



MASSACHUSETTS
GENERAL HOSPITAL

CANCER CENTER

MARJORIE E. KORFF PACT PROGRAM
PACTSM
Parenting At a Challenging Time

Toolkit to Help Educators Support Children of Parents with Serious Illness



This toolkit is interactive

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MARJORIE E. KORFF PACT PROGRAM
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Parenting At a Challenging Time

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Toolkit Overview

WHAT'S IN IT AND HOW TO USE IT

A TOOLKIT DESIGNED TO ASSIST EDUCATORS

A parent's serious illness is one of the most difficult challenges a child can face. Life at home may change overnight. For some children, school can be a refuge—a place where life goes on as before. For others, worries about the parent may result in changes in the child's behavior and in his or her ability to handle school work and relationships with peers.

A caregiver's illness also poses challenges for educators, particularly classroom teachers, who are usually closest to the affected child. Many questions arise: How can I comfort the child while still focusing on teaching an entire class? How should I respond to behavioral changes? How can I respect the privacy concerns of the family while

still answering children's questions and handling communication with the larger school community? How teachers and other school staff respond at this difficult time can make an enormous difference in the life of the child whose parent is ill.

We developed this toolkit for educators—classroom teachers, principals, school counselors, school nurses and others—who support students who have a parent with cancer or another serious illness. Educators can play a key role in nurturing these students, helping bolster their natural resilience, monitoring them for behavioral or academic challenges and working with the parents to help support the child.

GOALS OF THE TOOLKIT

The goals of the toolkit are to:

- Increase awareness of the likelihood that most educators will encounter a child whose parent has cancer or another serious illness
- Identify the roles educators can play in supporting such children
- Indicate particular aspects of child development and temperament that affect how a child may understand and cope with a parent's illness
- Identify situations in which the classroom curriculum may need to be adjusted
- Provide parent guidance information that educators can share with parents who seek their help
- Offer practical suggestions that educators can share with children whose parents are ill
- Provide strategies for communicating more effectively with both parents and children

USERS OF THE TOOLKIT

This toolkit contains three main sections; each contains information aimed at a different group:

- **For the Educator.** This section is designed for use by classroom teachers, principals, school nurses, school counselors and others who work with children of parents with serious illness. We encourage educators to read the contents of the entire toolkit, but particularly this section, when educators learn that the parent of a child in their school is ill. Educators will find specific parts of it helpful at different times, for example, before meeting for the first time with the parents, when observing the child for behavioral changes or when others in the school community ask questions about the illness or offer to help.
- **For the Parent.** We have designed this section for educators to share with parents. It contains suggestions for how parents can communicate with and help their children, and guidance about communication with the school and others in the school community. It also contains templates for letters that parents may use to communicate information about their illness and privacy choices to school staff.
- **For the Child.** This section is designed for use by children, and it may be given to parents for use with their children. Parents may want to suggest that older children read the material themselves, as a starting point for discussion.

For the Educator

For the Educator

FACT SHEET

- One of every four adults diagnosed with cancer in the United States is the parent of a child under 18¹
- Three million children in the United States have a parent who has been diagnosed with cancer¹
- The well parent's functioning has a significant impact on the child's well-being
- A student whose parent is seriously ill may be the only child in the class facing this challenge, and as a result the child may feel alone with his or her emotions
- Other children and school community members may have experiences with cancer or other serious illnesses which they share with the child; this can be confusing and even frightening for the child, especially if the person has died
- A child's developmental stage and temperament play a key role in how the child is able to understand and cope with the parent's illness
- Honest and age-appropriate communication between parents and children is essential, and there are ways educators can help support and guide parents who seek advice
- Children who are already vulnerable to stressors may need extra support to cope with this new challenge. Examples include children with preexisting anxiety, depression or attention difficulties
- Although symptoms of anxiety and depression are not uncommon for children with an ill caregiver, most children will continue to cope well
- Individual caregivers and children will differ in their choice about how private or public they want to be about the illness

¹ Weaver KE, Rowland JH, Alfano CM, McNeel TS. Parental cancer and the family: a population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer*. 2010;116(18):4395-4401.

CONSIDERING THE CHILD'S DEVELOPMENTAL STAGE

Each stage of childhood has its own set of expected challenges and behavior within the course of normal development. Being especially aware of these stages can help you distinguish the difficulties related to the additional strain of a parent's illness from those that are normal developmental challenges. Below, we summarize some of the common reactions to a parent's illness at various developmental stages.

Infants and Toddlers (0-2 years)

- Unable to understand or appreciate details of diagnosis, prognosis and treatment
- Sensitive to changes in routine or changes in caregivers
- Likely to shift to earlier, less mature behaviors (e.g., fussiness, difficulty with separations or bedtime)

Preschoolers (3-6 years)

- Limited ability to appreciate the details of diagnosis, prognosis and treatment
- Vulnerable to misunderstanding the reason that illness occurs and may blame themselves (e.g., "I hit Mommy and made her sick")
- May require repeated explanations of the same topics
- Increased sensitivity and difficulty with feelings—for example, may be very weepy about small frustrations, yet calm or silly when discussing the illness
- May incorporate themes of illness in their play, such as pretending to have their parent's symptoms
- Sensitive to changes in routines and rules; decreased limits and extra treats can worsen behavior
- May fear the illness is contagious and have fears of others, including themselves, becoming ill

School-Age Children (7-12 years)

- Better able to understand and appreciate most details of diagnosis, prognosis and treatment
- Understanding will be limited to cause and effect; may have more difficulty with nuance and uncertainty
- May become preoccupied with the unfairness of illness and unsuccessful treatment
- May need coaching about how to manage their anxiety
- May experience anxiety as physical symptoms such as stomachaches or headaches
- May seek extensive information to help tolerate their anxiety (e.g., wanting to visit the hospital, see a surgical scar or seek reassurance about the health of other important adults)
- Sensitive to the ways that an illness may affect their ability to participate and perform in their normal activities, such as school, sports and lessons
- May cope by staying very busy with either established activities or in ways related to the illness
- May seesaw between apparent distress and happy engagement in normal activities
- May have difficulty speaking directly about strong or difficult feelings

