Parenting Matters:
Talking with Children About Cancer

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Overview

- Current literature
- Children’s understanding of illness
- Strategies and tips for communication
- Legacy
- Available resources
- Questions/comments
The American Cancer Society estimates more than 315,000 adults between the ages of 25 and 54-years-old, parents to more than 592,000 children, are diagnosed with some type of invasive cancer each year.
What does the literature tell us?

- Children whose parents have cancer often have behavioral and psychological changes which go unnoticed.⁹

- Negative responses in children include: self-esteem changes, academic declines, and somatic symptoms generally elicited from anxiety.⁸

- Stress in children whose parents have cancer has been shown to be higher than stress in children treated for cancer themselves.⁴

- A child will be affected by a parent’s cancer diagnosis whether or not the child is informed of the condition.⁶
Literature, cont’d

- Anxiety levels are higher in children who are not informed about their parent’s condition compared to children who are informed.⁸
- In young children, behavior changes are common due to a lack of verbal language to express concerns or fears.³
- Adolescents have better responses when given age-appropriate, detailed information soon after a parent is diagnosed.²
- An important variable in adolescent coping ability is ongoing communication between parents and teens during the course of the illness.⁸
Facts About Children

• Kids will sense early on that something is wrong
• What children make up in their heads is often more scary than what’s actually going on
• Kids are much smarter than adults give them credit for
How Children Understand Illness

Adapted from American Cancer Society ¹
<table>
<thead>
<tr>
<th>Age</th>
<th>Understanding of illness</th>
<th>Children’s possible reactions</th>
<th>Parent’s possible responses</th>
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</thead>
<tbody>
<tr>
<td>Newborns/Infants/</td>
<td>• Limited awareness of illness</td>
<td>• Clingy</td>
<td>• Maintain schedules</td>
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<tr>
<td>Toddlers</td>
<td>• Can sense anxiety in parents</td>
<td>• Fussy, cranky, crying</td>
<td>• Physical contact</td>
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<td></td>
<td>• Aware of periods of separation</td>
<td>• Tantrums</td>
<td>• Relaxation techniques – music, baby massage</td>
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<td></td>
<td></td>
<td>• Regression – bedwetting, thumbsucking, etc</td>
<td>• Rely on others to help with support</td>
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<tr>
<td>Preschoolers (3-5</td>
<td>• Beginning level of understanding</td>
<td>• Regression</td>
<td>• Utilize concrete tools for discussion – dolls,</td>
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<td>years)</td>
<td>• Egocentric</td>
<td>• Hyperactivity</td>
<td>books, stuffed animals</td>
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<td></td>
<td>• May believe they caused illness and can catch cancer</td>
<td>• Separation anxiety</td>
<td>• Maintain schedules</td>
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<td></td>
<td>• Magical thinking</td>
<td>• Aggression</td>
<td>• Reassurance</td>
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<td></td>
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<td></td>
<td>• Encourage play</td>
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<td>• Show emotion, but utilize discretion</td>
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<td>• Be honest and open in age-appropriate way</td>
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<td>• Assure them they can’t catch cancer and didn’t</td>
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<td></td>
<td></td>
<td></td>
<td>cause illness</td>
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<td>• Model positive coping strategies</td>
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| **School-Age Children (6-12 years)** | • Understand more complex explanations of cancer diagnosis  
• May still feel responsible for causing illness  
• Understand a parent can die (9 years and older)  
• Still possess some egocentric and magical thinking | • Irritable, sad, crying  
• Anxiety, guilt, jealousy  
• Somatic complaints: headache, stomachache  
• Separation anxiety at school or camp  
• Hostility towards sick parent  
• Poor concentration, lower grades | • Use books to discuss  
• Reassurance  
• Maintain schedules  
• Discuss death even if child does not bring up  
• Teach positive coping strategies |
| **Teenagers (13-18 years)** | • Abstract thinking  
• Empathy  
• Think more like adults  
• Understand reasons for symptoms  
• May deny worry/concerns to avoid discussion  
• Understand complex relationships between events | • Want independence  
• Anger, rebellion, guilt  
• Anxiety, depression  
• Concern with being different from peers  
• Withdrawal  
• Physical symptoms  
• More likely to internalize | • Encourage discussion but respect privacy  
• Identify other trusted adults teens can talk to  
• Discuss family role changes  
• Provide expressions of love  
• Set limits  
• Don’t rely on teens to take on too many adult tasks  
• Provide resources for learning and support |
Strategies for Communication

- Plan to speak with children early on so they don’t hear it from someone else.
- Say the word CANCER.
- Use age-appropriate language.
- Be honest.
- It’s ok to answer questions with “I don’t know.”
- Maintain important rules and schedules.
- Reassure children there is a plan for their welfare.
Strategies, cont’d

