



Family-centred cancer care project

DIFFICULT CONVERSATIONS

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SECTION 1

When the cancer has returned/or spread



SECTION 2

When treatment is no longer an option

When the cancer has returned/or spread

Same broad principles as sharing the initial diagnosis:

- find out what the child knows
- correct any misunderstandings
- children need the facts – worry more when they aren't clear
- explain where in the body the cancer has returned and/or spread
- clear honest information – be as specific as possible
- don't give false hope
- often need to repeat information for younger children
- discuss the next steps, for example is there additional treatment
- explain what will change in their lives
- ask them is there anything else they would like to know

NB: Children's reactions will vary and be age dependent



Finding the



‘How do you think I’m doing from my cancer point of view?’

‘I need to explain that the cancer has come back & it is now in my tummy & bones’

‘The doctors & nurses are doing their best to help Mummy get better’

‘I will try more chemo to see if this will help to take the cancer away’

‘After the chemo has finished, I will have a scan & that will help us know if the treatment is working this time’

‘We are not so sure what will happen next, but I will tell you when I get more information’

‘I can hear that this is scary for you now that Mum’s cancer has come back. Is there anything else you would like to know?’



Questions children may ask!

Why has the cancer come back?

‘The surgery/chemo/radiotherapy worked hard at getting rid of some of the cancer but sometimes the cancer cells grow so fast that the bad cells come back’

Will it go away this time?

‘We hope so, but we need to wait and see how well the treatment works’

Is it my fault?

‘No, you did not cause the cancer to come back’

Will I get cancer?

‘Cancer isn’t like a cold and you can’t catch it’



SECTION 2

When treatment is no longer an option

Preparing a child for the death of their parent



Preparing a child for the death of their parent



THE FACTS

- A parent with children under 18 dies every 22 minutes in the UK
- One in 20 sixteen year olds have had a parent die

Adults who experienced the death of a close relative or friend as a child, often wish they had known more about what was going on at the time



WHY tell the children?

- Involving the children in what's happening is usually the best approach – if not, can lead to resentment
- Makes the children more secure at an upsetting time
- Lose forever the opportunity to say what they needed to say to the parent

Talking about death

These are not easy conversations to have

- Children's reaction vary greatly
- Their reactions can fluctuate
- This can be very difficult for parents
- Some parents will need help from HCPs

Preparing a child for the death of a parent is an extremely hard thing to do

Understanding children's reactions at different ages

Very young children (under 3 years)

- Can pick up that something serious is going on
- Can regress in some developmental behaviours e.g. toileting, feeding

Young children (3 - 5 years)

- May have heard about dying but may not understand what it means
- Often imagine that a dead person will come back or is living somewhere else

Older children (6 -12 years)

- Know about death
- Not always understand the emotions they feel

Teenagers

- Often find it harder than young children to cope
- Aware that this will mean a major change and loss in their life
- Need to know that their feelings will change a lot e.g. sad, angry, seek affirmation



The language we use

Use clear honest language

- Explain that the doctors, nurses and parents are doing everything possible to keep their Mum or Dad living for as long as possible
- There is no medicine or treatment that can take the cancer away
- Use simple words like 'dying'

CONFUSING TERMS for children:

'going away' – might feel abandoned

'going to sleep' – young children might then be afraid to sleep

'passed away' or 'lost' – may wonder why no one is looking for the person

Finding the



‘The doctors have said that the strong medicine or chemo isn’t working, Mummy’s cancer is continuing to grow in her body’

‘The doctors are going to stop giving Mummy the strong medicine because it is hurting her more than helping her’

‘The very sad thing is, this means that Mummy’s body can’t work properly’

‘What do you think this means for Mummy now their body can’t work properly?’

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‘It is very sad, but Mum is going to die’

‘It is so sad that Mum won’t be here anymore but Dad is still here and so is Granny, Grandad and also Auntie...’

‘Do you have any questions?’

Helpful tips

PREPARING TO TALK to the children

- Parent's need some time to deal with their own emotions before they can prepare their children for the death of a Mum or Dad
- If it is a two-parent family unit, usually best to talk to the children together
- It's not unusual for parents to need a lot of support from family, close friends. Healthcare professionals can also help
- Often helpful to rehearse information BUT don't try to have the perfect conversation

WHEN - when the parent is fairly calm
- earlier in the day, start of a weekend
- quiet and private place



Helpful tips

Communication is ongoing – you may need to repeat the message several times

It's ok for a parent to demonstrate emotion

Encourage children to ask questions - all questions are good questions

It's ok to say I don't know the answer, if unsure

Keep routine when and where possible

Tell the school that Mum and or Dad is going to die

It is ok and important for children to still have fun

Make your child feel secure, that they are loved and will be cared for



Questions children may ask!

Are you going to die Mummy?

‘I’m finding it really hard to say this but yes, I will soon die. I have done everything I can and I don’t want to die and leave you. It was nothing you did, said or thought that has made me ill. It’s not your fault.’

Why has the treatment not worked?

‘Even with the surgery and the strong medicines, the cancer is still growing and sadly the doctors and nurses can’t do anything more to stop it from spreading’

When is Mummy going to die? (asking for timescale)

‘I hope to be here in the summer, but we don’t know for sure. It’s unlikely I will be here at Christmas’

How is Mummy going to die?

‘Near the end Mummy will be very sleepy and my body will stop working. At the end my heart will stop beating’

Who will look after me?

‘Dad will still be here and will look after you. So is Granny, Granda and also Auntie...’

Preparing for death

Telling the child that their parent's death is imminent

'Have you noticed that Mummy is really sick today. The cancer has spread to so many parts of her body that her body is now not working. In the next couple of days/hours your Mummy will die and I feel really sad about this.'

Should the child be present at the death?

- This depends on many factors, such as the age of the child, clinical situation (agitation), and how the parents feels
- If appropriate, the child should have the information to make up their own mind

Preparing for death

What if the child wants to see the body?

They should have the information of what the body looks like and make up their own mind

Should the child attend the funerals?

- It is important for children to feel part of the funeral
- They need information on what will happen, who might be there and that people will be sad and it is ok for them to be sad
- It is an important opportunity for them to say goodbye

