



ST VINCENT'S
PRIVATE HOSPITAL
BRISBANE

A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

Communication: Essential to the future of palliative care

how to help parents prepare
children for the loss of a loved one.

Elisa Agostinelli, Ph.D.

Session outline

- Appropriate ways of communicating with children and their families about life, limiting illness, death and grief
- Developmentally appropriate understanding of life limiting illness, death and dying
- Activity
- Questions

Where do we start?

Processes

- Refer the parent to a social worker/ counsellor
- Assess parents' needs
- Have a talk to the parent/s about children and pre-bereavement
- See the child
- Give information educating them
- Giving tools and strategies

Where and when do we start?

Assessment

- Does the child already know about the disease of the loved one?
- What does he/she know?
- Has been introduced to the possibility of the loved one not surviving the disease?
- Do the parents want the child to know?
- What do they need from us?

Information needs to be:

- Timely
- Honest
- Accurate
- Age appropriate

4 major concepts a child need to understand death



Irreversibility

Non functionality

Universality

Non causality

OJ Sahler (2013)

Developmental understanding of death using Piaget Theory

Age	Piaget developmental stage	Concept of death	Reaction to separation from primary caregiver
0-2 INFANT	Sensorimotor Preverbal Reflexive Preverbal	No concept of death Preoccupied with <ul style="list-style-type: none"> • Fear • Pain 	Withdrawn Eating poorly Losing interest in the environment Fear of separation Pain Tantrum reacting to parent feelings/discomfort
2-6	Preoperational 3. Pre-logical 4. Development of representational symbolic language 5. Initial reasoning 6. initial reasoning	Egocentric Death is not forever Development of fears curiosity	Fearful that this can happen to them. Fearful they can get the same disease May blame themselves Worried about what is going to happen to them Regression

Developmental understanding of death using Piaget Theory

Age	Piaget developmental stage	Concept of death	Reaction to separation from primary caregiver
6-12	Concrete operational	Get interested in details (cemetery)	Suspect they might die
	7. logical	Get answers through observation	
	8. Problem solving only in the present and real object that can be manipulated	interested in what happens after death	Showing little emotion
12 Adolescence	9. develop logical functions	they understand logic and biology of death and death processes	
	Formal operational	Starting to think about the meaning of death but reality of possibility of personal death not accepted.	Acting out
	Comprehension of purely abstract symbolic concepts		Self harming Drugs alcohol
	Advanced logical functions		

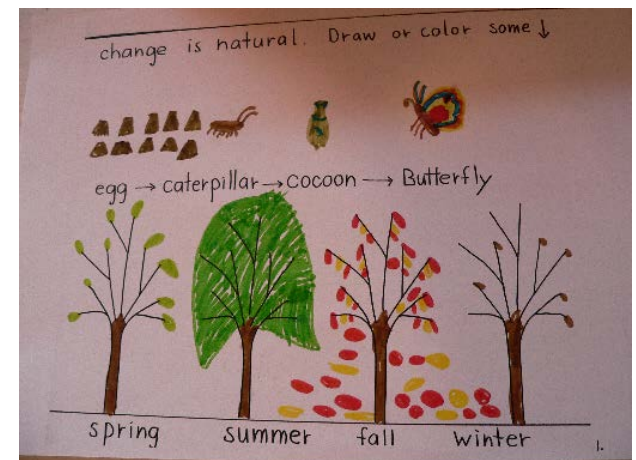
Questions children might ask to parents

Learning about death

- What does dead mean?
- Is it going to happen to me?
- Did I cause the death/illness?
- Is he /she going to die?
- When is my mum/dad going to die?



Learning about Change



Talk to the child about the parent's illness gives them the opportunity to:



- not feel isolated, having open discussion at home
- understand what is happening to their loved one, being less fearful of the unknown, less anxious
- having the opportunity of sharing their experience with children who are going through the same thing.
- Not feeling guilty about what happened

12 years old boy

OJ Sahler (2013)

Questions parents often ask

- When do we tell the children?
- How do we tell our child/ren?
- What do we tell our child/ren?
- Should they come to the hospital?
- Do we let them see the person dying?
- How do we prepare them?
- Why is she/he not crying?
- Should they go to the funeral?
- How do we explain the funeral/burial/heaven etc?



When do we tell the children?

- Provide information about the diagnosis first and the prognosis if possible
- Introduce the possibility of not successful outcome for the treatment
- Naturally follow the progression of the disease (stages of acquiring information)
- Open conversation during sign of changes in the patient
- Open the conversation about terminal stage
- Careful in giving a specific time frame might increase children anxiety

How do we tell our child/ren?

What do we tell?

