



CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope



What About us?: Children and Teens Living with Cancer in the Family

Sara Goldberger, LCSW-R
and
Vicki Kennedy, LCSW

Why Focus on Children, Teens and Their Families?



Each year in the US,
approx. 12,000 children
and teens younger than
19 are diagnosed with
cancer.
(2007 NCI SEER data)



But...

“Almost one quarter of adults with cancer in the U.S. are estimated to be parenting children under 18.”*

**NCI: Division of Cancer Control and Population, National Health Interview Survey (2008)*





Research Shows

- ❖ Children are at risk of developing psychological disturbance
- ❖ Parents avoid communication with children
- ❖ Parents need support when dealing with their children
- ❖ Children do have more potential to understand complex issues of illness than previously thought
- ❖ Parents under report children's distress and somatic symptoms



Coming Attractions

- ❖ Developmental view of children's understanding of cancer and death
- ❖ Common reactions and behaviors of children when cancer is in the family
- ❖ Family coping style considerations
- ❖ CSC's approach to meeting the needs of children teens and their families



Ages 6-8

Understanding of Cancer and Death

- ❖ Confusion about cancer facts
- ❖ Worry about immediate future
- ❖ Magical thinking
- ❖ Beginning to understand the permanence of death



Ages 6-8

Common Reactions/Behaviors

- ❖ Regression
- ❖ Heightened anxiety
- ❖ Questions about physical aspects of illness or death
- ❖ Expression of anger if routines are disrupted
- ❖ Feelings of guilt or anger



Ages 9-12

- Understanding of Cancer and Death


- ❖ Intellectual understanding of the meaning and impact of illness and the reality of death
- ❖ Understanding that death is inevitable
- ❖ Meaning of illness or death is centered on how it affects the child



Ages 9-12

Common Reactions/Behaviors

- ❖ May try to hide feelings
- ❖ May focus on how illness/death disrupts their life
- ❖ May fear others will become sick
- ❖ Commonly express fear and sadness as anger
- ❖ May blame themselves for illness or death



Adolescence

Understanding of Illness and Death

- ❖ Capable of thinking abstractly about illness, death and the meaning of life
- ❖ Understands many of the scientific details of illness and death



Adolescence

Common Reactions/Behaviors

- ❖ May struggle to be independent yet remain close to parent
- ❖ May not outwardly express feelings
- ❖ May direct anger towards family members



• Psychosocial Factors to Consider

- ❖ Family style of coping
- ❖ Family style of communication
- ❖ Child's relationship with the parent who is ill
- ❖ Pre existing family issues
- ❖ Previous experiences with illness or death



Psychosocial Factors to Consider (cont.)

- ❖ Cultural beliefs
- ❖ Home environment
- ❖ Cognitive ability
- ❖ Capacity to verbalize feelings
- ❖ Child's temperament



