**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.
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.
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.
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.
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.

**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.
2. **Organise 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.
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 organising your time. These can include meal times, recurring events (e.g., sports practices, games), shared interests (e.g., music, television shows), holidays and family gatherings.
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.
5. **Minimise 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.

**ORGANISING 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.
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.
4. **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 and gardening, and they are often eager to have concrete ways they can be helpful.

**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. **Realise 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. Primary 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.

Tips taken from:

