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13. ABSTRACT (Maximum 200 Words) Psychosocial interventions effectively reduce psychological morbidity in cancer patients, but young woman with breast cancer and their families have not yet been targeted for such intervention. A pilot study assessed the impact of breast cancer on the families of younger women, focusing on parental adjustment, family coping and the adjustment of preschool and school age children. Based on this pilot data, a Basic psychosocial intervention involving a group for breast cancer patients and their spouses and an Expanded intervention that adds groups for children were developed. Baseline data on 34 families enrolled reveals that the psychosocial functioning of 91% of the women was within normal limits, whereas 41% of spouses endorsed clinical levels of psychological distress. Children exhibited few emotional or behavioral problems, although school aged girls scored below boys in scholastic self-competence. Global scales of family functioning revealed competency in coping, with a subset of families exhibiting distress on measures of psychosocial functioning and family coping. No significant differences were found at 4-month follow up for families in the intervention groups. Analyses of the 8-month follow-up data, including predictors of response to the interventions are pending.					
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Table of Contents

Cover.....	1
SF 298.....	2
Table of Contents.....	3
Introduction.....	4
Body.....	4-19
Key Research Accomplishments.....	19
Reportable Outcomes.....	20
Conclusions.....	20-21
References.....	21
Appendix List.....	22
Appendix 1: Treatment Manual: Patient and Spouse Group.....	(75pages)
Appendix 2: Treatment Manual: Younger Children's Group.....	(64 pages)
Appendix 3: Treatment Manual: Older Children's Group.....	(104 pages)
Bibliography.....	23
Personnel.....	24

INTRODUCTION

Breast cancer in young women with spouses and children increases the risk of psychological morbidity not only for the patient but also for the family due to the substantial mutual effects of each family member's adjustment to the diagnosis and its future implications. Psychosocial interventions are effective at reducing psychological morbidity in cancer patients, but to date the young woman with breast cancer and her family have not been targeted for such intervention. A pilot study was conducted to assess the impact of breast cancer on the families of younger women, focusing on the effects of breast cancer on parental adjustment, family coping and on the adjustment of preschool and school age children. Based on this pilot data, a Basic psychosocial intervention involving a group for breast cancer patients and their spouses and an Expanded intervention that adds groups for the children were developed for this study. The effects of the Basic and the Expanded interventions on reducing psychological distress and enhancing coping in young women with breast cancer and their families were compared in the fourth year of this study.

BODY: STATEMENT OF WORK

Technical Objective 1: Conduct pilot study to assess: a) the psychological adjustment and parenting concerns of breast cancer patients with preschool and school age children and their spouses; and b) the emotional and behavioral functioning of the children. (Completed 6/98). Results detailed in Annual Report submitted 9/98.

Technical Objective 2: Design a Basic and Expanded psychosocial intervention for young women with breast cancer, their spouses, and children 12 years of age and under based upon the findings of the pilot study.

Task 1: Month 8-10: Analyze pilot data and finalize treatment manuals for intervention groups. (Completed 6/30/98). Results detailed in Annual Report submitted 9/98.

Task 2: Months 11-12: Subject recruitment for intervention study; Randomize patients to Basic, Expanded and Control groups; Send out pre-intervention assessment packets; Schedule appointments for child assessment for Basic intervention and Control groups (Completed 8/31/98). (Intervention group scheduled to begin 9/10/98 canceled due to low enrollment.)

Task 3: Months 13-16: Reformat Basic and Expanded interventions to increase participation; acquire educational materials required for revised interventions; submit revised proposal to institutional review board for approval. Subject recruitment for intervention study; Randomize patients to Basic, Expanded and Control groups; Send out pre-intervention assessment packets; Schedule appointments for child assessment for Basic intervention and Control groups. (Completed 12/31/98)

The intervention groups were revised to take place over four monthly sessions approximately 1-1/2 hours long, with patient/partner groups taking place simultaneously with the children's groups. The Patient/Partner group intervention manual and the two children's intervention manuals (one for children aged 4-6 years and one for children aged 7-12) were revised (1999 Annual Report, Appendices 1-3). The older child group was further divided in to sections for children aged 7-9 and those aged 10-12. Institutional Review Board approval was obtained for the revised intervention on 12/24/98.

Technical Objectives 3-4: Compare the effectiveness of Basic and Expanded psychosocial intervention and assess the impact of the children's intervention.

Task 1: Months 17-20: Randomize patients to Expanded Intervention, Basic Intervention and Control groups; Send out pre-intervention assessment packets and schedule pre-intervention child assessments; First cycle of intervention groups begins; Start data coding and data entry; Recruitment of participant families for the second intervention group cycle; Post-intervention assessment packets given to patients and post-intervention child assessments scheduled (Completed 4/30/99).

As subject recruitment was below the number necessary to randomize participants into three treatment conditions simultaneously, the decision was made to alternate cycles of the Basic and Expanded Intervention groups to increase the numbers of participants in each condition. Participant families for each intervention group cycle will be randomly assigned to either an Intervention group or the Control group. Ten families were recruited for the first cycle of the intervention (Expanded Intervention group, n=6 and Control group, n=4), which was started in January 1999 and completed in April 1999. Baseline and post intervention data was collected from participants. This data was coded entered into the study database.

Task 2: Months 21-24: Randomize patients to Basic and Control groups. Send out pre-intervention assessment packets and schedule pre-intervention child assessments; Second cycle of intervention groups begins; Continued data coding and data entry; Recruitment of patients for third intervention group cycle; Post-intervention assessment packets given to patients and post-intervention child assessments scheduled; Complete 8 month follow-up assessment for Cycle 1 subjects. (Completed 8/31/99).

Seven families were recruited to the second cycle of the intervention group (Basic Intervention group, n=5 and Control group n=2). Post-intervention questionnaires for Cycle 2 participants and eight-month follow-up questionnaires for Cycle 1 participants were coded for data entry and analysis.

Task 3: Months 25-36. Third through fifth group cycles are run, with procedures as described above in Tasks 1 and 2. (Completed 1/31/01).

Four participants and their families were recruited to the third cycle of the intervention group (Expanded Intervention group n=3, Control group n=1). This group was run between September 1999 and December 1999. The fourth cycle of the intervention group was delayed until March 2000 due to low subject enrollment. This group was completed in June 2000 and included 4 families (3 Expanded Intervention group families, 1 Control group family). The fifth cycle of the intervention group included 5 families (Basic Intervention group n=3, Control group n=2) and ran from October 2000 to January 2001.

Task 4: Months 37-45: No cost extension of 12 months. Fifth and Sixth cycle of intervention group are run; Continued data coding and data entry; Complete 8-month follow-up for Cycle 5 participants. (Completed 6/30/ 01).

The 8 month follow-up data were collected for the fifth cycle participants. The sixth and last cycle of the intervention group involved 4 families (Basic Intervention group n=3, Control group n=1) and ran from February to June 2001.

The principal investigator moved to the Children's Memorial Hospital in Chicago, Illinois in September 2000. The research assistant, Ms. Carole Mallick, who had worked on the study since May of 1998, managed the day to day recruitment of participants and organization of the intervention groups. Dr. Karen Woodall took the principal investigator's place as the psychologist co-leader of the intervention groups. Dr. Woodall is a senior clinical health psychologist who is very familiar with the intervention group as she consulted on the development of the group in the first year of this research project. The nurse educator, Ms. Linda Robertson, participated in all six cycles of the Intervention groups. The principal investigator returned to Pittsburgh, PA on a quarterly basis to review work on the research. Between visits, management of the grant was conducted by phone and email.

The primary difficulty that faced this study was participant recruitment. Eighty-four women were contacted regarding participation in this study from December 1997 and December 2000. Of these women, 44 (52%) agreed to participate and signed consent forms. Of those who did not participate, 7 were ineligible primarily due to the late stage of their breast cancer, while 33 chose not to participate. The most frequent reasons given for non-participation were scheduling conflicts, including the management of other stressors e.g., child with chronic illness (n=12), having a spouse or other family member who was not interested in participating or refused to let family participate (n=11), having no interest in the study (n=5), or reason not given/unknown (n=5).

Of the women contacted to participate in this study, 54 (64%) were recruited from the University of Pittsburgh Cancer Institute/Magee-Women's Hospital Breast Cancer Center and four Hematology-Oncology medical practices affiliated with the University of Pittsburgh Medical Center. Women recruited from the University of Pittsburgh Cancer Institute/Magee-Women's Hospital Breast Cancer Center were recruited by a University of Pittsburgh cancer Institute nurse, who attended the clinic on a daily basis to identify eligible participants. When an eligible patient was identified by chart review, the nurse asked the treating physicians for permission to describe the study to eligible patients.

Those patients expressing interest in the study were called by either the research assistant or the principal investigator who provided more detailed information about the study.

The affiliated Hematology-Oncology Medical practices were called on a 1-2 times per month to ascertain whether any eligible women could be referred to the study. Brochures describing the study were also displayed in the office waiting areas. As our largest source of referrals was the daily attendance and recruitment at the University of Pittsburgh Cancer Institute/Magee-Women's Hospital Breast Cancer Center, we made arrangements to expand our recruitment to another high volume breast cancer clinic, the University of Pittsburgh Cancer Institute affiliated Shadyside Hospital in Pittsburgh, PA. Although we already provided brochures and in-services to the Shadyside Hospital's oncology clinic staff, we negotiated with nursing staff to visit this clinic to describe the study in person to eligible breast cancer patients who gave nursing staff permission for us to discuss the study with them. The University of Pittsburgh Medical Center Institutional Review Board did not allow recruitment from non-affiliated medical offices.

The remaining 30 (36%) were recruited through ongoing television and radio public service announcements, advertisements in five different regional newspapers, paid advertisements on a radio station that targets a young to middle-aged female audience, and periodic postings on the University of Pittsburgh Medical Center's internet home page. Twice yearly in-services for clinical trial coordinators at the University of Pittsburgh Cancer Institute also were scheduled from September 1999 to December 2000, to increase study recruitment from affiliated hospitals. We also expanded our recruitment to include those women diagnosed with Stage III breast cancer, as their prognosis and treatment was comparable to those with Stage 2B Breast cancer. In spite of these efforts recruitment was lower than expected.

In our last report, we estimated that enhanced recruitment efforts during the final year of this study would lead to the enrollments of 8-10 more families. Nine families were enrolled during the last year, leading to a total participation of 44 families (10 pilot, 34 experimental) over the course of six intervention cycles (3 Expanded Intervention, 3 Basic Intervention Cycles).

Barriers to recruitment included competition for participants from several studies and the fact that we are recruiting only women who are premenopausal with early stage (i.e., Stages 0-2) breast cancer, with children between the ages of 3 and 12, who constitute a smaller segment of the population of women diagnosed with breast cancer. Although scheduling conflicts are cited as the modal barrier to participation, previous efforts to survey the participant population about alternate days, times, and format of study groups would not appreciably increase enrollment, as those declining participation cite being just "too busy" to participate.

Recommendations for future intervention groups given the low recruitment rate, would be to provide the groups on a twice-yearly basis in different time/day slots in order to enhance participation. It would also be important to supplement the "live" groups with a web page that could provide those whose schedules would not permit group attendance to

have access to the information provided to participants. Integration of video clips of the groups interactions for key components of the intervention for both adults and children on the web page would allow the valuable information shared by the participants to be conveyed to those who were not able to attend in person. This web page would also need to incorporate a means for web participants to comment regarding their experiences with the web-based information, both to the providers of the web-based intervention and potentially as well to web participants.

Summary of Baseline Data: Intervention Cycles 1-6 (n = 34 families)

Baseline data for participants in intervention Cycles 1-6 are presented below. Data from the pilot patients (n=10) were presented in previous annual reports. Development and comparison of the Basic and Expanded psychosocial interventions were the primary goals of this study. Data comparing the outcomes for those enrolled in the Expanded Intervention (n = 12 families), Basic Intervention (n = 11 families), Control Group (n = 11 families), will follow this section which summarizes the descriptive data on the participants upon study enrollment. Data gathered from participants (n = 34 families) upon study entry provide new information about the effects of breast cancer on parental adjustment, family adaptation and the adjustment of children. Demographic data for the sample are provided in Table 1.

Table 1
Family Demographics (n=34 Families)

Characteristic	M $\pm$ SD	N	%
Family			
Marital Status (Married)		30	88%
Number in household	4 $\pm$ 1		
Mother's age	40 $\pm$ 5	34	
Father's age	42 $\pm$ 7	32	
Children			
Gender (male)		35/62	56%
Age (years)	8.9 $\pm$ 3		
Ethnicity			
Caucasian		33	97%
Asian		1	3%
Breast Cancer Stage			
0		6	18%
I		10	29%
II		10	29%
III		7	21%
IV		1	3%

Table 1 (cont'd.)
Family Demographics (n=34 Families)

Characteristic	M $\pm$ SD	N	%
Time Since Diagnosis:	11mos. $\pm$ 9 (range: 1-33)		
Treatment at Time of Diagnosis			
Lumpectomy		20	59%
Mastectomy		12	35%
Radiation		17	50%
Chemotherapy		25	73%
Bone Marrow Transplant		1	3%
Mother's Education			
12 years		3	9%
13-16 years		23	68%
> 16 years		8	23%
Father's Education			
12 years		6	18%
13-16 years		18	53%
> 16 years		10	29%
Mother's Employment			
Full-time		8	23%
Part-time		12	35%
Homemaker		9	26%
Other (unemployed,disabled)		5	16%
Father's Employment			
Full-time		30	91%
Part-time		1	3%
Other (unemployed, retired)		2	6%

Parental Adjustment

The Symptom Checklist-90 Revised (SCL-90-R) (1) was used to examine parental psychological symptoms and general distress (Table 2). A large majority of the breast cancer patients (30/33, 91%) scored in the normal range on the nine SCL-90-R symptom subscales and the Global Severity Index (GSI), a measure of general distress. Nine of the 22 spouses (41%) who completed the SCL-90-R however, reported psychological symptoms (e.g., Hostility, Depression) and global distress in the clinical range, as defined by a GSI T score of 63 or greater, or a T score of 63 or greater on two subscales. This difference in the proportion of mothers and fathers falling in the clinical range was statistically significant (Chi-square, $df=1$, $p < .01$). The highest intensity symptom endorsed by the breast cancer patients (i.e., ratings of 2-4, on a 0-4 point scale for at least a third of the patients) was low energy. Spouses most often reported high symptom intensity for feelings of irritability, worry, feeling blocked getting things done, and self-blame.

Table 2
Parental Psychosocial Functioning

Symptom Checklist-90-R (SCL-90-R)		
Symptom Domains	Mothers	Fathers
	Mean (SD) (n = 33)	Mean (SD) (n = 22)
Global Severity Index (GSI)	52 (8)	55 (11)
Anxiety	51 (8)	52 (10)
Depression	54 (7)	57 (10)
Hostility	52 (8)	56 (11)
Interpersonal Sensitivity	50 (8)	54 (9)
Obsessive-Compulsive	54 (8)	57 (12)
Paranoid	45 (7)	51 (9)
Phobic Anxiety	46 (5)	50 (6)
Psychoticism	52 (8)	54 (11)
Somatization	53 (8)	47 (10)

*As SCL-90-R raw scores are gender normed, T-scores are used to compare mothers and fathers. The parents' T-scores on the symptom subscales and the GSI were derived from nonpatient norms.

Patient Quality of Life

The Cancer Rehabilitation Evaluation System (CARES) (2) was completed by the breast cancer patients to provide a multidimensional assessment of the impact of breast cancer on their quality of life, with higher scores indicative of more difficulties. The women's scores fell in the normative range on average, however, 15/33 (45%) of women at Baseline had one or more symptom domains 1 or more standard deviations above the norm (Table 3).

Table 3
Breast Cancer Patients' Quality of Life* (n=33)

CARES Domains	Mean (SD)
Global	51 (9)
Total Number of Problems	52 (10)
Average Severity	50 (8)
Physical	49 (10)
Psychosocial	50 (9)
Medical Interaction	52 (6)
Marital	54 (8)
Sexual	55 (8)

*T scores where the mean = 50, and SD = 10.

Family Adaptability & Cohesion

The Family Adaptation and Cohesion Scale, Version 2 (FACES II) (3) was used to assess family functioning. This scale characterizes families along the dimensions of Adaptability, the ability of the family to be flexible and responsive to change, and Cohesion, the emotional bonding that the family members have for one another. Sixty-eight percent of mothers and 76% of fathers described their families as "Balanced", i.e., moderate to high on levels of Cohesion and Adaptability, considered to be important to healthy family functioning (Table 4). Balanced family types were associated with lower CARES marital problem scores ($r = -.47$, $p = .008$), as well as lower scores on symptom scales on the SCL-90-R for mothers (Obsessive-Compulsive subscale: $r = -.39$, $p = .03$).

Table 4
Family Adaptability and Cohesion

Family Characteristics	Mothers (n=32)	Fathers (n=29)
	n (%)	n (%)
Cohesion		
Very Connected	14 (44)	6 (21)
Connected	15 (47)	19 (66)
Separated	2 (6)	3 (10)
Disengaged	1 (3)	1 (3)
Adaptability		
Very Flexible	6 (19)	2 (7)
Flexible	13 (41)	18 (62)
Structured	10 (31)	7 (24)
Rigid	3 (9)	2 (7)
Family Type*		
Balanced	8 (26)	2 (7)
Moderately Balanced	13 (42)	20 (69)
Mid-Range	9 (29)	7 (24)
Extreme	1 (3)	

*Combined Score for Adaptability and Cohesion

Family Coping

The Family Crisis Oriented Personal Evaluation Scale (F-COPES) (4) was used to assess family problem solving and coping behaviors. Women endorsed using the assessed coping strategies significantly more often than men as tested by paired t-tests (Table 5). Both women and men scored in the moderate range in the use of most coping strategies, with the exception of very high endorsement of "Passive Appraisal", the family's ability to accept problematic issues while minimizing reactivity. There was substantial variability among participants on the F-COPES, as reflected in the very large standard deviations for all but the Passive Appraisal subscale. "Reframing", the individual's capacity to redefine stressful events to make them more manageable, was associated with a lower number of problems endorsed the CARES Inventory ($r = -.41, p = .02$).

Table 5
Family Coping

Coping Strategies	Mothers (n=32)	Fathers (n=28)
	Mean Percentile (SD)	Mean Percentile (SD)
Acquiring Social Support	77 (23)***	58 (29)
Mobilizing Family to Acquire Help	78 (25)	66 (25)
Passive Appraisal	99 (3)	96 (7)
Reframing	69 (28)	61 (29)
Spiritual Support	48 (38)	43 (34)
Coping Total	83 (24)**	70 (28)

** p = .02, ***p = .004

Family Communication

Family communication patterns were assessed with the Family Problem Solving Coping Scale (FPSC)(5). This scale evaluates two patterns of communication important to how families cope with challenges: Incendiary communication (IC) and Affirming communication (AC) (Table 6). Fathers' and mothers' scores at Baseline were similar, with AC endorsed more often than IC. Total Positive Communication scores (TPCS) fell in the mid-range in relation to standardization samples. The mothers' FPSC scores showed a relationship with the Hostility subscale of the SCL-90-R (AC, $r = -.48$, $p = .004$; IC, $r = .44$, $p = .01$; TPCS, $r = -.47$, $p = .005$) and with the Marital (Distress) Subscale of the CARES (AC, $r = -.51$, $p = .002$; IC, $r = .60$, $p = .000$; TPCS, $r = -.57$, $p = .000$). These findings indicate that affirming communication is strongly associated with lower marital distress and hostility, providing support for the emphasis on communication skills in the intervention portion of this study. The fathers' IC scores were also positively associated with the Hostility subscale on the SCL-90 ($r = .39$, $p = .04$).

Table 6
Family Communication*

Communication Pattern	Women (n=33)	Men (n=29)
	Mean (SD)	Mean (SD)
Affirming Communication	12 (2)	12 (2)
Incendiary Communication	4 (3)	5 (3)
Total Positive Communication	23 (5)	22 (5)

* Possible Ranges: FPSC subscales (0-15), FPSC Total Score (0-30)

Child Behavior

Of the parents' 62 children, 46 were between 4 and 12 years, the age range of children eligible for the study's intervention groups. Baseline data were collected where possible for children younger than or equal to 48 months ($n=7$) and those older than 12 ($n=9$). The age appropriate Child Behavior Checklist (CBCL) (6-7) was used to assess any emotional or behavioral problems in the children, as well as the competencies of children aged 6 - 15 years in social, recreational and academic domains. All children aged 48 months and below had CBCL scores that fell in the normal range for all symptom subscales as well as for the Internalizing, Externalizing and Total Problem scores. A large majority (46/54; 85%) of the school-age children assessed with the CBCL evidenced few emotional or behavioral problems, with competency scores also within normal limits (Table 7). Eight school-age children (5 males, 3 females) demonstrated clinically significant levels of psychological distress, with half of these children falling in the clinical range for somatizing symptoms. Three of these children also evidenced competency scores in the borderline clinical range. Mothers rated their male children as more symptomatic on the withdrawn ($t = 2.03$, $df = 43$, $p = .048$) and thought ($t = 2.19$, $df = 44$, $p = .03$) problem scales.

Table 7**Children's Behavioral Symptoms (n = 54)**

Child Behavior Checklist (CBCL) /Children (4+ years)

Outcome Domains	Mean (SD)
<u>Problem Scales</u>	
Aggression	52 (3)
Anxiety/Depression	53 (5)
Attention Problems	52 (4)
Delinquency	53 (4)
Withdrawn	52 (4)
Social Problems	53 (6)
Somatic Complaints	54 (7)
Thought Problems	46 (9)
Externalizing Symptom Total	45 (8)
Internalizing Symptom Total	48 (10)
Total Behavior Score	46 (9)
<u>Competence Scales (6-12 yrs.) (n = 46)</u>	
Activities	48 (6)
Social	50 (6)
School	48 (8)
Total Competence Score	52 (9)

*T-Scores are presented so that the participants' scores can be evaluated in reference to the normative population. For the Problem Scales, scores of 50 are in the normal range, scores 67-69 represent borderline clinical scores, and scores 70 and above indicate clinically significant behavioral or emotional problems. For the Competence Scales, scores of 50 are in the normal range, scores 33-31 are considered borderline clinical scores and scores 30 and below fall in the clinical range.

Child Competencies

Thirteen children aged 4-7 completed the age/gender appropriate Harter Pictorial Scale of Perceived Competence (8) which comprehensively assesses the child's self-perceptions regarding peer and maternal acceptance, physical and cognitive competencies. Scores may range from 1-4. Their mean scores were medium to high across the four subscales: Peer Acceptance, $M = 3.01$, $SD = .60$; Maternal Acceptance, $M = 3.01$, $SD = .64$; Physical Competence, $M = 3.27$, $SD = .39$; Cognitive Competence, $M = 3.52$, $SD = .56$. The range for the subscale means was 1.80-4.0, with lower scores (those <2.50) more common on the maternal and peer acceptance scales.

Thirty-one children aged 8-13 years completed the Harter Scale of Perceived Competence Questionnaire (9) (Table 8). Both boys and girls on average scored at or above the standardization sample means on all subscales. Boys scored higher than girls did on scholastic competence ($t=2.27$, $DF=27$, $p=.03$).

Table 8
School-Aged Children's Perceived Competence

Competence Domain	Boys (n = 20)	Girls (n = 11)
	Mean (SD)	Mean (SD)
Athletic	3.02 (.70)	3.01 (.69)
Conduct/Behavior	3.08 (.46)	3.03 (.95)
Physical Appearance	3.27 (.61)	3.17 (.92)
Scholastic	3.39 (.52)	2.88 (.68)
Social Acceptance	3.26 (.62)	2.86 (.86)
Global Self-Worth	3.49 (.44)	3.15 (.78)

Technical Objectives 3-4: Compare the effectiveness of Basic and Expanded psychosocial intervention and assess the impact of the children's intervention.

Task 5: Months 46-49: Eight month follow-up for Cycle 6 participants is completed. Data analyses to compare treatment effects of Basic and Expanded interventions and impact of children's intervention upon child psychological adjustment and parenting stress.

As the sixth group was completed in June 2001, the 8-month assessments for these families will not be obtained until October 2001. Data analyses for this last assessment period will be run once all of the data from the sixth cycle are returned.

Comparisons of the Expanded Intervention, Basic Intervention and Control Groups on Outcome Variables

Comparisons between the two intervention groups and the control group were performed on global outcome variables, including mothers' adaptation to breast cancer (CARES Global Score), mothers' and fathers' psychosocial distress (SCL-90-R General Severity Index), and children's behavioral symptoms (CBCL Total Score) and competencies (Harter Scales Summary Scores and CBCL Total Competency Scale Score). Global measures are reported to provide preliminary insight into the impact of the interventions, as the 8-month data from Cycle 6 will not be available until October 2001. More detailed analyses that examine potential predictors of response to treatment, as well as family coping and communication characteristics that may influence outcomes will be examined once data collection is complete.

A major limitation to treatment comparisons is the reduced power to detect differences due to low participant recruitment. When this study was proposed it was estimated, based on similar studies being run at the University of Pittsburgh Cancer Institute, that 100 subjects could be recruited to participate in this study, (10 subjects in the pilot study, and 30 subjects assigned to each of the two treatment conditions and a control group). Actual recruitment was 10 subjects in the pilot study, and 34 subjects remaining to assign to all treatment conditions. Given the limitations of finding significant effects in such a small sample, as well as the potential to find associations that may not hold true in larger sample, the findings presented below need to be interpreted with great caution. It is the principal investigator's hope that the dissemination of the treatment manuals for this study will enable more groups to be run, with the potential for data to be collected to obtain a better evaluation of treatment effects. To this end, the treatment manual has been provided to other interested USARMC funded investigators who are involved in psychosocial interventions for breast cancer patients.

The patient groups (Expanded, Basic and Control) were first examined to determine if they were comparable at baseline, on factors that could influence treatment response, including: time since diagnosis with breast cancer, breast cancer stage, number of children, and baseline scores on major outcome variables (SCL-90-R GSI, Cares Total Score). There were no significant differences among the groups on these factors. Participants in the two treatment groups were comparable, with breast cancer patients attending 3.4 sessions and their partners attending 2.6 of the four group sessions on average.

Patient and Spouse Outcomes.

Repeated measures analyses of variance were used to evaluate changes in outcome measures at the four month follow up assessment. No significant differences were found among the Expanded and Basic intervention groups and the no treatment control group for the SCL-90-R General Severity Index (GSI), for both the women with breast cancer and their spouses. Similarly, no significant differences were found among the treatment groups and the CARES Total score at the four month assessment. Analyses to evaluate

group differences at the 8-month follow-up assessment will be performed after the 8-month assessment is conducted for Cycle 6 in October 2001. Additionally, analyses to evaluate subscales of the SCL-90-R and the Cares, as well as the family measures (FPSC, FACES, F-Copes) as they relate to treatment outcomes, will be performed once all data has been collected.

Children's Outcomes

Total symptom score on the Child Behavior Checklist (CBCL) at the four-month assessment did not differ from baseline for children enrolled in the expanded or basic intervention and control groups as assessed by repeated measures analyses of variance. Children's Total Competency scores on the CBCL also did not differ across groups at the four-month assessment. Further analyses will be conducted to explore relationships among competency subscales on both the Harter Scales and the CBCL, demographic variables, and parental outcomes across the control and treatment groups.

Summary

Forty-four families, including 62 children were recruited to the "Families Coping with Cancer Project". While data collection and analysis are not yet completed, the findings to date do provide some new information about family adaptation when a young mother has breast cancer:

- The psychosocial functioning of a majority of premenopausal breast cancer patients was within normal limits.
- Spouses endorsed more psychological distress than the patient did, emphasizing the importance of including the patient's partner in psychosocial interventions for young breast cancer patients.
- "Balanced" families, i.e., those moderate to high on levels of Cohesion and Adaptability, were found to endorse lower marital distress.
- The breast cancer patients reported using more coping strategies than their partners did especially significantly higher use of social support. The women's endorsement of more coping strategies than their partners, may help explain the higher level of psychological distress reported by the partners.
The cognitive coping strategy, "Reframing," was consistently associated with lower distress, especially for the breast cancer patient, and provides support for instruction in cognitive coping techniques in the intervention portion of this study.
- Incendiary speech was a significant predictor of marital distress. The association found between negative communication and distress supports the emphasis on communication skills in the intervention groups as well as the need to focus on the relationship between communication and distress for the fathers in particular.

- Most children were reported to exhibit few emotional or behavioral problems, although there was some preliminary evidence of gender differences in self-competence, with school age girls scoring below boys.
- Global scales of family functioning revealed a general pattern of competency in coping with cancer in the family, with a subset of families exhibiting distress both on psychosocial symptom checklists and measures of family coping.

The ultimate goal of this research is to provide information regarding the best design of a psychosocial intervention for the premenopausal woman with breast cancer and her family. This research should also provide information regarding which patients and families are at high risk for psychosocial distress, and thus assist in determining the best use of resources to meet the psychosocial needs of the young woman with breast cancer and her family.

Task 6: Months 46-49: Preparation of final report and publications.

Final report was submitted with an addendum to follow, once data collection is completed in October 2001. The following publications are planned:

Premenopausal women with breast cancer and their families: The importance of evaluating the partner's adjustment

Children of premenopausal women with breast cancer: Psychological Symptoms and Competencies in children aged 3-12.

Preventive mental health intervention for children whose mother's have breast cancer:
Part I: Group intervention for Preschoolers

Preventive mental health intervention for children whose mother's have breast cancer:
Part II: Group intervention for School Age Children

Preventive Psychosocial intervention for premenopausal women with breast cancer and their partners

KEY RESEARCH ACCOMPLISHMENTS

- Treatment Manual For Patient And Partner Group
- Treatment Manual for School-aged Children
- Treatment Manual for Preschool Children
- Completion of 5 & 6 Intervention Cycles; Completion of first and second assessments for sixth (final) Intervention Cycle

REPORTABLE OUTCOMES

Presentations of the Parent and Children's intervention groups developed for this study are being prepared for presentation at academic meetings. Presentation of the results of the intervention groups will be made as soon as sufficient numbers of participants are recruited to allow for comparisons among treatment conditions. The baseline data described above were presented as a poster and as a Platform presentation at the Department of Defense, Breast Cancer Research Program Meeting in June 2000, and Atlanta, Georgia:

Tarbell, S. Coping with breast cancer in young women and their families. Era of Hope, Department of Defense Breast Cancer Research Program Meeting, Proceedings, Volume II, p. 784.

Tarbell, S. Coping with breast cancer in young women and their families. Symposium: Breast cancer Issues in Premenopausal Women, Era of Hope, Department of Defense Breast Cancer Research Program Meeting, June 11, 2000, Atlanta, GA.

CONCLUSIONS

Thirty-four families, including 62 children were recruited to the treatment phase of the "Families Coping with Cancer Project". While low subject recruitment limited the power of this study to detect differences among treatment groups, data gathered from these families does provide some new information about family adaptation when a young mother has breast cancer.

The psychosocial functioning of a majority (91%) of premenopausal breast cancer patients was within normal limits as assessed by the SCL-90-R. In contrast, 41% of spouses endorsed psychological distress in the clinical range, emphasizing the importance of including the patient's partner in psychosocial interventions for young breast cancer patients. The women's quality of life as assessed by the CARES was in the normative range on average, however, 45% of the women had one or more elevated symptom domains. On the FACES II, 68% percent of mothers and 76% of fathers described their families as "Balanced", i.e., moderate to high on levels of Cohesion and Adaptability, considered to be important to healthy family functioning. Balanced family types were associated with lower marital distress on the CARES ($r = -.47$, $p = .008$). The cognitive coping strategy, "Reframing," as assessed by the F-COPES, was consistently associated with lower distress, especially for the breast cancer patient (CARES, Total Problems $r = -.41$, $p = .02$), and provides support for instruction in cognitive coping techniques in the intervention portion of this study. Family communication as measured by the FPSC, particularly incendiary speech, was a significant predictor of the marital distress ($r = .60$, $p = .000$).

A majority (53/62; 85%) of the children exhibited few emotional or behavioral problems

on the Child Behavior Checklist. A gender difference was found for self-competence, with school age girls scoring below boys in scholastic competence ($t = 2.271$, $df = 27$, $p = .03$) on the Harter Scale of Perceived Competence.

Any enhancement of coping skills and lowering symptom scores after participating in the intervention groups, may have been harder to detect in those families who already exhibited a positive psychosocial adaptation to breast cancer. In further analyses, the impact of the Expanded and Basic intervention on the psychosocial outcomes of the most distressed families will be investigated. It may turn out that the psychosocial interventions being tested worked best for those in distress. The low recruitment rate limits the power to draw conclusions from comparisons between the Expanded and the Basic interventions, especially in terms of whether children benefited most from direct intervention or whether they evidenced improvement in psychosocial adaptation by proxy--that is, through parental involvement in the intervention only. The ultimate goal of this research was to provide information regarding the best design of a psychosocial intervention for the premenopausal women with breast cancer and her family. This research should also provide information regarding the identification of which patients and families are at high risk for psychosocial distress, and thus assist in determining the best use of resources to meet the psychosocial needs of the young woman with breast cancer and her family.

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APPENDICES

Appendix 1: Treatment Manual: Patient and Spouse Group

Appendix 2: Treatment Manual: Younger Children's Group

Appendix 3: Treatment Manual: Older Children's Group

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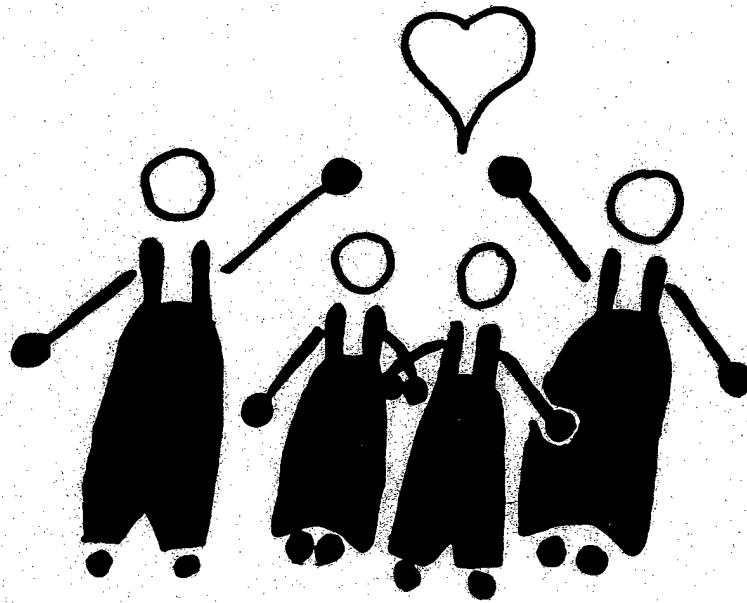
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FAMILIES COPING WITH CANCER PROJECT

Treatment Manual: Patient and Spouse Group



Funded by U.S. Army Materiel Command 1997-2001

Family Intervention for Young Women With Breast Cancer

**Sally E. Tarbell, Ph.D.
Principal Investigator**

WELCOME AND INTRODUCTION to the:

"Families Coping With Cancer Project"

A. INTRODUCTION

(Participants fill out nametags and are provided with a tote bag and notebook to file educational materials handed out during the group meetings.) Welcome to the Families Coping with Cancer Project. We are very pleased to have you here with us today. My name is Dr. _____. I am a health psychologist from the University of Pittsburgh Cancer Institute and this is _____, an oncology nurse educator, also from the UPCI. We will be meeting with you today for about an hour and a half. During this time we will give you an understanding of how this project came to be and what we hope to accomplish during our four meetings.

Young women with breast cancer and their families face many stresses. Coping with a serious illness and its treatment while you are young and actively raising children, and attempting to balance family, personal, work and health care concerns is an especially daunting task. Many available education and support programs for cancer patients do a good job of providing information about cancer and its treatment but few respond specifically to the needs of families like you, young couples with growing families. In fact there is relatively little research to guide the development of programs to help young women with breast cancer and their families cope with cancer and its treatment. This project aims to bridge this gap and has been funded for three years by the U.S. Army's Breast Cancer Research Program.

Before we go further and elaborate our plans for this group I think it would be helpful for each of us to introduce ourselves and especially for us to hear about what interested you in coming to this group. *(Start with the group leaders. Each participant is asked to say their name, something about themselves, what interested them in coming to the group and any topics or issues they would like to see addressed in the group. Leaders summarize comments by participants, reviewing the range of expressed interests and goals for the group. This exercise takes about 20-30 minutes).*

I would like to start with three basic assumptions guiding this project:

The first is our belief that breast cancer is a disease that affects the whole family--the woman, her partner, their children, parents and extended family. This disease also affects friends and colleagues. Most education and support groups for cancer patients focus on the patient only. While it is extremely important to attend to the specific needs of the individual fighting cancer, we believe that when you are a young woman with breast cancer, meeting your needs means attending to those of your family as well. We have asked both you, the woman who has had breast cancer, and your partner to attend this group. We do this because we know breast cancer has a significant impact on partners, and that their unique experience and concerns have been neglected and need to be heard and responded to. We also know that husbands often take on a major role in supporting their wife and children when a young mother is diagnosed with breast cancer and that their involvement is critically important to the health and well being of their wives and children. In fact, there is research indicating that the well parent plays an important role in buffering children from the stress of a spouse's illness. The spouses in this group can help us and help others by sharing your insights and concerns about changes brought about by breast cancer in the family, and ways you have learned to cope with these changes. We also will spend time discussing how children react to parental cancer, in particular how children of

different ages cope with an ill parent and the changes in family routines brought about by the illness, the kinds of behavioral issues that might emerge, and how to help your children cope optimally with illness in the family. *(For those in Expanded Intervention only: We also have developed an education and support program specifically for children whose mothers have breast cancer. I will talk more about this program in a few minutes).*

A second basic assumption of this project is that each person plays many roles simultaneously in life, being an individual with unique qualities, skills, interests, values, and goals, a partner in a marriage, and a parent. We have designed this group with an appreciation that a woman with breast cancer need not be defined by her disease or let the disease of breast cancer take control of any of these domains. Therefore we will spend time over the next few sessions looking at how to maintain the highest quality of life in all the roles you and your spouse play, i.e., keep illness in its place and not let it take over family life. To this end we will have sessions devoted to individual, relationship and parenting issues. I will discuss the particulars of the meetings to come in more detail in a few minutes.

The third basic assumption of this project is that you are all normal people dealing with extraordinary circumstances, and therefore we assume you come to this group with many strengths and skills for managing cancer and its personal and family impact. You are the experts on this experience. What we can offer you are some proven techniques to help you lighten your personal, interpersonal and parenting load. You also, I am sure, have much to offer each other, as you are all young families confronting a chronic disease and each of you has insights gained from your experiences that may be valuable to others in this group. We view this group as an opportunity for you to sharpen some of the tools you already have in your coping toolbox and to put some new tools into that toolbox (Like taking an elevator when you have a broken leg, it's not that you can't take the stairs it's just that there may be an easier way that frees up more energy for you to enjoy life and improve its quality.) Previous research has shown that education and support groups can improve the quality of life of cancer patients. While participation in these groups is not a treatment for cancer, but rather for the changes cancer brings about in family life, there have been two studies of patients with advanced cancer that have found an association between support group participation and longevity. Our goals in this group are more modest. We believe that if each member of the family can receive the information and support they need in order to adapt to the changes in their lives brought about by cancer, that this will better enable the woman with breast cancer and her family to cope. One family member's illness affects every other member of the family, whose responses in turn further change the family environment. Because we do not yet know what is the best way to provide a program for the whole family we are trying a few different approaches. For example, we are having some groups that directly involve parents only and others that include a parents' and a children's group. It is likely that both formats will be helpful to some families, and one of the goals of this project is to find out which format works best for which families, so that in the future we can provide the treatment that best matches a particular family's needs.

Now, let me review the agenda for our meetings. *(Participants are asked to open their notebooks to the Table of Contents).* We will take time today to examine your roles as parents and how to understand and respond to your child's reactions to illness. Even if your breast cancer occurred some time ago, it is likely that your children will still have some questions or issues related to your illness. *(Expanded Intervention only: Today your children will have the opportunity to have questions about cancer answered by our oncology nurse, our child life specialists, and our pediatric psychologist.)* At our second meeting, we will discuss stress management as a way for each of you to bolster your own personal resources in coping with breast cancer. We will discuss how your body responds

to stress and go over how to reduce this response. Some of the techniques of stress management, such as relaxation, can not only reduce stress but also have positive effects on your health such as lowering blood pressure and reducing physical symptoms such as headaches. We will also discuss how thoughts effect your mood and behavior and ways of thinking and coping that can effectively reduce stress. At our third and fourth meetings we will discuss techniques for improving communication within the family and with those outside the family, including friends, colleagues and the health care system. Finally, we will review how you can apply the skills you already have and some new you ones you may take from this project to ensure the best possible long term healthy outcomes for you and your family.

