



LIVING DYING

A Guide for Adults Supporting Grieving Children and Teenagers

Written by Ceilidh Eaton Russell, CCLS

Art work created by children and teenagers living with the death of a loved one

Dr. Jay Children's Grief Centre

A home for grieving hearts



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About this book

Supporting a child or teenager when a loved one is dying or has died is one of the most difficult tasks for caregivers. Family members, friends and caregivers who are helping a child to understand and grieve, when they themselves are also grieving, often feel overwhelmed and helpless.

Despite these feelings, you can help.

This book is intended to help you to understand the experience of a child or teenager; to know what support and information they need; and how to meet those needs in healthy, meaningful ways. Questions, quotes and strategies are based on clinical work with families who have helped children and teenagers learn to live with the death of a loved one. Strategies described in this book are meant to help you support a child or teenager no matter what their relationship to the dying person – or if it is the child themselves who is dying – and regardless of whether the death was expected or sudden and or even if it has already happened.

People are often unsure of what to do or how to help, since there is no way to stop death from happening or to make it less emotionally painful. That knowledge can be paralyzing for caregivers, making them feel as though there is nothing they can do.


The truth is that there is a great deal that can be done to help children and teenagers live with dying. Rather than living as though they can be protected from death, they need to know that there are people they can talk to who will love and support them.

You can help.

It will not be easy. Talking to children and teenagers about death and teaching them how to grieve requires that the adults supporting them face those issues and venture into the unknown for themselves.

Although this book contains concrete and practical information to help you support kids and teenagers, knowledge alone will not make the task of supporting them an easy one. Emotionally, it will still be difficult; you may feel unprepared, uncomfortable or afraid that you've missed something. You may not get the reactions you hope for, or worse. These feelings are not necessarily signals that you've done anything wrong; rather they indicate that you are doing something that is very difficult.

For children and teenagers, simply understanding that a loved one is dying and having emotional outlets and support will not take away their grief. That's okay; grief is healthy and natural, and the goal is not to take it away. For that reason, the aim of this book is to help grief be manifest rather than pushed aside, so that it can be shared by loved ones, offering a chance to support one another and to find a new way to live with a deeper understanding of life and relationships, together.



Thank you,

To all of the children who created the art for this book, and to the families who have shared their experiences, beliefs, fears and insights. This book is inspired by you; it is filled with your teachings and is dedicated to you and your loved ones.

To Valerie McDonald, thank you for sharing your wisdom, insight and energy, helping to shape and to edit this book.

To my family for all the ways you've helped me get here and contributed to this book through your own experiences, stories, tears, support... and editing.

To the team at the Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care for your collective wisdom, guidance and support, without which this book would not exist.



Introduction



Mysterious things remain mysterious, no matter how much we learn about them. Maybe what we learn most is some respect for their mystery, and some humility in the face of it. Dying and death are among those mysterious things. Dying asks for – even demands – an uncommon kind of learning from us. The simple truth is that we have to learn how to die, just as truly as we have to learn how to care for someone who is dying. How, though? In a culture that has so little tolerance for frailty and weakness and limits and dependence, dying stirs indignation and resentment instead of curiosity or humility. How has it come to be that dying, the most universal, inevitable and authentic of human experiences, has so few advocates, teachers or friends among us? How has it happened that dying, a knowable and reliable mystery of our lives, is so little known?

As long as we are content to see our dying and the dying of our loved ones as a physical, medical, biochemical event, we will continue to use internet blogs, sophisticated technology and information overload as the best ways of ‘handling’ death, and we’ll continue to expect physicians and hospitals to be the only true guides on a journey no one wants or believes in.

This handbook offers another way. The voices you’ll hear are of people who have lived what you are living, who have suffered what you are suffering, and who had you in mind when they helped put this material together. They are the voices of people who have learned some of what dying has to teach, and they are passing it on to you.

Dying is one of the truest teachers of life. Dying deepens the humanity of all who learn the demanding lessons about life that it has to give. That is the hard, trustworthy proposition that dying offers to us: Are we willing to live as we have never done before, at a time when it might seem most futile to do so? What if dying asks us all to live?

Stephen Jenkinson, MTS, MSW, RSW



Do talk with children and teenagers about dying and death

Why people avoid talking about death

Why people avoid talking about death

Parents and caregivers want to protect children and to help them be as happy and healthy as they can. This includes the desire to shield them from suffering the experience of loss. Since death cannot be prevented, children and teenagers cannot be protected from losing a loved one who is dying. Adults in this situation often think that the next best thing is to shield them from having to think, hear, see and talk about death. Even though this is done with good intentions, it does not help.

Avoiding talking about death does not stop anyone from thinking and worrying about it. Children and teenagers pick up on how the adults around them are feeling and acting and on what they are, or are not talking about, no matter how hard adults try to hide it. Until they can talk and ask about what's happening, children will use their imaginations to fill in the blanks with ideas that are often more frightening than the truth. Adults who avoid talking about dying and death in front of children and teenagers, send a message that children too should avoid talking or even thinking about it. Not only does this discourage children and teenagers from expressing themselves, they may also feel guilty for thinking about death.

Since death cannot be prevented, the best way to help kids and teens is to prepare them for what's happening by helping them understand, offering emotional support and including them in a meaningful and age-appropriate way.

Most adults do not feel that they completely understand death and often expect that it must be even more difficult for children and teenagers to comprehend. But anyone at any age can understand something about dying and death. Young children recognize that a person's body is not working the way it used to work and that symptoms are getting worse. Babies recognize that their loved one is not with them anymore and that their caregivers are upset. No matter how young the child, there is something that can be done to help live with what's happening.

"They're too young to understand death."

As children grow up, their understanding of what happened to their loved one, and the way that they talk about it and express their feelings, will evolve. When someone has died, young children may ask repeatedly, "When is he coming back?" or "Where did she go?" This is not because they don't believe what they've been told, but because concepts like time ('never' or 'forever') and space ('gone' to a place they cannot visit or see) are abstract and hard to imagine. They may keep asking until they are able to make sense of the answers. Each time children and teenagers start to understand death differently they will grieve the loss again, throughout their lives. This cycle does not mean that the child is 'regressing' or having trouble; this process is natural and healthy.

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To help even the youngest children, use clear, concrete language as early as possible. Two-year-olds may not yet know what the word 'dying' means, but every time they hear it and see what it refers to, their understanding will grow. Children who are told that a dying person is 'sick' or 'not doing well', are likely to worry in the future that they or anyone else who is 'sick' may die, too. Instead, using the word 'dying' even before the word has any meaning for the child, helps teach them that there is a difference. Consistently using clear and concrete language lays an important foundation for the child's understanding of dying and death that will continue to develop throughout their childhood.

"It's too soon. It could be months and I don't want them to worry all that time."

This fear may stem from the belief that dying happens fast, so if children know that someone is dying, they will constantly worry that death is imminent. But if an adult explains the dying process to them, children can understand that it can take a long time, and that they will have time to spend together with their loved one. The sooner children and teenagers know that someone they love is dying, the more time they have to make sense of what is happening, to ask questions and to do things that are important to them.

Many adults expect that once children hear the news, they won't be able to stop thinking about it; in reality that tends not to be the case. One of the ways that children grieve differently than adults is that they do it in 'chunks', both in the short and long term.

In the short term, children will think about the situation for a brief period of time – it could be as short as a few minutes, or longer, depending on the age and attention span of the child; and then in most cases, before it becomes overwhelming, they will naturally shift their focus to play. This is a way for children to regulate their emotions. They change their focus before reaching their maximum capacity for intense feelings or thoughts; it is not an indicator of denial or avoidance. When they are able to come back to thinking about death again, they will. In the long term, children go through phases or cycles of being more and less focused on death as they continue to process and find new ways of living with loss.

"I need to wait for the right time to talk to them."

It is unlikely that there will ever be a 'right time' because the death of a loved one will never feel 'right'. Most people do not feel comfortable telling children that someone is dying, knowing that it is one of the most emotional and difficult conversations to have.



