

A Dozen Lessons Learned from the PACT Program

Permission to include these lessons was generously granted by the PACT team at Massachusetts General Hospital.

- 1. Begin by identifying your medical condition.** Call your illness by its name - breast cancer or a brain tumor - and not a general word like lump, bump, or boo-boo. This helps reduce your child's fear that she might get your disease and lets her know you trust her with open and honest communication.
- 2. The worst way for a child to learn about troubling news is to overhear it.** News learned by accident is often confusing and inaccurate. Let your child know you trust her by telling her directly what is happening and what to expect.
- 3. Welcome all of your child's questions warmly.** Let your child know you are open to questions on any topic. Try to be available at times and in settings in which your child is more likely to talk with you. This may include the car, at the kitchen table, while you cook, or at bedtime.
- 4. Figure out the "real" question your child wants to ask.** Ask your child to tell you what he is wondering about and why. Your curiosity may help you and your child uncover underlying concerns or worries. Many times there is a specific concern that can be more easily answered than the initial question.
- 5. Not all questions require immediate or detailed answers.** It's all right to say, "That's a good question. I'll need to think about it or talk it over with my (doctor, nurse, social worker, spouse, or other family member) and get back to you."
- 6. Respect a child's wish not to talk.** Even a non-talker needs basic information, including any details that might directly affect him. But it's okay if your child doesn't want to have a discussion. You can check in with him to find out if he's hearing too much, too little, or just the right amount about your illness, treatment, and changes at home.
- 7. Don't let your child worry alone.** Encourage your child to share his worries with you. Sometimes people outside the family say unhelpful things with the kindest intentions. Ask your child to share what others may have said about cancer in general or about your particular condition. Let your child know how varied the illness is, and that someone else's cancer experience is unlikely to be the same as yours.
- 8. Keep the channels of communication open with key caregivers,** such as grandparents, caregivers, babysitters, coaches, and parents of close friends. Ask your child to help you identify who the key point-people should be. By keeping them in the communication loop, you make it easier for these caring adults to provide the appropriate emotional support and stable routine your child needs during your illness.
- 9. Try to maintain your child's usual schedule.** To help keep the routine as normal as possible, assign a point-person for each child. Post schedules, make lists, and use calendars to help your child and caregivers know what each day holds. Talk with each child's teacher and let your children know who they can go to if they have a hard time at school.
- 10. Protect Family Time.** Maintain regular telephone and visitor-free time when your child has your full attention. Use this time to check in on the details of your child's day. Some families designate a "captain

of kindness” who, with parental direction, helps friends and family determine ways to be most useful. This person can be a buffer, fielding phone calls and inquiries so that family time focuses on the children and not the parent’s illness.

11. Hospital visits often help children feel less worried. Adjust the length of the visit to what your child can comfortably manage by bringing an extra adult who can take your child for a walk or snack if necessary. Talk with your child after the visit to address any confusion or worries.

12. Take good care of yourself. This may include spending time with family and friends, engaging in favorite activities, or finding quiet time. It also includes seeking the information you need to feel confident about your medical care, getting treatment to minimize side effects, and getting support to address your emotional needs.

