

Fostering Resilience for Cancer Survivors

Resilience in children of parents with cancer



Certified Child Life Specialist



Help children and families cope with illness, injury and treatment by providing evidence-based, developmentally appropriate, therapeutic play, preparation and education to reduce fear, anxiety and pain.



Diagnosis

Who, What, When, Where and Why to tell the children about the cancer diagnosis



There is no right answer or perfect way...It depends on the family

- Who- A caregiver or loved one
- What- Honest and concrete information
- When- During diagnosis process or soon after diagnosis
- Where- In a comforting environment
- Why- Kids are intuitive and will know something is going on. They should be taught how to cope.

'After my first appointment I told my children. I didn't want them to hear me discussing my diagnosis in hushed tones, and felt I should tell them the truth at the earliest possible stage.'

Sharon

A lump was growing in my body that wasn't supposed to be there. It's called cancer. The doctors took it out in the operation I had. Now I will have treatment so that it doesn't come back.



3 most important things for children to know:

- 1) They did not cause this.
- 2) They can not catch it.
- 3) How it will impact their life.

“ Sooner or later they were going to find out. Why not tell them straightaway? I tell them frankly what is happening. I think they find it much easier to cope because they are ready for things. ”

*Susie, mother of three
children aged 12, 13 and 16*



Different views of cancer

Children's understanding of illness and their reactions to bad news will vary depending on their age, temperament and family experiences. You may find that siblings, even of similar ages, have quite different responses. These charts give an overview of children's needs at different ages and might help you work out how best to support them.

0-3 years



Newborns, infants and toddlers

Infants have little awareness of illness, but are aware of their parents' anxiety and other feelings. They are also aware of periods of separation from their parents and can get upset when the physical presence of a loving parent is missing. Toddlers may react to physical changes in their parent or relative or the presence of side effects (such as vomiting).

Possible reactions

- newborns and infants: becoming unsettled, especially if they need to be weaned suddenly
- newborns and infants: wanting to breastfeed more frequently for emotional comfort
- becoming fussy and cranky
- becoming clingy
- change in sleeping or eating habits
- colic
- toddlers: tantrums, more negativity (saying 'no')
- return to, or more frequent, thumb-sucking, bedwetting, baby talk, etc.

Suggested approaches

- maintain routines: ask any carers to follow the established schedules for your baby or toddler as much as possible
- give plenty of physical contact (e.g. hugging, holding, extra breastfeeding) to help them feel secure
- ask family members and friends to help with household tasks and care
- observe play for clues to how a child is coping
- use relaxation tapes, calming music or baby massage
- share your feelings and fears with others

3-6 years



Preschoolers

By the age of 3, children have a basic understanding of illness. Younger children may believe that they caused the illness (e.g. by being naughty or thinking bad thoughts); this is called magical thinking. They may also think cancer is contagious. It is natural for young children to be egocentric and think everything is related to them – Did I cause it? Can I catch it? Who will look after me?

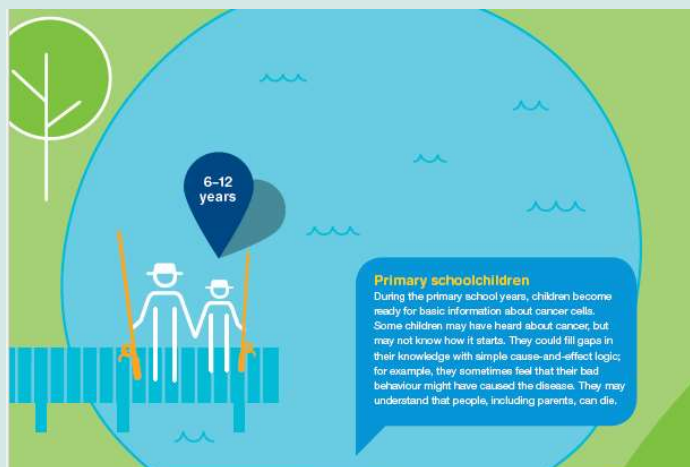
Possible reactions

- regression, e.g. starting to suck their thumb again
- comfort-seeking behaviours, such as using a security blanket or special toy
- fear of the dark, monsters, animals, strangers and the unknown
- trouble falling asleep or sleeping through the night, refusal to sleep
- nightmares, sleepwalking or sleepwalking
- bedwetting
- stuttering or baby talk
- hyperactivity or apathy
- fear of separation from parents or other significant people, especially at bedtime and when going to preschool
- aggression (e.g. hitting or biting), saying hurtful things or rejecting the parent with the cancer diagnosis
- repeated questions about the same topic, even if it has been discussed several times

