SURVIVAL KIT FOR FAMILIES

A tool kit to help patients/caregivers support children when someone they love has a serious illness

Special thanks to:
• Supporting Kidds
• Rosenblum Center
• The Wellness Community
• Health Psychology – HFGCC
• Cancer Care Management - HFGCC
Dear Parent/Caregiver:

Dealing with a serious illness in the family will likely bring forth many challenges. Children, regardless of age, are sensitive to any changes in normal routines and lifestyles. Often parents and/or caregivers do not know where to turn when it comes to supporting children through these experiences.

This guide is intended to help parents/caregivers have a better understanding of some of the normal reactions children experience when someone has a serious illness. Methods of helping children deal with serious illness are also provided. Information is both general and specific to developmental age.

In addition to information about serious illness we have also included a brief section about dealing with trauma. Children and adolescents who have experienced a traumatic event may have ongoing specialized and sensitive needs.

If after reading this guide parents/caregivers remain unsure of or concerned about how their children are coping, professional assistance is available. Included in this guide is a checklist of triggers to consider when evaluating whether children need help. Professional help may be found through school guidance counselors, pediatricians, private therapists/counseling agencies and spiritual or religious leaders.
# Table of Contents

**Serious Illness in the Family: Normal Reactions and Needs**

- Important reminders for parents/caregivers.................................................................4
- Important reminders for kids/adolescents .....................................................................5
- Common reactions to serious illness ..............................................................................6
- What helps people cope with serious illness .................................................................7
- Developmental considerations for reactions to serious illness .....................................8-10

**Special Circumstances**

- About children and adolescents and trauma ...............................................................11
- When to seek professional help ....................................................................................12

**Additional Resources**

- Cancer related information ..........................................................................................13-14
- Web-site references ......................................................................................................14
- Helpful books for families ...........................................................................................15
- Other resources ............................................................................................................16
- Personal notes ...............................................................................................................17
Important Reminders for Parents/Caregivers

Points to Consider:

Tips for talking about diagnosis/prognosis:
- Talk about it early on; children are more afraid when they don’t know what is happening.
- Prepare and practice what you want to say.
- Use age appropriate language.
- Have others there for support.
- Use a calm and reassuring tone; it is okay to feel sad but you can also model coping for your child.
- Give your child time to handle their emotions; children may get upset and withdraw from the conversation. Reassure them that their feelings are normal and that the door is always open to continue the conversation when they are ready.
- Encourage your child to ask questions; even though you might not have all the answers. Reassure them that you will do your best to find answers and get back to them.
- Reassure your child that they did not cause their parents to become sick.
- Go at an easy pace so your child doesn’t become overwhelmed with too much information.
- Be honest
- Convey hope
- Seek guidance from a professional (psychologists and social workers available), especially if your child has questions about death and dying.

Preparing for change:
- Discuss how family roles may change and what will remain the same.
- Prepare your children about what to expect regarding side effects of treatment. Hair loss, nausea, and other physical changes will be less scary if they are explained in advance and understood as part of treatment.
- Reassure your child that even though you might behave differently (e.g. need more rest, etc.) you still love them.

Staying connected to your child:
- If you are in the hospital stay connected through notes, letters, cards or calls to each other.
- At home, you may not be able to do what you used to with your child, but stay connected through alternate forms of affection (e.g. if you can’t carry or hold your child, hug them or situate yourself close to them) and activity (e.g. if you can’t run around with your child, engage in a less energy consuming activity).
- Allowing your children to help you (with age appropriate tasks) will help them feel connected as well. Remind your children that you appreciate their help, but that it also helps you to see them having fun and just being a kid.
- Remind your child that you are always available to talk.
- Have family meetings to update your children or allow your child to schedule one when he/she wants to talk.
- Continually remind your children you love them.
Important Reminders for Kids & Adolescents

When Someone You Love Becomes Ill or has a Serious Injury

Most kids have strong, scary feelings: sad, mad, lonely, worried, and confused. This is a normal reaction.

Grown-ups can also have difficulty with a serious illness. They are usually so strong and smart that it is hard to see them upset and confused. But little by little, they will feel better too.

It is scary when someone close to you gets hurt or sick. You might wonder if this can happen to you, if you are safe, and who will take care of you and provide reassurance. There will always be a grown-up to take care of you. Most of us live long, healthy lives.

