

FINAL REPORT AND ABSTRACT

for Project:
TLC (Together Learning to Cope): Supporting Children
Whose Families Face a Life-Threatening Illness

Ele's Place
Lansing, Michigan

NARRATIVE:

1. Purpose of Project and Relationship to SSA Title V Maternal and Child Health (MCH) Programs

Prior to 2004, meaningful support services for children in families coping with life-threatening illness were non-existent in the mid-Michigan area. Ele's Place recognized that a life-threatening illness can take a huge toll on the emotional and physical resources of the entire family, including children. Children often don't understand the nature of the illness and may have many worries and fears about what to expect, their needs may not be met because the family is focusing its energies on caring for the ill person, and their schoolwork, health, and social adjustment may suffer as they attempt to cope with the changes in their family. While hospices sometimes provide limited services to children in the family, the average length of stay in the hospice program prior to the death is only two to three weeks and the majority of deaths resulting from a terminal illness occur without hospice involvement.

To address this unmet need, Ele's Place developed a project proposal to implement a new program called Together Learning to Cope (TLC), which would provide support groups and related services for children and families coping with

a family member's life-threatening illness. This program includes offering peer support groups for children ages 3 – 18, along with support groups for their parents; providing consultations and referrals for families seeking support; and educating the community about the emotional needs of children faced with the challenges associated with having a seriously ill family member.

Our project was funded under the mental health program priority; this program is also related to the subject of palliative care/hospice.

Although both the Director of Michigan Department of Community Health (Janet Olszewski) and the State Title V Director (Douglas Paterson) were informed of our plans to implement the TLC program and they expressed their support of this initiative, we did not work closely with our state Title V MCH program on this project.

2. Goals and Objectives

The first goal was to develop and implement support services for children and their families coping with the life-threatening illness (LTI) of a family member. Objectives included developing partnerships with hospitals, hospices, and community agencies; providing an informational packet to families; offering phone consultation to families; offering informational workshops to families; providing a support group program; and making continual improvements to the program.

The second goal was to educate the community about the needs of children and families coping with the life-threatening illness (LTI) of a family

member. Objectives included developing and distributing informational materials to the community; making presentations to targeted audiences; and posting information on our website about how to help children cope with a family member's life threatening illness.

Our final goal was to ensure that our TLC services are culturally sensitive and accessible to all eligible families. Objectives included developing and implementing an outreach plan; increasing the number of participants of color in the support group program; and maintaining a diverse group of volunteers.

Each of these goals supported the primary purpose of this project: to address a previously unmet need in our community by developing and implementing support services (based on the model we have used for our bereavement support group program) for children coping with the life-threatening illness of a family member.

3. Methodology

The TLC Advisory Board was established in mid-2004, and the members have been instrumental in helping Ele's Place develop relationships with key community resources. They have also provided valuable advice about the needs and challenges faced by families coping with a life-threatening illness, and we have used their input to adjust our goals and expectations for the TLC program. In addition, the Advisory Board has assisted with developing informational materials; arranging for speaking opportunities; networking with community organizations; and recruiting volunteers.

Based on input we received from several families who had participated in our bereavement support group program after a parent's death, we decided the TLC support groups should follow the same basic model as our support groups for children grieving a death, using similar activities and discussion topics to help the children express their feelings and develop healthy coping skills.

Because we realized that families coping with a life-threatening illness have many demands on their time, we initially offered our TLC support groups on a bi-weekly basis (rather than weekly, as is the case with our bereavement groups). Participating families have told us that this frequency works well for them, and we continue to hold the TLC groups once every two weeks.

Ele's Place staff has also developed educational materials for families, school personnel and medical professionals; offered workshops and speaking presentations; and worked with our volunteers to promote the TLC program through our ongoing community outreach initiatives.

Our TLC support groups are led primarily by trained volunteers, keeping costs down. Initially, we recruited experienced bereavement support group facilitators to work with the TLC children's groups, to help ensure these groups would get off to a strong and effective start. (The parent groups are facilitated by social workers or other clinicians, who are paid for their time and expertise.) Now, we use a mix of experienced and newly trained volunteer facilitators to lead the children's groups, and this has worked well.