However, it is in communicating with children and teenagers, answering their questions, clarifying any misconceptions, reassuring them that they can talk about this and supporting each other, that many families find comfort.

“It will be hard no matter when I tell them. Can’t I wait until after he dies?”

There are many things that make it harder to talk to children about death when it has already happened. Adults are also grieving and find it harder to think clearly or support others. When adults are grieving, children and teenagers may try even harder to protect them. They will be less likely to ask questions or express their fears and concerns and this often leads to a sense of isolation. When they eventually find out what is happening and realize that information was withheld, kids often feel hurt and betrayed. We understand that adults may have things they want to say, or do, or give to a loved one before that person dies, or before they themselves die. They can only do these things if they know, or are willing to know that death is approaching. The same is true for children and teenagers. They may also have things they wish to say or do, but when they do not find out until it is too late, they lose that chance. As adults and caregivers it is our job to give them that chance, recognizing that their memory of this


precious time will be with them for life. It will be hard, but crying is not a bad thing. It reassures children to know that adults feel sad too, and that it is okay to show their sadness. Children and teenagers often avoid expressing their feelings because of the sadness and upset they fear it will cause for their caregivers. As well, when kids and teens do not see adults expressing their feelings, they learn not to show their own feelings and they learn to avoid talking about death. If you are worried about crying, you could tell them at the outset that you might cry during the conversation and that they might cry as well. Reassure them that crying is okay and that it is important to talk about this situation even though it is hard to do.

“It will be too hard; I’ll break down and won’t be able to stop crying.”

When someone cries, do not take that as a sign to end the conversation. Instead, take a break to reassure them that you will support them through this discussion and through the whole experience. Then return to the conversation to show the person how important it is to continue to talk about death despite how difficult it is. This teaches children and teenagers that they are capable of talking about death and that they will learn that they are capable of living with it.

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How to explain what is happening

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- Prepare yourself
 - Tips for talking to children and teenagers
 - Start with what they know
 - What to say, what not to say
 - Talk about ways to help the dying person

Prepare yourself

Before talking to children and teenagers, you can ask someone you trust to help you practice saying what needs to be said. You might also ask them to be there for support or to help you with the conversation when you talk to the kids.

Find a place where you will be able to talk and express emotions openly. Use books, pictures and drawings to help children and teens understand abstract things like a disease, or how the body works, or what a hospital looks like.

Keep in mind that no matter how much you prepare for the conversation there will always be surprises. When they arise, answer as honestly and clearly as you can.

Tips for talking to children and teenagers

- **Use clear, concrete language.**
Kids and teenagers are very good at learning and using new words but they may not always know their full meaning, or realize that there is something about the word or its meaning that they do not know. Clarify the meanings of new, abstract or medical words that you or they use.
- **Ask if there's anything they have been wondering or worrying about,** reassuring them that any questions or worries are 'okay'.
- **Always answer questions with honest, clear, concrete information,** and thank them for asking hard questions.
- **Check in often**
to see if what you have said makes sense, or if it would help to explain it in a different way.
- **When you do not have an answer, say so.**
It is okay for children to know that there are questions that adults and even doctors don't have answers to.
- **Pay attention to their reactions to what you say.**
When you notice a reaction, such as tears, fidgeting or a look of surprise, point out the behaviour and ask them if they can tell you what it was that you said that made them react that way.

Start with what they know

- **Ask them to describe what they know about the situation so far.**

If they use medical terms like “seizure” or “cancer”, ask what those words mean to them. Clarify misconceptions.

“I figured it out, when I had a cold I laid down on my pillow and then mom laid down on my pillow and then she got cancer.”

- 8 year old

- **Starting where they left off, describe the illness and how it works using clear, concrete language.**

Children understand cause and effect. They know that something is causing the symptoms they can see in their loved one. If kids do not know that a disease is causing those symptoms, and that the disease is beyond their control, they may believe that the illness is somehow their fault.

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Family visits to the hospital

- **Tell them that there is nothing they could have done to cause or avoid or cure this illness.**

If they had been angry or thought negatively about the person, they may believe they accidentally 'wished' the illness to happen, or that it was a punishment for their behaviour.

- **Reassure them that they cannot 'catch' this illness,** unless the disease is actually contagious. Explaining how the person got sick in the first place reassures kids and teens that this is true. In many cases there is no known cause for a disease. Doctors and researchers are still trying to figure out why some people get sick and others do not.

"When it's my turn for a brain tumour..."

- 7 year old

- **Explain treatments that were tried and the signs that they were not working.** Refer to concrete signs that the children have seen, such as a loss of strength or change in abilities. This is important 'proof' of a decline in health and of the efforts that were made by the medical team and the family to help the person they love.

Many kids and teenagers wonder if there was anything more that the dying person could have done to overcome the illness, rather than 'leaving' them behind.

They sometimes ask questions like, "Why didn't she try harder to get better?" Children and teenagers need reassurance that the dying person did everything possible to stay alive to be with them and that they loved being alive, just as the medical team and the family did everything they could to try to make that happen.

"What's the point of taking medicine if it can't make the disease go away anyway?"

- 12 year old

- **Explain the difference between medicine to treat disease and medicine to treat symptoms.** Helping them understand this difference reassures children and teens that although the disease cannot be cured, their loved one will still have help with their headaches, nausea, pain and other symptoms.

"If there aren't any more medicines to make my dad's cancer go away, what will the doctors do then?"

- 7 year old

- **Clearly say that the person is going to die.** To a child, phrases like "there's nothing more we can do" and "he's not going to get better" do not mean the same thing as "he's going to die." They have no way of knowing that the person will not stay in their current condition forever. Clarifying this fact is extremely important.

What to say, what not to say

Always identify the illness by name.

Some people avoid words like 'cancer' or 'tumour' because they think that it is less scary for children to hear the word 'sick' or to call a tumour a 'bump'. Unfortunately this is confusing for children. Any time someone else gets sick - including themselves - they'll worry that it could be the same sickness that the dying person had and that they could die from it. Even children who are too young to understand what 'cancer' means, understand that it is a different word than one that describes having a cold or a bump on the head from a fall.

Use the words "dying", "died" and "dead".

Explain that when people die, their bodies stop working. They stop breathing, their hearts stop beating and their brains stop working. That means that they cannot think, hear, see, smell, taste or feel. Because of that, they cannot be lonely, scared, hungry, bored or in pain. "Dying" is what happens as a person's body stops working. Sometimes it happens quickly and sometimes it happens slowly. Try to give children and teenagers as much clear and concrete information as they want to know.

Words and phrases to avoid:

- "She's gone into a deep sleep" – children may worry that anyone could go to sleep and never wake up, including themselves.
- "We lost him" – children may wonder where the person is and why no one is looking for him.
- "She passed away" – this is too vague for children to make sense of.
- "He's gone to be with God / angels" – this implies that the person willingly 'left', making children wonder why their loved one wouldn't rather be with them.
- "They're in a better place" – children may wish they could have made this place 'better' so that their loved one would have chosen to stay.

Once children understand what 'dead' means, they can also learn that some people use other words instead, like those in the examples above.

Talk about ways to help the dying person

Children and teenagers struggle with feelings of helplessness when they cannot change the medical situation and are often unable to be involved in the medical and physical care of the dying person. It is very important for adults to emphasize the significance of taking care of the dying person's emotional needs and relationships. Spending time with the person, doing familiar activities, expressing their feelings and making things for them are very meaningful ways of helping to care for their loved one.

