



5. TO FEEL HEARD AND LISTENED TO

The more opportunities siblings have to express their emotions the less emotional upset and fewer behavioural problems they are likely to experience. Encourage them to talk about the good, the bad and the guilt induced feelings. Feeling stressed can affect how a child feels, thinks and behaves. Children might find it hard to sleep, have headaches and stomach aches as a result of anxiety, tension and worry.

TIP:

- ✓ Let siblings know that they are important and their needs matter.
- ✓ Pay attention to any changes in sibling's feelings and behaviours and check in on them regularly. Any complaints of illness should be listened to in any case and a visit to the GP should be considered. Siblings therefore feel reassured that they are getting the same attention as their brother or sister.
- ✓ Helping siblings identify a 'safe adult' that they can talk to about their feelings.

6. ACCEPTING HELP FROM OTHERS

A positive parent child relationship and supportive family environment can help siblings adapt to adverse events in particular, expression of feelings, affection, shared decision making and problem solving.

TIP:

- ✓ Brothers and sisters who are too young to talk and understand what is happening will appreciate extra attention, play and cuddles from trusted adults such as grandparents, family members and friends.
- ✓ Say 'Yes' to help. Accept offers of practical support such as help with transport, meals, childcare and other daily activities so that you can have the emotional reserves to be there for your family.
- ✓ As siblings adjust to illness and changes in your family, you may wish to access direct therapeutic support from the Medical Social Worker. This will provide a space for siblings to express their feelings and identify positive coping skills.

7. INCLUSION

Siblings will have their own unique relationship with their brother or sister and there are lots of ways to involve siblings in the care of their brother or sister and help them feel included.

TIP:

- ✓ Try to encourage and involve the siblings in the care journey, talking to them about changes to the care or treatment of their brother or sister.
- ✓ Provide a role for siblings in care giving tasks that are appropriate for their age.
- ✓ Acknowledge the things siblings do to help their brother or sister.

8. SAFE SECURE ENVIRONMENT

While you as a parent may not be able to take away the source of your children's emotional pain, you can help ease their stress and make them feel secure, cared for and supported. Knowing what siblings are going through and taking steps to support them can help them feel included and allows you to deal with issues before they unfold. In general, how sibling's respond to the anticipated death of their brother /sister will be guided by the adjustment and coping styles of their parents. If the parents are able to model healthy coping strategies and create an environment of open, honest communication the siblings will be more likely to cope with grief and loss.

What is important to me as a sibling:

- ✓ IT IS IMPORTANT TO ME....to spend time with my sibling and make memories together if my sibling is hospitalised or not at home. I would like to have regular contact that would include phone calls, video chats or seeing them in person.
- ✓ IT IS IMPORTANT TO ME....to be given factual information about my sibling's illness and any changes that may be happening.
- ✓ IT IS IMPORTANT TO ME.... to share celebrations with my sibling such as birthdays, holidays and other meaningful milestones.
- ✓ IT IS IMPORTANT TO ME....to have regular one to one attention and special time with my parents where possible.
- ✓ IT IS IMPORTANT TO ME....to be included in conversations (where possible) about my sibling's care.
- ✓ IT IS IMPORTANT TO ME....to have some tasks, jobs or duties that allows me to care for my sibling.
- ✓ IT IS IMPORTANT TO ME....that if my sibling is nearing the end of life, I will get to know this information and choose how and when I say goodbye to them.
- ✓ IT IS IMPORTANT TO ME....to be able to talk about my feelings and be supported by other meaningful people in my life.
- ✓ IT IS IMPORTANT TO ME....to be a child and have fun.

(Adapted from www.ppcc/pa.org)



SUPPORTING THE NEEDS OF SIBLINGS

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Resources:

Marge Eaton Heegard 'When someone has a very serious illness'

Irish Childhood bereavement network
<https://www.childhoodbereavement.ie/>
CCLG.org.uk

Winston's Wish 'As Big As it Gets: Supporting a Child when Someone is Seriously Ill'

Patrice Karst 'The Invisible String'



Common Reactions and Experiences of Siblings

The Medical Social Work Department as part of the multi-disciplinary team offer psychological, emotional and practical support to families caring for a child with a life-limiting illness.

Being told that your child has a life limiting condition can be devastating, overwhelming and life changing for you and your family. When there is a child with an illness, family dynamics and functioning change to accommodate the ongoing care of the child. Similar to parents, brothers and sisters will experience a rollercoaster of emotions and have lots of questions. Their world has been turned upside down and they may not fully understand what is happening to their brother or sister. If you are worried about communicating with children and starting this conversation your Medical Social Worker can support you as parents in responding to the needs of your children, help siblings cope with changes in their family and reduce feelings of worry, isolation and anxiety.