It is ok to ask questions about the illness/injury and all the changes that are happening. Even grown-ups might not have all the answers, but they love you and want to help.

It is natural to feel angry. You may want to scream, “Why did this happen?” “Whose fault is it?” “Why didn’t anybody do anything to prevent it?”

It is natural to feel guilty. You may worry about an argument or a time when you were so mad that you wished the person would go away. You may wonder whether something you said or did caused the illness/injury. Everyone gets mad sometimes, even people who love each other. The event is not your fault.

Don’t worry if you sometimes have fun playing ball, hanging out with friends or watching TV while going through a difficult situation. It’s ok to not feel guilty.

If you feel sad, angry, worried or lonely, it is ok. Talk to people you trust.

Talk about the person who is injured or sick. Talk about hobbies, funny things the person did, things the person taught you, how you are similar to the person, what you liked most and disliked most about the person.
Common Reactions to Serious Illness

Listed below are some common reactions experienced by children and/or adolescents:

Initial reactions to illness/injury:

Social: social withdrawal and difficulty reaching out OR increased dependency on others unrealistic expectations of others

Physical: tightness in chest or muscles diarrhea or constipation dry mouth weakness lack of energy hollow sensation in stomach appetite disturbance

Emotional: extreme emotions and mixed feelings (sadness, guilt, loneliness, anger, anxiety) numbness, flat expression explosion, withdrawal, or repression of feelings regression to previously outgrown way of expressing emotions worry feeling abandoned and confused, lost or lonely grieving the loss of what was normal

Cognitive: confusion, sense of unreality poor concentration, forgetfulness general denial or disbelief that illness/injury has occurred pre-occupation that something bad will happen

Spiritual: questioning, blaming God, doctors or others no sense of direction or future (mostly in older children)

Behavioral: sleep disturbance absentmindedness restless, over-active lack of concentration not taking care of self loss of interest in activities acting out not completing homework crying, sighing appetite disturbance
What Helps People Cope With Serious Illness

- Information
- A clear understanding of illness
- Knowing that others have been through a similar illness or event
- A high level of self-awareness about current feelings of serious illness in the family
- Understanding of the normal reactions friends/family usually have when they experience a similar illness/event
- Being able to speak openly and honestly about concerns, feelings, and ideas relating to the illness/event
- Social support from school, clergy and/or other support
- Empower to contribute to some decisions related to illness/event
- Maintaining flexibility as a result of changes in old routines, rules, and structure
Developmental Considerations for Reactions to Serious Illness

Each child and situation is different; here are some general developmental differences for children involved with serious illness.

Age 2 and Under
Common Reactions
- Increased fussiness and irritability
- Increased clinging to adults
- Regression in behaviors or skills
- Reduced interest in curious exploration of the environment
- Increased awareness of the changes of the mood and safety of the home environment

What May Help
- Ensuring that an emotionally available caregiver is present
- Maintaining normal routines to the degree possible
- Reassurance and physical affection
- Providing various comfort devices such as special blankets, stuffed animals, soothing music
- Medical play – let them play with equipment

Ages 3 – 5 years old
Common Reactions
- Feeling abandoned, fearful and lonely
- Denial of the reality of the serious illness
- Regression in behaviors and skills
- Feeling sad, but often only for short periods
- Nightmares
- Increased non-compliance or aggression
- Confusion about serious illness

What May Help
- Consistent repetition of the facts surrounding the event
- Simple explanations about what is happening (e.g. doctor appointments, physical changes)
- Someone to support them and answer questions at all times
- Accurate, honest information geared to their level of language
- Physical contact, calm, soothing tones, quiet times
- Reassurances about their future, and any other concerns
- Discussions about what the patient, caregiver can no longer do (breathe, eat, play, etc.)
- Maintaining normal routines and expectations to the degree possible
- Medical play – let them play with equipment

** Children/adolescents may switch back and forth between reactions for each age category. **
Developmental Considerations for Reactions to Serious Illness - continued