Many children and teenagers have intense emotional struggles about being with the dying person. On one hand they want desperately to spend time in the company of their loved one, while on the other hand they do not know how, or may be afraid to do so. Some children worry that they will accidentally cause harm or upset the dying person. Older children and teenagers are increasingly aware of social expectations and instinctively try to adapt to what they perceive to be 'appropriate' behaviour. This struggle to behave 'appropriately' in such a difficult situation can be paralyzing for children and teenagers who do not

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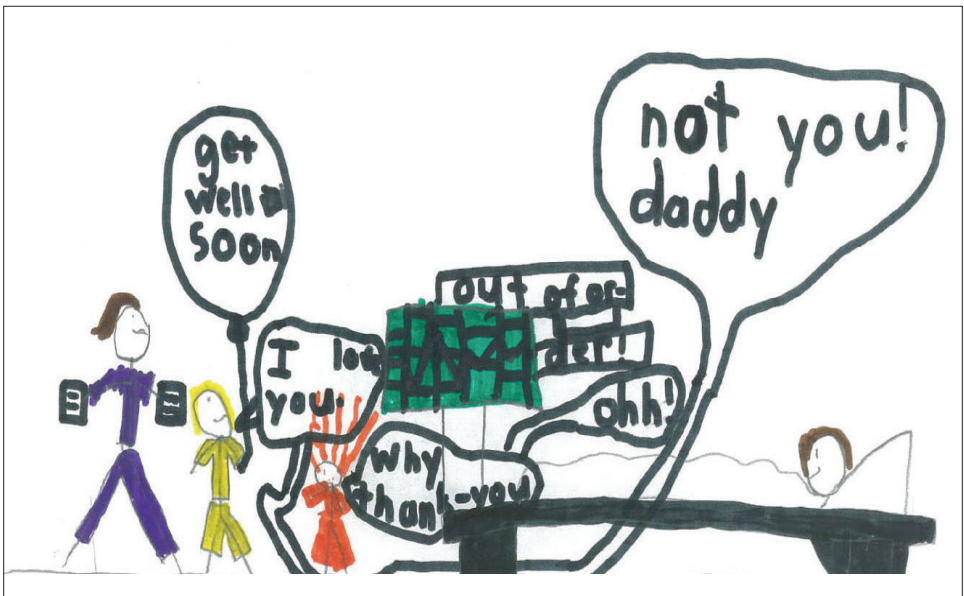


A child taking care of her father by visiting him in the hospital and creating art for him.

know what that interaction would look or feel like. Adults often worry that children are 'avoiding' reality and the dying person by spending more time away from home, when in fact the opposite is true; their intense desire to be present is outweighed by fear and discomfort. Reassure children and teenagers that they may feel awkward, that that is alright and that you will support them through this struggle. Encourage them and demonstrate how to interact and offer support, but especially how to 'just be' with the dying person.

Caretaking by creating

After discussing the fact that someone is dying, most people don't know what to do next. Having something constructive to do or to make for the dying person offers children and teenagers an outlet for their feelings and their energy. Depending on the ages of the children you might plan an activity ahead of time or bring supplies for an unstructured opportunity to create something special. As much as possible, consider the child's or teen's hobbies and preferences when collecting supplies so that they can use familiar and preferred media. Building a keepsake box out of LEGO®, making a collage from photos



Family visits to the hospital
Art work by children aged 5-7 years old.

or magazines, writing a letter or poem, beading jewellery, packing a 'comfort kit' of favourite clothes, books, music, etc., or cooking a special meal for the dying person are some of the many ways that children and teenagers can demonstrate their support. Using materials the child or teen is comfortable with maximizes their comfort and the sense that their creation reflects something of themselves.

While they're 'doing' or 'making' something, children and teenagers have a chance to process their thoughts; to ask questions and to express themselves; they often feel less vulnerable while they focus on an activity. Art and creative work also offer ways for children and teenagers to express emotions that they may not have words for since they experience new, more intense or conflicting emotions when they are grieving. As well, when they give something they've made to someone they love, children and teenagers aren't just giving a 'thing', they're literally giving the emotions that went into making it. Explaining that idea to kids and teenagers reinforces how meaningful these gifts are for the dying person. See also: "Activities" section.


Some children and teenagers may be uncomfortable or insecure about participating if they do not enjoy creative work or see it as 'baby-ish'. Using materials or working on projects of their choice is one way to help them overcome this, as is having an adult participate with them. However, if a child or teenager does

not want to participate in what you've suggested, do not force them. Let them know that your suggestion was one possibility but that you could help them do something of their own choosing, or help them find another way to support the dying person that is a better fit for them. Describing other times and ways that a child or teenager has supported others can help them recognize and appreciate their capacity to do so and may help them decide what to do in this situation. Most importantly, reassure them that they do not have to 'do' anything at all, that being with the dying person is incredibly significant in itself.

Caretaking by 'being' together

When a person's abilities and energy are affected by the illness it can be hard to know how children can interact with them. Think about what activities they used to do together and find ways of adapting them for the home, hospice or hospital. For example, if they used to draw together, encourage the child to draw with the person nearby even if they can't participate, or invite them to bring pictures in to decorate their room. If music was a common interest, help the child choose music for the person to listen to, or encourage them to record themselves singing or talking for the dying person to listen to. If cooking was a shared experience, the child could bring them homemade food. If stories were a common interest, the child could read a story or another adult could read to both the child and the dying person.

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No matter what activity they used to share, there is a way to adapt it so that the child can still participate and the dying person can still benefit from being part of this familiar and meaningful interaction. It is most important for the child to know that the dying person still enjoys their presence and company. Explain that even if the dying person interacts in a different way than they used to, or does not seem to be alert – they still feel the child's presence and love.

There are also practical ways that children and teenagers can be involved in caretaking. They might help the person to brush their teeth or put on moisturizer, get ice chips to chew, offer a massage, or even take care of things at home. Tasks that are typically seen as 'chores' such as walking the dog or helping to cook or do dishes can be meaningful ways for a child or teenager to help take care of their family, but only if they see it that way.

Talking to the child about what kind of help the family needs and what jobs they would like to help out with is important. Talking helps to ensure that they are comfortable with the role they will have and that they feel involved in taking care of the dying person rather than feeling like they have extra responsibilities and expectations during an already difficult time. Although 'caretaking' is an important opportunity for children and teenagers, they need help to take on an appropriate role that does not include an overwhelming amount of responsibility. Whatever tasks they choose, reassure them that you will check in with them often in case the responsibilities get to be too much or too hard, in which case you would help them find alternatives or take a break from those tasks.

Adults can help children and teenagers find meaningful ways to support others while encouraging them to also accept support from others. This can be modelled to kids by seeking help yourself and letting them know that you're doing so, as well as by creating opportunities for mutual emotional expression.

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Understanding developmental tasks

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Security

Control

Competence/ Self - esteem

Identity



From the time they're born until they reach adulthood, children are learning about their relationship with the world and people around them. They're working to develop a sense of **security, control, competence and identity**. Although children and teenagers are always building upon all four of these developmental tasks, each task will be a priority at different times in their lives. When a loved one is dying or has died, the significance of the developmental task that the child or teenager is most actively working on is often amplified.

Struggling to achieve a task or develop a skill that they have been unable to master and having it further complicated by circumstances around the dying person, kids and teenagers may feel a sense of failure, incompetence or helplessness which can generalize to other aspects of their lives. Try to talk to children and teens about what they're experiencing, keeping in mind that they may not have words to express these emotions. It can help to frame questions like "Some kids say it's really hard not to be able to help others feel better, or not to be able to control what's happening. Other kids say they don't feel like the same person any more. Have you been thinking about things like that, or anything else?"

Suggesting what other children and teenagers have struggled with addresses the fear that what they're feeling is not 'normal' or acceptable. At the same time it is equally important not to make them feel that they 'should' be struggling with the same things which is why it can help to offer a range of possibilities all in one question, as in the example above.

The following is a description of some ways that these developmental tasks may manifest themselves in grieving children and teenagers, ways to respond to their feelings, and strategies to help address the challenging situation.

Security

Kids who are beginning to realize that they can't protect others or be protected from death may feel unsafe even in familiar environments; or they may have nightmares. Children instinctively try to use strategies that provided a sense of security when they were younger – thumb-sucking, 'clinging' to caregivers, carrying a favourite toy, etc.