Abandonment – Siblings share a special bond and a special history with each other. Siblings may often experience ‘secondary losses’ and may feel they have lost their parents for a period of time or permanently whilst they attend to the child with a life limiting condition. This can profoundly change family dynamics and siblings can often feel neglected.

Increased Responsibility – When parents are unavailable for a variety of reasons, siblings often take on more duties in managing the household and caring for younger siblings.

Loss of Innocence – The world view of siblings can often be shattered and a marked sense of maturity is experienced as a family system adjust and function to terminal illness.

Guilt – Siblings often feel a sense of guilt for wanting to have their parents to themselves or wishing for life to be different.

Anger and Resentment – Many siblings feel anger for changes that have occurred in their family and life in general. Children often express anger and find it difficult to understand and accept the enormity of this life changing event and a lack of control over this situation.

Fear and Anxiety – Siblings are often fearful of other family members getting sick or dying and this can persist for years. The fragility of life is real and fears of what their future might be like. While siblings do adjust, their life is different and changed forever.

Reluctance or withholding their own needs – Siblings do not want to add to the burden of parents and often withhold their own needs. Siblings allow their own anticipatory grief go unnoticed and often disenfranchise from their own grief needs.

Somatic Symptoms – Siblings often present with psychosomatic symptoms- headaches, stomach aches, changes in eating and sleep patterns as they navigate significant family change and emotional turmoil as they adjust to terminal illness.

The needs of siblings

1. OPEN AGE-APPROPRIATE CONVERSATION

Often parents who are dealing with their own sadness and anxiety may be unable or reluctant to talk openly to siblings. Children can sometimes ask questions that can be difficult and challenging to answer, however it is important to answer the questions as honestly and age appropriate as possible.

Living with uncertainty becomes part of family life and conversations will need to change over time to address the changing care and treatment needs of the child. As a parent, being truthful can be painful but it can save a lot of pain and misunderstanding in the future and also builds the trust between you and your children.

TIP:

- ✓ Try and find a time that is right for you and your children and plan this conversation to prevent any mixed messages.
- ✓ Acknowledging questions siblings have makes them feel heard and valued and provides an open and safe environment to process their fears and concerns. Children will often not want additional information and they will feel a sense of reassurance when an explanation is given by trusted adults.
- ✓ The Medical Social Worker can support you as parents in communicating with your children based on the age and stage of development.



2. MAKING MEMORIES

Siblings benefit and enjoy opportunities to engage in keepsake and memory making activities. This can help facilitate emotional expression, enjoyment and creativity. Undertaking activities and sharing precious moments together as a family will maintain a continuous bond with your child and create special memories for the future.

TIP:

- ✓ The Medical Social Worker can support families to identify activities to enjoy with each other that will create memories and be a source of shared fun and meaning. Some examples of memory making activities include family hand sculptures, excursions, photobooks, video recordings, granting of wishes for special outings.

3. THE NEED TO BE A CHILD

Siblings, like adults have different responses to illness and changes in their family. Some children may act out, may try to be the perfect child and some may do both. In some instances siblings are keen to talk about illness, whilst others prefer not to talk. It should not be assumed that because a child shows little interest to discuss their sibling’s illness that they are in denial. Siblings often experience feelings of loneliness and isolation as family life changes and parent’s attention is focused on the ill child. Their emotional reactions and adjustment to illness needs to be assessed on a continuous basis. This depends on how the child/children are functioning in their day to day life in school, activities and social interactions.

TIP:

- ✓ Whenever possible, set aside some time for children to spend time with family and friends without focusing on illness.
- ✓ Encourage siblings to remain engaged in activities that are important to them.
- ✓ Let siblings know that they can have fun as a family.
- ✓ Reassure siblings that although there are new changes and challenges, family life will continue and there are lots of special family occasions/ events that will continue.

4. STRUCTURE/ROUTINE AND KEEPING LIFE ‘AS NORMAL’ AS POSSIBLE

Family routines and dynamics naturally change when a child is ill and can often cause confusion and distress for siblings. Siblings often experience feelings of loss of a “normal” family life and loss of their identity in the family. Parents may spend a lot of time at the hospital and medical appointments therefore siblings may need to be cared for by extended family members/friends.

TIP:

- ✓ Where possible maintain continuity and structure and accept help from family, friends, neighbours and other caregivers.
- ✓ It will help your children if you make sure that key people in their life know what is going on at home and any changes that are affecting them.