Workshop 6: End of Life Care: Communication and Compassion

“We cannot change the outcome, but we can affect the journey”

- Ann Richardson

The prospect of engaging in “end of life” conversations with families can feel daunting. The emotional reactions, cultural influences, language barriers along with a sense of powerlessness to change the inevitable outcome can make the experience challenging. It is important therefore we are clear on the benefits.

End of life conversations provide the opportunity to:

- Become proactive in planning the best way forward
- Provide the family with crucial information to reduce the unknown and make informed decisions
- Enable families to discuss their worries, fears and concerns
- Clarify the families wishes for the future
- Build trust through honest and open communication
- Optimise the child’s quality of life
- Help children feel less isolated and alone
- Help siblings process and accept the situation

Communicating with children

While professionals may wish to protect children by not telling them their prognosis (especially if they are very young) children are quick to pick up on signals, the reaction of others, the atmosphere in the room and their own health inform them all is not well. Not talking does not mean we are not communicating - avoidance in itself leaves a message.

If parents have chosen to avoid end of life discussions with their child, the child may feel isolated, anxious and overwhelmed with fear. While ultimately the decision to have these conversations lies with the parents it may be useful as health and social care professionals to highlight the benefits.

The benefits of talking to children

- Children will feel included rather than excluded and less likely to feel ignored or even abandoned
- Children can sense when 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

These should be seen only as suggestions; it is important we respect the parent’s decision on how much they ultimately choose to tell the child. Indeed, there may be times when the parents disagree between themselves over the amount of information to disclose.
## Tips for talking with Children

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<tr>
<th>Topic</th>
<th>Description</th>
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<tr>
<td>Make time to listen</td>
<td>Sit alongside, at the same level, try not to rush the conversation, avoid interrupting and listen attentively with a friendly expression</td>
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<tr>
<td>Connect</td>
<td>Introduce yourself, explain your role, establish ease and rapport with the child</td>
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<td>Respect space</td>
<td>Respect the child’s personal space, too close can feel intimidating, too far can feel distant</td>
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<td>Friendly environment</td>
<td>Bright walls, pictures and toys create positive child friendly messages</td>
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<td>Age appropriate</td>
<td>Be aware of the child’s age and stage of development, their awareness and understanding of illness and death</td>
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<td>Choose words</td>
<td>Use words and descriptions they will understand</td>
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<td>Avoid information overload</td>
<td>Too much talking can impact on the child’s concentration level</td>
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<td>Support and praise</td>
<td>Encouragement can really help. The more you build confidence, the more cooperative they are likely to be</td>
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<tr>
<td>Respect</td>
<td>Avoid patronising or making judgements. Do not make promises you cannot keep</td>
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<tr>
<td>Avoid assumptions</td>
<td>Remember no two children are the same, questions and responses will vary</td>
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<td>Observe carefully</td>
<td>Try to pick up on non-verbal messages. Encourage them to discuss their fears and concerns.</td>
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### Breaking Bad News

These 8 steps are adapted from a book by Justin Amery, “A Really Practical Handbook of Children’s Palliative Care for Doctors and Nurses Anywhere in the World”.

#### 1. Preparation

Find out all you can about the child’s condition and management. Anticipate questions the family might ask and consider your response. Plan the location, privacy is important. Determine who should attend. If different family members have different levels of knowledge it might be appropriate to see them separately. Though decision makers should be seen in the same time frame to avoid tension and conflict.

#### 2. Assess awareness of all involved

Consider the families current level of awareness:
- **Closed awareness** – The child is not aware of the diagnosis and those who know conceal it
Suspected awareness – The child is suspicious something is wrong but is not certain
Mutual pretence - Everyone knows but no one talks about it
Open awareness - Everyone knows and is open to talking about it. This is ideal. It allows for
fears and concerns to be addressed and for the child and family to feel more in control.

3. Probe how much the child and family know

Find out how much knowledge around the illness and prognosis already exists. Use active
listening skills.

4. Identify how much the child and family want to know

Be aware of the level of denial the child or family member may have. If they signal through
words or body language that they are not ready to be open, stop and review.

5. Manage denial and collusion

Balance the risks and benefits of allowing denial to continue. If the child is being isolated or
upset by the collusion, you may want to explain to the family that by not communicating they
may be inadvertently hurting / upsetting the child.

6. Apply a Warn, Pause and Check back approach (WPC)

Break the news into manageable chunks.
Warn – This gives the person a chance to prepare themselves and helps absorb difficult
information.
Pause - This offers the person the opportunity to decide whether they still want to go ahead.
If they agree (verbally or non-verbally) go ahead and share the first chunk of news.
Check back. Ask what they have understood and correct or reinforce as appropriate. If they
are ready to move on then share the next chunk of information using the same method.

7. Respond to feelings

Allow time to absorb information
Once the response settles repeat the process until:
1. No more news to share
2. They signal they have had enough
3. They have stopped hearing or absorbing
4. You feel they cannot take anymore (arrange a later meeting)

8. Plan and follow through

Discuss next steps, draw up a Care Plan, identifying options and sources of support,
emphasis availability for further question

If you found this section on End-of-Life Care interesting and you would like to find out more,
you can register your interest in the Psychosocial Support Training Package by emailing
megan.cruise@worldchildcancer.org