1. How to respond

Let them know that it's natural and 'okay' to need some extra comfort and security. Most importantly, do not scold or try to stop kids and teenagers from using their security-seeking behaviour, even if it seems inappropriate for their age (unless the behaviour is harmful to themselves or others). Forbidding a coping strategy will make them feel badly for needing the support and for 'choosing' an unacceptable behaviour, amplifying their need to be comforted. Instead, let them know that you've noticed that behaviour and that you want to find better ways to help them get what they need.

2. Supportive strategies

If they're at school, is there someone they can talk to, or hug when they need it? Can they phone someone at lunch for that extra reassurance? Writing a special note to keep with them during the day while they are at school, or letting them bring a special item belonging to a loved one can be a concrete reminder of the comfort they need when they are away from their family.

Control

Being unable to control the illness or their emotions can lead to a sense of helplessness, or a generalized lack of control over their lives. Some children and teenagers try to compensate by controlling other aspects of their lives such as school work, their appearance, hobbies, etc. They may try to gain an unrealistic amount of control through order (i.e. following rules, being very well behaved) and organization (i.e. being prepared), taking on extra responsibility in hopes that that may avert further loss or tragic events.

Other kids and teenagers will break rules in search of boundaries and external sources of control. They are looking for the reassurance that even though they feel out of control, someone else will be in control and will act responsibly.

1. How to respond

Regardless of whether their need for control is expressed by breaking rules or by taking on extra responsibility, the main messages kids and teenagers need to hear are the same. First of all, children and teenagers need to know that no amount of control, organization or responsibility, on their part or anyone else's could have prevented their loved one from dying, nor will it prevent anything that may happen in the future. They will need help overcoming the desire to control the uncontrollable and to live with the knowledge that some unpleasant things are unavoidable.

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The second message is that while there are important things that they can be in control of and be responsible for, there are other things that an adult, parent or caregiver will be responsible for, such as housing, food, rules, etc.

2. Supportive strategies

When their lives are in turmoil and everything seems vulnerable, maintaining limits, expectations, consistent routines and participation in familiar activities are extremely helpful for kids and teenagers. Consistency and familiarity lead to predictability which helps children and teenagers re-establish a sense of control. Helping the child choose things to be 'in charge' of – a particular chore, how to decorate their room, what to bring on a visit to their loved one, or planning a special day – can give them meaningful opportunities for control as well.

Competence / Self-esteem

Kids and teenagers wish they could protect their loved ones and may feel responsible to do so. They may see this person's dying as a sign that they are incompetent as protectors or caretakers. This feeling can be generalized to other skills or hobbies, and children and teens may start saying "I'm not good at that."

1. How to respond

Reassure kids and teens that when life is really hard people often feel like they're not good at handling things, but really, it's that these things are very hard to handle. You might talk about something you've struggled to feel 'good at' during a difficult time. You can also remind them that everyone needs help with some things, and needs to practice before they become good at it, that nobody can be good at everything. Also talk about the value of being good at struggling. Learning how and when to do something that's really difficult requires being good at struggling to do it.

2. Supportive strategies

Work together to write a list of all the things the child or teenager does to care for people around them and for themselves, or all the things they're 'good' at and enjoy doing. Include things they do at home, at school, and all aspects of their lives, making an effort to point those things out to the child or teenager every time they do them, in order to build their sense of competence.

Identity

Children and teenagers living with death begin to feel that the world is different than they thought, to see themselves differently and notice others treating them differently as well. The death of a family member raises questions about roles: "Am I still daddy's girl?" or "Am I still a big brother?" Kids often wonder: "I don't feel like the same person, so who am I now?" Hand-in-hand with this type of question is "Is he still my dad?" or "Do I still have a sister even though she died?"

1. How to respond

It is important to affirm for kids that dying doesn't change their relation to the person they love. Whether it is their mother, father, brother, sister, cousin, grandparent or friend, they will always be that to the child or teenager. In addition, no one will ever replace them. Even in cases where parents remarry or other siblings are born, those people may take on similar roles but will never replace the person who has died. Therefore, even though the person will die, the child or teenager will always continue to be a brother or sister, cousin, child and grandchild.

2. Supportive strategies

Talking about their different relationships and roles can help a child or teenager figure out who they are, and despite what's changed, recognize how these relations will always exist.

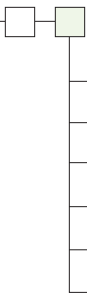
See also: "Reframing Relationships" section.

"Is she doing this because she's grieving or because she's a 2 year old?"

It is not always possible to know whether a particular behaviour is related to grief or to a child's development, but in either case the response that is needed from caregivers is the same. Children and teenagers benefit from clear and consistent expectations and on-going support, regardless of the source of the struggle or task that they're dealing with.



Recognizing children's grief

- 
- Distinguish between emotions and behaviours
 - Grieving over time
 - Balancing opposite ideas
 - Looking for distraction
 - Living a “double life”
 - Vulnerability

Grieving is often thought of as a phase that people must get through, or an emotional wound that must heal in order to get back to living and feeling 'normal' again. When grief is thought of this way, the death of a loved one is something that you should get over eventually and that grieving can or should be cured. But the way that a person, regardless of age, experiences and interacts with the world is fundamentally changed when a loved one dies. Everything looks and feels different, things that may have been taken for granted are no longer. Grieving is the lifelong process of learning how to live in this new and continually changing world. Grieving together connects people to one another, helping them find ways to keep the dead in their lives.

Grief can feel like heartbreak that will not be avoided or contained. It can only be pushed aside for so long before it pushes back, more strongly, overwhelmingly, without warning; it must be experienced and recognized in order to learn how to live with it. Good grieving offers a feel, though often an unwilling feel, for the end of things: the end of the day or the summer, the end of a friendship or the end of a life. Though nobody goes looking for this kind of understanding, when it presents itself it is the real beginning of being able to love being alive, not because life lasts forever, but because it does not.

Like adults, grieving children and teenagers experience a wide range of conflicting emotions including happiness, sadness, frustration, anger, guilt, loneliness, vulnerability, helplessness, betrayal and even relief. They may be surprised at the intensity of these emotions and be unsure whether they're 'acceptable' or 'appropriate'. The complexity and contradictory nature of these feelings makes it very difficult for children and teenagers to understand their emotions, let alone to label and articulate them. Instead, these emotions are often expressed through tears, emotional or physical outbursts, withdrawal or hyperactivity, changes in eating or sleep habits or physical symptoms such as headaches or stomach aches.

Sometimes kids find themselves having fun and then feel badly for being happy when someone is dying or has died. Children and teenagers need reassurance that it is okay to have different feelings at different times – or at the same time – and that the dying person would still want them to be able to play and be happy.

It is also common for a seemingly small, unrelated incident to trigger a strong emotional reaction. Because of how confusing and intense their emotional experience is, children are often unable to express all of what they are feeling, leading to a kind of stock-piling of emotions.

When this occurs, seemingly insignificant issues can be triggers for these accumulated feelings, leading to an emotional or physical outburst. Especially when their feelings are difficult to understand, intense emotions are extremely hard for children and teens to regulate. In these situations it is important to offer support that addresses their underlying emotions rather than to focus solely on what seemed to be the 'trigger'. For example, a child may lash out aggressively at a peer who has taken a toy from him. While it is important to address the aggressive behavior, he also needs support for his sense of loss which was aggravated by the loss of the toy.

Distinguish between emotions and behaviours

Children and teenagers need help to distinguish between emotions and behaviours, and to develop strategies to manage their behaviour. It is important to emphasize that there is nothing wrong with the emotions behind the behaviours. To this end, help them:

1. Name and express the emotion
2. See the difference between the emotion and the behaviour.
3. Believe that it is okay to feel the way they are feeling; they just might need a new way to express it.
4. Find a constructive way to address the emotion.