Ages 6 – 8 years old

Common Reactions
- Use thinking skills to deal with or better understand the serious illness. Ask a lot of specific questions
- Has difficulty putting concerns or feelings into words
- Identifies strongly with the person who is ill by adopting habits or roles of this individual
- Fear of being abandoned or of changes in their world
- Feeling guilty, blaming self for causing or not preventing the illness
- Compulsive care-giving: feeling responsible for the family’s future or happiness
- Body complaints such as headaches, stomachaches, restlessness, diarrhea, bedwetting
- Regression in behaviors or skills. Reverting back to behavior from an earlier age
- Fear and phobias resulting in difficulty separating, nightmares, refusal to do some activities

What May Help
- Permission to decide their own level of involvement in family activities
- A support person and role model for appropriate support
- Information and reassurances about their reactions and feelings, their responsibility for the event, their future, their safety
- Encouragement to engage in concrete daily activities (e.g. cooking, cleaning, eating)
- Encouragement to reconnect with child-oriented interests and activities
- Concrete factual information: Answers and explanations should be accurate and literal, without euphemisms
  Relate the event to any previous experiences
  Explain the illness in terms of body parts and functions (e.g. breathing, heart, brain, eyes)

Ages 9 – 12 years old

Common Reactions
- Anxiety and general fearfulness
- Covering up emotions and trying to appear normal (e.g. joking, acting tough, being cool)
- Concern about family members
- Concern about personal future and security
- Withdrawal or on the other hand, endless questions about the illness
- Body complaints such as headaches, stomachaches, restlessness, diarrhea, bedwetting
- Reverting back in behaviors or skills

What May Help
- Honest and accurate information about the illness
- Opportunities to ask their own questions
- Reassurance about their future (e.g. if the other parent were injured or became ill, who would care for them and how)
- Adults to model appropriate sharing of fears, thoughts and feelings
- Respect for privacy as required: privacy of their thoughts, feelings, writings
- Inclusion, as wished, in adult activities associated with the rituals, discussions, plans

** Children/adolescents may switch back and forth between reactions for each age category **
Adolescents

**Common Reactions**
- Symptoms of anxiety, such as body complaints, phobias, overly-cautious behavior
- Increased risk-taking or defiance (e.g. drug use, sexual activity, reckless driving)
- Fear of being singled out as different may lead them to cover up feelings and try to appear normal by joking, acting cool, pretending nothing has changed, etc.
- Concern about one’s future and security
- Interference with the developmental task of forming a sense of identity (e.g. attempting to grow up quicker rather than following their own path to self-identify)
- The naturally-occurring moodiness and defiance of teens can be intensified by the added stress of dealing with a serious illness
- Intense spiritual and philosophical questioning and doubt (e.g. wondering why bad things happen to the “good” people, angry with God)
- Teen may withdraw or become more dependent
  OR
- Teen may become more independent by distancing themselves from the family
- The normal struggle for independence may change
- Intense anger at the illness, and anger at the person who is ill. These displays may also serve to hide other feelings and to help the teen regain a sense of power and control
- Depression and guilt, accompanied by isolation or suicidal thoughts

**What May Help**
- Educating teens about the normal process of adjustment to help them see that what they are experiencing is normal, and that there are other teens in their same situation
- Honest and accurate information about the illness
- Discussion of philosophical concerns related to illness
- Highlighting the natural conflict between the normal tasks of adolescence vs. tasks of dealing with a serious illness
- Respect for the desire to keep some feelings and thoughts private
- Recognition that behavior may not accurately reflect underlying feelings (e.g. assume that the person is in pain and wants to receive information and support, regardless of the external behavior that may seem distant, disinterested, or testy)
- Communicating a tolerance for all feelings
- Providing specific coping tools (e.g. ideas for managing stress, journaling, exercising, relaxation, talking to a supportive other)
- Encouragement to focus attention and energy on teen pursuits and the future

**Children/adolescents may switch back and forth between reactions for each age category.**
Trauma involves an extraordinarily frightening event that overwhelms a person with feelings of terror and helplessness. Children who have witnessed or been involved in a traumatic illness feel totally defenseless. Their natural view of the world as a safe place is challenged.

Common Symptoms of Traumatized Children
- Difficulty paying attention in school
- Persistently avoiding places, events, or people associated with the trauma
- Being easily startled and hypervigilant
- Reverting to previously outgrown behavior (such as thumb-sucking, toileting accidents)
- Depressed mood
- Changes in sleeping or eating habits
- Reduced enjoyment in formerly pleasurable activities
- Complaints of pain without medical evidence of illness or injury
- Quiet, withdrawn or introverted behavior (particularly seen in girls)
- Persistent “flashbacks”, or experiencing terror in response to trauma-related triggers
- Over focus on self-blame and being “bad”

Important Points for Caring Adults
- Reactions to traumas are very individualized. Some children may have large reactions to seemingly small stimuli, while others may show little reaction to extreme stimuli. Responses are influenced by many factors such as temperament, availability of supportive others, history of exposure to traumatic events, and the nature of the event.
- Not all children who experience traumatic events will develop PTSD (post-traumatic stress disorder). However, many will experience acute distress and require some assistance to help them grapple with their concerns and reactions.

What Helps
- Having a caring, non-judgmental adult to listen to the child’s fears, retelling, and feelings (even the unpleasant feelings, such as rage, revenge)
- Continuing regular routines and rules, combined with the opportunity to retreat to a safe place when needed
- Expecting that the child will demonstrate some challenging or unsettling behavior, and not trying to make it go away prematurely
- Helping the child sort out any misunderstandings or distortions about the trauma
- Reducing the child’s exposure to situations that may cause triggers, such as scary movies, violent video games, and so on
- Being patient with the child’s fears and allowing the child to go at his or her own pace in taking risks; this is not the time to simply “get back on the horse”
When to Seek Professional Help

A child or family may benefit from professional help if there are additional family stressors, or if individual reactions are unusually intense, last a long time, cause physical symptoms, or greatly interfere with the normal tasks of daily living.

PROBLEM CHECKLIST – After an initial period of adjustment, be alert for:

Child:
Unable to share thoughts or feelings about the situation
☐ excessively clinging to adults or shows other signs of extreme anxiety
☐ threatens to hurt himself or herself or is unable to see anything positive about life
☐ withdraws socially
☐ is involved in high-risk behavior such as use of drugs or alcohol
☐ is unusually argumentative, aggressive, defiant or cruel to animals or other children
☐ has pronounced appetite loss, change of sleeping habits or other change in daily routine
☐ is failing and/or truant from school
☐ have constant physical symptoms such as stomachaches, fatigue or headaches

Other Factors:
☐ family member(s) has not been told the truth about the situation
☐ family member(s) had a very difficult relationship prior to the current event
☐ a family member has an untreated mental health or substance abuse problem
☐ parent feels overwhelmed by parenting demands
☐ family member(s) seems “stuck” in only one major reaction or feeling

There may be other risk factors; observe closely and be guided by your knowledge of the family.

IF YOU EVEN CHECK ONE OF THESE STATEMENTS, CONSULT A SPECIALIST:

How can I get help? It is very important to choose a mental health provider whom you feel is most qualified and whose style is comfortable for you. Ask your pediatrician, religious leader, school nurse, guidance counselor or a knowledgeable friend for referrals, and then interview two or three professionals by phone.

Ask about: the person’s experience in helping families cope with serious illness, which ages of children they usually see, how they approach this work (such as individual vs. family work), whether they are approved providers on your insurance plan, what their availability is and so on.

If there is any question that your family or child may need help, we urge you to consult a professional. He or she will be the best person to help you evaluate your situation objectively and judge which problems will diminish with time and which need more attention.
In our library, materials for and about children and cancer are located in several areas of the library. Books about pediatric cancer are located in QZ 275. Books on leukemia are in WH 250. Other non-fictional books pertaining to children and cancer are located in WS. Fictional books for children are found in PZ 7.

**TALKING TO CHILDREN ABOUT CANCER**

**BOOKS**

Here are a few titles you will find in the Junior Board Cancer Resource Library, Helen F. Graham Cancer center, Christiana Care Health System, Newark, DE:

<table>
<thead>
<tr>
<th>BOOK TITLE AND RECOMMENDED AGES</th>
<th>REFERENCE NUMBER</th>
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<tbody>
<tr>
<td>Because Someone I Love Has Cancer – Ages 6 - 12</td>
<td>WS 105.5 .A8 B388</td>
</tr>
<tr>
<td>Becky and the Worry Cup – Ages 4 – 8</td>
<td>PZ 7 H2327Be</td>
</tr>
<tr>
<td>Can I Still Kiss You?: answering your children’s questions about cancer – Ages 11- 14</td>
<td>WS 105.5 .A8 R965</td>
</tr>
<tr>
<td>Cancer in the Family - Adult</td>
<td>WS 105.5 .A8 H468c</td>
</tr>
<tr>
<td>Hair for Mama – Ages 4 - 8</td>
<td>PZ7 T589Ha</td>
</tr>
<tr>
<td>Helping Your Children Cope with Your Cancer - Adult</td>
<td>WS 105.5 .A8 V238h</td>
</tr>
<tr>
<td>How to Help Children Through a Parent’s Serious Illness - Adult</td>
<td>WS 105.5 .A8 M133h</td>
</tr>
<tr>
<td>Life Isn’t Always a Day at the Beach – Ages 5 - 12</td>
<td>WS 105.5 .A8 G211L</td>
</tr>
<tr>
<td>Moms Don’t Get Sick – Ages 9 – 12</td>
<td>WS 105.5 .A8 B797m</td>
</tr>
<tr>
<td>My Mommy Has Cancer - Ages 5 – 8</td>
<td>PZ 7 P239My</td>
</tr>
<tr>
<td>Mommy’s in the Hospital Again – Ages 5 – 8</td>
<td>PZ 7 P239Mo</td>
</tr>
<tr>
<td>Our Family has Cancer, Too! - Ages 12 and older</td>
<td>WS 105.5 .A8 C6371o</td>
</tr>
<tr>
<td>Paper Chain – Ages 4 – 8</td>
<td>PZ 7 B546Pap</td>
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<tr>
<td>Rainbow Feelings of Cancer – Ages 4 – 8</td>
<td>WS 105.5 .A8 M379r</td>
</tr>
<tr>
<td>Raising an Emotionally Healthy Child when a Parent is Sick - Adult</td>
<td>WS 105.5 .E5 R241r</td>
</tr>
<tr>
<td>Sammy’s Mommy Has Cancer – Ages 3 - 6</td>
<td>PZ 7 K79s</td>
</tr>
<tr>
<td>“They Never Want to Tell You”: children talk about cancer - Teens</td>
<td>WS 105.5 .A8 B368t</td>
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<tr>
<td>Tickle Tabitha’s Cancer-Tankerous Mommy - Ages 3 - 8</td>
<td>PZ 7 F811Ti</td>
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<tr>
<td>Tiny Boat at Sea - All ages</td>
<td>WS 105.5 .A8 S649t</td>
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<tr>
<td>What’s Happening to Mom?</td>
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<tr>
<td>Helping children cope with breast cancer – All ages</td>
<td>WP 870 W5554</td>
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<tr>
<td>When a Parent Has Cancer - Adult</td>
<td>QZ 201 H2953w</td>
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<td>When Mommy Had a Mastectomy – Ages 4 – 8</td>
<td>PZ 7 G855Whe</td>
</tr>
<tr>
<td>When Mommy is Sick – Ages 4 -8</td>
<td>PZ 7 SS451Wh</td>
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<tr>
<td>When Pete’s Dad Got Sick – Ages 4 – 8</td>
<td>PZ 7 B747Wh</td>
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<tr>
<td>When Someone You Love Has Cancer – Ages 6 - 12</td>
<td>PZ 7 L673w</td>
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<tr>
<td>When Your Brother or Sister Has Cancer - Teens</td>
<td>WS 105.5 .A8 W567</td>
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<td>Year My Mother Was Bald – Ages 8 – 13</td>
<td>PZ 7 S747Ye</td>
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<td>VIDEO TITLE AND RECOMMENDED AGES</td>
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<tr>
<td>My Mom Has Breast Cancer - Adult</td>
<td>WS 105.5 .A8 M995</td>
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<tr>
<td>We Can Cope - Adult</td>
<td>WS 105.5 .A8 W361</td>
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**WEB RESOURCES**

**Kids Cope**

[www.kidscope.org](http://www.kidscope.org)

Kids Cope was begun in 1994. Its purpose is to help families and children better understand the effects from cancer and chemotherapy in a parent. Its mission is the production and distribution of educational materials designed to accomplish that goal.

**Kids Konnected**

[www.kidskonnected.org](http://www.kidskonnected.org)

Mission is to provide friendship, understanding, education, and support for the children who have a parent with cancer, or have lost a parent to cancer.

