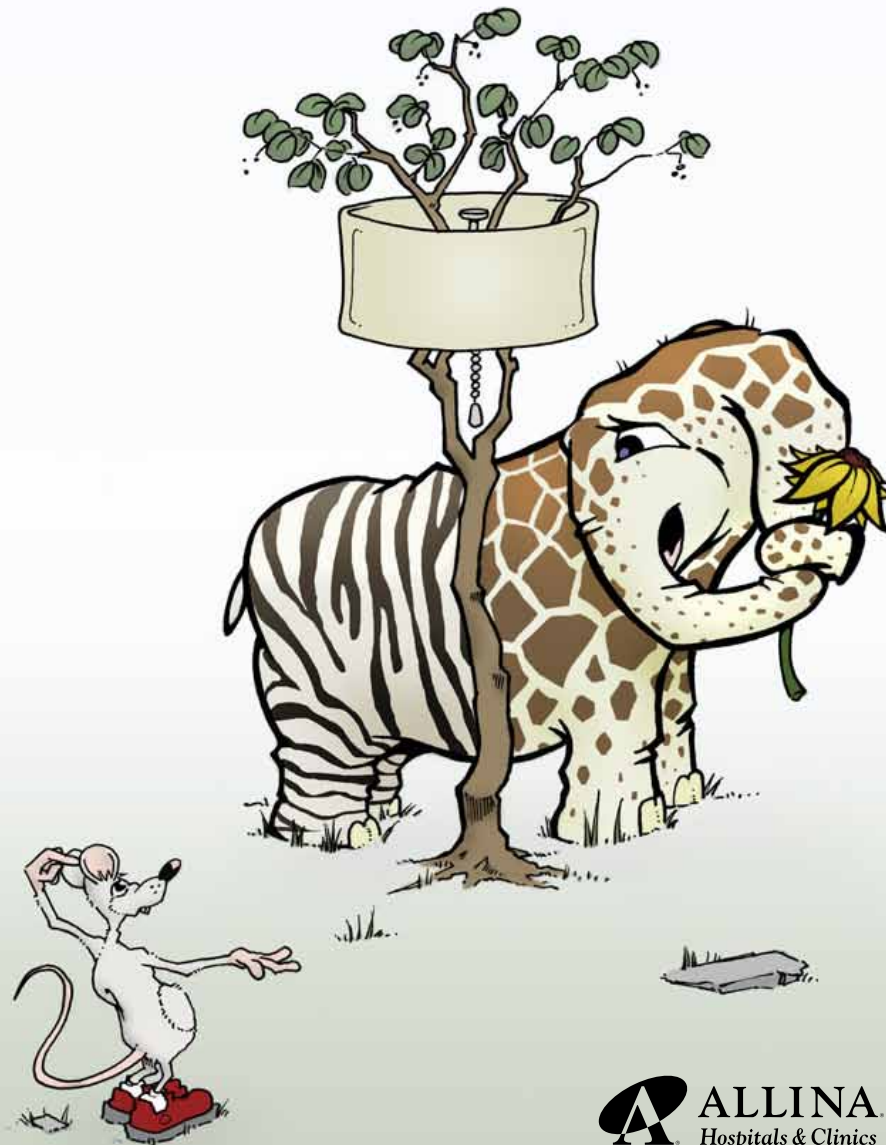


Facing Uncertainties



Facing Uncertainties

“I wanted a perfect ending. Now I’ve learned the hard way, that some poems don’t rhyme, some stories don’t have a clear beginning, middle and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what’s going to happen next.”

~ Gilda Radner



The most challenging times in our lives may be when life is shrouded by uncertainty, mystery or ambiguity. Cancer casts one’s life into a constant state of unknowns. Our physicians, the books we read, experts on the Internet and well-meaning friends try to tell us what we will face and how we should face it. Yet, the only thing we are certain of is our uncertainty.

Becoming comfortable with mystery and learning to live in the moment are lessons that are learned and forgotten and learned again. Trying to hold onto hope with one hand while we wrestle fear with the other is never easy. It is normal for us to want to protect our children from cancer’s challenges. But it is not truly possible. Children can sense our fear and insecurities. It is instead time to clasp hands and face the uncertainties together.

“Uncertainty will always be part of the taking charge process.”