• Talk to the child’s teachers and school counselor.
• Share truthfully but age appropriately.
• Check for misinformation.
• Encourage healthy expression of emotion (including crying).
• Remember that children learn through their parent’s behavior.
• Expect that each child may have a different reaction.
• Address the “D” word regardless of prognosis.
Diagnosis

• What is cancer
• How is cancer treated
• Type of cancer – where it is in the body
• Common questions children have about cancer = Five “C’s”
Five C’s

1. It’s called CANCER
2. Can’t CAUSE it
3. Can’t CATCH it
4. Can’t CONTROL it
5. Can’t CURE it
Treatment

- Children need to understand some basics about cancer.
- Prepare children for changes during treatment.
- Follow normal routines as best as possible.
- Consider a visit to the hospital at an appropriate time.
- Try to talk about the treatment in a positive way if possible, rather than dwelling on all the distressing or negative side effects.
- Try to involve children in preparation for treatment (picking out wigs, decorating scarves, etc.).
Recurrence

• If no recurrence, reassure the child there is no sign of the cancer now.

• Let them know the doctors will be doing everything possible to make sure the cancer doesn’t come back.

• Reassure the child that if there is a chance of recurrence, they will be informed.
Recurrence, cont’d

- If recurrence occurs, find out what the child remembers from the initial diagnosis.
- Explain that it has come back and will need to be treated with stronger medicines.
- Re-educate about basic cancer terms, the diagnosis, and the treatment plan.
- Remind children they will be cared for and reassure of plans.
- Re-visit conversation about death.
Progressive or Terminal Illness

• Begin by asking how they think it is going.
• “The doctors tried their very best medicines but the cancer seems to be growing instead of getting smaller…”
• Tell them about death only when you are certain it will happen in the near future.
• Avoid timelines (depending on age).
BRCA: To Tell or Not to Tell

- Assess your child’s age, maturity/understanding and anxiety.
- Determine reasons for wanting to disclose information.
- Discuss actual words to use.
- Take conversations one step at a time.
- Focus on positive aspects of knowing.
- Maintain open, ongoing communication.
- Dispel myths.

(Farkas Patenaude, et al)
Single Parent Households

- When the primary parent is diagnosed with cancer, grief may be compounded in addition to the breakup.
- Extra visits with the other parent might be helpful.
- Resolve problems between parents out-of-sight of the child(ren).
- Children will wonder who will take care of them so reassurance is important.
- If the parent who left the home is ill, make efforts to keep the child(ren) involved with that parent.
- Set up a support network so the child does not take on too much responsibility.
- Rely on friends/family for emotional support as opposed to the child(ren).
- Kids may feel even more isolated from their peers, so offer reassurances.
Behaviors to Watch For

- Withdrawal
- Agression
- Isolation
- Irritability
- Depression
- Regression
- Anger
- Decline in grades
- Other emotional changes
Reminders

**DO:**
* Be honest
* Limit details based on age
* Use age appropriate language
* Expect a range of emotions
* Watch for changes in behavior
* Feel comfortable expressing emotion
* Check-in

**DON’T:**
* Withhold information in efforts to overprotect
* Expect children to be sad for long periods of time
* Think if they aren’t talking about it, they aren’t thinking about it
* Worry if you don’t have the answer right away
* Be afraid to cry – this models healthy coping
Legacy Planning

• Buy cards and/or gifts for future birthdays, milestones, special occasions
• Letters
• Create a scrapbook or photo album
  ❖ Have a page dedicated to each family member
  ❖ Have a page for each stage/milestone in your life
• Create audio and/or video memories
• Make handprints in plaster
Kid to Kid: Learning to Cope When Your Parent Has Cancer

Available on DVD and
www.mdanderson.org/kiwi

**Also available in Spanish**
Helpful Resources

- MD Anderson’s KIWI Program: www.mdanderson.org/kiwi
- Cancer Care: www.cancercare.org
- The Children’s Treehouse Foundation: www.childrenstreehousefdn.org
- Kids Konnected: www.kidskonnccted.org
- Group Loop: www.grouploop.org
- Cancer Really Sucks: www.cancerreallysucks.org
- Camp Kesem: www.campkesem.org
- Cancer Support Community: www.cancersupportcommunity.org
“It’s not only children who grow. Parents do too. As much as we watch to see what our children do with their lives, they are watching us to see what we do with ours. I can’t tell my children to reach for the sun. All I can do is reach for it, myself.”

~ Joyce Maynard
Questions/Comments?
References


