshop were evaluated by participants on a standard 1 to 7 rating scale, with 7 as the maximum positive rating. All average ratings fell above 6: organization of the workshop was rated 6.3; clarity of objectives, 6.2; work of the facilitators, 6.6; ideas and activities presented, 6.0; the scope or coverage, 6.3; and the benefit from attendance, 6.7. An overall rating (6.5) was also obtained.

Written subjective evaluations by participants indicated that the opportunity to network and establish contacts with each other, and the good ideas passed from one leader to another, were the most positive features of their experience at this workshop.

COST:

The workshop was sponsored jointly by the Candlelighters Childhood Cancer Foundation (CCCF), the California Division of the American Cancer Society (ACS), and Parents Acting for Childhood Cancer Together (PACCT: a San Francisco-based family support group). Funds totalling \$7500.00 were received from these three organizations: from CCCF, \$5000; from ACS, \$1500; from PACCT, \$1000. The CCCF, University of Michigan and Federation for Children with Special Needs provided experts in childhood cancer self-help organizations, parent advocacy, and training program evaluation, to facilitate the event.

RECOMMENDATIONS:

Based on the successful completion of this workshop, discussions held during the event and comments of participants on the post-workshop evaluation forms, the following actions are recommended.

- Additional workshops should be held for other regions.

- Increased liaison between CCCF, ACS and local childhood cancer groups should occur. ACS should publicize information about such joint efforts in its network, and CCCF should publicize within newsletters and throughout its networks.

- Changes in the pre-workshop registration surveys are needed, in order to elicit more information on the specific activities pursued by each participating group (e.g., telephone trees, hotlines, transportation, relationships with other organizations, school systems and the hospital, advocacy efforts) and on the problematic issues faced by each group. If such information was fed back to all participants before the workshop began, they could arrive better prepared to discuss common issues and differences.

- Additional emphasis should be placed on using a combination of practice exercises with targeted feedback on leader performance and specific information related to leadership skills and techniques which can be used to facilitate running group meetings.

- Additional emphasis within these events should be placed on specific legislative agendas for families of children with cancer - for example, catastrophic health insurance coverage, coverage for chronic illness, legislation against discrimination in education and employment, and admission to the military. Such issues can also be better covered through more discussions or presentations.

- Groups expressed a desire to continue the networking begun in this workshop among Candlelighters groups and between ACS and groups. Continuance and extension of these relationships was planned through visits, calls, newsletters, etc.

- Participants expressed the desire to learn more about specific programs, with the intent of incorporating these into their groups' activities. Certain of these programs are from local groups (eg, family camps), while others are CCCF (hospital visitation) or ACS programs (school re-entry) or programs from other sources. A listing of these programs and information sources is contained in the Appendix.

- For those who participated in this training event, an annual reunion, or some other way of reporting on progress toward building and improving their groups would provide a continuing relationship and reduce the isolation group leaders report that they experience.

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Report on Group Development Workshop
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May 13-14, 1987

1) HISTORY AND SPONSORSHIP OF THE WORKSHOP

In June 1986, the Candlelighters Childhood Cancer Foundation approved a project to provide assistance in leadership and group development for self-help and support groups for parents of children with cancer in several regions around the United States. The proposed workshops were intended as a means of enhancing the leadership capability of those in current or future leadership positions within such groups. They were also viewed as a way for active parents to begin to share personal experiences in group leadership - to share information on common activities, benefits and problems of groups, exchange new ideas, engage in common problem-solving, and identify resources. Finally, the workshop provided a means of informally disseminating the results of recent research on childhood cancer groups.

SPONSORS: Over 250 local self-help and mutual support groups for families of children with cancer are part of the Candlelighters Childhood Cancer Foundation's network, and this project is one of several attempts by which Candlelighters supports, advises and assists such groups and their members. The event was jointly sponsored by Candlelighters, the California Division of the American Cancer Society, and Parents Acting for Childhood Cancer Together, a support group based in San Francisco. In addition, trained facilitators from the Candlelighters Childhood Cancer Foundation, the University of Michigan and the Federation for Children with Special Needs designed, implemented, and evaluated this training.

REPORT: This report is lengthy, and the detail of documentation is more extensive than usual in such reports. As this was a first attempt to pilot the workshop approach, we record and report the unique features of the training and participants' reactions to it, to assist in planning for future workshops.

2) PARTICIPANTS

21 parent leaders attended the training event, from 15 groups or prospective groups (a list of participants and addresses is contained in the Appendix, page 1). All but two participants were female. Most parents were from California-based groups, but two leaders from an Oregon group and one parent attempting to develop a group in Nevada also attended.

Two parent/professionals facilitated the workshop. Mark Chesler, Ph.D. is President of the Candlelighters Childhood

Cancer Foundation and Professor of Sociology at the University of Michigan. Betsy Anderson is a parent advocacy trainer and founder of the Federation for Children with Special Needs. The workshop event was documented by Toby Ayers, Ph.D., a research fellow in the Intervention Research Project, in the School of Social Work, the University of Michigan.

Two representatives from the American Cancer Society also participated in the workshop: Helen Crothers, MSW, ACS Associate Director, Service and Rehabilitation, and member of the ACS Children & Cancer Subcommittee; and Sara Perkins, MPH, ACS Project Coordinator, Service and Rehabilitation, and staff on the ACS School Re-Entry project. Their roles were several: to become informed about participating groups' activities and needs, inform participants about services that ACS can provide, assist in the facilitation of the workshop, and link to future program development and collaboration with local groups.

RESULTS OF PRE-WORKSHOP SURVEYS OF PARTICIPANTS

a) SURVEYS ADMINISTERED: Two surveys were administered prior to the workshop. 1) Preliminary information on the participating groups was initially collected through a mail survey as a part of the registration process. A copy of this preliminary survey is found in the Appendix (page 3). 2) During the introductory period of the workshop, participants were asked to provide information on the activities of their groups. A checklist of possible activities and potential benefits from group membership was completed by each participant (a copy of this checklist follows; summarized results are found in the Appendix, page 4).

These pre-workshop surveys had several purposes. First, they provided information to help guide the workshop facilitators in talking about specific group activities. In addition, participants' answers were summarized and fed back to them later in the workshop. Finally, the survey provides information which can assist in evaluating longer-term effects of the training (by re-administering the checklist at a later time), by allowing comparisons - for example, do activities become more diversified in the months following the training? Are more of a range of benefits to members reported?

b) SUMMARY RESULTS OF PRE-WORKSHOP SURVEYS:

MEMBERSHIP: Five of the 21 participants indicated that they did not currently lead an active group, but were attempting to begin one. Of the active groups, eight reported meetings were held monthly. The number of regular attendees was between 6-10 in six groups, 10-20 in three groups, and 25-30 in two groups. Mailing lists also varied, from 20 to 2000 newsletters distributed.

ACTIVITIES: Participants were asked to review a list of six common activities of groups, and rate each activity engaged in by

their group, by importance.

PRE-WORKSHOP INFORMATION ON GROUPS

1. We'd like to get some idea of the specific things people do (did) at group meetings. For each potential activity, please place a check in the appropriate column that best describes how often people in your group do (did) these things. (*If you do not have an active group, please answer according to what you think people might do at these meetings.*)

	A lot	Some-times	A Little	Never
a. Talk about the stresses on the family	_____	_____	_____	_____
b. Talk about very personal feelings	_____	_____	_____	_____
c. Discuss recent advances in treatment	_____	_____	_____	_____
d. Learn how to deal with emotional issues	_____	_____	_____	_____
e. Give feedback to Doctors or Nurses	_____	_____	_____	_____
f. Plan to change things in the hospital (clinic)	_____	_____	_____	_____
g. Raise money for the hospital	_____	_____	_____	_____
h. Plan to get together socially	_____	_____	_____	_____
i. Visit other parents at home	_____	_____	_____	_____
j. Contribute funds for needy families	_____	_____	_____	_____
k. Plan group activities	_____	_____	_____	_____
l. Discuss how to recruit new members	_____	_____	_____	_____
m. Pressing for change in social policies that affect us	_____	_____	_____	_____

2. How much do your members personally benefit from the group in the following areas? Please check the appropriate column. (*If you do not have an active group, please answer according to how you think people might benefit from these groups.*)

	Much benefit	Some benefit	Little benefit	No benefit
a. Getting information about cancer	_____	_____	_____	_____
b. Understanding the treatments	_____	_____	_____	_____
c. Learning who's who on the staff	_____	_____	_____	_____
d. Learning my "rights" as a parent	_____	_____	_____	_____
e. Coping with my child's problems	_____	_____	_____	_____
f. Dealing with my child's school	_____	_____	_____	_____
g. Coping with problems in my family	_____	_____	_____	_____
h. Coping with the death of my child	_____	_____	_____	_____
i. Developing self-confidence	_____	_____	_____	_____
j. Being helpful to other parents	_____	_____	_____	_____
k. Getting help from other parents	_____	_____	_____	_____
l. Meeting others with similar problems	_____	_____	_____	_____
m. Coping with public attitudes toward my child's condition/illness	_____	_____	_____	_____
n. Feeling part of a larger group	_____	_____	_____	_____
o. Getting help from the medical staff	_____	_____	_____	_____
p. Being an active part of the medical care system	_____	_____	_____	_____
q. Changing things in the hospital	_____	_____	_____	_____
r. Being supported, approved of	_____	_____	_____	_____
s. Learning to cope differently	_____	_____	_____	_____
t. Feeling freer to express my feelings	_____	_____	_____	_____
u. Learning how to be a leader	_____	_____	_____	_____
v. Feeling spritual uplifting	_____	_____	_____	_____
w. Talking about my child	_____	_____	_____	_____
x. Expressing and learning compassion	_____	_____	_____	_____

Activities selected as more important:

EMOTIONAL SUPPORT was most frequently selected as the most important group activity.
INFORMATION was ranked second.
VISITATION was ranked third.