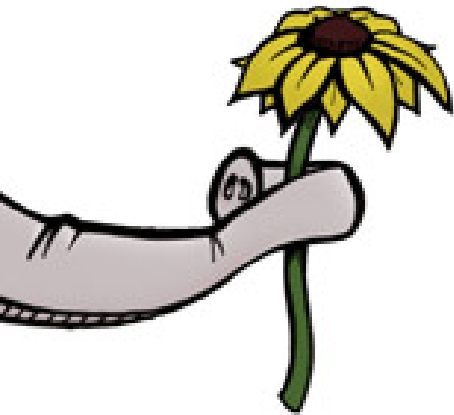
~ Harold S. Geneen

Remember that your uncertainties may be different than your children’s. How you cope with uncertainty will deeply influence how your children will deal with it. You do not need to turn all unknowns into knowns. Allow the shreds of uncertainty to settle around all of you and try to become comfortable with not knowing. Sometimes a leap of faith will transport you and your children beyond uncertainty. Sometimes focusing on something else positive and out into the future will help. And sometimes screaming and yelling will vent the frustration.

We know that if we can identify and talk about our uncertainties and doubts, so can our children. Together, you and your children can learn to live with uncertainty. Hope does not always mean cure. You can hope for many things amid uncertainty. And we can all learn to live in hope. Holding hope in one hand and uncertainty in the other is achievable. Focusing on hope can get you and your children through the adversities cancer presents.

“Once you choose hope, anything’s possible.”

~ Christopher Reeve



Facing Uncertainties

Three Inevitable Questions

There are many uncertainties with cancer, but three questions seem to loom as the main unspoken “elephants in the room;”

- Will life ever be normal again?
- Will the cancer be cured?
- Will you die?

In this section we offer answers to these three looming questions you are almost certain to hear from your children, followed by five simple steps to successfully face the uncertainties of your illness together. Subsequent pages provide specific age-appropriate ideas for what to say, do and observe with your children. There are also numerous resources for each age group in the *Ideas and Resources* section.

Will Life Ever be Normal Again?

The most common expression we hear from cancer patients and their families is, “I just want things to go back to normal again.” But life does not go back to normal. Instead, you learn to live a new normal. And each child needs to learn how to adapt to the new normal. You, as the parent, lead the way into this time. Your acceptance of the changes will make it easier for your children.

“The only normal people are the ones you don’t know very well.”

~ Alfred Adler



Some parts of life will still be the same and it is important to underscore those for your children. Find a name for the new normal in your home and family, such as LAC (Life after Cancer) or LWTE (Living with the Elephant). Identify the things that will stay the same. Explain the plan for the parts that will have to change. Have your children help with this.

Will Your Cancer be Cured?

This question begins at diagnosis and returns frequently. Your children will ask if you are better now and if the cancer is gone. When you do not have an answer for this, or if the answer is no, tell the truth. Don't sugarcoat it as children can see through it. Allow time to let the truth sink in and for the feelings to be shared among the family members.

If you believe you will be cured despite your physician's concern, tell your children what you believe to be true. Even if you do not believe you will recover, let your children know that you and they should continue to hope for the best and try to be ready for the changes that might come. Children need to understand the difference between your hopes for the future and the reality of your disease or what is likely to happen. You can hope to live forever or beat the cancer, but be certain you are being honest with yourself and your children. Whether your cancer will or will not be cured, there is always hope.

Children need to know if and when your hope for a cure changes. You may still keep a firm grip on hope, but you may have taken some of your "hope eggs" out of the "cure basket." Refocus your hope on more readily attainable achievements, such as being at your child's first soccer game in the spring, attending Aunt Lynda's wedding, going fishing again or just having a good laugh once today.

"Locking onto one kind of hope shuts the door on other possibilities."

~ Ted Bowman

The next related question your child will ask is, "What will happen next and what will change?" As with your description of the new normal, let your children know what you know. Put it in their language. Predict only what you can and leave the rest alone.

Some cancers come back and some just stay with us. Many types of cancer are being viewed as chronic illnesses. Children need to know how you and they might recognize if the cancer comes back. For example, are there tests that can be done, or what symptoms might announce its return? Share any ideas you may have with your children about what you might do if it does come back, such as treatments you may pursue or surgery that may be required. Again, let them know what the possible outcomes may



be. Children of all ages, just like adults, do better when the possibilities have been discussed.