Cancer Support Community

Meeting the needs of Children and Teens

❖ Group Loop™



❖ Kid Support™



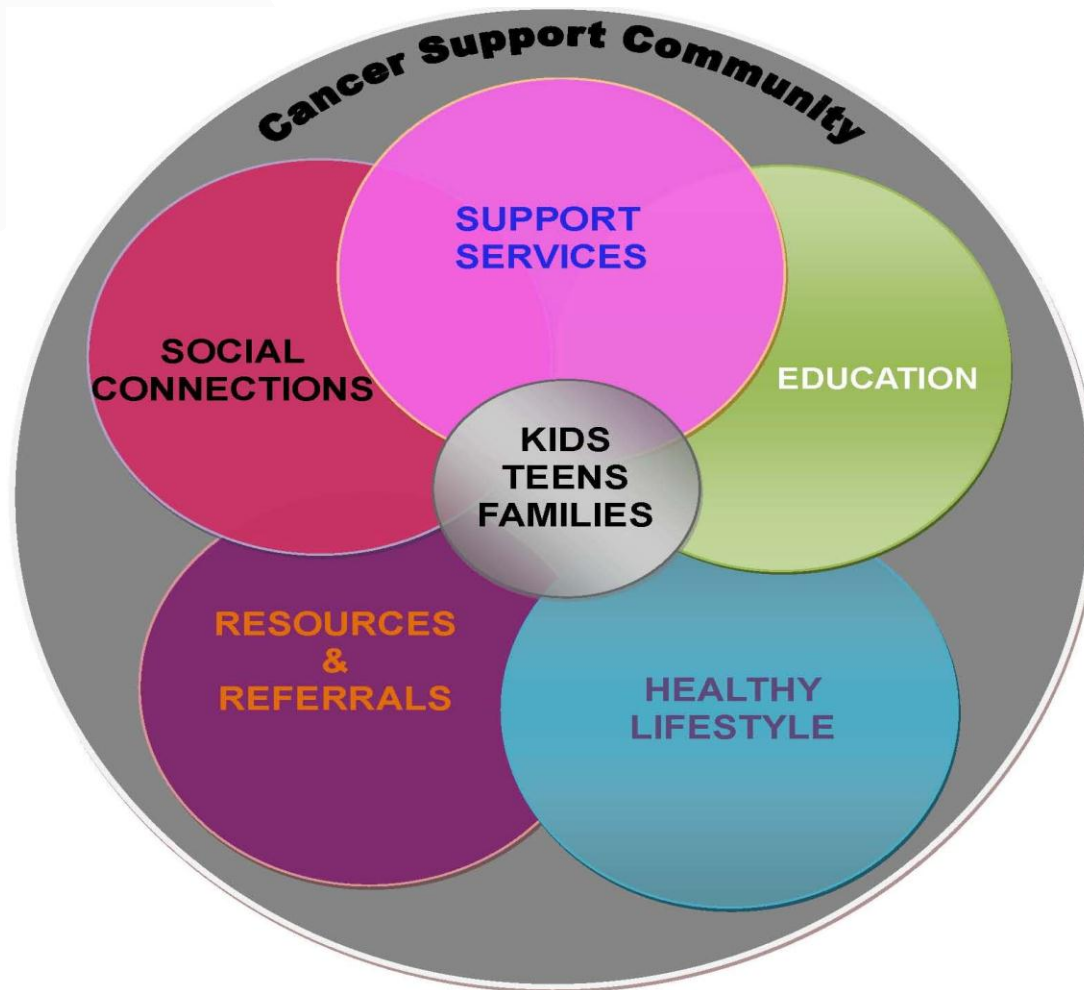


Cancer Support Community Children Teen & Family Initiatives

• CTF Program Goals:

- ❖ Increase the number of families with children participating in CSC program.
- ❖ Educate and empower children and teens with age-appropriate information about cancer and its treatment.
- ❖ Reduce parental concern around communication related to cancer and cancer treatment.
- ❖ Reduce isolation of teens and children by providing sustaining community of support

Children Teen & Family Initiatives





Group Loop ~ The Need

- ❖ AYA programs are often geared to those 13-35
- ❖ AYA programs often include adult survivors of childhood cancer
- ❖ Data shows that teens with cancer report feeling socially isolated from their peers