Adolescents (13-18 years)

- Capable of comprehending the details of diagnosis, prognosis and treatment, including the uncertainty
- May turn to friends and important adults other than parents as primary sources of support
- Their understanding of the illness and of the parent's limitations may not translate into sensitivity or pitching in, in the way parents may hope; may appear selfish to parents
- May engage in risk-taking behavior to manage their distress
- Commonly feel guilt, unhappiness and/or anger as the demands of a parent's illness are at odds with their normal developmental tasks, such as increased independence and engagement with peers
- Older adolescents may be ambivalent about pursuing greater independence during the illness (e.g., applying to college far from home)
- Degree of closeness to the ill caregiver (in comparison to a well caregiver) may affect the way in which an adolescent responds to the challenges of serious illness

THE ROLE OF TEMPERAMENT

Temperament refers to a child's consistent manner of reacting to his or her environment and coping with potentially stressful situations. Aspects of children's temperaments include his or her baseline mood, activity level, curiosity or shyness around new situations or people, level of attentiveness and persistence with challenging tasks, and flexibility and adaptive thinking.

A particular child's temperament may make him or her more or less successful in confronting challenges. It may also make that child easier or more difficult to parent or teach. Just as parents are often aware of the significant differences in temperament among children in the same family, you have a wealth of experience in recognizing these differences among students. Students confront smaller-scale challenges on a daily basis in the classroom, for example, negotiating social relationships among their peers and overcoming academic difficulties. In your teaching, you regularly utilize a child's temperamental strengths to reinforce the child's success in many areas of functioning and to strategize methods for accommodating temperamental challenges.

A child's temperament affects how he or she copes with a parent's serious illness. During a parent's illness, you can often be most helpful by identifying a child's particular coping strengths and supporting these to bolster the child's resilience throughout the course of the illness. Some temperamental qualities that may be associated with increased resilience include:

- Ability to feel strong emotions without acting on them
- Ability to focus attention and is able to persist with challenging tasks
- Exhibiting self-control
- Generally feeling comfortable with new people and experiences

Recognizing situations in which a particular child has been less resilient or has had trouble coping in the past may also identify areas that warrant more support. When children are experiencing stressors like a parent's illness outside the classroom, helping the child to succeed at school can improve the child's overall ability to tolerate the changes and worries that occur when a parent is seriously ill.

SUPPORTING THE CHILD IN THE SCHOOL SETTING

In addition to its impact on the family, a parent's serious illness presents both challenges and opportunities for classroom teachers and other school staff. (We often refer to "parents" in this document, but are mindful that oftentimes the caregiver is a single parent or another relative.) The following suggestions may help you support children during this difficult period.

1. Convey confidence in the child's resilience, and be mindful of your own emotional response.

Children are attuned to signs of concern and can sense your own feelings of worry; doing your best to respond as you did prior to learning this information will help the child feel more comfortable at school. For instance, try to greet the child and parent in the same manner you did before learning of this news. Also, if a child speaks to you about a parent's illness, try to listen in the same warm, empathic way that you would for any information the child communicates.

2. Develop a communication strategy with the child's parents.

You are an important resource for parents in monitoring how their child is coping with a parent's illness. Families need a simple, effective mechanism for communicating information about the illness and their child's needs to the school staff. Often, this is most effectively accomplished by designating a single point person in the school with whom the parent primarily communicates. This can be the principal, school nurse, classroom teacher, guidance counselor or other support staff with whom the family feels comfortable.

Ideally, this point person will have an initial conversation with the parent(s). The point person should ask whether the classroom teacher or others at the school should initiate discussions about the illness with the child, as well how much information the parents would like to be disseminated (e.g., to other teachers, other parents). It is essential to respect a parent's wishes even if you would prefer greater openness. The point person might also help the parent to consider how difficult secrecy can be and discuss potential communication

strategies. (See the more extensive discussion of the family's privacy in the "[For the Parent](#)" section.) It is also very helpful for the point person and parent to make a plan for regular communication; parents may prefer email, phone calls or in-person conversations.

Be especially sensitive to families in which the parents are divorced or separated, or in which there is discord between the child's non-custodial parent and the caregiver: you will have to balance respect for both parents' concerns for their child against the recognition that the ill parent has the right to decide what information to provide to the other parent regarding the specifics of the illness.

3. Gather information about the illness in order to be effective in providing support.

Parents vary in how much information about their illness they want to share, and it can feel intrusive for school staff to ask a lot of detailed questions. Instead, let the parent offer the information he or she feels comfortable discussing. If there is information remaining that feels important to know, you can gently ask a few broad questions to spark more discussion. Be sure to keep the focus on the child and the information needed to support him or her. Don't allow concern or curiosity to lead you to feel urgency to learn details of the parent's illness before the parent indicates a willingness to share. Developing a relationship in which the parent feels comfortable sharing can lead to follow-up conversations in the future. The following are some questions you may want to ask the parent:

- Is there any information about your illness or treatment that you think might be important for us to be aware of? Are there any upcoming hospitalizations that may cause separations?

- What information does your child know about the illness and how does he or she understand it?
- Are there particular concerns or fears that your child has about the illness?
- Does the parent want the teacher or another point person to check in with the child about how they are doing? What are the child's feelings about this? Note that some children will regard school as a place where they can feel free from discussions about the illness, and this preference should be respected when appropriate
- How does the parent feel about having other families in the school community know about the illness (see #4)? A related question is whether the family has designated anyone (e.g., another relative, a close friend) to coordinate the flow of information and/or offers to help
- How do you want to communicate with us about the illness (e.g., by phone, email or in-person conversations)?

4. Find out the family's wishes for support. When considering ways the school can support the family during the illness and its treatment, keep in close touch with the family regarding their wishes and those of the child. Should the family decide to let the school community know about the illness, many people will want to be helpful. If the family feels comfortable, the school community can provide significant support. For example, other parents can prepare meals for the family, drive the child to school and extracurricular activities and help with household chores such as lawn care or snow removal.

5. Adjust academic expectations as necessary.

Closely observing a child's ability to engage in academic activities will allow you to adjust expectations when the child is not able to perform at the usual level. Letting parents know that it is helpful to be aware of new stresses at home (e.g., particularly difficult times in the course of treatment, discussions about a parent's prognosis) may help predict when the child might need additional accommodations.