Are there topics or issues you are wondering about or would like to see covered that we have not yet mentioned? *(Leave time for group members to respond. Hand out 3 x 5 cards on which participants can list any issues or concerns they would like to see covered. This will help assure that the group will be responsive to participants' interests and concerns within the context of the planned agenda for the four group sessions).* You also can catch up with us after the group today if you have questions or comments about any aspect of the group.

I will next tell you about the format of the group meetings. The group will work best with your active participation. From month to month we may ask you to do little practice assignments to try out the ideas and skills we discuss in the group at home. The start of each group will begin with a review of your experiences or comments about the prior meeting's topic of discussion. We will then provide a brief educational discussion about the current meeting's topic, lasting 15 - 20 minutes. We will take the remainder of the group to apply or practice the skills or issues brought up in the educational discussion. *(For those in the Expanded Intervention, the last 5 minutes of the group will be taken up with a review of what the children were working on in their session and ways to reinforce their learning during the month.)*

We also want to propose some group rules. One is that to make it comfortable to talk about your experience with cancer in the family, we ask that you not discuss other participant's stories outside of the group. This does not mean you are not to think about or discuss issues brought up by the group in between meetings--far from it. We think this group can be most effective if the skills and issues we talk about here are applied in your every day life and that you bring back your experiences to the group. We just ask you to use discretion, and not discuss other group members' names or particulars outside of the group. *(Take time to answer participant questions. The oncology nurse educator leaves the parent group to provide education to the children's groups.)*

B. EDUCATION

Children's adjustment to parental illness. As was emphasized earlier, cancer is a family experience. Parents have a critical role in shaping the impact of a family member's illness on their children. A child's fundamental needs when a parent is ill have been well described by Dr. Harpham, a physician and mother, who herself has been fighting cancer for several years. She defines these as follows:

1. **Satisfying basic emotional and physical needs;**
2. **Understanding at their level what is happening, in terms of the parent's initial diagnosis, treatment and any ongoing care; and**
3. **Reassurance that they will be cared for no matter what happens.**

Today we will consider some ways to meet these fundamental needs of children through our discussion of communicating with your children about your illness and the changes it brings to family life. Establishing open and honest communication is essential to maintaining the child's trust. While it can be very hard to share your illness experiences with your children, they know something is going on even if they are not told directly. Sometimes their thoughts about what might be happening can be worse than reality and cause them a great deal of distress. When you are able to keep communication open you have the opportunity to correct any misperceptions, reassure them, and help them to cope with their concerns. This does not mean overwhelming your children with information they cannot understand or giving them unnecessary details. It does mean taking time to provide them with honest information about a parent's illness that they can understand. And, if they ask for information you can be pretty sure that they have been thinking about their question and that they need you to fill them in. We will take time in a few minutes to describe how to provide information to children of various ages, and also how to tell if your child is having difficulty coping with the changes cancer has brought to the family. Communicating with your children about your illness is an ongoing process and does not stop after you have shared information about your diagnosis and treatment. Even when you have completed treatment and all the outward signs of your illness are gone (e.g., hair loss, return to old routines) a child will still likely have questions and issues about your illness that will come up again and again. It often takes several discussions over an extended period of time for children to learn how to cope with your illness. And, as children grow and change very rapidly, it is often necessary to revisit old issues again as the child matures and needs to reexamine old concerns in a new way.

I am wondering if any of you have experiences you can share with the group on your efforts to talk with your children about your/your wife's illness and what sort of things may have helped or hindered your communication? (*Group leaders solicit participants' examples and use this opportunity to highlight the importance of developmentally appropriate, honest communication.*)

We will turn now to a review of how illness is understood by children at different ages, the kinds of concerns they have about parental illness, some things you can do to help them cope, as well as behaviors that may signal they are having difficulty coping. Throughout this discussion we encourage you to share examples of your own experiences with discussing your illness and treatment with your children, as each of you have things you have learned that can benefit others in the group. (*Review Handout: Children's Understanding of Parental Illness by Developmental Stage.*)

D. BRIDGE TO CHILDREN'S INTERVENTIONS (Expanded group only)

Today your children will be introduced to the purpose of the group and the topics to be covered in their meetings. The topics they will explore will include their perspective on how they coped and are coping with illness in the family, how to identify and appropriately manage their feelings, relaxation and problem solving exercises, and skills for getting along with others. Throughout the children's groups there will be a strong focus on their feeling good about themselves and reinforcing their self-esteem, as it appears that these are the areas that are affected most by a parent's illness. Their group is structured so that the children have a regular routine each meeting including: an introduction to the topic of the session, a review of what they were working on in the previous session, some time for play, games and stories that pertain to the issues being covered, a snack, and then a practice activity to reinforce what they have learned between meetings. Typically this will be a book you and your child can read or an activity that you can do together between our meetings.

Each meeting we will take some time to review what your children are doing in their groups so that you can help reinforce the skills they are learning. Today the children's groups focused on helping them get to know one another, on how each of them is special and unique, and also on the ways they are alike, including that they all have moms who have been sick. They will be provided with developmentally appropriate information about cancer and hear stories by other kids whose mom's have had cancer. We hope that hearing the stories and listening to other children in the group will help your children "normalize" the experience of cancer and help correct any misperceptions they may have about cancer and its treatment. The younger children heard stories and made a group banner. The older children drew pictures of themselves and started a scrapbook to record the different activities they will be doing over the course of the group. We also are asking the children to notice something fun that they do with their family, as they will talk about the fun things they do with their families at the next meeting. *(Leaders ask for questions from the participants regarding the children's groups. Children's group leaders join the parent group with the children and briefly review the children's activities).*

Handouts for the Families Coping With Cancer Project

Patient and Partner Group

Session 1

CHILDREN'S COPING WITH PARENTAL ILLNESS

DEVELOPMENTAL STAGE	CHILD'S CONCERNS	WHAT MAY HELP	BEHAVIORAL CONCERNS
Preschoolers Egocentric and magical thinking	Separation	Consistent Support	Loss of previous mastered skills, e.g. toileting, dressing Extreme distress at separation
		Explore child's understanding of the parent's illness and it's treatment to correct any misperceptions, e.g., they did not cause cancer; they cannot catch cancer	
School-age children Concrete thinking	Understanding of illness and treatment Able to wonder and worry at a more sophisticated level, concerns about death	Seeing parent in medical setting Give concrete explanations using pictures, diagrams and drawings Insure children are informed. Take child's cue to talk about feelings and concerns	Child withdraws socially Difficulty coping with school or other usual activities Sleeping or eating problems Low mood or irritability Aggressive or regressive behavior

DEVELOPMENTAL STAGE **CHILD'S CONCERNS** **WHAT MAY HELP** **BEHAVIORAL CONCERNS**

May feel vulnerable, guilty, intense emotions such as anger, sadness	Insure children's feelings and concerns are acknowledged	
May feel that they are a burden or that their activities are not important	When parents can't be there, have another adult fill in at games, school functions and other activities	
May have trouble with peers or isolate self	Encourage child to talk about peer problems so that solutions can be found. Inform school about parent's illness	

Adolescents

Abstract thinking	Initiate open and honest communication about illness and its impact on the adolescent and family	Changes in school performance Sleep and eating disturbances
Able to more fully understand illness and its consequences		

DEVELOPMENTAL STAGE	CHILD'S CONCERNS	WHAT MAY HELP	BEHAVIORAL CONCERNS
	Conflict between the need to feel independent and the need for support and reassurance	Encourage contact with supportive peers and adult figures, e.g., coach, teacher	Low mood or irritability High risk behaviors: smoking, drinking, drugs
	May have increased responsibility for household and care of siblings	Acknowledge adolescent's valuable contributions and attempt to find other resources to meet household needs so that adolescent's needs can also be met	
		Validate adolescent's perceptions and problem solve for solutions to make the best of changed circumstances	

Resources:

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RESOURCES FOR PARENTS

Books

Cancer Related

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Internet

<http://www.oncolink.upenn.edu/>

A very comprehensive website on cancer, with links to the National Cancer Institute and several cancer organizations.

<Http://www.kidscope.org/>

A website for an organization formed to help children and families better understand the effects of cancer and chemotherapy in a parent.

Books for Children

Cancer Related

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Lite, L. A Boy And A Bear: The Children's Relaxation Book. Plantation, FL: Specialty Press, 1996. Ages 3-10.

Lobel, A. Frog and Toad Are Friends. New York: Harper, 1970. Ages 3-5.

Maguire, A. We're All Special. Santa Monica, CA: Portunus Publishers, 1995. Ages: 3-6

Mayer, M. All By Myself. New York: Golden Books, 1983. Ages 3-6.

Mayer, M. I Was So Mad. New York: Golden Books, 1983. Ages 3-6.

McBratney, S. Guess How Much I Love You? Cambridge, MA: Candlewick Press, 1994. Ages: 3-6.

Moser, A. Don't Pop Your Cork On Mondays! The Children's Anti-Stress Book, Kansas City, MO: 1991. Ages 6-11.

Moser, A. Don't Feed The Monster On Tuesdays! The Children's Self-Esteem Book, Kansas City, MO: 1991. Ages 6-11.

Moser, A. Don't Rant and Rave on Wednesdays! The Children's Anger-Control Book, Kansas City, MO: 1991. Ages 6-11.

Moser, A. Don't Despair on Thursdays! The Children's Grief-Management Book, Kansas City, MO: 1991. Ages 6-11.

Palmer, P. The Mouse, The Monster, and Me: Assertiveness For Young People. San Luis Obispo, CA: Impact Publishers, 1977. Ages 8-12.

Patz, N. To Annabella Pelican from Thomas Hippopotamus. New York: MacMillan, 1991. Ages 3-6.

Payne, L. We Can Get Along. Minneapolis, MN: Free Spirit Publishing, 1997.

Schlein, M. The Way Mothers Are. Morton Grove, IL: Albert Whitman & Co., 1993. Ages 3-7.

Shapiro, L. The Very Angry Day That Amy Didn't Have. King of Prussia, PA: Childsworld/Childsplay, 1994 (800-962-1141). Ages 7-12.

Viorst, J. Alexander and the Terrible, Horrible, No Good, Very Bad Day. New York: Alladin Paperbacks, 1987. Ages 4-8.

Viorst, J. The Good-Bye Book. New York: Alladin Paperbacks, 1988. Ages 3-6.



RESOURCES FOR BREAST CANCER SURVIVORS & THEIR FAMILIES

Books

Bloch, A. & Bloch, R. Guide for Cancer Supporters: Step-By-Step Ways To Help A Relative Or Friend with Cancer. R. A. Block Cancer Foundation , Inc., (816) 932-8453.

Harpham, W. After Cancer. New York: W.W. Norton, 1994.

Hermann, J. Wojkowiak, S., Houts, P., & Kahn, S. Helping People Cope: A Guide For Families Facing Cancer. Harrisburg, PA: Pennsylvania Department of Health, Cancer Control Program, 1988. (1-800-722-2623).

LaTour, K. The Breast Cancer Companion. New York: William Morrow, 1993.

Love, S. Dr. Susan Love's Breast Book. Menlo, Park, CA: Addison-Wesley, 1990.

Nessim, S. & Ellis, J. Cancervive: The Challenge Of Life After Cancer. Boston: Houghton Mifflin, 1991.

Schover, L. Sexuality and Fertility After Cancer. New York: John Wiley & Sons, 1997.

Spiegel, D. Living Beyond Limits. New York: Times Books, 1993.

Weiss, M. & Weiss, E. Living Beyond Breast Cancer: A Survivor's Guide For When Treatment Ends and The Rest of Your Life Begins. New York: Times Books, 1997.

Internet Resources:

<http://www.oncolink.upenn.edu/>

A very comprehensive website on cancer, with links to the National Cancer Institute and several cancer organizations

<http://cancernet.nci.nih.gov/occdocs/cis.html>

National Cancer Institute Cancer Information Service

<http://www.cancer.org>

Web page of the American Cancer Society

<http://www.cancercare.org/>

An organization with many resources on coping with cancer

<http://cancernet.nci.nih.gov/canlit/canlit.htm>

Search for literature of more than 70 predefined topics in the National Library of Medicine's CANCERLIT database

<http://www.acor.org>

Association of Cancer Online Resources: List of online resources.

<http://www.mskcc.org>

MSK Web: Memorial Sloan-Kettering Cancer Center's web site provides a wide range of information for medical professionals, patients, their families and the general public.

<http://cancernet@icicc.nci.nih.gov/>

PDQ: NCI's comprehensive cancer database, extensive register of ongoing and closed clinical trials.

<http://www.y-me.org>

Y-ME National Organization for Breast Cancer. Material about support groups nationwide. Information on breast cancer. First person accounts of breast cancer survivors and their family members.

<http://www.lbbc.org>

Living beyond breast cancer. Helpline, breast cancer information.

<http://www.nabco.org>

National Alliance of Breast Cancer Organizations. Information and access to support groups nationwide.

Organizations

American Cancer Society
1-800-ACS-2345

Cancer Care, Inc.
1180 Avenue of the Americas
New York, New York 10036
(212) 221-3300/(800) 813-4673

National Alliance of Breast Cancer Organizations (NABCO)
37th Street, 10th Floor
New York, New York 10016
(212) 719-0154

National Cancer Institute (NCI)
Cancer Information Service
31 Center Drive MSC 2580
Building 31, Room 10A16
Bethesda, MD 20892-2580
(800)-4-CANCER

University of Pittsburgh Cancer Institute
Education Center for Patients, Families and the Public
7 Main, Montefiore University Hospital
Hours: Monday-Thursday 8:30 - 4:30, Friday 8:30 - 3:00
(412) 692-4704

University of Pittsburgh Cancer Institute
Cancer Information and Referral Service
(800) 237-4724 or (412) 624-1115

CANCER CARE

Briefs



Cancer Care, Inc.®

National Office
1180 Avenue of the Americas
New York, NY 10036
(212) 221-3300

Cancer Care Counseling Line
1-800 813-HOPE (1-800 813-4673)

Helping Children Understand Cancer: Talking to a Child About Illness in the Family, or about Their Own

Cancer is a complicated disease to understand, even for adults. There are many types of cancer and no easy way to describe them, especially in simple terms. But if your child has cancer, or if you or someone in your family does, discussing it with your children may be the most important thing you do. Because when someone in your family has cancer, it affects the entire family, including your children.

"Protecting" Children Can Sometimes Make Things Worse

When cancer strikes a family, children sense that something is wrong, even if they don't know what it is. Talking it over with them, using words that they can understand, is always better than trying to hide it from them. If you keep things from them, children can imagine that things are even worse than the real situation.

For example, it is not uncommon for young children to think their actions somehow caused a parent or sibling to get cancer, perhaps from something "bad" that they did. It is important to not only communicate with your children, but to listen to them to make sure they understand what is happening. No matter what their age, there are ways to communicate with children about cancer, treatment, and, if necessary, life and death.

How to Tell Your Child That You or Someone in Your Family Has Cancer

When a child's life is touched by cancer, it can cause a great deal of emotional trauma — mostly because any kind of serious illness is *scary* to a child. Fortunately, as a parent, you can help your child overcome many of his or her fears, often by simply explaining the situation in a calm, reassuring way.

To help you talk to your child about someone in your family who has cancer, Cancer Care offers the following tips on communication:

1. Tell Them About the Illness. Although cancer is complicated, there are ways of discussing it that are appropriate for a child of any age. For very young children, "Mommy is very sick, so she has to go to the hospital to get well again," is usually enough; for older children, a more detailed explanation is better. The more they can know, the less helpless and afraid they will feel.

2. Practice Your Explanation Beforehand. It will be a great help to your child if you can be as calm and objective as possible when you discuss cancer, especially if you are the one who is ill. You should practice the conversation with your spouse or a friend, so that you can focus on your child's fears, and put aside your own for awhile.

3. Remove Any Blame. The younger children are, the more they think the world centers around them, and the more likely they are to feel responsible for a parent or sibling's illness. Assure them by saying that nothing they nor anyone else did caused the cancer.

4. Explain to Them that Cancer is Not Contagious. Most children first experience sickness when they get a cold, measles, or some other childhood disease that might have been fairly contagious. It is important that you explain to them that cancer is not contagious. They will probably already be afraid that someone else in the family will now get it. Assure them this is not true.

5. Try to Balance Optimism and Pessimism. Telling your child that someone will be "all better" will only make them more confused and upset if it is not true. On the other hand, being very pessimistic can scare them needlessly. It is usually best to try to offer a realistic but hopeful assessment of the situation.

6. If You Have Cancer, Try to Stay in Contact. If you are in the hospital for any extended period of time, your children may think that you don't want to be home with them. Staying in touch will help reassure them that your illness has nothing to do with how much you love them.

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7. Take Your Children's Feelings Seriously. It is common for children to have many different reactions when they learn a parent or sibling has cancer. These can include anger, sadness, guilt, fear, confusion, and even frustration. All of these responses are normal. Let them know that it is *ok* for them to have lots of different feelings — you may have many of them, too.

8. Answer Questions Honestly. Discussing cancer with a child can be difficult, especially when there are so many questions that adults or even doctors cannot answer. It is best for you to be as honest as you can with your child, and to not be afraid to say "I don't know" if you don't. For children, the amount of information you give them is usually less important than making them feel comfortable with what you say.

9. Help Children Understand Treatment. Children's greatest fears often spring from what they don't know. Their imagination often creates a picture that is worse than what is really happening. Explain the treatment process, in a way that is appropriate to their age — don't forget, it is easy for a child to imagine something like chemotherapy or radiation therapy is "bad" because it can cause hair loss, nausea, and other unpleasant side effects.

10. Prepare Your Children for the Effects of Treatment. Cancer and

cancer treatment can often dramatically affect someone's appearance. Physical changes such as hair or weight loss can sometimes frighten them, or make them think a person is "changed" or "different." It is best to explain to them beforehand, so they are prepared. For example, "When mommy was sick in the hospital, she lost weight, and her hair fell out — but don't worry, it will grow back. And she's still the same mommy on the inside."

11. Let Children Help, But Don't Burden Them with Responsibility. It is important to let children know that they can help their parent feel better; it will make them feel less helpless if you let them run an errand, bring a glass of orange juice, or do some other task that is appropriate for their age. But be careful not to burden them with too much. The stress of having someone ill in the family can be great. They will need lots of time to just play, relax, and be children.

12. Be Prepared to Discuss Death. This is a complicated topic, but if you or your family member is very ill with cancer, you should be prepared to discuss death with your children. It is impossible in this short space to suggest ways to discuss this with your child. You may want to consult with a trained counselor or clergy first. One of the most important things to remember is to take your child's age into

account — pre-schoolers, for instance, do not understand that death is final; school-age children tend to know that dead things don't eat or breathe or sleep; by the age of ten, children begin to understand that death is the end of life.

Regardless of your child's age, when discussing death, remember three things: 1) Try to use very clear, specific terms. Being vague will only confuse your child. 2) Do not use terms like "sleeping forever" or "put to sleep", because children will think sleeping is like death, or be afraid that if they sleep, they might die. 3) Finally, be patient. It will take a long time for a child to fully understand, and to accept, any type of loss. They certainly will not understand the first time you try to tell them.

Remember, when cancer strikes a family, children know something is wrong. Trying to protect them will only make them imagine the worst, and will prevent you from helping them understand and eventually accept what is happening. If you need help in talking to your children, don't be afraid to ask for it. Being a parent doesn't always prepare you for every situation, and being unsure of what to say is no reason to be ashamed. ☹

* Many parts of this brief were liberally borrowed from Lynne S. Dumas' book, "Talking With Your Child About A Troubled World," published by Ballantine Books. Our thanks for her permission of use.

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Cancer Care is a nonprofit organization whose mission is to help people with cancer and their families. Staffed by professionally trained oncology social workers, each year Cancer Care reaches more than 50,000 cancer patients and family members through one-to-one counseling, specialized support groups, educational programs, and telephone contact, providing guidance,

information and referrals. All of Cancer Care's services are free of charge. Cancer Care also offers financial assistance for transportation to and from chemotherapy and/or radiation therapy, child care, home care, pain medication or other treatment-related costs on a restricted basis.

Cancer Care offers direct services through its national toll-free number

—1-800-813-HOPE — and through its offices in New York, New Jersey, and Connecticut. While separate and apart from other cancer organizations, Cancer Care works closely with major hospitals and other health institutions to bring desperately needed care to people with cancer and their families. Cancer Care, Inc. was founded in 194 on the principle that "living does not end when cancer begins." ☹

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For additional copies or for more information, please contact your local Cancer Care office, or call 1-800- 813-HOPE.

Handouts for the Families Coping With Cancer Project

Patient and Partner Group

Session 2

SESSION 2

OBJECTIVE:

1. Participants gain an understanding of physical and psychological stress responses and ways to manage stress, especially as it relates to cancer in the family.
2. Participants have the opportunity to share their experiences of breast cancer in the family with other women and their partners.

OUTLINE:

1. Review of the last session's topics.
2. The body's response to stress, including: relaxation demonstration.
3. The mind's response to stress, including: cognitive distortions, controllable and uncontrollable stressors, problem-solving, emotion-focused and avoidant coping strategies.
4. Bridge to children's intervention groups (Expanded Intervention Only).

SUPPLIES:

1. Name tags
2. Pens
3. Parking passes/child care reimbursement (Basic Intervention Only)
4. Refreshments: Coffee/bagels/napkins/plates/cups

HANDOUTS:

1. Relaxation Audiotape
2. Handout: Resources on Stress Management, Coping and Communication
3. Handout: Cognitive Distortions and Rational Alternatives
4. Handout: Methods of Coping
5. Handout: Resolve Method of Problem Solving

SESSION 2

STRESS MANAGEMENT: Your Body and Mind's Responses to Stress

A. REVIEW

(Group leaders ask participants for their comments about any issues discussed in the last group session and about the resource list and handouts provided. Parents in the Expanded Intervention are asked about their experiences with the books/activities that were recommended to them and their children.)

B. EDUCATION, Part 1: Your Body's Responses to Stress

Today we will be working on filling your "energy bank account". Some things we do help build our reserves, giving us the energy to do the things we like to do and the things we have to do. Examples would be a good night's rest, a talk with a close friend, hobbies, exercise, enjoying a job well done, and vacations. *(Leaders prompt group members for other, personal examples)*. Other things we do may deplete us such as not eating well, not getting enough sleep, attempting to do too many things and having too little time to do them and so on. *(Again, leaders prompt group members to offer their own examples of things that deplete their energy)*. In order to minimize our withdrawals and maximize our deposits it is important to understand the stress response and the things you can do to counter it. Today we will be talking about the impact of stress on your body and some things you can do to reduce or lessen its effects.

To begin, you are all experts on stress having coped with breast cancer in the family. I am wondering what are the things you feel and what changes you notice in your body when you are feeling stressed. *(Leaders prompt members to provide personal examples of how they identify their physical responses to stress)*.

From research done in the early part of this century we now know that our bodies have characteristic ways of responding to stress. Our mind and bodies actually change in response to stress. We call this response the "fight or flight" response. The fight or flight response is so named because the changes that occur to our body make it easier for us to fight or flee a potential stressor. This response probably developed over thousands or millions of years and was important to our ancestors to help them survive dangers, like fighting or running away from a ferocious animal. The changes in our body that occur with the fight or flight or stress response include:

- Increased muscle tension
- Increased heart rate
- Increased blood pressure
- Increased respiration
- Increased sweating

Other changes that occur include: dilation of your pupils, slowing of digestion, your hands and feet may get cold, and a narrowing of attention, with your senses becoming hyperalert so that you may respond quickly to the stressors.

The stress response is mediated by many different chemicals in the body, an important one being adrenaline or epinephrine. The arousal we feel provides us with great strength and speed for a short period of time and is essential to our ability to respond effectively when immediate action is called for. Once released, the stress response is often followed by feelings of tiredness, even exhaustion. Eventually we return to normal after resting.

Today we do not usually need to fight or flee to manage the stresses of our life, but our bodies still respond to stress in this characteristic way. For example, you may get upset about being stuck in traffic, but you can't get out of your car and fight with the other drivers, nor can you flee. If the stress response is chronically provoked with no opportunity for release, there can be a build up of tension. You can begin to feel like a bomb ready to explode, and you may let go of this tension inappropriately by blowing up at a friend or a family member.

(Leaders: What sorts of things do you do when you feel this build up of tension? Does anyone routinely use exercise or relaxation to cope with feelings of stress?)

Relaxation and exercise are among the best ways we can let go of this tension as it accumulates.

Today we will focus on learning some ways to relax that can help you release the tension that builds up from the repeated activation of this stress response. Before we begin this exercise, I would like to emphasize two more points about the stress response.

One is that stress can occur because of any sort of physical or mental stressor. Even if we are only thinking about a potentially stressful experience, the stress response can be generated. The body can't always tell the difference between a real event and one that you are thinking about. Thoughts can be stressors too. As an example, I imagine all of you can vividly recall the mental stress of waiting for the results of the breast biopsy and the way you felt at the time. *(Leaders prompt group: What thoughts went through your mind? What feelings went along with them?)* Thoughts can also be calming and help you reduce stress. *(Can you think of any examples? Leaders prompt group members to recall a self-comforting or calming thought).* And this is why we will practice a relaxation exercise in a few minutes that will include a part that focuses on relaxing imagery, that is, using your mind to calm your body and decrease your stress response. We will further discuss your mind's responses to stress and cognitive/psychological coping strategies in the second half of today's session.

The second point I would like to make is that **stress is cumulative and we each get signals from our bodies and minds when we are reaching our threshold.** We generally start feeling uncomfortable. Some of those signs can be feelings of anxiety or irritability, or physical symptoms, such as headaches and being tired. Each individual may have a unique set of signs. *(Take time to discuss with the group their own unique signs of stress.)* Sometimes we may experience a full blown stress response, with all of the physical and mental changes mentioned earlier, at other times we may notice small changes, like feeling a little more tension in our bodies. What do we do when we get these signals? Do we ignore them or do we take time to notice these stress signals and do something about them? You can think of these signals like the temperature light on your car. If you are driving along and the temperature light goes on, is this a good thing or a bad thing? It can be a bad thing because something is wrong with your car, but on the other hand it can be a

good thing because you know something is wrong and you can do something about it. Now, what would happen if you taped up the light when it went on or ignored it entirely? Chances are the car would break down. The point I am trying to make is that we experience the signs of stress in our body and in our mind and what we need to do is pay attention when that light goes on, and make some effort to release the tension.

Remember that the stress response isn't a "bad" thing. Just like the warning light on our car, we need it to alert us to potential danger and to mobilize ourselves for action. But as we don't always need to be in a state of high alert and poised for action, we can take steps to reduce the tension that can come with the stress response.

Finally, it is important to emphasize that there is no evidence that stress causes cancer. You cannot give yourself cancer by worrying or by getting overwhelmed by stress. We do know however, that individuals with cancer who have participated in a variety of psychosocial interventions designed to reduce stress have experienced improvements in quality of life and physical symptoms. *(The oncology nurse educator leaves the parent group to visit the children's groups to answer any remaining or new questions about cancer and its treatment.)*

C. PRACTICAL TRAINING

Today I will be leading you through some relaxation exercises. *(Have you ever practiced a relaxation exercise before? If so, tell me about your experience with the relaxation exercise. How was it helpful?)*

Relaxation produces the mirror image of the stress response in your body: your heart rate, blood pressure and breathing rate decrease, your muscles loosen and become less tense, and as the blood vessels dilate you may notice that your hand and feet get warm. Mentally, relaxation is characterized by feelings of calmness and well being. In other words it is the opposite of the stress response.

The relaxation exercise you'll be learning has three parts. The first part involves practicing some deep breathing. Deep breathing or "abdominal breathing" is when you bring the air as deeply as you can into your chest and abdomen. Your chest and abdomen actually expand, much as if you had a balloon in your belly expanding each time you inhale. When you exhale the chest and the abdomen flattens again. Because you are giving your lungs extra space to fill up with these deep breaths, your breaths are actually fuller than with chest breathing alone. This type of breathing brings about feelings of calmness and relaxation for reasons that are still not altogether clear to physiologists. This is a simple yet really effective way to elicit the relaxation response. In the second part, you will practice a progressive muscle relaxation exercise in which you will be tensing and relaxing muscles throughout your body. This exercise will help you become aware of tension in various parts of your body and of ways to reduce that tension. In the third part you will practice bringing a pleasant image to mind which you may use to help you relax even further. All three different strategies to relax can be effective, but one may work best for you. It will be up to you to practice these exercises and to decide for yourself what works best. Relaxation, like any other skill, requires practice in order for you to benefit most from it and to get the most benefit from this exercise. I have taped this exercise for you so you can go home and practice it. *(Ask the participants if they have tape players. If not, the patient may borrow one from the clinic for the duration of the study).* It is best to practice this exercise at least once a day, preferably not after meals and not before bedtime.

Relaxation Exercise

To begin, get yourself into a comfortable position, and when you are practicing at home find a time and place where you will not be interrupted for about 10-15 minutes. You may need to give some thought to how you can arrange this time for yourself on a regular basis.

You may wish to close your eyes to help you focus on the exercise. First, begin to pay attention to your **breathing**. Notice where your breaths are coming from. Are they coming from your chest or further down in your abdomen? I am wondering if you can breathe deeply enough so that you can feel your breath coming from your abdomen. You may want to place your hand on your abdomen to feel it expanding each time you inhale. Take a few moments to see if you can deepen your breathing. As you begin to pay attention to your breathing simply notice the air going in and out. In and out. As you focus on your breathing, you may be able to imagine yourself breathing in relaxation and breathing out all tension. Just notice the natural and relaxing rhythm of your breathing. Now, I would like you to take a deep breath, hold and let go. Again, deep breath, hold and let go. One more time deep breath, hold, and let go. Return now to the natural and relaxing rhythm of your breathing.

Progressive Muscle Relaxation

Next is an exercise in which you will become aware of tension in your body and then practice ways to reduce this tension.

First, direct your attention to your right arm. Put your right arm out straight, make a fist and tighten your whole arm from the tips of your fingers to the top of your shoulders. Pay special attention to the areas that are particularly tight or tense. Relax and lower your arm, bending it at the elbow and bringing it to rest by your side. Notice how it feels to have those muscles loosen and relax.

Now, put your left arm out straight and make a fist, and tighten your whole arm from the tips of your fingers to the top of your shoulders. Once again, pay special attention to the areas that are particularly tense. Relax and lower your arm, letting go of any tension that might be there. Notice how it feels to let those muscles loosen and relax. Just relax.

Next, we'll turn to the muscles of your face, starting with your forehead. Wrinkle up your forehead, until your entire forehead is really, really wrinkled your muscles tense and your skin furrowed. Feel how tight it is. Now relax, letting go. Feel the muscles loosen, and relax.

Now, close your eyes very tightly. Feel the tension as it radiates around your eyes. Now relax. Notice the difference in the way your eyes feel as you loosen the muscles.

Now, clench your teeth and tighten the muscles in your face. Feel the tension as it moves throughout your whole jaw. Now gradually relax your jaw, feeling the sensation of letting go.

Now, shrug your shoulders bringing both shoulders up towards your ears as if you wanted to touch your ears with your shoulders. Note the tension in your shoulders and up your neck; study it for a moment. Now let it go. Notice the difference in the way your muscles feel when you relax.

Now, tighten up the muscles in your stomach. Make the stomach very hard. Now relax. Let the muscles become loose once again. Just let go and relax. Notice the difference between the tension and the relaxation. Now lift your right leg and turn your toes toward you and tighten your whole leg. Feel the tension in your thighs, knees, calves, and arch of your foot and toes. Study that tension for a moment. Now gradually relax and lower your leg.

Now, lift your left leg and once again turn your toes toward you and tighten your whole leg. Feel the tension in your thighs, knees, calves, all the way down to your feet and toes. Study it. Now relax your leg, bending your knee and lowering it. Feel the tension leaving your body from your hip to your knee down your leg to the tips of your toes.

Now, simply breathe deeply and calmly. Focus your attention on your breathing. I am wondering if you can begin to feel the relaxation flowing into your body with your breath. Let your breath take relaxation to each part of your body. If you sense tension anywhere in your body, see if you can use your breath to bring relaxation to it. Just keep breathing feeling the relaxation deepening more and more with each breath. Breathing in relaxation, breathing out all tension. Just relax.

Imagery

Now, I am wondering if you can bring to mind a very pleasant image. Whatever image you would like is just fine. As you begin to get an image of a very pleasant place in your mind, I am wondering if you can get all of your senses involved in this image. Maybe this image can become so clear that you can see the sights there are to see, smell the air, hear the voices and any other sounds that you may hear in this very pleasant place. Feel what it is like to be there with all your senses. Take some time to get this very pleasant image clearly in your mind and then stay with it for a while. When you are ready, gradually let this image dissolve in your mind and come back to the rhythm of your breathing. Open your eyes when you are ready.

(The leaders will then debrief the participants about their experience with the relaxation exercise e.g., on a scale of 1-10 where 1= not relaxed at all and 10 = very relaxed, how relaxed do you feel right now? What parts of the exercise worked or didn't work for you? Leaders also hand out an audiotaped relaxation exercise for practice.)

Practice your relaxation exercise at least once per day, and keep track of how relaxed you feel on a 1-10 scale where 1= not relaxed at all, and 10 = very relaxed, both before and after you practice your relaxation. Don't get discouraged if you don't feel deeply relaxed when you first start to practice. Relaxation is a skill that takes time to master, like learning to ride a bicycle or drive a car. It may feel awkward at first, but with practice you will be able to relax deeply and enjoy the experience. Let's take a moment to anticipate what things might get in the way of your practicing this exercise. What steps can you take to make sure you get some time to relax? We will review the relaxation exercise next time we meet.

D. EDUCATION, Part 2: Your Mind's Responses to Stress

(Leaders pass out all handouts). We have been talking about stress reduction and relaxation with an emphasis on the **body's** response to stress--the fight or flight or stress response. We will finish up today by focusing on our **mind's** responses to stress--how our thoughts and feelings influence our experience of stress.

Psychological stress responses are the negative thoughts and feelings that occur when we do not feel able to cope. Negative thoughts, including "catastrophizing" statements such as: "I can't cope with this" "This is the worst thing that could happen" are often accompanied by negative feelings like anxiety, fear, frustration, tension, fatigue, guilt, hopelessness, and depression. When we focus on these feelings, we become less able to problem-solve and make needed decisions.

Alternatively, using calming and positive "self-talk" when we are in a challenging situation can be a very effective way to manage our emotional reactions to stress. An example would be telling ourselves to relax and slow down when we find our mind racing in reaction to stress, or distracting ourselves from upsetting thoughts by focusing on more positive things. We can also give ourselves encouragement by statements such as "you can do it" and "in time this will get better" and by not making things appear better or worse than they are. We are not always accurate in the way we think about things and at times we may distort the picture. These inaccurate ways of thinking about things are called cognitive distortions. **How we think strongly influences how we feel and how we behave, and thus cognitive distortions will limit our ability to respond effectively to a stressor. Recognizing these distortions in our thinking is a first step toward developing more effective coping strategies.** We have listed some common cognitive distortions on your handout, entitled "Common Cognitive Distortions and Rational Alternatives" which you can read to learn more about ways of thinking that can exacerbate feelings of stress.

Think back to a recent time when you felt stressed, and then try to identify the thoughts that you had related to that stress. *(Ask participants to share their recollections, especially how their thoughts influenced their physical and emotional reactions to the stressor. Consider the following example: When you first heard that you had cancer (your wife had cancer) what did you think? How did you feel? Discuss how they appraised the threat and their ability to cope).* Emotions are greatly affected by the way we look at things. When an event occurs we try to make sense of it and our emotional response is a consequence of how we interpret this event. By changing how we think about things, how we evaluate a stressful situation, we can change how we feel. **Our evaluation of a stressor, how we think about it and what we say to ourselves about it, will have a very direct impact on how we feel and what we do in response to it.** While certain events are almost universally considered stressful, e.g., the death of a loved one or being diagnosed with cancer, the impact of these events still depends on the individual's thoughts. If your point of view is that a stressor challenges you beyond your capacity to cope, you are more likely to experience the psychological and physical responses that occur with stress. *(Discuss situations that the participants find stressful/uncomfortable. How did the participants' thoughts about the stressful situation affect how they felt? Explore differences and similarities in spouses with regard to what they find stressful, and how it can help to know each other's vulnerabilities and strengths to best support each other in times of stress.)*

METHODS OF COPING

If we believe there are things we can do to manage a stressful situation, then the threat is reduced and we are less likely to experience a stress response. There are many different ways of coping and no one correct way to deal with stress. Different coping strategies are effective at different times and we all use many different coping responses. Coping responses can include actions to directly change what is wrong and thoughts that lessen the emotional impact of the situation.

The first step in coping with stress is to determine whether the stressor or problem you are dealing with is uncontrollable or controllable. An example of an uncontrollable problem is the weather. It is impossible to change the weather, no matter how much we may want to or how hard we may try. Another group of problems are those that are controllable. This type may include things like waiting in the checkout line at the supermarket. While it is difficult to predict something out of the ordinary happening that will prolong your wait (like the register breaking down), it is possible to minimize the wait by doing things like shopping at off-peak times when the store is not so crowded, or stocking up on items so you don't have to go to the store quite as often. In this way, problems such as waiting in the checkout line are more controllable than problems such as bad weather.

Once you have determined whether the stress you are confronting is controllable or uncontrollable, **the next step is to consider which type of coping strategies will work best for that kind of a stressor.** Although there are many ways to deal with problems, we are going to discuss two main ways of coping: **problem-focused** coping and **emotion-focused** coping. Problem-focused coping refers to concrete, practical strategies we use to directly address the problem. An example would be wanting information about different kinds of cancer treatment and going to the library to get it. Emotion-focused coping involves accepting the situation, or thinking about pleasant things to take our mind off of what is bothering us. An example of this strategy would be to focus on your relaxation skills when you feel yourself getting anxious about a clinic visit. Drs. Richard Lazarus and Susan Folkman were two of the first researchers to find that particular types of coping are more effective for particular types of problems; that is, matching the coping strategy with the problem for the best outcome. For example, for an uncontrollable problem like the weather, it is probably better to do emotion focused coping--accepting the weather and telling yourself that you can do your outdoor activities on another day. There is nothing you can do to change the weather. You must accommodate--change your plans or behavior to fit the situation. Thus we can successfully cope with a stressful situation without changing it. For another situation, such as waiting in the supermarket checkout line, you can switch lanes to a shorter line or go shopping when the store is not as crowded--these are examples of problem-focused coping. Doing emotion-focused coping while waiting in the checkout line, such as thinking about pleasant things, may take your mind off the wait, but it won't get you out of the store quicker.

There is also a third type of coping--avoiding the stressor. **Avoidance coping** includes the things we do to distance ourselves from a problem and to not think about it. Because avoidance coping is generally less effective than the other two strategies, we will not focus on it other than to briefly identify its benefits and costs. Some examples are: refraining from thinking about something that distresses us, avoiding people or situations that bother us, denying feelings, daydreaming, and trying to distract ourselves and reduce tension by smoking, eating, sleeping or drinking. Avoidance coping may be a first strategy for dealing with a stressor, like refraining from reading informational brochures about cancer and chemotherapy when you are first diagnosed with cancer because you are feeling overwhelmed. These strategies can provide some immediate relief and can even be helpful in giving us time to adjust to a stressful situation, especially one over which we have no control. However, while these behaviors can help us feel better in the short term, they may distract us from using more active coping methods to solve our problems and thus can be less effective. If used in situations where more active coping strategies might provide effective solutions, feelings of distress such as anxiety, depression, guilt and physical discomfort may actually get worse.

We have included Coping and Problem-Solving Handouts today, which you may find helpful in identifying effective coping strategies.

E. PRACTICAL TRAINING

Now let's consider some potentially stressful situations. We would like you think about what type of coping strategies (problem-focused, emotion focused or avoidant) you might use to deal with these particular situations and evaluate how well your strategies work.

Example 1: You/Your wife need(s) to go to the doctor for a check-up. What sorts of thoughts go through your mind? What coping strategies might you use to reduce the potential stress of this medical appointment?

Example 2: For this example, I would like you to draw from your own experiences. Think of a situation that is stressful for you. (Discuss the situation and associated thoughts and feelings). What coping strategies could you use to reduce the stress of this situation?