Suggested approaches

- provide brief and simple explanations about cancer; repeat or paraphrase when necessary
- talk about cancer using picture books, dolls or stuffed animals
- read a story about issues such as nightmares or separation anxiety
- assure them that they have not caused the illness by their behaviour or thoughts, nor will they catch cancer
- explain what children can expect; describe how schedules may change
- reassure them that they will be taken care of and will not be forgotten
- encourage them to have fun
- listen and be alert to their feelings, which they may express through speech or play
- let children get physical activity every day to use up excess energy and provide an outlet for any anxiety or aggression
- continue usual discipline and limit-setting






6-12 years

Primary schoolchildren
 During the primary school years, children become ready for basic information about cancer cells. Some children may have heard about cancer, but may not know how it starts. They could fill gaps in their knowledge with ample cause-and-effect logic; for example, they sometimes feel that their bad behaviour might have caused the disease. They may understand that people, including parents, can die.

Possible reactions	Suggested approaches
<ul style="list-style-type: none"> irritability sadness, crying anxiety, guilt, envy physical complaints, e.g. headaches, stomach-aches trouble sleeping sudden worry about the well parent's health separation anxiety when going to school or away to camp regressive behaviour hostile reactions like yelling or fighting, including towards the sick parent poor concentration, daydreaming, lack of attention poor marks withdrawal from family and friends difficulty adapting to changes fear of performance, punishment or new situations sensitivity to shame and embarrassment trying to be extra good 	<ul style="list-style-type: none"> be alert to their feelings (expressed through speech or play) and let them know you care use books to explain cancer and treatment use sport, art or music to help children express and manage their feelings assure them that they did not cause the cancer by their behaviour or thoughts, and that it is not contagious reassure them about their care and schedule and tell them that it's okay to have fun let them know that their other parent and relatives are healthy give them age-appropriate tasks to do around the house tell them that you won't keep secrets and will always tell them what is happening help them understand that what their schoolmates say may not always be right – encourage them to check with you discuss the issue of dying if your kids bring up the topic see also ideas for preschoolers (page 9)

10 Cancer Council



12-18 years

Teenagers
 During adolescence, young people start to think more like adults and may want lots of information. They are able to understand complex cause-and-effect relationships, such as illness and symptoms. Although they understand that people are fragile, they are more likely to dary fear and worry to avoid discussion. They may prefer to confide in friends, and act as if friends are more important than family.

Possible reactions	Suggested approaches
<ul style="list-style-type: none"> wanting to be more independent and treated like an adult regression – wanting more nurturing, becoming very insecure and dependent on parents, or lapsing into previous behaviours, such as watching children's TV shows critical view of how adults react to or handle the situation depression or anxiety worry about being different anger and rebellion poor judgement and risk-taking behaviour (e.g. binge drinking, smoking, staying out late, unsafe sex) withdrawal apathy physical symptoms from stress (e.g. stomach-aches, headaches) more likely to turn feelings inward, which means adults are less likely to see reactions worry that they will also get cancer, particularly if they're a daughter of a woman with breast cancer 	<ul style="list-style-type: none"> notice any differences in their behaviour and ask them about it – this can open the door to a conversation about their concerns encourage them to talk about their feelings, but realise they may find it easier to confide in friends, teachers or other trusted people provide plenty of physical and verbal expressions of love talk about role changes in the family provide privacy as needed encourage them to maintain activities and friendships; talk about finding a balance between going out and staying at home set appropriate limits provide opportunities for counselling don't rely on them to take on too many extra responsibilities provide resources for learning more about cancer and getting support let them know that you don't always want to talk about cancer – you still want to chat about things like homework, sport and friends see also ideas for younger children (opposite)