6. Develop a support team for the child.

Consider creating a "resilience team" to help support a child with a parent with serious illness. This may be particularly helpful when a child has multiple teachers, coaches and other contacts. The team could meet regularly to share observations about how the child is doing and brainstorm about ways to further support the child. A member of the team (e.g., the point person, if one has been designated) can communicate with the parents directly, sharing the team's observations and ideas with the parents and sharing any updates from the parents with the team.

WATCHING FOR RED FLAGS

Most children adjust extremely well to a parent's illness. Some children, however, may be predisposed to have a more difficult time coping. The degree of difficulty depends upon the child's temperament, experiences, and any developmental challenges that he or she may have experienced prior to the illness.

As an educator, you can be very helpful to parents by observing the child in the school setting and communicating about any concerning changes—red flags. If the child struggles, you can provide additional support in various ways. For instance, the guidance counselor or another trusted adult might meet with the child to talk about what would help. Possibilities might include providing extra help in areas of difficulty, lessening the child's workload, letting the child make up tests or meeting with the child (and perhaps a friend) for lunch. You may also want to talk with the other school staff about changing some aspects of the curriculum that might be particularly stressful for the child (discussed in "[Adapting the Curriculum](#)"). If the child has continuing difficulties, you may want to talk with the parents about accessing outside resources, such as consulting the pediatrician and/or mental health professional.

As a way of determining if any additional support may benefit the child, it can be useful to ask these questions:

- 1. How different is the child's behavior?** Consider whether the changes you see in the classroom are a clear change from before the parent was diagnosed with the illness.
- 2. Has the child demonstrated a significant change in how he or she interacts with peers and school staff?** Some children will become more withdrawn and will not interact with others in the way they did prior to their parent's illness. Conversely, others may become more irritable and angry than they have been in the past. These may be transient changes related to a new diagnosis or a change in treatment or prognosis, or they may be completely unrelated to the parent's illness. If the changes persist, they are more likely to cause problems and may require further evaluation.
- 3. Does the child respond as he or she has in the past to methods for reducing distress?** If the child does not respond to previously effective techniques for reducing distress or behavioral problems, this may indicate that the level of distress requires further evaluation and treatment.
- 4. Does the child respond to increased support?** Some children will demonstrate temporary changes in their level of functioning related to particularly challenging periods of a parent's illness. If the child responds to increased support in the classroom at this time, it is likely that they will continue to function normally when the acute stressor is removed or lessened. If the child does not respond to increased support, however, you should speak to the child's parents to determine whether a change in support strategy or an increase in services is necessary.
- 5. Is the child able to make academic progress?** While there may be a need to adjust academic expectations during this difficult time, children should continue to make academic gains in accordance with developmental expectations. It can be easy to assume a child is not doing well because of stress at home, so it is important to consider if a child's struggles may be due to an unrelated learning difficulty. Coordinating resources in the school (e.g., an IEP or a 504 plan, extra tutoring) can be challenging for parents under any circumstances. Parents who are dealing with the additional stress of illness may benefit from having the designated point person in the school take on some of the organizational help that the parent might have otherwise been handling.

ADAPTING THE CURRICULUM

Because themes of illness and loss can be found in various aspects of the curriculum, it is important to anticipate that some assignments may be difficult for a child who has an ill parent.

If you are considering adjusting the curriculum in light of a parent's illness, be sure to speak to the student's parents about what they are comfortable with and what they think their child will be comfortable with. The following list summarizes a number of issues to consider when you are thinking about making adjustments to your planned curriculum; see also the "[Handling Teaching Challenges](#)" section for some concrete scenarios involving children of different ages.

- 1. Health and science classes commonly contain information regarding illness.** Alert the parents about any upcoming lessons that may contain this type of information or discussion. This will give the parent the chance to talk to the child ahead of time about whether the child wants to participate.
- 2. Literature often contains themes of loss and grief.** Some children will find this material helpful in processing their feelings, while others will find that it makes coping more difficult. Exploring how the student has tolerated emotionally charged literary themes in the past may help to determine their reaction to particular readings. You may want to consider adjusting the curriculum if the student previously has had a hard time coping with such emotional themes.
- 3. Integrate non-specific activities and lessons about positive coping.** Activities such as drawing pictures of supportive adults or comforting activities can be helpful for a young child with a parent who is ill, as well as for other students in the class. Older children may be able to write about people who have been supportive, or what they find comforting when they are worried.
- 4. Consider integrating age-appropriate lessons about illness into the curriculum.** Even when students do not want to discuss their parent's illness directly, curriculum aimed at general themes of illness and treatment may be helpful for the student with the ill parent, as well as for other students. Such lessons may help dispel myths about illness such as cancer, and inspire other students in the class to be understanding and supportive. Ideally, such lessons could be built into the curriculum proactively rather than in response to the news of a parent's becoming ill. The Livestrong Foundation (see the "[Additional Resources](#)" section) has an example of a curriculum aimed at various developmental levels that discusses these themes.

HANDLING TEACHING CHALLENGES

This section presents four different scenarios, each involving a child at a different development stage. Each lists a number of questions for you to ask, along with actions you could take in the classroom. Of course, these represent only a few of the scenarios you might face as an educator, but they may help guide your thinking and stimulate discussions about ways to support a child.

1. Young child. It is Mother's Day and you are planning a "mommy's breakfast" for your preschool class; all the children's mothers will come to school and be served a special breakfast. You become aware that 5-year-old Anna's mother, who is undergoing treatment for lupus, has been hospitalized with complications from the treatment and will not be able to attend the breakfast. Here are some important questions to ask when thinking about how to best support Anna.

- How have you observed Anna coping with past challenges in the classroom?
- Can you find out from Anna's family whether Anna would like to attend the breakfast with another important family member or whether she would rather skip the breakfast? It may be helpful to let them know if other children in the class will be attending with another caregiver
- What information regarding Anna's mother's illness has the family chosen to share with the school community?
- If Anna will attend the breakfast with someone other than her mother, would she like help explaining why her mother is not there?