Children also need to know that the more serious effects of cancer will not always be visible. "Cancer may still be in mommy, but we will live with it. It will be a part of our lives."

It is true, and can be said, that cancer research is going on all the time and new treatments are being developed, possibly while you are dealing with your cancer. And sometimes, cancer really does just seem to miraculously go away. You can tell your children that you will hope for a new treatment or that your cancer just goes away, but you will also deal with what is real right now.

"I am not afraid of dying. I just don't want to be there when it happens."

~ Woody Allen

Will You Die?

Death is a universal uncertainty and a very real fear for most of us. We gradually come to terms with death throughout the course of our lives. Our answers and feelings vary at different stages of our lives. Cancer puts this subject right there in the room like an even bigger elephant.

Parents often struggle the most with the concept of death when they think about prematurely leaving their children. Frequently, discussions are ignored or at best minimized. The fear of addressing death can make the times when death is very near even harder and the loss more difficult for everyone.

Death needs to be discussed just like all the other tough issues. As it is confronted, the fears can lessen some as the uncertainties are addressed. There is such a thing as a good death.

Children learn about death at early ages. They see dead birds, insects, and animals lying by the road. Often they have lost a pet and, most certainly, many see death on television. They hear about it in fairy tales and in nursery rhymes. Some experience it in their own families or neighborhoods. Children's understanding of death depends on their experiences, their developmental level, their parents' acceptance and communication, and the beliefs the family holds.

Ask your children what they know about dying and death. Be with them in their fears, in their indifference and in their anger. There is no right way to understand death, nor is there only one way of coping with it.

There may be times of hospitalization and changes in the home environment with increased medical needs that create a clear sense that things are getting more serious. Children need to be included, but not forced to be a part of this. Watch for opportunities to discuss fears that may arise from these changes and what might happen next. Prepare them for the changes with discussions, examples, even pictures and photographs.

See the *Ideas and Resources* section for materials and resources to help children whose parent is dying.

“You cannot change the direction of the wind,
but you can adjust your sails.”

~ Anonymous



Five Basic Steps to Facing Uncertainties Together

1. Accept the uncertainties. Take your children with you on your journey through cancer treatment. Let them know what you know, as well as what you don't know. By sharing your uncertainties, they can verbalize their own. It is okay to be uncertain.
2. Begin by naming the uncertainty you share, such as, “We do not know if the cancer will come back.”
3. Reassure your children that even if the two of you don't know an answer, you will be okay. Children have a harder time accepting the unknown, but more importantly they need to be reassured that even if the answers aren't clear, they will be okay and that someone will be with them every step of the way. For example, you may say, “That is something I do not know the answer to now, but I do know that we will look for the answer together. Even if we do not find the answer, we will be alright. There are lots of things we do not know; like if it will snow tomorrow. Even when the weatherman says it will snow, sometimes it does not.”
4. Talk about your family's beliefs and practices. For some families there is comfort in spiritual beliefs or religious practices. There are many books that deal with uncertainty for children, both religious and secular. Look through them to see what might fit for your family and children.
5. Keep the communication lines open and the dialogue ongoing. Discussions take time and often require repetition as doubts and uncertainties reappear.

“Hope is the thing with feathers
That perches in the soul,
And sings the tune – without the words,
And never stops at all...”

~ Emily Dickinson

Keep in Mind

Talking about the hard stuff will not make it happen any more than not talking about it will keep it from happening.

If it is mentionable, it is manageable – like the “elephant in the room.”

Your uncertainties and those of your children may be different.



Know there are times when words just do not work— but being together does.

Facing and talking about fear is better than living in fear.

Children face tough stuff slowly and need time to adjust.

Children will be more resilient when someone believes they can be.

Some things will never be understood.

Find what gives you and your children energy; avoid what drains energy.

Children don't always appear to be listening, but often they are.

There is laughter amid sorrow and sorrow amid joy.

Be in the moment with your children, whenever you can be.

Be careful about putting all your “hope eggs” in the “cure basket” – there are many things to hope for.

Most children are good at hope... and wishing and dreaming.