Activities selected as least important:

FUNDRAISING was most frequently selected as the least important group activity.
CHANGES IN MEDICAL OR PSYCHOSOCIAL CARE was also ranked very low.

PROBLEMS: Participants were asked to describe the biggest problem faced by their group. The most common answers were concerned with participation and involvement of parents in the group: increasing interest, and getting people who come to meetings to participate in fundraising, group operations or on the Board; getting new parents; overcoming energy loss due to travel distance; a lack of funds.

COOPERATION WITH MEDICAL SYSTEM: 11 groups indicated they received assistance from local medical staff, and 6 groups reported that hospital staff were actively involved in the group. For the most part, this staff activity consisted of providing information, seminars, and serving as speakers at meetings, helping plan and coordinating activities, serving on the Board, providing referrals, and participating in group activities. Several groups reported problems in gaining staff help in publicizing the group's existence and in gathering referrals.

COOPERATION WITH ACS: 7 groups reported receiving assistance from the American Cancer Society, in the form of funds, facilities, videos, brochures, library, duplicating, printing and paper, referrals, promotions, advice, conferences or workshops. 5 of the groups reported no assistance from ACS: 1 group did not know what assistance might be available; 1 stated help was not offered by ACS; 1 received help from alternate organizations.

3) DESCRIPTION OF THE TRAINING

DESIGN: This event was conceptualized as a beginning point, an attempt to enhance the leadership of self-help and support groups as an organized means of helping large numbers of families with diverse needs (in contrast to training such persons to provide peer support on a one-to-one basis). A second major intent was to establish a continuing dialogue among groups and between the ACS and groups in the California area. Thus, the event was designed to facilitate the sharing of new ideas and existing programs and networking among participants.

General concerns addressed within the workshop included:

- What are common needs of self-help groups and members?
- What kind(s) of groups and group activities do these needs suggest?
- How does one lead a group?
- What organizational structures seem to work?
- How can one facilitate parent-professional collaboration?
- How may groups reach out to resources available in their community?
- How can we help each other?

The style of presentation was primarily participatory rather than didactic. Group members shared their own experiences as leaders and parents, the difficulties they had faced and the lessons they had learned from the experience of leading a self-help group. Activities and small group discussion increased participation. Practice in leading groups and modeling of leadership skills was provided by asking volunteers to lead various activities. Within various sections of the workshop, lectures by the facilitators, demonstrations, and practice exercises were also utilized.

TRAINING SITE: The workshop was held at the Mercy Center outside of San Francisco. This convention center included conference rooms and a dining facility; in addition, a room was provided for each participant for Wednesday night.

SECTION 1: INTRODUCTIONS: PARTICIPANTS AND WORKSHOP PURPOSES
(Wednesday, 10:00 - 12:00 am)

Mark Chesler outlined the planned agenda for the two-day group development workshop. Dr. Chesler provided a brief history of the Candlelighters Childhood Cancer Foundation, which provides linkages between more than 250 self-help and support groups in the United States and ten other countries. About fifteen years ago, CCCF was founded as a local, Washington D.C.-based self-help group for parents of children with cancer. Now an international organization, Candlelighters works to assist local groups to provide programs for families, to identify solutions to the problems of living with and treating childhood cancer, and to promote communication between parents and the medical, psychological, social and educational services professionals who treat their children. The CCCF provides direct services such as a parent newsletter, a youth newsletter, educational materials, an information hotline for families, and advocacy functions for families facing insurance and employment discrimination problems. (A list of materials available from CCCF is included within the Appendix, page 5). About a year ago, a decision was made by the CCCF to pilot a regional skills enhancement workshop for self-help group leaders, in order to help groups further develop the services they offer at a local level.

Helen Crothers, Associate Director of Service and Rehabilitation for the California Division of the American Cancer Society presented an overview of the increasing support for childhood cancer issues within the California ACS, and the recent collaboration between ACS and Felicia Lowe Schwartz of the PACCT self-help group based in San Francisco. Betsy Anderson, of the Federation for Children With Special Needs, provided a history of parent involvement with mutual support and self-help organizations and discussed this organization's programs in developing working relationships and coalitions among parent groups with similar aims, and in training parent advocates.

PARTICIPANTS: After the explanation of the purposes of the workshop and an introduction to the facilitators and organizers, the participants introduced themselves and their organizations. Each expressed the general needs of their group, and explained why they were attending this workshop.

The needs expressed by participants during the introduction were very similar to their responses on the two pre-workshop surveys, primarily related to group-building, membership, participation and attendance, getting support from and difficulties with medical staff, travel distance, and a lack of resources. The diversity of needs of members was also noted (including a wide range of income levels). To meet these needs, some groups had a range of different activities, but others felt they didn't know how to provide a diversity of activities to meet diverse needs. Other participants felt overwhelmed by the amount of work to be done: some had huge geographical areas to cover; others noted problems with turnover in group leadership and membership largely related to the child's illness ("...our energy comes and goes"); some felt they were overextended.

Person-to-person sharing allowed many of these leaders to express a sense of isolation and loneliness, and their own need to talk to others dealing with the same difficult leadership issues as they. It was clear from their statements and enthusiasm that these participants were very glad to talk to other leaders: some noted that networking and coordination between groups was a major need. It is indicative of this isolation and need to share with others like themselves that the introductory section of this workshop lasted far longer than anticipated, encompassing the entire two hours and extending into the lunch period.

DISCUSSION TASK: Given this introduction to groups' needs and activities, participants were asked to discuss two general questions during the lunch period:

- What are the needs of parents; what issues or problems are they facing?
- What needs do the groups address?

This discussion was used as the basis for the following section of the workshop.

SECTION 2: PROGRAMMING ON THE BASES OF PARENTS' NEEDS, INTERESTS AND CONTRIBUTIONS

(Wednesday, 1:00 - 4:00 pm)

After lunch, participants split into two subgroups, one facilitated by Dr. Chesler, one facilitated by Ms. Anderson. Each used the above general questions as a basis for discussions. The subgroups discussed:

- a) who are, and should be, members of the group
- b) typical needs and problem issues for families
- c) needs of the group as a whole
- d) program areas and/or suggestions for activities which can assist in meeting typical family needs.

Finally, participants met together to present a summary of their subgroup discussions, and to compare conclusions. These discussions are outlined below.

a) POTENTIAL MEMBERS AND/OR HELPERS OF THE GROUP were viewed broadly. Participants tended to view an open, diverse membership as an important goal for their groups: family, friends, professionals and members of similar groups.

Primary members, of course, are parents - of newly diagnosed children, of children in treatment, of long-term survivors, of terminally ill children. For bereaved families, continuing support is also important, as the group is a means of maintaining bonds and assisting the grief process. However, the issue of mixing parents of living and deceased children in meetings generated much discussion. Many participants agreed this interaction was needed, but had to be handled carefully. Some suggested that it is hard for bereaved parents to share at meetings; it's painful for them to talk about their experience and to hear about other children's treatment. Moreover, parents of living children with cancer may be awkward or fearful in front of them. However, bereaved parents also can demonstrate to others that one can survive such an experience. Some groups have meetings attended by all categories of parents, while others run separate group meetings for parents of living and parents of deceased children. Some do both.

Involvement of the family as a unit (rather than the more common situation of only one parent, typically the mother, being involved with the group) was discussed as the ideal situation, with involvement by fathers as well as mothers, and by grandparents and siblings. In addition, the special problems of single-parent families were noted. Activities such as camps, which facilitate the involvement of entire families as well as close friends, were suggested.

Participants wanted to include families from various socioeconomic levels, various racial and ethnic groups and/or who speak various languages. As one participant noted, however, "it's hard to come if you're the only one". This issue of providing help to a diverse range of parents (not only white, middle class mothers) was discussed at length. Groups felt they needed to develop the capacity to connect with many types of

people, and to operate a group in a way that is comfortable and helpful for them. In one group, a spanish-speaking subgroup has begun; in another, the hospital provided translators. Depending on the kind of resources the group has, different ways of contacting parents of diverse backgrounds can be pursued: abbreviated information programs can be offered in community centers or other neighborhood sites; meetings can be held outside the hospital - at libraries, churches and other public places; public transportation can be arranged to make activities more accessible; groups can do more extensive outreach to agencies and religious organizations which deal with ethnic and minority issues and populations.

Participants also indicated an interest in forming coalitions or collaborative arrangements with others interested in similar issues. Thus, health professionals were seen as potential members of the group and/or contributors to it. Participants noted, however, important differences between the style and goals of helping provided by parents in the group and by professionals; they approach problems in different ways and with somewhat different goals. Parents also felt that while their experience made them experts, professionals with formal help and training can contribute educational information, knowledge about resources, and different perspectives on the problems parents face. Other support groups and/or agencies dealing with cancer or other chronic illnesses or disabilities also were viewed as potential sources of resources and support. Participants noted the potential benefits of setting up coalitions between groups, adding to each others' strengths.

b) PERCEIVED NEEDS OF FAMILIES: Each subgroup enumerated what they felt were the most common or paramount needs of parents and families. The conclusions of the two subgroups have been combined and are presented below.

Understanding and Support:

- * deal with the impact of illness on the family: work to keep the family together, explore sibling issues
- * social acceptance for the child: deal with hair loss, re-entering school and the community
- * opportunities for serious talking about emotions, in a safe, supportive atmosphere
- * deal with bereavement issues

Information about:

- * social services (medical insurance, financial assistance)
- * medical treatment
- * formal and informal hospital rules
- * parents' rights in hospital
- * helpful ways of coping
- * practical ideas on child rearing, childcare, parenting
- * ways to handle common problems (employment, dealing with funerals, school, child discipline)

Education for others:

- * hospital/clinic staff - about parent needs and problems
- * school personnel

Practical help:

- * financial assistance
- * arrange for cooking, cleaning, childcare
- * respite care
- * pursue families' complaints about staff or hospital

Social Activities:

- * social activities (potlucks, picnics)
- * recreational activities for the child and entire family (camps, vacations, outings)
- * home visits

A chart detailing the relationship between parents' needs (or stresses) and common self-help group activities was distributed. This chart, which illustrates a wide range of activities which may be undertaken by different groups, is attached (refer to the Appendix, page 6).

c) PERCEIVED NEEDS OF GROUPS: Primary needs of groups included insuring that the group not only survives but functions well. Suggested strategies included delegating responsibilities, being bold about asking others for help, sharing tasks and scouting out talent and unique abilities among members and in the community. Hospitals, community agencies, ACS and others can also be used to help meet parents' needs.

Moreover, group success depends on being able to meet parent needs, and to develop programs that help people. Different parents have different needs, and it was seen as particularly important to help parents of both surviving and deceased children. Referrals were another area of special need; it was pointed out that because of the many problems with typical systems of referral, expectations of the group leaders must be realistic. There is the potential for conflict with hospitals (around issues such as patient/family confidentiality) that may make an effective system of referral of families to the group quite difficult.

Thus, participants emphasized the need to create good working relationships between groups and the medical care system. While the pre-workshop survey responses indicated that "making changes in the system of medical care" was an infrequent activity, discussions during the workshop repeatedly emphasized needed changes in hospitals and systems of care: needs for additional services, concerns about parents' rights within the hospital, the need for greater sensitivity of caregivers to parents and patients, the need for information.

Research indicates that different groups organize themselves to meet these needs in very different ways (Nathanson, 1986; Yoak & Chesler, 1985). Some groups are formally organized, with

elected officials, committees, regular business meetings, and official charters and by-laws (perhaps including a tax-exempt status). Others are quite informally organized, operating as small discussion groups, often without officers or by-laws. Many groups fall in-between these extremes. Depending upon who the members are, and what their goals are for one another and for the group, each of these structures may make excellent sense. Similarly, some parent groups operate with only minimal help from medical professionals, while others involve professionals in many aspects of the group's operation. Indeed, some groups are led almost completely by professionals, like staff-led discussion groups rather than parent self-help groups. Most groups operate with some regular connection and collaboration with professional staff members, while maintaining control and leadership of the group in parental hands. In this matter, as above, different working arrangements will best suit different parents and groups with different goals, access to resources and available time, energy and talent. CCCF provides many suggestions regarding how local groups can be organized in Nathanson's excellent handbook, "Organizing and Maintaining Support Groups for Parents of Children with Chronic Illnesses and Handicapping Conditions".

d) PROGRAMMATIC SUGGESTIONS: Participants continued by discussing and developing lists of group programs and activities which may help meet parents' needs. The focus was upon assuring a range of small-scale but diverse programs which match the range of needs of potential members. Since parents do not always have all the same needs, different groups will establish different priorities among these programs. Following is a synthesis of suggestions from the two subgroups.

Programmatic Suggestions:

- * identify and develop special individual and group talents
- * provide activities
 - safe social activities
 - full-family activities such as camping
 - casual staff/parent interactions (potlucks)
- * provide emotional support
 - hospital visitation programs
 - telephone networks
 - group meetings: for talking
 for information
 for inspiration
- * provide information through speakers:
 - be sensitive to parents' requests
 - clue speakers into parents' needs
- * provide emergency funds:
 - as an incentive for group membership
 - as a way to identify needy families
 - buy needed items for families
 - buy toys or other things for clinics

- * develop information resources:
 - packet of materials for newly diagnosed
 - cooperate with hospital
- * develop "help lists"
 - coping strategies (eg, help from friends, diaries, humor)
 - practical parenting (nutrition, safe activities)
 - how friends can help (babysit; provide or arrange entertainment for children or the group; help with newsletter; carry out an activity from start to finish - a day at the beach or a party)
- * target specific groups for special programs
 - fathers
 - ethnic minority groups
 - medical, school and agency staff
- * reinforce parents and staff through public recognition

During these discussions, several group leaders expressed a fear of retaliation from medical staff for the activities they wished to pursue, for attempts to change hospital procedures or to raise questions and complaints about problems in treatment. One participant noted that her group confronted this problem directly, by indicating to medical staff exactly what kinds of behavior were desired or undesirable. This was done by giving monthly awards: a Compassionate Care award to a specific staff member, and a Bogie award to "the unnamed person who bugs us the most"; while the latter staff member is not named, their undesirable behavior is clearly described.

SECTION 3: LEADING GROUPS AND GROUP MEETINGS (Wednesday, 7:00 - 9:00 pm)

VIEWING A FILM (7:00 - 8:15 pm): During the evening session, an ACS-produced film was shown and discussed: "When A Child Has Cancer: Helping Families Cope". The purpose was to demonstrate and model a parent leading a discussion of the film's content after viewing. Therefore, the group again split into two subgroups; in each, a volunteer parent led a brief discussion, and was provided with feedback on their leadership behavior.

In addition, this exercise demonstrated the potential usefulness of an educational film - that is, how interesting and useful group discussions can "spin off" the film. For example, topics which arose during discussion of the film included the involvement of husbands in treatment and in the group, the potential relationship between a lack of such involvement and long term negative effects in families, and reasons why some fathers to become more involved in the group and their child's treatment. It was concluded that the group discussion setting may be especially threatening to men. One alternative offered was involvement in activities within much smaller family-based groups, where men can more easily establish friendships and feel more in control.

LEADERSHIP SKILLS FACILITATION ACTIVITY (8:20 - 9:00 pm):

This exercise dealt with dilemmas which may be faced by support group leaders as their group attempts to assist parents. To provide additional practice in leading focused group discussions, small groups of participants were given brief descriptions of seven commonly encountered problem situations, to be used as the basis for a discussion. (These are contained in the Appendix, page 7, along with a handout provided to participants on small-group leader behavior).

The purposes of this exercise were to provide an opportunity for selected participants to directly practice important group facilitation skills, to receive feedback on leadership performance, and to model these skills for the remainder of the group. A volunteer leader-facilitator was selected by each small group, and each group selected two scenarios as stimuli for discussion. In the course of these discussions (about a 10-15 minutes per scenario), members were to attempt to come to an understanding of the issues, the differing perspectives of different members, and constructive ideas or strategies which might be of help.

For example, one group discussed situation #4: "You have had a nice small group of families for a few years but are aware that few, if any, families other than white middle class are members. Should this be an issue and if so, how might it be addressed?" The group selected this scenario because they felt it described their membership: white, middle class and well-educated. They discussed the problem of families who need help but won't ask for it, and of group members who don't want to make the effort to reach out to people who are "different". They suggested ways to contact families in the hospital. Cultural differences, as well as potential discrimination, were felt to be blocks to involvement, making some families feel uncomfortable or unwanted within the group. For many families the real block to involvement were more basic issues of survival; time, money and opportunity to become involved in the group may not be readily available.