2. Middle-school child. In your fifth-grade classroom, you are planning to read a novel that contains significant themes of loss. Will, a 10-year-old boy in your classroom, has a father who has been diagnosed with lung cancer and is undergoing treatment. His grandmother died of a similar cancer eight months ago. Will's parents are divorced and he lives primarily with his mother. Will has been quite reserved and private regarding his father's illness and treatment, and this behavior is consistent with what you have observed about his temperament in the past. Consider the ways in which the book's themes could be helpful or distressing to Will:

- If Will's parents have established communication with the school, be sure to inform them that he will be reading this book so that they can talk to him about his feelings about it
- Decide whether Will would like to be approached directly about the content of the book or would prefer to seek guidance himself if he needs it. To guide this decision, take into account your knowledge of Will's coping style as well as his parents' input
- Consider the possibility that Will may find the content too distressing and may benefit from being excused from reading this particular book and invited to read a different book. Ideally, present this choice to everyone in the class so Will does not feel singled out

3. Young adolescent. Yasmine, a 13-year-old girl in your eighth-grade health class, is an eager learner who has shown a particular interest in discussions of various medical illnesses over the past year. Recently, her father was diagnosed with cancer and is undergoing treatment. You are unaware of the specifics of his diagnosis, treatment and prognosis. As you approach the start of the unit on cancer, how can you support Yasmine's interest and learning while being respectful of the possibility that this unit might be particularly difficult for her?

- If Yasmine's parents have established communication with the school, alert them about the upcoming cancer unit so they can discuss whether Yasmine would like any particular accommodations
- Be open to a range of possibilities. At one extreme, Yasmine may want to give a presentation about cancer and her parent's experience. At the other, she may not want to acknowledge any connection to the disease and may not even want to participate in the unit
- Although you know about Yasmine's family situation, don't assume she is the only student affected by cancer. Consider alerting all the parents about the content of the health unit and inviting them to share personal concerns or experiences

4. Older adolescent. Michael is an 18-year-old senior in high school who is finishing his applications for college. He has identified schools in various locations, some far from home. Michael's mother has been receiving treatment for cancer and her prognosis is poor. His father lives out of state. How can you support Michael in making decisions about college in the context of the immediate uncertainty? How could you help ensure that Michael can finish the school year if his mother dies?

- Prior to his mother's illness, what factors were important in Michael's thinking about applying to colleges away from home versus those near home?
- How well has Michael been able to access and utilize support when needed?
- How much of a loss do you think Michael would feel if he chose a school closer to home that was not a top choice?
- Who are the other important adults in Michael's life who could assist with these decisions?

For the Parent

For the Parent

This section contains information for parents living with the challenges of serious illness who are seeking help from educators about how best to help their children understand their illness and cope with its effects both at home and at school. This information includes a variety of strategies that may help parents communicate with their children and maintain routines for them during the illness.

Earlier sections of this toolkit have discussed the importance of respecting parents' choices regarding communication with their child's school and the larger community. Many parents find it helpful to write letters when they are first diagnosed, explicitly describing the situation, their decisions about who should know about the illness and their wishes for how others should communicate with their child regarding the illness. This section also contains several templates for such letters.

PARENTING STRATEGY #1: COMMUNICATING WITH YOUR CHILD ABOUT YOUR ILLNESS

1. Talk to your child about the illness. It is natural to want to protect your child from the distress and uncertainty associated with your illness. However, children of all ages know that something has changed when a parent is ill. When children are left alone with worries about unspoken changes, their assumptions about what is happening can be scarier than the truth. Providing your children with information about your illness gives them language to express their concerns and allows them opportunities to ask important questions. Even children who do not ask a lot of questions or exhibit significant worry benefit from information. Without direct communication about your illness, your child may learn about it by overhearing conversations. This may deliver the unintended message that the illness is too scary to talk about.

2. Refer to your illness by its medical name. While the name for an illness may sound scarier or more foreign to children, referring to your illness by its name from the start can prevent confusion for your child when he or she hears this word at some time during your treatment. Parents are often tempted to refer to their illness with a nonspecific name such as “boo-boo” to make it more relatable and less scary for their child. Unfortunately, this often has the unintended consequence of causing the child to fear that his or her own “boo-boos” will be similarly serious or will require similar medical attention as your illness.

3. When to tell your child you are ill. In deciding when to tell your child about your illness, it is helpful to give as clear a description as possible about your diagnosis and the treatment plan. This often requires waiting a period of time in order to have specific information. However, it is important to balance the benefit of waiting with the risk that your child will overhear discussions about your illness. If that occurs, your child may

misunderstand what he or she has heard. Also, he or she may have more trouble trusting that you will share information in a timely manner with them.

Another consideration is that changes in a parent resulting from the illness may be noticeable to a child before a clear diagnosis and treatment plan is established. In that situation, you should share enough information about the illness to explain these changes. One option is to tell your child a team of doctors is working to find out what is wrong and that you will share the information when it is available.

4. Welcome your child’s questions. Let your child know you are interested in discussing any topic related to your illness that he or she wants to talk about. If there are particular times when your child is more likely to talk (e.g., during car rides, at bedtime), try to make yourself available to discuss questions or concerns at those times. If your child appears to be having a difficult time stating a question, try to figure out if there is an underlying concern that the child feels unable to express. If you don’t have an answer to a particular question, it is often better to tell your child that you will seek further information from your doctors than to give immediate information that may not be accurate.

5. Respect your child’s wish not to talk. Children of all ages have varying desires and abilities to communicate their thoughts and feelings. Check in with your child regularly to determine if he or she is hearing too much or too little information about your illness. If your child is having trouble articulating their question, it may be helpful to try to figure out the general feeling or worry behind it, and talk about that. Striking a balance between being open and available but not intrusive is helpful for encouraging open communication.

PARENTING STRATEGY #2: MAINTAINING YOUR DAILY SCHEDULE AND FAMILY ROUTINE

1. Maintain your child's daily schedule as much as possible.

During treatment for a serious illness, it can be difficult to maintain a child's often-busy schedule. Doing so often requires enlisting relatives and friends to provide transportation and supervision when your treatment occupies significant time or leaves you feeling unable to handle these activities. While there will inevitably be unavoidable changes in your child's schedule at times during your illness, familiar routines can provide children with a sense of security in the face of many confusing and unpredictable changes in their lives. A child's familiar daily routine can serve as an important reprieve from worries about your medical condition. Many parents naturally make this a priority, and continuing these already established routines has a significant positive effect on children during the time of illness.

