Workshop 1: The emotional impact of childhood cancer

Everyone is unique

The emotional impact and reaction to childhood cancer will vary from one person to another. There is no textbook reaction as everyone is uniquely different.

Here are 8 common emotional reactions to a cancer diagnosis experienced by family members.

**Shock**
“What is the doctor telling me?” “I'm in a nightmare, this can't be real.” “There must be some mistake.”

**Numb**
“Why don't I feel anything?”, “Why am I not crying?”

**Denial**
“This isn't happening.” “This doesn't happen to our family.” “Everything will be fine, a short time in hospital, then back to how it was.”

**Confusion**
“I'm nodding, but I don't understand”, “What does this all mean?”

**Fear**
“What will happen to my child?” “What will happen to me?” “How do I tell my child?”

**Panic**
“I can't cope.” “I can't make these decisions now.” “I want to run away.”

**Anger**
“This is unfair, we are good parents.” “What have I done to deserve this?”

**Guilt**
“My child is being punished for things I have done wrong in my life.” “Did I do something to cause this?” “Why didn't I bring him/her to hospital sooner?”

More than one reaction may be experienced at any one time and these may change throughout the cancer process.

**During the treatment** for example emotions might include *sadness, powerlessness and stress*, the latter potentially leading to irritability, lack of concentration and a decline in personal health.

**Post treatment** may generate emotions such as *abandonment, uncertainty, and worry.*

**10 tips for supporting families manage their emotional reaction**

1. Remember for many families, hospitals will appear overwhelming and intimidating places, spend time putting families at ease.

2. Families are unlikely to be familiar with medical terminology, remember to explain what terms mean.

3. People’s perception of cancer is shaped by their knowledge and experience, find out how much families already know.

4. Be aware of how cultural and spiritual influences can shape behaviour.
5. Check whether the family have access to a support network of family or friends.

6. Allow time for information to be absorbed.

7. Confirm understanding of information provided.

8. Encourage questions.

9. Reassure families.


Find out more on how to support families, by visiting the page on ‘How to support families when a child has cancer’.

The Child

The emotions felt by a child being diagnosed with cancer will vary enormously. Age, family circumstances, education and experience of illness will have an influence on their reaction. Beware not to overlook the emotions of the child. It is crucial that the child’s emotions remain central and are recognised and supported.

During the cancer process the child may experience:

- **Loneliness**: In an unfamiliar environment there may be few familiar faces that a child feels comfortable talking to.

- **Confusion**: Families may feel it is in the best interest of the child to “protect” them from conversations about cancer, however, a lack of information can increase a child’s level of confusion and anxiety.

- **Sadness**: Missing family and friends, feeling unwell and being in an unfamiliar environment can leave a child overwhelmed with sadness.

- **Fear**: A lack of information can increase a child’s level of fear and dread. Their imagination begins to paint worst case scenarios of pain, cancer treatments and death.

- **Anger**: This can be channelled towards all those they hold “responsible” for their current situation including doctors, nurses, parents and siblings.

- **Frustration**: At the losses experienced such as freedom, independence, good health and family and friends.

- **Loss of confidence**: Perhaps feeling self-conscious at changes to appearance, missing school and falling behind or the lack of social interaction with others can lead to a loss of confidence.

- **Guilt**: Feelings of guilt for the hurt caused to others; “My mum is crying because of me”. “It is costing money we don’t have”. “Did I do something wrong?”
One way to minimise the negative emotional impact on children is to encourage families to talk openly and honestly to their child. This can reduce a child’s confusion and anxiety.

**Why it is beneficial for parents to talk to their child about cancer:**

- Children will feel included rather than excluded and less likely to feel abandoned.
- Children can sense something is wrong even when the subject is avoided.
- Talking can create an atmosphere where children feel comfortable asking the questions that have been playing on their mind.
- Family conversations can bring families closer together and provide mutual support.

**The Emotional Impact of Bereavement - 5 Stages of Grief**

The 5 Stages of Grief was first proposed by Elizabeth Kübler-Ross in her 1969 book on Death or Dying. It is useful in that it provides a framework for those grieving to recognise some of the emotions they may be feeling. It is important to emphasise that not everyone goes through all stages nor do they necessarily experience them in a prescribed order, some may switch back and forth, some may spend much longer in one stage than another.

The 5 stages: Denial, Anger, Bargaining, Depression and Acceptance

Are you interested in exploring each stage of grief in my details and learning more about how we can support families at each stage? If so, register your interest in the Psychosocial Support Training Package by emailing megan.cruise@worldchildcancer.org

**The emotional impact on you, the healthcare professionals**

Healthcare professionals working within paediatric oncology in low to middle income countries experience high levels of stress.

The repeated exposure to death and dying, pain and suffering, moral and ethical dilemmas regarding treatment decision, the intensity and complexity of treatment and managing professional boundaries as well as staff shortage and high workloads are amongst some of the stressors experienced when working within paediatric oncology and palliative care.

During the workshop we provide an opportunity for you to reflect on the emotional impact your work has on you and to discuss this with colleagues in a supportive and safe environment.

Emotional responses from the child, their family and the healthcare professionals will vary greatly. Workshop One of the Psychosocial Support Training Package examines these emotions in more detail and provides an opportunity to reflect on how families and professionals are impacted by childhood cancer.

If you found this section useful and would like to find out more, you can register your interest in the Psychosocial Support Training Package by emailing megan.cruise@worldchildcancer.org