At the conclusion of the discussion period, participants again re-joined the full group and provided feedback to their volunteer leaders, focusing particularly on positive aspects of their facilitation of discussion.

VIDEOTAPE: A videotape was shown on summer camps for ill children that are offered through the ACS for children was shown. Participants were informed about the availability of a camp resource directory, which included information on nine California-area camps.

SECTION 4: LEADING DISCUSSIONS AND SOLVING PROBLEMS RELATED TO
MEDICAL STAFFS
(Thursday, 9:00 - 10:45 am)

GROUP PROBLEM-SOLVING EXERCISE: The purposes of this task were to work as a group on issues which are typically problematic for parents, and to provide additional development and modeling of leadership skills. Participants were given a list of scenarios (refer to the Appendix, page 11) which focused on staff-parent interactions related to: institutions (4 scenarios); the group (3 scenarios); individuals (3 scenarios). Examples are given below.

Institution: "Your support group feels that a parent who can represent your desires and concern ought to be a regular part of the staff. Then that person can liaison both ways - with the staff and with parents. You have heard of similar "Parent Advocacy" or "Parent Representative" programs at other hospitals and want to adopt it at your institution."

Group: "Your support group meets outside the hospital, and has been having difficulty discovering who are newly diagnosed patients, and what their family names and addresses are."

Individual: "You are sitting across the hospital room from your 5 year old child. It is necessary for a new IV line to be begun. The young intern is obviously having difficulty finding the vein; he has missed the "stick" three times and is beginning to perspire nervously."

Three groups were formed, and a volunteer leader and recorder were selected by each subgroup. Each subgroup was instructed to take 20-25 minutes to discuss one scenario, then to take a final ten minutes to give feedback to the volunteer leader on their performance. A second scenario (in a different category) was then selected, and another discussion and feedback session was held.

This section of the workshop ended with Dr. Chesler's wrap-up within the full-group setting, which focused on the interaction between the three categories of problems dealt with in this exercise: problems with institutions, group-level problems and individual problems. Problem areas and solutions overlap and often occur simultaneously, as the group works to improve the institutional system of care, builds itself as an organization, and acts as an advocate or intermediary to help individual parents.

SECTION 5: MAINTAINING GROUPS OVER TIME: CONCERNS ABOUT LEADERSHIP CHANGES AND HELPING AT TIMES OF RELAPSE, TERMINAL ILLNESS AND DEATH OF A CHILD
(Thursday, 11:00 - 12:00 am)

This period dealt with issues participants felt were important but which had not been specifically included in the pre-planned agenda. Two issues were proposed by members: (1) recruiting and preparing new persons to take over group leadership; and (2) talking with parents whose children have relapsed, are terminally ill or have died.

Participants broke into two subgroups, with those wanting to discuss leadership issues in one room, and those preferring to discuss issues related to helping families through hard times in another. Splitting the group in this way allowed both discussions to occur in a more manageable and intimate small group setting, and allowed sufficient time for each issue to be treated in depth. However, it was clear that both issues were very important to everyone; thus, a summary of the discussion and conclusions of each subgroup was held for all participants together.

a) PASSING THE TORCH OF LEADERSHIP TO NEW LEADERS

Participants discussed the problems involved in recruiting and preparing new leaders for the group, and how the group can function well through these transition periods. The problem of defining long-term and short-term goals for the group also was discussed, with participants concluding that the purposes and benefits of the group should be defined, and the responsibility for meeting the goal and techniques used should be clear (who is to do what, and how?). It was especially noted that goals should be realistic, because most groups have limited resources. In addition, needs will shift across time, so goals, programs and leadership should be dynamic and flexible.

Participants developed a wealth of suggestions for facilitating the leadership transfer process; these are enumerated below. They generally are concerned with delegating tasks as a way to both avoid burnout and to making the transition easier (that is, insuring that the work and responsibility are spread among a number of people, so no one person has to "do it all"). Several other suggestions dealt with structuring the group to insure there will be enough people to carry out activities and tasks.

Use of a teamwork approach:

- * delegate tasks among a number of people
- * share tasks with new leaders
- * use a "buddy system" with the new leaders
- * take risks and ask people to volunteer for tasks
- * be unafraid to say "no; others can take over that task"
- * personally train new leaders (teach them the ropes)
- * trust new people to do things their own way

Preparation for leader's departure:

- * have an explicit strategy for torch-passing
- * prepare others; consult with them
- * train others: "we are our own faculty"
- * train others through skills workshops
- * begin by delegating small tasks to new leaders; test each other, then go on to larger tasks
- * read the "chemistry" of the group and know when to change leadership
- * understand the unique abilities of each core member
- * pass resources along
- * understand that if the old leader must move on, it is possible the group may change radically or even cease, and old leaders shouldn't feel guilty

Group structure:

- * set leader tenure limits; for example, 2 year terms
- * have interim or rotating leaderships
- * allow the group to change, ebb and flow as leaders change over; also as needs may change
- * one group has a 2-tier structure, families in treatment and support families who are off treatment, so take responsibility for the bulk of the group work

b) PARENTS WHOSE CHILDREN HAVE RELAPSED OR BECOME TERMINALLY ILL, AND BEREAVED PARENTS

The other parent subgroup discussed the issue of how to talk to and help parents whose child has relapsed, is terminally ill or has died. This subgroup included a parent of a child who had died recently and a parent of a child who had relapsed. Both these parents opened their hearts and minds to other members, answering questions and modelling a process of giving and receiving information and help. Thus, in addition to discussion of techniques of helping such parents, this group experienced these processes directly, and shared deep feelings of pain and compassion for one another. It was a discussion like many others that occur in local groups: an intense and moving exchange, complete with tears of sadness and of the joy of meaningful connection with one another.

These parents developed a list of suggestions for ways to be sensitive to the needs of parents who are experiencing very traumatic situations. These suggestions were presented to and discussed by the full group at the end of this session.

At Diagnosis:

- * establish bonds
- * share personal experiences and emotions
- * stress the caring for each other
- * do practical things to help the family

At Relapse:

- * provide even more practical help, e.g., with siblings
- * keep in touch with the family; don't lose contact
- * find out if the immediate family is supportive or not
- * don't allow anxiety or fear to paralyze you as a helper

If Terminal:

- * all of the above
- * find out how the family wants to deal with the death; if they want to be alone, let them; if not, join them
- * be with the family if they want you to; offer to sleep over and provide help
- * be open to the family allowing the child to die as they wish, in the company of whoever they wish
- * feel free to show emotion and cry

At Death:

- * give the family time alone, but -
- * let them know you're there when they need you
- * it's never too late to send a card or make a call; remember anniversaries (the family will)

SECTION 6: REACHING OUT TO AND WORKING WITH OTHERS
(Thursday, 1:00 - 4:00 pm)

THE ROLE OF CCCF: Dr. Chesler emphasized the special role that the Candlelighters Childhood Cancer Foundation plays in aiding families of children with cancer and their local support groups. Just as individual parents are not alone when they join a local support group, local groups are not alone when they are linked into the CCCF network. The very fact of a national organization means we are connected with one another. The Foundation's educational materials, and their staff's or board's presence at meetings of medical and social work professionals, means that the needs and concerns of families of children with cancer constantly are shared with a wide variety of audiences. In this way professional and community support for local support groups is enhanced. Thus, CCCF's role as a representative and advocate of self-help and support groups for families of children with cancer paves the way for medical staff and ACS acceptance of these groups, and of the new programs that our families and children desperately need. As this workshop demonstrates, CCCF also helps "pass on" the experience and wisdom of local group leaders, increasing the vitality and effectiveness of other groups throughout the nation.

The "Affiliation Agreement" between CCCF and ACS, in force since 1980, provides some guidance to local parent groups seeking to create working relationships with local and state affiliates of the American Cancer Society. ACS has urged its Divisions and Units to establish liaison with parent groups and to assist them in their development and operation. CCCF continually urges local

group leaders to make contact with local ACS officials, to cooperate in providing services to children and families, and to aid them in their professional education programs. It was noted that many parent group leaders, and many local ACS officials, do not know that this agreement exists, that there are collaborative relationships between CCCF and ACS at a national level, and that ACS provides financial support to CCCF. Local group leaders were urged to initiate local liaisons, to seek ACS support for their outreach and educational programs and to inform ACS staff and volunteers of the needs of childhood cancer families and groups.

THE ROLE OF ACS: Ms. Crothers clarified the role of the California ACS in relation to local self-help groups for childhood cancer. Currently, there is much variation in the amount of assistance local groups receive from their local ACS office, as there is no nationally-defined standard as to how ACS should relate to these groups. However, one result of this workshop is that the information Ms. Crothers has gained from participants will be shared with ACS. She suggested that specific bylaws may help to define this relationship, and believes that in the future there will be a greater acceptance of childhood cancer issues as high priority in ACS. It was noted, however, that parent groups need to continue to make their needs and agendas clear to ACS, and to request services (as noted earlier, 5 of 12 groups represented at this workshop had received no assistance from ACS).

