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Helping Children Manage Uncertainty,

Explaining Cancer Recurrence to a Child and Helping Them Cope

to your cancer care team as you think about letting the children know about the recurrence. You could also reach out to your support system to help you talk to your children.

Some people might not want to tell their children that the cancer is back out of fear that this will upset the child or cause them to worry more. Even though it is true that children are likely to be upset when they learn the cancer has come back, keeping them informed of what is going on might help them worry less and build trust.

Here are some things to consider before or when telling children that a loved one's

done. The family activity schedule may need to be changed to work around more intensive treatment. You might need to make other arrangements for the kids so that their routines can continue, with other people filling in, until you are feeling better. Even though you can't do certain things, you might be able to substitute some activities that won't take quite as much energy. Arrange times to be together to watch TV, read a book, make up a story, play a board game, or whatever else you can think of to spend time with your children. Kids would rather you be there even if you're a little tired, than not there at all.

When thinking about helping children cope with this news, remember:

- Children can't always tell you in words but may show you how they feel. You might notice your child being more dependent, worrying more, or being out of character. They might also express themselves through drawing, coloring, or playing. It is important that the parents or guardians pay close attention to how and what the children are doing
- Ask the children frequently how they are doing and what can be done to help them feel better.
- Children might regress (act younger) when they are under stress. For example, a child who had just become toilet trained might start having accidents. Other children might begin to have separation anxiety or difficulty paying attention in school.
- Children might worry about their loved one dying. When talking to a child about dying, be honest and let them know that sometimes people do die from cancer and while there is no way to know what's going to happen, let the child know about the outlook of the person's cancer in a way that is appropriate for their age, and let them know that if you find out something new or different, you will let them know. This does not mean that parents should tell their kids everything they know as soon as they know it. It means that children should be given truthful information when they need it to cope well from day to day. If the loved one is a parent or guardian, they might need to seek help from a professional to help them process their own feelings and discuss ideas to and tips for talking with their children.
- Children thrive on routine and predictability. If the person whose cancer has come
 back lives in the same household as the child, try to keep their routine and way of
 life as close to normal as possible. Communicate with the child any expected
 changes. This will help increase their sense of security.
- Children should be told that although no one knows for sure why some people get cancer, it's certain that the child did nothing to cause the loved one's cancer to come back.

• Tell the children that it is OK for them to refuse to talk about their loved one's cancer coming back with others.

Find out as much information as possible about how the child is doing. This could

Hyperlinks

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Preparing a Child for the Death of a Parent or Loved One

Children can often sense when things are wrong around them. It is important to be as open as possible about what is going on, so that the children may continue to trust those around them. Knowing what is going on can also help them worry less, process their emotions better, and cope better with the changes. While most of the information here focuses on a parent of a child dying, it could also apply to any loved one in the child's life.

- Children's possible reactions to learning a parent is dying
- When should children be told that a parent is dying?
- Talking to children about death
- Reassure children they will still be cared for
- Help children open up about their feelings
- · Keep the child informed as the loved one nears death
- Spiritual and religious beliefs may help comfort children
- Consider involving people at your child's school

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Children's possible reactions to learning a parent is dying

Children of different ages have different understandings of death and what it might mean to them. It is important to keep this in mind as you support children who are facing the death of their loved one.

Talking to children about death

You'll want to have some uninterrupted time and a quiet place. Consider having the other parent, or another trusted adult with you. If you don't have someone to help you, ask your social worker, nurse, or doctor who might help you explain things to your child.

Talking to children and preparing them for the death is important, but it's even more crucial if the child has only one parent. The child knows that the parent provides all or most of their care and will probably worry who would do it if they weren't around.

This is a tough talk to have with your child, and you may have to rehearse before you can do it without getting very emotional yourself. When you're ready, give yourself some uninterrupted quiet time with your child. You can open the subject by saying that you know that children often worry about who would care for them if a parent couldn't, or if their parent died. This lets the child know that you won't be shocked or upset with them if they ask questions. You can see how the child responds to this statement before you explain your back-up plans. Again, if you don't think you can handle this talk on your own, get help. Don't feel that you must do everything by yourself.

