



Talking to children and young people about death and dying -how and when to share information

This information sheet is designed to support our sheet, **Serious illness in the family**. It contains information and practical ideas for how and when to approach conversations around illness, death and dying.

A common misconception is that this looks like one, big conversation with children about their illness, sharing everything about diagnosis and future prognosis in one. In reality, we know it's far more manageable to talk about it in bite sized chunks, focusing on what we know is happening in the present, and updating information as and when things are changing. This way, it's possible to help them prepare step by step for what's to come.

What to share and when

When someone close to a young person is diagnosed with a terminal illness, you should begin with an initial conversation to share the name of the illness, and what part(s) of the body it affects. You might say:

“Mum/Dad has had a problem with [give the symptom]; they have been to the doctors, who have done some tests, and have told us they have an illness called [give the proper name and explanation]. They are going to need some treatment, which will involve...”

It's important not to promise someone will actually get completely better, when that's not the case.

It's also important to avoid using euphemisms or metaphors, such as 'battling' and 'fighting', as this can cause confusion and anxiety, especially in younger children or those with special educational or learning needs. Similarly, using broad, unclear terms such as 'poorly head or tummy' can lead to unnecessary confusion and anxiety for children around less serious, common childhood illnesses.

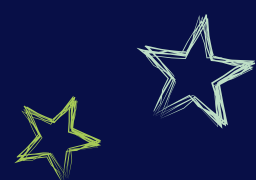
As changes occur, it's important to update children on the differences between symptoms of an illness getting worse, and temporary side-effects of treatment.

You can add in each change as a piece of information, just like adding the next piece of a jigsaw. Build on earlier conversations when sharing new information and check what has been understood and remembered, putting right any misconceptions. You might say:

“What can you remember about the last time we talked about X...?”

“Can you tell me what you think that means?”

“I have a bit more new information for you today...”





Managing emotions

Your child might not always ask questions or start conversations about illness or their feelings about it. They may not recognise they are struggling or may not want to bring things up that might upset others in the family. You can show them it's ok to talk to you by paying attention to, recognising, and naming what they might be struggling with.

This might sound like:

“I've noticed you seem [worried/angry/distracted/quieter], does that sound right?”

“I'm wondering if you wanted to talk about X [name the topic]?”

Remind them that there is no right or wrong way to feel about what is happening and resist the urge to 'fix the problem' - simply listening and acknowledging feelings is often enough for young people to feel seen, heard and understood – we know we can't 'fix' the real problem, but we can listen and support.

This might sound like:

“It's understandable to feel that way when something like this happens.”

“What can I do to help you in this moment? What might help you feel calmer?”

Responding to questions

Having shared what is known, if your child has further questions, remember not to project too far into what might happen in future, reassuring them you will tell them when things are changing. This can help to hold some anxiety.

If you don't know the answer to your child's question, it's ok to say:

“We just don't know that right now, but I promise I will tell you when we know more.”

Encourage your child to ask questions and regularly allow time for them to do this. It's ok to say you don't have some of the answers, or to delay the conversation if it feels too difficult at the time.

Questions about treatment and care plans for everyone in the family are common and are quite practical to answer. However, the question parents often dread the most is this: 'Is Mum/Dad/are you going to die?' Not every young person will ask this, but if they do, it's important to answer honestly. A truthful response that helps hold fear or anxiety might look like this:





“We now know that Dad/Mum’s illness isn’t ever going to go away completely, but the doctors are doing what they can to help them feel as well as possible for as long as possible, and when things are changing, I promise I will tell you.”

When end of life is near

When the time comes that your special person’s end of life is looking imminent, it’s important to update young people this is happening in the near future, and to give them the opportunity to spend time with them and say goodbye, if they want, and are able to.

You might want to say something like this:

“We now know that Mum/Dad’s illness has got worse, their body is beginning to shut down, and the doctors think they are likely to die very soon.”

Visiting at end of life

Being able to spend time with a loved one as they near end of life can be a tough, but powerful experience for all members of the family. It gives people the chance to process what is happening and to say goodbye.

Preparing young people for what they will see/hear at a dying person’s bedside can make this feel less scary and more manageable. Offering choices around if/when/how long to visit for is helpful at this stage. Reassure young people that they have choices around whether to talk to or touch their special person, and give them permission to distract themselves with activities or to step away from the person’s room if they need to.

For further guidance and advice please visit our website:
www.seesaw.org.uk