It was emphasized that when requesting services from ACS, it is helpful to have an affiliation to the Candlelighters network, even if it is an informal one. The CCCF provides a strong credential for local groups.

The specific services available to groups were presented by Ms. Crothers and discussed by the group. The available services are listed below. In addition, the California ACS wishes to develop an information and guidance manual for parents of children with cancer. (She noted that independent prior research indicates that the California ACS has an extraordinary history of outreach to self-help groups and for programs dealing with childhood cancer).

Programs:

- * hotel guestroom program
- * school integration program on advocacy and re-entry
- * public affairs program
- * workplace programs
 - advocacy for work re-entry
 - special educational program for business and industry

Practical help:

- * home care and gift items
- * transportation to and from treatment
- * special needed items (such as wigs)

Education:

- * computerized information resource databases (covering treatments, for example)
- * patient education libraries

Counseling:

- * (some) crisis counseling for parents

Legislation:

- * lobbyist in Washington, D.C.

MAKING CHANGES IN HOSPITALS: Ms. Anderson described political processes for becoming involved in improving hospitals at the stage of planning for construction of facilities, using as an example the Massachusetts Ten Taxpayer Group (TTG) process. She described her own experience in a coalition of health care groups which formed a TTG. The TTG process allowed parents to meet with hospital staff and officials in a planning context rather than in crisis periods, a less threatening and more cooperative way to interact. This group was able to facilitate many improvements in the design of a new hospital which better met families' needs. The group of Massachusetts parents evaluated the medical care system through informal feedback from parents and written questionnaires and presented this information to medical staff. The importance of constructive ways of presenting feedback was mentioned, by targeting strengths as well as areas to be improved, and how.

FCSN has done national surveys of hospitals and state health departments across the nation, and a report on this is available from Ms. Anderson. It includes questions about Parent Advisory Committees which have a voice in hospital decision making. Hospitals and health departments are said to be increasingly supportive of formal parent involvement but are unsure about how to arrange this.

COMBINING OUR STRENGTHS THROUGH GROUP COALITIONS, AND IMPACTING LEGISLATION: Ms. Anderson presented material on working with other groups with similar aims, and establishing coalitions in order to be able to have impact on broader issues - for example, on policy at the state and national levels. There are important "mega-issues" that affect all ill children, such as insurance, health care financing, employment discrimination and public education programs. These are difficult to tackle as a single group, but easier when many childhood cancer groups within a state work together, or when groups dealing with many types of childhood illnesses band together around a single issue.

Ms. Crothers provided information (including a handout; refer to the Appendix, page 13) on three areas of legislation at the California and national levels which may impact families of children with cancer - one state-level proposal related to employees, one to proposed funding cutbacks in the state, and one related to Public Law 99-457 at the national level.

Ms. Anderson presented further information on P.L. 99-457, which amends the original P.L. 99-142 requiring Individualized Education Plans for special education students. While the original law was not written specifically for chronically ill children, they are now included within it, and there is an emphasis at the federal level on addressing the needs of children with a wide variety of chronic physical illnesses.

CCCF also provides groups with current information on legislation specifically concerned with childhood cancer issues, through its newsletter and other published materials. The Metropolitan Washington Chapter of Candlelighters is the registered lobbyist for parents of children with cancer, and is able to help local groups pursuing State or municipal issues.

POTENTIAL CONTINUING RELATIONSHIPS: Dr. Chesler and Ms. Anderson discussed with participants several ideas for continuing the relationships established through this workshop.

a) The group can act as consultants or person-to-person resources for each other, through visits or telephone networks. Persons from other groups often can contribute a different perspective, viewing problematic issues in new ways.

b) Periodic written communications can keep groups in touch with ideas and programs around the state, and/or between states. Groups can contribute to the national Candlelighters newsletter, or other groups' newsletters, to let others know what they are doing and what materials they may have to share. In addition, groups can exchange newsletters, allowing the "recycling" of good ideas among groups.

c) Groups can involve themselves in legislative issues, by reacting to proposed legislation which may impact members. CCCF and ACS will be of help in connecting groups and assisting the process.

d) Groups can seek out and exchange resource and program information, through settings such as this workshop. In addition, exemplary hospital or school programs can be shared with other hospitals/schools. Often, there is a greater inducement to change when institutions are presented with a model successfully used in other institutions.

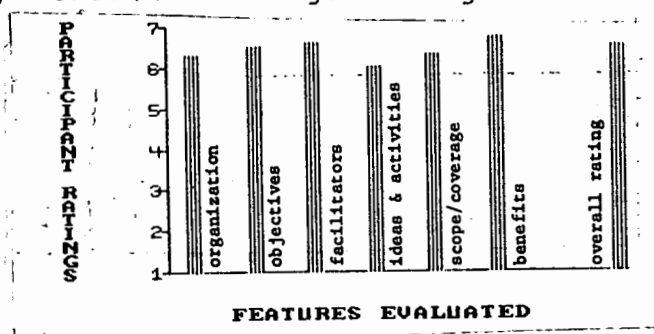
e) An opinion poll or survey of members of a number of groups can be organized (an example of a parent questionnaire was provided; refer to the Appendix, page 14). The results of such a survey can be powerful ammunition for change efforts; for example, participants gathered for this workshop represent groups in many areas across California. Combined information on needs, desires, problems and solutions can be of help in convincing hospitals and state and local governments to provide needed services and programs.

f) Groups can participate in the outreach and networking programs of the CCCF. The Candlelighters Foundation publishes a parents newsletter (circulation over 22,000), a youth newsletter (circulation over 8,000), various materials related to group programs, and information about new medical and legislative advances related to childhood cancer. It also "represents" parents' concerns to the ACS and to individual professionals and professional groups (APON, APOSW, etc.), and the general public, in meetings, committees, speeches, and articles. By so doing it helps multiply the resources available to children and families. Over 250 local self-help and mutual support groups currently are involved in the Candlelighters' network, and the strengthening of this organization is a vital source of future support for children with cancer and their families. Such strengthening will occur by national Candlelighters' efforts to reach out to local parents and groups, but it also can be furthered by the vigorous initiatives of local groups.

4) POST-WORKSHOP EVALUATION

At the end of the workshop, participants were asked to provide written evaluative feedback about the event. A copy of the "post-workshop reaction form" is contained within the Appendix (page 18); it includes both open-ended questions and numerical rating scales. 15 participants returned completed forms. Summaries of their most frequent responses on these items are summarized in the sections below.

OBJECTIVE RATING SCALE: Six specific features of the workshop were rated by participants on 7-point Likert scales, with 7 as the maximum positive rating. An overall rating was also obtained. These standard rating scales were taken from a workshop evaluation system by McCallon (1974, Learning Concepts, Inc., Austin, Texas). Average ratings are below:



These average ratings were compared to established norms derived from McCallon's sample of 40,000 participants attending a variety of types of educational and training workshops; this is done to help control for a general tendency of workshop participants to rate their training positively. Results on all scales except two (objectives and ideas/activities) fell well above the 50th percentile, that is, above the average ratings from all the workshops in McCallon's sample. Workshop

participants, on the average, rated the benefit from attendance item higher than 92% of the 40,000 sample. In contrast, the normed percentile rank for the clarity of the workshop's objectives was 40%. Possibly, this figure was lower than the average of McCallon's sample partly because the participatory nature of the workshop; specific behavioral objectives for training were not entirely appropriate. Moreover, as a "pilot" effort, some objectives were clarified only during the workshop. The presentation of ideas/activities was rated lowest, at the 31st percentile rank. At first glance, this low rating appears to contradict the most frequent responses on the open-ended items, that the sharing of ideas was one of the major positive features of the workshop. However, the wording of this item implies presentation of ideas by the facilitators, while in this workshop many of the best ideas came from the participants themselves through the discussions.

STRENGTHS: The greatest number of comments indicated the strongest feature of the workshop was the sharing of ideas between participants and exchanging information about different groups' activities (see above re: ideas/activities). A related issue, the opportunity to network with other groups, was viewed as a strength by several participants.

Several positive comments targeted the emphasis on developing leadership skills and the opportunities the workshop provided to gain practice in leading a discussion. Almost all felt the workshop covered the most important issues about self-help groups for families of children with cancer.

IDEAS GAINED: Participants were asked whether they could identify three good ideas gained during the training. 33 good ideas were mentioned. The four most common categories of ideas produced dealt with: a) activities for the child and family; b) means of helping bereaved families; c) how to begin a group; and d) ideas for leading and running groups.

WEAKEST OR MISSED FEATURES: Fewer comments were received about weak features than about the strong features of the workshop. The most frequently cited criticisms included a need for more specific information in several areas (group dynamics, fundraising, legislative work, public speaking, running meetings, delegation of responsibilities, subcommittee work). Such topics should be expanded in future workshops.

In addition, the process of breaking the group into subgroups for exercises and discussions was viewed as problematic: it was felt that all wanted to participate in all discussions, and since this was not possible, additional time needed to be spent to summarize the work of each subgroup within the larger group. However, time was viewed as a more important problem. Some presentations were thought to be too lengthy and complex, in particular the sections on legislative issues, developing group coalitions and training parent advocates. Dissatisfaction with these sections may also have occurred

because much of their content was generic, not specifically keyed to the concerns and agendas of childhood cancer groups. Future workshops should place the primary emphasis on cancer-related content and materials.

5) COST:

The workshop was jointly sponsored by the Candlelighters Childhood Cancer Foundation, the California Division of the American Cancer Society, and a San-Francisco-based support group for families, Parents Acting for Childhood Cancer Together. Their individual contributions toward the total cost of \$7,500. were:

CCCF	\$5000.
ACS-Ca.	1500.
PACCT	1000.

These funds covered room and board costs for all participants, grants for extraordinary (air) travel costs, fees and expenses for facilitators, and workshop materials.

6) FUTURE PLANS AND RECOMMENDATIONS

The California workshop was a first-trial "test" of a group development and leadership enhancement effort for leaders of self-help groups for families of children with cancer. Based on the successful completion of this event, discussions of group needs held during the event and comments of participants on the post-workshop evaluation forms, the following actions are recommended.

- Additional workshops should be held for other regions.
- Increased liaison between CCCF, ACS and local childhood cancer groups should occur. ACS should publicize information about such joint efforts as this training workshop in its network, and CCCF should publicize within newsletters and throughout its networks.
- Changes in the pre-workshop registration surveys are needed, in order to elicit more information on the specific activities pursued by each participating group (e.g., telephone trees, hotlines, transportation, relationships with other organizations such as school systems and the hospital, advocacy efforts) and on the problematic issues faced by each group. If such information was fed back to all participants before the workshop began, they could arrive better prepared to discuss common issues and differences.
- Additional emphasis within these events should be placed on using a combination of practice exercises with targeted feedback on leader performance and specific information related

to leadership skills and techniques which can be used to facilitate running group meetings.

- Additional emphasis within these events should be placed on specific legislative agendas for families of children with cancer - for example, catastrophic health insurance coverage, coverage for chronic illness, employment legislation, discrimination in employment, admission to the military. Such issues can also be better covered through more discussions or presentations.

- Groups expressed a desire to continue the networking begun in this workshop among Candlelighters groups and between ACS and groups. Continuance and extension of these relationships was planned through visits, calls, newsletters, etc.

- Participants expressed the desire to learn more about specific programs, with the intent of incorporating these into their groups' activities. Certain of these programs are from local groups (eg, family camps), while others are CCCF (hospital visitation) or ACS programs (school re-entry) or programs from other sources. A listing of these programs and information sources is contained in the Appendix, page 18.

- For those who participated in this workshop, an annual reunion, or some other way of reporting on progress toward building and improving their groups would provide a continuing relationship and reduce the isolation group leaders often experience.

APPENDIX

Parent Group Development Workshop
Roster of Participants

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PARENTS GROUP DEVELOPMENT WORKSHOP - PRELIMINARY GROUP SURVEY

1. Name and Address of Group (if you currently have no group, please respond to the last question below):
2. Group Contact, Telephone Number:
3. How often does your group meet: Weekly 1 Bi-weekly 1 Monthly 8
Other 1 as needed
4. How many people regularly attend? _____ How many do you have on your mailing list? _____
↳ 9 groups = 5-20 people
1 group = 20-50 people
5. Do you have a newsletter or regular mailing? Yes No _____ (If yes, please bring 25 copies to share at the workshop)
6. Rank your major group activities in order of priority (rank 1 as most important, 6 as least important):
First provide emotional support _____ do fund raising
Second provide information _____ make changes in health care system
_____ conduct social activities third visit parents and children
7. Does your group get help from local medical personnel or from the hospital? Yes 11 No _____ Are there any staff members active in the group? Yes 6 No _____
If yes, briefly describe what they do: Speakers, make referrals, plan + advise
8. How do you learn of parents of newly diagnosed children?
Group contacts - 6 groups
Hospital referrals - 7 groups
ACS links - 2 groups
9. Does your group get any assistance from the ACS? Yes 7 No 5
If yes, what type of assistance:
Brochures, printing, library, advice

If no, why not:
10. What is the biggest problem facing your group:
Level of participation
Travel distance
Finding new people
11. If you are thinking of setting up a new group, briefly describe the kind of group you'd like to see:

Signed by _____
Print name here:

Return along with registration form in enclosed envelope to the California Division of the American Cancer Society no later than April 25, 1987.

PRE-WORKSHOP INFORMATION ON GROUPS

1. We'd like to get some idea of the specific things people do (did) at group meetings. For each potential activity, please place a check in the appropriate column that best describes how often people in your group do (did) these things. (*If you do not have an active group, please answer according to what you think people might do at these meetings.*)

	A lot	Some- times	A Little	Never
a. Talk about the stresses on the family	10	3	3	
b. Talk about very personal feelings	6	7	3	
c. Discuss recent advances in treatment	3	6	6	1
d. Learn how to deal with emotional issues	6	3	6	
e. Give feedback to Doctors or Nurses		5	8	3
f. Plan to change things in the hospital (clinic)		3	8	4
g. Raise money for the hospital			4	12
h. Plan to get together socially	3	12	1	
i. Visit other parents at home	1	7	4	4
j. Contribute funds for needy families	6	6	1	3
k. Plan group activities	9	6	1	
l. Discuss how to recruit new members	5	7	3	1
m. Pressing for change in social policies that affect us	2	7	3	4

2. How much do your members personally benefit from the group in the following areas? Please check the appropriate column. (*If you do not have an active group, please answer according to how you think people might benefit from these groups.*)

	Much benefit	Some benefit	Little benefit	No benefit
a. Getting information about cancer	8	4	4	
b. Understanding the treatments	9	4	3	
c. Learning who's who on the staff	5	7	2	2
d. Learning my "rights" as a parent	9	5	1	
e. Coping with my child's problems	11	5		
f. Dealing with my child's school	7	5	3	1
g. Coping with problems in my family	7	7	2	
h. Coping with the death of my child	4	4	4	1
i. Developing self-confidence	4	9	3	
j. Being helpful to other parents	13	3		
k. Getting help from other parents	11	5		
l. Meeting others with similar problems	13	2	1	
m. Coping with public attitudes toward my child's condition/illness	4	10	1	1
n. Feeling part of a larger group	8	5	2	1
o. Getting help from the medical staff		6	8	1
p. Being an active part of the medical care system	6	8	1	1
q. Changing things in the hospital		6	7	3
r. Being supported, approved of	9	6		1
s. Learning to cope differently	9	7		
t. Feeling freer to express my feelings	11	4	1	
u. Learning how to be a leader	2	6	4	4
v. Feeling spritual uplifting	3	6	5	1
w. Talking about my child	15	1		
x. Expressing and learning compassion	13	3		
y. Other (Please specify: <u>not feel alone</u>)	1			

Materials available from the CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION, 1901 Pennsylvania Ave., N.W. (Suite 1001), Washington, D.C. 20026, Tel: (202) 659-5136.

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION QUARTERLY NEWSLETTER

Articles on living with and treating pediatric/adolescent cancer, for and by parents of children with cancer, physicians, nurses, social workers, child life workers, other medical and psychosocial professionals.

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION YOUTH NEWSLETTER

Quarterly newsletter for young people with cancer, and siblings living with cancer. Written and illustrated by youthful cancer patients, siblings, medical and psychosocial professionals.

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION PROGRESS REPORTS: BONE MARROW TRANSPLANTATION IN CHILDHOOD CANCER (Special Issue), 1985, (5).

Ten articles by physicians, nurses, social workers, parents on the state of the art, decision-making process, patient/family psychological response, family issues, funding, alternatives to total irradiation, isolation versus non-isolation and informed consent.

THE CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION BIBLIOGRAPHY AND RESOURCE GUIDE. (1987).

Annotated bibliography of written and audio-visual materials, and other resources, relevant to many aspects of childhood cancer.

ORGANIZING AND MAINTAINING SUPPORT GROUPS FOR PARENTS OF CHILDREN WITH CHRONIC ILLNESSES AND HANDICAPPING CONDITIONS. Washington, D.C., Association for the Care of Children's Health, 1986.

Aid for parents forming new groups, maintaining ongoing groups, struggling to revive fading groups; patient/parent/family needs; group roles, philosophy, operation, activities, formation, organization and structure; relationships to professionals, larger organizations and parent coalitions.