- Be as honest as you can about what's going on
- Let them know that it is okay to feel angry, confused, sad, or scared.
- Reassure them that their feelings are normal
- Reassure them you have planned so they will still be cared for

Ask your child if they've noticed any changes, and what they think these changes mean. Don't assume that you know what's going on in your child's mind. You must ask.

Use the right words

It's tempting to avoid them, but it's important to use the words "die" and "death" rather than "pass on," "go away," "go home," "go to sleep," or other terms that make death sound nicer. Younger children often don't understand what these nicer-sounding words really mean and may not fully understand what you're trying so hard to say.

Since a child's understanding is based on what they can directly experience, death should be explained in terms such as these.

- Death means that we'll no longer see the person we love except in our hearts and minds.
- Death means the person will no longer be physically there in our lives.
- They'll no longer be with us as they were before, but we'll still have memories of them.
- Be sure to explain that when a person dies, they don't feel anymore; the heart doesn't beat anymore; the person doesn't breathe.
- Since young children don't understand that death is final, be sure to say that death is not like a trip; you don't come back from being dead. Also, make it clear that death is not like sleeping.
- Using a simple story book is a good way to help explain this. Talk to your health care team, ask a local librarian, or check the resources section to get recommendations.

Depending on their age and many other factors, some children may not be able to really grasp that a parent is dying, and their first reaction is often one of disbelief. They might also feel angry. Reassure the children that this is normal. Children might also wonder who will take care of them when their parent dies. If you have plans already, be sure to share them with your children so they know what to expect.

Be prepared to repeat this conversation

Young children will probably not understand what death is and what it really means the first time they hear it. You may have to repeat this discussion many times for them to fully understand. If a child doesn't want to believe what you've told them, they may ask the same questions repeatedly, often as if the conversation had never happened. They might do this hoping that the answer will be different the next time, hoping that

somehow what they've been told isn't true.

Although this is painful for the adult, it's a key part of preparing the child. In time, the child will accept the reality. This process is how the child comes to accept that life can and will go on without the parent.

Reassure children they will still be cared for

A lot of parents fail to plan for what will happen to their children if they die. It's important to make those arrangements and let your children know about them in age-appropriate ways. If a family doesn't have relatives or friends who are logical choices as caregivers, there are social service agencies that can help find possible caregivers. This is a very painful issue to deal with on top of the cancer, but it's something that should be done. It's one way a parent can reassure their children that they will always be cared for – no matter what happens. If the children are older, you might want to get their input on who would become their caregiver.

Parents should share the plan with their children in an open and honest way. If a single-parent household, the children should be told the back-up plan in case the parent dies. If a two-parent household, the children should be told what changes to expect. Planning and talking to them about it lets them know how important they are to you. They should also be assured that they will always be cared for, if a parent dies. They should also be reassured that it is OK to ask questions and express their feelings.

Help children open up about their feelings

Depending on their age and personality, children often try to protect their parents from knowing their true feelings. It is ok to cry in front of your children because it can give them permission to cry. Give a name to it, explain that you are letting your feelings out and that it is healthy to do this. Asking your children if they are angry and reassuring them that feeling this is way is normal could open the door to a helpful and healing discussion. Underneath the anger or emotion being displayed, there's often a deep sadness which needs to be recognized and shared to move on. While these feelings can be painful to express and to listen to, getting them out into the open can take away some of their power and help people feel closer.

Teenagers might have a harder time expressing their feelings. They also should be encouraged to talk to their parents, guardians, or a trusted adult.

Keep the child informed as the loved one nears death

No matter the age of the child, preparing a child for the death of someone they know

their parents, finding the right balance between time spent with a sick parent and time spent on other aspects of their lives can seem challenging.

Teens can help around the house, and it's natural to depend on them to pitch in during a crisis. In fact, teenagers get satisfaction from being trusted enough to help when the family is in upheaval. It's important to ensure the teen is still able to have time with friends, take part in school activities, and have parts of their lives separate from the family. It's good to check in every now and then to see if the balance between home and the rest of their lives is being maintained.

