



Tips for the *journey*

A guide from



Lost & Found
grief center



This booklet is designed to help you and your family navigate the changes you are facing due to a serious illness. The ideas come from healthcare professionals, child development and mental health professionals, and the experiences of other families who have been a part of the Journeys' program at Lost & Found Grief Center.

This booklet does not need to be read in one sitting. Neither is it meant to be a list of things to do. In fact, no one can or should do everything listed! Rather, this booklet is intended to give suggestions you can consider when you encounter specific challenges and would like ideas that have helped other families. We hope this booklet will be an encouragement to you as your family's story unfolds.

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Communicating About Illness and Treatment

Be Honest

Children and teens can sense when something serious is happening in the family. If they are not told the truth, they often imagine something even worse than the truth. Children are resilient and will be better able to cope with difficult changes if they know what they are facing. Finding an adult who expresses gratitude about being lied to as a child is extremely rare. However, many adults express gratitude that their family communicated openly and honestly about difficult topics.

Use Age-Appropriate Language

Children do not need to be told all the details about a diagnosis or treatment plan, but they do need to hear the basic facts in age-appropriate language. You can find helpful resources online that give age-appropriate terms for discussing a variety of diagnoses and treatments. These can be found by using the search term "how to explain (name of diagnosis or treatment) to children," or "how to explain (name of diagnosis or treatment) to teens."

Use "We" language

As often as possible remind your children that you are there for them, and that you will get through this tough time together. Use phrases such as "We will get through this;" "We may not know exactly how, but together we can do this;" "We are having a tough time and we can help each other manage;" and "We are a team."

Talk About the Medical Team

Learning about the medical professionals who are treating the person who is ill can be reassuring to children. When children are told that a medical team is working together and doing its part to help the person who is ill, the treatment process can become less mysterious for them. This also gives children a sense that the person who is ill is being well cared for and is doing what he or she can to treat or manage the illness.



Address Misconceptions

Periodically asking children and teens what they understand about the illness or current treatment processes will create opportunities to correct misunderstandings. Young children particularly need to know the illness is not their fault. Additionally, children and teens with Internet access will often search for medical information but may not be able to determine what is and is not credible information. Children may need to hear explanations multiple times in order to develop a more accurate understanding. As children and teens reach new cognitive milestones, they will typically have new questions.

Prepare for Treatment Side Effects

When children are sick, they usually take medicine, begin to feel better, and return to normal functioning. Because of that experience, they will not automatically understand that treatment protocols for serious illnesses may cause the person who is ill to feel worse and experience limitations or restrictions. To help children cope with these changes, talk with them before procedures and new medications, preparing them for the fact that there might be side effects. Let children know of potential changes in the person's appearance, movements, behaviors, or feelings. Also, children often worry how much pain the ill family member is experiencing; thus it is helpful to let children know how the pain is being managed.

If Needed, Prepare for Goodbyes

Reassure your children the person who is ill is doing what he or she is able to do to get better. If the illness progresses to a point where treatment is no longer an option (or if the person who is ill chooses to discontinue treatment), gently let your children know so they can make the most of the remaining time with their loved one. Help children identify meaningful ways to say goodbye at the appropriate time. Many children who were not told of an impending death of a family member live with regret over things they wish they could have said or done to express their love before the opportunity was gone.

Emotion Coaching

Children and teens typically need help identifying and expressing the wide variety of emotions they feel when a loved one has a serious illness. They also need to have their feelings validated and normalized.

Due to the stress of the illness and treatment, children and teens often have less emotional capacity to deal with other stressors in their lives, which can lead to overreactions to seemingly small issues. Help your children and teens to know there is a gap between what they feel and what they do. They can learn to control their behavior by choosing healthy ways to express their feelings instead of reacting instantly without thinking.

Concepts that children and teens need to learn

Emotions are neither good nor bad in themselves. They are tools that help us understand ourselves and are either comfortable or uncomfortable to experience. For example, feeling angry about something can give us the energy needed to change what we can about a difficult situation.

Feeling many different and even contradictory emotions at the same time is normal.

We may not have control over what we feel, but we can learn to control how we behave and what we say.

All feelings are okay.

We all have control over the activities we choose to do in our free time, and the activities we engage in do have an influence on how we feel. Help your children identify and participate in activities that tend to make them feel better.

When feeling an emotion, ignoring or "stuffing" the emotion can create problems. Stuffing emotions requires a lot of energy that could be used for other things and often leads to damaging blowups later.