2. Organize your child's routine in a way that is accessible to others.

Your illness and its treatment will require a significant amount of your attention. This will make it more difficult to maintain the organization and planning of your child's important daily activities. A child's schedule can be complex, encompassing his or her home routine (e.g., wakeup time, meal times, homework schedule, bedtime rituals), school assignments and project deadlines, music lessons, sports practices and games, and more. If you have several children, planning and coordination become even more complex. Putting all these events on paper in a form such as a calendar can make the schedule much easier to monitor. It can also allow others, including your child, to share the responsibility

for keeping track. Even if you are not certain of all the exact dates and activities, the calendar will give everyone in the family an opportunity to review and update the information. Web-based calendars such as Lotsa Helping Hands (lotsahelpinghands.com) can provide convenient ways to organize the information efficiently and allow easy communication with friends and relatives who want to help.

For times when someone else might be caring for your child, be sure to write down such information as your child's eating and sleeping routines, the names and phone numbers/email addresses of your child's teachers, coaches, friends and their parents, and any other special information that may be helpful to your child.

3. Establish a family routine. In establishing a family routine during your illness, consider daily, weekly and seasonal family activities that you and your family already enjoy, and make them a priority in organizing your time. These can include meal times, recurring events (e.g., sports practices, games, recitals), shared interests (e.g., music, television shows), vacations and holiday gatherings. Just as maintaining a predictable daily routine is important for your child, maintaining a predictable routine of family time provides security and comfort for your child during a challenging time. It may not be possible to maintain all of your valued routines, so you will need to prioritize which are most important and determine which will continue to be feasible during your illness.

- 4. Share family meals.** Family meals provide a valuable opportunity for the family to sit down together to share the day's activities. It may also be a good time to share information about your illness, its treatment and any concerns that your children may have. This is a way to ensure that all members of your family have the same information and to learn from others' questions. It can also serve as an opportunity to receive updates about your child's schedule and to plan with other family members how to meet their upcoming needs.
- 5. Minimize disruptions during family time.** Family time that you designate in the evenings and on weekends should be a time when the focus is solely on your child and the rest of your family. Ensuring that this time is not interrupted may require letting others know that during particular hours (e.g., dinner time, when putting your child to bed), you will be unavailable for outside communication. When family time is interrupted by discussions about your illness, it can amplify the disruption that the illness has caused and lessen your child's ability to enjoy these special times. It also can increase the chance that your child could overhear distressing news rather than hear it from you at a planned time. Consider turning off your phones during these times.

PARENTING STRATEGY #3: ORGANIZING A SUPPORT TEAM FOR YOUR TREATMENT

- 1. Gather medical information.** Providing consistent routines for your child and planning family time will require you to obtain as much information as possible from your medical providers. Helpful information includes treatment course, possible adverse effects from your illness and/or its treatment, prognosis and likely length of treatment. This information may not always be immediately available and may change during the course of your treatment, but having a general idea as to what challenges are likely can make it easier to plan ahead for your children.
- 2. Use familiar caregivers and routines.** Familiar adult caretakers are reassuring for children and lessen the sense of unpredictability associated with the treatment process. It is important, particularly for younger children, to maintain these caregivers as much as possible while possibly expanding the context in which these familiar adults provide care for your child. For example, a grandmother who picks up the child from school every day may also need to bring the child to sporting events when you are not available.
- 3. Designate a “Minister of Information.”** Treatment of a serious illness involves generating a lot of information, much of it frequently changing. Many caring people will likely be interested in your condition, and keeping them informed will require continual repetition of updates on your health status. Such communication can become overwhelming during the course of a difficult treatment. Assigning another person, such as a relative or close friend, to manage the collection and dissemination of treatment-related updates (subject to your privacy concerns) can keep others aware of your condition without burdening you with having to convey the information yourself. Letting the Minister of Information handle this also will free more time for you to discuss more personal aspects of your illness and treatment with close supports.
- 4. Designate a “Captain of Kindnesses.”** The onset of an illness often results in an outpouring of support from a community. Organizing and accepting this support so that it is helpful and not onerous can be a significant task. The family or school may want to designate a Captain of Kindnesses, perhaps another parent in your child’s class at school, to manage the offers of support. With someone coordinating offers in this way, generous individuals can be directed to helpful tasks that make them feel useful. This also allows you to identify areas where you could use the most help. Examples of ways that classroom parents and others can help include preparing meals for your family (which can be delivered via the Captain of Kindnesses), driving your child to school and extracurricular activities and helping with shopping and household chores. Please see the appendix for many resources available to assist with this planning.
- 5. Delegate routine tasks.** During your illness, it may be useful to conserve your energy for the important things where your presence is what matters, not the completion of the task, for example, putting your child to bed and attending special events. As you decide what tasks to accept help for and which to do yourself, consider whether your presence or the task’s completion is more important. It is often possible to delegate routine or less important tasks to others. Relatives and friends (or school volunteers) can help with things like routine shopping, laundry, lawn care and snow removal, and they are often eager to have concrete ways they can be helpful.

PARENTING STRATEGY #4: TALKING WITH YOUR CHILD ABOUT DEATH

Many parents with serious illnesses say their children's questions about the possibility of death are the most feared and most difficult to answer. This can sometimes lead well-intentioned parents to avoid discussing death with children or to dismiss the questions altogether by saying something like, "We all die sometime." But doing so can leave a child feeling alone and can perpetuate unnecessary fears.

Most people find it very difficult to think about the possibility of death as they face a life-threatening illness. However, even if your prognosis is excellent, it can be helpful to think about how you can respond to children's questions about death, before they are asked. The more prepared you feel for this conversation, the likelier it is that you will pick up on your children's worries about the possibility of your death. The following are broad guidelines for discussing death with children. These are difficult conversations and we encourage you to talk to professionals or other important people in the child's life as well.