The TLC program offered by Ele's Place is unique in our state of Michigan, and it is one of only a very few services in the country addressing the

needs of children who are coping with the stresses of living with a family member's life threatening illness. Most existing services for children target the hospice population, when a death is imminent, and are thus designed to help children prepare for a death, rather than offering support during the time that the family is coping with the diagnosis and treatment, and all the changes and stresses that accompany a very serious illness.

4. Evaluation

Records have been kept of the number of people served in the support group program, as well as through telephone consultation and education/outreach activities. Families who have participated in the TLC support group program have been asked to complete periodic and exit surveys assessing their satisfaction with the program, and the results from these surveys are used to help us determine if modifications are needed to better serve the needs of those seeking our support. Although these satisfaction surveys have been the primary evaluation tool used to assess the strengths and benefits of the TLC groups, we have also asked participants to complete self-assessments at enrollment.

The consistently positive results from these surveys confirm that we are achieving our goal to provide meaningful support for children and families who are coping with a family member's life-threatening illness.

5. Results/Outcomes (Positive & Negative)

Ele's Place began offering the TLC support groups in December 2004, with 6 families participating. In the final year of the grant (3/1/08 – 2/28/09), 114 family members participated in the support group program: 51 adults and 63 children.

As of the end of the five-year grant period, a total of 266 family members – 116 adults and 150 children in 85 families – have participated in the groups. The racial/ethnic identification of participants is as follows:

African American	6 (2.3%)
Caucasian	219 (82.3%)
Hispanic	7 (2.6%)
Multi-racial	30 (11.3%)
Native American	1 (0.4%)
Not reported	3 (1.1%)

The racial/ethnicity demographics of the program participants are similar to the demographics for the population in the market area we serve.

In addition to the support group program, information and consultation contacts over the phone about the TLC program have totaled 583 during the five-year grant period. We have mailed 337 information packets to families considering participation in the TLC program. It is significant to note that in a sizable number of these situations (at least 25%) the ill person died before the

family could enroll in the TLC groups, and consequently, the family ended up participating in our bereavement support group program.

Dozens of presentations to medical professionals and other community members have been made over the past five years. During the past year (3/1/08 – 2/29/09), we made 23 presentations specifically about the TLC program and the needs of children coping with a family member's serious illness. Another 17 general presentations about Ele's Place were made during this time period, and each of these included information about TLC services as well. As part of our effort to educate the community about how to support children and families coping with a life-threatening illness, our staff developed new brochures, book lists, and informational handouts (see #6 for a list of these products).

Based on the feedback we have received from TLC participants and from our community partners, we believe that our TLC program is a valuable and worthwhile asset, filling a need that is not met by any other programs or services in the area. Parents report that they are able to talk about the illness with their children more readily after attending the TLC program, and children report feeling less alone and more willing to express their feelings. Many of the TLC families who have experienced the death of the family member who was ill have transitioned to our bereavement support group program, which indicates they feel the support they are receiving from Ele's Place is important to them.

When we developed our plans for the TLC program, we had estimated that within five years, we would annually serve 120 children, plus their parents, in the TLC support groups. Our actual numbers are just over half that amount. We

have learned that families with a seriously ill family member are faced with significant barriers to seeking support, much more so than we had expected. These families are coping with additional demands on their time and resources as a result of the illness. On a different level, they are also coping with trying to balance their family's need for normalcy and for hope with their need for extra support. Despite the fact that our emphasis is on living with a life-threatening illness, not coping with a terminal illness or preparing for death, some families have shared that they feel attending the TLC program would mean they are giving up hope. This attitude may be partially influenced by the fact that Ele's Place is well known as a resource for bereavement support. However, the informational sessions that we have held with medical professionals in the local hospital have resulted in some increases in the number of referrals to our program. We will need to continue to commit resources to outreach, education, and marketing.