Cancer conversations 11

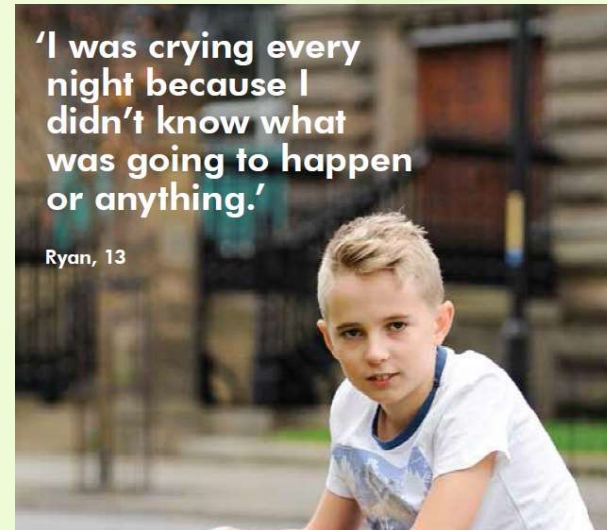


During Treatment



Explaining Treatment and Medication Side Effects

- Physical changes
 - scars from surgeries
 - loss of hair
 - weight changes
- Lack of energy to play with child or attend events
- Frequency and routines of treatment
 - Weekly clinic visits
 - Daily radiation



Including Children in Parents Care

- Have them help with medical care when possible such as flush lines, turn on equipment, pick out supplies
- Bring them to an outpatient visit so they can get to know the medical team caring for their parent
- Have teens update caring bridge pages
- Have them go on short walks with parent as it will help decrease stress for both child and parent



'I was always really worried about my dad and I didn't know what I could do. I couldn't make him be able to do the things that he wanted to.'

Siana, 14



Additional Tips

- Communicate with the child's school
- Help the child find a safe person they can always talk to
- Encourage children to maintain friendships and normal activities
- Be sure each child knows who is taking care of them
- Have emergency plans- how to communicate to them, where they go if it's the middle of the night, etc
- Maintain rules and limits you have set as a parent
- Reaffirm that you will keep children updated on changes of care



When Cure Is No Longer Feasible



Talking About Death

- “There is no medicine that will make mommy/daddy better.”
- Death is a natural part of life and no one can ever be sure when that will happen.
- Use concrete words such as “death” and “die”, not phrases like “passed away”, “resting”, “going to sleep.”
- Give little bits of information at a time when each child is ready for it.
- Reiterate that this is no one's fault and that everyone did what they could.



What words should I use?

If you need to prepare a child for the death of someone they care about, it can be confronting to find the right words to use. See pages 50-51 for tips on how to answer specific questions.

When advanced cancer is diagnosed

“Some people with this sort of cancer get better, but some don't. I am going to do everything I can to get better.”

“Some people with this sort of cancer recover, but most don't. I'm planning to do everything I can to keep the cancer under control, and I will always let you know how the treatments are going.”

When end of life is near

“Daddy is very sick now. The doctors say there isn't any medicine that can make him better. We think that means he is going to die soon. We will try to spend some special quiet time together.”

“The doctors say that the treatments haven't worked for Dad. There isn't anything else they can do. We think that means Dad will die soon. We want to make the most of the time he has left.”

To explain death

“When Grandma died, her body stopped working – she stopped breathing and her heart stopped beating. A dead body can't move or talk and it can't feel anything. It also can't come back to life. We won't be able to see Grandma again, but we will always know she loved us.”

“I have some very sad news. Grandma died last night ... Is there anything you'd like to know about how Grandma died?”

Words for different ages

- Younger children
- Older children



Different views of death

In preparing children for the loss of a parent or another significant person, it can help if you understand how death is perceived at different ages. Do not underestimate the impact of a bereavement, even if the child is very young or does not seem sad. Their grief may be expressed through play or behaviour.

0-3 years



Newborns, infants and toddlers

Babies don't have any knowledge of death, but can sense when their routine is disrupted and when their carers are absent. Toddlers often confuse death with sleep and do not understand its permanence.

Possible reactions

- babies: unsettled and clingy
- toddlers: may worry persistently about the well parent and think that they or their behaviour caused the advanced cancer
- may also be angry with parents for not being able to give them more attention

Suggested approaches

- avoid explaining death as 'sleeping', because that can cause distress about sleep
- provide comfort
- be prepared to patiently answer the same questions many times
- maintain routines and boundaries

Preschoolers

By the preschool years, children are starting to understand the concept of death but struggle with its permanence (e.g. they may ask when the dead parent is coming home). Young children don't have an adult concept of time and understand only what's happening now.