Tips on coaching your children as they learn to regulate emotions and cope with challenging times

Help your children label and discuss their emotions.

- Play games that teach about feelings. You can find age-appropriate games online by searching for “feelings games” or “emotion regulation activities.”
- Read books about emotions with your child. Asking children, “Why do you think the character pictured here might feel sad/scared/lonely?” can give them a safe way to talk about what they themselves are feeling.
- Use puppets, play telephones, or stuffed animals with younger children, as these offer a safe way to share feelings.
- Discuss emotions with older children and teens when you are not face-to-face, such as in the car or while doing household chores together. These types of situations often create a safer environment for teens to open up about emotional topics.

Let your children know that when they feel intense emotions, they can ask to take a break and choose a healthy way to express the emotion.

A break helps them calm down, before they respond to the situation that created the intense feelings. For example, a child’s classmate might tease him or her about having a sick family member. Instead of responding in anger and hurting the other child, your child can ask for some time to talk with a trusted adult before deciding how to respond to the classmate.

Brainstorm healthy ways to express feelings with your children. At a time when life is relatively calm, create a coping box and/or list with your child.

- The list can include topics such as, “When I feel sad/angry/frustrated/embarrassed/happy/worried) I can....” The list can include what to do specifically when experiencing the feelings in different places, such as at school, home, a store, or a friend’s house.
- Based on the ideas on the list, help your child put together a coping box (or portable kit) that includes items such as facial tissues, a stress ball (or other fidget toys), and drawing materials.
- You can also designate a special corner in your house as the “feelings corner” where any member of your family can go when feeling overwhelmed. Include various coping tools in the corner such as a punching bag, large stuffed animal, jump rope, small bouncy ball, and calming scents.

Help your children use technology responsibly when they are stressed.

Take time with your children to identify a variety of apps that can help them express their emotions and/or calm down from intense emotions. Monitor your children as they use technology to ensure they are not ignoring emotions or withdrawing from others for extended periods of time.

Coping with Changes

A serious illness brings many changes to a family. Often, just as your family is getting used to a treatment regimen, a side effect of a medicine, or an illness symptom, something about the illness or treatment could change and throw your family life into upheaval. Next are tips on how to ride the waves of change that confront your family.

Give each family member plenty of grace.

Coping with a serious illness is hard work. Remember family members are doing the best they can under tough circumstances. Let your children know you appreciate their efforts whenever they attempt to be flexible (whether the attempts are successful or not). Have patience with each other as you try new ways of coping and find creative ways to demonstrate love to each other.



Make sure your children know each morning who will be taking care of them at various points of the day.

Keeping children and teens informed about who will take them to school, pick them up from school, take them to extracurricular activities, and where they will sleep each night allows children to plan and feel more secure.

Remember the basics.

Human beings tend to feel cranky when they are dehydrated, hungry, or overtired! When family members are stressed, the best first step is to make sure these basic needs have been met.



Let go of expectations when appropriate.

Life isn't the way your family anticipated it would be. Adjusting the expectations your family has of life, of each person in the family, and what family life should look like can decrease stress levels.



Give your children choices.

When coping with an unpredictable illness in the family, children need to feel a sense of mastery and control as often as possible. This can be accomplished by giving them small choices.

Communicate less about daily chores.

For children, consider making or buying a visual schedule consisting of pictures of daily activities that have a magnetic backing for posting on the refrigerator or a magnetic board. The pictures can also be a visual reminder to children of their chores, and the magnets can be moved from a “to-do” side to a “done” side. This can decrease the amount of communication necessary to ensure chores are completed. A similar visual system can be used with a family calendar for older children and teens.

Let your children know how they can help.

Let your children know what they specifically can do to help the person who is ill. Giving your children concrete ideas will help them feel helpful as they face the changes brought by the illness. Sometimes you may need to let children know that the best thing they can do is to give the person who is ill (or the caretaking parent) space for a specific amount of time. At other times you may need to ask your children or teens to take on extra chores around the house. Explain to your children that they can also help by continuing to focus on doing their best in school and by taking time to do things that are fun. Having moments of fun can recharge children, teens, and adults which results in more energy to handle changes.

When appropriate, allow children to help take care of the person who is ill.

