

Guide to 'This is about me *and you*'

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To accompany the interactive workbook

Important information.
Please read before using the book.

About the workbook – This workbook has been specially written to help communicate difficult information to children when a parent or prime carer ('parent' is used subsequently to include prime carers) is terminally ill. It is designed particularly for use with children aged from 4-14 years. The book uses simple language that children can understand. It needs to be filled in by parent and child working closely together, providing a valuable shared experience. The book does not need to be completed all at once. It can readily be filled in a few pages at a time. It is important to remember that children are not able to concentrate on painful feelings for very long and they will almost certainly need to have things explained more than once.

When a parent is terminally ill, communicating with children about the approaching death is extremely difficult and often avoided. However, children tend to fantasise about things they are not told about or do not understand. It has been shown that when such fantasies are not discussed and the reasons for them explained, this can lead to unhappiness in a child leading to disruptive behaviour and longer term problems.

The aim of the book is to open vital channels of communication and begin to explain and help children to understand what is happening to their parent and to their family. Children can be encouraged to voice thoughts and fears, and allowed to ask different and sometimes difficult questions about the illness, about loss and about death. It is important to help develop a child's self-esteem and natural resilience by showing them that they are valued for who they are, what they can do, and their place in the family. Children need a lot of reassurance and physical contact to confirm that someone will continue to look after them and care for them.

Some families have expressed the additional value of having such a workbook as a way of keeping important memories that have been shared after the parent has died.

Using the book – This book is designed to be used by you and your child, working together. You can enjoy choosing a photograph of yourself to paste on the front cover, and fill in the name by which the child knows you. When space has been left for pictures, photographs may be used in some places, though often a drawing by the child will be more fun. It is helpful to ask the child about the drawings and try not to interpret what you see or hear. Words like “Tell me about it” are very encouraging and listening to the child is essential. Often completing the pages together brings out areas of communication that have been too hard to talk about.

Death & Dying - Often parents and children are concerned about dying and death. The more these concerns are shared, the less they cause isolation and loneliness resulting in unnecessary anxiety. It is as well to consider in advance questions that may arise about death and funerals. Children benefit from learning what their parents honestly believe, whether religious or not.

When talking to children about these subjects, ideas that have worked in the past are:

What happens when people die?

- When a child asks such a question, you can reflect the question by “What do you think happens?” This is also a time for the parent to share, according to their family culture and beliefs.

What happens to the body?

- When people die their body does not work anymore. It is carefully wrapped and put into a special box called a coffin and there is a funeral. The coffin may be cremated, which means that it is burnt at a crematorium. The ashes may be kept, scattered or buried. Alternatively, a coffin may be buried in the ground at a cemetery. Explain that families often put special words on a headstone to mark the grave.

What happens to people after they die?

- If you have a religious faith, you may already have talked about death, the after-life or heaven. The following analogy of the caterpillar and butterfly has been used and is very easily understood by children. The caterpillar comes to the end of its life and does not need its body any more. It leaves its body and becomes a butterfly, and flies away. In the same way, when someone dies, it is comforting to think that although they have left their body, their ‘soul’ still exists as a continuing bond.
- Some parents explain that although they are not sure what will happen, they are sure they will be remembered and have a special place in the child’s memory.

Something important to remember, is that it is unhelpful to say that dying is like going to sleep. This could make a child scared of going to sleep. It is more helpful to say that when people die, their body stops working. They appear to be asleep but when people sleep, their bodies work very well.

It is important to realise that there are still many things that children can and will enjoy. It is a good idea to use the last page to end with talking something positive in the child’s life.