

Siblings and the last days of life

This information sheet is about supporting siblings who have a dying brother or sister. It is important to involve siblings in the last days of your sick child's life so they have a sense of feeling included, needed and remaining connected with their brother/sister and as a family.

Telling a sibling that their brother/sister is dying

It is often difficult for parents to find the words to tell a sibling that their brother or sister is dying. It may come as a big shock to some children, whilst others may have known this for some time. There are no perfect words and no perfect time to have this conversation.

Some suggestions that may help you to prepare include:

- Talk over what you plan to say with your partner, family member or even your Care Team to help prepare yourself
- Have the conversation in private, away from extended family, friends and your dying child
- Do not overload them with a lot of medical information unless they ask
- Use the words dying and death to help their understanding
- Answer any of their questions with as much honesty as you can
- Go at their pace and allow them the opportunity to ask more questions at a later time

This may be the sibling's first experience of death and thinking about a loved one dying can cause anxiety. They may be afraid of what death looks like or concerned about the suffering their sibling may experience. It is helpful to share with the sibling, the information you have been provided by your Care Team and/or other resources, about what your child's death may look like.

If you would like your child's siblings to be involved in a family meeting, please talk with your Care Team. Alternatively, a separate meeting can be arranged that is just for siblings.

Siblings spending time with the dying child

You may be worried about whether siblings should see your sick child in case they find it too distressing. Seeing can be so much better than just imagining what their brother or sister is going through, even when the reality is a difficult one. Experience tells us that siblings benefit from being asked if they want to come and see their brother or sister. You can help prepare them by talking about the environment that your sick child is in, such as the children's ward or ICU or explaining what

they look like. It may be helpful to show siblings photos of their brother or sister or arranging a Facetime call from the bedside as preparation for what they may see. You can also help them prepare by planning what they want to tell their brother or sister, even if the brother or sister is unable to respond.

The only time it would be best not to bring a child to see a dying brother or sister is if the sibling does not want to visit. But, even then sometimes talking about what the sibling is afraid of may help overcome his or her distress so that a visit becomes possible. However, it is important that you don't add additional pressure to visit if the child has made it clear that they do not want to.

If siblings choose to spend time with their brother or sister, it may be helpful to consider some activities such as creating a family hand print piece of art, taking photos or watching a favourite TV show or film together.

For those siblings who wish to spend time with you and the dying child, they may be reluctant to leave the hospital and/or house. This is understandable and they should not be forced away. However, it is important that they still continue to be cared for and that a close family member or friend makes sure they are eating, drinking and also getting enough rest.

Siblings viewing their brother/sister after a death

You may be feeling uncertain about whether you should allow your child to view their brother/sister after their death. You may hear others suggest to you that this would be too upsetting. Experience tells us that if a sibling wishes to view their brother/sister, it is important to try and do this as this benefits their understanding of the finality of death. It can also help reduce any fear about death, as many families report how peaceful their child looks.

If siblings are not in the room when their brother/sister dies, it is important to prepare them for what they may see and feel when they visit. Siblings may wish to help you bath your child or choose a toy to go with their brother/sister.

Siblings and funerals

It can be very helpful for siblings to attend the funeral of their brother/sister. It is important that they are also given a choice as to whether they wish to attend, as some may not.

Funerals can help siblings participate in the family ritual of honouring their brother or sister who has died and to gain support from your community. It is, however, important to explain to siblings what will happen at the funeral, what takes place in a burial or a cremation. If you are not sure how to have this conversation please speak to your Care Team as they may be able to offer some guidance and resources.

If siblings are attending the funeral, it may be helpful to organise another trusted adult to look after them. It can be hard to feel connected to your child's funeral whilst also having to support their sibling/s during the ceremony. If a sibling wants to leave the ceremony, possibly because they are finding it too hard or are feeling restless, another trusted adult can support them to do so.

Sibling grief

Each sibling will have their own unique relationship to the child who has died. Therefore their grief will be unique to them as well. Children and young people grieve differently than adults which can be uncomfortable for some adults.

A brother or sister's grief is influenced by their age, their developmental stage, personality and the family, cultural and religious influences in their lives. Understandably you may have concerns about how your other children will manage their grief.

Some common worries that children have following the death of their sibling are:

- Did I cause the death?
- Will I die or will other loved ones die?
- Who will care for me?

Speaking in an honest and age-appropriate way with siblings can help them adjust more easily to their loss. Encouraging and supporting them in planning the funeral service can also help them to feel included, give recognition of the unique relationship they had with their sibling and further aid their understanding of the feelings of grief.

Remember that grief is not always visible but it doesn't mean that your child is not grieving.

Common grief responses in children

Children under 5 years may:

- Be affected by the emotions of those around them
- Grieve in doses, alternating between displaying grief and playing as if nothing has happened
- Ask confronting questions about death
- Become fussy or show signs of insecurity
- Feel guilty or responsible for their sibling's death

- Act in ways that are younger than they are e.g. bedwetting
- Act out their feelings rather than talk about them

Children of primary school age may:

- See death as reversible or become more anxious about the possibility of others dying
- Be curious about death and burial rituals and ask detailed questions
- Take time to absorb the reality of what has happened and may not appear immediately affected by the death
- Be quick to blame themselves for their sibling's death
- Worry about their parents who are grieving and feel a sense of responsibility for making them happy again
- Act out feelings rather than talk about them
- Be concerned about what their peers think and a sense of isolation

Helping children with their grief

- Listen and talk with them. Children need time and to feel safe in order to express how they are feeling. Be patient, honest and consistent with your response
- Include children in decision making when appropriate, such as funeral plans or which day of the week to return to school or an activity
- Provide safety and security. Try to maintain routines and firm, but fair boundaries as much as possible
- Provide creative opportunities for expression, such as drawing, craft activities or storytelling

Common grief responses in teenagers and young adults

Teenagers and young adults may:

- Grieve in doses, breaking their grief into bearable amounts, but this can sometimes result in intense outbursts
- Experience a multitude of emotions that come and go, but feel confusing and at times overwhelming
- Feel guilty that they were unable to save their sibling
- Not want to talk about their grief
- Have problems sleeping or oversleeping
- Feel alienated from their peers

Helping teenagers and young adults with their grief

- Be available- provide them with an accepting, open environment in which to grieve
- Convey to them it is okay to feel the emotions they feel and the thoughts they have, and that you will be there for them if they want to talk
- Invite teenagers to talk about their loss and their sibling, however, if they do not want to you also need to respect this.

- Teenagers often look to their peers for support when times are tough. Encourage them to connect with their friends in a safe environment
- Like all of us, teenagers learn from the behaviour they sense and observe. The more they observe healthy communication and the natural expression of feelings when grieving, the more likely they are to understand and accept the emotions they may be feeling. Remember that even for adults, talking about such feelings is difficult especially at the beginning of grief.
- Reassure them that it is okay to have a different grieving style than yourself

When to seek help

With good information and support, children and young people can learn to understand and adapt to their grief. However, if you are concerned by their behaviour or feel that more assistance than you can provide is required please contact your child's Care Team.

Support yourself

It can be difficult to support a grieving child when you are grieving too. Grief can also make you doubt yourself and distrust your parenting decisions. You also won't be in a position to provide support to your other children if you first don't take care of yourself.

You can access bereavement support or referrals to local bereavement services from your child's Care Team. Alternatively, your GP can make a referral to a counselor or psychologist.

