

# WHEN SOMEONE IMPORTANT IS DYING - MANAGING ANTICIPATORY GRIEF



When we are told that someone significant in our lives is going to die, we can feel very bewildered and distressed. These feelings are called 'anticipatory grief'. Our feelings of pain and loss stem from imagining what life will be like without the person who is dying. We begin the grieving process in anticipation of the death that is about to take place.

There may be a considerable amount of fear associated with the impending bereavement, fear of being alone and fear of change.

The emotions experienced during anticipatory grief can be just as intense as the grief experienced after bereavement.

Anticipatory grief is broadly assumed to be a positive response to expected loss, even though it can be very painful and at times complex and confusing.

Anticipatory grief provides a person with an opportunity to begin working through the profound changes that typically come about after someone close to them dies.

It can help to begin to adjust to the impending loss. It can provide time for family members to prepare for what will occur after death, creating the opportunity to spend time with our loved ones, convey our love, and figure out how to let go.

It's important to remember that anticipatory grief is not an inevitable response to a loved one's imminent death, nor is it a guarantee that the person affected will feel more or less grief after the bereavement. Everyone is different and every child or young person who is anticipating the death of someone important in their lives will have different feelings and responses.

For children and young people who are anticipating a death, the complexity of their anticipatory grief can be heightened by their worries about the uncertainty of their future; exactly how, when and where the person will die, who will take care of them after the death, how their routines will change, and so on.

Anticipatory grief can include feeling grief not only for this current expected bereavement, but it can also bring back feelings of grief about past historical bereavements and the speculation about future bereavements.

The losses that can be hard to bear can start long before the terminally ill person dies. The deterioration in their physical health might mean that family routines change dramatically; family finances might be very different if a breadwinner is affected by the terminal illness, the role of family members might change if someone becomes a care giver to the dying person, the physical environment of the house might change if medical aids and equipment are being used, visits to the GP and the hospital might become frequent and could disrupt other routines.

Huge change takes place within the family and the home environment, and all of this has an impact on the children and young people involved. The most important thing to remember is that anticipatory grief is a normal process, even if it is not discussed as often as post-bereavement grief.



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## HOW CAN WE HELP CHILDREN AND YOUNG PEOPLE?

For every child or young person who is facing an anticipated bereavement, there will be lots of other things going on in their lives, and all of those other factors are likely to have an impact on how they manage their anticipatory grief.

It can be helpful to think about three distinct areas when you are supporting a child or young person who is going through anticipatory grief:

### 1. The individual child or young person

the feelings and concerns that they have, how these are impacting on their wellbeing, behaviours and relationships, how they are coping with those feelings and concerns and what support they have in place

### 2. Their interactions with the dying person

how the child or young person is interacting with the dying person, what sort of conversations and communications they are having, how open and honest are they being, what issues are arising in their relationship with the dying person, how are they still spending time together

### 3. Interactions with family members, friends, school

how is the child or young person interacting with the wider family, their friendship groups, their teachers at school etc. What issues and concerns are arising

## SIGNS AND SYMPTOMS OF ANTICIPATORY GRIEF

The signs and symptoms of anticipatory grief are often similar to post-bereavement grief. Grief is often defined as progressing through stages, such as anger, sadness, denial, anxiety and acceptance. However, there is of course no single experience of anticipatory grief.

A child or young person might experience many recognisable symptoms, or just a few, including:

- Sadness/tearfulness
- Anger
- Loneliness
- Anxiety
- Guilt
- Desire to talk, or not to talk
- Fear
- Fatigue
- Emotional numbness
- Poor concentration
- Difficulties with appetite or sleep patterns



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## SIGNS AND SYMPTOMS OF ANTICIPATORY GRIEF (CONTINUED)

Anticipatory grief can also have some characteristic signs and symptoms that are distinct from post-bereavement grief. These signs might include:

- An increasing concern for the person dying, particularly if they are suffering, and a sadness at losing the person they used to be as their health deteriorates and they lose cognition, independence and physical strength
- Imagining or visualising what the person's death will be like
- Getting ready for what life will be like after a loved one is gone, which might include emotionally 'pulling away' from the dying person
- Loss of hope for the future, or extreme sadness at the fact that the future will be very different to the one they imagined
- Being in a state of heightened anxiety - when we know a death is imminent our bodies are often in a state of hyper-alertness – we panic whenever the phone rings or we receive a text message. This can become mentally and physically exhausting

While anticipatory grief is normal, there may come a time when it gets in the way of a child or young person's ability to cope, and this is where grownups can provide support and the child or young person could be referred to Balloons for grief support.

## WAYS TO HELP

- Let children and young people know that it's OK to express the pain of grief, even though the death hasn't happened yet. Remember - anticipatory grief is normal - feeling grief before a death is normal. Support your child or young person to acknowledge that, although the person hasn't died, they are grieving
- Create a safe time and space for them to share their concerns and their fantasies about what is going to happen
- Try to keep channels of communication open within the family. Just like we all grieve differently; anticipatory grief is different for everyone. Others in your family may be experiencing and coping with anticipatory grief in different ways. Keeping the lines of communication open can help everyone to better understand one another
- Encourage them to think of the best way of processing their fears. This will be different for everyone – it might be through keeping a diary or a journal, through letter writing, through drawing, painting or modelling
- Encourage the child or young person to find ways of combatting the stress and anxiety of anticipatory grief by staying physically healthy. Look at sleep patterns, eating patterns, exercise patterns – what can be positively done to protect sleep, eating and physical wellbeing?
- Encourage the child or young person to connect with others – try to help them to stay connected with their friends, carers and support networks

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## WAYS TO HELP (CONTINUED)

- Help them to understand that anticipatory grief doesn't mean they are giving up on the person who is dying. There comes a time where we often accept that an illness is terminal and that recovery is no longer a possibility. Though it is a reality, there can be a feeling of guilt that comes with that acceptance. Support the child or young person to focus on what they are doing – still supporting, caring, loving, creating meaningful time together. Help them to shift their energy from hope for recovery to hope for meaningful, comfortable time together until the person dies
- Think about the time that the child or young person spends with the dying person. One of the opportunities that anticipatory grief offers us is the chance to make the most of the time we have with our loved ones. Spending time with the dying person in ways that are significant to the child or young person might be very important. This might just be about watching TV together, playing games, or reading together
- Let the child or young person's school know what is happening at home, and agree together how they can be supported at school

## LOOKING AFTER YOURSELF

- Very importantly - take care of yourself. Always remember that you can't take care of others if you don't take care of yourself. Reach out for specialist help when you need it. Sometimes it's right for all of us to say - "I need help". Talking it through with someone outside of the family can be very helpful. Contact us if you would like some support.

## AFTER THE DEATH, REMEMBER:

- Relief is normal - In the case of anticipated losses there can be months or even years after a terminal diagnosis and before the terminally ill person dies. When someone dies there can be a sense of relief that is completely normal, but that can also create feelings of guilt. Remember that feeling relief after an anticipated death does not mean you loved the person any less. It is a normal reaction after a stressful and overwhelming time in your life. You can support your child or young person to understand that too
- Don't assume anything - just because the loss was an anticipated loss, don't assume this will either speed up or slow down the grief process after the death. We all grieve differently

Anticipatory grief can be painful, but no child or young person has to suffer it alone, and no care giver has to work through their worries about their children alone. Balloons can help