Limit children’s exposure to participating in difficult medical caretaking activities. For example, children can help by getting a glass of water or a blanket. Asking children to do something such as participating in dressing changes for a wound should typically be avoided. If caretaking duties are overwhelming, consider asking the medical team about palliative in-home care options.

Regularly schedule time for family meetings to talk about the difficult things as well as the happy things that are happening.

This will help family members keep life in perspective and is a reminder that the family is more than the illness. Family meetings provide a good opportunity to update family members on the illness and treatment, and to let children ask questions. This reassures children you will keep them informed about the progression of the illness and that they won’t be kept guessing about what might be going on. If you sense your children have questions they find difficult to ask aloud or feelings they find difficult to express, keep an interactive journal or question box in which each child writes his or her questions or statements. For example, they might write, “Will mom lose her hair from the chemo?” or “I hate that you and Dad didn’t get to go to my basketball game.” You can reply when you feel able to do so.

Coping Through Play

Play is the primary way children make sense of their world. Intentionally creating opportunities for play will help your family better cope with challenging times. Remember, even during difficult times, taking time to have fun as a family is healthy.

Large-Muscle Play

Intense emotions such as anger, helplessness, and frustration can create energy in the body. A good way to discharge the energy safely is through large-muscle play.

This type of play can include:

- running
- playing on playground equipment
- doing gymnastics
- dancing
- jumping rope
- playing team sports
- participating in drama club or marching band
- participating in a program such as Boy Scouts or Girl Scouts
- participating in a civic club, such as a group that picks up trash

If your children are already involved in a sports team or club of some type, try to find ways to continue that involvement if possible. Often groups that children or teens are already involved in become positive sources of support during tough times. However, if continuing is not possible, make sure your children have opportunities for alternate large-muscle activities and connecting with peers.

Small-Muscle Play

Small-muscle play typically includes use of the hands or face. These activities can help children who seem to be picking at things (e.g. picking at the tablecloth, picking at their sibling).

This type of play can include:

- playing a musical instrument
- playing video games
- making funny faces
- cooking or baking food
- manipulating playdough or concocting slime
- drawing
- fashioning jewelry
- doing craft projects
- creating scrapbook pages or collages

Many of these ideas can also be used to make an encouraging gift for the person who is sick or for the other parent/caregiver who is doing extra duties to keep the family functioning.



Medical Play

Children often feel helpless when facing a family member's illness and one way to facilitate a sense of mastery and control is through medical play.

Give your child the opportunity to play "doctor."

- Help your child choose a doll or stuffed animal that will be the "patient." Blank muslin dolls are particularly effective as they give children the opportunity to create the patient exactly as desired (these can be purchased, or instructions on how to make the dolls are available online).
- Provide medical items, such as a toy medical kit, bandages, medical tape, medical scissors, masks, gloves, irrigation syringes, cotton balls, gauze, and tongue depressors.
- You can also provide other play items that can represent the illness or treatment. For example, a ball made out of playdough can be used to represent a tumor, or a camera in a square box can be used to represent a CT scanner.
- Let your child play "doctor" or whatever member of the medical team he or she chooses.
- Let your child control the play and follow his or her lead.

Additionally, you can purchase medical play items, such as miniature wheelchairs, to be used with a playhouse or in a sand tray.

Medical items needn't be limited to playing doctor; they can also be used creatively in craft projects. Using medical items in a fun way helps decrease children's anxiety related to their loved one's illness and treatment.



Calming and Soothing Activities

During high stress periods, children need ways to calm or soothe their nervous systems.

Activities that can help include:

- blowing bubbles
- making calming glitter jars
- creating a find-it bottle
- playing barber shop or beauty shop
- daydreaming about a safe or happy place
- playing with sand or water
- running their hands through items such as uncooked rice or beans
- coloring or finger painting
- playing with shaving cream

Other activities that are calming and help family members take a break and focus on something other than the illness include:

- writing a letter or email to a friend
- giving and receiving hand or foot massages
- deep breathing
- asking for a hug
- meditating
- praying
- doing yoga or Pilates poses
- counting forwards or backwards
- walking in nature
- reading
- rocking in a rocking chair
- singing
- taking a bath
- watching fish swim
- eating comfort food in moderation
- popping bubble wrap
- learning a new language
- rhythmically bouncing a ball
- doing jumping jacks
- journaling in pictures or words

The use of technology in moderation can also be helpful, but preferably should not be used close to bedtime, and should be monitored to make sure the activity is not emotionally draining or anxiety inducing.