MAKING CONTACT: A PARENT-TO-PARENT VISITATION MANUAL.

Washington, D.C., Candlelighters Childhood Cancer Foundation, 1987. (Developed in cooperation with the Association of Pediatric Oncology Social Workers).

The why and how of parent-to-parent visitation, designing a volunteer program, training guide for visitors.

"Family support groups". Presentation by Grace Powers Monaco to the American Cancer Society Second National Conference on Human Values and Cancer, 1978.

Parents'/families needs for information, guidance, understanding; ways in which Candlelighters meets these needs with parent/youth support groups, parent representatives, newsletters, conferences, McDonald houses.

STRESS AND SOCIAL SUPPORT AMONG PARENTS OF CHILDREN WITH CANCER

Categories of stress

Sources of social support

Self-help group activities

Intellectual

Confusion
 Ignorance of medical terms
 Ignorance of where things are in the hospital
 Ignorance about who the staff is
 Unclearity about how to explain the illness to others

Medical staff
 Social work staff
 Scientists

Lectures by staff
 Handbooks
 Library of articles and videotapes
 Newsletters
 Information sharing among parents

Instrumental

Disorder and chaos at home
 Financial pressures
 Lack of time and transportation to hospital
 Monitoring treatments
 Reallocation of family tasks

Social work staff
 Family members
 Friends
 Neighbors and co-workers
 Institutional representatives

Funds for wigs, prostheses, parking
 Transportation and parent lodging
 Efforts to improve local medical care
 Fund-raising for research or added services and staff

Interpersonal

Needs of other family members
 Friends needs and reactions
 Relations with the medical staff
 Behaving in public as the parent of an ill child...and stigma

Family members
 Close friends
 Medical and social work staff
 Other parents of ill children

Reference group identification
 Meeting new people like oneself
 Having someone to talk with

Emotional

Shock
 Lack of sleep and nutrition
 Feelings of fear, defeat, anger, sadness, powerlessness
 Physical or psychosomatic reactions

Close friends
 Spouse
 Social work staff/psychologist

Professional counselling
 Peer counselling
 Sharing intimate feelings

Existential

Confusion about why this "happened to me"
 Uncertainty about the future
 Changes in future goals, careers
 Uncertainty about God, fate and a "just world"

Clergypeople and fellow congregants
 Philosophers

Talking about religious beliefs
 Sharing the struggle
 Creation of a community

SITUATIONS FOR DISCUSSION

1. Election of new officers will be coming up within the next couple of months. The parent who started the group is moving out of state. Even though there are a number of people with potential for leadership no one seems eager to come forth. Discuss issues and possible strategies.

2. Sue is a very energetic and capable member. Since her daughter's death she has devoted all her time to the group. She volunteers for everything and others just seem to sit back and let her. As a group leader what concerns might you have and what might you think of doing.

3. Jim is a sincere but outspoken parent who has ideas and opinions about everything. Often this works well for the group but there have been occasions when some in the group have had different opinions or have felt shortchanged in the decision-making process. You definitely don't want to lose Jim's contributions. What issues are there and how might this be tactfully addressed.

4. You have had a nice small group of families for a few years but are aware that few, if any, families other than white middle class are members. Should this be an issue and if so, how might it be addressed.

5. Families have been getting together for a couple of months. A number of activities have been proposed and it's been very pleasant but things don't seem to be moving. What suggestions might offer direction.

6. Some parents attended the meeting last night for the first time. They weren't very articulate and seemed to have different backgrounds and interests from other members. Can or should groups be all things to all people.

7. Momentum is building in your group but things are definitely still in the formative stages. A coalition of disability groups wants you to become members and is anxious to have your vote for increased community services. Some are anxious to join but others are unsure about the implications. What is the best course.

someone who hasn't said anything, but if they seem very much on the spot, let them off by moving on to someone else. Another idea can be to go around the group so that each person just naturally gets a turn.

7. The situations are very likely to remind people of things they are involved in or experiences they have had. Personal experiences are excellent for people to draw on, and it is fine to let the group go on a bit, because points made can be directly relevant to someone's situation. As the leader, try to gauge how much time to spend and when to pull the group back to task if too much time seems to be being directed to an issue of limited interest or to just one individual.
8. Encourage participation by reinforcing people's responses. This definitely does not mean you must personally agree with them but rather that you feel they are adding to your own and the group's understanding of the range of opinions and ideas people have.
9. Some suggestions for awkward moments:

If there is silence, when you first try to elicit a response from the group, don't be afraid to just wait a few moments. Even though it can be slightly uncomfortable, often that's what leads someone to jump in. You might try rephrasing or expanding upon the question.

When someone has stated an extreme approach which others seem to disagree with but no one says anything: it may be that they don't want to get into a disagreement. You might ask whether anyone else has another idea or ask how others think this approach might be received--this way they are responding to you.

When someone goes on for too long: at as graceful a moment as possible say, "Now let's hear from some others," or something of that nature. It may be necessary to create a physical diversion by standing up and cutting in politely.

When someone has a burning issue that needs attention: you can acknowledge the seriousness of their problem and
a. perhaps offer to speak with them at the end of the session; b. offer to call them at another time; c. ask if anyone in the group would be willing to assist (later) or suggest resources that might be of help. d. Another possibility, if you feel the matter needs immediate attention, is to ask the group's permission to focus on it instead of the planned discussion.

When, in a group, only one person is a parent or a social worker or a doctor, etc., and feels obliged to be an apologist for the category they presume they are viewed as representing: be upfront that so-and-so is in a tough



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Collaboration Among Parents and (Health) Professionals — CAPP

Notes for Small Group Leaders

Please read over the Situations for Discussion beforehand so you have some familiarity with them. Even though we would really like to have most of the discussion come from the group, sometimes it's necessary to get them started.

1. Ask individuals to say who they are and, depending on time (or whether this has already been done), something about their child or their job or the topic under discussion. This should be very brief and you might model this by beginning yourself.
2. Either decide what situation to begin with or give the group a minute to skim over the sheet and say which one(s) they'd prefer. The advantage to the second is obviously that people are likely to choose ones that they have particular interest in or experience with.
3. Introduce the situations with something like:
"We're going to select one or two situations, more if we have time, and try to understand the different issues and perspectives represented and see if we can come up with some constructive approaches." . . .or something along those lines.
4. Keep in mind the following purposes:
 - To help participants identify their own perspectives
 - To recognize that others may respond differently
 - To practice articulating their own responses or approaches
 - To get immediate feedback on how others perceive those
 - To listen carefully to what is being said and how it's being expressed
 - To give constructive feedback to others
 - To value using or serving as a soundboard
5. TRY TO HAVE MOST OF THE ISSUES AND THE APPROACHES COME FROM THE GROUP. This reinforces the part that they have to play and can encourage them to see each other as resources. You may well want to make some comments but wait until they have had a chance to try out some ideas (after all, you've had a headstart). Otherwise, you will become "the expert" and they may hesitate to say anything, feeling you have all the answers.
6. Try to give everyone an opportunity to participate. Some people will always have something to say, others need to be drawn out. You might consider directing a question to

someone who hasn't said anything, but if they seem very much on the spot, let them off by moving on to someone else. Another idea can be to go around the group so that each person just naturally gets a turn.

7. The situations are very likely to remind people of things they are involved in or experiences they have had. Personal experiences are excellent for people to draw on, and it is fine to let the group go on a bit, because points made can be directly relevant to someone's situation. As the leader, try to gauge how much time to spend and when to pull the group back to task if too much time seems to be being directed to an issue of limited interest or to just one individual.
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When, in a group, only one person is a parent or a social worker or a doctor, etc., and feels obliged to be an apologist for the category they presume they are viewed as representing: be upfront that so-and-so is in a tough

position and doesn't need to speak for all.

10. Give some balance to things and try to bring out some different viewpoints if they don't seem to come naturally from the group. It is not necessary for the whole group to come to agreement.
11. Ensure that no category or group is being stereotyped. If negative experiences come out, as they may, acknowledge the frustration or anger, but ensure that the responses recognize that not all parents or not all doctors, etc., act in the same way.
12. Finally, make sure that your comments and approaches have a place for everyone--parents, professionals, others who may be present. Consider this as a way to model the idea that we're all in this together and that it is our ability to identify, use, and expand upon all the ideas and resources we can, as creatively as possible, that makes our relationships and circumstances satisfying and the whole greater than the sum of its parts.

Betsy Anderson
1986

Problem-solving scenarios focussing on staff relations:

Individual

You are sitting across the hospital room from your 5 year old child. It is necessary for a new IV line to be begun. The young intern is obviously having difficulty finding the vein; he has missed the "stick" three times and is beginning to perspire nervously.