6. Publications and Products

Ele's Place created the following products as resources for families and community members:

- TLC brochure – description of services provided, eligibility, and other basic information about this program
- Book lists for children, teens, and parents – books for various age groups about coping with a family member's illness, living with a life-threatening illness, and related topics

- Helping a Child Cope with a Family Member’s Life Threatening Illness – tips written by Ele’s Place social workers for parents, teachers, and others who work with children
- Tips for Medical Professionals - “Talking With Children About the Life-Threatening Illness of a Family Member”
- Tips for School Administrators and Teachers – “Helping Students Cope With the Life-Threatening Illness of a Family Member
- Therapist Referral List for Families Dealing with a Life-Threatening Illness
- Together Learning to Cope Program Activities Manual (activities for TLC children’s groups)
- Websites for Families and Children on Coping with Life-Threatening Illnesses
- “Anticipatory Grief – a Family in Crisis” – PowerPoint presentation for Grand Rounds at Lansing’s Sparrow Hospital, October 2008 (similar versions of this presentation have been made to other groups during the grant period)
- “What About Me? Well Children Need Support Too!” – PowerPoint presentation to the Foglio conference on Spirituality and Medicine, East Lansing, October 2008
- TLC Family Bulletin – newsletter with general information, reminders, and updates for all families enrolled in the TLC support groups (published two times/year)

- Ele's Place "Heart to Heart" newsletter – articles related to the TLC program:
 - December 2004 cover story – "Supporting Kids Before and After a Death"
 - March 2005 TLC story – "What does the new TLC program have to do with grief?"
 - September 2005 – "TLC Program One Year Old"
 - December 2005 cover story – "We All Need Help"
 - March 2008 cover story – "Teresa's Story"

We have also created the following products/publications, primarily for internal use, as part of this project:

- Guidelines for Ele's Place Staff: Responding to requests for information about helping children cope with the life-threatening illness of a family member
- Surveys used as part of our evaluation system:
 - Adolescent/Child Self-Evaluation – completed by older children and teens at enrollment or during the first night at TLC
 - Parent/Caregiver Rating of Child's Adjustment at Opening – completed by parents for each child they bring to the TLC program
 - Facilitator Rating of Child's Adjustment at Opening – completed by the support group facilitators for each new child in their group
 - TLC Family Survey – periodic survey administered to all parents/caregivers enrolled in the TLC program two times per year

- TLC Program Satisfaction Survey – parents are asked to complete this when their family ends their participation in the TLC support groups

We also developed enrollment forms for families and Ele's Place staff to complete when a family begins participating in the TLC program, along with various record-keeping forms (lists of group members, support group facilitator attendance records, etc.).

Copies of most of the items listed here can be found in the Appendices.

7. Dissemination/Utilization of Results

Ele's Place staff members have shared information, brochures, handouts, etc. related to this project with other professionals who work with grieving children each time we attend the National Alliance for Grieving Children Annual Symposium. We have also shared information about our TLC program with other children's grief programs in Michigan via our periodic networking meetings.

The number of participants in the TLC program is one of the statistics provided to donors, volunteers and other supporters in the annual report we have published for the past three years.

8. Future Plans/Follow-up

Since Ele's Place began offering support services for children who are coping with a family member's life-threatening illness, we have been able to witness how these children benefit from their participation in our TLC support

groups. Although the numbers of families who have attended the TLC program has not been as great as we had hoped it would be, we still know that the families who do participate find it to be a very worthwhile and helpful experience.

Ele's Place plans to continue to provide our TLC support groups at no cost to participants on an ongoing basis. In addition, we will continue to promote the availability of this program through our outreach to medical professionals and others in the position to refer families.

Funding for the TLC program will come primarily from the donations and grants we receive for our programming in general. To ensure financial support for all of our programs on a long-term basis, Ele's Place has implemented specific, comprehensive plans to develop and sustain relationships with individual and corporate donors. These plans are based on following a nationally recognized, sustainable fundraising model which focuses on building relationships with donors and securing multi-year pledges. In addition, we have established an endowment fund with our local Capital Region Community Foundation to help ensure our long-term financial stability.

Certainly, the current economic climate is of concern to us, because some of our major donors have suspended making their pledge payments. However, Ele's Place has always received strong support from our community, in large part due to the excellent reputation we have for making a significant and positive difference in the lives of grieving children, and we are hopeful that this support will continue.

Fortunately, the TLC program relies heavily on the in-kind contributions of time, knowledge and energy from our volunteers, including the Advisory Board members, TLC support group facilitators, and outreach ambassadors, and we can count on this support continuing.

