Supporting young people and chlidren who are living with anticipatory loss adn grief when someone they love is dying

While you won't be able to take away the pain of someone's grief, being supportive in a range of ways can make a huge difference to their experience of loss.

What is Anticipatory Grief?

Anticipated grief is the normal reaction that occurs when we know we are going to lose someone or something very important to us, for example, if someone we love is expected to die. Grief helps us to gradually adjust to the reality of the loss and the changes it brings. It is never easy and it's different for everyone.

Anticipatory grief often involves experiencing many of the same emotional, physical,vmental, social and spiritual reactions that grief after a death involves, but it is also unique. Waiting for the death to happen and being helpless to do anything to stop it can be just as overwhelming and painful for some people as after the death has occurred. People can feel always on alert and that they find and lose hope as quickly as breathing in and out. It can be a confusing time, with many mixed feelings, as this comment illustrates:

I found myself wanting her to die soon because it was all so awful for her, and for me. Then I'd feel so guilty for wishing that. Sometimes it felt like she was somehow already a memory and that part of her had already died. But she was still so alive. I would get really angry, then sad, sometimes guilty and, even pretend it wasn't even happening. And I could get incredibly anxious…It was like a roller-coaster of emotion that no one would ever choose to ride…. It was confusing and exhausting…
Daughter of a mother with terminal illness

Anticipatory grief is not just about the expected death and the loss of someone we love. it's about grieving for what we could call secondary losses as well. These are the other losses that happen because the person is so ill and will die. For example, it might be the loss of future shared plans, the loss of normal routines, changes in the levels of the person's functioning (e.g. loss of their speech), loss of our sense of security in life. It is multi-dimensional.

How does it effect children and young people?

Anticipatory grief is unique for each individual – whatever their age or stage. Its level of intensity will be influenced by such things as:

- The age and stage of development of the child or young person
- Their personality and the kind of coping skills they have learned or seen
- Previous experiences they have had of death or loss
- The duration and nature of the person's illness or injury
- If any other stresses are ongoing, such as illness, school worries, relationship tensions, financial pressures etc
- The level of support available to them and to their other family members
- The nature of their family's relationships
- Their beliefs or understandings about death and after death
- What they know and understand about the situation

Young people need:

- To understand that the person is ill/injured and is dying
- To be reassured it is not their fault (this is a very common thought of children and young people)
- To have explained accurately to them what death means, in words they will understand
- To be allowed to ask questions and have them answered honestly

- To be allowed to grieve about the situation in their own ways
- To know and be reassured that they are loved, safe and cared for
- To be included in things, as much as possible – not to be shut out
- To be told honestly about what's happening as things occur, and what to expect (for example, how the patient's appearance might change and why different people appear, such as medical staff, social workers, minister etc)
- To be allowed to go on living and enjoying their world in their own ways (For example, adults are often confused when playing quickly resumes as normal.)

The costs of anticipatory grief for children and young people may include things such as :

- Higher levels of family stress and strain
- More separation from each other
- Routines disrupted
- Confusion, mistaken thinking, misunderstandings
- Fear, worry, guilt, overwhelming emotion
- Less communication
- Increased family conflict
- Increased financial pressure
- Withdrawal from each other
- Detachment from the person who is dying
- A greater desire to 'be good' and to please
- A decline in good behaviour as things get too much to manage
- Lack of attention from adults, especially those closest
- Lack of understanding that they also are grieving – in their own ways

The Questions most commonly asked or worried about by children and teens

Children and young people most often need these questions answered when anticipated loss and change affect them:

- Did I cause this to happen? Is it my fault?
- Who is going to take care of me?
- Am I/are we going to be okay?
- Is it going to happen to me? or to someone else I love?

Knowing this, if possible try to answer these things before the child or teen may need to ask themselves. Repeat key information, often, and say key things directly to them, looking right at them. Remember to tell your child or teen that they are loved and safe—often.

Tips for helping them through

Recognise that they will be grieving—even if it's not obvious. Watch them. Listen to them. Watch their play. Watch their behaviour. Hear their words—or hear their silence. Do this over time. Many children and young people show a reaction to loss quite some time after it has happened – weeks, months, even years.

Let them know that the grief reactions they're experiencing are normal—and they're real and important not only to them, to you also, because you care about them and how things are for them. Be aware that some may have delayed grief reactions, or may deal with things by using denial and avoidance, or others may be numb and unable to feel anything for a time. This is normal, but if it continues after considerable time or causes growing concern, seek professional advice. See skylight resources—website www.skylight.org.nz or call 0800 299 100—for more on grief reactions.

Reassure them that their basic needs will be met. It is not uncommon for children or teens to be worrying about things like, who will take me to practice today, who's going to look after us, or who will cook dinner or help me with my homework. Simple things, but very much an important part of their life rhythms.

Help them to say what needs to be said. Find out what they may feel needs to be said or done before the person dies. They may want to find ways to say goodbye in different ways. One way of thinking about it is helping them find ways to say lots of little goodbyes—bit by bit—so they feel more ready when the person does die. (Often adults need the very same thing). Help them make this possible. For example, use a visit, a phone call, a letter, card or email, a taped message, a videoed message, a picture, a photo…

Be open and honest. While honesty can be hard, it can also be a relief. Many times children and teens report they knew what was really happening even though they hadn't been told. Information needs to be clear and understandable for their development level.