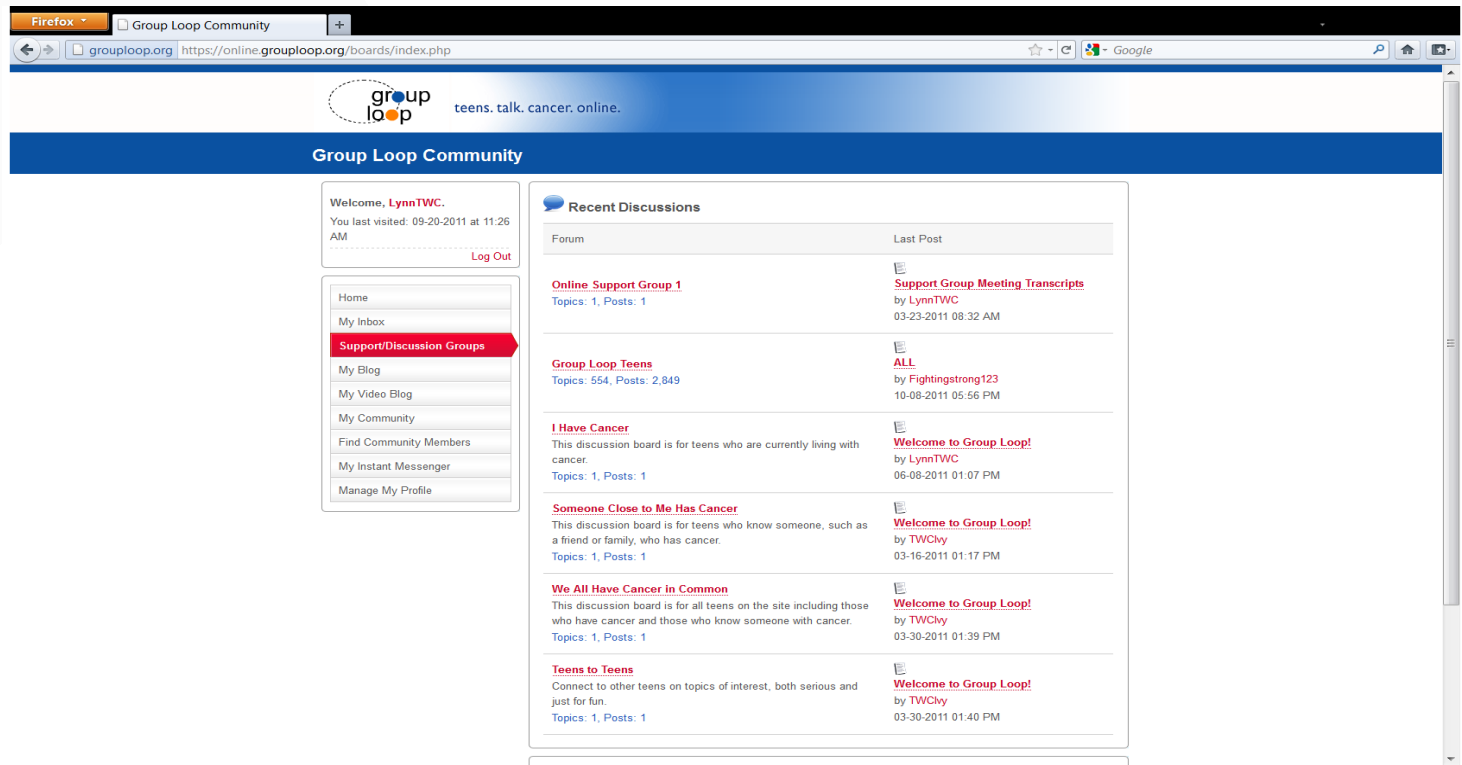
The Solution

teens. talk. cancer. online.

www.grouploop.org



My Group Loop



The screenshot shows the Group Loop Community website. The browser window has a single tab titled "Group Loop Community" with the address bar showing "https://online.grouploop.org/boards/index.php". The website header features the "group loop" logo and the tagline "teens. talk. cancer. online." Below this is a blue navigation bar with the text "Group Loop Community".

On the left side, there is a sidebar with a "Welcome, LynnTWC." message and a "Log Out" link. Below this is a menu with options: Home, My Inbox, **Support/Discussion Groups** (highlighted in red), My Blog, My Video Blog, My Community, Find Community Members, My Instant Messenger, and Manage My Profile.

The main content area is titled "Recent Discussions" and contains a table with two columns: "Forum" and "Last Post".

Forum	Last Post
Online Support Group 1 Topics: 1, Posts: 1	Support Group Meeting Transcripts by LynnTWC 03-23-2011 08:32 AM
Group Loop Teens Topics: 554, Posts: 2,849	ALL by Fightingstrong123 10-08-2011 05:56 PM
I Have Cancer This discussion board is for teens who are currently living with cancer. Topics: 1, Posts: 1	Welcome to Group Loop! by LynnTWC 06-08-2011 01:07 PM
Someone Close to Me Has Cancer This discussion board is for teens who know someone, such as a friend or family, who has cancer. Topics: 1, Posts: 1	Welcome to Group Loop! by TWClvy 03-16-2011 01:17 PM
We All Have Cancer in Common This discussion board is for all teens on the site including those who have cancer and those who know someone with cancer. Topics: 1, Posts: 1	Welcome to Group Loop! by TWClvy 03-30-2011 01:39 PM
Teens to Teens Connect to other teens on topics of interest, both serious and just for fun. Topics: 1, Posts: 1	Welcome to Group Loop! by TWClvy 03-30-2011 01:40 PM