In the short-term, this project (developing and implementing support services for families coping with a serious illness) and the federal grant we received to support this initiative have been very successful. Ele's Place has been able to expand our services to address a previously unmet need, and we have educated many medical professionals and others about the importance of providing appropriate emotional support to the well children in a family when one of the family members is seriously ill.

We have also strengthened our relationships with the medical community through the community outreach and education that has been an important part of this project.

While the long-term impact of this project is not fully known yet, we believe we have made significant progress in helping the community better understand just how devastating a family member's life-threatening illness can be for the well children in the family, and how important it is to provide appropriate emotional support for these children during this challenging time. The families that have participated in our TLC program have consistently told us that, as a result of attending our support groups, their children are better able to cope with their often overwhelming feelings and all of the changes they must face due to their

family member's illness. We have been gratified by these endorsements of our work, and look forward to continuing to serve children and families in this way.

ANNOTATION:

The TLC Program at Ele's Place provides emotional support services for children ages 3 – 18 (and their families) who are coping with the life-threatening illness of a family member. Prior to the development of this program, there were no options in our community for children to receive the support they need to help them deal with the worries, fears and anxiety, along with the feelings of isolation and confusion, that resulted from a family member's serious diagnosis and illness. Through the TLC support groups, children facing these tremendous challenges have the opportunity to share their feelings with peers in similar situations, thus reducing their sense of isolation and despair. In addition, through carefully designed activities and discussions, they learn how to express and cope with their feelings. As a result, these children are less apt to have behavioral problems at home or school, and they are more apt to share their concerns with their parents. As a part of this project, Ele's Place developed a variety of materials for families, health care providers, educators and others to help them provide more effective support for children coping with a family member's life-threatening illness.

KEY WORDS:

Anticipatory grief; Adolescents; Bereavement; Caregivers; Children; Cultural Diversity; Cultural Sensitivity; Depression; Emotional Support; Families; Family Support Services; Grief; Life-threatening Illness; Mental Health; Peer Support Programs; Stress; and Support Groups

APPENDICES:

ELE'S PLACE

RECOMMENDED BOOKS FOR CHILDREN WHO ARE COPING WITH THE LIFE-THREATENING ILLNESS OF A FAMILY MEMBER

AFRAID TO ASK: A Book for Families to Share About Cancer by Judylaine Fine: Provides good information and opportunities to talk together about what to expect when a family member has cancer. All ages.

ANOTHER LOOK AT THE RAINBOW by The Center for Attitudinal Healing: Children age 6 – 21 talk about living with a terminally ill sibling. All ages.

BE A FRIEND – Children Who Live With AIDS Speak by Wiener, Best & Pizzo, et al: Children with HIV or AIDS share their hopes and fears. All ages.

THE “C” WORD – Teenagers and Their Families Living With Cancer by Elena Dorfman: Photo essays of five teenagers living with cancer. Ages 12 and up.

CANCER IN THE FAMILY: Helping Children Cope With a Parent’s Illness by Sue P. Heiney, Joan F. Hermann, Katherine V. Bruss, and Joy L. Fincannon: A guide for parents published by the American Cancer Society; includes a workbook for children.

FOREVER IN MY HEART by Jennifer Levine: A story/workbook to help children understand and express their feelings when a parent is dying. Ages 5 – 12.

I WILL SING LIFE by L. Berger and D. Lithwick: Inspiring stories and poems from children living with life-threatening illness. Ages 8 and up.

KEMO SHARK by Charles N. Center: A booklet explaining chemotherapy to young children. Ages 4 – 10.

MOMMY’S IN THE HOSPITAL AGAIN by Caroline Stearns Parkinson

MOMS DON’T GET SICK by Pat Brack: Describes how all family members are affected when the mother is very sick.

MY BOOK FOR KIDS WITH CANCER by Jason Gaes: The story of an 8-year-old who successfully battles cancer. Ages 7 – 12.

MY DADDY’S CANCER: An Interactive Book for Children by Cindy Klein Cohen: Answers children’s questions. Ages 3 and up.

MY MOMMY HAS CANCER by Caroline Stearns Parkinson

MY STUPID ILLNESS by Katy Tartakoff: A photo-journal to be completed by a child with a life-threatening illness. All ages.