Memory-Making Activities

Family activities often end up at the bottom of the priority list due to all the tasks required to deal with a family member's serious illness. However, finding time to create new, positive family memories is vital to the emotional health of your family. These activities can be simple and don't need to take a lot of time. Doing fun activities together nurtures strength for the hard times.

Consider:



Create handprint collages that include each family member's handprint. Make one for each member of the family to keep. This can be done once a year to mark the growth of each person in the family.



When the person who is ill is feeling able to answer questions, children can act as journalists or family historians by writing a story about each person in the family and their lives so far.

This can be done, even by young children, through asking easy questions such as each person's favorite color or song.



Purchase a plate or platter and have family members use indelible markers to draw or write on the plate. They may write what they are thankful for or words they feel describe the family.



If the person who is ill has a hobby, he or she can share life-lessons learned from participating in the hobby. This can be digitally recorded.



Technology can provide creative adaptations for family playtime.

For example, avatars in online games can be controlled with minimum movement by the person who is ill. Or, the family can take a virtual vacation together by watching travel shows and researching more facts about the location on the Internet.



When possible, plan simple outings that can be done spontaneously whenever the person who is ill has a few hours of feeling well.

Identifying Sources of Support

For children and teens in the family:



Create a contact list (including phone numbers) of supportive people your children know from school, church, the neighborhood, or other community groups in which your family is involved. Make sure the supportive people are ready to be called upon.



Ask the medical team if there are medical professionals who might be able to serve as supportive resources to your children such as child life specialists, psychologists, social workers, or chaplains.



Read age-appropriate books about the human body and books about specific illnesses with your child. Reading nonfiction books will increase children's understanding of health-related topics. Additionally, reading biographies and fiction books that give examples of how others have coped with illness in their families can encourage children and teens.



Inform your children's school counselors and teachers about the illness and ways they can help your child cope at school. Talk with your children before talking with the school staff to learn what your children themselves feel would be helpful, and with whom they feel comfortable sharing information.



Make sure children know contingency plans for emergencies to help reduce their anxiety about the unexpected (e.g. if the person who is ill suddenly needs to be hospitalized during the day, their aunt will pick them up from school).

No one should go through tough times alone.

Finding resources within your community may take time but will be worth the effort.

For adults in the family:

Choose at least two trusted friends to play specific roles. You may want to rotate through several friends, perhaps asking different friends to take on these roles for one or two months at a time.

Minister of Information

Ask a reliable friend to be a “minister of information” to communicate updates you provide to family and friends.

You can refer others to the minister of information for the latest information. You can also let the minister of information know exactly what type of information to give to different people.



Find reputable resources related to your specific situation.

Consult medical or local librarians when searching for reliable information about illnesses and treatments.

Ask a friend to look online for additional resources. Having a friend do online research can spare you from reading worst-case scenarios that are typically worry-inducing and not helpful.

Look for a local or online support group created to help families facing the specific illness with which your family is coping.



Captain of Kindness

Select a person to be a “captain of kindness” to coordinate offers of assistance from friends and family.

Update the captain of kindness on specific things your family needs, such as taking children to activities, mowing the lawn, delivering meals or restaurant gift cards, or sending encouraging or humorous notes.

When family members or friends ask how they can help, refer them to the captain of kindness.

Your family and friends really do want to help! As the saying goes, friendship is built on mutual debts. Ask for help when needed! Remind yourself you will have the opportunity to return the favor in the future.



Looking to the future with hope



As you walk this illness journey as a family, take hope that the tough times can have a silver lining. Even in the midst of dark days, humans, and particularly children and teens, can be resilient. Whatever the result of the illness, instead of bouncing back to the way things were before the serious illness, you can each arrive at a different place having grown in positive ways as a result of the challenges.

Even though you did not choose the suffering, you can choose to make something redemptive out of it. Families who pull together to face hard times in supportive ways can cultivate deeper levels of empathy and compassion, values that are sorely needed in the world.

Going through difficulties is an opportunity to grow closer as a family, to teach children and teens coping skills they will use throughout their lifetimes, and to learn just how strong your family can be.

Remember, amid this stormy time in your family's life, don't forget to play in some puddles and search for rainbows along the way!

Lost & Found Grief Center's Journeys Program provides support to families and adults coping with the advanced serious illness of a loved one. Please call the Lost & Found office for more information.



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We strive to improve lives in our community by providing help, hope, and healing through professional grief support services.