Older children and teens might want to be there when a parent is dying. If the parent is OK with that, this should be supported. Some conflicting feelings are normal since there's fear and uncertainty involved. It might be useful to ask someone from the medical team to describe what's most likely going to happen.

Spiritual and religious beliefs may help comfort children

A family's cultural, spiritual, or religious beliefs are often very important in how they understand death and cope with it. For example, if people believe in life after death, death may be seen as a new beginning. Sharing your beliefs with your children can help them process the news and death better. Your clergy person may be able to help you and your child through these discussions.

Consider involving people at your child's school

It's important that parents speak to the child's teacher and/or school counselor about the illness and death of the parent. The school staff can then watch your child and let you know if they notice any problems. If a child is troubled, it will often show up in the school setting, and a teacher who isn't aware of what's going on in the child's life isn't prepared to help them to cope with it.

Sometimes older children don't want anyone outside of the family to know what's going on. They worry about what their peers will think. In general, children don't like being different from their friends, and those concerns need to be heard. It's important for you to try to get the child to talk about what they're feeling. But try to respect their desire for privacy, too.

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How Children Understand Illness and Death

Infants or very young children

come back. It often takes time and growing up for them to realize that the parent they loved will not return.

When death is very close, the child should know that soon the parent will die. Help them understand by using phrases like, "Soon their body won't work anymore." "They won't feel or breathe anymore." or "Their heart will stop." If you say things like "Mommy will go to sleep," the child will realize at some point that Mommy didn't wake up. Children told these kinds of stories can become afraid to go to bed at night – it's important to tell the truth and use the right words.

Some ideas for talking with children in this age group:

Give very simple explanations of what's happening and repeat them often.
 Check on the child's understanding of what's happening. Remember that the child

 Give simple explanations for crying and sadness. For example, "I just feel a little sad and a little tired today. It makes me feel better to cry and get it all out of my system. Now I feel better."

Children ages 6 to 8

Children this age are better able to understand death, including that death is permanent. Some children may see it as a monster, ghost, or some other such creature. Death often takes the form of an outside person who can come to catch them and if they run fast enough, they can escape. Children in this age group worry about monsters under the bed, witches, or devils, and it can be hard to reassure them that such creatures don't exist. They may also think that the other parent or another loved one could have prevented the illness or death from happening.

Children at this age may come up with their own explanations of things, like why a sick parent won't play with them ("Mommy doesn't love me anymore because I told her I hated her.") It's important to explain changes right away. ("Mommy can't play with you because she's sick. She loves you a lot and still wants you to have fun.") Once children believe their own interpretation, it can be hard to change their minds, and it requires lots of repetition and reinforcement.

Be patient trying to convince a child that a parent has really died. Don't be hard on yourself if it seems like you can't get through a child's normal defense against such a difficult reality.

Here are some tips that may help:

- Keep the child up to date about the parent's illness and treatment and be sure to explain what the child sees and hears. You may need to keep repeating this information.
- Prepare the children for bedside visits and explain what they will see. Give more information and offer time for questions after.
- Answer all questions honestly, including, "Will Mom (or Dad) die?" Get help from the social worker and cancer care team if needed.
- Listen for unasked questions and pay attention when the child talks about fears and concerns.
- Encourage and help youngsters to identify and name feelings.
- Encourage expressing and talking about feelings, especially anger, and safe ways to do it.

- Teach the child what anxiety feels like and how to manage it.
- Assure the child that it's OK to be upset, sad, anxious, or angry and that their parent still loves and cares for them.
- Tell the child when <u>death is getting close</u>¹ and let the child visit and be with the parent. Describe the parent's condition and make suggestions as to what the child might say or do. Just touching the parent can mean a lot to the child. Tell the child to focus on an area of the body that looks the same (such as hands). Tell the child to talk to the parent and tell the parent about his/her day.
- Find out if the cancer center has special groups for kids with cancer in the family.
- It's OK for the child to see the parent cry or be angry if the child understands that they're not to blame for these feelings. Try to help them understand that it's normal to have strong feelings and it's good to express them.
- At least one adult should give the child permission to ask them questions and express feelings that the child thinks might upset others.
- If parents have trouble listening to the child's distress because of their own, get family, friends, social workers, or other professionals to help talk with and listen to the child.
- If a child is having trouble in school, explain that it's normal for school performance to suffer a bit when a parent is in the hospital, and you are not upset with them.
- Tell the child that it's hard for everyone in the family, but that you are there for them.
- Assure the children that this is not their fault, they didn't cause the cancer or the death.