OUR FAMILY HAS CANCER, TOO! By Christine Clifford: Interactive pages that encourage children to ask questions. Ages 7 – 12.

OUR MOM HAS CANCER by Abigail and Adrienne Ackermann: Two sisters share their personal experience. Published by the American Cancer Society. Ages 5 – 9.

PAPER CHAIN by Claire Blake et al: Focus on children's coping. Ages 3 - 8

SAMMY'S MOMMY HAS CANCER by Sherry Kohlenberg: Shows the changes that occur when someone is sick and how family members can help each other. Ages 3 – 8.

WHAT ABOUT ME? When Brothers and Sisters Get Sick by Alan Peterkin: Reassuring to children coping with a sibling's illness. Ages 5 – 10.

WHEN A PARENT HAS CANCER: A Guide to Caring for Your Children by Wendy S. Harpham: A helpful resource for parents that also includes *Becky and the Worry Cup*, an illustrated children's book.

WHEN A PARENT IS VERY SICK by Eda LeShan: Helpful for children and parents. Age 8 – 13.

WHEN ERIC'S MOM FOUGHT CANCER by Judith Vigna: A story of hope.

WHEN MOMMY IS SICK by Ferne Sherkin-Langer: A supportive book for children coping with a parent's illness. Ages 4 – 9.

WHEN SOMEONE HAS A VERY SERIOUS ILLNESS by Marge Heegaard: A workbook to help children understand their feelings. Ages 5 – 12.

WHEN SOMEONE IS VERY SICK by Jim and Jane Boulden: An activity book for kids ages 6 – 12.

WHY ME? Coping With Family Illness by Ann Kosef and F. Watts: Interviews and stories of young people coping with serious illness, either their own or in their family.

THE YEAR MY MOTHER WAS BALD by Ann Speltz: Covers an understanding of cancer and its treatment as well as the feelings children have when their parent is ill. Age 8 – 13.

ELE'S PLACE

RECOMMENDED BOOKS FOR TEENS WHO ARE COPING WITH THE LIFE-THREATENING ILLNESS OF A FAMILY MEMBER

AFRAID TO ASK: A Book for Families to Share About Cancer by Judylaine Fine: Provides good information and opportunities to talk together about what to expect when a family member has cancer. All ages.

BREAST CANCER: Questions and Answers for Young Women by Carole G. Vogel: Excellent information about breast cancer and related issues for adolescent girls.

THE "C" WORD – Teenagers and Their Families Living With Cancer by Elena Dorfman: Photo essays of five teenagers living with cancer. Ages 12 and up.

COPING WHEN A PARENT HAS AIDS by Barbara Hermie-Draimin: Honest information about what to expect. Ages 12 and up.

ELE'S PLACE

RECOMMENDED BOOKS FOR PARENTS ABOUT HELPING CHILDREN COPE WITH THE LIFE-THREATENING ILLNESS OF A FAMILY MEMBER

CANCER IN THE FAMILY: Helping Children Cope with a Parent's Illness by Sue P. Heiney, Joan F. Hermann, Katherine V. Bruss, and Joy L. Fincannon: From the American Cancer Society, a guide for parents and workbook for children.

BREAST CANCER: Common Reactions of Children and How to Help by Jane Brazy, M.D. and Mary Ircink, R.N.

CAN I STILL KISS YOU? Answering Children's Questions About Cancer by Neil Russell: Questions and answers based on the author's journal of his own experience with cancer.

HELPING YOUR CHILD HANDLE STRESS by Katherine Kersey: Practical advice for parents to help children cope with stress.

HOW TO HELP CHILDREN THROUGH A PARENT'S SERIOUS ILLNESS by Kathleen McCue: A supportive and practical guide to children's special needs when a parent is seriously ill or dying.

HOW TO SUPPORT YOUR CHILDREN WHEN SOMEONE THEY LOVE HAS CANCER: Sharing the News and Helping Them Understand: Chapter 9 in *When Life Become Precious* by Elise NeeDell Babcock.

MOMS DON'T GET SICK by Pat Brack with Ben Brack: The author describes her reactions to the diagnosis and treatment of breast cancer. Comments by her 10-year-old son are included.