3-6 years



Possible reactions

- may feel it is somehow their fault
- may be angry with their parent for not giving them enough attention
- can react as if they were much younger when under stress
- may have frightening dreams
- may keep asking about death

Suggested approaches

- watch their play for clues to their feelings
- offer comfort
- answer questions in an open, honest way
- maintain routines and boundaries

6-12 years



Primary schoolchildren

By the primary school years, children may understand death but often don't have the emotional maturity to deal with it. Younger children may think death is reversible and that they are responsible.

Possible reactions

- may be openly sad or distressed
- may express anger
- may worry about being responsible for the death, but also might blame someone else
- may ask confronting questions about what happens when somebody dies
- may be more able to talk about their feelings and act sympathetically

Suggested approaches

- encourage them to talk, but realise they may find it easier to confide in friends, teachers or other trusted people
- provide plenty of physical and verbal expressions of love
- be sensitive but straightforward
- discuss changes to family roles
- provide privacy as needed
- maintain routines and boundaries

Teenagers

Teenagers can understand death, but may not have the emotional capacity to deal with its impact. They need as much preparation as possible for a parent's death. Teenagers are often more distressed when their parent is ill than after the death.

Possible reactions

- may deny their feelings or hide them in order to protect you
- may think they can handle it alone and not look for support, or may distance themselves from family and talk to friends instead
- may react in a self-centred way and worry about not being able to do their normal activities
- may express distress through risk-taking behaviours (e.g. skipping classes, experimenting with drugs and alcohol, acting recklessly)
- worry that death is frightening or painful, and struggle with their own mortality

Suggested approaches

- encourage them to talk about their feelings with friends or another trusted adult
- support them to express their feelings in positive ways (e.g. listening to music, playing sports, writing in a journal)
- negotiate role changes in the family
- maintain routines and boundaries
- let them know that support and counselling are available (see page 51 for some options)
- offer them the opportunity to participate in a public or private memorial service

12-18 years



How to Prepare Kids for Death

- Give choices and control when possible and respect their wishes.
 - Do you want to visit the hospital? Do you want to hold moms hand? Do you want to go to the funeral?
- Talk about who will take care of them when parent dies.
- Create positive rituals prior to death (Kissing Hand book).
- Engage in family memory making activities (family tree with hand prints).



Resources/References

After a Loved One Dies- How children grieve and how parents and other adults can support them:

<https://www.thewatsoninstitute.org/wp-content/uploads/2017/10/New-York-Life-Foundation-Bereavement-Guide-After-a-Loved-One-Dies-.pdf>

American Cancer Society: <https://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer.html>

A Guide for Young People Taking Care of Someone with Cancer:

<http://be.macmillan.org.uk/Downloads/CancerInformation/ChildrenAndYoungPeople/MAC13009youngcarersE04lowrespdf20171115.pdf>

The Gathering Place: <https://www.touchedbycancer.org/resources>

Helping Children When a Family Member has Cancer: https://www.cancercare.org/publications/22-helping_children_when_a_family_member_has_cancer#

Kids Connected: <https://www.kidskonnected.org/>

Preparing a Child for Loss:

<http://be.macmillan.org.uk/Downloads/CancerInformation/ChildrenAndYoungPeople/MAC15372childforlossE1lowrespdf20151223.pdf>

Sesame Street Grief: <https://www.sesamestreet.org/toolkits/grief>



Resources /References

Sesame Street: When families grieve:

https://cdn.sesamestreet.org/sites/default/files/media_folders/Media%20Root/Grief_CaregiverGuide.pdf

Talking with Children and Teenagers When an Adult has Cancer:

<http://be.macmillan.org.uk/Downloads/CancerInformation/LivingWithAndAfterCancer/MAC5766talktochildlowrespdfFP20170307.pdf>

Talking to Kids about Cancer: A guide for people with cancer, their family and friends:

<https://www.cancerwa.asn.au/resources/2016-06-21-talking-to-kids-about-cancer.pdf>

When a Parent has Cancer

http://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/When_a_Parent_Has_Cancer.pdf

When Your Parent has Cancer: A guide for teens: <https://www.cancer.gov/publications/patient-education/when-your-parent-has-cancer>

McCue, K. (1994). How to help a children through a parents serious illness.



Comments or Questions?

Becky Halagarda, MSW, CCLS, CTRS

Child Life Specialist

bhalagarda@umm.edu

410-328-7440