- Start asking what they know
- What do they think is happening with mum?
- What do they know about cancer?
- This will give the parent/worker the opportunity of opening the conversation.
- Tell them they can ask any questions and you will let them know everything you know (knowing reduce their anxiety)
- Answer question truthfully and in a simple way
- Children tend to engage in magical thinking (mum is sick because I did not help at home)

Questions parents often ask



- Should they come to the hospital?
- Do we let them see the person dying?
 - Individual choice. It depends on the family, the child, the condition of the patient, developmental stage, how long they have to adjust, if the child want to visit.
 - 16 year old Aaron
 - his brother Barry 10 years old
 - Does the patient want the visit?
- How do we prepare them? 9 years old Sophie at home with mum

What about resistant parents?

- Assess parents' reasons for being resistant to talk about death
 - Parents' job is **protecting** their kids from pain
 - They are also going through a very difficult time
- Try to explain the need of talking to children (children already know!)
- Support them in the difficult decision making process
- Ultimately parents know their children better (**you are not the parent**)
- We have to respect their wishes and the patient's wishes.
- But we need to help them to deal with these conversations.
- Reaffirming what they are doing is ok

Good communication can be prevented by:

1. The desire to protect

- Parent protecting child
- Parent protecting parent or themselves
- Child protecting parent

2. Silent Stoic Person



Questions parents often ask

- Why is she/he not crying?
- Should they go to the funeral?
- What can they do at the funeral?
- How do we explain the funeral/burial/heaven etc.?



Case scenario 1

Family of 4. Mum is 35 years old with cancer. She just came back from another hospital stay due to serious bowel obstruction. Children 8 and 11. She was diagnosed 2 years ago. The children are aware of the cancer but having seeing mum up and down sick for so long, they think is another down. However, this time mum was told that she has few months to live. The parents, after a conversation with the counsellor, decided to initiate the conversation with their children.

Get into feeling:

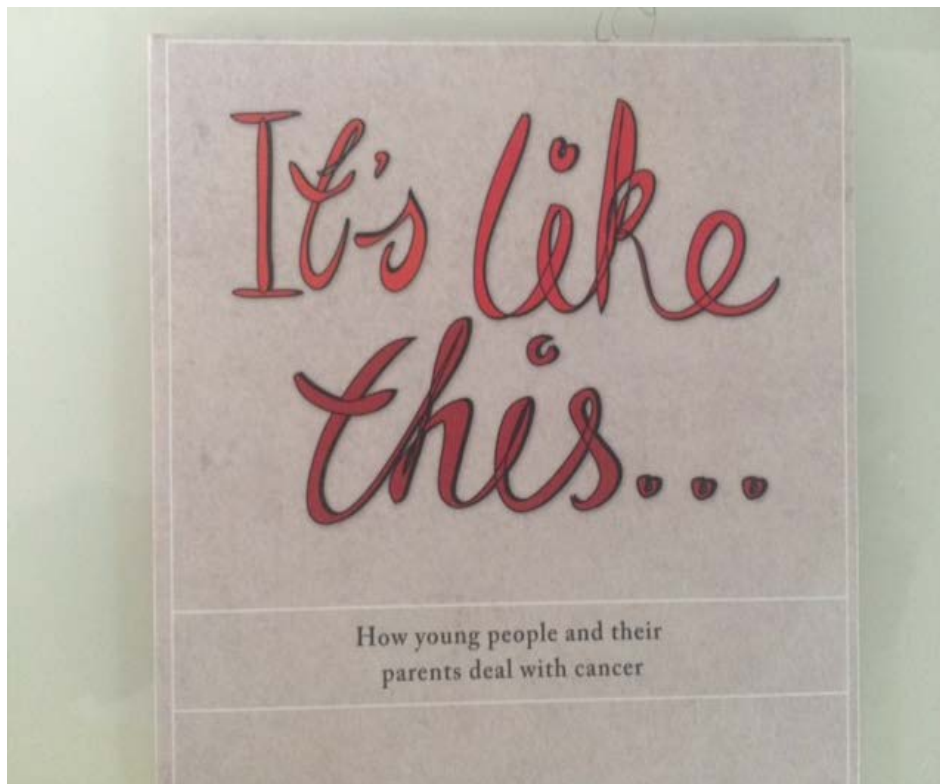
How did you feel when you played the role of the parent?

How did you feel when you played the role of the child?



It is like this

Young people whose parent is diagnosed with cancer



Canteen & Redkite

REMEMBER 4 WORDS



Being: Sit with the pain of the child/family –don't try to fix it

Humility: We can never understand completely the pain of our clients/patients

Acceptance: Everybody is free to choose how they grief

Respect: Culture, family, beliefs