PARENTING THROUGH CRISIS: Helping Kids in Times of Loss, Grief and Change by Barbara Coloroso

WHEN A PARENT HAS CANCER: A Guide to Caring for Your Children by Wendy Harpham: This comprehensive guide for parents, written by a cancer survivor, includes a children's book.

WHEN SOMEONE IN YOUR FAMILY HAS A SERIOUS DISEASE by Sally Dunning: A guide for adults who want to help children cope with a family member's illness. Available from Arbor Hospice in Ann Arbor; call 734 662-5999.



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Helping a child cope with a family member's life-threatening illness

Communicate Honestly

- Understand that everyone in a family will be affected by the life-threatening illness of a family member.
- Communicate honestly and clearly with children about the diagnosis, using age-appropriate language.
- Reassure children that they did not cause the illness.
- When appropriate, explain the treatment and possible side effects to help children anticipate and prepare for these experiences.
- Before taking a child to the hospital to visit the ill person, talk with the child about what they will see. Describe the way the person will look and what kind of equipment is being used.
- If a child can't or won't see the ill person, encourage other ways of maintaining contact or communication, such as letter writing, pictures, etc.

Understand Their Feelings

- Children will have many different feelings – accept and acknowledge their feelings, and help them find safe outlets.
- Feelings of anger, jealousy, worry, and guilt are common. At times children may seem very self-centered – give them extra attention and reassurance whenever possible.
- Understand that children may tell us more about their feelings through their behavior than with words. Your child may not know what he or she is feeling, or may not be able to put the feelings into words.
- Understand that misbehavior may be a response to the stresses created by the illness in the family. Try to address the feelings underlying the behavior while setting appropriate limits on unacceptable behavior.

Limit Unnecessary Changes

- Maintain normal rules and expectations for behavior; this helps children feel more secure in the midst of confusing changes.
- Keep routines as normal as possible. Prepare children for any anticipated changes in the family routines and schedules.

- When routines must be disrupted, offer children choices whenever possible.
- Find ways for children to help, but be cautious about expecting too much responsibility.

Seek Support

- Communicate with school personnel and caregivers about the illness in the family, including what the children have been told and how to respond to their questions.
- Seek out support for yourself and your family. Many people want to help, but don't know what to do until they're asked. It's OK to ask for what you need.
- Take time for yourself. You are probably being pulled in many different directions, but you will not be able to help your children if you don't find ways to take a break and "recharge your batteries."

Please call Ele's Place at (517) 482-1315 if you have any questions about this information, or you would like information about our Together Learning to Cope program for families dealing with a life-threatening illness.

Talking With Children About the Life-Threatening Illness of a Family Member

Tips for Medical Professionals

A life-threatening illness impacts not just the patient, but everyone in his or her family, including children. Adults in the family may be preoccupied, irritable, anxious and impatient. Family roles and routines often change, and resources may be stretched thin. During such times of family crisis, children need more attention, support and understanding within their family, but the family is often so focused on meeting the needs of the patient, that it becomes very difficult to know how to help the children as well.

Children may have many questions and concerns about the illness, but they often have difficulty expressing them and may not ask directly. The most common themes are these:

1. Did I make this happen? Is this my fault?
2. Will I get sick, too?
3. Who will take care of me? How will this affect me?

Honest information, conveyed in an age-appropriate manner, can help children cope more effectively with the stress and worry caused by the serious illness of a family member. The following guidelines are suggested for medical professionals:

- Ask the child to tell you what they know about the illness. This will give you a baseline for discussion, and will allow you to correct any misunderstandings.
- Respect children's ability to handle honesty. They want to know what is happening, and need to have that information in order to make sense out of the changes they see happening. Use the name of the disease and avoid euphemisms.
- Keep explanations simple, using age-appropriate language; do not overwhelm a child with too much information.
- Reassure the child that their thoughts, words or actions did not cause the illness.
- If the illness is not contagious, reassure the child that he or she cannot "catch" it from the sick family member. If there is a threat of contagion, let the child know what can be done to protect him or her.
- Give general information about the expected treatment and side effects that may impact the child.
- Be prepared for questions about whether the person who is sick will die. Encourage realistic hope but do not make false promises.
- Show interest and concern about how the child is doing. Acknowledge that this may be a difficult time for the child, and ask about their worries and questions.
- Help the parent identify and access supportive services and information. Ele's Place has information and workshops for parents on how to help their child cope with the life-threatening illness of a family member.



