# Children as Caregivers for a Loved One With Cancer

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# Children as Caregivers for a Loved One With Cancer

## TABLE OF CONTENTS

All people depicted in the photographs in this booklet are models, used for illustrative purposes only.

*Dealing with a family member or another loved one with cancer is difficult for anyone. For children who also have caregiving duties, the challenges can be even harder.*

When a parent, grandparent, sibling or friend gets sick, the impact is tremendous. Relationships change along with responsibilities, along with emotional turmoil.

Caregivers come in all shapes and sizes, and caregivers help their loved ones in many different ways. A caregiver is anyone who helps someone who needs it. Older children, including teenagers, have capabilities that young children do not have, but even the youngest among us provide love, care and support. Studies show that as many of 7% of all caregivers in the United States are children under the age of 18.

Whether they provide this support daily, weekly or on occasion, children have their unique needs as well as how they view the world. This booklet is intended as a companion to our other title, "Talking to Children When a Loved One Has Cancer," which goes into more depth about discussing details of the actual diagnosis and treatment. This booklet will discuss how children provide help as caregivers and how the adults around them can help them.

# Children as Caregivers

Children of all ages may find themselves as cancer caregivers. Their abilities and what they can handle, however, depend on their age and understanding. Regardless, what they provide can have enormous benefits, whether the actions are large or small.

## Practical Forms of Care

A wide range of physical tasks can help a family dealing with cancer. These help conserve time and energy for the person with cancer to concentrate on treatment and getting better. These tasks do not have to be related to the diagnosis or treatment themselves.

Everyday forms of help include:

- Doing chores and cleaning around the house
- Fixing meals
- Caring for pets
- Running errands and shopping for groceries

These can depend on what the child is capable of doing. For example, a teenager can drive to pick up groceries or supplies, while a young child can walk the dog or make sure the pets are fed.

Older children can also help with treatment-related responsibilities. These include:

- Scheduing and keeping track of appointments
- Assisting with medication and dosages
- Transportation to appointments
- Taking notes and asking questions during appointments

These duties are more complex, but a capable adolescent or teenager can often do them. Other examples include helping translate, keep track of bills or organize documents. If it is a parent who is sick, the older child may take some charge of their siblings.

## Emotional Forms of Care

Not all caregiving is of a physical nature. Helping a loved one also involves their emotional wellbeing. The youngest children can lift the spirits, while older children can have deeper conversations about treatment and beyond.

Emotional caregiving includes keeping the loved one company, encouraging mindfulness, participating in exercise, asking how they would like to handle special events and more. Especially in the case of siblingsbut even grandparents and other adults, kids enjoy a sense of play, which helps everyone recharge and bond.

## Helping Other Caregivers

A child taking care of chores can free another family member to spend more time focused on the one with cancer or refresh their own energies. Doing their homework in a timely way, fixing dinner, shopping for groceries or taking care of pets can free an adult to do more complex things.

# Communicating With Children

You know your child best, what they can handle and understand. However, it is common for parents to withhold information to protect their children. This is understandable as an impulse, but may do more harm in the long run. Children are perceptive and know that something is wrong. They may fill the gaps of silence not only with fears and worries of their own, but incorrect thoughts and assumptions. Consider this framework to help your child:

**Clarifying relationships and needs**. With their world shifting around them, they will benefit from knowing what to expect. Will mommy be sleeping more often? Who will get them dinner? Will they still be going to school?

**Help them define who they are.** Children can be uncertain of their role within family units during sickness. Understanding their role and duties – including homework, going to bed on time, and so on – can help.

**Keep the communication open.** Create a time or place for questions about the diagnosis, treatment and expectations. This will let them feel more in control of what they know and safe in who they are.

# The Impact of Caregiving On Children

Not only must a child who is a caregiver react to their loved one's diagnosis, they must face the impact of their additional responsibilities. Children show what are called somatic responses, which are when emotional distress shows in physical symptoms.