You may notice that you and your partner have different ways of coping with stress. This can become particularly apparent when there is a crisis, like finding out you have breast cancer. (*Ask for comments from participants regarding this point*). Sometimes these differences in coping can cause strains in a relationship. For example, one partner may engage in problem solving coping to confront a stressor by actively seeking social support and information and the other may need time to reduce his/her immediate distress and use emotion-focused coping methods. In general, a coping strategy is not good or bad, and each person needs to identify strategies that work best for her/himself and the type of stressor he/she is facing as we just discussed. When coping strategies in a couple are "mismatched" it helps to acknowledge that each individual is trying to cope the best way he/she knows how, and to learn ways to communicate with each other that can help bridge these differences in coping. As good communication is so critical to good coping, we will focus on skills for communicating with your partner, the health care system and your children over our next two sessions.

F. BRIDGE TO CHILDREN'S INTERVENTIONS (Expanded group only)

This week your children are learning about feelings. In particular they will be learning how to monitor and label feelings, and practice ways to regulate or manage their feelings. They will also work on learning how to accurately identify emotions in others. We have included some books on feelings for children of different ages that you may want to read with them over the next month, as this will help reinforce their learning.

Your children also discussed learning different things they do to relax. They too practiced a relaxation exercise. You may be able to help reinforce each other in practicing your relaxation exercise by doing it together with your children. (*Leaders ask for questions from participants regarding the children's groups. Children's group leaders join the parent group with the children and briefly review the children's activities*).



RESOURCES ON STRESS MANAGEMENT, COPING AND COMMUNICATION

Stress Management

Benson, H. The Relaxation Response. New York: William Morrow, 1975.

A classic source on relaxation; what to do, how it works.

Caudill, M. Managing Pain Before It Manages You. New York: Guildford Press, 1995.

Information on relaxation, pain management, coping and communication.

Davis, M., Eshelman, E., & McKay, M. The Relaxation and Stress Reduction Handbook. Fourth Edition. Oakland, CA: New Harbinger Publications, 1995.

Information on relaxation, coping, time management, nutrition and exercise.

Coping

Burns, D. The Feeling Good Handbook. New York: Penguin Books, 1989.

Managing depression and negative thinking.

Clark, L. SOS Help for Emotions: Managing Anxiety, Anger and Depression. Bowling Green, KY: Parents Press, 1998.

Strategies for managing difficult emotions.

Seligman, M. Learned Optimism. New York: Knopf, 1991.

Managing your thinking and the role of optimism in mental and physical health.

Communication & Relationships

Alberti, R. and Emmons, M. Your Perfect Right, 7th edition. San Luis Obispo, CA: Impact publishers, 1995.

Managing interpersonal problems with assertiveness.

McKay, M., Fanning, P., and Paleg, K. Couple Skills: Making Your Relationship Work. Oakland, CA: New Harbinger Publications, 1994.

Communication skills, negotiation, anger and conflict management.

Smith, M. When I Say No I Feel Guilty. Bantam: New York: 1985.

Help with assertiveness.

Tannen, D. You Just Don't Understand: Women and Men In Conversation. New York: Ballantine Books, 1990.

How men and women differ in their way of communicating and how communication between men and women can be improved.



COGNITIVE DISTORTIONS AND RATIONAL ALTERNATIVES

Cognition refers to the way we think about things. Using calming and positive "self-talk" when we are in a challenging situation can be a very effective way to manage our emotional reactions to stress. An example would be telling ourselves to relax and slow down when we find our mind racing in reaction to stress, or distracting ourselves from upsetting thoughts by focusing on more positive things. We can also give ourselves encouragement by statements such as "you can do it" and "in time this will get better" and so on. Other cognitive coping strategies include: focusing on the positive, telling ourselves to take things one step at a time, praying and trusting our belief in God or a higher power, and not making things appear better or worse than they are. We are not always accurate in the ways we think about things and at times we may distort the picture. These inaccurate ways of thinking about things are called cognitive distortions. As mentioned in the group, how we think strongly influences how we feel and how we behave, and thus cognitive distortions will limit our ability to respond effectively to a stressor. Recognizing these distortions in our thinking is a first step toward developing more effective cognitive coping strategies.

Some common cognitive distortions and rational alternatives are listed below:

1. All-or-none or either-or thinking: Tendency to evaluate personal qualities in the extreme or to see things as black or white. Example: Since I've had cancer I'm a "sick person" - I will never be healthy again.

Rational Alternatives: Attempt to see things along a continuum, or in terms of "shades of gray" rather than black or white. Think in terms of percentages, e.g., "I am 80% sure that I can get back to my old routines."

2. Overgeneralizing: The thought that because it happened once it will occur over and over again. Example: A friend at work seems uncomfortable talking to me since I told her/him that I (my wife) had breast cancer--conclusion--I guess I won't be able to be friends with him anymore.

Rational Alternatives: Avoid thinking in absolutes i.e., "always", "never", "everybody", "nobody", "all", "none" and so on. Think about things in terms of "sometimes", "often", "perhaps" or "may not".

3. Catastrophizing - Blowing things out of proportion. Example: After learning about her diagnosis of breast cancer, Claire thought her illness would ruin the life of her spouse and her children.

Rational Alternatives: Look at the situation comprehensively and realistically, considering positive, neutral and negative consequences.

4. Disqualifying the positive - Rejecting or not noticing positive experiences. Maintaining a negative belief even though it is contradicted by experience. Example: Someone tells you that you are looking good today, and you disqualify it by thinking - they're just being nice.

Rational alternatives: Attempt to get out of a negative mental groove by allowing yourself to see the positive side of your experiences.

5. Assumed intent: This is "mind-reading". Example: Your doctor seems very quiet when he comes into the office--you assume that his silence is bad news and that there is cause for concern when, in fact, he just has indigestion.

Rational alternatives: Take the opportunity to get direct information to check out whether your beliefs are founded.

6. Personalization: Tendency to see oneself as the cause of some negative external event which in fact you had no control over. Example: If only I had exercised more regularly then I would not have gotten cancer.

Rational alternatives: Gather and examine information to see if it supports your beliefs.

7. Fractured Logic: This is where you take one event and draw unwarranted conclusions from it. Example: Because I yelled my spouse, he/she will think I want a divorce.

Rational alternatives: Avoid drawing conclusions from one interaction. Consider this communication in the context of several interactions and see whether your conclusion still makes sense.

8. "Shoulding": Making a wish, want or preference a "should". You have a firm set of rules about how you and other people should act and you get very irritated or angry when they don't behave as you think they should. Example: The kids are being irresponsible by not helping out with the dishes today--they should help out with the dishes every day.

Rational alternatives: "Shoulds", "Oughts" and "Musts" reflects one's values. Others may or may not share these same values or may be acting under special or exceptional circumstances, of which you may or may not be aware. Consider being flexible in your expectations of other's behavior.

9. Labeling: Putting a label on another person rather than being descriptive and behavioral. Example: Your spouse is unreliable and irresponsible because he/she forgot to pick up the children's medicine at the drug store. Rather than your spouse forgot on this occasion to get the children's medicine.

Rational alternatives: Limit your observation to the circumstance. Don't generalize beyond the particular instance of the behavior of concern.

10. Magnification: When an event is given more emotional weight than it deserves. Example: If I can't be there for my son's play then he will be devastated.

Rational alternatives: Look at the evidence does and does not support this assertion. Determine whether your conclusion fits with the evidence or reflects one side only.

By avoiding these distortions and seeing things for what they really are we are using cognitive coping techniques.



METHODS OF COPING

If we believe there are things we can do to manage a stressful situation, then the threat is reduced and we are less likely to experience a stress response. The first step in coping with stress is to determine whether the stressor you are dealing with is **uncontrollable** or **controllable**. An example of an uncontrollable problem is the weather. It is impossible to change the weather, no matter how much we may want to or how hard we may try. Another group of problems are those that are controllable. This type may include things like waiting in the checkout line in the supermarket. While it is difficult to predict something out of the ordinary happening that will prolong your wait (like the register breaking down), it is possible to minimize the wait by shopping at off-peak times or stocking up on items so you don't have to shop as often. In this way, problems such as waiting in the checkout line are more controllable than problems such as bad weather.

Once you have determined whether the stress you are confronting is controllable or uncontrollable, the next step is to consider which type of coping strategies will work best for that kind of a stressor. Research indicates that stress is more effectively managed when we match specific coping strategies with particular types of stressors. Although there are many ways to deal with problems, and no one "correct" way to cope, two main ways of coping are problem-focused and emotion-focused coping.

- **Problem-focused coping** refers to concrete, practical strategies we use to directly address a controllable stressor. An example would be wanting information about different kinds of cancer treatment and going to the library to get it.
- **Emotion-focused coping** involves accepting the situation, or thinking about pleasant things to take our mind off of what is bothering us, when we have no control over a situation. An example would be using your relaxation skills when you feel yourself getting anxious about a clinic visit.

There is also a third type of coping--avoiding the stressor. **Avoidance coping** includes things we do to distance ourselves from a problem. Some examples are: refraining from thinking about something that distresses us, avoiding people or situations that bother us, denying feelings, and trying to distract ourselves and reduce tension by smoking, eating, sleeping or drinking. Avoidance coping may be a first strategy for dealing with a stressor, like refraining from reading informational brochures about cancer and chemotherapy when you are first diagnosed with cancer because you are feeling overwhelmed. These strategies can provide some immediate relief and can be helpful in giving ourselves time to adjust to a stressful situation, especially one over which we have no control. However, while these behaviors can help us feel better in the short term, they may distract us from using more active coping methods to solve our problems and thus can be less effective in the long term. If used in situations where more active coping strategies might provide effective solutions, feelings of distress may actually get worse.



RESOLVE METHOD OF PROBLEM SOLVING

- STEP 1:** **RELAXATION.** The connection between problem solving and relaxation is strong. Problem solving begins with relaxation to help calm you and focus your attention and energy on the problem. Even a few deep breaths can help you let go of tension and prepare you for your problem solving efforts.
- STEP 2:** **STATE THE PROBLEM.** State what the problem is and be sure to break the problem down into its component parts. For example, if your problem is weight loss, you need to specify the particular aspects of managing weight loss that are problematic e.g., eating out, exercising, stress related eating, nutritional knowledge. You will need to go through problem solving efforts for each part of the problem.
- STEP 3:** **OUTLINE YOUR RESPONSES.** Identify what your typical responses are to managing each part of the problem.
- STEP 4:** **LIST YOUR ALTERNATIVES.** List alternative responses to your current way of managing each part of the problem. Brainstorm--think of as many alternatives as possible. Try to not make judgments of the alternatives at this stage. The more possibilities you come up with, the more likely you will find good solutions.
- STEP 5:** **VIEW THE CONSEQUENCES AND CHOOSE A SOLUTION.** Examine each alternative response with regard to its pluses and minuses. Choose the solution(s) that offer you the most with a minimum of "cost".
- STEP 6:** **ELABORATE A PLAN AND EVALUATE THE RESULTS.** Plan how to make the solution(s) work. Consider what first step you can make to get started on the solution. Taking small steps helps build success into problem solving efforts. For example, if you are attempting to lose weight focus on one or two specific behavior changes to start, such as reducing the amount of fat in your diet or starting an exercise program, rather than attempting to totally revise your diet and commit yourself to a strenuous exercise schedule all at once. Once you have tried a solution, evaluate its effectiveness. It is important to keep in mind that any solution you try represents an opportunity for learning about yourself and the problem you are trying to solve. There is no such thing as a poor solution as long as you can use it as an opportunity to learn how you might design a better solution to your problem.

SESSION 3

OBJECTIVES:

1. Participants gain an understanding of effective methods of communication in close relationships
2. Participants are introduced to the use of assertive communication, especially for use in interacting with the health care system
3. Participants have the opportunity to share their experiences of breast cancer in the family with other women and their partners.

OUTLINE:

1. Review of the last session's topics.
2. Listening Skills.
3. Speaking Skills.
4. Assertive Communication Skills.
5. Bridge to children's intervention groups (Expanded Intervention Only)

SUPPLIES:

1. Name tags
2. Pens
3. Parking passes/childcare reimbursement (Basic Intervention Group Only)
4. Refreshments: Coffee/bagels/napkins/plates/cups

HANDOUTS:

1. Effective Communication Audiotape
2. Handout: Effective Communication Skills
3. Handout: Assertive Communication
4. Handout: More on Assertive Communication
5. Book: How to Talk So Kids Will Listen and Listen So Kids Will Talk by A. Faber & E. Mazlish

SESSION 3

COMMUNICATION I: Interacting Effectively with Friends, Family, And the Health Care System

A. REVIEW

(The group leaders will review the participants' experiences with the relaxation exercises. Discussion should include how many times they practiced relaxation, what aspect of the training they found most helpful e.g., deep breathing, progressive muscle relaxation, and/or imagery, the degree to which the exercises enabled them to relax as well as any difficulties with the relaxation practice. The group leaders should reinforce the use of relaxation strategies, i.e., to release the physical tension associated with stress, promote feelings of well-being and reduce physiological stress responses. Group leaders should also ask for comments about the cognitive coping strategies reviewed in the last session).

B. EDUCATION, Part I: Listening and Speaking Skills

Today we will be talking about communications skills. We will spend two sessions on communication, as our ability to communicate effectively is vital to solving problems, getting and giving information, and establishing and maintaining our relationships with others—all central to coping with stress. We all spend a great deal of our lives communicating. Yet, as vital and as common as this activity is, few of us have been taught or have systematically practiced the skills necessary to communicate **effectively**. Communication has a dual potential. (It's a double-edged sword). It provides a way to better understand each other better as well as the opportunity to misunderstand each other, to support each other and solidify relationships as well as create greater distance and estrangement, to gather accurate information that helps us make decisions, solve problems, and resolve conflicts or not. A major source of enjoyment as well as stress in our lives comes from our conversations with others. Having satisfying interactions with others depends on the choices we make about the words, attitudes, and behaviors we bring to any conversation—that is, our communication skills. Some of you are already skillful communicators—in this case what we discuss today can be a good review to help you further solidify those skills. Others of you, like most of us, may never have had the opportunity to be taught these skills. If this is the case, we encourage you to stay open to the communication tools we will be presenting and to give yourself a chance to try them out and see for yourself whether they can make positive difference in your interactions. The pay-off for effective communication is great – as can be the stress resulting from ineffective communication.

ADAPTING COMMUNICATION TO FIT YOUR GOAL

So how do we distinguish effective from ineffective communication? To some extent, what **effective communication skills are depends on the goal you have for a given interaction**. Sometimes, like with a health insurance company representative, your goals might be to get specific information or to get them to take some action you want. The skills required in this type of interaction – when a specific outcome and not the quality of the relationship, per se, is the major goal – are **assertion skills**. We will discuss this class of communication skills at the end of this session. First, we'll concentrate on skills needed for preserving supportive, close relationships – as between a husband and wife – where it's not only important that we get what we want in a concrete way from interactions with our partner but also very important to preserve feelings of mutual affection and trust. Now,

let's break down effective communication into it's most basic components, listening and speaking, and discuss them in more detail.

LISTENING

First, let's review the **goals** of effective listening and then we will talk about the **specific skills** for meeting these goals.

The first objective of effective listening is to obtain accurate information. This is necessary to make correctly informed responses and to solve any problems that are identified. If we don't accurately understand what the other is trying to say, we may find ourselves reacting to an inaccurate interpretation of their message. We may hear conflict, disagreement, criticism, and threat where there is none – or at least not to the degree we misperceive it to be – and we may react defensively and argumentatively before we have an accurate understanding. Let's take an example: A couple has recurring conflict when one of them comes home late from work and the other complains. They argue each time about whether the lateness could have been avoided, whose needs should take priority and so on. The real "problem", however, may not be that one spouse comes home late repeatedly, the real underlying issues may be about their respective needs for independence, support and financial security. Until these needs, concerns, and point of view are accurately understood, the behaviors that lead to conflict are likely to continue, and a solution that addresses both persons' needs won't be possible. We can't solve problems or meet needs until we accurately know what the problems/needs are.

The second goal of effective listening is to enable our partner to feel understood. This is a basic need of human interactions. Conflicts can arise and escalate when partners don't feel that the other hears or understands what they're trying to say. When someone knows they've been heard and understood, there often is no need to reiterate their position or express it more strongly and loudly! Often, enabling our partner to feel that we understand their feelings or opinions is the most potent way to help them feel respected, validated by and connected to us. Very often, no "solution" other than giving our partner a chance to be heard and understood is necessary or wanted!

The pay-off for effective listening is your partner is more likely to listen to and try to understand your feelings and point of view.

(How can you tell someone is really listening to you? How would you describe good listening behavior? Group leaders will refer to member's responses when providing further information about good listening behaviors below.) Let's get specific about what behaviors facilitate communication by writing them on the board.

Guidelines for Effective Listening:

Non-Verbal Behavior. Show that you are listening and interested by your non-verbal behavior: make eye contact; keep an open posture facing the speaker; lean forward to show interest; use gestures (such as head nodding) and brief utterances (such as "uh huh" or "yes") to encourage the speaker; avoid reacting with "editorial" facial expressions (e.g., smirks, eye-rolling); don't try to listen and do something else at the same time (e.g., watch TV, read the paper, do household tasks).

Eliminate Distractions. Choose a time and place when both people can concentrate on the conversation, and eliminate distractions, e.g., turn off the TV; go somewhere

you won't be distracted. Note that both the listener and the speaker have a role to play here. Before starting an important discussion the speaker should make sure that it is a good time for their partner to listen. It's not realistic to expect your partner to give you their full attention if they are in the middle of a favorite TV show or sports event or working on some project. When saying "No" to a partner's request to talk, two things are important to minimize your partner's feeling "blown off". First, acknowledge your partner's request and state why this isn't a good time. Second, try to identify a time when you will be available to your spouse.

Try not to interrupt. Interrupt the speaker only if something is getting in the way of your continuing to be able to concentrate, listen, and understand, e.g., physical discomfort, a strong emotional reaction or you are so confused you can't follow the speaker. Interrupting grabs the conversational ball away from the other person. Whenever possible, wait until it's time for you to become the speaker to ask questions as they may move the conversation in the direction of your curiosity instead of where the speaker wants to take it.

Attend to the speaker's feelings. Concentrate not only on what the other is saying about events or other people – the facts – but also on how he or she is affected by or reacts to these events or people, that is, their feelings, wishes, and conflicts. This means, "listening beneath the words" for how the speaker feels about what they are saying even if they aren't describing how they feel. The best way to get this information is to "put yourself in the speaker's shoes" as you listen and ask yourself the following: If I was the speaker how would I be feeling, especially about myself as a person? What would I be hoping and wishing for? What conflicts would I be experiencing? Information about the speaker's feelings can be gathered from their nonverbal communication, as well as from the words they use. When we attend very closely to both the speaker's message and his/her feelings we create the opportunity to truly understand the other's experience--to empathize with the speaker.

(It can be difficult to listen empathically when the speaker is upset and expressing anger a complaint, or criticism. It may be useful at these times to recognize that the speaker is doing what he/she feels he/she needs to do to insure physical and emotional survival. If you try, you will be able to see how the speaker's words and actions are designed to help him/her cope and survive. Some people have very poor coping strategies-- they boast, belittle, criticize in an attempt to seem powerful, intelligent, or to get needs met. If the speaker's words are offensive to you, remember that these words are part of that individual's way of coping, no matter how maladaptive or misguided. If you are put off by a speaker's words, it may help to ask yourself what physical or emotional need the speaker is attempting to meet e.g., does the speaker feel threatened? Asking yourself these questions and keeping this perspective in mind can help you to listen with empathy. Of course, listening to offensive words is difficult, and at any time you can also let the speaker know that you will not continue to listen unless they can be less critical, etc.)

Listen With Openness. Being able to see the other person's point of view also means being willing to momentarily suspend our own opinions, judgments or perceptions, even when we may strongly disagree with the other's point of view. This isn't easy! It's much easier to pass judgment on what you hear, to stop listening, to prepare your response, etc. However, by doing so you will miss the opportunity to know and understand the speaker's point of view, and to expose yourself to new information and new experiences. It does not require that you agree with the speaker's point of view – just that you suspend expressing your own feelings and opinions until after your partner knows that you've understood accurately what they think and feel.

When your mind is open there is room for the speaker's message to enter and be understood. This type of listening demonstrates respect to the speaker and tells him/her that you value them as a person, regardless of whether you agree with his/her perspective.

Let the speaker know what you've heard and understood. To make sure that you have not misunderstood and to let your partner feel understood you have to respond to the speaker. Briefly report your understanding of the speaker's point of view in your own words at a pause in the conversation. Be sure not to simply "parrot back" the speaker's own words. Simply paraphrase what your understanding is of the message and the message "beneath the words". You also may need to ask for further information to assure that you understand what the speaker is trying to convey. After you've responded to the speaker, she/he may clarify or correct something you've misperceived. Accept corrections from the speaker. The speaker is the only expert about what message he/she intended to send.

"Blocks" to Effective Listening

Good listening also means avoiding certain behaviors that can interfere with our ability to accurately hear the speaker. Many "listening blocks" occur by our interrupting the speaker or taking our focus of attention away from the speaker. They include:

Mind reading: Not taking what the speaker says at face value. Assuming you already know what the speaker is going to say, drawing conclusions, making interpretations, "reading in" criticism, and disregarding what he/she is actually saying

Filtering: Only hearing part of the message e.g., listening only to those issues you want to respond to

Judging: Forming a judgment about what the speaker has to say, or listening for the purpose of gathering evidence to assign blame to or criticize the speaker

Rehearsing: Planning what you will say in response to the speaker, rather than listening

Daydreaming: Letting your mind wander

Advising: Offering solutions or suggestions when unsolicited. Wait until the other has requested it and until it is time for you to express your opinion. Offer a sympathetic ear and allow the speaker to find his/her own answers first

Derailing: Attempting to get the speaker off a topic that is uncomfortable or re-directing the speaker, sometimes with humor

(Can you think of others?)

The audiotape we will provide you discusses these and other listening "roadblocks" in greater detail. "Advising", "Derailing", and "Placating" commonly arise when a speaker is expressing negative feelings that are uncomfortable for the speaker and/or the listener. These listener responses may be used with the best of intentions, i.e., to offer advice or to comfort the speaker. They may also result because the listener wants to avoid the discomfort associated with the emotion or topic the speaker is expressing. For example, listeners sometimes say things like "Don't be so upset. You shouldn't be worrying about that," in an attempt to reduce the distress of the speaker. This type of response can make

the other feel worse – that they are being judged as “wrong” in their feelings and that they are not understood and not accepted.

SPEAKING

Now, let's review the **goals of effective speaking** and then we will talk about the **specific skills** for meeting these goals.

The first goal of effective speaking is to express your wishes, needs, and feelings as fully, honestly, and accurately as is needed. (Again, the extent to which openness is warranted depends on the goal and nature of the relationship.) Open, honest, effective expression does not mean, “letting it all hang out”. If we care about the impact on others of what we say and how we say it, then some deliberation and restraint before speaking are advisable.

The second goal of effective speaking is to make it easier for others to listen to and to understand you and to motivate your listener to respond to your needs. In order to do this you must learn to express yourself in a way that minimizes any sense of threat or defensiveness that the other might experience in listening to you. This is not so important in ordinary conversation, but it is very important when you are trying to work through a problem or conflict, as it allows you and your partner to focus on important aspects of the problem and work toward solutions.

Guidelines for Effective Speaking

Show understanding and respect for the other person's point of view before you express your own. In an ordinary back and forth discussion when you've taken a turn as listener, this is taken care of if you've made an empathic, reflective statement about what you heard. You can also show your understanding of the other person even when you are the one initiating the topic. For example, suppose you'd like your kids to stop dropping their coat on the floor as soon as they enter the house. You might say: “I know you're tired when you come home from school and just want to crash for a bit...” That is, say something that will make the person feel understood, not threatened. When you first acknowledge the other person's point of view or needs, it decreases the other's defensiveness and increases their openness to listening to you.

State your opinions, perceptions, wishes, feelings, and recollections subjectively. This means making “I statements” instead of “you statements” – speaking on the subject of yourself and how you see things or feel and only on the subject of yourself. Instead of saying “You're making me angry,” take responsibility for your own feelings by saying “I feel angry when...” “I can see why you feel that way” vs. You really get bent out of shape don't you”. When we state our wishes and desires in subjective terms (e.g., “I'd like it if...” “I want...”), the other person is less likely to feel challenged and threatened. If, on the other hand we talk about what is objectively so, how things should be, how most other people do things, what is correct, morally right, and so on, then there is the implication that we are the authority and that our listener is wrong. Others are apt to disagree with us or feel challenged and defensive when spoken to this way.

Express your feelings. Feelings are often a very important, sometimes the most important aspect of a conflict. For example, stating “It discourages me when I see things lying around after I just finished cleaning.” or “I feel nervous and antsy when we're

running late for an appointment," makes the other person aware of how you feel and may change their perception of the situation and can evoke concern, sympathy, and cooperation.

Be specific rather than global in your feedback. For example, instead of saying: "The family room is always a mess. You never pick up" try, "When I walked into the family room this morning and saw things strewn about after I cleaned it yesterday, I felt really discouraged and annoyed." Being specific and concentrating on the actual behaviors which you'd like to see changed, rather than on generalizations, makes your statements more credible and tends to lessen the other's defensiveness. When making a request for change, try to pinpoint times, places, and circumstances that have led to your desire to see change. It's also important to be specific about what behavior change you want. For example, instead of saying, "I want you to be more considerate," or "I don't want to be taken for granted," say "I'd appreciate it if you would bring your dirty dishes up from the family room rather than leave them there for me to pick up the next morning."

State the positive. We often have positive feelings or attitudes about the other person that are related to the issue at hand or which serve as our motivation for requesting changes. These positive feelings and perceptions may go unstated, and as such, we lose the opportunity to motivate others to be open to listening to and responding to what we are saying. For example, when making a request that a spouse help with readying the children for bed it would be important to acknowledge the positive first: "I really appreciate that you take over entertaining the kids when you come home so that I can get dinner together without interruption."

It is especially important, when requesting a change in behavior, to state your view of the benefits you and the other person would derive if the other person would help you to meet your needs. To illustrate this, let's return to the above example of the spouse asking for help with the children at bedtime.

"I really appreciate the way you take over entertaining the kids when you come home from work so that I can get dinner together without interruption – especially when I know you're looking for some peace and quiet at the end of the day. And I know that you do your share of childcare in lots of other ways. I'd appreciate it if you could help me with getting the kids bathed and ready for bed at night as well. I often feel frazzled and worn out at the end of the day when I have to get both of them ready. By the end of this I often don't have the energy or time to just spend a little while talking or watching TV with you, and I miss that. It would help me feel less stressed if we could divide up that job, and I think that I could have more energy and be more relaxed so that we could have a little quiet time together in the evening."

Paying attention to these skills, and avoiding the pitfalls just mentioned, can help ensure effective communication. Now, I would like the group to try an exercise in active listening.

C. PRACTICAL TRAINING

For this exercise you will divide up into pairs with one of you taking the role of the speaker and the other the role of the listener. It doesn't matter what the speaker chooses to talk about, but it might be easiest to do this exercise if you pick a topic that genuinely interests you. The listener will then summarize what the speaker has said and the speaker will let you know if you left anything out. Next, you will reverse roles.

As a **speaker**, your job is to follow these rules:

1. Explain your point of view clearly and briefly. Be specific. (Avoid absolutes e.g., "always", "never")
2. Talk in terms of yourself and your experiences. Describe your feelings and needs. Use "I" statements. (*Review differences between "I" and "You" statements*)
3. Stop and let the listener paraphrase.

As a **Listener**, use active listening skills, including:

1. Be aware of the speaker's and your own non-verbal behaviors.
2. Listen closely to really understand your partner's feelings, opinions, and needs.
3. Paraphrase what you hear, to be sure you are listening accurately--not only to what the speaker is saying, but also equally to the speaker's feelings about their experience. Suspend judgment of the speaker's point of view. (Avoid minimizing, discounting what is said.)
4. Ask questions to clarify only
5. Don't interrupt

Notice that the listener skills are more demanding than the speaker skills!

Now that we've reviewed the guidelines for good listening and speaking skills, we would like to do a little role-play to show you what the two different roles--attentive listener and speaker--would look like. Pay particular attention to what the listener does and doesn't do. Notice that the listener may stay in that role--just reflecting back what he or she hears for several exchanges. Generally we encourage you to do just that--to keep listening for as long as you can, until your partner is finished or until you won eagerness to speak is getting in the way. (*Leaders will briefly demonstrate a 2-3 minute interaction to exemplify listener and speaker skills. Leaders ask for any comments or questions to further clarify the exercise. A 3 x 5 card with the speaker and the listener rules printed on them is handed to the pairs. Each pair will spend 5 minutes in one role, and then switch roles for the second five minutes. After all pairs have completed this exercise, the group members will be prompted to share their experiences with this exercise with the other group members. The group leaders will use this opportunity to reinforce the skills introduced above.*)

(*Hand out audiotape on Effective Communication to participants.*) In this audiotape a husband and wife are talking -- first ineffectively and then using effective communication skills. Play this audiotape before our next session, and when you listen try to notice specific differences in the behaviors of the couple between the two interactions. Also notice the different outcomes in the two interactions.)

B. Education Part 2: Assertive Communication

(Depending on the time that remains, portions of this section may need to be carried over to the next session.) We will now turn to communication skills that are useful not only for close relationships, but also are especially helpful for dealing with getting your needs met in the health care system. As mentioned earlier, we call this set of skills assertive communication.

Assertive communication is a way of expressing how you feel and making requests that respects both your needs and those of the person you are addressing. It is an "I count, you count" way of communicating. Beyond just stating your rights and needs, being assertive means you can disagree with someone openly, you can ask for clarification and information, and you can say no. Some major advantages of this style of communication are your active participation in negotiating important decisions, getting what you want without alienating others, and positive self-esteem from respectfully exchanging feelings and ideas. In short, when you are an assertive person, you can be more relaxed in interpersonal situations, thus good assertion skills are another important way to minimize and cope with stress. Assertive behavior needs to be distinguished from two other basic styles of communication that tend to be less effective.

One is **Passive** communication. In this style, feelings, thoughts and opinions are withheld, expressed indirectly or only in part. It is a "You count, I don't" way of communicating. Some advantages of passive communication are that you don't have to take a stand and are often able to avoid conflict. However, the disadvantages are that you have to live with other's decisions when your needs are not met and concerns are not voiced. Passive communication skills can lead to depression, frustration and anger. Passively enduring too many occasions of perceived unfair treatment can lead to hostile blow-ups and interpersonal conflicts. Consistent use of this style of communicating can also lower self-esteem, as you deny your own needs, while accommodating the needs of others.

A third basic style of communication is **Aggressive**. In aggressive communication, the speaker clearly states his/her feelings, opinions and needs, but at the expense of someone else's feeling and needs. It is an "I count, you don't" style of communicating. The advantage of aggressive behavior is that you may get your way as others do not want to argue with you. The disadvantage is that others may come to avoid you and go behind your back to get what they want or need. Aggressive people also tend to acquire enemies who can undermine their ability to get what they want in the long run.

While nearly everybody can be assertive in some situations, assertiveness is a skill that each individual may find easier to use in some situations than in others. One of the situations in which many people find it difficult to be assertive is when dealing with the health care system. In fact, one study showed that patients go to a doctor's visit with an average of four questions they wish to ask and leave their visits having asked, on average, only 1.5! *(Ask participants for comments about what situations they have found difficult in interacting with the health care system and what useful strategies they have found).*

There may be several reasons why it is difficult for patients and their families to assert themselves with health care personnel. One may be the fear they'll antagonize or alienate their health caregivers if they are perceived as making too many demands. This fear can be exacerbated by their vulnerability and dependency on the expertise of medical professionals during times of illness as well as by the manner of some caregivers.

Another reason that patients may avoid expressing their needs is that they have a history of trying to get answers to questions or responses to needs that were unsuccessful or, worse,

led to annoyance or anger on the part of the other person. Such negative past experiences can result in anxiety and fear of disappointment whenever the person is faced with having to ask for things or demand their rights in the future.

An undesirable consequence of these fears is that the individual may delay bringing up questions or stating his/her needs promptly. The longer the delay, the more likely the person will feel stressed and angry, such that when the person finally does bring up the issue, they are likely to do so when something has happened that is "the last straw" or when their anxiety has reached a peak. Under such circumstances, it is even less likely that the person will be able to assert him/herself skillfully, e.g., "without venting". An unskillful approach is more likely to lead to disappointing results or annoyance from the other – thus, perpetuating both the person's negative expectations about being able to get what they want and their pattern of avoidance.

In your handouts is a sheet called "Assertive Communication" which provides some examples of assertive, passive and aggressive behavior regarding some common health care situations. Let's review these examples and the costs and benefits of assertive, passive and aggressive communication in each.

(Leaders review as many examples as time permits and encourage participants to read second handout with further details about assertiveness. The leaders should also encourage participants to comment on their own experiences with getting their needs met in the health care setting.).

Summary of Communication Skills. Effective communication is a complex skill and to become a master at it takes thoughtful effort and practice. Some of the skills we discussed today may be new and may not feel natural to you, but as with any new skill the more you practice, the more natural these skills will feel. When you try these skills, notice any changes that occur in your conversations. Then, if you like what happens, you can adopt these ways of communicating as your own. We hope you will listen to the audiotapes and review the handouts for this session. The communication skills we discussed today not only apply to your conversations with adults, but also to your children. At our next session, we will discuss in detail how these guidelines work with your children and review the issues we have been discussing over the past few months.

E. BRIDGE TO CHILDREN'S INTERVENTIONS (Expanded group only)

This week your children are learning about coping and problem solving strategies, similar to what we discussed in our last session. They will discuss how to use problem solving to cope with their feelings. They also will talk about friendships--how to be a friend and how to cope when others may not behave in friendly ways. Younger children will explore how friends help them feel good by playing with them and doing things together. Older children will discuss problem solving and assertiveness in regard to dealing with peers. You also will be provided with age appropriate books on coping and friendships that you may read with your child over the next month to help them continue learning about ways to cope and ways to establish good friendships. *(Leaders ask for questions from participants regarding the children's groups. Children's group leaders join the parent group with the children and briefly review the children's activities).*

Handouts for the Families Coping With Cancer Project

Patient and Partner Group

Session 3



EFFECTIVE COMMUNICATION

Effective communication helps reduce stress:

- by getting accurate information needed to make decisions, solve problems and conflicts;
- by enabling you to get and give emotional support;
- by providing the means to establish, maintain and “repair” relationships with others.

Listening and speaking skills form the basis of effective communication.

LISTENING SKILLS

Goals of effective listening:

- Obtain accurate information.
- Avoid conflict due to misunderstanding.
- Enable the speaker to feel understood.

Effective Listening Guidelines

It is difficult to really listen. Most of us only listen partially to one another. Consequently, we may make assumptions about another's communication that are inaccurate. Good listening requires attention to verbal and non-verbal messages as well as the feelings being expressed and the needs behind those feelings. Some guidelines to effective listening are listed below to help you in your efforts to communicate effectively.

1. **Listen with your body.** Show you are paying attention by maintaining eye contact and an open posture, and use nonverbal encouragers such as nodding.
2. **Reduce distractions.** Negotiate a better time to talk if it's not possible for you to pay attention at the moment.
3. **Don't interrupt** (even with questions, if possible).
4. **Listen with empathy.** Try to hear the feelings beneath the words. Focus on the speaker's point of view.
5. **Listen with openness.** Temporarily suspend your own opinions, judgments or perceptions so that you can truly understand the speaker.
6. **Clarify:** Ask for further information as needed to assure you understand what the speaker is saying.
7. **Paraphrase:** Briefly summarize what you have heard, including your understanding of the speaker's feelings. Paraphrasing helps assure the speaker that you are listening and helps you remember what has been said.

Ineffective Listening: Behaviors to AVOID

Giving advice. It may seem like the right thing to do when someone presents a problem, but advice-giving often undermines the conversation by taking the focus away from the speaker and the thoughts and feelings he/she is attempting to convey, and bringing it to your problem solving abilities, which may or not be wanted.

Minimizing the speaker's feelings or point of view. when you respond. You may want to offer comfort, but this type of response often makes the speaker feel that they are being told they are wrong to think and feel the way they do.

Criticizing and correcting when you respond. You don't need to agree with what you have heard to acknowledge the speaker's point of view and feelings.

Mind-reading. Not taking what the speaker says at face value, but interpreting the speaker's words and drawing your own conclusions.

Rehearsing. Preparing your response rather than listening to the speaker.

Filtering. Only hearing part of the message, e.g., listening only to those issues you want to respond to.

Daydreaming. Letting your mind wander.

Derailing. Attempting to get the speaker off a topic that is uncomfortable by changing the topic or using humor to avoid the topic.

SPEAKING SKILLS

Goals of effective speaking:

- To openly and honestly convey your thoughts, feelings and wishes;
- To make it easier for the listener to listen to and understand you;
- To motivate the speaker to respond to your needs;
- To protect your own efforts to have your point of view understood.

Effective Speaking Guidelines

1. Show an understanding for the other's point of view and feelings before you express your own. This helps reduce defensiveness and motivates the other to listen to you.
2. Be "subjective". State your thoughts feelings and recollections by making "I" statements rather than referencing objective "facts", "shoulds", or what's "true", "right" or "correct."
3. Express how you feel. Feelings are often a major motivation for what we do and what we ask from others.
4. Be Specific in what you are asking for or objecting to. Avoid absolutes and generalizations about the other's behavior or character, e.g., "You always leave a mess...", "You are difficult.."
5. State the Positive. Express positive feelings or attitudes you have about the other person that are related to the issue at hand. For example, when requesting more time with your spouse: "I think it's great that you are coming home earlier now and can spend more time with the kids. I think it's really important that we spend time together as a family. I also am feeling that I miss you and I would like to spend some time together, just by ourselves."



ASSERTIVE COMMUNICATION

Breast cancer presents many challenges to women and their families. Communicating assertively with family, friends, and the health care system is one way to decrease stress and meet challenges effectively.

Assertive communication is a way of expressing how you feel and making requests that respects both your needs and those of the person you are addressing. It is an "I count, you count" way of communicating.

In **Passive** communication feelings, thoughts and opinions are withheld, expressed indirectly or only in part. It is a "You count, I don't" way of communicating.

In **Aggressive** communication, the speaker clearly states his/her feelings, opinions and needs, but at the expense of someone else's feeling and needs. It is an "I count, you don't" style of communicating.

Below are some examples of situations you may encounter, along with examples of assertive, passive and aggressive responses.

1. Your doctor keeps you waiting 2 hours for your appointment.

Passive: That's OK Dr. Smith. Your time is very important. I can wait.

Aggressive: Storm out of the office and give the receptionist a piece of your mind.

Assertive: I understand you are busy Dr. Smith, but I appreciate being seen in a reasonable amount of time. What can we do to prevent this from happening again?

2. Your family insists that you keep up a happy front regardless of how you might be feeling inside.

Passive: Tell everyone you are fine, even when you are not.

Aggressive: Lash out at anyone who asks you how you are doing.

Assertive: Be honest about your feelings. Ask directly for support from those around you. Specify what others may do to help e.g., I would really appreciate it if you could put the children to bed as I am feeling very tired tonight.

3. You have questions about your medical treatment.

Passive: You agree to undergo a particular treatment even though you have questions about alternative treatments.

Aggressive: Tell the doctor that you can always go to another clinic if he/she doesn't help you.

Assertive: Write your questions down in advance. Take notes during your visit. Bring someone along who can help you sort through the information you are provided. Ask questions when you don't understand. Ask for information to be repeated as needed. Ask for who you can contact should you have further questions.



MORE ON ASSERTIVE COMMUNICATION

Assertive communication is based on these assumptions:

1. You are the best judge of your thoughts, wants, needs, and feelings.
2. Therefore, you are the best advocate for expressing your point of view and needs. This means you are responsible for making your needs known.
3. Just as others have the right not to be responsible for making sure your needs are known, you have the right not to anticipate others' needs and wishes.
4. You have the right to differ from others in your perspective, opinions and needs because you are unique.
5. You have a right to express your position and to try to negotiate differences.
6. You have the right not to take responsibility for others' problems.
7. You have the right to say "No".
8. You have the right to ask for help or emotional support.
9. You have the right to be inconsistent.
10. You have the right not to justify what you feel, need, think if you don't want to.

Guidelines for Effective Assertion

Most of the skills necessary for effective assertion parallel those needed in effective communication generally, and are aimed at decreasing defensiveness and increasing cooperation in others.

Prepare and define clearly what you want to achieve and keep your goal in mind as you ask for change

Arrange for a mutually convenient time and place to discuss your issue.

Acknowledge your awareness of the other person's needs and perspective.