When children and teenagers 'act out', their behaviour is often indicative of a struggle to understand, express and regulate their feelings. The first step to help them overcome this is to help them distinguish between emotions and behaviours, recognizing that although they may not be able to control whether they feel sad, angry or otherwise, they can control their behaviour and reactions to others.

In some cases children and teenagers may adopt behaviours that are potentially harmful to themselves or others, whether physically, psychologically, legally or otherwise. If you are concerned that your child's or teenager's behaviour is potentially harmful you can contact their family doctor, paediatrician, school social worker or a children's mental health centre in your area for more information or a referral to a professional counsellor. If you live in Canada, you, the child or teenager can contact Kids Help Phone to access support and referral services at 1-800-668-6868.

Grieving over time

Children and teenagers grieve in 'waves' in both the short and long term. The intensity, duration and frequency of these 'waves' is not linear or predictable.

As a way of regulating their emotions, many kids instinctively switch their focus to play when they become overwhelmed with intense thoughts or feelings. To adults this can look like avoidance; many parents worry that a child who is playing is not grieving when in fact, a child can go back and forth, or even grieve and play at the same time.

Some children incorporate dying and death into their play, by acting out funerals, being 'ghosts', drawing, singing about the person who died. Many adults are concerned when children and teenagers are focused on the person and on death – talking, crying or expressing themselves in other ways – when in fact, these are signs of healthy grieving.

Over time the way that children and teenagers grieve will evolve. Children who had a minimal understanding of time when their loved one died, will struggle as they begin to realize the meaning of being 'gone forever', and will seem to grieve more as time passes. On the other hand, a 6 year old might say that their loved one died 'a long time ago' after a period of time that does not seem long to the adults in their life.

It is important to remember that a year is 1/6 of a 6 year old's life, but it is a much smaller fraction for an adult. Saying that it was a 'long time ago' does not mean it isn't hard to deal with or that it is insignificant to the child.

In the long term, grief that seems to recur is not a sign of regressing, even if it looks the same as it did when the child was younger. This cycle of grieving is natural and healthy. In most other situations in life, saying that a child is 'doing well' means that they're not having difficulty or struggling emotionally. In the case of living with the dying and death of a loved one, 'doing well' means the opposite – grieving includes experiencing and expressing intense emotions.

Balancing opposite ideas

Children and teenagers are capable of balancing two opposite ideas at the same time

"If she gets better... but when she dies..."

- 7 year old

For example, a girl whose sister was dying spoke of wishing for her to get better, talking about what they would be able to do if her wishes came true, but in the same conversation described how sad she would feel when her sister eventually died. Some adults might hear this statement and worry that the child is in 'denial' while others will avoid telling them that someone is dying in case they "Take away their hope". In reality, kids and teenagers are able to do both – know what's real and hope for something different. As adults we need to provide information about reality in order to help them find their own balance.

Looking for distraction

People often struggle to take their minds off what's happening and say how difficult it is that everything "reminds" them of the dying person and death. But, although it is counter-intuitive, the only way to address these feelings is to purposely focus on what's happening and to do something meaningful about it. When people talk about not wanting to be 'reminded', what they're often trying to avoid thinking about is their feeling of helplessness. Even though the situation cannot be changed, there are still constructive and meaningful things that can be done to care for the person both physically and emotionally. By doing something constructive for the dying person, people can begin to address those feelings of helplessness. Some people do this by making something creative or comforting for the dying person, or in their honour, or as a memorial.

See also "Memory Building Activities" section

"I just can't stop thinking about it."

-12 year old

Living a “double life”

Children and teenagers often describe feeling strange about going to school where ‘everything’s normal’, whereas at home everything is different. On the other hand, some kids and teens have teachers and peers who do know what’s happening and they may feel awkward because of it. Either way, two different sets of expectations for behaviour, routines, roles and relationships contribute to this feeling.

“It’s like I have two different lives.”

- 12 year old

To help children and teens, find out if there are questions or situations they’re afraid of and help them practice what to do in those circumstances. Talking to their teachers to establish appropriate, consistent expectations and accommodations, and identifying a supportive classmate or teacher they can talk with when they need to, will start to bridge the gap between the two environments and will help a child feel better prepared to deal with these situations.

Vulnerability

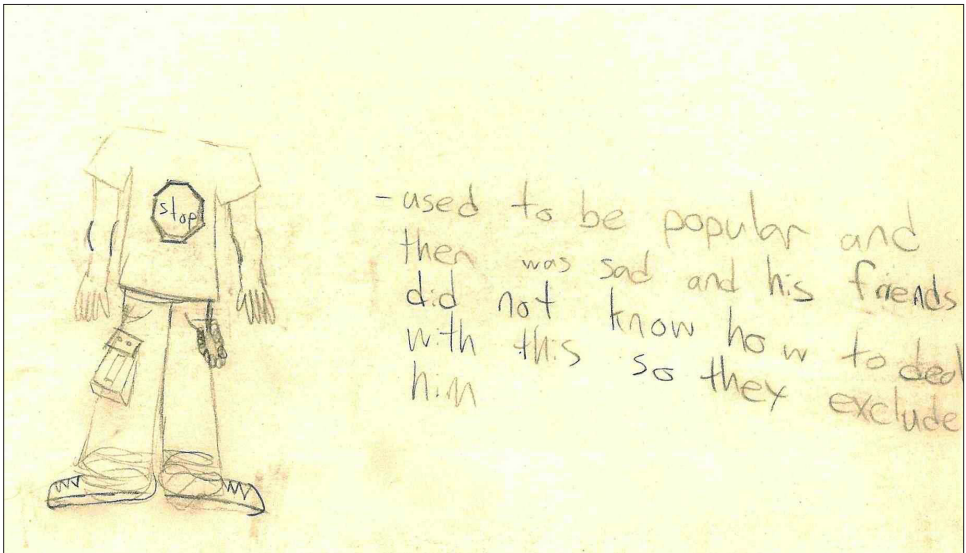
Although most children do not have words to use to describe it, the death of a loved one causes feelings of vulnerability. They may say things like “I feel naked, like everyone can see inside me” or “I realized any of my friends could just move away at anytime” or “everything good in the world is gone”. Kids and teens who used to feel confident that their parents could protect them from everything, that good conquers evil, that bad things happen in movies and to other people, learn quickly when a loved one dies that they are vulnerable to a whole host of things they hadn’t worried about before.

“Everything just feels different.”

- 18 year old

When someone dies children begin to wonder about questions like: “Will it happen to me too?” or “What if my parents die? Who will take care of me?” Questions like this do not have easy answers because the truth is that we never know who will die or when. These are also questions that are very hard for children to ask. They often feel guilty for thinking about another person dying and do not want to upset anyone by asking the question. It is important to reassure them that it is natural to worry about those questions and then answer honestly and avoid saying things like “I’m not going to die” since kids and teenagers in this situation are beginning to realize that nobody can, or should promise that.

Instead, validate their fears and talk about all the ways you're taking good care of yourselves so that even though you can't guarantee that nobody else in their life will die, you can all do your best to stay healthy, strong and safe. It is also very important for children to know that no matter what happens, there will be people who will take care of them. Although no one wants to imagine that worst-case-scenario, it reassures children to know who would care for them if anything were to happen.



Portrait of a young teenage boy struggling to be included by peers. Drawn by a 12 year old boy.

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Reframing the relationship

When someone they love is dying, children and teenagers grieve the fact that they will lose this person forever. If they can find ways to include the person in their lives even after they die, then they don't have to 'lose' that person. Instead, they have to find a new way to maintain the relationship. Kids and teens will still grieve the death because maintaining a connection won't take away their sense of loss, but it can help them find ways of living with that loss.

Children and teenagers can understand that love and relationships exist between people even when they're far away from each other, so although being dead is different than being far away, their love and relationship can continue to exist in a different way as well. To help them make sense of this, talk to kids and teens about the impact that the dying person has had on their life. Ask them what they learned from this person, or what values, beliefs, common interests or hobbies they shared.