- Headaches and stomachaches
- Separation anxiety
- Stress and lack of sleep
- Confusion, worry

These can result in missing classes, inability to focus on homework, acting out and other behaviors. They may try to hide their emotions, because they are seen as problems for others. Parents may not realize how hard their children are taking the situation, as they concentrate on their larger concerns.

Fortunately, for many children, these stress responses do get better over time, but can take time and attention. Helping a parent, sibling or other person get through treatment can even have some benefits of growth as they reaffirm bonds with others, strengthen their own sense of purpose and maturity and show new responsibilities.

However, these effects are vastly improved when normality is retained – when parent-child and other roles are reaffirmed and the duties of caregiving and handling cancer come along with being and remaining a child.

# Managing the Stress of Children

Children greatly benefit from the structure of their ordinary lives, from going to school, to doing homework, to seeing friends and participating in favorite activities. This isn't always easy when a loved one has cancer.

If possible, see if you can address some of these concerns for your child:

- **Feeling Isolated.** Dealing with cancer can make your child feel alone and different from their peers.
- **Struggling at School.** Keeping up with schoolwork and maintaining grades can be difficult given other responsibilities.
- **Missing Friends and Activities.** Your child may feel like the world and formative experiences are going on without them.

Finding time for them to feel special, be with friends and simply be a child helps refuel their energies for future caregiving while continuing to learn and grow.

Whether they are taking care of a sibling, parent, grandparent or anyone else, children often try to hide their worries, not wanting to add to everyone's challenges. These invisible burdens can accumulate and have consequences. A child is still a child.

- **Validate and normalize their emotions.** Guilt, frustration and resentment are real feelings. They may also feel separate and different from their peers, and that everything is "unfair."
- **Discuss the diagnosis.** Using simple words about the diagnosis and treatment will help them understand and be more confident about the situation.
- **Set up times each day to discuss their feelings.** A set time can make them feel safe to share their feelings while still being a kid at other times.
- **Encourage open communication.** Ask them what they may want to know, or not know, and tell them that it is okay to not want to know everything.
- **Maintain routines and structure.** Structure sets expectations of what to do and when, giving a sense of safety and confidence.
- **Help maintain boundaries.** Allow them to say 'yes' or 'no' to new requests and to prioritize themselves as needed.
- **Ask how they want to be involved.** Do they want to be at appointments or know how decisions are made? Allow them to change their mind, if they would like.

Be open and honest with each other. With internet and social media, more information is accessible, which can be both good and bad. Let both of you be open and honest.

# Adjusting to New Roles Within the Family

Cancer can overturn the dynamics within a family. A parent might suddenly be weakened and require more help around the house. An older sibling might need help from a younger brother or sister to do things they could have easily done before.

These changes can be difficult to navigate emotionally and in terms of self-identity. It can be scary when an older, athletic brother is now very sick, or a mother who could help with homework is now foggy from her chemotherapy treatment. A range of emotions are completely natural. As much as they are motivated by love and devotion, a child may also feel resentment or even jealousy for the attention they receive.

Try to validate and work with these emotions, which is better than hiding them. Emphasize new bonds that are formed as well as new personal strengths and abilities. Changes can be framed not as requirements but new opportunities for growth, love and learning.

Whenever possible, prepare your child for upcoming changes in treatment. Maintain routine as much as you can and seek ways to make them feel special and appreciated.

# Holidays and Special Occasions

Holidays, birthdays and special occasions are some of the most important events in a child's life. Usually, these moments are filled with joy and celebration, but for young caregivers they take on a different tone. Guilt for wanting to celebrate, sadness that things are not the same as before, or even anger and confusion.

Giving children more control over the event may soften the impact of how different things are this year. They can decide on what is important to them and what to prioritize in terms of activities to do or traditions they want to uphold.

It is perfectly understandable to feel as if things are 'wrong,' or different, but there are still opportunities to make things special and create new memories. Some tips:

- Prepare and plan for what to do ahead of time
- Ask your child about what traditions they want to keep, change, or simplify
- Consider smaller, quieter gatherings
- Find creative ways of including the loved one – in person, virtually or symbolically by way of mementos or keepsakes

Ask what is important to your child – to take a break from caregiving, spend time with friends, do as much as you usually do or something different?