State the positives in your experience of the other person.

Express your problem and needs as specifically as possible.

Describe your feelings so that the other person has a better understanding of how important an issue is to you.

State your feelings and needs subjectively (Use "I" statements).

Use assertive body language. Maintain eye contact. Speak clearly, audibly, and firmly (this doesn't mean using an angry tone). Avoid an apologetic tone of voice.

Help motivate the other person to give you what you want by describing the positive consequences – for you but also for him/her and for your relationship. If dealing with someone who has a history of being uncooperative, state the alternative way you will take care of yourself if your request is not met. This doesn't mean making a threat, which tends to elicit anger. Stating the consequences of non-cooperation is not designed to hurt the other person but to clarify how you will take care of your interests. For example, you might say "If you are unable to schedule a time to discuss these issues, I will make an appointment with another of your colleagues to do so."

Compromise when you can. For example: "What would you need from me to feel OK about doing this the way I would like?"

Some ways to assist assertive communication with health care providers:

Write down your questions, listing the most important ones first.

Be ready to describe simply and briefly the symptoms/concerns that brought you to the MD (i.e., location, when did it start, how often does it happen, what makes it better/worse, what have you tried so far, what your concerns are)

Know the medications you are taking and the dosage for each.

If you feel that your concerns require more than a 15-minute appt., ask the receptionist to schedule more time when you are setting up your appt.

Clarify your expectations beforehand. Are you looking for a diagnosis, symptom relief, or a treatment plan (i.e., information, analysis, advice, understanding, reassurance or any combination of the above)?

Extra strategies for success with assertiveness:

Avoiding manipulation:

Broken Record: For those who won't take no for an answer (your 6 year old) or for those who refuse a reasonable request (your managed care company), choose a concise sentence to be your broken record:

Examples:

Your six-year-old won't take no for an answer: "Jon, I am not going to give you any more candy. I know you want more but I am not going to give you any more candy...."

Your managed care company refuses a reasonable request: I know you usually don't allow specialist visits more than once every three months but as I am experiencing some symptoms I believe I need to be seen earlier. I know this is not your policy but I need to be seen earlier....

Assertive Delay: Put off a response to a challenge until you have more information and know exactly how to respond: "I need to think about this some more. Let me call you back"

Dealing with derailing:

Delaying: I know you need to speak with your supervisor but I need an answer today. When may I call you back to get an answer? (Assertive inquiry and broken record.)

Nickel and diming: The other person wants to debate the legitimacy of your request or the magnitude of the problem, etc. Use a content to process shift: "I feel that we are quibbling now and have gotten off the main point. As I said I am concerned about these symptoms I have been having and I am requesting an early appointment with my doctor." Remember you have a right not to justify what you are asking for.

Denial: "We are always responsive to your requests and return your phone calls in a timely way." Assert what you have observed and experienced in behavioral terms: "It may seem that way to you but what I have experienced is that I have made three phone calls over the past two days and I have not yet spoken to someone who can help me with my request."

SESSION 4

OBJECTIVES:

1. Participants extend their understanding of effective communication to skills of particular relevance to conversations with children.
2. Participants review the life changes brought about by cancer and the ways the skills discussed in the group can help reduce stress and enhance "life after cancer."
3. Participants have the opportunity to share their experiences of breast cancer in the family with other women and their partners.

OUTLINE:

1. Review of the last session's topics.
2. Effective Communication with Children.
3. Personal changes brought about by cancer in the family.
4. Review & Feedback.
5. Bridge to children's intervention groups (Expanded Intervention Only)

SUPPLIES:

1. Name tags
2. Pens
3. Parking passes/Childcare reimbursement (Basic Intervention Group Only)
4. Refreshments: Coffee/bagels/napkins/plates/cups
5. Four Posters on communication with children
6. Post-Intervention questionnaires

HANDOUTS:

1. Handout: Effective Communication with Children
2. Handout: Aspects of My Self Exercise
3. Handout: Priorities Exchange Exercise

SESSION 4

COMMUNICATION II: Effective Communication with Children; Personal Changes Brought about by Cancer in the Family; Review and Feedback

A. REVIEW

(The group leaders will ask the participants to report on their experiences with the communication skills discussed last session, responding to any difficulties encountered and acknowledging successes.)

B. EDUCATION

This is our last session. In the first part of our session we will discuss how to apply the communication skills we have been working on to your interactions with your children. In the second part of our session we will do a brief exercise to examine personal changes brought about by cancer in the family. We do this exercise to help focus your thoughts on how you may use the skills we have worked on in this group to enhance any positive changes you have noticed in your own life and relationships with others, and to minimize the impact of any negative changes that have occurred. We will end today's session by taking time to review what we have accomplished in this group and to get your feedback and comments.

(Leaders provide Effective Communication with Children handout.) **Listening to children.** Just as with adults, your conversations with your children will benefit from the use of good listening and speaker skills. Of course with children it gets more complicated as their own communication skills are still developing and their developmental level will affect their ability to understand what you are trying to communicate. *(For those in the Expanded Intervention Only: The group leaders will remind the participants that the children's groups have devoted a lot of time to helping children develop good communication skills by helping them to identify and cope with their feelings and to learn ways to solve problems by "using their words".)* Today we will focus on ways to help your children deal with their feelings. Much of the information we will be discussing comes from the work of Adele Faber and Elaine Mazlish, who have written some well-known and helpful books on childrearing, such as "How To Talk So Kids Will Listen And Listen So Kids Will Talk", which you received last time we met.

Helping children deal with their feelings. Anyone who is a parent is well aware that children's feelings have a direct influence on how they behave. An angry child is apt to talk back to you or hit his/her sibling. A happy child may ask to help with the dishes, or assist a sibling with his/her homework. This is not rocket science. The tough part is helping kids manage their feelings and by doing so controlling their behavior. One of the most important things we can do in this regard is to accept their feelings. It is common for parents to be uncomfortable with some of their children's feelings. Some examples would be when children are angry and hit their sibling, or call each other names. When we see these types of behaviors we want to stop them immediately and to do so we may say things like: "There's no reason to be so upset," (Think of how you have felt when someone has responded this way.) Or "You two always behave this way when you are tired so it's early to bed tonight". What these types of responses do is invalidate, ignore, minimize or explain away the feelings that led the children to the problem behaviors in the first place. When we do this on a regular basis we prevent both the children and ourselves from learning to recognize their feelings and learning to deal with them in appropriate ways. When we tell a

child who is angry that there is no need to be so upset we are fundamentally denying their feelings (their experience of a situation). From the child's point of view, when we deny his/her feelings, we can confuse them e.g., "Why does mom say I shouldn't be so upset when Michael just broke my Lego building?" enrage them, "Not only did Michael break my Legos, but mom is yelling at me now!" and show them that we don't appreciate their point of view e.g., "I just spent an hour setting up this building and Michael comes along and breaks it and all mom cares about is my yelling at him. What about how I feel?" Admittedly, we may not like the feelings they are expressing and certainly we do not need to tolerate any aggressive or mean behaviors that arise from their feelings. However, we will not be able to help them behave in different ways unless we help them identify their feelings and learn appropriate ways to behave when they experience those feelings. We don't have to accept how the child expressed their feelings (how they behaved) to accept the feelings themselves. Let's look at another example to reexamine what can happen when we ignore or acknowledge our children's feelings, and how things can be different when we pay attention to those feelings and help the child learn how to deal with them appropriately.

Scenario # 1: Provide cartoon of parent ignoring the child's feelings and child's response (Show cartoon C)

Scenario # 2: Provide cartoon of parent acknowledging the child's feelings and the child's response. (Show cartoon C)

What do you think accounts for the different outcomes from these two different scenarios?

(Ask participants for their reactions. If at this time participants are having difficulty understanding how this approach can be helpful, an adult demonstration can be enacted where one group leader takes the role of the angry person and the other of the a partner who denies or minimizes the angry person's feelings. [Angry person: "I asked you to come home early so that we could make it to Sam's little league game!" Partner: "Well, there is no need to be so angry. I am sure we can get to game at another time."] Solicit feedback from the group about how the partner's response may have aggravated the angry person and what alternative responses might have been more helpful. The group leaders can provide feedback about how the participants' suggestions would have worked from the perspective of the role they are playing).

As a guide to how you can help children deal with their feelings, the following suggestions are offered:

1. Listen with full attention (Show cartoon A)
2. Instead of questions and advice, acknowledge the child's experience. (Show Cartoon B)
3. Pay attention to feelings and give them a name. (Cartoon C)
4. Instead of explanations and logic, give a child his/her wishes in fantasy (Cartoon D)

(Leaders will solicit comments from group members and help clarify any questions or concerns.)

Some cautions:

1. Negative emotions need special attention.

2. When some children are upset they do not want to talk about their feelings. Sometimes just your presence or giving them time and space to calm down can help.

3. Try to match the child's level of intensity. Don't over or underplay their emotional reactions.

C. PERSONAL CHANGES BROUGHT ABOUT BY CANCER IN THE FAMILY

For the past several weeks, we have discussed and practiced stress management and communication skills as ways to enhance quality of life and cope with cancer in the family. Now we will take a more philosophical turn and use this last session to examine how cancer has affected your view of yourselves and how it may have changed your priorities for yourselves and your families. To this end we will do an exercise that focuses on clarifying characteristics of your self that you see as most central and value most. Then we will discuss how to bring your activities into line with who you are and what you value in life, using the coping and problem-solving skills we have been discussing over the last few months. This is a brief exercise and we fully appreciate that examining your personal and family characteristics and goals is a complex, lifelong process. However, we hope that it will provide you with some insight and information about yourselves and your priorities that will help guide you in your future efforts to cope with your lives "after cancer." (Leaders provide "Aspects of My Self" handout).

Exercise 1: "Aspects of Myself Exercise"

Step 1. List all of the aspects of your life before being diagnosed with breast cancer or before your wife was diagnosed. Consider important aspects of your self--those characteristics without which you would not be you. These can be roles that you play (mother, father, sister, brother, boss, homemaker, etc.); activities that you do (volunteer, hobbies) specific characteristics of your self (body image, personality characteristics, beliefs); places that are important in your life or any combination of the above.

Step 2. Draw lines connecting any aspects you feel are related.

Step 3. Circle all aspects of your life that have been affected by breast cancer.

Step 4. Indicate with a +/- whether these aspects have been positively or negatively affected by cancer.

Step 5. Answer the question at the bottom of the page about your satisfaction with your life before you/your wife was diagnosed with cancer.

When you are finished, turn to the next page and list all aspects of your life after being diagnosed with breast cancer (since your wife's diagnosis with breast cancer). Proceed through steps 2 - 4 above again. Do step 5 for your satisfaction with your life after you/your wife was diagnosed with breast cancer. Consider how cancer may have changed your self-image--What aspects of your self have changed? What aspects remain the same? Consider which characteristics of your self are most important to your living life as fully as possible. Consider how the skills we have been discussing and practicing in this group can help you meet your personal and family goals.

(You also may want to try an exercise called the Priorities Exchange, [provide Priorities Exchange handout] that is designed to help you define family priorities and to problem solve about how to have family activities reflect family priorities.)

D. REVIEW AND FEEDBACK

Leaders will briefly summarize the goals and activities of the Families Coping With Cancer Project and then open the floor to the participants so that they may review and comment upon their experiences in the group. Leaders should try to help participants identify the most and least useful aspects of this group experience.

E. BRIDGE TO CHILDREN'S INTERVENTION (For Expanded Intervention participants only.)

This session the children will be reviewing what they learned by working on a scrapbook compiled from activities they have been doing over the course of the group. They will also receive a certificate, acknowledging their achievement in completing this group. They will end by having a little party to celebrate their accomplishments and to say good-bye to the other group members. *(Leaders ask for questions from participants regarding the children's groups. Children's group leaders join the parent group with the children and briefly review the children's activities. Children are presented with Certificates of Accomplishment when they join the parent group.)*

Handouts for the Families Coping With Cancer Project

Patient and Partner Group

Session 4



EFFECTIVE COMMUNICATION WITH CHILDREN

Just as with adults, your conversations with your children benefit from the use of good listening and speaker skills. Of course with children it gets more complicated as their own communication skills are still developing and their developmental level will affect their ability to understand what you are trying to communicate. One of the most important skills in communicating with children is helping them to deal with their feelings.

As a parent you likely are well aware that children's feelings have a direct influence on how they behave. An angry child is apt to talk back to you or hit his/her sibling. A happy child may ask to help with the dishes, or assist a sibling with his/her homework. The tough part is helping kids manage their feelings and by doing so control their behavior. One of the most important things we can do in this regard is to accept their feelings. It is common for parents to be uncomfortable with some of their children's feelings. Some examples would be when children are angry and hit their sibling, or call each other names. When we see these types of behaviors we want to stop them immediately and to do so we may say things like: "There's no reason to be so upset," (*Think of how you have felt when someone has responded this way.*) or "You two always behave this way when you are tired so it's early to bed tonight". What these type of responses do is invalidate, ignore, minimize or explain away the feelings that led the children to the problem behaviors in the first place. When we do this on a regular basis we prevent both the children and ourselves from learning to recognize their feelings and learning to deal with them in appropriate ways. When we tell a child who is angry that there is no need to be so upset we are fundamentally denying their feelings (their experience of a situation). From the child's point of view, when we deny his/her feelings, we can confuse them e.g., "Why does mom say I shouldn't be so upset when Michael just broke my Lego building?" enrage them, "Not only did Michael break my Legos, but mom is yelling at me now!" and show them that we don't appreciate their point of view e.g., "I just spent an hour setting up this building and Michael comes along and breaks it and all mom cares about is my yelling at him. What about how I feel?" Admittedly, we may not like the feelings they are expressing and certainly we do not need to tolerate any aggressive or mean behaviors that arise from their feelings. However, we will not be able to help them behave in different ways unless we help them identify their feelings and learn appropriate ways to behave when they experience those feelings. We don't have to accept how the child expressed their feelings (how they behaved) to accept the feelings themselves.

As a guide to how you can help children deal with their feelings, the following suggestions are offered*:

1. Listen with full attention.
2. Instead of questions and advice, acknowledge the child's experience.
3. Pay attention to feelings and give them a name.
4. Instead of explanations and logic, give a child his/her wishes in fantasy.

Some cautions:

1. Negative emotions need special attention.
2. When some children are upset they do not want to talk about their feelings. Sometimes just your presence or giving them time and space to calm down can help.
3. Try to match the child's level of intensity. Don't over or underplay their emotional reactions.

*These suggestions are set forth in Adele Faber and Elaine Mazlish's book, "How to Talk So Kids Will Listen and Listen So Kids Will Talk", and we encourage you to read this book for more suggestions about effective communication with children.

Aspects of Myself Exercise

My life before my wife's breast cancer diagnosis	My life since my wife's breast cancer diagnosis
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

1. How satisfied were you with your life before your wife was diagnosed with breast cancer?

1	2	3	4	5	6	7
Not at all satisfied						Very satisfied

2. How satisfied are you with your life since your wife was diagnosed with breast cancer?

1	2	3	4	5	6	7
Not at all satisfied						Very satisfied

Aspects of Myself Exercise

My life before breast cancer	My life since breast cancer
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.

1. How satisfied were you with your life before you were diagnosed with breast cancer?

1	2	3	4	5	6	7
Not at all						Very
satisfied						satisfied

2. How satisfied are you with your life since you were diagnosed with breast cancer?

1	2	3	4	5	6	7
Not at all						Very
satisfied						satisfied



Priorities Exchange

1. In column 1, list the 10 major activities you engage in a typical week.
2. In column 2, prioritize these items in terms of which activity you spend the most time with on top, and progressively the items you spend the least time with on the bottom.
3. In column 3, reprioritize the items again, but this time list the activities that bring the most meaning to you those items that make life worth living, on top, and the items of lessening personal value towards the bottom. You may add new items to the list you wish you could get to do, but usually do not have the time.
4. Draw lines between similar items in columns 2 and 3. Do you have large X's or do your lines go mostly straight across? What does this mean to you?
5. What can you do to spend more time engaged in those activities that make life worth living? What has to go to bring this more centrally into your life?

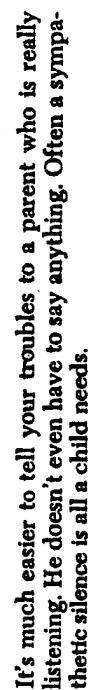
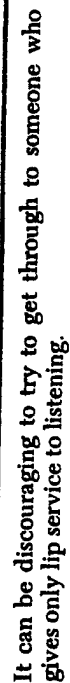
Major Activities	Time Spent (Most to Least)	Most Important Activities
1.	1.	1.
2.	2.	2.
3.	3.	3.
4.	4.	4.
5.	5.	5.
6.	6.	6.
7.	7.	7.
8.	8.	8.
9.	9.	9.
10.	10.	10.

Posters for the Families Coping With Cancer Project

**Patient and Partner Group
Session 4**

INSTEAD OF HALF-LISTENING,

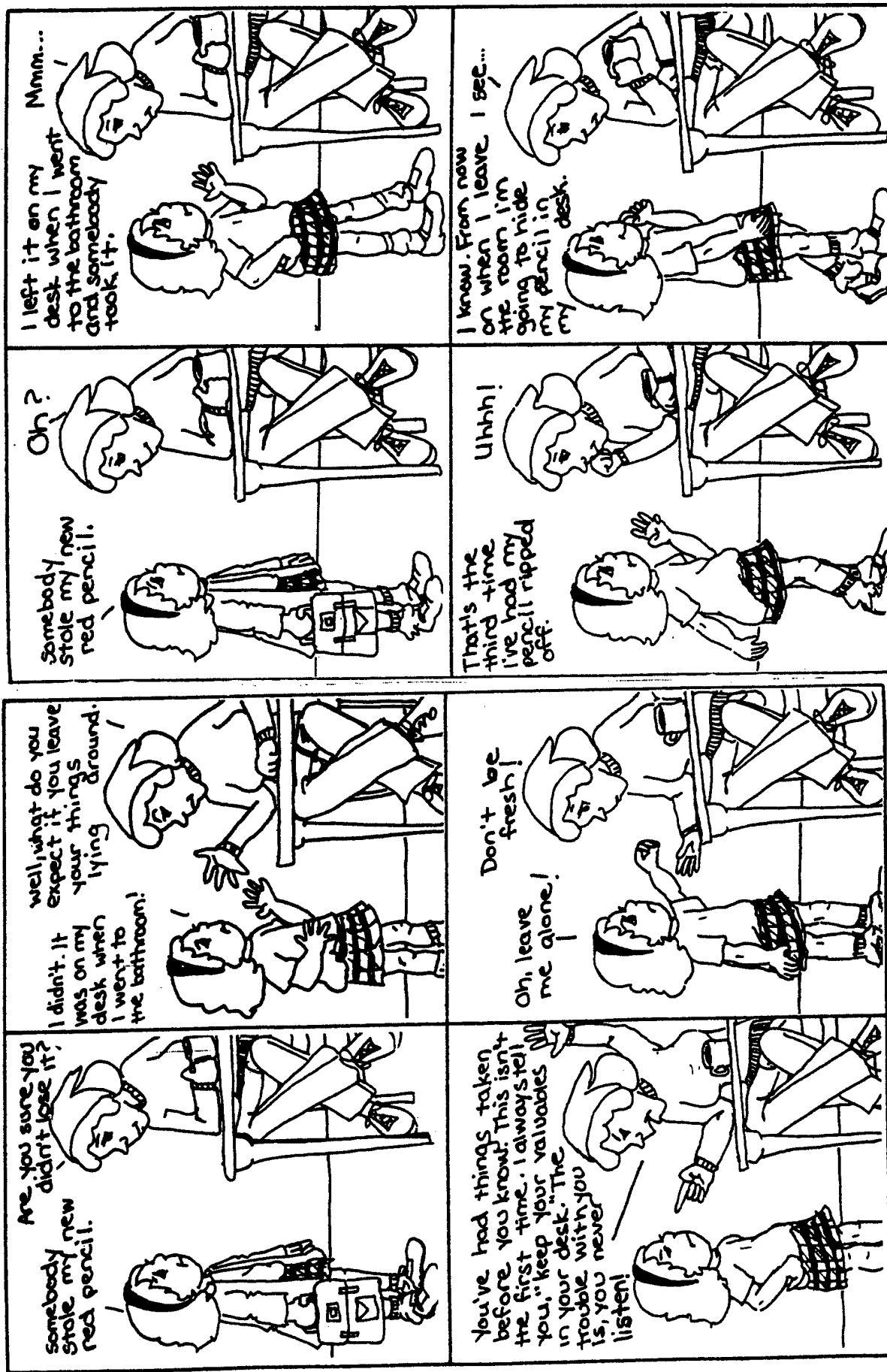
I. LISTEN WITH FULL ATTENTION.



From: How To Talk So Kids Will Listen & Listen So Kids Will Talk, by Adele Faber and Elaine Mazlish, 1980. Avon Books, New York.

INSTEAD OF QUESTIONS AND ADVICE,

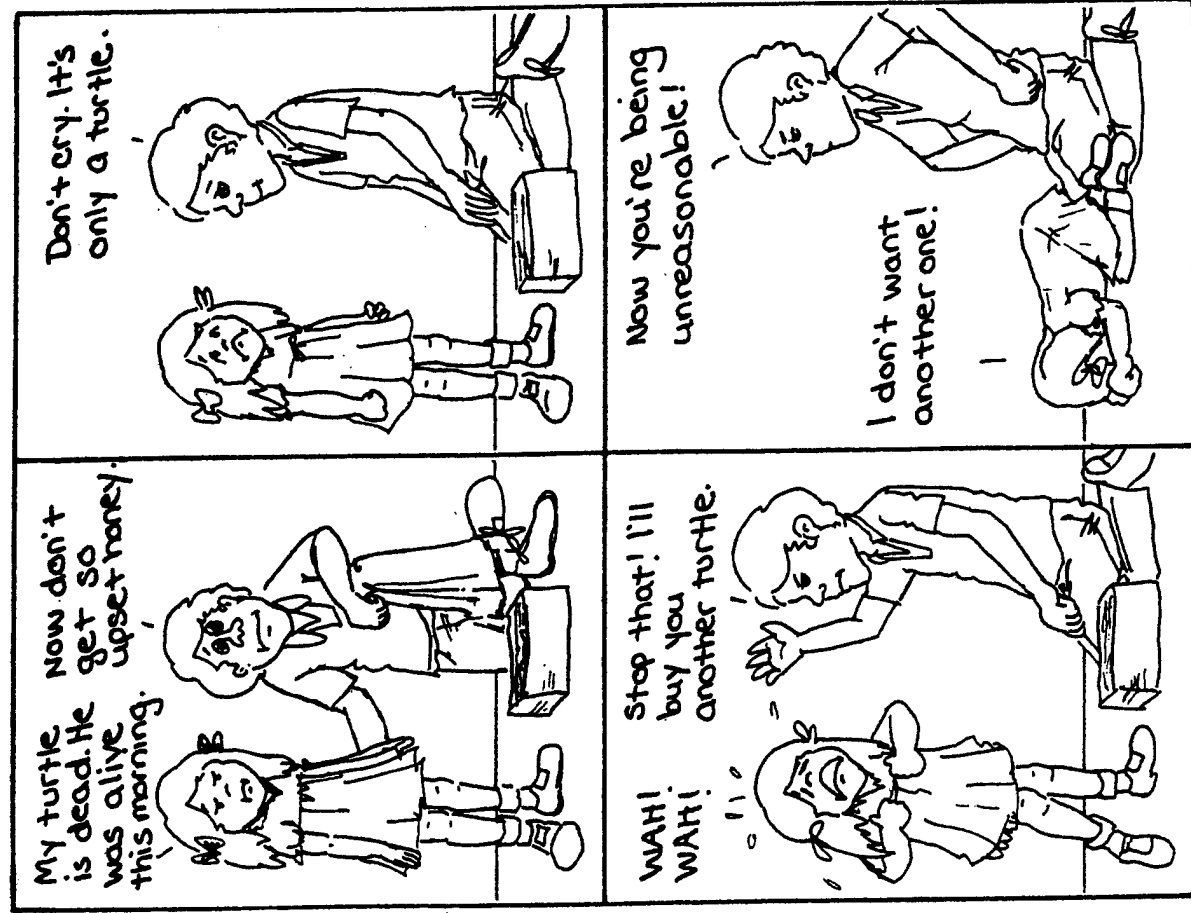
II. ACKNOWLEDGE WITH A WORD—"Oh . . . Mmm . . . I see."



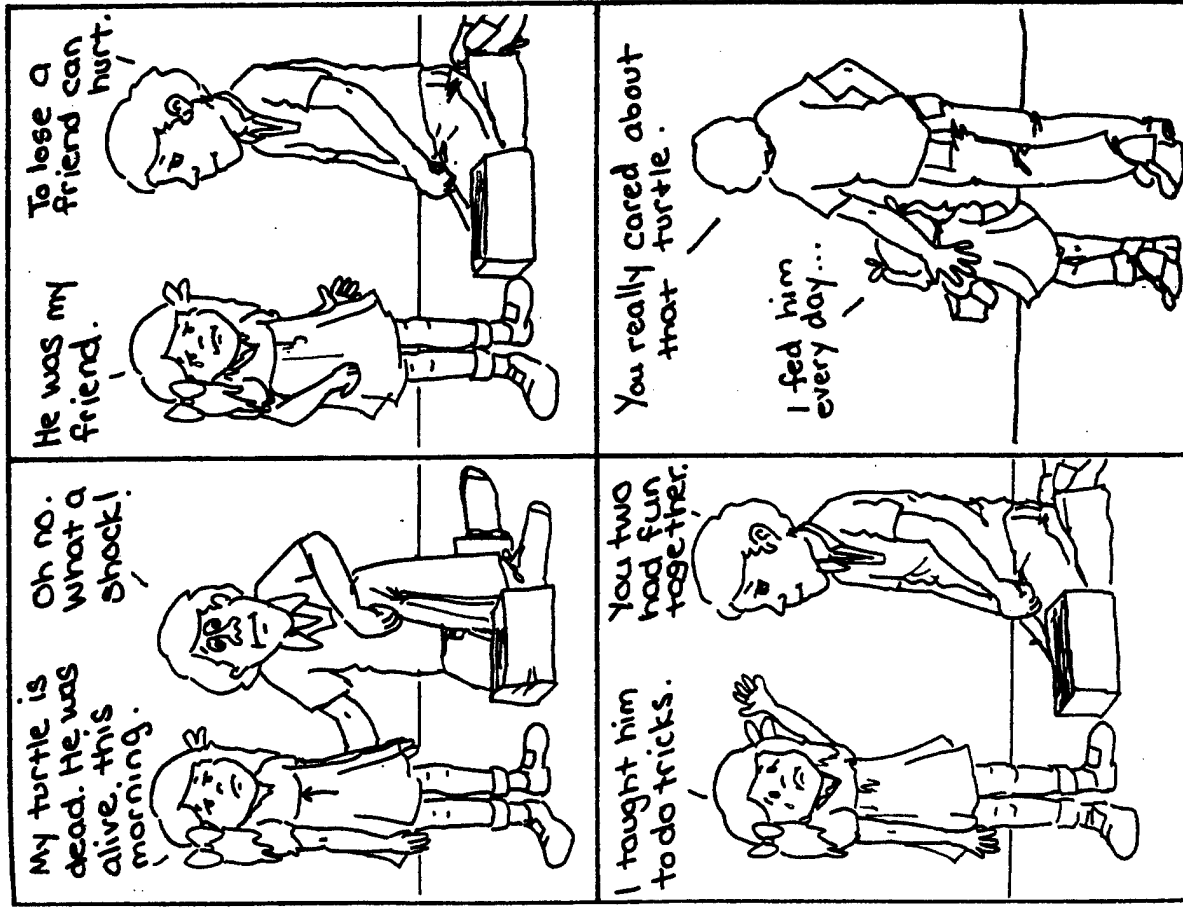
It's hard for a child to think clearly or constructively when someone is questioning, blaming, or advising her.

There's a lot of help to be had from a simple "Oh . . . ummm . . ." or "I see." Words like these, coupled with a caring attitude, are invitations to a child to explore her own thoughts and feelings, and possibly come up with her own solutions.

From: *How To Talk So Kids Will Listen & Listen So Kids Will Talk*, by Adele Faber and Elaine Mazlish, 1980. Avon Books, New York

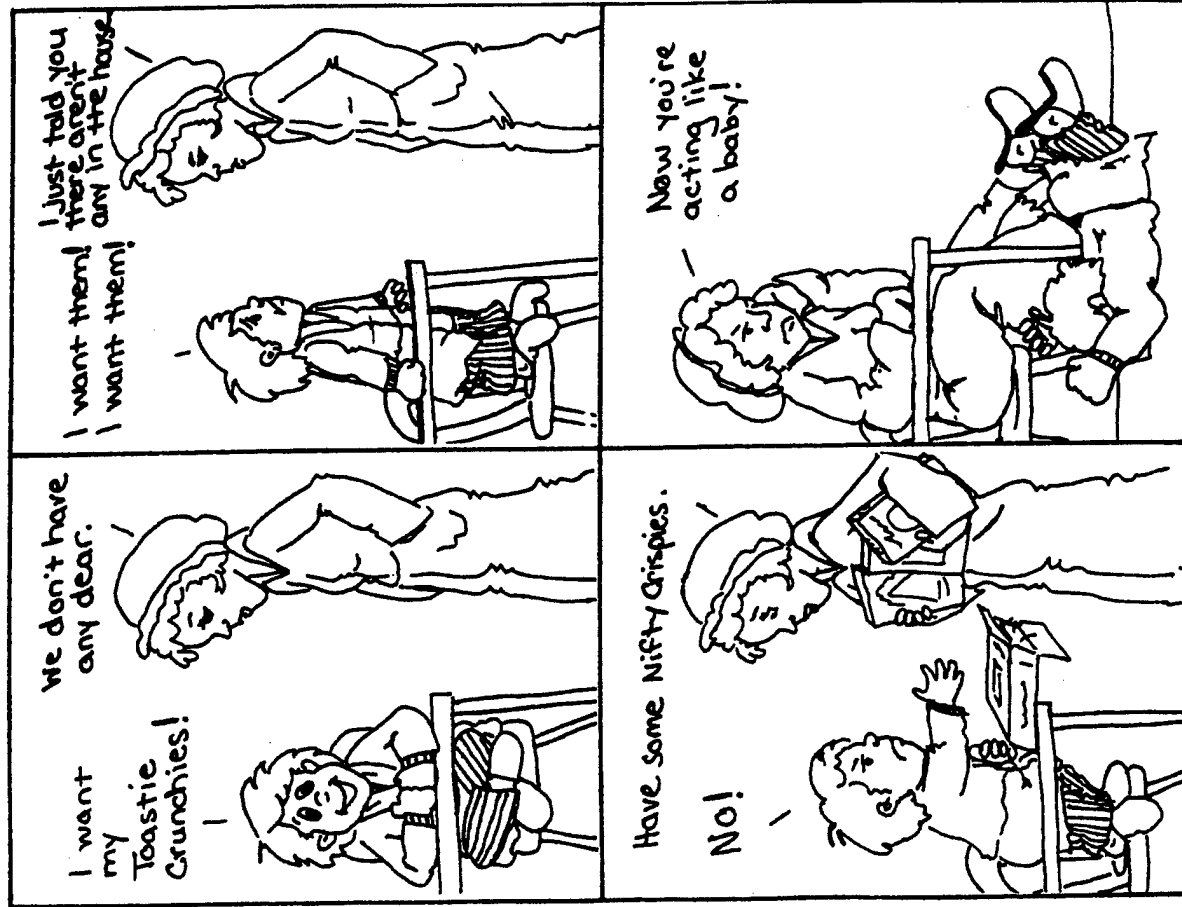


It's strange. When we urge a child to push a bad feeling away—however kindly—the child only seems to get more upset.

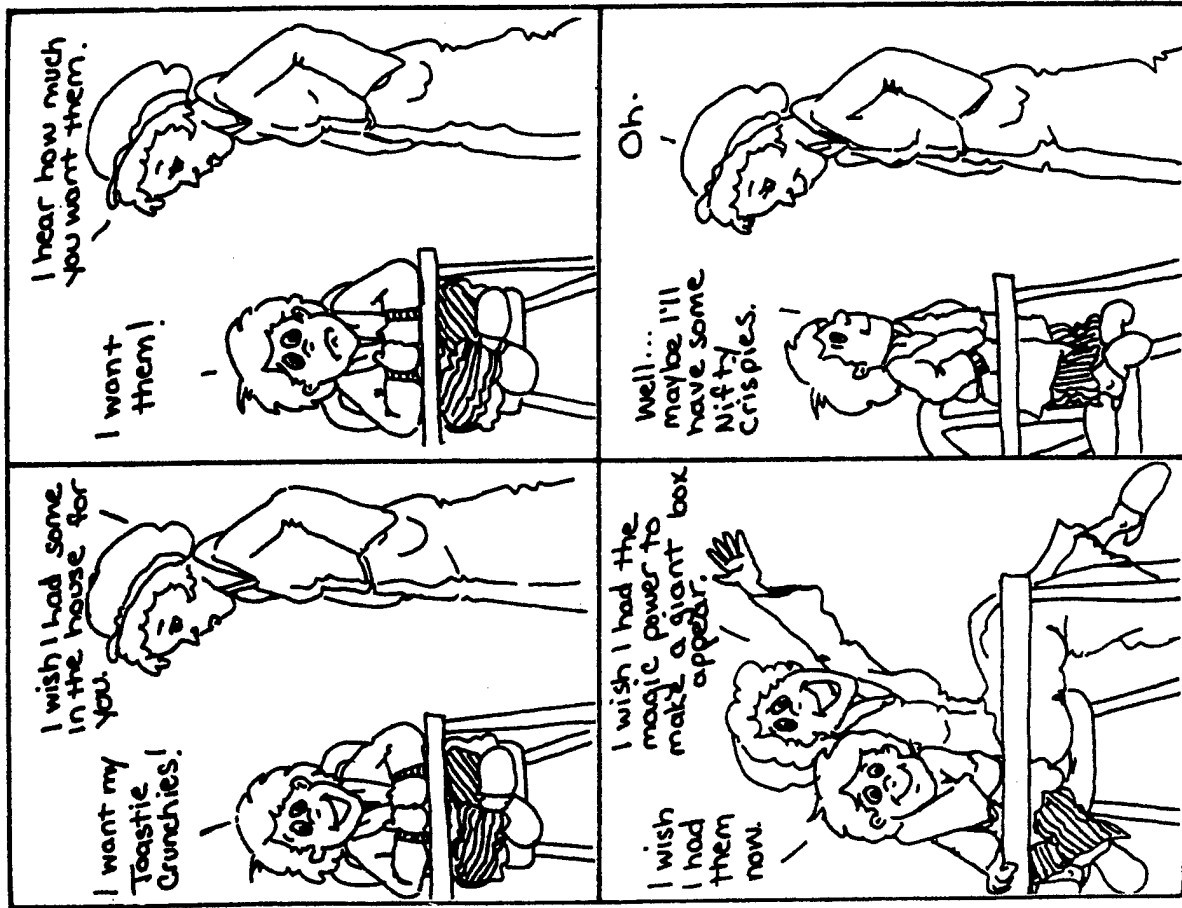


Parents don't usually give this kind of response, because they fear that by giving a name to the feeling, they'll make it worse. Just the opposite is true. The child who hears the words for what he is experiencing is deeply comforted. Someone has acknowledged his inner experience.

INSTEAD OF EXPLANATION AND LOGIC,



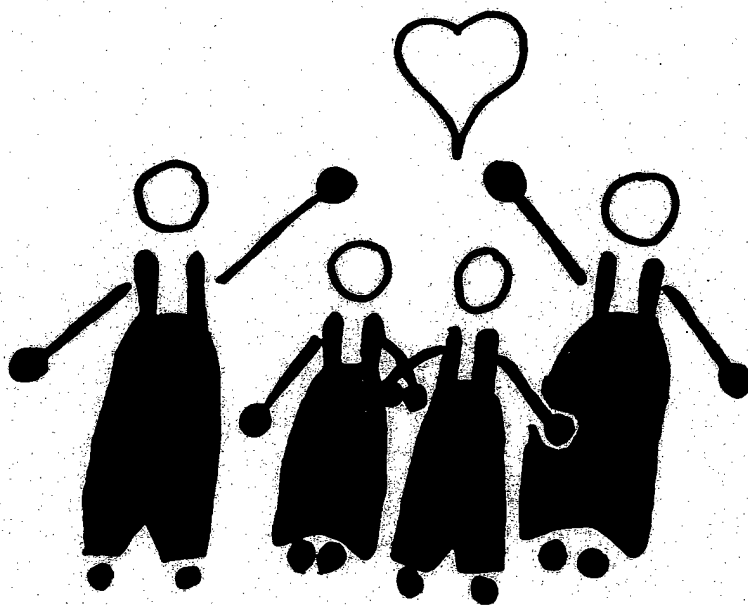
When children want something they can't have, adults usually respond with logical explanations of why they can't have it. Often the harder we explain, the harder they protest.



Sometimes just having someone understand how much you want something makes reality easier to bear.

FAMILIES COPING WITH CANCER PROJECT

Treatment Manual: Younger Child Group (Ages 4-6)



Funded by U.S. Army Materiel Command 1997-2001

Family Intervention for Young Women With Breast Cancer

**Sally E. Tarbell, Ph.D.
Principal Investigator**

Session 1: Ages 4-6

"All About Our Group, Our Families And Cancer"

Oncology Nurse Educator Materials

Handouts

Take-home

2

Session 2: Ages 4-6

"All About Our Feelings And Relaxing"

Handout

Take-home

3

Session 3: Ages 4-6

"All About Solving Problems And Being Friends"

Materials

Handout

Take-home

4

Session 4: Ages 4-6

"All About What We've Learned And Saying Goodbye"

Handouts

Take-home

5

6

7

8

SESSION 1

ALL ABOUT OUR GROUP, OUR FAMILIES, AND CANCER

Main Objectives:

1. Build rapport and group cohesion
2. Reinforce individual strengths
3. Normalize experiences
4. Provide accurate information about cancer and correct misperceptions

Outline:

1. Introductions
2. How we're different/ how we're the same
3. All about families and cancer
4. Snack and review
5. For next time

Materials:

1. Polaroid camera & film
2. Name tags
3. Introductory song or rhyming poem/closing song or taped music
4. Crayons/markers
5. Roll of newsprint
6. Brown, yellow, red, and black yarn
7. Brown, blue, and green "eyes"
8. Glue, glue sticks
9. Stuffed animals (i.e., lion, elephant)
10. Animal doll family
11. Bubbles
12. Snacks
13. Scrapbooks (1 for each child)
14. Boom Box
15. Oncology Nurse Educator Materials

Session Books:

We're All Special A. Maguire (1995)
All By Myself M. Mayer (1983)
Leo the Late Bloomer R. Kraus (1971)

Session Handouts:

Page 1: All About What I Look Like

Take Home Books:

When Eric's Mom Fought Cancer, J. Vigna (1993)
Paper Chain, C. Blake et al. (1998) (they keep)
Guess How Much I Love You, S. McBratney (1995)

Take Home Handouts:

A Small Book of Big Words (FOR PARENTS)
For Home #1: More About...Families and Cancer

I. INTRODUCTIONS (10 mins.)

(The Facilitator should be wearing a nametag when the children arrive. Children are assisted with writing their names on nametags as they enter the room. Two Polaroid pictures of each child are taken. Children will sit in a circle. Each child will have 1 of his/her Polaroid pictures in front of him/her. The other picture is set aside for placement in their personal scrapbook to be handed out later in the session.)

Once all of the children arrive, the Facilitator will use an introductory song or a rhyming poem, introducing her/himself and then naming each child who is in the group. This introductory song or rhyming poem will be used at the beginning of each session to assist the children's transition to the group and to reinforce group cohesion.

The facilitator will need to be flexible with the time spent in each activity below, depending on the number of children in the group and their specific interests. For example, with fewer children the activities may be expanded to take more time, whereas with larger numbers of children the activities may need to be shortened to get in all that is planned for the session).

Welcome to our group. We will be doing a lot of different things, like playing games, reading stories, singing songs, and making pictures. Today, we will have a special visitor, a nurse who will join us when we have a snack a little later. We need to have some rules for this group so that everyone can get along and be friends. One rule is to quiet down when I go like this. (Facilitator puts finger to lips.) Another rule is to share the things that are in this room. Another rule is to take turns and listen to each other. Does everyone understand?

You each have a picture of yourselves. Hold it up so everyone can see. (Children hold up their pictures.) Now, put your picture in front of you and stand up. We're going to play a game. (In the game children walk around in a circle to music and the person who is "it" stops when the music stops, picks up the picture in front of him/her and shakes that person's hand. In the next round, someone else is "it.")

II. HOW WE'RE DIFFERENT/ HOW WE'RE THE SAME (40 mins.)

(Get out the roll of newsprint and lay it on floor with some crayons and markers). We're going to make a banner about this group. It's important for the banner to show that everyone here is an important part of the group.

(Facilitator calls the children, one by one, and instructs each child to sit at a spot next to the roll of newsprint. The Facilitator traces each child's hands on the roll of paper in the color of child's choice and writes his/her name. When banner is done, the facilitator hangs it on the wall.) What a good banner. The group is made up of everyone here. One thing that I notice is that everyone's hand is different. (Point out differences among pictures with children's input, e.g., size, crayon color).

Each of us is different in special ways. Here's a book about how everyone is special. (Facilitator reads We're All Special.) One way that you are special is that no one else looks exactly like you. (Pass out Page 1: All About What I Look Like). This page consists of a body outline. Provide children with different color googly eyes and yarn to match their features, i.e., green eyes, blue eyes, brown hair, blond hair. The Facilitator helps the children choose features that match their own and glue them onto the cut out. Children can take some time to color the rest of their picture.) We are going to place your pictures in your own special scrapbook. We will add to this scrapbook each time we meet. You can take this scrapbook home after our last meeting. (The Facilitator places the child's picture along with the Polaroid photographs in each child's scrapbook.)

The ways that we are different from each other are the things that us special. (Using Lion and Elephant stuffed animals.) For instance, Ms. Lion has a special mighty roar that protects the other animals. Mr. Elephant's has a special trunk he can use to wash himself and his babies. Each of you has different ways that you are special too.

(Facilitator reads two books described below. If time is short the leader may choose to read only one.)

Book 1 : All By Myself by Mercer Mayer

You all do some important things all by yourself. Here's a story about learning how to do things all by yourself. (Facilitator reads All By Myself by Mercer Mayer. For each picture in book ask: Who can do _____ all by themselves? Allow time for children to respond.)

Book 2: Leo the Late Bloomer by Robert Kraus

There are some other things that adults and bigger kids, maybe some of your friends or brothers and sisters, can do but that you haven't learned how to do yet. Let's read this story now. (The Facilitator reads: Leo the Late Bloomer by Robert Kraus.) What did you think of that story? What could Leo do when he needs help? (Children respond. Facilitator emphasizes asking for help from an adult or older sibling.)

We've talked about the ways that we're special. One way that we're all the same is that we're in this group. Another way that each of you is alike is that your moms are/have been sick.

III. ALL ABOUT OUR FAMILIES (20 mins.)

(Using animal family.) This is the Bunny family. This is the daddy bunny, the mommy bunny, and the little girl bunny and boy bunny. (Facilitator elaborates on family roles. Facilitator elicits children's responses about their own families, i.e., "What color is your mommy's hair?", "What is your brother's name?")

(Using mother bunny.) One day the mommy bunny got a hurt right here. (Points to chest of the mother bunny.) She had to go to the hospital. I wonder why she went to the hospital? Can anyone guess why? (Children respond.) Did any of your moms go to the hospital to sleep overnight? Did you go to the hospital to see your mommy? What do you remember about the hospital? One thing that was different for the baby bunnies when their mom got cancer was that they missed her more because she was at the hospital sometimes. Do you think that they worried when she was at the hospital? (Children respond. Facilitator addresses issues that emerge from group discussion and responds accordingly.)

(While children are engaging in imaginative play with the stuffed animals.) What things have you wondered about or been worried about since your mom has been sick with cancer? When a mom or dad in a family is sick, it can change the way family members feel. It can also change how they get along with one another. Have you noticed some changes in how you feel or how you get along with others since your mom has been sick? There are also a lot of things about families that don't change when someone is sick. For example, most people still care about each other and want to help each other. What stayed the same in your family?

V. SNACK AND REVIEW (10 mins.)

(Get out snack and ask children to assist with tasks e.g., pass out the napkins, pass out the drinks)

Today, we have a special guest with us for snack time. Her/His name is (name of oncology nurse). She/He is a nurse who takes care of people who have cancer. (Oncology nurse educator introduces him/herself and offers to answer any questions the children have about cancer and its treatment.)

Now, let's talk about what we did today. I'll write these things down so that we can show your parents all the important things you did today. (*Children say what they did during the session and the facilitator writes their comments on newsprint.*)

VI. FOR NEXT TIME (5 mins.)

For next time, I'd like you to tell about something fun that your family does together.

(Facilitator sings or plays closing song/music.)

(Children meet their parents at the parents' group. Facilitator summarizes what was accomplished during the session. Facilitator gives feedback to individual sets of parents regarding their child's participation in the group and gives handout sheets to parents. The parents generally are very welcoming of this feedback and sufficient time needs to be allotted for each family. Depending on the group size, the parent group may need to end 10-15 minutes early to assure that the facilitator gets a chance to meet with each family before they leave.)

Oncology Nurse Educator Materials

for

The Families Coping With Cancer Project

Children's Cancer Education

by Oncology Nurse Educator

The oncology nurse educator joins each of the children's groups for approximately 10-15 minutes during the first and second sessions. The nurse also lets the children know that s/he is available to answer their questions individually, both before and after the sessions. Although there are prompts used to initiate the children's discussion of cancer and its treatment, the specific content discussed varies with the children's questions and thus the nurse needs to be flexible in responding to the unique issues brought up by a particular group of children.

Younger Children's Group (Ages 4-6)

The nurse typically takes a few minutes to observe children in the group in order to evaluate their cognitive level and social interactions before s/he is introduced by the facilitators. The nurse describes him/herself as a nurse who works with women like their moms. The younger children generally have questions about what nurses do and who takes care of their mom when she goes to the doctors. The nurse generally tries to relieve any anxiety the children have regarding medical treatment and to show that doctors and nurses are just people like they are. The younger children are not shown pictures of cancer cells or cancer treatment unless they ask a specific cancer related question where a picture could help answer their question.

Older Children's Group (Ages 7-12)

The nurse introduces him/herself as a nurse who works with people with cancer. S/he selects a few key words such as cancer, chemotherapy, radiation, and tumor from the handout, "A Small Book About Big Words", and asks the children if they know what these words mean. S/he goes over these topics one at a time. S/he also encourages the children to share the handout with their parents and to bring it back and ask questions at future meetings. Pictures of a cancer cell, chemotherapy being administered, and a radiation machine are used to augment the discussion, as they help the educator respond to frequently asked questions, e.g., How does my mom get her chemotherapy?, What is a radiation machine?, How does a cell change into cancer?. The nurse tries to involve all the children in the discussion and to provide them with an opportunity to ask questions.

Discussion centers around the children's questions after the key words have been reviewed. For example, often a child in the group will know others with cancer and the child will want to discuss how that individual is the same or different from their mom. The children also commonly discuss changes in their family since their mom was diagnosed with cancer. It is emphasized to the children that routines will get back to "normal" once their mother is through treatment and feeling better.

Examples of frequently asked questions and nurse responses:

Can I catch cancer from my mom?

First, the nurse tries to find out why the children are asking this question, since in most instances the children know of other people in one family who have had cancer. Then the nurse reassures the children that they cannot "catch" cancer from their mothers. The nurse also explains that we do not know exactly how cancer occurs but that we do know that it is usually caused by a combination of things. The nurse does not typically give examples as the children often mention causes they are aware of and the nurse then validates or negates the cancer risk factors they cite.

Will my mom die from cancer?

The nurse honestly tells them that there is no guarantee that their mothers will not die from their cancer, but she also states that the mothers in this group have cancer that was caught very early and that we are very hopeful that their mother's cancer will be cured. The nurse also states that the treatment the doctors are giving/have given their mothers (chemotherapy &/or radiation) is to kill any cancer cells that could possibly have been left behind after the operation to remove the cancer.

Will my mom lose her hair?

This depends on what treatment your mother is receiving. Radiation will not cause hair loss unless it is given to the head and your mother is receiving radiation to her breast. Chemotherapy most often will cause hair loss.

Will her hair grow back?

The nurse reassures the children that their mother's hair will grow back. Generally the hair will come out about 3-4 weeks after the first treatment and it will begin to grow back about 3-4 weeks after the last treatment. It may grow back the same as it was before chemotherapy, but for some women it grows back in a different color and it may change from straight to curly or vice versa. The nurse stresses that all mothers are different and things can be different for each one of them, so they should not compare. She also stresses that their mom is still their mom regardless of their hair!

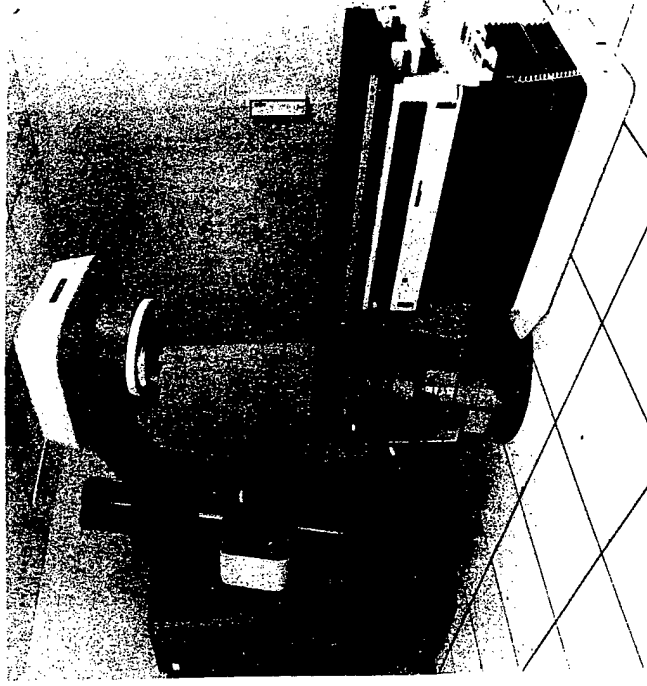
Are all cancers the same?

No, there are over a hundred types of cancer and even numerous types of breast cancer. Many types of cancer require different treatment and that is why you cannot compare people. The doctors and nurses who care for your mom are very knowledgeable about cancer and its treatment and will work with your mom to find the best treatment for her.

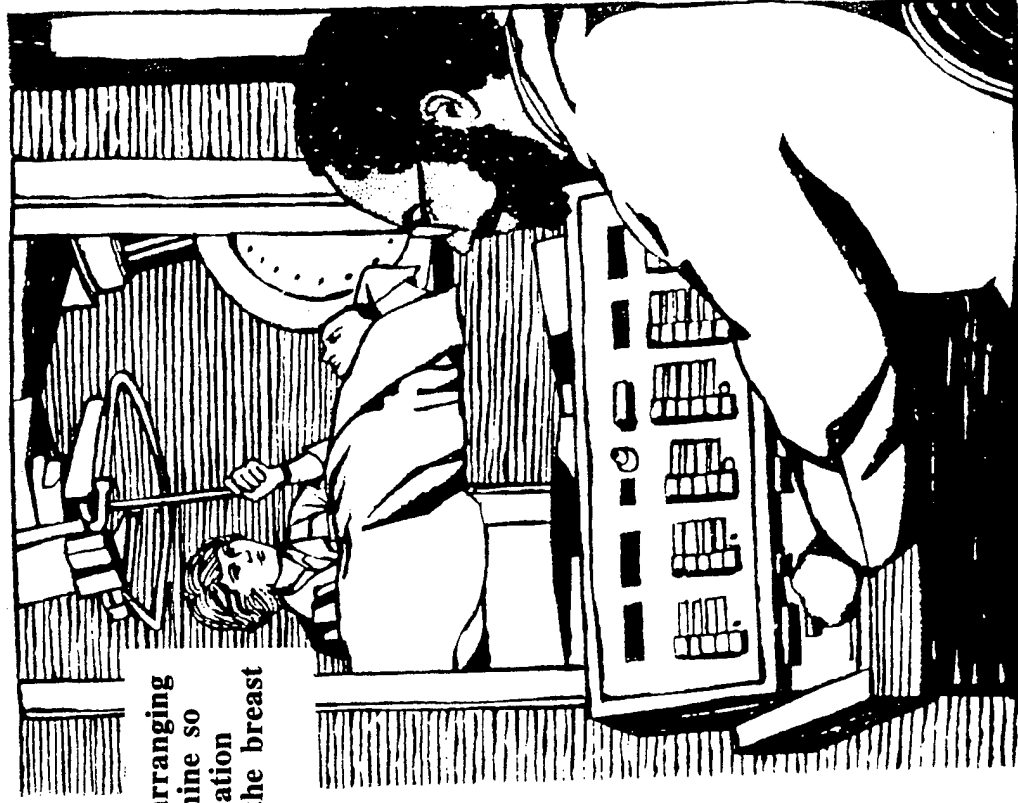
Will the cancer come back?

Hopefully not but that is why your mom will be seen by a doctor who specializes in cancer for the rest of her life. She will have blood tests and x-rays at different times to make sure the cancer has not returned. If the cancer does return, her doctors will know and they can start treatment early when cancer is most curable.

Radiation (X-ray) Therapy



Radiation Machine



Person arranging
the machine so
that radiation
goes to the breast
only

Individual behind window works the radiation machine.

This person can see the patient and the patient can talk to them at all times.

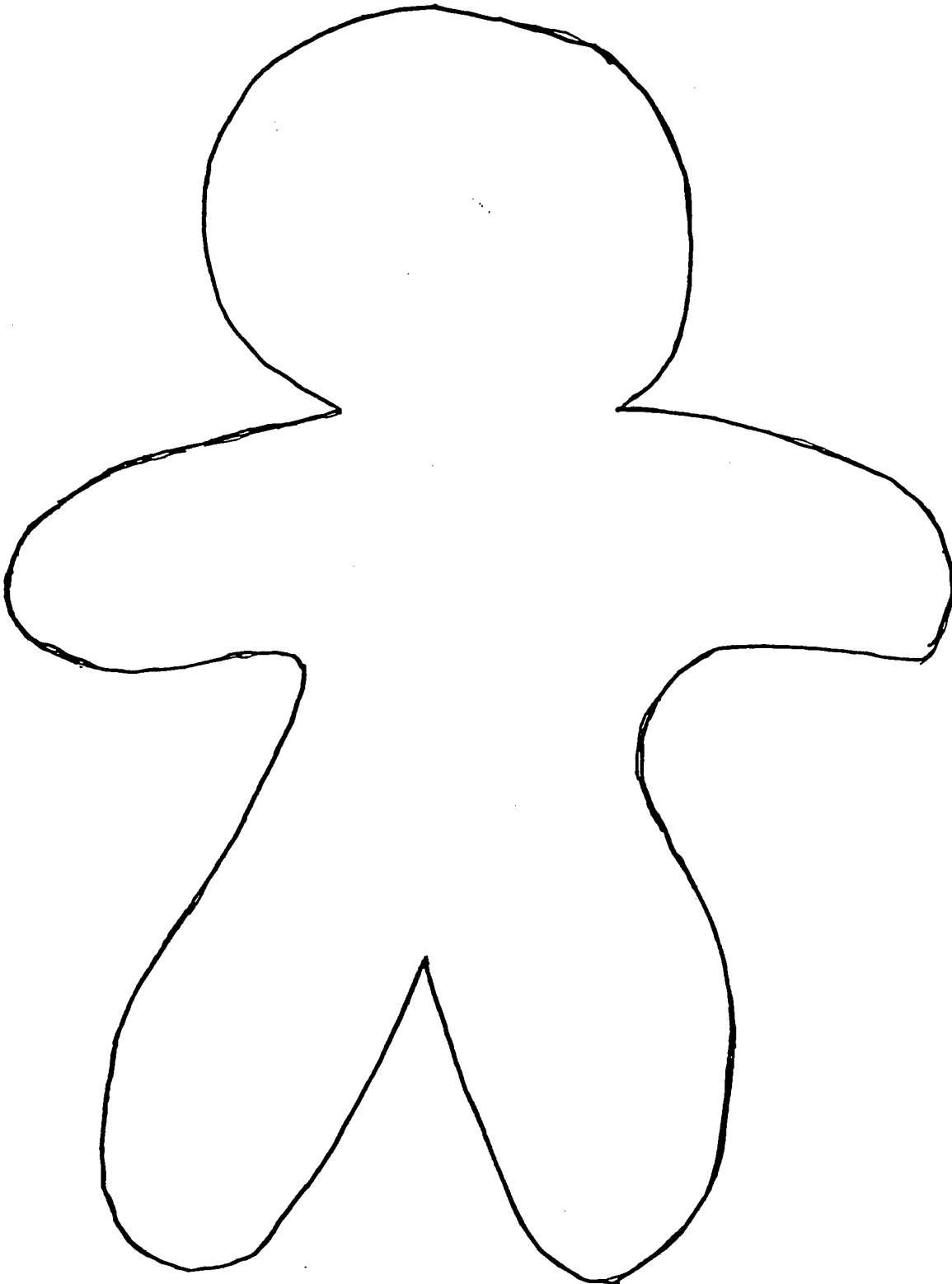
Handouts for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 1



All About What I Look Like



Name _____

Take-homes for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 1

A SMALL BOOK OF BIG WORDS



Anemia (a-nee'-mee-a)---A person with anemia has too few red blood cells. They may feel tired and weak. The doctor may have the patient take pills or they may have to receive a blood transfusion.

Analgesic (an -all -gee -sick)---Medicine that is taken for pain such as Tylenol.

Anesthesia (an -a -the -zha)---Given for an operation that makes you sleep and you don't feel pain.

Antiemetic (an -tie- e -met- ick)---Medicine that stops sickness in the stomach or throwing up. It may be given before chemotherapy or after chemotherapy.

Biopsy (bye'-op-see)---During a biopsy the doctor removes a little piece of tissue or tumor where there may be cancer. This can be done with a needle or a knife it depends where the part of the body is located. Sometimes this is done as an operation. The tissue that is removed is then examined under a microscope to see if there are cancer cells in it.

Benign Tumor (bee- nine two'-mer)---An unhealthy growth that is not cancer and does not spread to other parts of the body.

Breast Cancer (breast can'- sir)---Abnormal cells that have grown in the breast.

Blood Counts---Blood looks like a red liquid when we cut ourselves, but it really is made up of many things of different shapes and sizes. These different shapes are known as blood cells, they are white, red and platelets. Blood counts are very important since they tell the doctor many things. White blood cells fight infection, red blood cells carry oxygen to the lungs and platelets help us to stop bleeding when we get cut.

Bone Marrow (bone mar'-row)---The red stuff in the middle of a bone. This is where blood is made. It leaves the bone marrow and travels into the veins and arteries or blood vessels.

Cancer (can'-sir)---Cancer is a disease where in a small part of the body the cells grow too fast or too much. You cannot catch cancer nor can you make it happen. There are many kinds of cancer.

CAT Scan or CT Scan---A picture (x-ray) of the inside of the body. The pictures are taken by a special camera that takes pictures through the skin. It does not hurt.

Cells (sells)---Cells are tiny parts of the body that cannot be seen by the eye. Many of these cells make up our body. Everything living is made up of cells.

Chemotherapy (kee-moh'-ther-a-pee)---A special medicine used to get rid of the cancer. It may come in the form of a pill, or as a liquid that is given as a shot or through the veins in the arm or hand or a small tube in the chest. Sometimes we nickname chemotherapy, "chemo".

Checkup---A visit to the doctor.

Clinic (klin'-ick)---A special place where doctors and nurses help people like your mom get better.

Cured---When the cancer is all gone. Sometimes doctors wait for the cancer to be gone for many years before they say someone is cured.

Diagnosis (dye-ahg-no'-sis)---This gives the person's sickness a name. Breast cancer is usually diagnosed using the biopsy, which was discussed earlier.

Hormone (hor- moan)---A chemical made in our bodies that help it work right. The body makes many different kinds of hormones. Sometimes we need hormones in larger amounts then the body produces so there are hormones that can be taken as a pill.

Immune System (i-mune- sis -tim)---The parts of the body that fight infection and cancer.

Infection (in-feck'-shun)---When a tiny living thing like a virus gets into the body and grows. Sometimes people call an infection a "bug" but it is not like an ant.

Intravenous (in- tra- ve'-nus)---Using a vein to give medicine.

Lymph Nodes (limf -nodes)---Tiny bumps located all over our bodies. These bumps help fight infection and cancer. Cancer can also go to these bumps and they will become bigger.

Lump---Any kind of unhealthy cell growth that occurs in the breast or anywhere in the body. It looks like a ball of skin, but it is really made up of tiny cells.

Lumpectomy (lump- ec- toe -me)---Removing the lump through an operation.

Lymphedema (limf -e -dee- ma)---A swelling in the arm. This usually happens on the side of the body where the cancer was removed from the breast. It is the result of a collection of fluid. Mom may have to exercise her arm or wear a special covering that looks like a heavy stocking to help decrease the swelling go away.

Mammogram (mam- o'- gram)---A picture (x-ray) of the breast that is done to see if there are any lumps (tumors) in the breast.

Mastectomy (mass-tech- toe- me)---An operation to remove the breast or a part of it.

Oncologist (on-call'-ah-gist)---A doctor who treats people with cancer.

Oncology (on-kah'-lah-gee)---The study of cancer.

Operation (op-er-a'-shun)---When the doctor makes a cut in the skin to fix or remove something underneath the skin. People cannot feel anything during an operation because they are given medicine called anesthesia to make them sleep and feel no pain. After the doctor is finished he/she stitches the cut with thread. When the cut is healed there will be a small scar but it will fade in time. Scars do not hurt once they are healed.

Platelet (plate-let)---A blood cell that helps you stop bleeding if you get cut.

Radiation Therapy (ray-dee-aye'-shun ther'-ah-pee)---A type of treatment to get rid of cancer. It is done by aiming a special machine that looks like a big camera at the cancer. Mom lies under the machine and it sends out x-rays (which are energy we cannot see) that destroy the cancer. The doctors who work with radiation are trained to make sure the x-rays are sent to the area of the body where the cancer is located. Although mom is alone in the room with the machine there is someone who can see and hear her through a window in case she would need anything. Mom cannot feel anything when she is treated with radiation. Sometimes radiation does cause the skin to get red like if you get sunburn. Radiation does not hurt but it may make mom tired.

Radiation Oncologist (ray -dee- aye'- shun on- call'- lah gist)---A doctor trained in the use of radiation therapy to treat cancer.

Remission (ree-mish'-on)--- The cancer is gone. This is not the same as a cure. Remission can last for a short or long time.

Tumor (two'-mer)---A lump or bump. It may or may not be cancer.

Revised 8/99

FOR HOME #1 MORE ABOUT...FAMILIES AND CANCER

REVIEW:

1. Every person has strengths, skills, and things that he or she is proud of.
2. All kids who have a parent with cancer have similar feelings, like sometimes feeling sad, angry, or scared.
3. Family support and open communication is important for children's adjustment when their parent has cancer.
4. When a parent has cancer, everyone in the family is affected. Some things in families change because of cancer. However, other things in families stay the same.
5. Children may have misconceptions about cancer. Some children may believe that they are responsible for their parent's cancer. Also, young children's fears about separation from parents is accentuated when a parent is dealing with a serious illness.

TO DO:

1. Make an extra effort to show your child that you notice his or her strengths. The attached sheet lists some ways to tell your child that you are proud of him or her.
2. Read When Eric's Mom Fought Cancer, by J. Vigna, with your child. You may want to ask your child the following types of questions as you are reading the story:
 - I wonder if you ever felt sad/scared/angry when I was sick with cancer?
 - What was hardest about when I was in the hospital? What helped you feel better?
 - Where do you think the cancer came from?
 - What things about our family are the same as they used to be before the cancer?
3. Have a "special time" with your child at least one time this month. A "special time" activity is a fun activity. Everyone who participates agrees about what to do. Examples of "special time" activities are:
 - playing a board game
 - reading a book that the child chooses
 - renting a movie of the child's choice
 - drawing a picture or working on an art activity together
 - going out to get an ice-cream cone
 - having a picnic

MORE BOOKS:

Guess How Much I Love You by S. McBratney

PREVIEW:

In the next group, your child will be learning to identify different feelings. Also, your child will be learning different ways to relax, like deep breathing, imagery, and muscle relaxation.

SESSION 2

ALL ABOUT...

OUR FEELINGS AND RELAXING

Main Objectives:

1. Increase ability to monitor and label internal emotional cues
2. Facilitate self-efficacy in terms of emotion regulation and management
3. Learn and practice muscle relaxation
4. Learn and practice deep breathing and imagery

Outline:

1. Transitioning to group
2. All about feeling
3. Shake it out
4. Muscle relaxation
5. Deep breathing and imagery
6. Snack and review
7. For next time

Materials:

1. Introductory song or rhyme; Closing song/music
2. Group banner
3. Stress pictures from Don't Pop Your Cork on Mondays
4. Emotion floor puzzle: ABC Feelings by Adage Publications (1993)
5. Crayons/markers
6. Name Tags
7. Body outlines, one per child, each on a page of large newsprint
8. Shake My Sillies Out, Raffi audiotape
9. Boom Box
10. Bubbles & bubble-wands
11. Pre-cut balloons & blue construction paper
12. Feelings poster
13. Yarn
14. Stickers, pictures, and other decorations for balloons
15. Snacks
16. Newsprint
17. Scrapbooks
18. Glue and glue sticks
19. Small ball
20. Oncology Nurse Educator Materials

Session Books:

Double Dip Feelings, B. Cain (1990)

I Was So Mad, M. Mayer (1983)

Don't Pop Your Cork on Mondays (or photocopy of anger pictures), A. Moser (1988)

The Moon Balloon, J. Drescher (1996)

Session Handouts:

Page 2: All About Having Fun With My Family

Page 3: How Are You Feeling Today?

Take Home Books:

Boy and a Bear, L.. Lite (1996)

All My Feelings At Home, S. Conlin & S. Friedman (1989)

Moon Balloon, J. Drescher (they keep)

Take Home Handouts:

"Shake Your Sillies Out", tape (Raffi)

For Home #2: More About...Feelings and Relaxing

I. TRANSITIONING TO GROUP (15 mins.)

(Facilitator plays or sings introductory song or says rhyming poem. Group banner should be displayed. Children and facilitator sit together in a circle. Facilitator welcomes each child, referring to him/her by name.) **How has everybody been? Who can remember the rules for the group?** *(Facilitator briefly reviews group rules with children i.e., all must share, take turns and listen).* **Today we will do a big puzzle, talk about feelings and practice some fun ways to relax. We will also have a visit at snack time from the nurse who came last time, and she will answer any questions you may have about cancer/your mom's illness.**

Who would like to tell about a special and fun time that they had with their family since we met last time? *(Facilitator passes out Page 2: All About Having Fun With My Family.)* **Draw a picture of what you did that was special and fun with your family.** *(Children draw pictures.)* **Now, who would like to show their picture to the group?** *(Facilitator points out emotional elements of the pictures. Example: "I can tell that you are having fun and are happy because you have a smile on your face in the picture.")* **We will save these pictures and put them in your scrapbook.**

II. ALL ABOUT FEELINGS (25 mins.)

(Facilitator reads Double Dip Feelings and asks for comments about the book from the children.)

Here is a big puzzle for you to do. *(Facilitator gets floor puzzle out and children complete. As they are completing the puzzle, facilitator asks children to identify the feelings that go with the various faces. Facilitator distributes Page 3: How Are You Feeling Today?)*

For each child: **Color the face that shows how you feel right now. After the children have completed their picture, the facilitator asks the children to describe the feeling they picked.** *(Facilitator gathers pictures to place in children's scrapbooks.)*

(Facilitator gets out the body outlines and labels them with the emotions the children have identified, e.g., "happy," "sad," "frightened," "mad.") **Our faces show how we feel. We also feel feelings in other parts of our body.** *(Facilitator asks each child to indicate on the body outlines).* **Where do you feel [sad, happy etc] in your body?** *(Children are asked to choose a color or crayon that means the emotion and color that part of the body. Facilitator does this for each child using the body outlines.)*

Do you think that you can do things to change your feelings? Let's say you

feel mad--show me how you look when you feel mad. How would you change that feeling? Here's a story about feeling mad. (*Facilitator reads I Was So Mad.*)

(*Facilitator shows lion, monkey, bull, ostrich, and turtle pictures from Don't Pop Your Cork on Mondays to illustrate that people show they are mad in different ways.*) People act in different ways when they are mad. Some people are like a lion. (*Have children act out each animal.*) **Which one are you like when you are mad, a lion, a monkey, a bull, an ostrich, or a turtle?** (*Children take turns responding.*)

III. SHAKING IT OUT (10 mins.)

Here's another trick to help calm down. (*Facilitator gets out a small ball.*) Look at this ball. This is a mad ball. Pretend this mad ball is inside of you. Make it bounce and shake all through your body. (*With facilitator prompting, children pretend ball is in various parts of their bodies.*) Stop the ball from moving. (*Children stay still.*) Suck the mad ball up into your mouth and push it out. (*Children act out.*) Look at how slimy the mad ball is now. Kick it or throw it out the door. (*Children act out.*)

Here's a song about shaking it out. (*Facilitator plays audiotape, Shake My Sillies Out.*)

IV. DEEP BREATHING AND IMAGERY (30 mins.)

Now, let's see how slow and deep you can get your breathing to be. (*Get out bubbles. Model taking deep breaths and blowing out bubbles. Children practice taking a big breath and blowing it out slowly while making a bubble. Next, ask children to sit or lie down in a relaxed position.*) Now, here's another game to play. Pretend that your belly is a big red balloon. Take a deep breath. Breathe in slowly through your nose until the balloon feels full. Hold it. Count to five--1-2-3-4-5. Then breathe out through your mouth. Breathe out the red air from the balloon. Continue filling up the balloon with air. 1-2-3-4-5 and breathe out the red air. Ok, sit up now. How do you feel? (*Children respond. Facilitator comments on consistencies among children's reports of how they feel and their face, body, and/or verbal cues (i.e., "I can see that you feel good now because you are sitting still and listening.")*)

Here's a book about some other things that help kids relax. (*Read The Moon Balloon.*)

(*Pass out pre-cut balloons, blue construction paper, yarn, and stickers, pictures, etc. to decorate.*) Now you can make your own Moon Balloon. You can

decorate it any way you would like and when you are done we will put it in your scrapbook.

V. SNACK AND REVIEW (10 mins.)

We are pleased that *(oncology nurse)* is here with us for snack time today again. Do you have any questions you want to ask him/her? *(Nurse leaves after questions are answered.)* Let's talk about what we did today. I'll write what we did down so that we can show your parents all the important things you did today. *(Children list what they did during the session and facilitator writes their comments on newsprint.)*

VI. FOR NEXT TIME (5 mins.)

For our next group, I would like you to tell about something you did to relax and practice "shaking your sillies out."

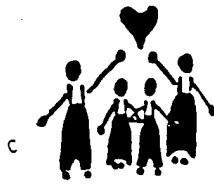
(Facilitator sings/plays closing song/music.)

(Children meet their parents at the parents' group. Facilitator summarizes what was accomplished during the session and hands out "More About...Feelings and Relaxing." Facilitator should give feedback to individual sets of parents regarding their child's participation in the group. Again, depending on the size of the children's group, extra time may need to be allotted for debriefing the parents regarding their child's group activities.)

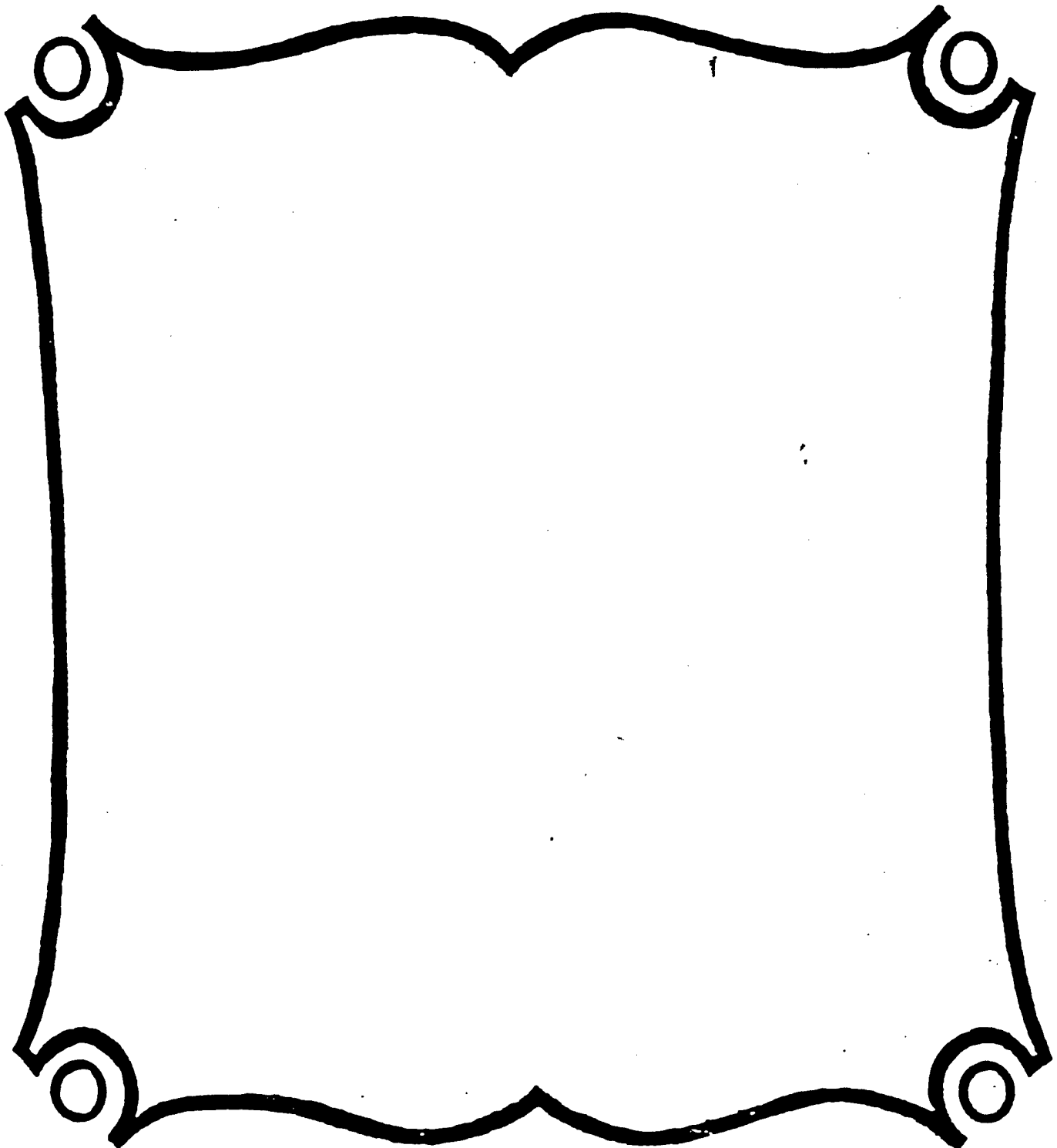
Handouts for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 2



*All About Having Fun With
My Family*



Name _____



How Are You Feeling Today?



HAPPY



FRIGHTED



ANGRY



SAD

Name _____

Take-homes for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 2

FOR HOME #2
MORE ABOUT...FEELINGS AND RELAXING

REVIEW:

1. There are many different kinds of feelings. Our behaviors, thoughts, and moods tell about how we are feeling. Kids and adults experience the same kinds of feelings.
2. Children can do different things to manage their feelings. In the group, your child practiced some ways to change his or her feelings--for instance, breathing and relaxing his or her muscles to change angry or scared feelings and to calm down.

TO DO:

1. Display the "How Are You Feeling Today?" poster in your home where everyone in the family can see it. As part of your family's daily routine, have each person in the family point to the face that shows how they are feeling.
2. Help your child practice relaxing with the audio-tape "Shake Your Sillies Out," by Raffi. Play this tape at least 2 times before the next group.
3. Read The Moon Balloon, by J. Drescher with your child, encouraging him or her to practice relaxing like the characters in the book. This is a good book to read at bed time. Try to read this with your child at least 2 times before the next group.

MORE BOOKS:

A Boy and a Bear by L. Lite

All My Feelings at Home by S. Conlin and S. Friedman

PREVIEW:

In the next group, we will be discussing what it means to be friends and ways to make and keep friends.

SESSION 3

ALL ABOUT...

SOLVING PROBLEMS AND BEING FRIENDS

Main Objectives:

1. Continued generalization of relaxation techniques
2. Learning steps in problem-solving
3. Learning assertive skills

Outline:

1. Transitioning to group
2. Problem-solving
3. Assertiveness
4. Being friends
5. Snack and review
6. For next time

Materials:

1. Introductory song
2. Group banner
3. Getting Along ("Bullying" and "Intolerance" activity sheets)
4. Pig noses
5. Snacks
6. Closing song
7. Crayons/markers
8. Child puppets (boy and girl)
9. Newsprint
10. Mouse and monster masks, straws
11. Mirrors
12. Scrapbooks

Session Books:

I'm Mad, E. Crary (1992)

Frog and Toad Are Friends, A. Lobel (1970)

Session Handouts:

Page 4: All About Relaxing

Page 5: Problem-Solving Steps

Take Home Books:

Frog and Toad are Friends, A. Lobel (1970)

The Good-Bye Book, J. Viorst (1988)

We Can Get Along, L. Payne (1997)

Take Home Handouts:

For Home #3: More About...Solving Problems and Being Friends

I. TRANSITIONING TO GROUP (10 mins.)

(Facilitator plays or sings introductory song or says introductory rhyme. Group banner should be displayed.)

(Children and facilitator sit in a circle. Facilitator welcomes each child, referring to him/her by name. How has everybody been? Who can remember the rules for the group? (Facilitator briefly reviews group rules with children i.e., all must share, take turns and listen.) Who would like to tell about one thing they did at home to relax? (Facilitator passes out Page 4: All About Relaxing). This is a picture for you to color. On it are all of the ways to relax that we talked about. (Children color picture. Facilitator collects pictures to place in scrapbooks.)

II. PROBLEM-SOLVING (25 mins.)

So there are lots of tricks that you can do when you want to calm down. Let's read this book about a little boy who feels mad and see if we can name lots of things that he can do to relax. (Read I'm Mad. Stop reading to ask children to name the problem the boy is having. Also, stop to ask children, "What will the boy do next?" Have children act-out what they think the boy will do next. Also, have the children act out **what will happen next (i.e., the consequences of how the boy chooses to deal with his angry feelings).**

You did a very good job of thinking of ways the little boy could solve his problem. The first step is to name your feeling. What feeling did the boy in the book have? (Children respond.) The second step is to think of things you can do to feel better and try one out. What are some good things that the boy in the book did? (Children respond.) The last step is to tell yourself "Good job!" (Facilitator hangs "Problem-Solving Steps" illustration on wall. Group recites steps.) Here is a page for your book for you to color and to remind you about the steps for solving problems. (Hand out Page 5: Problem-Solving Steps. Children color their pages.)

(Using a child puppet, the facilitator and children sit in a circle and make up a group story about the puppet and his/her problem and how he/she goes about solving it.) Let's make up a story together about our friend here (holds up child puppet.) As we go around the circle everyone will contribute to the story. I'll give you the beginning of each part of the story and we'll go around the circle, having you fill in the spaces in the story. Ready?

This puppet's name is (child next to facilitator completes.) [Name of puppet] has a problem. The problem is (next child completes.) This problem makes [Name of puppet] feel (next child completes.) [Name of puppet] thinks of

many different things he/she can do to solve the problem and feel less [feeling]. One thing that [Name of puppet] thinks of doing is *(next child completes.)* Another thing is *(next child completes. Continue until 3 or 4 possible solutions are identified.)* The thing that [Name of puppet] tries first is *(child completes.)* When [Name of puppet] tried [first solution] what happened? *(Child completes. Continue until story is completed with an ending that reflects an effective coping response.)*

III. ASSERTIVENESS (30 mins.)

Today, we're going to talk about how each of you is a good friend to other people. Also, we're going to talk about how each of you is a good friend to yourself.