You and your 9 year old child have been sitting in the clinic waiting room for 2 hours. It is now your turn to see the doctor and staff. After a brief examination the physician indicates that she wants to do a bone marrow aspiration, and asks your child to walk to the laboratory. Your child begins to cry, and the doctor says, "C'mon, it won't be bad...you've had this before."

Your teen-age daughter has just been diagnosed with Osteogenic Sarcoma. The Physician tells you that they know how to cure this illness, and that an amputation and following chemotherapy is the standard treatment. He asks for your permission to place your daughter on a research protocol. You ask whether there is information about the illness, the treatment, the research, etc. The physician tells you that there is not much available in lay language and that it is all pretty technical but he will answer any of your questions.

Group

Your support group meets outside the hospital, and has been having difficulty discovering who are newly diagnosed patients, and what their family names and addresses are.

A social worker and a nurse meet regularly with your support group. Recently, several group members have expressed a desire to discuss some problems they have been having with the radiotherapy section of the hospital. The nurse and social worker seem uncomfortable with this topic, and steered the conversation away from it last week. When it came up again they suggested that the radiotherapy section was probably doing the best they could, since they were having staff problems, and that it would be fruitless to discuss this topic when there were other issues obviously on the minds of many parents.

One of the nurses who is a regular member of the parent support group has missed the last two meetings. Moreover, she seems to be quite "down"; sad a lot and not willing to take time to talk with parents or children on the wards. She does her job, but that's about it. You really miss the personal warmth, outpouring or caring, and extra time and energy this nurse used to have available.

Institution

Your support group feels that it is having difficulty getting the staff to change procedures for the treatment of children with cancer in the general-purpose emergency room of the hospital. You have spoken several times with the Oncology nurse who often comes to group meetings, but so far nothing has happened.

Parents in your group would like the opportunity to make a presentation to the pediatric residents and interns who are part of the hospital. These students want to hear from parents what it is like in a family with a child with cancer. Three parents, including yourself, are asked to make about a half-hour presentation, and then to be available for questions. What would you plan to cover in this presentation, and how?

The Hospital Director has announced that the Pediatric Oncology clinic is being shut down at the local hospital. In the future, the children of the parents in your group will be served in the hospital in the next city, 35 miles away.

Your support group feels that a parent who can represent your desires and concerns ought to be a regular part of the staff. Then that person can liaison both ways - with the staff and with the parents. You have heard of similar "Parent Advocacy" or "Parent Representative" programs at other hospitals and want to adopt it at your institution.

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LEGISLATIVE ISSUES

1. Seeking New State Legislation

Seek a bill to entitle employees to family leave in cases involving the birth, adoption, or serious health condition of an underage dependent, with adequate protection of the employee's employment and benefit rights, and to establish a commission to study ways of providing salary replacement for employees who take any such leave.

2. Appealing Proposed State Educational Cutbacks

Governor Deukmejian has proposed major cutbacks in the public education budget for the next fiscal year. Especially hardhit will be special education services for children with disabilities and gifted children. Prior to June, there is still time to appeal for a rescission in these proposed cutbacks, which could adversely affect special education services available under Public Law 94-142 to children with cancer.

3. Providing Input to Drafted Regulations for New Law

Public Law 99-457 now mandates new amendments to the Education of the Handicapped Act for special education services to children age five and younger. The opportunity exists to provide critical input to the drafting of regulations so as to insure our children's specific needs will be met (see attachments).



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COLLABORATION BETWEEN PARENTS AND HEALTH PROFESSIONALS

These questions ask parents to consider and comment on their needs and participation in the health care system. This questionnaire will probably be most effective if parents and health care providers work together to make any desired changes in questions or format and to prepare for follow up once responses are received. Background questions are also needed.

A. Information

1. I have access to all the information I need about my child's care, treatment and condition(s).

yes _____ no _____

2. Both long-term and short-term aspects of my child's care and treatment are discussed.

yes _____ no _____

3. I read my child's medical records:

a. never

b. occasionally

c. regularly

4. The ways I like to get information are:
(check all that apply)

_____ directly from our doctor

_____ directly from others on the health care team

_____ in writing

_____ at a medical library

_____ other(describe)

5. My child's teachers have enough information to understand my child's health care needs at school.

yes _____ no _____

B. Communication

- 1. I am automatically included as part of the health care team.

1	2	3	4	5
almost never				always

- 2. When we go to clinic, I know why we're there and what to expect.

1	2	3	4	5
almost never				always

- 3. I feel I can communicate my needs and those of my child (when appropriate) to the staff.

1	2	3	4	5
almost never				always

- 4. My child is included in conversation and encouraged to ask questions and comment on his/her care and treatment.

1	2	3	4	5
almost never				always

- 5. There is time during appointments to cover all the things I feel are important.

1	2	3	4	5
almost never				always

- 6. I can always reach someone (by tel.) to ask questions or further discuss care.

1	2	3	4	5
almost never				always

- 7. The health professionals communicate well together about my child's needs and treatments.

1	2	3	4	5
almost never				always

- 8. When my child is hospitalized, there is adequate communication between those who provide out-patient care and those providing in-patient care.

1	2	3	4	5
almost never				always

B. Communication (continued)

9. The health professionals communicate well with teachers and others in my child's school system.

1	2	3	4	5
almost never				always

C. DECISION-MAKING

1. I am presented with options for care and treatment.

1	2	3	4	5
almost never				always

2. I am given information about the risks and benefits of the (above) options.

1	2	3	4	5
almost never				always

3. I usually have enough information to make the decisions necessary for my child's care.

1	2	3	4	5
almost never				always

4. I feel decisions are made for me.

1	2	3	4	5
almost never				always

5. There is a plan for involving my child in decision-making.

1	2	3	4	5
almost never				always

6. The other parts of my child's life are considered in planning care and treatment.

1	2	3	4	5
almost never				always

7. The rest of our family members' needs are taken into account when planning care and treatment.

1	2	3	4	5
almost never				always

B. Communication (continued)

9. The health professionals communicate well with teachers and others in my child's school system.

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almost never				always

7. The rest of our family members' needs are taken into account when planning care and treatment.

1	2	3	4	5
almost never				always

C. Care and Treatment (continued)

8. I have enough information and preparation to carry out the care my child needs at home.

1 2 3 4 5
almost always
never

9. I am regularly asked to give feedback on how prescribed treatment is going.

1 2 3 4 5
almost always
never

D. Health Care Services

1. Overall, I would rate health care services my child receives:

1 2 3 4 5
poor excellent

2. What are the best aspects of this care?

3. What could be improved?

Please use the remaining space to comment on any of your response.

Developed by Betsy Anderson
October 1984

Group Name:

My Initials:

POST-WORKSHOP REACTION FORM

1. What were the strongest features of the workshop?

What were the weakest features of the workshop?

2. Did the workshop cover the issues you think are most important about self-help groups for childhood cancer? yes no

If important issues or needs were missed, what were these?

If you feel there are portions we should omit from future workshops, what are these?

3. Please circle a rating for each statement.

The <u>organization</u> of the workshop was:	Excellent	7 6 5 4 3 2 1	Poor
The <u>objectives</u> of the workshop were:	Clear	7 6 5 4 3 2 1	Vague
The work of the <u>facilitators</u> was:	Excellent	7 6 5 4 3 2 1	Poor
The <u>ideas & activities</u> presented were:	Very Interesting	7 6 5 4 3 2 1	Dull
The <u>scope or coverage</u> was:	Very Adequate	7 6 5 4 3 2 1	Inadequate
My <u>attendance</u> should prove:	Very Beneficial	7 6 5 4 3 2 1	No Benefit
<u>Overall</u> , I consider this workshop:	Excellent	7 6 5 4 3 2 1	Poor

Workshop Reaction
Page 2

4. Did you meet any people you especially wish to stay in touch with?
Who were they?

5. We'd like to know more specifically what you may have gained.
If you can, list 3 good ideas you'll carry away from the workshop
and whether you think your group may implement any of them.

Workshop Reaction
Page 2

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SOURCES FOR AVAILABLE INFORMATION ON PROGRAMS

<u>PROGRAM OR ACTIVITY</u>	<u>INFORMATION SOURCE</u>
Family camps	Ron Van Winkle (Yorba Linda, CA) and: Candlelighters (see special issue of newsletter)
TLC Workshop program	Felicia Lowe Schwartz (San Francisco, CA)
Parent Consultants	Jeanne Frater (San Diego, CA) and: Helena Richards Division of Pediatric Oncology Rhode Island Hospital 593 Eddy Street Providence, RI 02902 and: Linda Messbauer Pediatric Hematology/Onc. UR Cancer Center Rochester, NY 14642
Parent questionnaires	Penny Kreinberg (Portland, OR) and: Mark Chesler (University of Michigan)
School Re-Entry Program	Candlelighters and: Sara Perkins (CA ACS)
Hospital Visitation Manual	Candlelighters
Parent Advocacy and Coalitions	Candlelighters and: Betsy Anderson Federation for Children with Special Needs