Tell the child's teachers, coaches, and other school staff about the family's cancerool staff about t

Children in this age range want reassurance that their parent loves them. Some want to hug the parent or hold their hand. Some are comforted by exchanging gifts or cards with the parent. These small gestures can become treasured memories for the child.

Children ages 9 to 12

Children this age may have feelings of sadness and loss during terminal illness and after a parent's death. They may even feel embarrassed about their outbursts of strong emotions. They can understand more about serious illness and the finality of death, if

and their responses to the parent's illness (if they want to do this).

 Arrange for one family member or trusted friend to take a special interest in the child.

Teens

Teenagers have an adult understanding of death but might not have adult coping skills.

They may have a particularly tough time with the loss of a parent. This is easier toiyou keepst imita when the loss of a parent.

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Helping a Child Cope with the Loss of a Loved One

How a child grieves will be affected by their age, development, their relationship with the person who died, how the child is cared for after their loved one's death (especially if the person who died is the parent), how the child communicated with the family and how the parent(s) or caregivers communicate with the child and grieve themselves. Other changes, challenges, and losses might also impact how a child will grieve.

Children often will feel sad or show other emotions for a short time, then go back to their usual activities or go play with friends. Adults might mistakenly think that the child has already gotten over it, or that the child doesn't fully understand the loss. Some children grieve in spurts; moving back and forth between grieving and being interested in everyday things. This can go on for years after the/F2 10 7ms2..4ualdr_____ 2 0.62745 rg ack nrth bet

Keeping an open channel of communication with the child after the death of a loved

teens. These can be safe outlets for emotions and good sources of support and encouragement.

Signs that a child might need extra help after a parent's death

Depression and complicated grief in children can look different from an adult's. Look for a change in behavior, like sudden changes in grades, withdrawal, or losing friends. Some children might seem more angry and irritable than depressed.

Complicated grief is different from the usual grieving process. It's marked by how long it lasts, how much it interferes with the child's life, or how severe it is. Sometimes, a child will seem to be stuck in the process of grieving. Grief reactions or mourning processes like this are not only unusual, but are also unhealthy. If it's severe and lingers, the child might need professional help to get through the grieving process.

These problems can show up months or even years after the parent's death. If a child seems to be having trouble, it could mean a more serious problem than the usual grief response to losing a parent. Extra help is needed if a child:

- Displays or talks about feeling angry, sad, or upset all the time
- Cannot be comforted
- Has more nightmares than usual
- · Admits to thinking of suicide or of hurting himself or herself
- Changes from one mood to another quickly
- Has declining grades
- · Withdraws or isolates himself or herself
- · Acts very different from usual
- Has appetite changes
- Has low energy
- · Shows less interest in activities
- Has trouble concentrating
- · Cries a lot
- Has trouble sleeping
- Daydreams or seems distracted a lot of the time

When a child shows any of these symptoms, it may help to offer more support. But if the usual ways of handling these problems aren't working, or if the problem goes on for more than a couple of weeks, the child may need extra help. (For more serious problems, such as if the child is thinking about hurting himself or herself, help is needed right away.)

It may help to talk to the child's pediatrician, school counselor, or with the social worker or counseling staff at the hospital where the parent was treated. These experts know how children tend to react to losses like this, and they may be able to offer ways to help with the problem. They can evaluate the child and make sure that any needed help is given. They may also be able to suggest books, videos, and/or children's support groups that may help. Rarely, a child may need to see a psychiatrist for medicine or counseling

Hyperlinks

 www.cancer.gov/about-cancer/advancedcancer/caregivers/planning/bereavement-pdq#_62

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