Family portraits, dad's presence is strong, although different since he died.

A child whose father started to teach her how to draw might keep practicing after he dies, thereby continuing to learn something special that he taught her. A teenager who enjoyed learning to cook with his mother could continue cooking, practicing what she taught him and doing something they enjoyed together – now ‘for’ her instead of ‘with’ her. A girl whose brother loved animals, might volunteer in an animal shelter. If the dying person is a relative, children and teenagers can be reminded that they share some of the same genes, so part of their loved one will be alive in their own bodies and minds. Although they are not with the people they love, kids can find a great deal of meaning and value from maintaining a connection in these ways.

Talking with children and teenagers about what they have shared with loved ones can lead to a broader discussion about ancestry. For children who find it hard to understand that they will still be related to a loved one even after they die, (i.e. “How can she still be my mom?”) learning about relations to people who died before they were born, such as a great-grand-parent, can help to reframe what it means to be related. Connections with ancestors through personality traits, skills, and physical resemblance, traditions and beliefs offers a broader perspective on the meaning of ‘family’ and can help a child or teenager develop a deeper sense of their role and belonging. Talking about ancestors also demonstrates that people can be remembered and honoured even though so many years have passed since they died.

Creating traditions and memorials are another way to keep a loved one in children’s lives. If there were games they played together, or trips they made to the park or special places, families could plan a special day – once a week or month or year – to do those familiar and meaningful activities as a kind of ritual or occasion in honour of the person. Celebrating birthdays, anniversaries and other special days and talking about the person at those times are other ways to keep those who have died in their lives. Some families recognize the person who is missing every night at bedtime or dinner by lighting a candle or giving a blessing.

Creating memorials might include making scrap-books, memory boxes, collages of special photos, a garden for growing the person’s favourite flowers or a special tree. Making artwork or writing letters to bring to the cemetery is another kind of ongoing memorial.

Including children and teenagers in choosing and planning these activities, memorials, traditions or events to honour the person who died offers them incredibly meaningful opportunities. Talk to children and teenagers about all of the ways that love, relationships and special bonds extend beyond a physical body, both with people who are alive as well as with those who have died. Including the person who is dying in this conversation, if possible, can offer incredible comforts to everyone and can help children later on as well, when they reflect on this discussion.

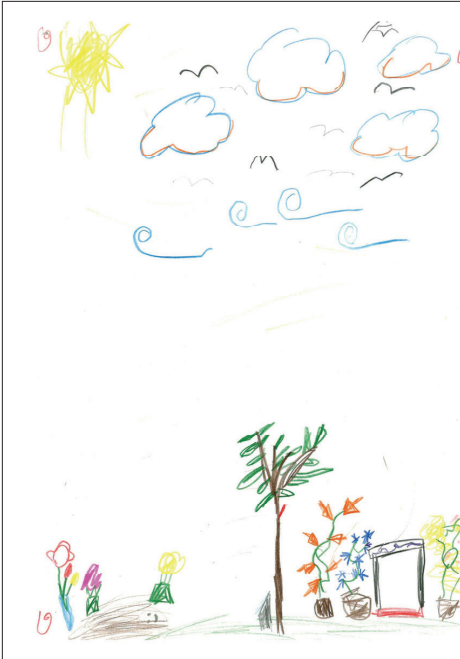
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Portraits of 3 girls, "still sisters" after one sister died.



"Are we still triplets?"



Visiting the cemetery where a loved one is buried.

Being able to express their feelings, grieve and connect with the dying person and their family while their loved one is still alive reinforces that their bond goes far beyond a physical body. Including children and teenagers in choosing and planning these activities, memorials, traditions or events to honour the person who died offers them incredibly meaningful opportunities.

What if the child did not have a good relationship, or did not like the person?

Relationships can be complicated and difficult; children should never be made to feel that their feelings about the person who is dying or about the situation are 'wrong', or that there is a 'right' way to feel. Remembering and grieving someone are not the same as approving of their way of doing things when they were alive. Children and teenagers may be left with feelings about what they wish had been different about the person or their relationship with him or her. They may feel that the person set an example of 'what not to do'. Regardless of what thoughts or feelings the child or teenager has, it is important that they can express them and be supported in dealing with them. In fact, children and teenagers who have had difficult relationships often have an even harder time making sense of their emotions, so they need extra encouragement and support in order to do so. They are also likely to need help dealing with other people's reactions or expectations about how they are feeling. Most importantly, reassure them that they are not to blame for the way the person may have treated them or for the nature of their relationship; that there is nothing wrong with any emotions or thoughts that they might be struggling with.



**Searching
for meaning**

Throughout the process of the illness, dying and death of a loved one, children and teenagers try to make sense of what's happening and why, just like the adults around them. This search for meaning is often expressed through their questions which often do not have easy answers, or any answers at all. If that's the case, try not to feel that you need to give children and teenagers answers, but be someone to wonder out loud with, and offer company and support.

"Does it mean we didn't love her enough?"

- 7 year old

Even when children understand in a rational way that they did not directly cause the death, their feelings of helplessness can still make them think they should have done something more, or differently. When children express a question or fear like this, reinforce that there was nothing they or anyone else could have done to stop the person from dying and recognize their underlying feeling of helplessness.

"I bet he's sad that he's dying, but I bet he's also glad because he's had such a good life."

- 5 year old

As they sort through their ideas and feelings, children may say things that go from one extreme to the other. Their search for meaning will not be linear or predictable and it is natural for their ideas to seem to be all over the place.

They will try out many different ideas before they find ones that fit and then with age and experience they will revisit the process, continuing to search for meaning as they grieve in the short and long term.

"It's not the best thing that's ever happened, but it's made me realize how important my family is and the people I love."

- 9 year old

Children and teenagers are able to hold onto the way they feel about the fact that someone is dying or has died, while at the same time recognizing that something positive can happen in spite of, or even because of the death. For example, realizing how important the child's family is does not remove the sadness of the person dying; rather both things are true and important at the same time.

"I never thought of myself as a strong person before."

- 14 year old

Not only do children try to find meaning in illness and death, but they find out what it means for them as a person. For some children and teenagers, realizing that they can live through the death of a loved one is evidence that they are capable of much more than they'd thought.

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Although it is important not to push children towards accepting a meaning that they haven't yet come to, we can certainly validate and appreciate the meanings that they do pursue.

"What is it like to die?"

- 7 year old

Answering this can mean answering any or all of 3 questions:

1. What does 'dead' mean?

Answer concretely. When someone is dead it means their body, including their brain, has stopped working. They cannot see, hear, smell, feel, move or think. Because of that, they're not lonely or hungry or hurting or bored or scared.

2. What happens to your body after you die?

Again, be concrete. If the person is going to be buried, explain that they will be in a special box, called a 'casket' in the earth, and that the spot will be marked so people will know where they are. In the case of cremation, tell the child that the person wanted their body to be turned into ashes, and where they wanted those ashes to be kept, buried or scattered.

If they want to know more you can say that a 'crematorium' is a special room or machine that is hot enough to turn the person's body into ashes. Remind them that nothing will cause the person pain since dying means that they cannot feel anything anymore.

3. What happens to the rest of you?

Children and teenagers who believe in a soul or a spirit that is separate from the physical body wonder deeply about this and may have their own ideas about what happens. Answer according to your own and the child's beliefs. If you do not know what you believe you can say so, and discuss different ideas that other people have. Children may ask this question repeatedly of different people or even the same person as they try to integrate people's ideas into their own understanding of life and death.

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Attending funerals

Children of all ages can be prepared to attend funerals and memorials and can benefit greatly from being included. Young children who need help understanding abstract ideas about their loved one being 'gone' can see for themselves where their body will be. Many children appreciate being able to put something in the person's casket, writing something to be read at the service, choosing a piece of music to be played or carrying flowers to the cemetery.