# School and Other Activities

The network of outside relationships can provide an important foundation for a child's wellbeing. This starts with school, where they receive the benefits of structure and activities. In many cases, children enjoy going to school while being caregivers, as it gives them a change of scenery and allows them to see friends, but they may bring their emotional burdens to school, show distraction and have trouble focusing.

Schools may have counselors or other staff that can help. It's a good idea to inform the school about your family's situation, your child's duties at home and their emotions. Teachers and coaches can keep an eye on them so that they can address changes in a healthy manner. You can discuss with them how much of information should be shared with anyone else. They can also arrange for how work and tests should be done.

One-on-one counseling, connecting with a mentor or peer matching (speaking with others in similar situations) and support groups can also boost a child's resilience in addition to what outside organizations can offer.

# Cancer*Care*'s Free Support Services and Programs

It can be very difficult to handle cancer along with the needs of your loved ones, and adjusting to the necessary changes in your life can be challenging.

Cancer*Care* can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how Cancer*Care* helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.

# Communicating With Your Health Care Team

As you manage cancer and caregiving, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

**Start a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with the diagnosis and its treatment. You can separate your journal or notebook into different sections to help keep it organized.

**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific as possible.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.

**Bring someone with you to your appointments or have them be present during telehealth sessions.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person you bring may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, like a tablet or smartphone, ask if you can use it to take notes. Writing notes will help you review the information later.

**Incorporate other health care professionals into your team.** Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care physician or your specialist if needed.
- Ask your oncologist to send a summary of your visits to your primary care physician and all doctors involved in your care.

Remember, there is no such thing as over-communication.

## MORE ABOUT CHILDREN AS CAREGIERS

# Frequently Asked Questions

**Q: Counseling or support groups might be good for my loved one who is a caregiver. How do I bring this up to them?**
A: Although your loved one may benefit from counseling or a support group, they may resist if approached directly. Try to avoid using guilt or other strong demands that may trigger their fears or uncertainties. They should always seek counseling from their own desire.

Instead, you could say, “You haven’t been yourself lately,” or, “I’ve noticed you’ve not been sleeping well.” You could then suggest that there are professionals that have helped others with these situations. Try to normalize getting help, saying that many people do it, and that there is nothing wrong or unhealthy about seeking care for themselves. In fact, it is quite the opposite.

**Q: Are there studies showing the effects of cancer caregiving on child development?**

A: Children are incredibly resilient. Most children eventually rebound from the challenges they face and there are even some benefits from caregiving, from feeling grown-up and useful, seeing oneself as a natural leader to knowing how to be a good and empathic friend. There are developmental milestones met while going through these times, but ultimately the fears and worries about a sick loved one are very difficult and have a lasting impact.

There is a balance between recognizing the strengths of being a child caregiver and making sure that we protect young caregivers and ensure that they can grow and develop as children. Do not be afraid to seek counseling, support groups and other forms of assistance, both for your loved ones and for yourself.

# Resources

**CancerCare® for Kids**
800-813-HOPE (800-813-4673)
www.cancercare.org/forkids

**American Cancer Society**
800-227-2345
www.cancer.org

**National Cancer Institute**
800-422-6237
www.cancer.gov

**Sibling Support Project**
425-362-6421
www.siblingsupport.org

**SuperSibs!**
888-417-4704
www.supersibs.org

**The Dougy Center**
503-775-5683
www.dougy.org

## BOOKS

**Butterfly Kisses and Wishes on Wings**
By Ellen McVicker www.butterflykissesbook.com
2006

**How to Help Children Through a Parent's Serious Illness**
By Kathleen McCue, MA, CCLS and Ron Bonn
St. Martin's Griffin; New York, New York
2011

**Cancer Hates Kisses**
By Jessica Reid Sliwerski and Mika Song
Dial Books: New York, New York
2017

This booklet was made possible by Eisai Inc. and Pfizer.

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