What the Teens are Saying

- ❖ 63% report talking to other teens is the #1 reason they log on
- ❖ 89% reported discussion boards are their favorite part of the site
- ❖ 96% feel GL is a safe site



Kid Support™

Program Goals

- ❖ Reduce stress of cancer in the family by providing support and teaching skills
- ❖ Strengthen the family bond by enhancing communication about cancer
- ❖ Improve age-appropriate knowledge of basic cancer concepts

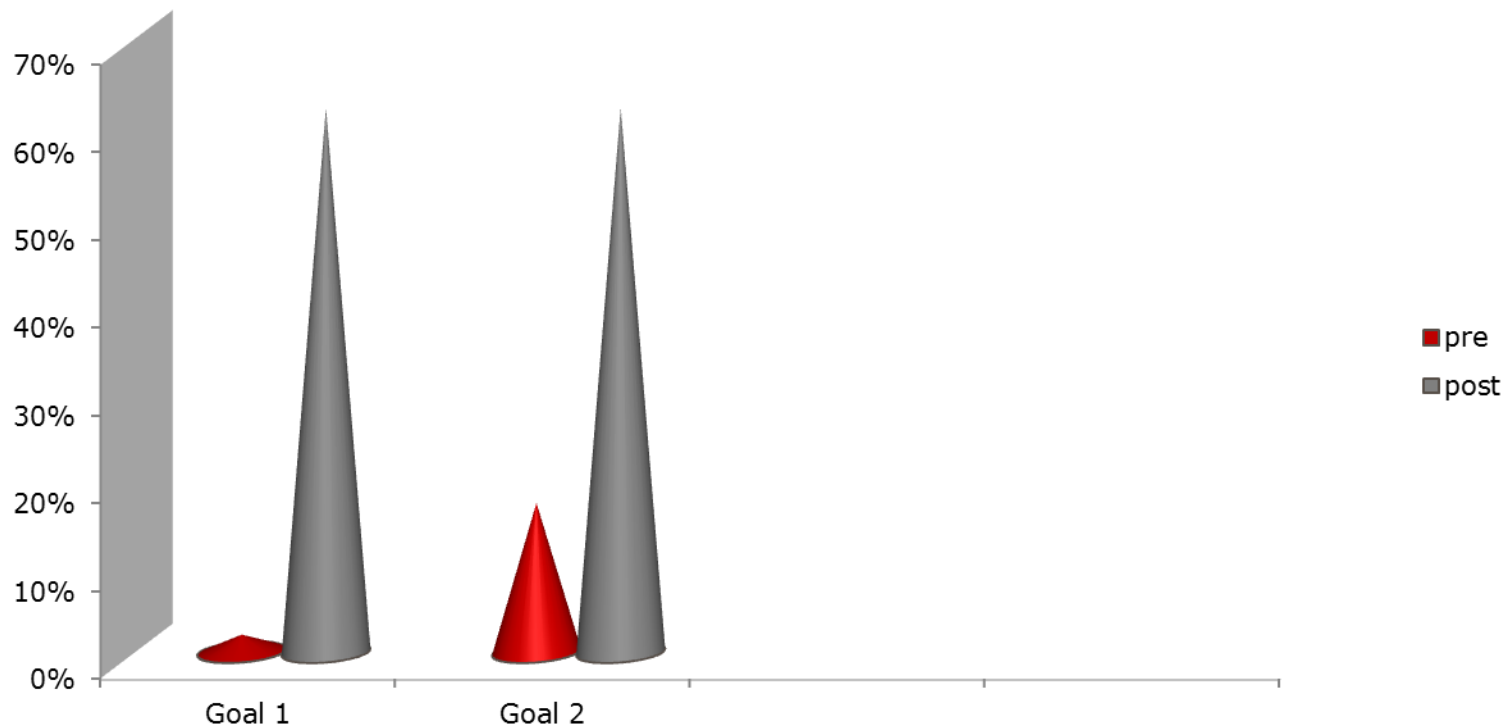


Kid Support Sessions

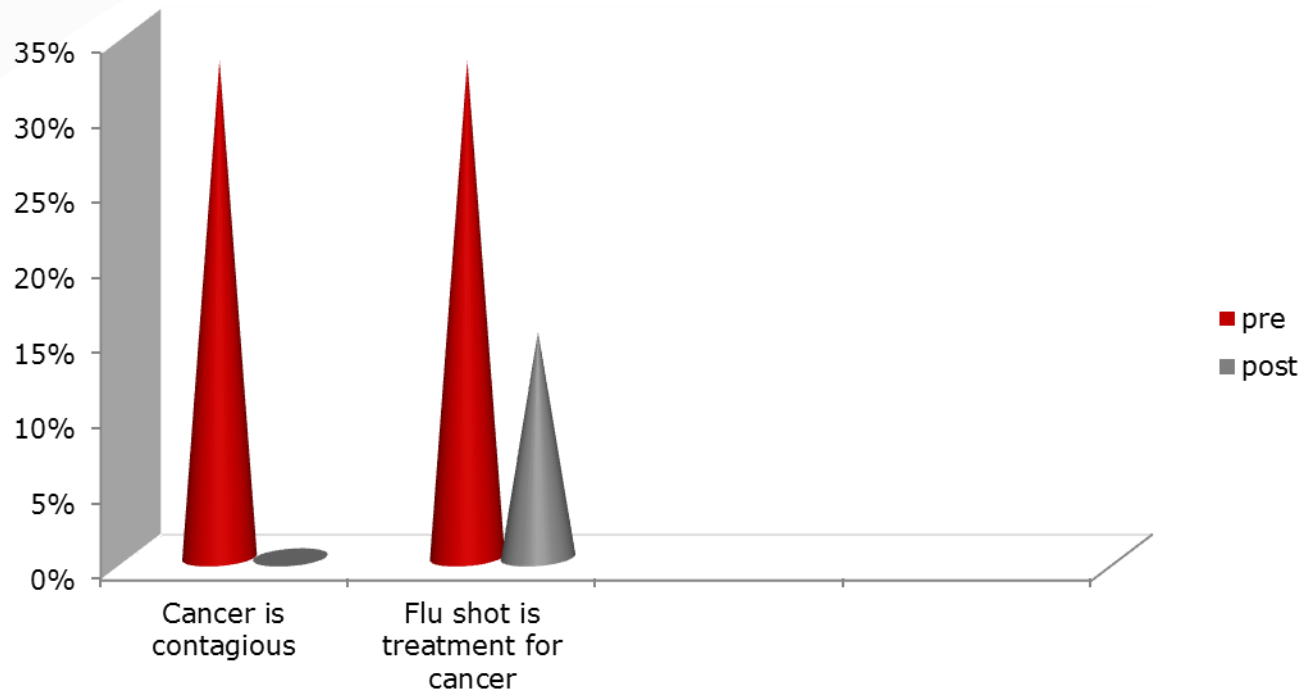
1. Getting to Know each other
2. Understanding Cancer
3. Understanding Feelings
4. Talking about Change
5. Learning to relax
6. Talking about Loss and Death
7. Appreciating Ourselves
8. Solving Problems
9. Putting it all Together
10. Celebrating



Kid Support Outcomes (Skills and Communication)



Kid Support Outcomes (Education)





Parent Feedback

98.6% of parents surveyed at the end of the program indicated they would recommend KS to others.

Kid Support has had a significant effect on my young daughter. At six years old it has been difficult for her to understand exactly what I am going through. She is learning so much about my cancer and, more importantly, how she can best process her emotions. One of the reasons this program is so effective is that she is learning and interacting with kids going through similar situations. The emotional connection helps her realize that she is not alone in this. It is that sense of unity that has truly benefited my daughter. It has enhanced her understanding and inner strength. I am so grateful for the positive impact the Cancer Support Community has had on me and, most importantly, my beautiful daughter.

~Jeffrey R.





Thank you!

The Freed Foundation

May and Stanley Smith Charitable Trust

The Amgen Foundation

TJX Foundation

Ann Speltz

CSC Children Teens and their Families Brain Trust:

Jen Scully

Jen Sinclair

Brian Weemhoff

Cancer Support Community Affiliates