These are valuable opportunities for children to express their feelings and to feel included as important members of the family or community who are grieving. Find out how or if the child or teen would like to participate to ensure that the experience will be meaningful for them no matter what their role.



Children helping their family carry their father's casket at his funeral.

Before the funeral, tell the children what they are likely to see and hear. Reassure them that although they will see adults crying, that's okay because it is a healthy way for adults to show that they're sad. Seeing adults grieve models healthy emotional expression. At the same time, let them know that it is okay for them not to cry or to feel any other feelings besides sad. If there will be an open casket, tell the children that the person will look different than they used to. Their skin will feel tight and cold and their face will look different,

partly because of make-up but also because they're not animated – smiling, talking, frowning, etc. Seeing this can help children understand that the person they love is not in their body anymore. The best thing to do is to talk to the child or teenager ahead of time, let them know what they can expect and give them the chance to decide for themselves when and if they'd like to see the person's body.

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Children attending their father's funeral.



Most importantly, talk to the children about what to do if they feel overwhelmed at the funeral. If their caregivers are grieving their own loss, it helps to identify another trusted adult who can be available if the children need to leave. They can use a signal like 'thumbs up' or pointing to a door to indicate the need to leave. Reassure them that they do not have to do anything they're uncomfortable with. Whether they observe, participate or need to leave during the service, it is all okay and it is most important for them to tell an adult what they need.



Children attending their father's funeral.

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Emotional expression



- Expression through talking
- Expression through creative outlets
- Expression through physical outlets

Expression through talking

When adults around them are upset, children and teenagers are less likely to ask questions or to say how they're feeling. For all of these reasons they need adults' encouragement to express themselves in a range of ways.

Tell kids and teens often that they can talk to you about how they're feeling and raise any questions or worries they might have, not only when they seem to be struggling but also during quiet moments together. You might need to raise the topic a few times before a child or teenager is comfortable enough to express themselves. Kids may know that you want to help but still be unsure that it is okay for them to talk, so they need those repeated opportunities to open up. For some children and teens talking will not be a comfortable way to express themselves and that is okay. They do not need to talk a lot about what's happening, but they need to know that they can when they need to. As an alternative to talking, writing poetry or stories with words or with pictures, keeping a journal or diary offer the benefit of being able to have their thoughts expressed while maintaining their privacy. For kids who are concerned about upsetting others by expressing themselves or if they fear they may be judged for what they're thinking, these forms of writing can be an alternative, or can offer a way to 'practice' expression while working towards talking to someone.

POEM

for Ken Danson:

Daddy, I'll never forget,
sitting on the water
watching the sunset.

Seeing the stars and the moon
in our little canoe,
the water bugs darting,
just me and you.

We said what beauty the world
could create,
I wish life hadn't brought us this
terrible fate.

But, I'll try my best in sports
and hockey,
I hope I'll fulfill what you
expected of me

and I know you'll be watching
from up above,
and I know you know which person
I truly love.

I knew you were perfect the
second we met,
I love you, daddy,
and I'll never forget.

By Adrienne Danson
11

Expression through creative outlets

Art, music, puppets, stories, dramatic and imaginary play are all healthy ways for kids and teens to express emotions regardless of whether they have words for the feelings they're expressing. In their play, children may act out or draw what they believe is happening, or what they wish were happening instead; or they may be role-playing a scenario that is neither reality, nor what they wish for. Gently asking "Is that how things seem to you or is that what you wish were happening? Or is it something completely different?" will help you find out what's behind their play and allow you to clarify misconceptions, if they exist. If a child does understand what is happening and says that their play is expressing what they wish for, it is okay to tell them that you wish for something like that too, even though you know that it's impossible for a wish like that to come true. Whether they are expressing fantasy or reality, whether it seems strange, dark, unusual or even if it is the same way the child played before they were dealing with death, expression through play is natural, age appropriate and healthy. Regardless of what their play reflects, be careful not to take a child's play too literally, keeping in mind that they have an amazing capacity for imagining, and you can never be sure what's behind their play unless they tell you.

Expression through physical outlets

People of all ages commonly have physical symptoms related to grief, such as changes in eating and sleeping habits, headaches, fatigue, etc. Children and teenagers need physical outlets to help overcome those physical symptoms. Exercise that the child or teen enjoys is a good outlet for physical symptoms and may also help them express and regulate their emotions. Adults can teach them to take deep breaths and count to ten as a way to calm down after getting worked up, or talking about how a sport can help them to let out feelings. Many activities can also be adapted to include physical and emotional expression. For example, children can express feelings by writing or drawing pictures of things they're struggling with, taping their writing or drawings to a wall outside and using them as targets to throw water balloons at. Alternately, a game like "Simon Says" can be adapted so that instructions are physical actions related to emotions. Instructions like, "Simon says stomp your feet like you're mad" or "Wave your hands like you're frustrated" are some examples. By participating in physical activity with kids, adults can model emotional expression and give kids a chance for them to practice expressing and regulating their feelings. Children may also need more physical contact, like holding someone's hand, or they may need more hugs and affection when they are grieving. Try to follow a child or teenager's cues or ask "Would you like a hug?" and as much as you can, offer them what they need in response, whether it is more or less physical contact and affection.



Activities

- Expressive activities
- Caregiving activities
- Memory-building activities

Doing or making something for the dying person gives children and teenagers a constructive outlet for their feelings and their energy. Participating in an activity with them is an ideal opportunity for adults and children to be together, to learn what each other is thinking and feeling, and to support one another. Spending time doing something meaningful together during such a difficult experience reassures children and teenagers that although things are changing, their family is still a family.

While they're 'doing' or 'making' something kids and teens have a chance to process their thoughts, ask questions and express themselves, and they often feel less vulnerable while their focus is on an activity. Art and creative work offer a way to express emotions that children and teenagers may not have words for, and allows them to give a gift, along with the emotions that went into making it. Tell them that their gift is very meaningful because it is both a gift of a thing and a gift of feeling.

On the other hand, children and teenagers can benefit from using art as a way to express and make sense of what they're going through without the art having a specific purpose or function. Allow kids to be creative without a particular purpose or outcome in mind. Making something for themselves or just for fun is also beneficial.

The following are some activities to help children and teenagers express themselves and to develop and maintain meaningful connections with loved ones. Activities can be modified to suit the preferences, abilities and ages of people involved, and can be done at any time, even after the person has died. The most important thing to consider is choosing the most meaningful activity for the people participating.

For many of these activities, especially with younger children, it is important that a supportive adult is present, if not participating directly in the activity. Unless privacy is important to the child or teenager, participating or being present allows adults to model emotional expression, clarify misconceptions, answer questions, respond to fears, better understand and validate their experience and offer the support they need.



Expressive activities

Journaling

Messages for others – Children and teens who have something they wish they'd said or done, can still write or draw messages for the person who has died. If the child believes in heaven, messages can be tied to a helium balloon to carry it up to the person, or can be burned or buried, with the person's body or separately. It is important for children to know that they will not receive a message back in the same way.

If a child or teenager is dying, they can write in journals, create scrapbooks, video diaries, or letters to leave important messages for loved ones to feel their presence at special times. Alternately, children and teenagers could help an adult create something for themselves or for others.



Arts & crafts

Painting, colouring, photography, drawing pictures or creating abstract art; using PLAY-DOH® or clay; making collages from photos or magazines; making mosaics, beaded jewellery, papier maché, or creating any other craft that kids and teenagers enjoy offer valuable opportunities for them to express themselves and create something meaningful, whether the project is made as a gift, decoration or memorial.

Music

Choosing to create or to listen to music that reflects how they're feeling can be a way to express themselves without having to verbalize their emotions and also demonstrates to the listener that others can relate to this emotional experience. Finding music that helps them feel calm or comforted offers a way for children and teenagers to cope as well as to realize they can impact their own emotional state. Dancing and drumming also offer these benefits as well as being a physical outlet.

Stories

Encouraging a child to write a story or a play, a song or a poem, or for the adult to write the story and encourage the child to illustrate it, offer other means of expression and capture the child's experience and perspective.