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Helping Students Cope With the Life-Threatening Illness

of a Family Member

Tips for School Administrators and Teachers

The diagnosis of a life-threatening illness affects not only the person who is ill, but has a ripple effect that impacts their immediate family members, extended family, friends, and colleagues. Children with a seriously ill family member are coping with a multitude of challenges in almost every area of their functioning – emotional, social, cognitive, physical, and spiritual. Children need the support of caring adults to help them navigate this new territory; teachers, school counselors, and other educators are in a unique position to help them.

Ideally, parents and educators can function as partners in the child's education and well-being at school. The following suggestions are intended to provide some guidance in being a helpful resource for children and their families.

Communicate with parents

- If you notice significant changes in a child's behavior or school performance, contact the parent and inquire about any circumstances that might be affecting the child.
- If a parent notifies you that a family member has been diagnosed with a life-threatening illness, try to meet with the parent in person to discuss their situation and their child's needs.
- Learn what the child has been told, and what information the parent is willing to have shared with other school personnel and/or students.
- Inquire about any changes the parent has noticed in the child's functioning, and any concerns the parent has about the child.
- Share your observations of the child, and discuss how best to handle any problems or concerns that arise at school.
- Ask the parent to keep you informed, and/or ask if they would mind if you contacted them periodically.

Be supportive to the student

- When appropriate, include the child in your meeting with the parent.
- Invite the child to talk with you if needed – then be available and practice active listening skills if the child seeks you out.
- Work with the child to develop a plan for addressing problems or concerns.
- Maintain normal rules and routines, being careful not to single the child out for special treatment, but allowing some flexibility to meet his or her needs.
- Be sensitive to material in the curriculum and the classroom that may impact the child, and help the class to process these issues thoughtfully.



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**Cover Story from March 2008 edition of Ele's Place "Heart to Heart"
Newsletter**

- How the TLC Program Helped One Family

Teresa's Story

On March 31, 2007, our son Michael was diagnosed with Leukemia. We were devastated. It was very hard not only on my husband and me, but on our other children as well. The children knew something was wrong when I did not come home from the hospital on the day Michael was diagnosed. Their aunt explained to them that Michael was very sick and had cancer. The "C" word was very scary to our family because Grandpa and several family members died due to cancer in the last couple of years. They thought Michael would die just like they did. My son Joey said, "I felt bad because Michael was too young, only four years old."

Over the next month, the children were bounced around to various family members because my husband and I were at the hospital all the time. Looking back, that month was a blur. I operated on autopilot. I had to write everything down in order to remember what I needed to do each day.

The hospital gave us information about Ele's Place. I had heard about Ele's Place when they first opened and thought, "Oh, what a great place," but I had no idea they offered programs for families with a sick family member. I was relieved that we were able to get into Ele's Place as quick as we did. I knew my children's lives were turned upside down and eventually it was going to hit them.

Ele's Place has helped Michael's siblings deal with his illness by talking and doing activities to help them express their feelings. At Ele's Place, they are around their peers who feel the same way and that helps them. Now that Michael has been going through treatment and the children know he will be okay, they are starting to think he is spoiled. I try to help them understand and Ele's Place helps with that, too. When Michael gets extra attention or is having mood swings due to the steroids, the children are able to go to Ele's Place, express their frustration, and know they are not alone in feeling that way.

To know there is a place like Ele's Place gives me some peace of mind. Even though parents are consumed with sick children and the payment of medical bills, they still worry about the welfare of the other children. Our insurance company would not pay for the costs of therapy and counseling, and I wondered how we were going to afford all of this. To know there is a no cost support program like Ele's Place, not only for children but also the parents, helps tremendously.

My children love Ele's Place. On Friday nights, they say, "Come on! Come on! We want to go to Ele's Place!" The people there are so nice, warm, welcoming, and understanding. You can say you hate your doctors or whatever is bothering

you and let it go. I strongly recommend Ele's Place for anybody that is suffering like my family was.