- 1. Realize that children at different developmental stages understand death differently.** A child's developmental stage influences the way he or she thinks about death just as it influences how the child understands illness as a whole. Infants and toddlers do not have a concept of death and are unable to be prepared for death before it occurs. Preschool-age children believe death is reversible and may think that a parent who has died will return later. They may also imagine that their own unrelated actions caused a parent's death. Elementary school-age children understand that death is permanent. They may be more likely to focus on the facts of what happens when a parent dies. Adolescents are able to think about death in the same way adults do. This allows them to imagine how it will feel when the parent is no longer present and can lead the teen to feel very sad about the future.
- 2. Greet and answer questions about death with the same openness and thoughtful response as other questions about your illness.** Many parents avoid talking about death in an effort to protect their children from thinking about it. When questions about death arise, leaving them unanswered or discouraging discussion about death can leave children alone with their worries. This can result in a child's worrying more about death than the illness warrants, or it may leave the child unprepared if death does, in fact, occur.
- 3. Try to discover your child's underlying worries.** Being aware of your child's developmental understanding of death can be helpful in anticipating worries that a child may not express directly. When children of any age ask about death, they are often also worried about their own security. The underlying question may be whether the parent can be relied on to provide support in the future and whether they themselves are safe. When your child asks a question, it is important for you to probe for more information about specifically what he or she is worried about. Exploring the worry in more detail lets your child know it is common to have these worries, and it models the fact that it is safe to talk about the worries with you.

Children often have a fairly narrow time window in mind when they ask about the likelihood of a parent dying. Even if you think it is likely that the illness will shorten your lifespan, you might still reassure your child by saying, for example, "No one is worried about my dying now. I am planning on and doing all I can to live a long, long time, and I will let you know if things change."

- 4. Balance uncertainty with reassurance.** It is difficult to provide children with a balance between realistically acknowledging that future health is not guaranteed and reassuring them about the current stability of the illness. They need to know they will be taken care of, regardless of the course of the illness, and they need to appreciate the importance of life in the here and now. This task can be made even more difficult if the course of the illness or the outcome of treatment is significantly variable. Telling children that the treatment team is working hard to treat the illness and explaining how this is being done can reduce the worry associated with uncertainty.
- 5. When death is likely in the coming weeks, make your child aware.** Let your child know that your illness has progressed despite your best efforts to remain healthy. Give your child the information you have about what to expect as your illness progresses. Allow for continued hope, but encourage preparation for the possibility of death. Give your child the opportunity to let you know about any feelings of regret or guilt they have so that you can give forgiveness. Let your child share any feelings of anger toward you as well, so that you can explain that these feelings are normal and do not diminish the love you share. Tell your child that he or she is well-loved and some of the many reasons why.

SHARING INFORMATION—SAMPLE LETTERS

At some point after your illness is diagnosed and you have told your child about it, you may decide to share the information with your child’s classroom teacher and possibly other school staff. You will want to be sure they understand what your child is going through so they can help support your child and alert you about any behavioral changes they observe in your child.

When you tell the school about your illness, be clear about what your child knows, what kind of communication you want them to have with your child about the illness and whether they should tell others (e.g., other parents in the class). Writing a letter that explicitly states your choices is the most reliable way to present accurate information and avoid errors or miscommunications that may occur later on. It will be helpful to follow up on the letter with a conversation with a trusted member of the school staff, to further describe your wishes and make a plan for supporting your child.

We have put together a template that you might find helpful in composing your own letter. It contains blanks for you to fill in once you have made certain key decisions about what to communicate. In each case, a few alternative items are suggested. Before you start writing, though, be sure you have decided how you want to handle these important points:

Basic information

- How have you described your illness (e.g., the word you have used) and its treatment to your child?
- Who else have you told about your illness?

Your desired level of privacy

- Do you want your child’s teacher, or another educator such as the school nurse, to talk with your child about your illness and their feelings and specific requests about it? (Some children will not want to talk about the illness at all at school.)
- Do you want to inform the rest of the school community or a subset of it (e.g., the other parents in your child’s classroom) about your illness? If so, do you prefer the school to communicate this information or do you want to write a letter yourself?

Requests regarding your child

- Do you want your child’s teacher and other school staff to observe your child for any behavioral or academic challenges?
- Should they communicate directly with you or through a point person designated by you or the school?
- Do you want the school to adjust your child’s workload in any way?
- Do you want the school to alert you if your child’s class will be undertaking any lessons, projects or events that might be particularly upsetting for your child (e.g., a book involving grief or loss)?

Contact information

- Assuming that you are sharing information about your illness, have you designated someone to serve as your family’s Minister of Information? (See “[Parenting Strategy #3](#)” earlier in this section.)
- Again, assuming that you are sharing information about your illness, have you designated someone to serve as your family’s Captain of Kindnesses? (See “[Parenting Strategy #3](#)” earlier in this section.)

SAMPLE LETTER #1: FROM THE PARENT TO THE CLASSROOM TEACHER AND/OR OTHER EDUCATORS

This template is for the initial letter that you write to your child's teacher, the principal or another contact person at school. Your intention is to notify the school about your diagnosis and start a dialog about what will happen next.

Dear (name of educator):

Include basic information:

I am writing to let you know that I have been diagnosed with (name of illness). (Child's name) knows that I (am sick, have X type of cancer) and we have told (him/her) that treatment will involve (type of treatment) over the next (X period of time). At home, we refer to the illness as (words used by the child to understand the diagnosis) and to the upcoming treatment as (words used by the child to understand the treatment plan).

Include requests regarding your child:

It would be very helpful if you could let (me/us) know if you observe any behavioral changes in (child's name). We would also appreciate learning in advance about any school work that may involve cancer, illness, or death, in case these assignments are upsetting to (child's name).

Depending on how your child has been handling school in the past, you might want to say

EITHER (if your child has been doing well):

Our clinical team has reassured us that children who are doing well in school generally continue to do well but might benefit from some accommodations (e.g., reduced workload) at certain times.

OR (if your child has been struggling):

Our clinical team has advised us that for children who are already struggling with academic or behavioral concerns, this can be a particularly difficult time.