Sometimes kids and adults aren't good friends to other people. They yell at other people, or fight with them, or don't listen to them. They are like monsters. Other times kids and adults aren't good friends to themselves. They don't ask for help and they don't stand up for themselves. They are like mice. *(Pass out mice and monster masks for children to color.)* These masks are for you to color and wear when we pretend to be mice and monsters. After we pretend to be mice and monsters, we'll talk about ways to not be either a mouse, or a monster, and instead be a good friend to other people and yourself. *(Children color masks.)*

Ok, everyone hold up his or her mouse mask. Let's see what you look like when you're a mouse. *(Children look at themselves in the mirror and act-out the part of a mouse.)* Who would like to tell about a time when they were a mouse? *(Children respond.)* Who can think of something that [child] could have done to not be a mouse? *(Children respond.)* Ok, everyone hold up his or her monster mask. Let's see what you look like when you're a monster. *(Children look at themselves in the mirror and act-out the part of a monster.)* Who would like to tell about a time when they were a monster? *(Children respond.)* Who can think of something that [child] could have done to not be a monster? *(Children respond.)*

Here's a picture that we can use to talk about how to get along and be friends. *(Show group "Bullying" poster. Refer to "Bullying" activity sheet. Ask "Direct" questions on "Bullying" activity sheet)*

What's happening in this picture?
How do you think the pig that is using the pen feels?
How can you tell what the pig might be feeling?
Why would the other pig say, "I want that pen NOW!"

Who would like to act-out the parts in the story? (*Facilitator gives pig noses to children who will be role-playing. All interested children should have a chance to do the role-play.*) **What is the problem here? Which pig is acting like the monster? Why is it wrong to act like that pig?** (*Reinforce that the other pig has rights, which are not being respected.*) **What could the other pig do next?** (*Children respond and act-out.*)

IV. COPING WITH FEELING LEFT OUT (20 mins.)

Facilitator puts "Intolerance" picture on the wall. Ask "Direct" questions on "Intolerance" activity sheet: What's happening in this picture? How are all four of the zebras alike? What's the difference between the lone zebra and the others? Is that difference a good reason to leave the zebra out? Why or why not? How do you think the single zebra feels? Who would like to act-out the parts in the story? (All interested children should have a chance to do the role-play.) What could the lone zebra do next? How would the story end? Who would like to act out the ending of the story? (All interested children should have a chance to do the role-play.)

Ask "Reflective" questions on "Intolerance" activity sheet:

Have you ever felt left out of something because you were different? (How were you different?)

When you were left out, how did you feel?

What finally happened?

Have you ever left someone else out because that person was different?

How did you feel about that?

Have you ever worried that you were different because your mother has cancer? What did you do? What else could you have done?

IV. BEING FRIENDS (10 mins.)

Here is a book about being friends. (*Facilitator reads Frog and Toad are Friends.*)

V. SNACK AND REVIEW (10 mins.)

While we are having snack, let's talk about what we did today. I'll write these things down so that we can show your parents all the important things you did today. *Children list what they did during the session and the facilitator writes their comments on newsprint.*

VI. FOR NEXT TIME (5 mins.)

Next time I would like you to tell about something fun that you did with a friend. Also, next time will be our last meeting and we will talk about all the things we have done together and have a special party to say good-bye.

Facilitator sings closing song/plays closing music.

(Children meet their parents at the parents' group. Facilitator summarizes what was accomplished during the session and hands out: "More About...Solving Problems and Being Friends." Facilitator should give feedback to individual sets of parents regarding their child's participation in the group and allow sufficient time for doing so.)

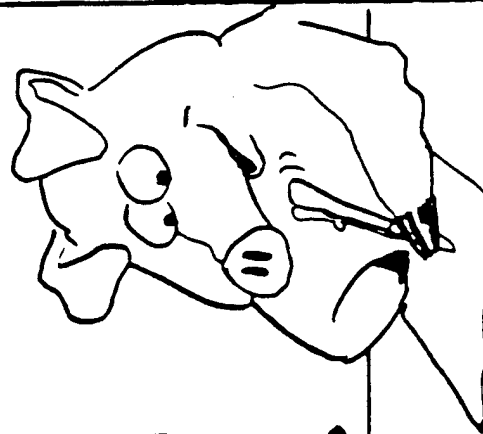
Materials for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

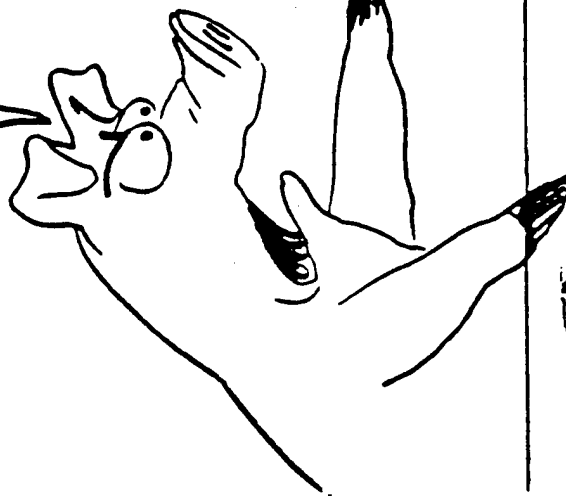
Session 3

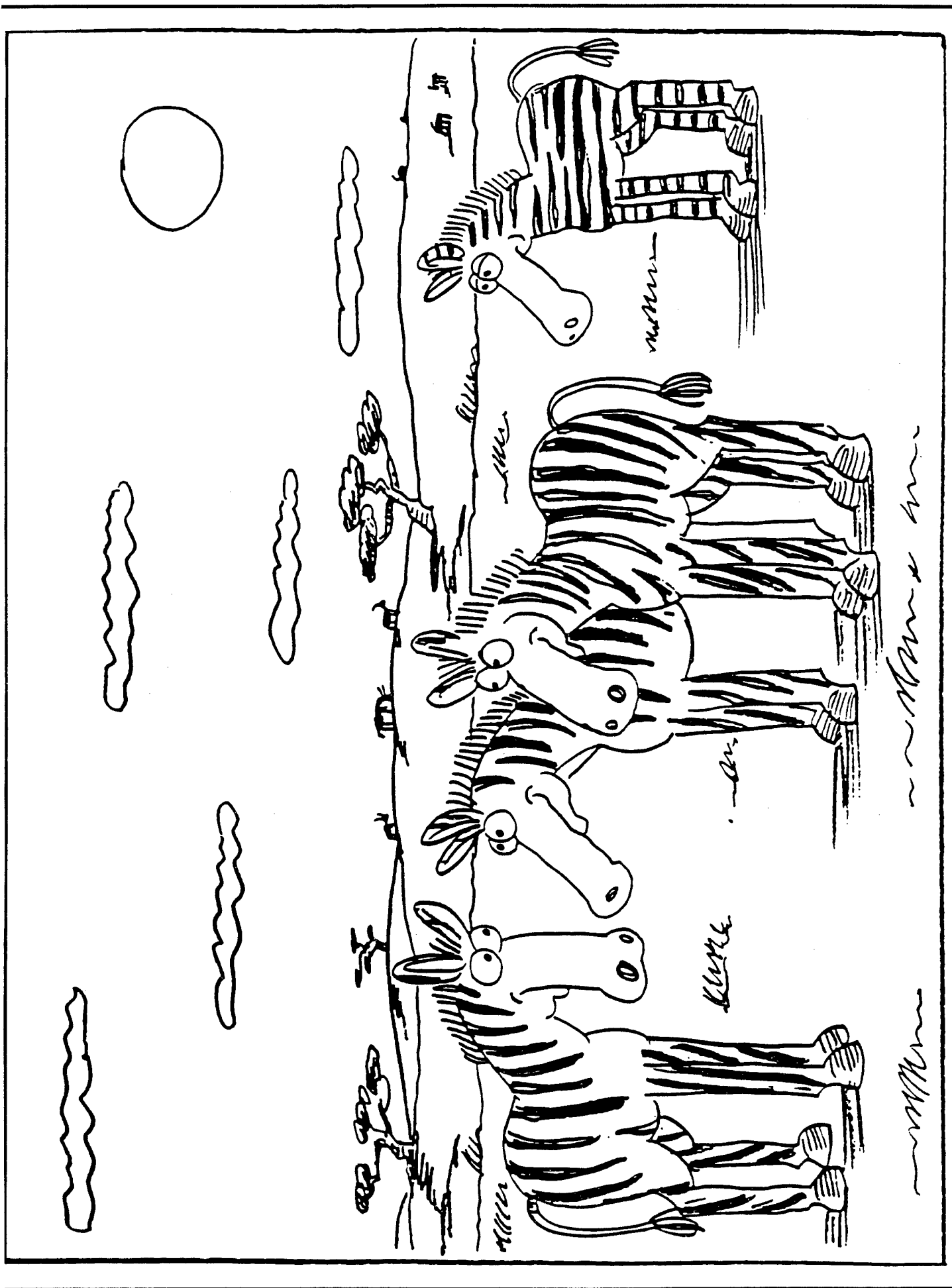
I WANT TO
USE YOUR
PEN.

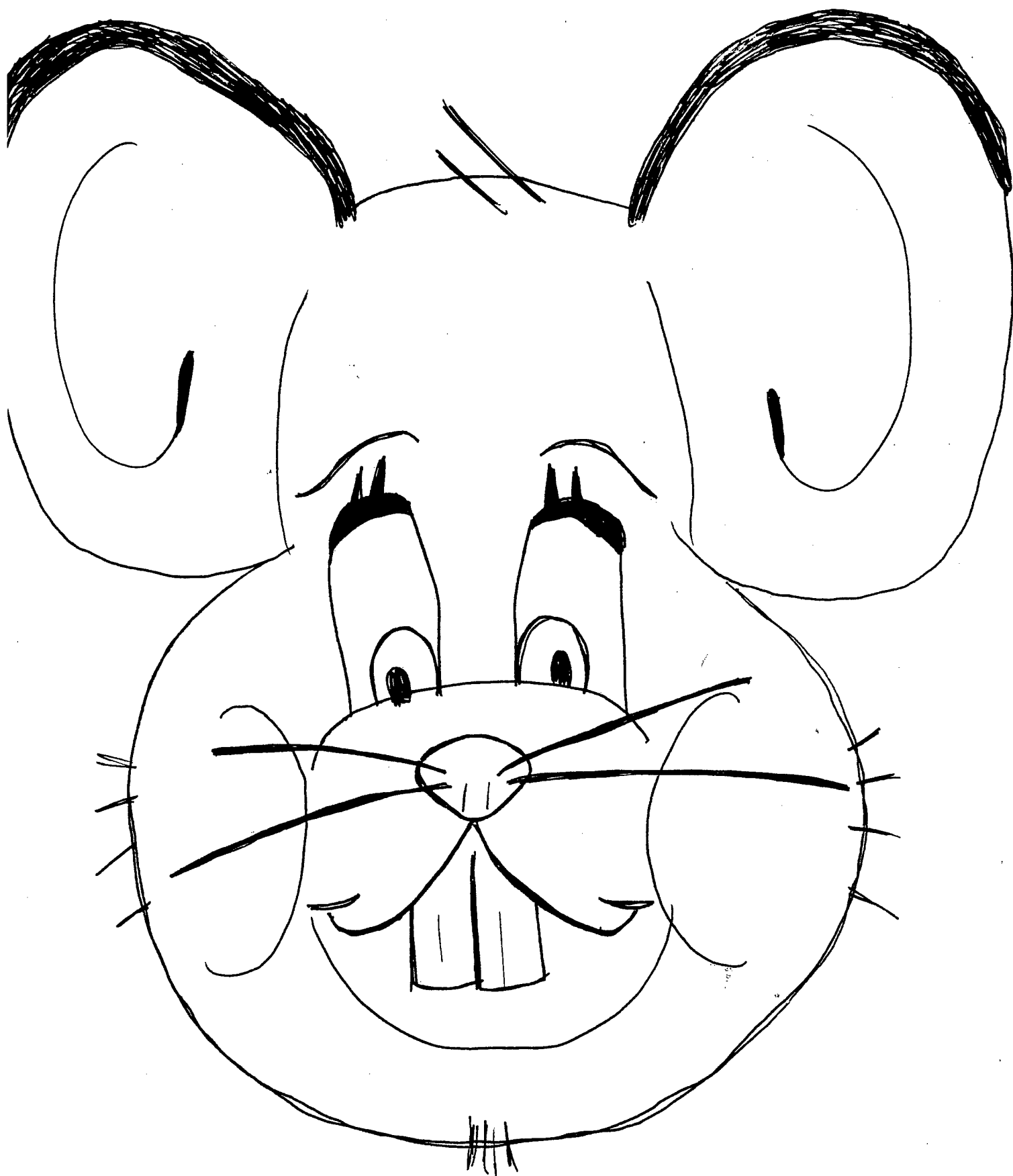
IN A
MINUTE.



I WANT THAT PEN
NOW!







MOUSÉ



MONSTER

Handouts for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 3



All About Relaxing

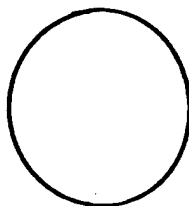
Tense



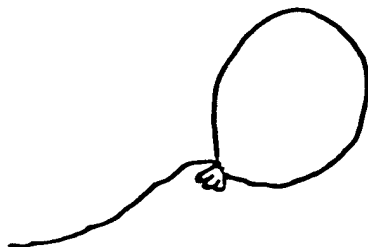
Relax



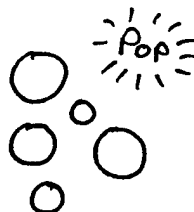
"Ball Trick"



"Moon Balloon"



"Bubble Trick"



Pictures from:

Moser, A. & Pilkey, D. (1995). Don't Pop Your Cork on Mondays. Kansas City, MO: Landmark Editions Inc.

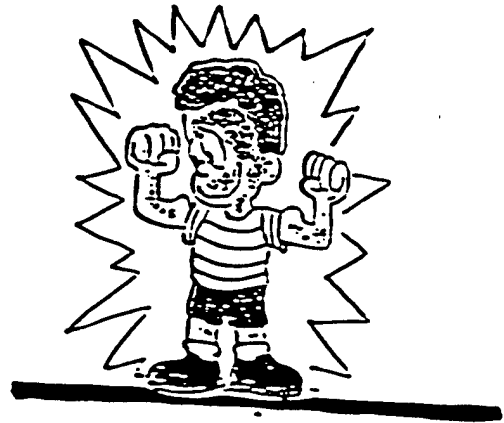
Name _____



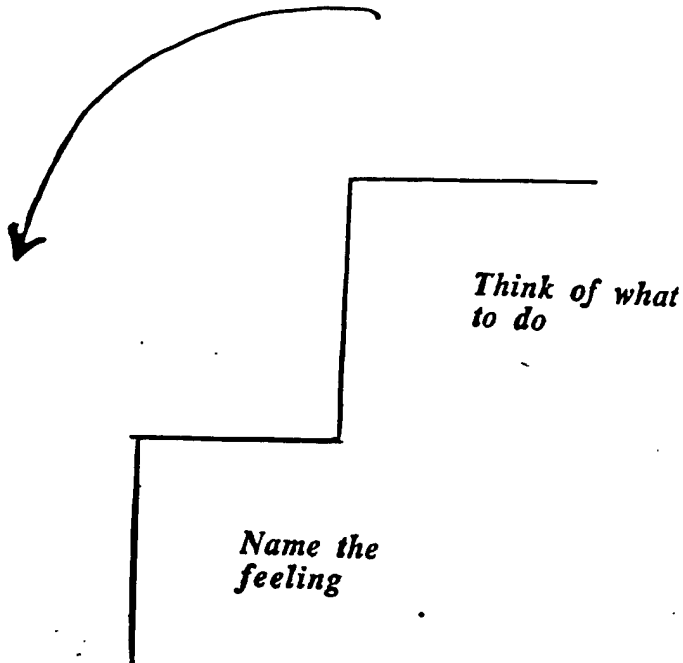
Problem Solving Steps



Try something else



GOOD JOB



Pictures from:

Moser, A. & Pilkey, D. (1985). Don't Poo Your Cork on Mondays. Kansas City, MO: Landmark Editions Inc.

Name

Take-homes for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 3

FOR HOME #3
MORE ABOUT...SOLVING PROBLEMS AND BEING FRIENDS

REVIEW:

1. Kids (and adults too!) can use the following steps to manage their feelings:
 - Name the feeling
 - Think of what to do to feel better and try one out
 - Tell yourself "Great Job"
2. Aggressive, or acting like "a monster," means not respecting the rights of others. Passive, or acting like a "mouse," means not respecting your own rights. Assertive means respecting both your rights and the rights of other people.

TO DO:

1. Take opportunities throughout the month to talk about friendship with your child. Books, like We Can Get Along, by L.M. Payne, can help stimulate discussion and your child's thinking about what it means to be friends. Also, television show, like "Arthur" and "Sesame Street," and videos, like "Winnie the Poo," teach children about friendship.

MORE BOOKS:

Frog and Toad Are Friends by A.Lobel
The Good-bye Book by J. Voirst

PREVIEW:

Next group will be our last meeting. Both you and your child may experience sadness, anxiety, a sense of accomplishment, all of the above, or other feelings in anticipation of the last group. Books like The Good-bye Book, by J. Voirst, and drawing pictures of the group or what they learned in the group are some ways to help your child express his or her feelings about saying good-bye to the facilitators and other children.

SESSION 4

ALL ABOUT...

WHAT WE'VE LEARNED AND SAYING GOODBYE

Main Objectives:

1. Continue discussion of friendship
2. Reinforce skills learned in the group
3. Facilitate closure

Outline:

1. Transitioning to group
2. When friends leave
3. Review of sessions and compiling scrapbook
4. Saying goodbye
5. Party
6. Presentation of certificates of accomplishment

Materials:

1. Introductory song/rhyme
2. Group banner
3. Manila envelopes
4. Straws
5. Cut-out small triangles.
6. Decorations for "mailboxes"
7. Plain paper
8. Crayons/markers
9. Snacks
10. Closing song/music
11. Certificates of Accomplishment
12. Two child puppets (boy & girl)
13. All previous activity pages
14. Scrapbooks
15. Scissors
16. Glue/glue sticks
17. Decorations for scrapbooks
18. Elephant & lion puppets

Session Book: To Annabella Pelican from Thomas Hippopotamus N. Patz (1991)

Session Handout: Page 6: All About My Friends

Take Home Handout: "Catch Them Being Good" (for parents)

Take Home Book: Scrapbook

I. TRANSITIONING TO GROUP (10 mins.)

(Facilitator plays/sings introductory song or says introductory rhyme. Group banner should be displayed.) **How have you been? Who can remember the rules for the group?** *(Facilitator briefly reviews group rules with children i.e., all must share, take turns and listen).* **Who would like to tell about something that they did with a friend?** *(Children respond. Facilitator passes out Page 6: All About My Friend.)* **Here is a page for you to draw a picture of your friend.** *(Children draw pictures.)* **Who would like to show their picture to the group?** *(Children share pictures with the group. Facilitator should prompt children by asking what the friend's name is, how old he/she is, what they like to do together, etc. Facilitator gathers pictures for placement in scrapbooks.)*

II. WHEN FRIENDS LEAVE (10 mins.)

(With child or animal puppets.) **This is [name] and this is [name]. They are best friends and they live near each other. Who here has a best friend?** *(Children respond.)* **[Name of one puppet] is moving to a different place and so the two won't be able to play together anymore. [Name of puppet] is feeling sad because she will miss her friend. Has anyone here had a friend that moved to a different house or a different school?** *(Children respond.)* **How did you feel? Sad? Mad? Scared?** *(Children respond.)* **Well, what [name of puppet] feels mostly is sad. She tells her friend that she is sad that he is moving away. She also tells her mom that she feels sad. She feels better when her mom reminds her that even though she will not see her friend everyday anymore, she can still write letters to him and send him pictures. Also, her mom takes a picture of both of them for each to keep. When they look at the picture they feel happy because they remember the fun they had playing together. (To the children who reported that they had this experience). Do you remember doing fun things with your friend whom moved? So even though you don't see your friend anymore, you can still remember the fun times you had playing with them.**

III. REVIEW OF SESSIONS AND COMPILING SCRAPBOOK (25 mins.)

You each did a lot of work in the group. I have all the pages that you have done during our meetings. Let's look through the pages all together now so that we can talk about all the things we did. *(Facilitator goes over each page of scrapbook) and elicits children's feedback about each activity and highlights important points of each activity. Facilitator should also ask about what each child liked best, thought was most fun, thought was hardest, etc. Each child is given his/her scrapbook.)* **You are each going to get your scrapbook and you can decorate the cover however you would like.**

IV. SAYING GOOD-BYE (20 mins.)

(With elephant puppet.) Elephant is going to feel a little sad when the group is over because she won't be able to spend time with you anymore. She will remember you though and all the fun things we did in this group. What are the feelings you have about saying goodbye to our group/each other?

Facilitator reads To Annabella Pelican from Thomas Hippopotamus.

One way to say good-bye to a friend is to make them a picture or to write them a letter letting them know that you will miss them. Let's do this now as a way to say goodbye to each other. *(Facilitator passes out manila envelopes, straws; cut-out flags and helps children assemble "mailboxes." Children decorate mailboxes. Facilitator passes out plain paper and helps children write notes or draw pictures for each other.)* When you are done, put the picture or letter in the mailbox of the person that you made it or wrote it for.

V. PARTY (15 mins.)

(Get out snacks for party and ask for volunteers to do different tasks (e.g., pass out the napkins, pass out the drinks, put empty cups in the trash can, etc.).

VI. DISTRIBUTION OF CERTIFICATES (10 mins.)

(Children join parents group. Facilitators should already have Certificates of Accomplishment made up for each child. Facilitators make brief comments about group as a whole, i.e., strengths of children, what was learned, importance of practicing skills, purpose of scrapbook) and then present each child with certificate. Afterwards, facilitators talk with parents, give feedback, answer questions, etc.)

Handouts for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 4



All About My Friend

A large rectangular box with a decorative border. The border is composed of a series of small, dark, horizontal and vertical lines that form a frame around the central area. The corners of the box are marked with small circles.

Name _____

Take-homes for the Families Coping With Cancer Project

Younger Child Group: Ages 4-6

Session 4



TEN WAYS TO "CATCH 'EM BEING GOOD"

Good Job!

You are trying so hard.

I like how you are sharing.

Thank you for picking up your toys.

I LOVE YOU.

Thank you for showing me that you are listening.

WAY TO GO!

I like to spend time with you.

You did a good job calming down.

I LIKE IT WHEN YOU SAY "PLEASE."

Certificate of Award

This certificate celebrates

for

Signed _____

Date _____

Shoot for the moon. Even if you miss,
you'll land among the stars!—Les Brown

FAMILIES COPING WITH CANCER PROJECT

Treatment Manual: Older Child Group (Ages 7-12)



Funded by U.S. Army Materiel Command 1997-2001

Family Intervention for Young Women With Breast Cancer

**Sally E. Tarbell, Ph.D.
Principal Investigator**

Session 1: "All About Our Group, Our Families, And Cancer"

Oncology Nurse Educator Materials

Handout, "All About Me"

Take-homes: Ages 7-9

Ages 10-12

2

Session 2: "All About Our Feelings and Relaxing"

Materials

Handout, "How Are You Feeling Today?"

Take-homes: Ages 7-9

Ages 10-12

3

Session 3: "All About Solving Problems And Having Friends"

Materials

Handout, "Problem-Solving Steps"

Take-homes: Ages 7-9

Ages 10-12

4

Session 4: "All About What We've Learned And Saying Goodbye"

Materials

5

6

7

8

SESSION 1
ALL ABOUT...
OUR GROUP, OUR FAMILIES, AND CANCER

Main Objectives:

1. Build rapport and group cohesion
2. Reinforce individual strengths
3. Normalize children's experiences of parental cancer
4. Provide accurate information about cancer and correct misperceptions

Outline:

1. Introductions
2. How we're different/ how we're the same
3. All about families and cancer
4. Snack and review
5. For next time

Session Materials:

1. Name tags
2. Polaroid Film and Camera
3. (2) Microphones
4. Interview questions
5. Newsprint
6. Crayons/markers
7. Tape
8. Snacks
9. Attendance Sheet
10. Oncology Nurse Educator Materials

Session Books:

When Eric's Mom Fought Cancer J. Vigna (1993)

Session Handout:

Page 1: All About Me

Take Home Books:

Younger children (Ages 7-9):

Paper Chain C. Blake et al. (1998) They Keep

Older children (Ages 10-12):

Vanishing Cookies M. Goodman (1990)

Take Home Handouts:

A Small Book About Big Words (all children)

More About My Family & Cancer:

- Younger Child Version (Blue)
- Older Child Version (Green)

I. INTRODUCTIONS (20 mins.)

Throughout the course of this intervention, several activities are divided up by age to assure that children across the age range in this group (i.e., 7-12) will participate in activities that are matched to their developmental level. We have found it helpful to have 2 group leaders for this intervention if the group is large enough (6 or more children), as this enables the leaders to individualize the content for the younger (those aged 7-9) and the older participants (those aged 10-12). If the participants are all close in age, then there is no need to divide the children up into separate groups for these activities.

(Facilitators should be wearing name tags when the children arrive. Children are given name tags when they arrive. Two Polaroid pictures of each child are taken.)

(Facilitators introduce themselves.) Our names are ____/____. Welcome to the group. We're glad you are here. We are going to meet one Saturday morning a month for 4 months. We will be doing a lot of different things in this group. We think most of it will be fun. You will be learning some new things, talking, drawing, making stories, and playing games. Let's go around the circle, and I'd like you each to say your name. (Children introduce themselves.)

Now that we know who is in the group, we need to think of some rules for our group. What rules should we have for the group so that we get things done and so that everyone gets along with each other? (Children suggest rules and facilitator writes them on newsprint. If not mentioned, facilitator adds rule about respecting one another.) An important rule is to listen when someone else is talking. That means looking at them and not talking while they are talking. Who can show me what they look like when they are listening? How would I know when you're not listening? What would you look like? It is okay if you do not want to talk or answer a question. Sometimes kids feel like sitting and listening and not talking and that's okay. It's also a good idea for you to talk to your parents about what we do here. We also will be filling your parents in about our activities. And while it is OK to talk about the kids in the group and what we do here, it is NOT OK to say means things about other kids in the group or to say anything about them that you wouldn't want said about yourself. (Facilitators can demonstrate this point by a brief role-play.) Do you have any questions about the group rules?

*****Younger (7-9 years):** We're going to play a game now that will help everyone get to know each other. I'd like each of you to pretend that you are television reporters on the news. When you are the reporter you will use a microphone (*Show microphones.*) and interview your partner. You can ask them questions about themselves. Here are some questions you may want to ask. (*Pass out interview questions.*) We are going to go first to show you how to do it. (*Facilitators interview each other.*) OK, now it's your turn. Turn to the person next to you. First, one will be the reporter and will use the microphone and ask the questions. Then the person who answers the questions will get to interview the next person. We'll go around the circle.

*****Older (10-12 years)** We're going to play a game that will help everyone get to know each other better. I'd like each of you to pretend that you are television reporters on the news. When you are the reporter you will use a microphone (*Show microphones*) and interview your partner. You can ask them questions about themselves. What are some questions that a reporter might want to ask a person that he or she is interviewing? (*Children generate a list of questions. Facilitators can add some other questions that are light-hearted, i.e., What is your favorite pizza topping? Facilitators should write these questions on newsprint.*) These are good questions. You can ask these questions and you can also make up others to ask that aren't on this list. Here are some microphones to use when you are the reporter. Also, you should write down the information you get about the person you are interviewing. When you are the person being interviewed, you will be answering the reporter's questions. If the reporter asks a question that you don't want to answer, you don't have to answer it. So, pick a partner now. One person will be the reporter first and will use the microphone. When I tell you, you will switch and the person being interviewed will be the reporter. (*Children begin the activity. After about 5 minutes, the facilitator instructs the children to switch roles. After the interviewing exercise, each person will introduce the person they interviewed to the group. Facilitators will introduce each other first.*)

II. HOW WE'RE DIFFERENT/ HOW WE'RE THE SAME (20 mins.)

(*Facilitator passes out Page 1: All About Me.*)

*****Younger:** Here is a page for you to draw a picture of yourself. (*Children complete drawings. Facilitator tapes Polaroid pictures and drawings on large roll of newsprint, creating group banner.*)

*****Older:** Here is a page for you to draw a picture of yourself and something that you like or like to do. (*Children complete drawings. Facilitator tapes Polaroid pictures and drawings on large roll of newsprint, creating group banner.*)

(When children are done with their pictures, the facilitator hangs the banner on the wall.) What a good picture of the group. The group is made up of everyone here. One thing that I notice is that everyone's picture is different. *(Point out differences among pictures i.e., physical features, what they indicated that they liked).* Who would like to show the group their picture and tell what they are doing in the picture? Each of us is different in special ways. For instance, no one else looks exactly like you. Another thing that makes us different from each other is the strengths that we have, the things that we do well and that we are proud of. Kids have different strengths. For instance, one kid's strength may be that she gives soccer her "all" and another kid's strength may be that he tries hard in school or helps out with chores at home. Who would like to tell about a strength or a talent they have? *(Children respond.)* You already have a lot of strengths and talents. One important thing that we're going to be talking about in this group is how to use your strengths and talents to solve problems or to feel better when you have a problem. It's good that we all have different strengths and talents because you can teach each other and learn different skills from each other. For instance,... *(Facilitators use an example based on what two of the group members report are strengths for them.)*

We've talked about the ways that we're unique. Each of us looks different, likes different things, and has different strengths. There are other things that we have in common. Things that make us alike or are the same about us. Who can think of something that is the same about everyone in the group? *(Children respond. Facilitator writes these on newsprint.. If no one lists "our moms have cancer" as a way that everyone in the group is the same the facilitator says: Another way that everyone in the group is the same is that their moms and dads are participating in a group like this one. Also, everyone who is here has a mom who has been sick with cancer. For the rest of the time today, we are going to talk about our families and about cancer. Later on today, we will have a visit from our nurse who will answer any questions you may have about cancer.*

III. ALL ABOUT OUR FAMILIES AND CANCER (35 mins.)

This is a story about a little boy whose mother has cancer. *(Read When Eric's Mom Fought Cancer, stopping at points in the story to pose questions to the group.)* For example: Do you remember when you found out that your mom had cancer? How did you feel? One thing that changed for Eric was that his mother couldn't spend as much time doing things with him because her treatment made her feel tired a lot. Has anything changed for you since your mother started treatment for cancer? Who has helped take

care of you? What has stayed the same in your family? Why did Eric hit the snowman? Did you ever feel angry like Eric? What did you do?

At the end of the story when Eric heard the word "cancer" he was confused and scared. He didn't know what cancer was. The word "cancer" is confusing to many kids, and adults too. Some people know a lot about cancer and about how people with cancer get better, like your mother's doctors. People that know some things about cancer are your parents and maybe some of you in this room. Maybe you know a lot about cancer. Other people may not know much about cancer. They might not have a parent or other family member who has cancer, or they might not be around adults that can help them understand what cancer is. *(Facilitator introduces the oncology nurse educator to the group.)* If Eric met an oncology or cancer specialist, what questions do you think he might ask? *(Facilitator writes the children's questions down on newsprint, and the oncology nurse educator addresses questions as they are asked by the group. Important issues to cover include: beliefs about the etiology and contagiousness of cancer, beliefs about personal responsibility, disease prognosis, understanding of treatment.)*

V. SNACK AND REVIEW (10 mins.)

(Get out snack and ask helpers to complete different tasks e.g., pass out the napkins, pass out the drinks, pass trash can). While we are having a snack, let's review what we did today. I'll write these things down so that we can show your parents all the important things you did. *(Important topics to list are: meeting each other, talking about what our strengths are; talking about how we're the same; talking about how we're different, learning about cancer.)*

VI. FOR NEXT TIME (5 mins.)

(Facilitators show children home materials). I have some practice sheets to remind you about what we did today. Also, the practice sheets explain what to do before you come back next month. One thing is to do a fun activity with your family that you can tell about. Another thing is to bring in a comic strip, picture, or book about families, or tell about a movie or television show that you saw about families that reminds you about your own family. Also, there is a book for you to borrow to read at home. You may want to ask your mom or dad to read it with you. *(Pass out "More About...My Family and Cancer.")*

(Children meet their parents at the parents' group. Facilitators summarize what was accomplished during the session and briefly describe the children's home activities. Facilitators should give feedback to individual sets of parents regarding their child's participation in group.)

Oncology Nurse Educator Materials
for
The Families Coping With Cancer Project

Children's Cancer Education

by Oncology Nurse Educator

The oncology nurse educator joins each of the children's groups for approximately 10-15 minutes during the first and second sessions. The nurse also lets the children know that s/he is available to answer their questions individually, both before and after the sessions. Although there are prompts used to initiate the children's discussion of cancer and its treatment, the specific content discussed varies with the children's questions and thus the nurse needs to be flexible in responding to the unique issues brought up by a particular group of children.

Younger Children's Group (Ages 4-6)

The nurse typically takes a few minutes to observe children in the group in order to evaluate their cognitive level and social interactions before s/he is introduced by the facilitators. The nurse describes him/herself as a nurse who works with women like their moms. The younger children generally have questions about what nurses do and who takes care of their mom when she goes to the doctors. The nurse generally tries to relieve any anxiety the children have regarding medical treatment and to show that doctors and nurses are just people like they are. The younger children are not shown pictures of cancer cells or cancer treatment unless they ask a specific cancer related question where a picture could help answer their question.

Older Children's Group (Ages 7-12)

The nurse introduces him/herself as a nurse who works with people with cancer. S/he selects a few key words such as cancer, chemotherapy, radiation, and tumor from the handout, "A Small Book About Big Words", and asks the children if they know what these words mean. S/he goes over these topics one at a time. S/he also encourages the children to share the handout with their parents and to bring it back and ask questions at future meetings. Pictures of a cancer cell, chemotherapy being administered, and a radiation machine are used to augment the discussion, as they help the educator respond to frequently asked questions, e.g., How does my mom get her chemotherapy?, What is a radiation machine?, How does a cell change into cancer?. The nurse tries to involve all the children in the discussion and to provide them with an opportunity to ask questions.

Discussion centers around the children's questions after the key words have been reviewed. For example, often a child in the group will know others with cancer and the child will want to discuss how that individual is the same or different from their mom. The children also commonly discuss changes in their family since their mom was diagnosed with cancer. It is emphasized to the children that routines will get back to "normal" once their mother is through treatment and feeling better.

Examples of frequently asked questions and nurse responses:

Can I catch cancer from my mom?

First, the nurse tries to find out why the children are asking this question, since in most instances the children know of other people in one family who have had cancer. Then the nurse reassures the children that they cannot "catch" cancer from their mothers. The nurse also explains that we do not know exactly how cancer occurs but that we do know that it is usually caused by a combination of things. The nurse does not typically give examples as the children often mention causes they are aware of and the nurse then validates or negates the cancer risk factors they cite.

Will my mom die from cancer?

The nurse honestly tells them that there is no guarantee that their mothers will not die from their cancer, but she also states that the mothers in this group have cancer that was caught very early and that we are very hopeful that their mother's cancer will be cured. The nurse also states that the treatment the doctors are giving/have given their mothers (chemotherapy &/or radiation) is to kill any cancer cells that could possibly have been left behind after the operation to remove the cancer.

Will my mom lose her hair?

This depends on what treatment your mother is receiving. Radiation will not cause hair loss unless it is given to the head and your mother is receiving radiation to her breast. Chemotherapy most often will cause hair loss.

Will her hair grow back?

The nurse reassures the children that their mother's hair will grow back. Generally the hair will come out about 3-4 weeks after the first treatment and it will begin to grow back about 3-4 weeks after the last treatment. It may grow back the same as it was before chemotherapy, but for some women it grows back in a different color and it may change from straight to curly or vice versa. The nurse stresses that all mothers are different and things can be different for each one of them, so they should not compare. She also stresses that their mom is still their mom regardless of their hair!

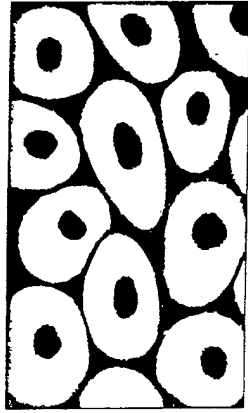
Are all cancers the same?

No, there are over a hundred types of cancer and even numerous types of breast cancer. Many types of cancer require different treatment and that is why you cannot compare people. The doctors and nurses who care for your mom are very knowledgeable about cancer and its treatment and will work with your mom to find the best treatment for her.

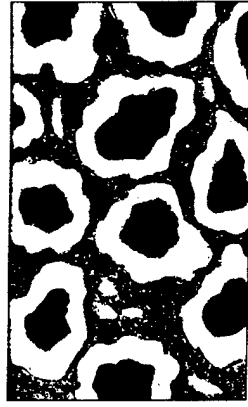
Will the cancer come back?

Hopefully not but that is why your mom will be seen by a doctor who specializes in cancer for the rest of her life. She will have blood tests and x-rays at different times to make sure the cancer has not returned. If the cancer does return, her doctors will know and they can start treatment early when cancer is most curable.