**Super Sibs**

[www.supersibs.org](http://www.supersibs.org)

Helps children redefine the "cancer sibling" experience - by providing needed support services and by helping to draw out the greater and important lessons that may benefit these children later in their own lives.

**American Cancer Society**

[www.cancer.org](http://www.cancer.org)

Provides specific information about talking with children about diagnosis, treatment and advanced cancer.
## Helpful Books for Families

### About Serious Illness

- **The Rainbow Feelings of Cancer** (Martin & Martin, 2001) .............................................. 5-11
- **When Someone Has a Very Serious Illness** (Heegaard, 1997) ........................................... 6-10
- **Promises** (Lewin, 2000) ........................................................................................................ 6-10
- **How to Help Children...Parents’ Serious Illness** (McCue, 1994) ........................................ 6-10
- **Cancer in the Family: Helping Children Cope...** (Heiney et. al., 2001) ................................ 6-10

### About Feelings

- **Glad Monster Sad Monster** (Emberley & Miranda, 1997) ..................................................... 3-7
- **When I Feel Angry** (Spelman, 2000) .................................................................................... 3-9
- **When I Feel Sad** (Spelman, 2002) ....................................................................................... 3-9
- **When I Feel Good About Myself** (Spelman, 2003) ............................................................... 3-9
- **What Makes Me Happy?** (Anholt, 1995) .............................................................................. 3-9
- **Today I Feel Silly & Other Moods...** (Curtis, 1998) ............................................................... 3-9
- **Sometimes I Feel Like A Mouse** (Modesitt, 1992) ............................................................... 3-9
- **I’m Mad** (Crary, 1992) ........................................................................................................... 3-9
- **When I Feel Scared** (Spelman, 2002) ................................................................................... 3-9
- **When Mommy Was Mad** (Janell & Mathers, 2002) ............................................................ 4-9
- **Let’s Talk About Feeling Sad** (Berry, 1996) .......................................................................... 4-9
- **Scared? From Fear to Courage** (Roca, 2002) ................................................................. 4-10
- **The Scaredy Cats** (Bottner, 2003) ...................................................................................... 4-10
- **How Are You Peeling? Foods with Moods** (Freymann & Elffers, 1999) ......................... 2-12
- **Mad Isn’t Bad** (Mundy, 1999) .............................................................................................. 5-11
- **What To Do About Your Child’s Moods and Emotions** (Israeloff, 1998) ...................... Adol
- **Letting Go of Anger** (Potter-Effron & Potter-Effron, 1995) .............................................. Adol
- **Understanding Teenage Depression...** (Empfield & Bakalar, 2001) ........................... Adol

### About Parenting

- **How to Say It to Teens** (Heyman, 2001) ............................................................................. Adol
- **Siblings Without Rivalry** (Faber & Mazlish, 1998) ........................................................... Adol
- **An Ounce of Prevention** (Shapiro, 2000) ......................................................................... Adol
- **The 7 Worst Things Parents Do** (Friel & Friel, 1999) ....................................................... Adol
- **Raising an Emotionally Intelligent Child** (Gottman, 1997) ........................................... Adol
- **The Difficult Child** (Turecki, 1989) .................................................................................. Adol
- **How to Talk So Kids Will Listen & Listen...Talk** (Faber & Mazlish, 1999) ................... Adol
- **Wonderful Ways to Love a Child** (Ford, 1995) ............................................................... Adol
- **1-2-3 Magic: Effective Discipline for Children 2-12** (Phelan, 1995) ......................... Adol
- **A Parent’s Guide to the Teen Years** (11 to 14 years) (Panzarine, 2000) ................. Adol
**Other Resources**

**American Cancer Society**
www.cancer.org
provides specific information about talking with children about diagnosis and treatment of early and advanced cancers

**American Psychological Association**
www.apa.org Website provides extensive section on childrens’ issues as well as find a psychologist feature.

**Delaware Psychological Association**
www.depsych.org Find a psychologist feature

**Delaware Guidance Services for Children and Youth**
www.delawareguidance.org
(302) 652-3948 Agency offers counseling services to children and adolescents

**www.kidshealth.org**
Comprehensive website devoted to childrens’ health issues.
Extensive section on emotions and behavior. Resources written directly for parents/caregivers as well as children and adolescents.

**www.kidsandtrauma.org**
Extensive website devoted to assisting children/adolescents who have experienced trauma.