Include the family's privacy choices:

Depending on whether you want to share information with other members of the school community, you may want to say

EITHER (if you don't want to share information):

We have decided that at this point we prefer that this information not be shared with other children or their parents.

OR (if you do want to share information):

We think it might be helpful to (child's name) and the rest of our family to share this news with (other parents in the class, the school community). We (plan to write a letter to them, would like to discuss with you the best way of doing this).

Include your child's privacy choices:

Depending on whether your child wants the teacher to check in with him/her, you may want to say

EITHER (if the choice is not to talk about it):

(Child's name) has told us that (he/she) wants school and social activities to be places where he does not need to worry about my health, and (he/she) would prefer not to discuss the illness at school.

OR (if the choice is to talk about it, at least occasionally):

(Child's name) has told us it would be all right for you to check in with (him/her) about how (he/she) is doing and whether (he/she) needs any special help.

Describe plans for further communication:

I hope we can work together to help (child's name) cope as well as possible during my illness.

If you have decided to designate caring others to manage communication and offers of help, you may want to inform the school staff:

Given the challenges of my treatment, our family has designated (name and contact number of the "Minister of Information") as the person to whom other people in the community can direct questions about my illness. (Name and contact number of the "Captain of Kindnesses") has offered to help us out by accepting and organizing any offerings of support from the school community.

I hope we can talk soon and figure out the best way to keep in touch during this time. Thank you very much for your support of (child's name) and our family.

Sincerely,

(Parent's name)

SAMPLE LETTER #2: FROM THE PARENT TO THE OTHER PARENTS IN THE CLASSROOM (OR TO THE WHOLE SCHOOL COMMUNITY)

Some parents prefer to write letters (or emails) directly to other parents, while others prefer the school to handle the communication. If you decide to write the letter yourself, this template might be helpful.

Dear Parent:

I am writing to let you know that I have been diagnosed with (name of illness) and I will be beginning treatment soon. Our child, (child's name), has been told about my illness. I want to let you know about my situation because my treatment may limit my ability to be involved in activities in the classroom. It may also cause some changes in my appearance that your child may notice, and (child's name) may mention my illness to your child.

If you have asked the teacher not to mention the illness explicitly, you may want to say this:

I have asked that the school not address my illness directly in the classroom, but I want you to be aware of it so you can answer questions your child may have.

If your child does not want to discuss the illness at school, you may want to say this:

(Child's name) has told us (he/she) wants school and social activities to be places where (he/she) does not need to worry about my health, and would prefer not to discuss the illness at school.

Include contact information (if you have chosen to identify these supports):

Given the challenges of my treatment, our family has designated (name and contact number of the "Minister of Information") as the person to whom other people in the community can direct questions about my illness. (Name and contact number of the "Captain of Kindnesses") has offered to help us out by accepting and organizing any offerings of support from the school community.

We appreciate your support of our family and your consideration of my wishes during this difficult time.

Sincerely,

(Parent's name)

For the Child

For the Child

We hope the following suggestions will be helpful to children. Educators may want to suggest that parents let older children read this material themselves and that they use it with children of all ages as a springboard for discussions at home.

YOUR PARENT'S ILLNESS

- 1. Be a part of family discussions.** Talk with your family about your concerns. Ask questions about what's on your mind—for example, how long will your parent be in treatment? Will your parent need to be away from home for long periods of time? Will you still be able to do the things that you have always done? Be involved in planning for how to take care of the added responsibilities around the house while your parent is ill.
- 2. Create shared memories.** Your parent's illness may cause changes in the ability to do things that he or she has always done before. While your parent is feeling good, be sure to suggest sharing meaningful activities together to help everyone cope with the stress of the illness. If your parent develops more symptoms that limit his or her activities, you may need to be more creative and figure out some new ways to share each other's company, such as sharing movie nights or exploring new activities that do not require significant physical activity (art, knitting, reading). Sharing in the discovery of new interests can be a nice way to stay connected amidst the many other changes in your family's life.
- 3. Don't worry alone.** Many children do not like to talk to their sick parent about their worries because they don't want the parent to worry about them or because they think their worries are silly. However, when these worries are not discussed, there is no opportunity to determine how realistic they are. By talking through your worries you can figure out their likelihood, and you can focus your thoughts on preparing yourself for what is more likely to happen.
- 4. Maintain healthy routines.** Sometimes, a parent's illness requires many adjustments in a family's usual schedule. It is important to try to maintain your usual schedule and routines as much as possible. These include school, hanging out with friends, extracurricular activities and household responsibilities. Structure and routine provide a sense of security and remind you that much of your life remains the same, even with this difficult new challenge that your family is facing.

- 5. Let other adults care for you.** While your family is dealing with illness, they will likely need to focus more on your parent's health and treatment. This does not mean that they care any less for you or think that you are less important. Your parents will need to make decisions about when they are able to help you with something themselves and when they need to ask a trusted adult to help you. For example, a relative or family friend might drive you to school or activities. Be involved with your parents in determining some trusted family and friends with whom you will feel comfortable when you need support.
- 6. Think about your own goals.** Your parent's illness will bring with it new worries and responsibilities. Sometimes it can be difficult to find a balance between providing support for your parent and continuing to work toward your own goals. During your parent's illness, you will still encounter new academic and social experiences and challenges. Let yourself continue to focus on your own goals and relationships. When your parent sees that you are having positive experiences, it will reduce worry about how the illness is affecting you. Staying busy in ways that are not related to your parent's illness can also better equip you to be supportive to your parent when needed.

Additional Resources

Additional Resources

This section contains a list of helpful resources beyond what is possible to include in this toolkit—organizations and websites providing support to parents and children; resources aimed particularly at children; and a list of helpful books.

MARJORIE E. KORFF PARENTING AT A CHALLENGING TIME (PACT) PROGRAM

mghpact.org

Parenting At a Challenging Time (PACT) is a program based at the Massachusetts General Hospital Cancer Center. The website contains many resources, such as guidelines for parents as they work to understand how best to support their children and families while they navigate their own diagnosis of cancer and a list of publications by PACT staff members for parents and professionals.