Reassure them when grieving by adults around them is intense. It can be confusing and even scary for children and teens when adults close to them express grief very intensely. However, it is also important for them to know, and to see, that grief is normal and that things will gradually settle. In this situation it can be very helpful to have other caring adults looking out for the needs of the children and teenagers, until the adults closest to them are more able to support them themselves.

Talk with your child using simple, clear language they will understand. Take into account your child's age, stage of development, personality and character, and any earlier experiences of loss.

- Give them 'bite-sized pieces' and give them time to chew on them.
- Repeat key information later. They may need to be told more than once, as they might not have taken things in.
- invite questions. If you don't know the answer, say so, or find out.
- Answer questions as directly as possible.

Keep them informed about what's happening, especially if it involves them, and if they're older, consult with them if and when you can.

Physical touch can be uniquely reassuring – a hug, a hand held, a back rubbed.

Be aware of the many different kinds of losses that they are facing. Anticipatory grief means also grieving for such intangible things as your changed family identity, your lost sense of security and loss of future expectations. Help children recognise these. Give voice to them— gently.

Encourage and perhaps help them make a scrapbook or make a memory box. Activities like these involve reflecting positively on the past. It helps them solidify their relationship with the person who is ill and gives them something they can continue to hold onto, even after the death. It can also provide opportunities to speak to their loved ones about memories, or about stories they hadn't heard of when they were young etc. In some situations the person dying is very keen to be a part of creating such a record,and it can be an activity that helps them also. Everyone's different—it may not suit some people.

Help maintain a sense of structure and routine. This is important even for young people in a time which is so unpredictable. Being able to anticipate things that will happen and can be counted on can help balance their sense of the unpredictable. Even a small amount of structure in the middle of so much change can help give them a greater sense of security and of control.

Make one-to-one time with them. It can be such a hectic time with more people around than usual. Making individual time with your child or teen every day means you can give them space to voice their thoughts, feelings and any worries and fears. Or just to be close together and encourage each other. Don't ever underestimate the power of such focused attention. An older sibling or cousin, or adult relative, can often offer great one-to-one support. They may need to be asked.

Keep them as healthy as possible. Grieving is hard work. Help them get good and regular food, to drink enough water and get enough sleep every day.

Avoid the would'a, could'a and should'a approach. It's common to wish things had been different or that we had done things differently, and it's common to have times of feeling resentful, regretful and even guilty. Children and teens can often feel that something they have done has made this thing happen; however irrational it may sound, it is very important to address this. They need reassurance and a positive approach to making the most of the time ahead before the person dies. Suggest things they could do—they might be wanting to, but not knowing how to start.

Teach them about death. It's not uncommon for kids and even teens to not really understand what happens when someone dies. They can have some very blunt questions and be quite fascinated by the practical aspects of it all – which some adults can find unnerving. Give them clear, honest information about death. The information needs to be clear and understandable at their development level. Share your beliefs with them as parents, or if you are not a parent, check and see what the parents would like to have their children understand about death and what happens to someone after death. IMPORTANT NOTE: Be aware that children of all ages can use 'magical thinking' to find a way to manage death. For example, if I am really good, then the person will not die. Or, if I eat my vegetables then they will be pleased and will come home. Or, if I look after my younger siblings and run the house, then they will get better. They may seem irrational thoughts, but they can be very powerful. Gently check from time to time what it is they do understand about death, and the situation generally, and correct them if they have significant misunderstandings and expectations (of themselves or others).

Encourage them to share any worries or fears they might have. Take the time to listen to them well. Even if they seem irrational fears, they can have a significant effect on their lives, so never laugh them off.

Help them anticipate the progression of the person's illness and changes that may occur. Medical staff can help with this, as you may be unsure yourself.

When visiting, find out what they know about the person's illness**.** Update them as required. Mention what to expect, eg visible changes, equipment, other people who may not be recognised, medical support staff etc. Invite questions. Perhaps consider short visits, or popping in and out and spending time outside or in a lounge in between. Be aware that for some children or teens, visiting may be extraordinarily difficult. If so, they may need extra support, reassurance and encouragement before, during and after the visit. Never force a frightened child to visit. After the visit, encourage questions or comments.

Listen to them – to what's said and to what's not said… Listen even if they want to talk about ordinary things. You never know when they will want to ask questions or to make comments - often it is when they are most relaxed.

Be patient with them if they seem not their normal old selves, remember they aren't dealing with their normal old situation! They need room for normal reactions. However, keep up boundaries and core expectations for behaviour. This is important.

Include them in events and preparations for the funeral – children and young people are often better able to manage these things than adults expect. More than that – they can bring to events something special which lifts everyone's spirits.

Seek counselling support for them if they seem overwhelmed and unable to manage. Getting them professional support now may make life more manageable further down the line.

Read to them—or suggest books for them to read
Ask at your local community or school library for suggested titles that deal with death and dying. There are some great new books around, both fiction and non-fiction. Contact skylight for suggestions on 0800 299 100.

Here are some ways you could encourage discussion and expression in children or teens:

Encourage physical activity and sport
Run, jump, play, dance, walk etc to get stored up energy out
Talk about what happened
with young children, using a doll house, puppets, stuffed animals, phone
with teens, maybe while driving or taking a walk somewhere. It can be helpful doing something as you talk.