Cells

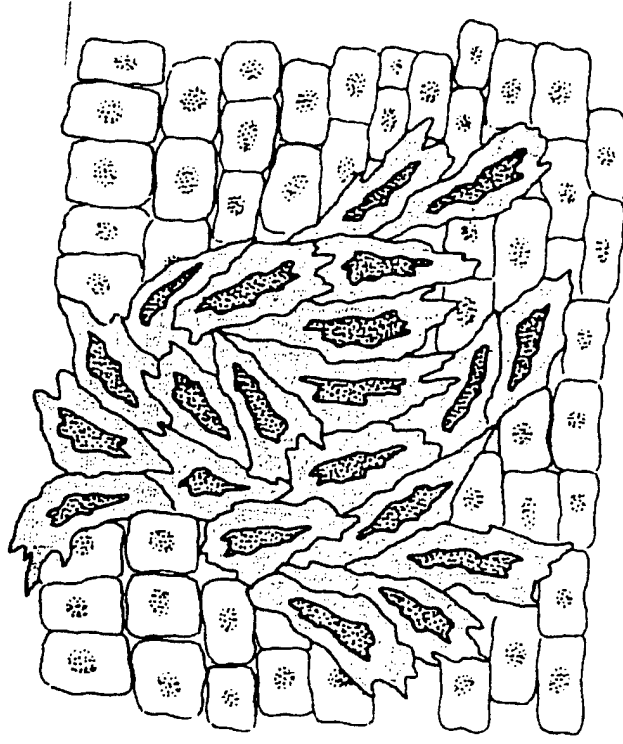


Normal cells

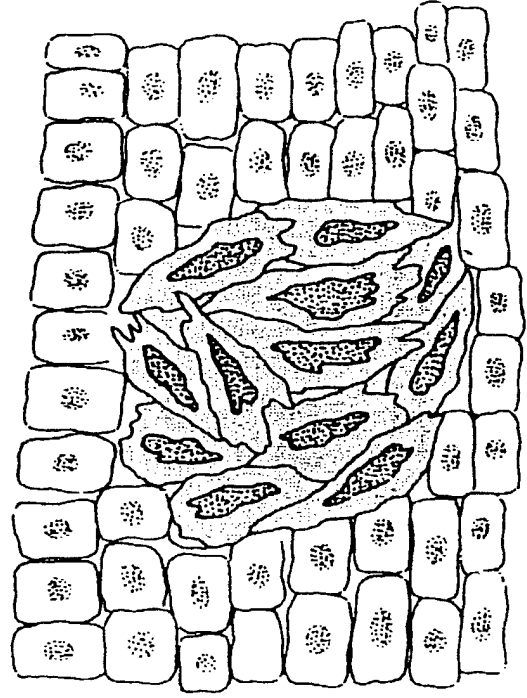


Cancer cells

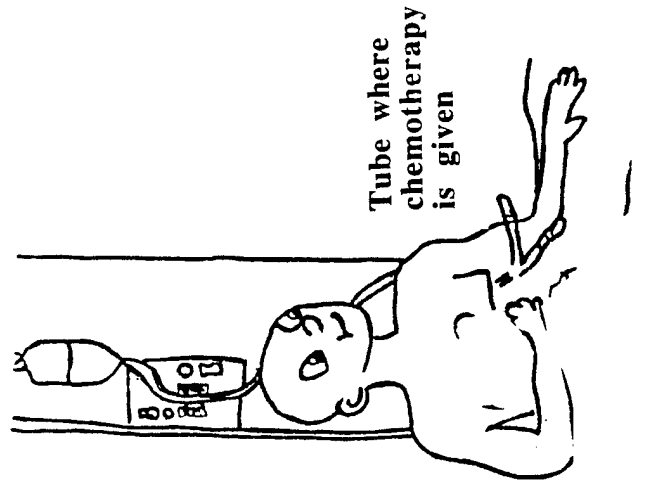
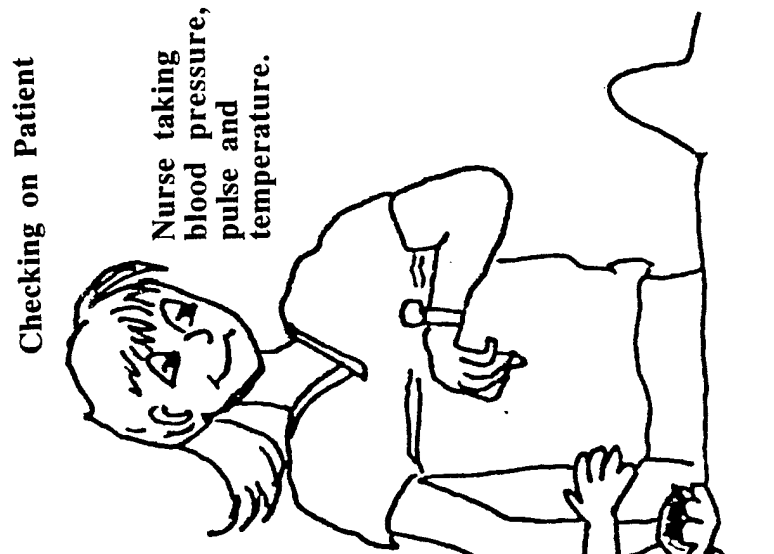
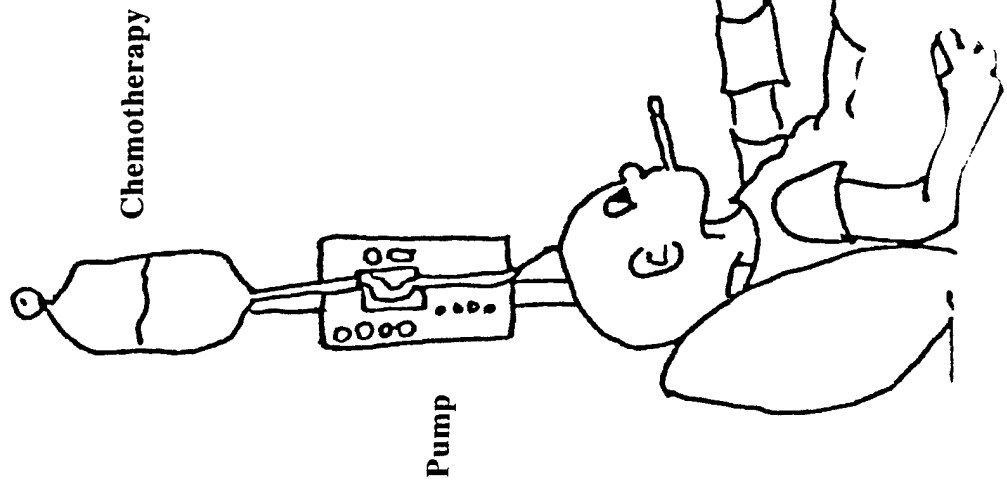
Cancer Tumor Growing



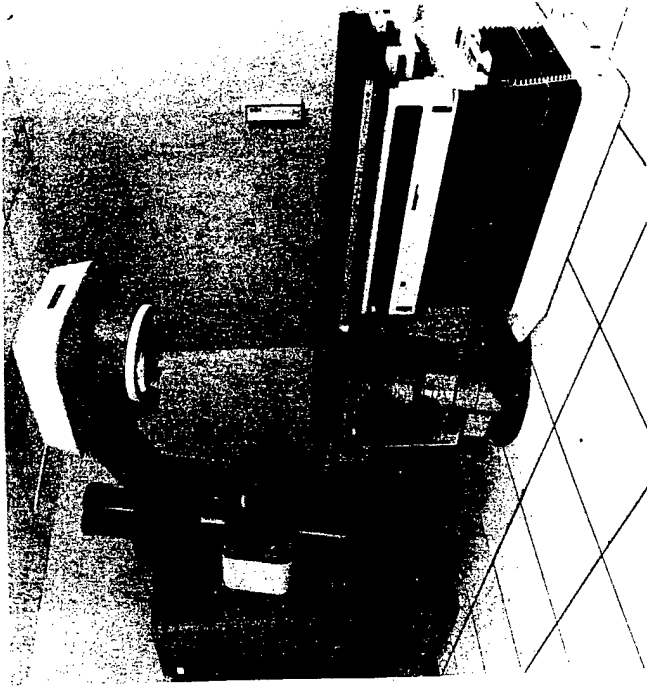
Cancer Tumor



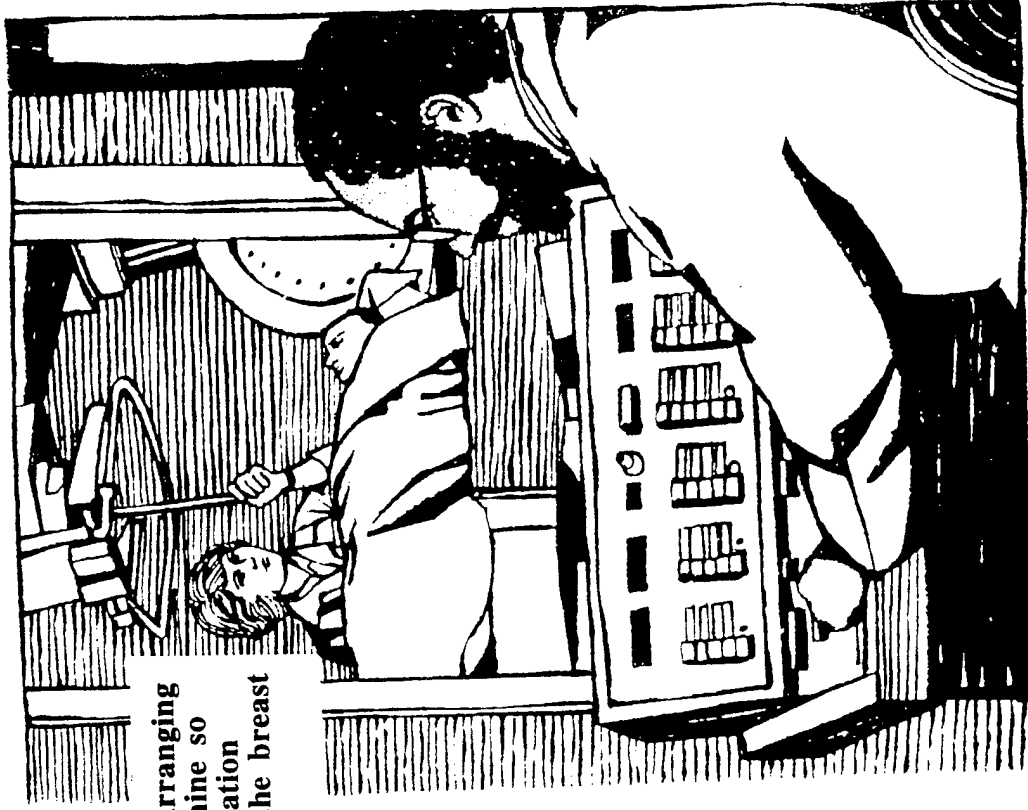
Woman Receiving Chemotherapy (Medication)



Radiation (X-ray) Therapy



Radiation Machine



Person arranging
the machine so
that radiation
goes to the breast
only

Individual behind window works the radiation machine.

This person can see the patient and the patient can talk to them at all times.

SMALL BOOK OF BIG WORDS



Anemia (a-nee'-mee-a)---A person with anemia has too few red blood cells. They may feel tired and weak. The doctor may have the patient take pills or they may have to receive a blood transfusion.

Analgesic (an -all -gee -sick)---Medicine that is taken for pain such as Tylenol.

Anesthesia (an -a -the -zha)---Given for an operation that makes you sleep and you don't feel pain.

Antiemetic (an -tie- e -met- ick)---Medicine that stops sickness in the stomach or throwing up. It may be given before chemotherapy or after chemotherapy.

Biopsy (bye'-op-see)---During a biopsy the doctor removes a little piece of tissue or tumor where there may be cancer. This can be done with a needle or a knife it depends where the part of the body is located. Sometimes this is done as an operation. The tissue that is removed is then examined under a microscope to see if there are cancer cells in it.

Benign Tumor (bee- nine two'-mer)---An unhealthy growth that is not cancer and does not spread to other parts of the body.

Breast Cancer (breast can'- sir)---Abnormal cells that have grown in the breast.

Blood Counts---Blood looks like a red liquid when we cut ourselves, but it really is made up of many things of different shapes and sizes. These different shapes are known as blood cells, they are white, red and platelets. Blood counts are very important since they tell the doctor many things. White blood cells fight infection, red blood cells carry oxygen to the lungs and platelets help us to stop bleeding when we get cut.

Bone Marrow (bone mar'-row)---The red stuff in the middle of a bone. This is where blood is made. It leaves the bone marrow and travels into the veins and arteries or blood vessels.

Cancer (can'-sir)---Cancer is a disease where in a small part of the body the cells grow too fast or too much. You cannot catch cancer nor can you make it happen. There are many kinds of cancer.

CAT Scan or CT Scan---A picture (x-ray) of the inside of the body. The pictures are taken by a special camera that takes pictures through the skin. It does not hurt.

Cells (sells)---Cells are tiny parts of the body that cannot be seen by the eye. Many of these cells make up our body. Everything living is made up of cells.

Chemotherapy (kee-moh'-ther-a-pee)---A special medicine used to get rid of the cancer. It may come in the form of a pill, or as a liquid that is given as a shot or through the veins in the arm or hand or a small tube in the chest. Sometimes we nickname chemotherapy, "chemo".

Checkup---A visit to the doctor.

Clinic (klin'-ick)---A special place where doctors and nurses help people like your mom get better.

Cured---When the cancer is all gone. Sometimes doctors wait for the cancer to be gone for many years before they say someone is cured.

Diagnosis (dye-ahg-no'-sis)---This gives the person's sickness a name. Breast cancer is usually diagnosed using the biopsy, which was discussed earlier.

Hormone (hor- moan)---A chemical made in our bodies that help it work right. The body makes many different kinds of hormones. Sometimes we need hormones in larger amounts then the body produces so there are hormones that can be taken as a pill.

Immune System (i-mune- sis -tim)---The parts of the body that fight infection and cancer.

Infection (in-feck'-shun)---When a tiny living thing like a virus gets into the body and grows. Sometimes people call an infection a "bug" but it is not like an ant.

Intravenous (in- tra- ve'-nus)---Using a vein to give medicine.

Lymph Nodes (limf -nodes)---Tiny bumps located all over our bodies. These bumps help fight infection and cancer. Cancer can also go to these bumps and they will become bigger.

Lump---Any kind of unhealthy cell growth that occurs in the breast or anywhere in the body. It looks like a ball of skin, but it is really made up of tiny cells.

Lumpectomy (lump- ec- toe -me)---Removing the lump through an operation.

Lymphedema (limf -e -dee- ma)---A swelling in the arm. This usually happens on the side of the body where the cancer was removed from the breast. It is the result of a collection of fluid. Mom may have to exercise her arm or wear a special covering that looks like a heavy stocking to help decrease the swelling go away.

Mammogram (mam- o'- gram)---A picture (x-ray) of the breast that is done to see if there are any lumps (tumors) in the breast.

Mastectomy (mass-tech- toe- me)---An operation to remove the breast or a part of it.

Oncologist (on-call'-ah-gist)---A doctor who treats people with cancer.

Oncology (on-kah'-lah-gee)---The study of cancer.

Operation (op-er-a'-shun)---When the doctor makes a cut in the skin to fix or remove something underneath the skin. People cannot feel anything during an operation because they are given medicine called anesthesia to make them sleep and feel no pain. After the doctor is finished he/she stitches the cut with thread. When the cut is healed there will be a small scar but it will fade in time. Scars do not hurt once they are healed.

Platelet (plate-let)---A blood cell that helps you stop bleeding if you get cut.

Radiation Therapy (ray-dee-aye'-shun ther'-ah-pee)---A type of treatment to get rid of cancer. It is done by aiming a special machine that looks like a big camera at the cancer. Mom lies under the machine and it sends out x-rays (which are energy we cannot see) that destroy the cancer. The doctors who work with radiation are trained to make sure the x-rays are sent to the area of the body where the cancer is located. Although mom is alone in the room with the machine there is someone who can see and hear her through a window in case she would need anything. Mom cannot feel anything when she is treated with radiation. Sometimes radiation does cause the skin to get red like if you get sunburn. Radiation does not hurt but it may make mom tired.

Radiation Oncologist (ray-dee-aye'-shun on-call'-lah gist)---A doctor trained in the use of radiation therapy to treat cancer.

Remission (ree-mish'-on)---The cancer is gone. This is not the same as a cure. Remission can last for a short or long time.

Tumor (two'-mer)---A lump or bump. It may or may not be cancer.

Revised 8/99

Handouts for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 1



All About Me

A large, decorative rectangular frame with rounded corners and ornate scrollwork at the top and bottom. The frame is intended for a child to write their name and other information.

Name _____

Take-homes for the Families Coping With Cancer Project

Younger Children: Ages 7-9

Session 1

FOR HOME #1
MORE ABOUT...
MY FAMILY AND CANCER

REVIEW:

1. Every person has strengths, skills, and things that he or she is proud of. One thing that I am good at or proud of is

2. There are other kids like me—all of the kids in the group for instance—whose mom was sick with cancer. One thing that I know and like about another kid in the group is

3. My family is

4. When someone has cancer, the bad cells in a part of their body grow quickly and form a tumor. The tumor crowds out the good cells. The medicine that people who have cancer take is called chemotherapy. The chemotherapy is very strong medicine. It needs to be strong in order to get rid of the bad cells. Because the chemotherapy is so strong, it hurts some of the good cells too, like the cells that make hair grow. This is why some people who are taking chemotherapy lose their hair. Cancer is not contagious, meaning that you can't get cancer from another person who has cancer. Cancer is not caused by other people. For instance, moms don't get cancer because of anything that their kids do.

5. Cancer changes lots of things in families. One thing that changed in my family because of cancer is

6. Cancer does not change everything about families. A lot of things about my family have stayed the same. One thing that stayed the same in my family is

7. One thing that I learned today about cancer that I didn't know before is

TO DO:

1. "Special time" is when families do things together that are fun. "Special time" can involve kids and anyone in their family. Sometimes "special time" is for a kid and one parent or grandparent. Sometimes the whole family has "special time" altogether. Each person agrees about what the activity will be for special time. This month, have a "special time" with your family. Write about your "special time" below:

When? _____

What did you do? _____

Where did you have "special time"? _____

Who was there? _____

How did you feel? _____

2. Comic strips, pictures, books, movies, and television shows tell stories about how people get along with each other. For next time, bring a comic strip, picture or book that tells about families OR talk about a movie or television show that tells about families.

MORE BOOKS TO READ:

When Eric's Mom Fought Cancer by Judith Vigna.

PREVIEW:

Next time we'll be talking about different kinds of feelings and learning ways to relax!

MY NOTES:

Take-homes for the Families Coping With Cancer Project

Older Children: Ages 10-12

Session 1

FOR HOME #1
MORE ABOUT...
MY FAMILY AND CANCER

REVIEW:

1. Every person has strengths, skills, and things that he or she is proud of. I have strengths, skills, and things that I am proud of like:

2. There are other kids like me—all of the kids in the group for instance—whose mom was sick with cancer. Some things that I know and like about another kid in the group are:

3. To me, "family" means:

4. When someone has cancer, the bad cells in a part of their body grow quickly and form a tumor. The tumor crowds out the good cells. The medicine that people who have cancer take is called chemotherapy. The chemotherapy is very strong medicine. It needs to be strong in order to get rid of the bad cells. Because the chemotherapy is so strong, it hurts some of the good cells too, like the cells that make hair grow. This is why some people who are taking chemotherapy lose their hair. Cancer is not contagious, meaning that you can't get cancer from another person who has cancer. Cancer is not caused by other people. For instance, moms don't get cancer because of anything that their kids do.

5. Cancer changes lots of things in families. Some of the things that have changed in my family because of cancer are:

6. Cancer does not change everything about families. A lot of things about my family have stayed the same. Some of the things that are the same now as before my mom got cancer are:

7. One thing that I learned today about cancer that I didn't know before is:

TO DO:

1. "Special time" is when families do things together that are fun. "Special time" can involve kids and anyone in their family. Sometimes "special time" is for a kid and one parent or grandparent. Sometimes the whole family has "special time" altogether. Each person agrees about what the activity will be for special time. This month, have a "special time" with your family. Write about your "special time" below:

When? _____

What did you do? _____

Where did you have "special time"? _____

Who was there? _____

How did you feel? _____

2. Comic strips, pictures, books, movies, and television shows tell stories about how people get along with each other. For next time, bring a comic strip, picture or book that tells about families OR talk about a movie or television show that tells about families.

MORE BOOKS TO READ:

Vanishing Cookies by Michelle Goodman.

PREVIEW:

Next time we'll be talking about different kinds of feelings and learning ways to relax!

MY NOTES:

SESSION 2

ALL ABOUT...

OUR FEELINGS AND RELAXING

Main Objectives:

1. Increase ability to monitor and label feelings
2. Facilitate self-efficacy in terms of emotion regulation and management
3. Introduce muscle relaxation
4. Introduce deep breathing

Outline:

1. Transitioning to group
2. All about mom
3. All about feelings
4. Snack and review
5. For next time...

Session Materials:

1. Comic-strips/pictures about families
2. Group banner
3. Markers/ highlighters
4. Large newsprint
5. Relaxation Script from Coping Skills Interventions, pp. 28-32, S. Forman, Jossey-Bass, San Francisco (1993)
6. Name tags
7. Feelings poster
8. Glue, glue sticks, tape
9. Pre-cut balloons
10. Blue construction paper
11. Yarn
12. Stickers
13. Watercolor paper
14. Watercolor paints and brushes
15. Snacks
16. Oncology Nurse Educator Materials

Session Books:

Beginning to Learn About Feelings R. Allington & K. Cowles (1991)

The Moon Balloon J. Drescher (1996)

Don't Pop Your Cork on Mondays A. Moser (1988)

Coping Skills Interventions for Children & Adolescents S. Forman (1993)

Session Handouts:

Page 2: How Are You Feeling Today?

Take Home Books (all children):

Moon Balloon (they keep)

Don't Pop Your Cork on Mondays

Take Home Handouts/Supplies:

In "Baggie" :

Handout: "More About My Feelings and Relaxing"

- Younger Child Version (Blue)
- Older Child Version (Green)

MAGIC ISLAND Relaxation for Kids, audiotope, B. Mehling & M. Highstein, California, Publications (1990)

"Today I Feel" magnets, from ChildLife Council (WWW.childlife.org) (they keep)

I. TRANSITIONING TO GROUP (20 mins.)

(Children and facilitators sit in a circle. Facilitators welcome each child.) Who was able to find a comic strip or picture about families that they brought? (Children share comic strips/pictures. Facilitator provides comic strips/pictures if members did not bring them. Facilitators should prompt children to respond to what is going on in the picture and how the characters are feeling.) Who would like to tell about a movie or television show they saw that was about families? (Children respond.)

Who would like to tell the group about something fun they did with their family since we last met?*(Facilitators should point out elements about children's relationships with their families that have not been altered by cancer.) Today we are going to spend some time talking about feelings, but before we do that we have invited our nurse to come back to spend some time with you to answer any questions you may still have about cancer. (Oncology nurse educator spends approximately 10 minutes responding to the children's questions).*

II. ALL ABOUT OUR FEELINGS (15 mins.)

Today we're going to talk about feelings, happy feelings and other kinds of feelings too. What is one kind of feeling that someone could have?*(Children respond. Facilitator writes children's responses on newsprint.) Good. You already know a lot of words for different feelings. We're going to talk some more about these feelings and talk about some other feelings too.*

*****Younger:** *(Facilitator reads Beginning to Learn About Feelings. Facilitator uses feeling faces for the following exercise.) I have some pictures that show different feelings. Let's see if you can guess the feeling that goes with each picture. (Facilitator holds up faces and children name the feeling.) How could you tell that this face was for (specific emotion)? How do you look when you are feeling (specific emotion)? (Children act out emotions. Facilitator distributes Page 2: How Are You Feeling Today?) Color the face that shows how you feel right now.*

*****Older:** **Here is a poster that has faces showing different feelings.***(Facilitator uses feelings poster.) There is a game that we can play using this poster. We are going to go around the circle and each person can pick a face, say the feeling, tell about a time that they had the feeling. Then everyone in the circle can tell about a time that they had the feeling too. If you want to pass, you can. When you pass, you have to go up and pick a different feeling to talk about. (Children play game. Facilitator distributes Page*

2: How Are You Feeling Today?) Color the face that shows how you feel right now.

III. MANAGING FEELINGS (15 mins.)

Here's a book that talks about what to do to change stressful feelings into relaxed feelings. *(Facilitator reads: Don't Pop Your Cork on Mondays. Facilitator should make comments and ask questions while reading e.g., When you are mad, are you like the monkey, the bull, the ostrich or the turtle? What exercises do you like to do? Do you think you can do that to calm down? Then the facilitator gets to the page describing "Shake your tension away", the facilitator suggests that the participants try to shake their tension away.)*

IV. MUSCLE RELAXATION (10 mins.)

(Each child lies down or sits on the floor.) Here's a game we're going to play to help us learn more fun ways to calm down. In this game you are going to do some pretending. Listen carefully and follow the directions for the game. *(Facilitator reads script for Progressive Muscle Relaxation, using relaxation script from Coping Skills Intervention Book).*

V. DEEP BREATHING (15 mins.)

(While children are in relaxed position.) Now, there's one more part of the game to do. Pretend that your belly is a balloon. Take a deep breath. Breathe in slowly through your nose until the balloon feels full. Hold it. Count to five—1-2-3-4-5. Then breathe out slowly through your mouth. Continue filling up the balloon with air. 1-2-3-4-5 and breathe out. Keep breathing in and out and filling up your belly like a balloon.

Ok, when you are ready sit up. How do you feel? *(Facilitator comments on consistencies between children's reports of how they feel and their face, body, and/or verbal cues i.e., "I can see that you feel good now because you are sitting still and listening.")*

Here's a book about some other things that help kids relax. *(Read The Moon Balloon.)*

***Younger: *(Pass out pre-cut balloons, blue construction paper, yarn, and stickers to decorate.)* Now you can make your own Moon Balloon. You can decorate it any way you would like.

*****Older.** *(Pass out watercolor paper, watercolor paints, and brushes.)* Now you can make your own Moon Balloon. Your balloon can look any way you would like.

IV. SNACK AND REVIEW (5 mins.)

Get out snack and ask helpers to complete different tasks (e.g., pass out the napkins, pass out the drinks, pass trash can.)

While we are having snack, let's review what we did today. I'll write these things down so that we can show your parents all the important things you did today.

V. FOR NEXT TIME... (5 mins.)

(Facilitator shows children the take home materials while explaining what they involve.) I have some practice sheets to remind you of what we did today. Also, the practice sheets explain what to do before you come back next time. One thing is to keep track of times that you felt mad, sad, happy, or scared. Another thing is to practice relaxing by listening to a tape that you can borrow to take home. *(Pass out "More About My Feelings and Relaxing.")*

(Children meet their parents at the parents' group. Facilitators summarize what was accomplished during the session and briefly describe the children's home activities. Facilitators should give feedback to individual sets of parents regarding their child's participation in the group.)

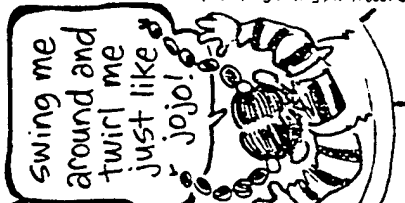
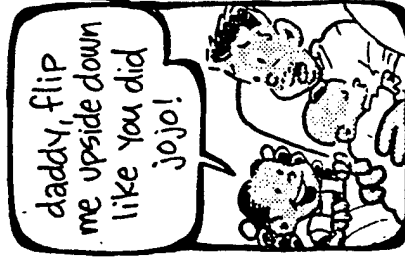
Materials for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 2

Jump Start

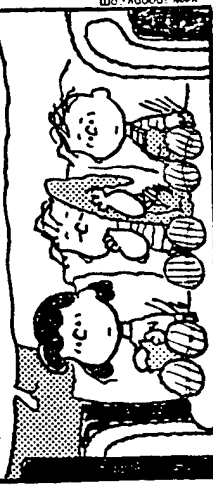
By Robb Armstrong



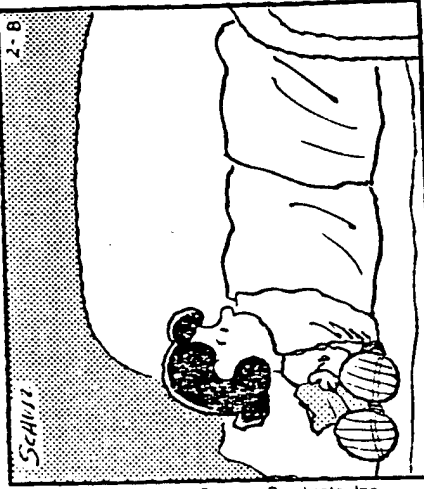
By Charles Schulz

Peanuts

I'LL HAVE TO ADMIT THAT IN
MANY WAYS WE ARE A CLOSE
FAMILY.. BROTHERS AND SISTERS
JUST NATURALLY TEND TO BE
THAT WAY.. SUCH CLOSENESS
IS VERY ADMIRABLE ...



...HAVING SAID THAT..



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"Relaxation Script" from: Coping Skills Interventions for Children and Adolescents, by Susan G. Forman, Jossey-Bass Publishers, San-Francisco, 1993, pp. 28-32.

(floppy, relaxed, limp). Koeppen (1974, pp. 17-20) developed the following relaxation training script based on imagery.

Hands and Arms

Pretend you have a whole lemon in your left hand. Now squeeze it hard. Try to squeeze all the juice out. Feel the tightness in your hand and arm as you squeeze. Now drop the lemon. Notice how your muscles feel when they are relaxed. Take another lemon and squeeze it. Try to squeeze this one harder than you did the first one. That's right. Real hard. Now drop your lemon and relax. See how much better your hand and arm feel when they are relaxed. Once again, take a lemon in your left hand and squeeze all the juice out. Don't leave a single drop. Squeeze hard. Good. Now relax and let the lemon fall from your hand. (Repeat the process for the right hand and arm.)

Arms and Shoulders

Pretend you are a furry, lazy cat. You want to stretch. Stretch your arms out in front of you. Raise them up high over your head. Way back. Feel the pull in your shoulders. Stretch higher. Now just let your arms drop back to your side. Okay, kitten, stretch again. Stretch your arms out in front of you. Raise them over your head. Pull them back, way back. Pull hard. Now let them drop quickly. Good. Notice how your shoulders feel more relaxed. This time let's have a great big stretch. Try to touch the ceiling. Stretch your arms way out in front of you. Raise them way up high over your head. Push them way, way back. Notice the tension and pull in your arms and shoulders. Hold tight, now. Great. Let them

Note: The relaxation training script based on imagery is reprinted from Koeppen, A. S. (1974). Relaxation training for children. *Elementary School Guidance and Counseling*, 9, 17-20. © AACD. Reprinted with permission. No further reproduction authorized without written permission of American Association for Counseling and Development.

"Relaxation Script" from: Coping Skills Interventions for Children and Adolescents,
by Susan G. Forman, Jossey-Bass Publishers, San-Francisco, 1993, pp. 28-32.

Learning to Relax

29

drop very quickly and feel how good it is to be relaxed.
It feels good and warm and lazy.

Shoulders and Neck

Now pretend you are a turtle. You're sitting out on a rock by a nice, peaceful pond, just relaxing in the warm sun. It feels nice and warm and safe here. Oh-Oh! You sense danger. Pull your head into your house. Try to pull in your shoulders. It isn't easy to be a turtle in a shell. The danger is past now. You can come into the warm sunshine and once again, you can relax and feel the warm sunshine. Watch out now! More danger. Hurry, pull your head back into your house and hold it tight. You have to be closed in tight to protect yourself. Okay, you can relax now. Bring your head out and let your shoulders relax. Notice how much better it feels to be relaxed than to be all tight. One more time, now. Danger! Pull your head in. Push your shoulders way up to your ears and hold tight. Don't let even a tiny piece of your head show outside your shell. Hold it. Feel the tenseness in your neck and shoulders. Okay. You can come out now. It's safe again. Relax and feel comfortable in your safety. There's no more danger. Nothing to worry about. Nothing to be afraid of. You feel good.

Jaw

You have a giant jawbreaker bubble gum in your mouth. It's very hard to chew. Bite down on it. Hard! Let your neck muscles help you. Now relax. Just let your jaw hang loose. Notice how good it feels just to let your jaw drop. Okay, let's tackle that jawbreaker again now. Bite down. Hard! Try to squeeze it out between your teeth. That's good. You're really tearing that gum up. Now relax again. Just let your jaw drop off your face. It feels so good just to let go and not have to fight that bubble gum. Okay, one more time. We're really going to tear it up this time. Bite down. Hard as you can. Harder. Oh, you're really working hard. Good. Now relax. Try to

"Relaxation Script" from: Coping Skills Interventions for Children and Adolescents,
by Susan G. Forman, Jossey-Bass Publishers, San Francisco, 1993, pp. 28-32.

Coping Skills Interventions

relax your whole body. You've beaten the bubble gum.
Let yourself go as loose as you can.

Face and Nose

Here comes a pesky old fly. He has landed on your nose. Try to get him off without using your hands. That's right, wrinkle up your nose. Make as many wrinkles in your nose as you can. Scrunch your nose up real hard. Good. You've chased him away. Now you can relax your nose. Oops, here he comes back again. Shoo him off. Wrinkle it up hard. Hold it up hard. Hold it just as tight as you can. Okay he flew away. You can relax your face. Notice that when you scrunch up your nose that your cheeks and your mouth and your forehead and your eyes all help you, and they get tight too. So when you relax your nose, your whole face relaxes too, and that feels good. Oh-oh. This time that old fly has come back, but this time he's on your forehead. Make lots of wrinkles. Try to catch him between all those wrinkles. Hold it tight, now. Okay, you can let go. He's gone for good. Now you can just relax. Let your face go smooth, no wrinkles anywhere. Your face feels nice and smooth and relaxed.

Stomach

Hey! Here comes a cute baby elephant. But he's not watching where he's going. He doesn't see you lying there in the grass, and he's about to step on your stomach. Don't move. You don't have time to get out of the way. Just get ready for him. Make your stomach very hard. Tighten up your stomach muscles real tight. Hold it. It looks like he is going the other way. You can relax now. Let your stomach go soft. Let it be as relaxed as you can. That feels so much better. Oops, he's this way again. Get ready. Tighten up your stomach. Real hard. If he steps on you when your stomach is hard, it won't hurt. Make your stomach into a rock. Okay, he's moving away again. You can relax now. Kind of settle down, get com-

Learning to Relax

31

fortable, and relax. Notice the difference between a tight stomach and a relaxed one. That's how we want it to feel—nice and loose and relaxed. You won't believe this, but this time he's really coming your way and not turning around. He's headed straight for you. Tighten up. Tighten hard. Here he comes. This is really it. You've got to hold on tight. He's stepping on you. He's stepped over you. Now he's gone for good. You can relax completely. You're safe. Everything is okay, and you can feel nice and relaxed.

This time imagine that you want to squeeze through a narrow fence and the boards have splinters on them. You'll have to make yourself very skinny if you're going to make it through. Suck your stomach in. Try to squeeze it up against your backbone. Try to be as skinny as you can. You've got to get through. Now relax. You don't have to be skinny now, just relax and feel your stomach being warm and loose. Okay, let's try to get through that fence now. Squeeze up your stomach. Make it touch your backbone. Get it real small and tight. Get as skinny as you can. Hold tight now. You've got to squeeze through. You got through that skinny little fence and no splinters. You can relax now. Settle back and let your stomach come back out where it belongs. You can feel really good now. You've done fine.

Legs and Feet

Now pretend that you are standing barefoot in a big, fat mud puddle. Squish your toes down deep into the mud. Try to get your feet down to the bottom of the mud puddle. You'll probably need your legs to help you push. Push down, spread your toes apart, and feel the mud squish up between your toes. Now step out of the mud puddle. Relax your feet. Let your toes go loose and feel how nice that is. It feels good to be relaxed. Back into the mud puddle. Squish your toes down. Let your leg muscles help you push your feet down. Push your feet. Hard. Try to squeeze that mud puddle dry. Okay. Come back

**"Relaxation Script" from: Coping Skills Interventions for Children and Adolescents,
by Susan G. Forman, Jossey-Bass Publishers, San-Francisco, 1993, pp 28-32.**

32

Coping Skills Interventions

out now. Relax your feet, relax your legs, relax your toes.
It feels so good to be relaxed. No tenseness anywhere.
You feel kind of warm and tingly.

Handouts for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 2

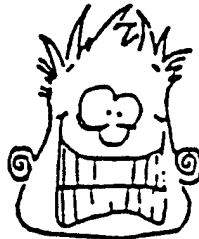
How Are You Feeling Today?



EXHAUSTED



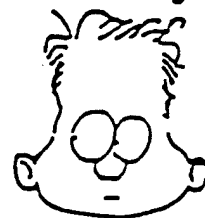
CONFUSED



ECSTATIC



GUILTY



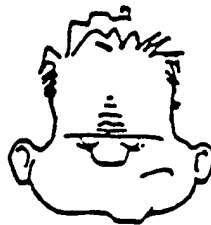
SUSPICIOUS



ANGRY



HYSTERICAL



FRUSTRATED



SAD



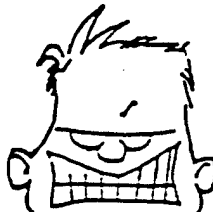
CONFIDENT



EMBARRASSED



HAPPY



MISCHIEVOUS



DISGUSTED



FRIGHTENED



ENRAGED



ASHAMED



CAUTIOUS



SHUG



DEPRESSED



OVERWHELMED



HOPEFUL



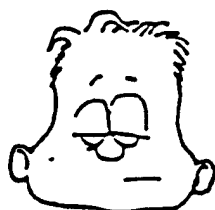
LOVELY



LOVESTRUCK



JEALOUS



BORED



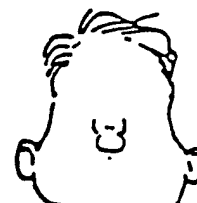
SURPRISED



ANXIOUS



SHOCKED



SHY

Take-homes for the Families Coping With Cancer Project

Younger Children: Ages 7-9

Session 2

FOR HOME #2
MORE ABOUT...
MY FEELINGS AND RELAXING

REVIEW:

1. There are lots of different feelings. Mad, sad, happy, and scared are some feelings that I have. Two other feelings are:

2. There are things that I can do to change my feelings. Some ways calm down when I feel mad or scared are talking with a friend or adult that I trust, "shaking it out," exercising, tensing and relaxing my muscles, and taking deep breaths from my belly. This is a picture of my favorite way to calm down.

3. One thing that I learned today about feelings and relaxing I didn't know before is:

TO DO:

- 1. Keep track of your feelings! For each feeling below write what was happening and what you did to calm down.**

I felt MAD when

I calmed down by

I felt SCARED when

I calmed down by

I felt HAPPY when

I felt even HAPPIER when

I felt SAD when

I felt better when

2. Practice relaxing with the audio-tape "Magic Island" by B. Mehling and M. Highstein. Play this tape at least 2 times before the next group meeting.

MORE BOOKS:

Don't Pop Your Cork on Mondays by A. Moser

PREVIEW:

Next time we'll be talking about making and keeping friends!

MY NOTES:

Take-homes for the Families Coping With Cancer Project

Older Children: Ages 10-12

Session 2

FOR HOME #2

MORE ABOUT...

MY FEELINGS AND RELAXING

REVIEW:

1. There are lots of different feelings. Mad, sad, happy, and scared are some feelings that I have. Some other feelings are:

2. There are things that I can do to change my feelings. Some ways calm down when I feel mad or scared are talking with a friend or adult that I trust, "shaking it out," exercising, tensing and relaxing my muscles, and taking deep breaths from my belly. My favorite ways to calm down are:

3. One thing that I learned today about feelings and relaxing I didn't know before is:

TO DO:

- 1. Keep track of your feelings! For each feeling below write what was happening and what you did to calm down.**

I felt MAD when

I calmed down by

I felt SCARED when

I calmed down by

I felt HAPPY when

I felt even HAPPIER when

I felt SAD when

I felt better when

2. Practice relaxing with the audio-tape "Magic Island" by B. Mehling and M. Highstein. Play this tape at least 2 times before the next group meeting.

MORE BOOKS:

Don't Pop Your Cork on Mondays by A. Moser

PREVIEW:

Next time we'll be talking about making and keeping friends!

MY NOTES:

SESSION 3
ALL ABOUT...
SOLVING PROBLEMS AND HAVING FRIENDS

Main Objectives:

1. Reinforcing relaxation skills
2. Learning steps in problem-solving
3. Assertiveness training
4. Applying problem-solving to real-life situations

Outline:

1. Transitioning to group
2. Problem-solving
3. Not a mouse/ not a monster
4. Coping with bullies
5. Coping with feeling left-out
6. Snack and review
7. For next time

Session Materials:

1. Group banner
2. Crayons/markers
3. Xeroxed pictures of coping techniques from book
4. Newsprint
5. Mouse and monster masks, straws
6. Mirrors
7. Getting Along materials/posters ("Bullying" and "Intolerance")
8. Name tags
9. Snacks

Session Books:

The Mouse, the Monster, and Me P. Palmer (1977)

Bully on the Bus C. Bosch (1988)

Session Handouts:

Page 3: Problem-Solving Steps

Take Home Books:

How To Be A Friend L. Brown & M. Brown (1998) (Ages7-9/Grades 1-3)

Reflections from a Mud Puddle M. Anderson (1998) (Ages10-12/Grades 4-6)

Take Home Handouts:

"More About Solving Problems and Having Friends"

- Younger Child Version (Blue)
- Older Child Version (Green)

I. TRANSITIONING TO GROUP (10 mins.)

(Children and facilitator sit in a circle. Facilitator welcomes each child.)

Who can tell about what they did to relax since our last group? *(Children respond. Photocopied pages of relaxation strategies should be displayed to facilitate the participant's recollection of these techniques. Children are asked to describe their relaxation strategy to the group and the situation in which they used it for each of the following stress reduction methods.)* **Did anyone use exercising to relax? Did anyone use "Shake it off" to relax? Did anyone use tensing and relaxing your muscles or breathing to relax? Did anyone use deep breathing, thinking of this/her favorite thing, or thinking of their moon balloon to relax? Did anyone use another way to relax?**

Do you think that you will be able to exercise or use "shake it off" or muscle relaxing, or deep breathing again when you want to relax? What might make it hard to do these things to calm down? What would help make it easier? *(Children respond. Write on newsprint.)*

II. PROBLEM-SOLVING (25 mins.)

Let's see if we can help the boy in this story solve his problem. *(Read Bully on the Bus, stopping at appropriate points to prompt.)* **What is Jack's problem?** *(Write children's responses on newsprint.)* **What can he do about it?** *(Write on newsprint. Children respond. If listed in book, turn to that page and read.)* **What will happen next?** *(If in book, turn to page and read outcome. Write on newsprint.)* *If not listed in book: What do you think will happen? You did a very good job thinking of what to do to deal with the problem. First, you named the problem. Then you thought of solutions for dealing with the problem. Then we saw what happened when a solution is picked. Here are steps for solving problems. (Hang "Problem-Solving Steps" on wall. Group recites steps.)*

Here is a page for your book for you to color and keep to remind you of the steps are for solving problems. *(Hand out Page 3: Problem-Solving Steps. Children color their pages.)*

III. NOT A MOUSE/ NOT A MONSTER (15 mins.)

Today, we're going to talk about friendship--how each of you can be a good friend to others and how each of you can be a good friend to yourself.

Sometimes kids and adults aren't good friends to other people. They yell at other people, or fight with them, or don't listen to them. They are like

monsters. Other times kids or adults aren't good friends to themselves. They don't ask for help and they don't tell other people what they need. They are like mice. Who can think of more words to describe a monster? *(Prompt for what a "monster" looks like and what s/he acts like.) (Facilitator writes on newsprint).* Who can think of more words to describe a mouse i.e., what s/he looks and acts like? *(Facilitator writes on newsprint.)*

*****Younger:** *(Pass out monster and mouse masks for children to color.)* These masks are for you to color and wear when we pretend to be monsters and mice. After we pretend to be monsters and mice, we'll talk about ways to not be either a monster or a mouse, and instead to be a good friend to other people and to yourself. *(Children color masks.)* Ok, everyone hold up their monster mask. Let's see what you look like when you're a monster. *(Children act-out the part of a monster.)*

*****Older:** Who would tell about a time when they were like a monster? *(Children respond. Facilitator should reflect emotion behind child's behavior e.g., "Boy, it sounds like you were really mad about....". Ask child how else he/she could of responded to not be a "monster.")* Who else can think of something that [child] could have done instead of being a monster? Who would like to tell about a time when they were like a mouse? *(Ask child how else he/she could of responded to not be a "mouse.")* Who can think of something that [child] could have done instead of being a mouse?