OTHER ORGANIZATIONS AND WEBSITES

American Cancer Society (ACS)

cancer.org

Provides information on talking to children about cancer, as well as numerous other cancer-related topics.

American Psychosocial Oncology Society (APOS)

apos-society.org

Provides a free helpline to connect patients and families with local counseling services, as well as webcasts for professionals on topics such as “Cancer 101 for Mental Health Professionals” and “Psychosocial Aspects of Cancer Survivorship” (co-sponsored by the Livestrong Foundation).

American Society for Clinical Oncology (ASCO) – People Living With Cancer

cancer.net

This organization’s website offers a variety of educational information for patients and families.

BreastCancer.org

breastcancer.org

Provides medical information about current treatments and research in breast cancer care and survivorship.

Camp Kesem

campkesem.org

A camp run by college students that provides children affected by a parent’s cancer with a life-changing camp community that recognizes and understands their unique needs.

Cancer Care

cancercares.org

Provides free professional help to all people affected by cancer through counseling, support groups, education, information, referral and direct financial assistance. The organization offers online, telephone and face-to-face support groups to those affected by cancer.

**Cancer Support Community
(The Wellness Community)**
cancersupportcommunity.org

National nonprofit organization providing free online and in-person support and information to people living with cancer and their families.

Comfort Zone Camp
comfortzonecamp.org

Comfort Zone is a free bereavement camp for children who have experienced the death of a parent, sibling or primary caregiver. It includes confidence-building programs and age-based support groups that work to break down the emotional isolation that grief often brings. The camps are offered to children ages 7-17, and are held year-round across the United States. The offices are located in:

California
Massachusetts
New Jersey
Virginia

Council of Dads
councilofdads.com

Bestselling author Bruce Feiler was a young father when he was diagnosed with cancer. Worried about his daughters, he asked six men to form a “Council of Dads” to help guide them through their lives. This site is designed to help other parents, male or female, do the same.

Cove Center for Grieving Children
covect.org/programs

Provides family and children’s programs designed to address the unique needs of children and teens in Connecticut who have experienced the death of a significant person in their lives. The main focus of all Cove programs is to help grieving children and teenagers learn healing and coping strategies, as well as creative communication that helps validate their emotions and guide them toward transforming their unresolved grief.

**Dougy Center: The National Center
for Grieving Children and Families**
dougy.org

Offers free support in a safe place where children, teens, young adults and their families grieving a death can share their experiences. The center offers support and training locally, nationally and internationally to individuals and organizations seeking to assist children in grief. The organization is supported solely through private support from individuals, foundations and companies.

Kids Konnected
kidskonnected.org

Provides friendship, understanding, education and support for kids and teens who have a parent with cancer or have lost a parent with cancer. The website contains a variety of helpful resources and information on groups and camps that support children and their parents.

Livestrong Foundation
livestrong.org

Offers information and services to cancer survivors and the professionals who care for them.

Living Beyond Breast Cancer
lbbc.org

A national education and support organization whose goals are to improve the quality of life after breast cancer and to help patients take an active role in ongoing recovery or management of the disease.

Lotsa Helping Hands
lotsahelpinghands.com

Provides free, private, web-based communities for organizing friends, family and colleagues—your circles of community—during times of need. Families can easily coordinate activities and manage volunteers using this organization’s intuitive group calendar.

Massachusetts General Hospital Cancer Center – Helping Kids Cope
massgeneral.org/cancer/helpingkidscope

Dedicated to addressing concerns when either the parent or the child has cancer. Provides useful information on a wide range of cancer types. The Helping Kids Cope program at the Mass General Cancer Center provides a helpful book list for parents and children.

National Cancer Institute
cancer.gov

Offers information about cancer types and treatments, as well as information about coping with cancer. NCI has published a helpful booklet called *When Your Parent Has Cancer: A Guide for Teens*.

Rainbows International Grief Support For Children
rainbows.org

International children’s charity dedicated to helping youth successfully navigate the very difficult grief process.

Young Survival Coalition
youngsurvival.org

Through action, advocacy and awareness, seeks to educate the medical, research, breast cancer and legislative communities and to persuade them to address breast cancer in women 40 and under. It also serves as a point of contact for young women living with breast cancer.

RESOURCES ESPECIALLY FOR CHILDREN

Sesame Street – When Families Grieve sesameworkshop.org/grief

Provides kits (available in English and Spanish) containing a DVD, a guide for parents and a *Sesame Street* children’s story. The website presents families’ personal stories about coping with the death of a parent as well as strategies that have helped these families move forward.

Arthur – When Someone You Know Has Cancer assets-livestrong-org.s3.amazonaws.com/media/site_proxy/data/5c300d79915fa5bb590fd913d4252047d564b3a9.pdf

A cartoon activity booklet is provided by Livestrong for families based on the episode of *Arthur* called “The Great MacGrady,” in which Arthur and his friends all react differently to the news that Mrs. MacGrady has cancer.

HELPFUL BOOKS

McCue, Kathleen. *How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist*. New York: St. Martin's Griffin; 2011.

dePaola T. *Nana Upstairs and Nana Downstairs*. New York: Puffin Books; 1973. A storybook about death.

Faber A, Mazlish E. *How to Talk So Kids Will Listen and Listen So Kids Will Talk*. New York: Harper Resources; 1999.

Fitzgerald H. *The Grieving Teen: A Guide for Teenagers and Their Friends*. New York: Fireside Books; 2000.

Harpham WT. *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York: Perennial Currents; 2004.

Kremenz J. *How It Feels When a Parent Dies*. New York: Knopf; 1981.

Rauch PK, Muriel AC. *Raising an Emotionally Healthy Child When a Parent Is Sick*. New York: McGraw-Hill; 2006.

Viorst J. *The Tenth Good Thing About Barney*. New York: Aladdin Paperbacks; 1988. A storybook about death.

ACKNOWLEDGMENTS

We appreciate the work of Bonnie Ohye, PhD, and Jeffrey Bostic, MD, who were authors on previous toolkits and whose content has been referenced in the creation of this toolkit. Special thank you to all the families who have shared their parenting challenges with our PACT clinicians since the beginning of this program in 1996. Their combined wisdom and dedication to their children has been at the core of our collaborative work.