Books, movies

Sharing stories about death with children, or for older kids and teenagers to read or watch on their own, offer reassurance that

others have lived with a similar situation, may suggest a new perspective on the experience and may offer a context in which to think about death that is a little less vulnerable. Whether you read or watch a movie together or know that they are reading or watching something, you could ask questions like "Is there anyone in the story who seems to feel or act like you do?" For kids and teens who are less comfortable talking openly you can ask broader questions like "Is there anything in the story that seems familiar?" Follow their cues about whether they want to talk or not, respecting their privacy as much as possible. They may need to process what they're reading or watching on their own without the vulnerability of expressing their thoughts.

Emotional release

Although art is a means of expression on its own, the chance to release emotions can be maximized by adapting artistic activities. This is also an ideal context to talk to kids about how all feelings – including feelings that are thought of as 'negative' ones – are okay and that it is important to have ways of expressing them that are not harmful to anyone.

- Using washable markers and large pieces of paper, kids can draw or write about everything that is bothering them. Tape the decorated paper to a tiled shower wall, garage door or outdoor brick wall and encourage them to

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throw water balloons or squirt water guns or syringes (without the needle tip) at the pictures to wash them away. Alternately kids could use this paper as a target and throw rubber balls or other appropriate items at it.

- Using fabric paints or markers and a pillow case, a child can draw their frustrations or nightmares. When the pillow case is dry encourage the child to use it as a punching bag.
- Using PLAY-DOH® or papier maché helps kids build a representation of what is bothering them. Let them decide whether they would rather keep it as a reminder of what they have overcome, or destroy it.

Physical release

Going for a walk or run, skipping rope, playing catch or a sport can release physical tension safely. Many children and teenagers benefit from using physical activity to exhaust themselves, draining the tension, frustration or anger that was overwhelming. Make sure they take appropriate safety precautions, such as wearing a bike helmet while riding, or having someone accompany them on a walk or run as necessary.

Caregiving activities

Hug

Cut a piece of fabric longer than the child's reach and wider than their hands with fingers spread apart. Trace arms and hands stretched out so that it looks like a scarf with hands on the ends. Use markers, fabric paint, glue and decorative materials to add messages, symbols, pictures of memories, etc. Children and teenagers can make these to give to the person who is dying or they can make it together for the child to keep. When the person dies the hug can be put in the casket, or can be a keepsake for their loved ones.

Strength beads

Help children and teenagers write a list of all the things that inspire them or bring strength in difficult times – e.g. loved ones, faith, hobbies, etc. Choose a bead to symbolize each source of strength or inspiration and decide how many of each bead will represent the impact it has. Use these beads to make a necklace, bracelet, keychain or decorations. Children and teenagers can make these for themselves or for the person who is dying as a way of caretaking.

□ Modification

Rather than choosing beads as symbols, decide on a shape or colour to represent each source of strength or inspiration. Use paints, markers or pencils and paper or fabric to design and decorate a mandala or a flag with the chosen symbols or colours.

Memory-building activities

Quilt of comfort

Using fabric paints, draw a grid on a blanket or piece of fabric. Each square can be decorated by a different person, or can be decorated in its own theme. Pictures, words or symbols can be used to express memories, shared experiences, jokes – anything that is meaningful to the person who is dying and the children involved. This quilt can be used as a comfort while the person is sick, can be buried with them or kept by the family.

Memory beads

Talk to children and teens about all of the things they have learned from the dying person including skills they were taught, shared values and ways that the person was a role model. Alternately, beads could represent specific memories. Write a list of all of the memories or things that they taught and find a bead to represent each item. Use these beads to make a necklace, bracelet, keychain or decorations as a concrete reminder. Children and teenagers can make these for themselves, for the person who is dying or both.

□ Modification

Instead of using beads, cut long, narrow triangles out of paper and write or draw a memory on each one. Starting at the wide end of the triangle, tightly roll the paper around a toothpick or pencil to form a long bead and glue the narrow end. String these beads to make a necklace or bracelet.

Quilts, pillow cases, stuffed animals

can be made from clothes belonging to the person who is dying, or their favourite linens and fabrics to be kept by their loved ones.

Family tree

Have each family member trace a hand on construction paper. Cut out the hands as well as a tree trunk shape from a different colour of paper. The family can work together to paste their hands on the tree to look like leaves, writing about each person on their hand/leaf.

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The tree can be decorated with paint, beads, string, flower petals or any other familiar materials and framed.

□ Modification

Extended family members can be included by cutting out different shapes or extra handprints and writing about them as well. This can be a chance to talk about family members who may not be seen as often but who are still part of the family.

Gardening

Planting and maintaining a garden helps children understand the cycle of life, growth and death, as well as giving them a meaningful and tangible way to care for a living thing. Growing a garden in honour of a loved one is a way to maintain a connection and do something for them.

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Horses, shoe: Sydney (Daughter)
 Fairy Dust: Abby (Daughter)
 4 flowers: Parents
 4 hearts: The family
 L+D=♥: Lisa Plus Dale = Love.
 3 flowers: First flowers Lisa taught
 Noty (Niece) how to Draw.
 3 stones: all the sisters.
 He
 Butterfly: For Death of Lisa.



Funeral card



Memory boxes and time capsules

Collect mementos, artwork, photos, pieces of clothing or jewellery, CD's, videos, magazines, etc., that hold meaning for the family. Kids can decorate boxes or build them from LEGO®, popsicle sticks, cardboard or wood. Collecting things to go into the box can be done by anyone, for anyone, but is most valuable if worked on together. It can be kept in the family's home, buried in the garden, or in another special place.

Think of me when...

Talk to children and teenagers about how they will remember their loved one, or if they are dying themselves, how they want to be remembered. Help them think of times and places that are meaningful, shared experiences, interests, hobbies, values and any other ways that the dying person has influenced them. Based on this, think about times, places and ways to recognize and honour the person.

Special occasions

Birthdays, anniversaries, holidays, and memorial gatherings are opportunities to honour and remember the person who has died. Talking with children and teenagers about their loved one and the meaning of the special occasion makes the most of this opportunity to remember and to continue to include them in the kids' lives.

Rituals

Family night, dinner time, bedtime, or daily routines can be times when the person's absence feels strongest. Starting a routine like lighting a candle at dinner, having a photo to say 'goodnight' to, taking a moment every day to talk to, or about the person who has died can help their presence continue to be felt.

Supporting a 'cause'

Children and teenagers could collect and donate special belongings to a charity or volunteer for a meaningful cause like an animal shelter, food bank, tutoring, or anything else that feels 'right'. Making donations or volunteering on an on-going basis can offer continued opportunities for connecting with the person and as a way to honour them.



About the Centre and the Author



**Ceilidh Eaton Russell, MSc, CCLS**

Ceilidh Eaton Russell is a Child Life Specialist with the Dr. Jay Children's Grief Centre and a PhD student in the department of Family Relations and Applied Nutrition at the University of Guelph. In her clinical role she supports children and families living with the dying and death of a family member, and educates professionals about supporting and communicating with grieving children. Ceilidh is currently involved with studies exploring family communication when a child has a life-threatening illness, and children's experiences when a sibling is dying.

The Dr. Jay Children's Grief Centre

provides specialized counselling services for children living with the dying and death of a loved one, and to dying children and their families, in their homes, in their communities and at the Centre. We also provide mentorship and expertise to professional medical and counselling communities in the areas of children's grief and pediatric palliative care.

The multidisciplinary team provides support to families and other team members around communicating with children about illness, dying and death, maintaining relationships and meaningful interactions between the dying person and their loved ones, teaching families how to grieve together and support each other in healthy and age appropriate ways, and helping to strengthen family relationships and to live the experience of dying.

To learn more, visit
www.TheDrJayChildrensGriefCentre.ca



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Cover art by a 7 year old girl depicting her sister smiling from the gravesite where she is buried