IV. COPING WITH BULLIES (15 mins.)

Here's a picture that we can use to talk about how to be friends. *(Show group "Bullying" poster. Refer to "Bullying" activity sheet. Ask "Direct" questions on "Bullying" activity sheet.)* What's happening in this picture? How do you think the pig who is using the pen feels? How can you tell what the pig might be feeling? Why would the other pig say, "I want that pen NOW!"?

Let's see if we can use what we've learned about solving problems to think of solutions to this problem. *(Facilitator writes problem-solving steps on newsprint.)* What is the problem? Which pig is acting like the monster? Why is it wrong to act like that pig? *(Reinforce that the other pig has rights that are not being respected.)* Let's list all the things that the other pig could do next? *(The list should include "monster" and "mouse" responses.)* What do you think some "good friend" (i.e. assertive) responses to the pig would be? *(Children role-play a few good friend responses.)*

V. COPING WITH FEELING LEFT OUT (10 mins.)

(Facilitator puts "Intolerance" picture on the wall. Ask "Direct" questions on "Intolerance" activity sheet.) What's happening in this picture? How are all four of the zebras alike? What's the difference between the lone zebra and the others? Is that difference a good reason to leave the zebra out? Why or why not? How do you think the single zebra feels? What could the lone zebra do? How do you think the story will end?

(Ask "Reflective" questions on "Intolerance" activity sheet.) Have you ever felt left out of something because you were different? How were you different? When you were left out, how did you feel? What finally happened? Have you ever left someone else out because that person was different? How did you feel about that? Have you ever worried that you would be left out of the group if other kids knew that your mother had cancer? What did you do? What else could you have done?

VI. SNACK AND REVIEW (10 mins.)

Get out snack and ask helpers to complete different tasks (e.g., pass out the napkins, pass out the drinks, pass trash can. When children are finished with snack and coloring.) Ok, let's review what we did today. I'll write these things down so that we can show your parents all the important things you did today.

VII. FOR NEXT TIME (5 mins.)

(Facilitator shows children take-home materials.) For next time, I'd like you to write a short story or a poem about friendship, draw a picture or make a collage about friendship, or prepare to tell about a television show or movie about friendship. Also, I'd like you to bring a picture of a friend with you. The friend can be another kid, a neighbor, a brother or sister, or an adult like a teacher. *(Pass out "More About...Solving Problems and Being Friends.)"*

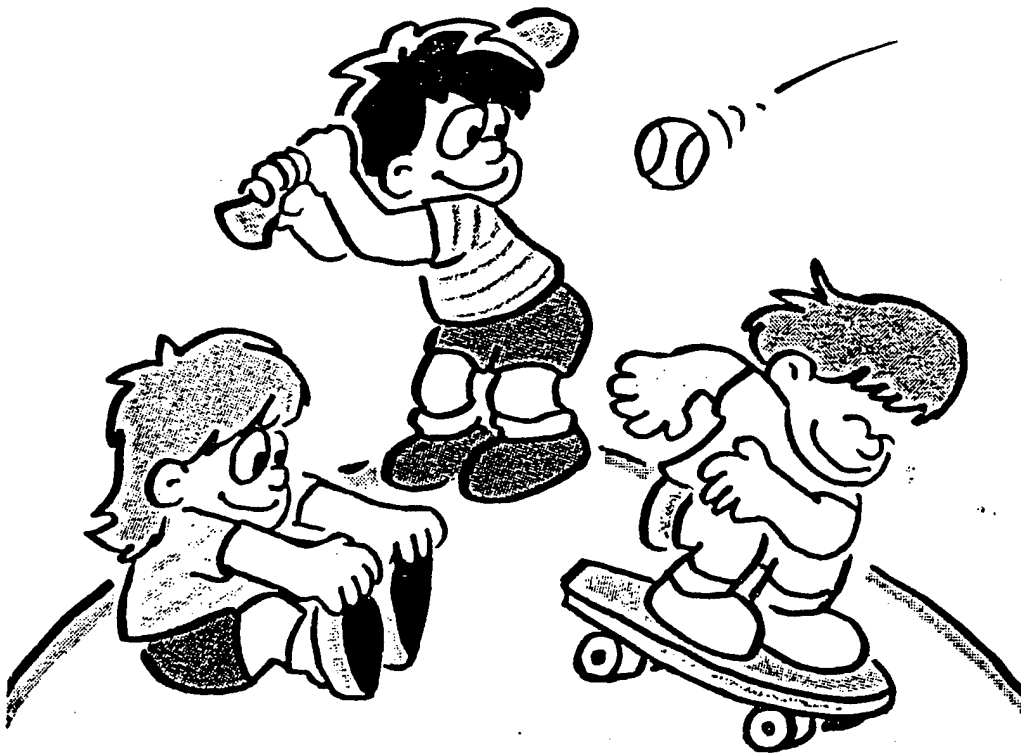
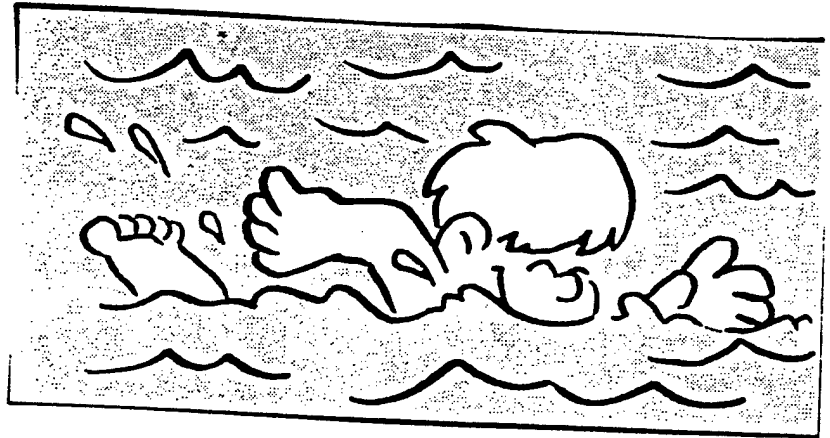
(Children meet their parents at the parents' group. Facilitators summarize what was accomplished during the session and briefly describe the children's task for next week. Facilitators should give feedback to individual sets of parents regarding their child's participation in the group.)

Materials for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 3

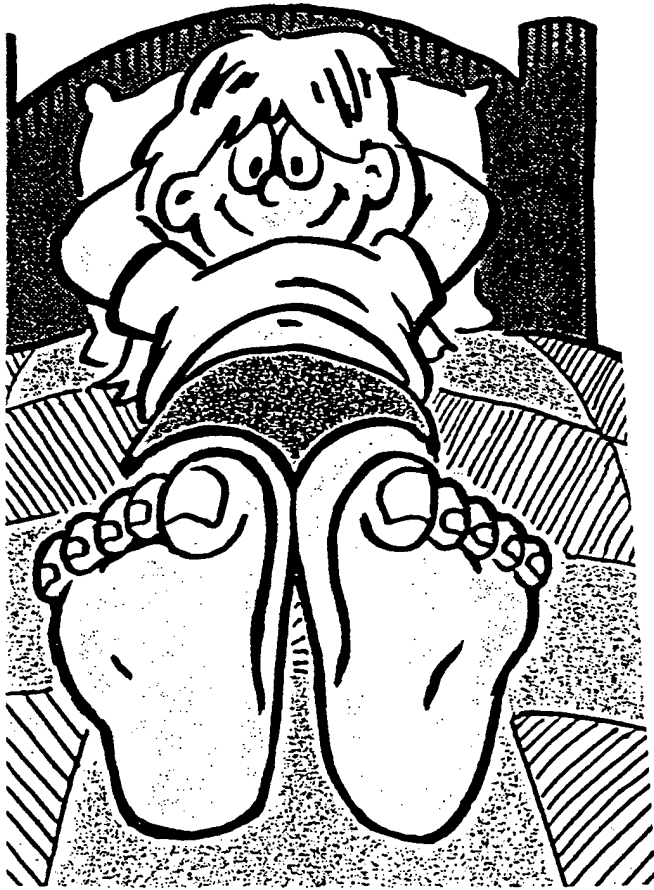
EXERCISE



SHAKE TENSION AWAY

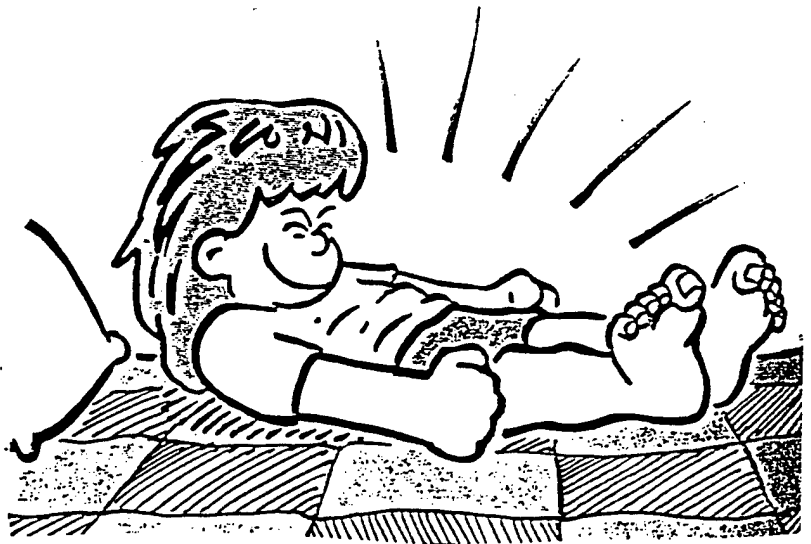


MUSCLE RELAXATION



FIRST, GET COMFORTABLE

THEN, TENSE YOUR MUSCLES



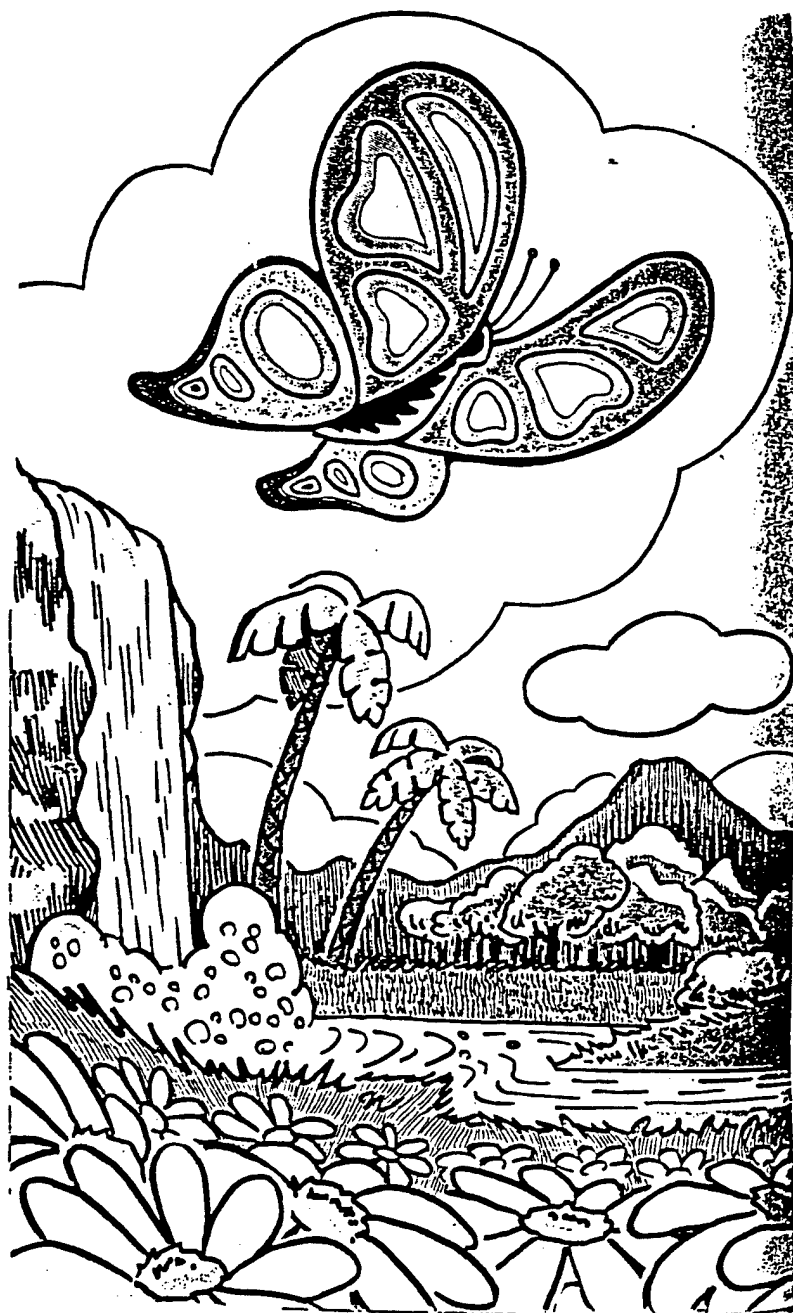
LAST, RELEASE AND GO LIMP

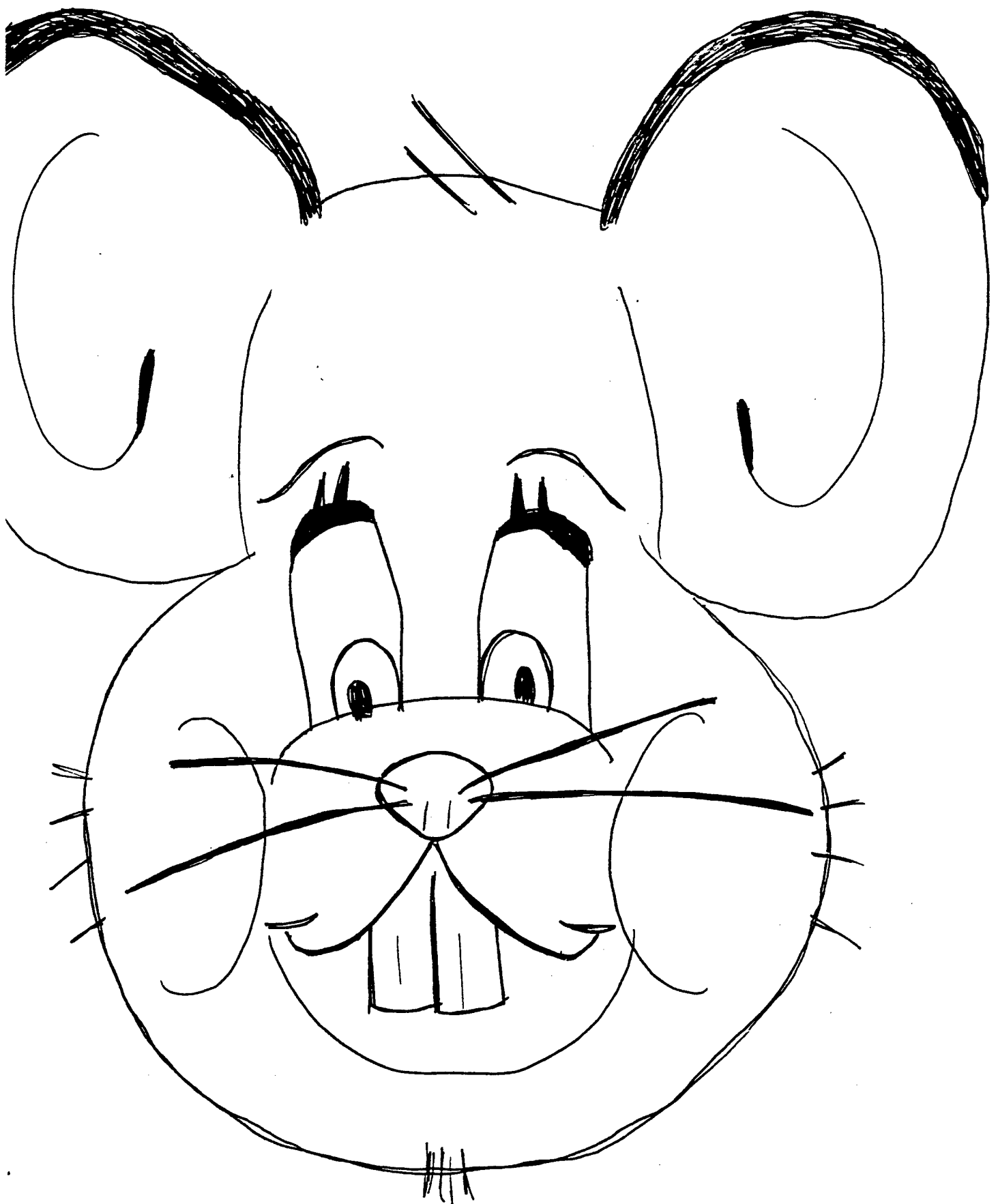
LIKE A RAG DOLL

BREATHING



IMAGINATION

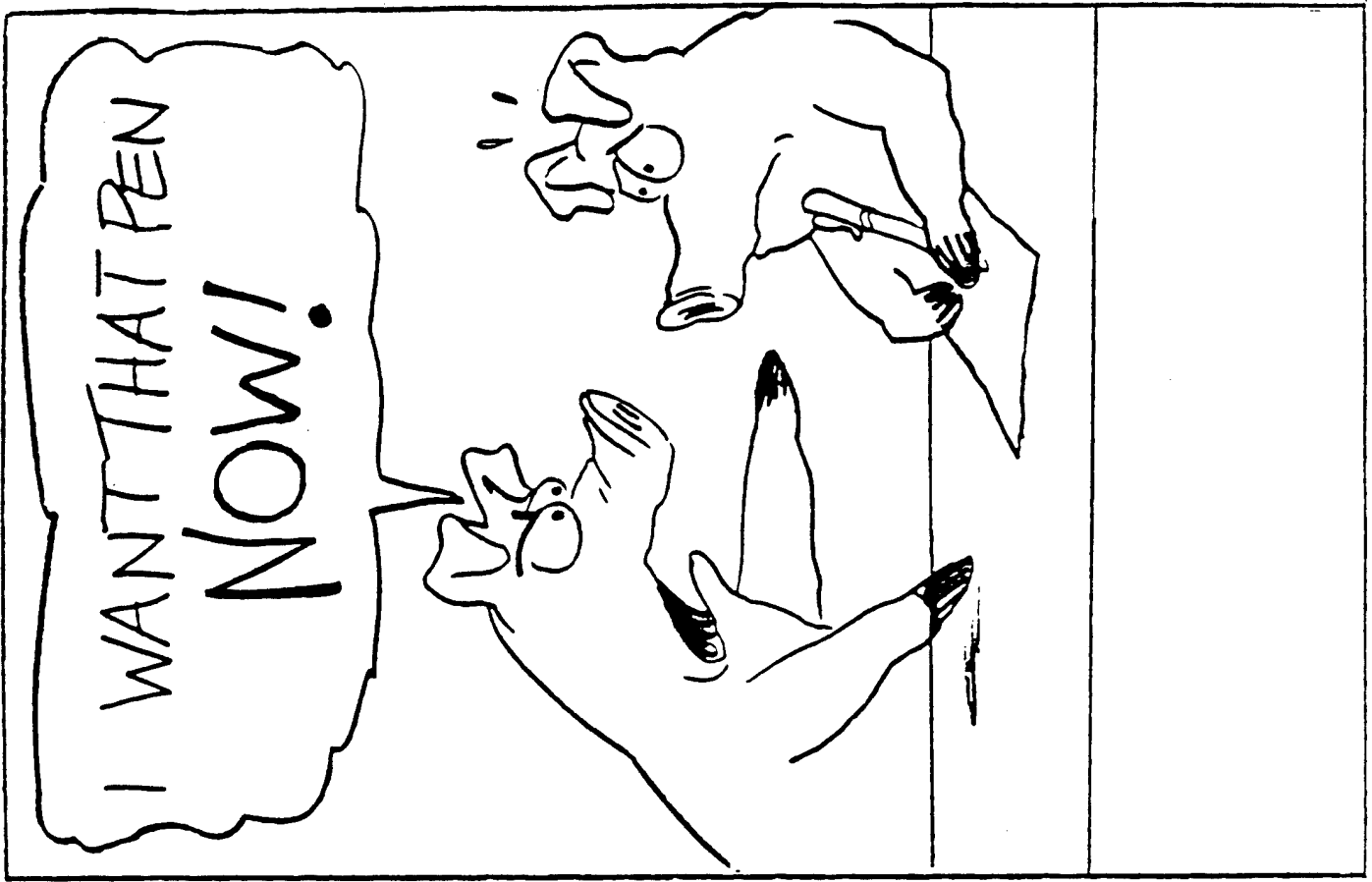
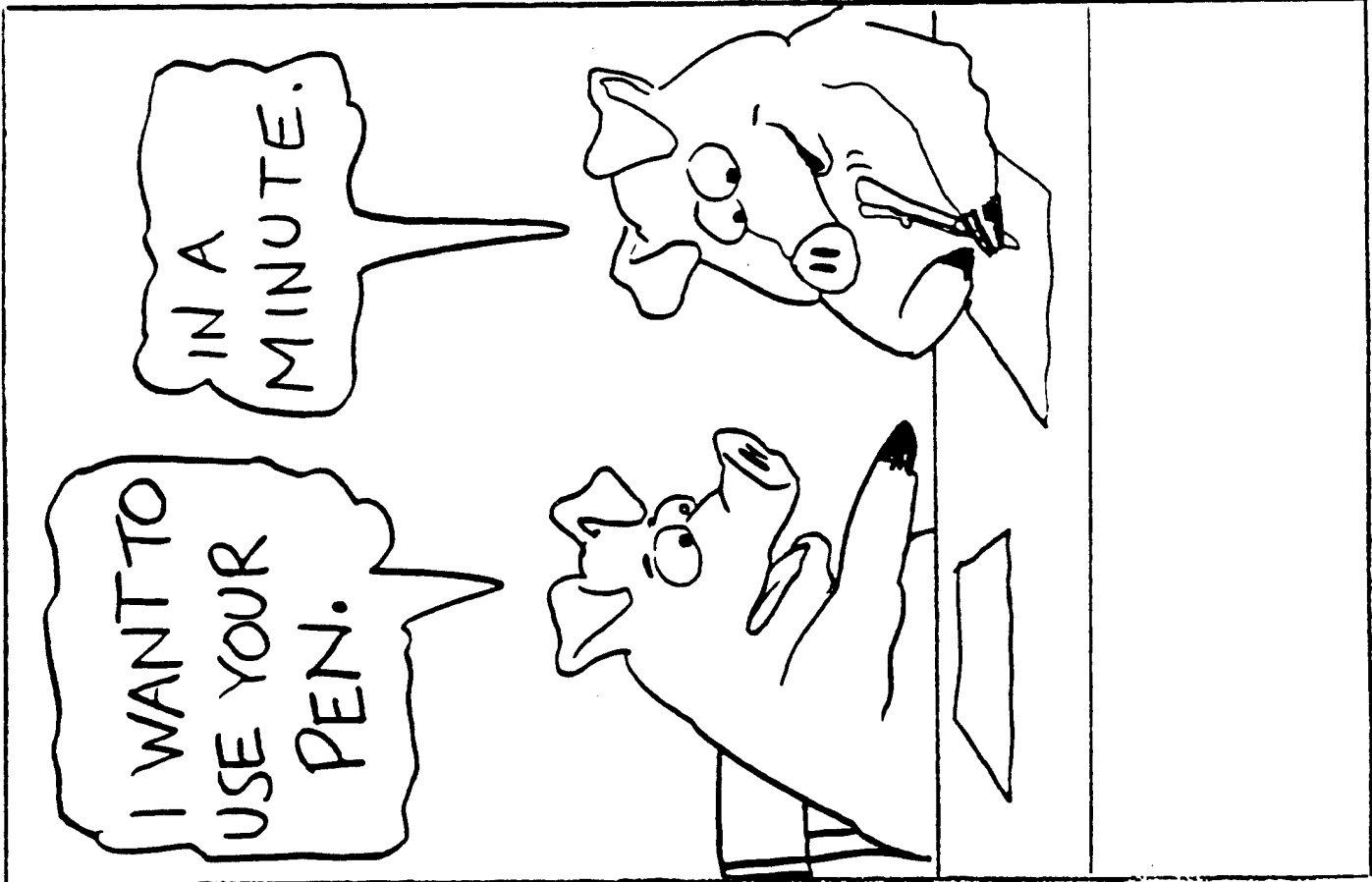


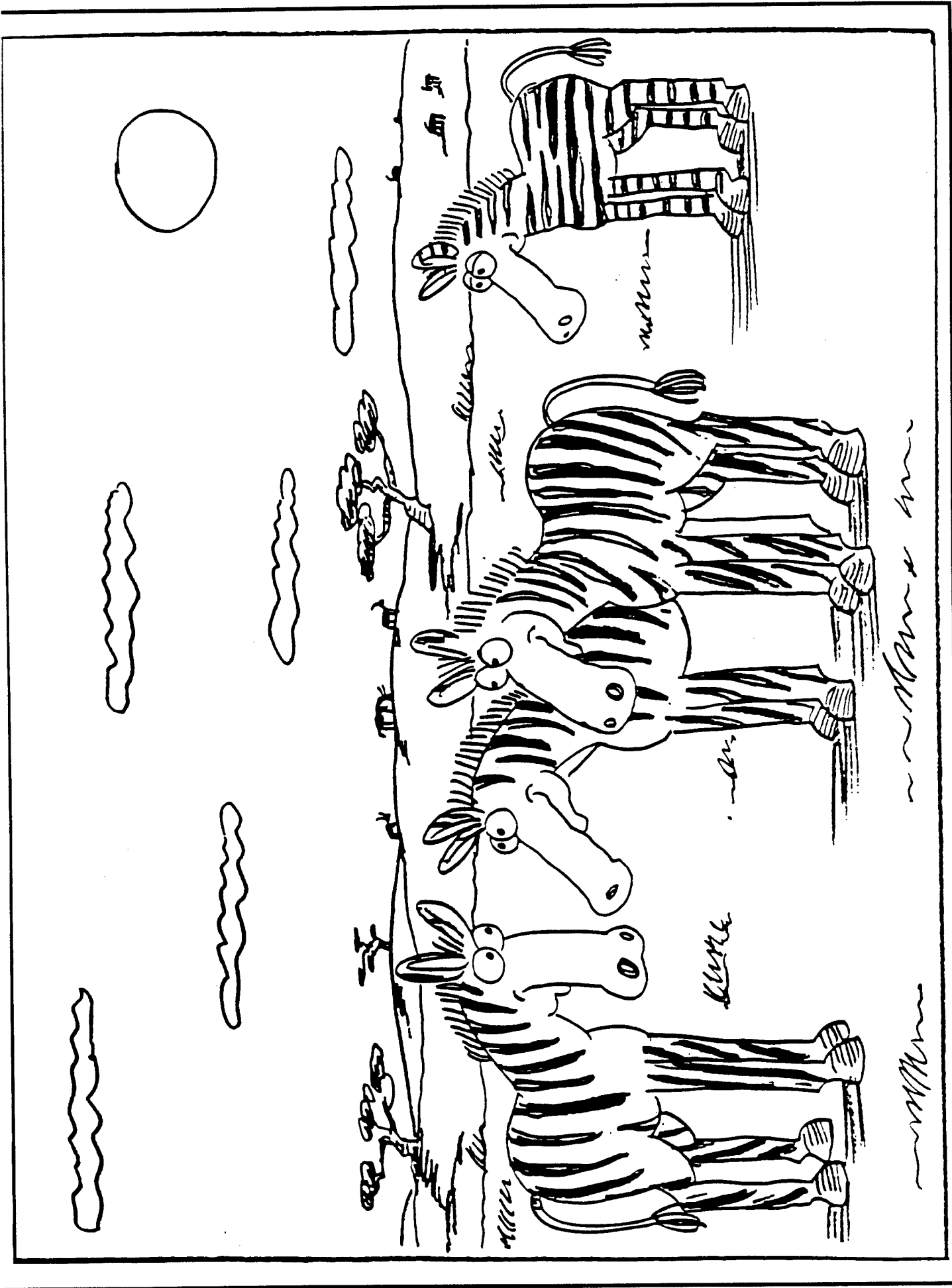


MOUSE



MONSTER





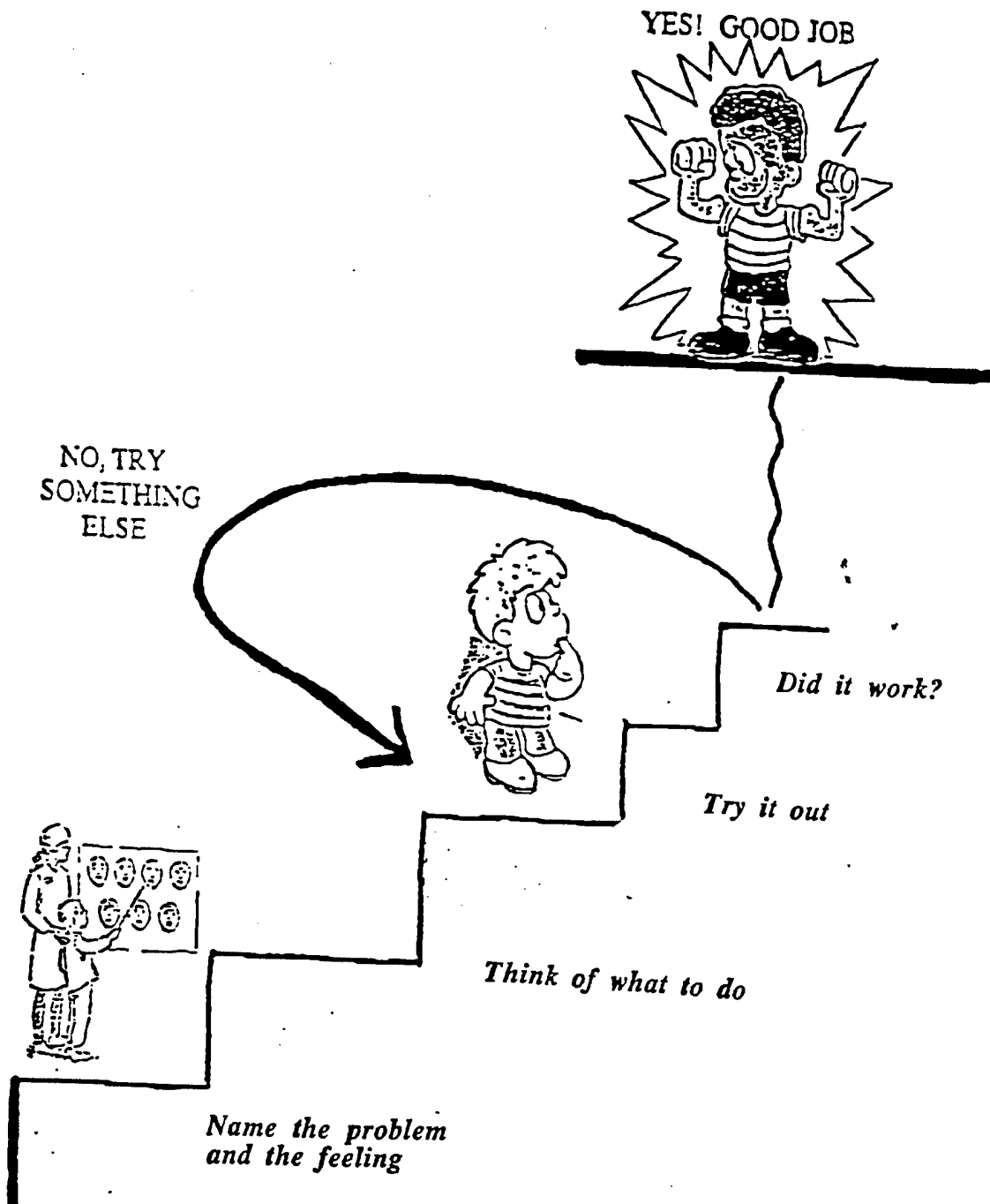
Handouts for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 3



Problem-Solving Steps



Pictures from:

Moser, A. & Pilkey, D. (1983). Don't Pop Your Cork on Mondays. Kansas City, MO: Landmark Editions Inc.

Name _____

Take-homes for the Families Coping With Cancer Project

Younger Children: Ages 7-9

Session 3

FOR HOME #3

MORE ABOUT...

SOLVING PROBLEMS AND HAVING FRIENDS

REVIEW:

1. The steps to solving problems are:

Step #1: Name the problem and feeling that you have

Step #2: Think of things to do to solve the problem or feel better

Step #3: Pick something to do

Step #4: Try it out

Step #5: Did it work? Good job! OR Try something else!

2. Acting like a MONSTER means not listening to other people and hurting other people with actions or words. Acting like a MOUSE means not standing up for yourself and not asking for help when you need it. Everyone acts like a MONSTER or a MOUSE sometimes. Being a good friend to others means listening to them and not hurting them. Being a good friend to yourself means asking for what you want, saying "no," and letting other people know how you feel.

This is a picture of me being a good friend to others and myself:

3. One thing that I learned about solving problems and being friends that I didn't know before was:

TO DO:

1. Bring a picture of a friend to the next group.

2. Write a story or a poem about friendship.

OR

Make a collage about friendship.

OR

Prepare to tell the group about a movie or television show that is about friendship.

MORE BOOKS TO READ:

How To Be a Friend by I. Brown and M. Brown.

PREVIEW:

Next time is our last group. We'll be talking about what it's like to say good-bye to friends. You may want to talk with a parent or another adult that you trust about what it might be like to say good-bye to the adults and other kids in the group. Also, we'll be having a party and a presentation of certificates to celebrate your accomplishments in group!

MY POEM, STORY, OR COLLAGE ABOUT FRIENDSHIP:

MY NOTES:

Take-homes for the Families Coping With Cancer Project

Older Children: Ages 10-12

Session 3

FOR HOME #3

MORE ABOUT...

SOLVING PROBLEMS AND HAVING FRIENDS

REVIEW:

1. The steps to solving problems are:

Step #1: Say what the problem/feeling is

Step #2: List as many solutions as you can

Step #3: Decide what would work best

Step #4: Try it out

Step #5: Did it work? Good job! OR Try something else!

2. Acting like a MONSTER means not listening to other people and hurting other people with actions or words. Everyone acts like a MONSTER sometimes. One time when I acted like a MONSTER was:

Next time, instead of acting like a MONSTER, I could:

3. Acting like a MOUSE means not standing up for yourself and not asking for help when you need it. Everyone acts like a MOUSE sometimes. One time when I acted like a MOUSE was:

Next time, instead of acting like a MOUSE, I could:

4. One thing that I learned about solving problems and being friends that I didn't know before was:

TO DO:

1. Bring a picture of a friend to the next group.

2. Write a story or a poem about friendship.

OR

Make a collage about friendship.

OR

Prepare to tell the group about a movie or television show that is about friendship.

MORE BOOKS TO READ:

Reflections From a Mud Pond by M. Anderson

PREVIEW:

Next time is our last group. We'll be talking about what it's like to say good-bye to friends. You may want to talk with a parent or another adult that you trust about what it might be like to say good-bye to the adults and other kids in the group. Also, we'll be having a party and a presentation of certificates to celebrate your accomplishments in group!

MY POEM, STORY, OR COLLAGE ABOUT FRIENDSHIP:

MY NOTES:

SESSION 4
ALL ABOUT...
WHAT WE'VE LEARNED AND SAYING GOODBYE

Main Objectives:

1. Reinforce skills learned in group
2. Facilitate closure

Outline:

1. Transitioning to group
2. When friends leave/saying good-bye
3. Review of sessions and compiling scrapbook
4. Party
5. Certificates of accomplishment.

Session Materials:

1. Group banner
2. Shoe boxes (one for each child)
3. Newsprint
4. Markers/crayons
5. Wrapping paper
6. Ribbon
7. "I like ____ / I'll miss ____" notes
8. All previous pages
9. Scrapbooks (to keep)
10. Decorations for scrapbooks
11. Glue, glue sticks
12. Scissors
13. Compliment signs decorated like presents
14. Party food
15. Certificates of Accomplishment

Session Book : To Annabella Pelican from Thomas Hippopotamus N. Patz (1991) (7-9 year olds)

Take Home Book: Scrapbook

I. TRANSITIONING TO GROUP (10 mins.)

(Children and facilitator sit in a circle. Facilitator welcomes each child.)

Who brought a picture of a friend with them today? (Children who brought pictures share them with the group.) What makes this person a good friend? Who wrote a short story or a poem about friendship that they would like to share with the group? Who would like to tell about a television show or movie they saw about friendship? Who would like to show a collage that they made about friendship? Who would like to tell about a friendship they have and what makes it special?

What makes the kids in this group friends?

II. WHEN FRIENDS LEAVE AND SAYING GOOD-BYE (30 mins.)

Has anyone had a friend that moved? What was that like? Some kids feel sad when a friend moves. Has anyone felt that way? What made it easier? Do you remember doing fun things with your friend who moved? Remembering the fun times you had with your friend can help you feel close to that friend, even though you may not play together anymore. Even though you don't see your friend anymore, you can still remember the good times you had together and you can keep in touch by writing letters or talking on the phone.

(If group is comprised of younger children, i.e. those aged 7-9, read To Annabella Pelican from Thomas Hippopotamus. If children are older, continue with questions below.)

Kids in a group like this may have different feelings when the group stops meeting. How do you think you will feel when this group stops meeting? What do you think that you'll remember about the group or the kids you met here? If you feel sad that the group is ending, what do you think you can do to feel less sad?

*****Younger:** *(Hold up signs describing attributes. Signs should be decorated to look like presents.) Who is someone in the group who is "good at listening"? Who is someone in the group who is a "good at sharing"? etc. Now we're going to play another game. I'm going to say something that I will miss about someone here and you try and guess who I am describing. (Children respond to facilitator and then have opportunity to describe what they will miss about a peer.)*

*****Older:** You are going to have a chance to give and receive compliments now. I'd like you to make your compliment box look like a present. *(Pass out shoe boxes, decorative supplies. Children make their boxes.)* Now it's time to give each other compliments and let each other know what you will miss about that person. Put a note in everyone's box. You can write them on these pieces of paper ("I like ____/ I'll miss" notes) and put them in their compliment boxes. *Children work on their notes.* You can read your notes now. How do you feel when you read the good things people have to say about you and what they will miss?

III. REVIEW OF SESSIONS AND COMPILING SCRAPBOOK (20 mins.)

You each did a lot of work in group. I have all the pages that you did. Let's look through the pages all together now so that we can review all the things that we've done. *(Facilitator goes over each page of scrapbook and elicits children's feedback about each activity and highlights important points of each activity. Facilitator should also ask about what each child liked best, thought was most fun, thought was hardest, etc. Also, facilitator takes photographs and pages off of group banner and gives them to children to incorporate into their scrapbooks.)*

(Each child is given his/her pages and a scrapbook.) You are each going to get a book to put all of your pages in. You can decorate the cover in whatever way you want.

V. PARTY (15 mins.)

(Get out snacks for the party and ask helpers to complete different tasks , e.g., pass out the napkins, pass out the drinks, pass trash can, etc.).

VI. DISTRIBUTION OF CERTIFICATES (15 mins.)

(Children join parents group. Facilitators should already have Certificates of Accomplishment made up for each child. Facilitators make brief comments about group as a whole (i.e., strengths of children, what was learned, importance of practicing skills, purpose of scrapbook) and then present each child with certificate with child's name and individualized goal/accomplishment at the top. Afterwards, facilitators talk with parents, give feedback, answer questions, etc.)

Materials for the Families Coping With Cancer Project

Older Child Group: Ages 7-12

Session 4

I Like _____

I'll Miss _____

I LIKE HOW YOU LISTEN

I LIKE HOW YOU RAISE YOUR HAND

I LIKE YOUR SMILE

I LIKE HOW YOU ARE
A GOOD HELPER

I LIKE HOW YOU TRY HARD

I LIKE THE PICTURES
YOU DRAW

I LIKE HOW YOU SHARE

I LIKE HOW
YOU ARE A GOOD FRIEND

Award

Certificate of

This certificate celebrates

for

Signed _____

Date _____

Shoot for the moon. Even if you miss,
you'll land among the stars!—Les Brown