St Nicholas Hospice Care Families and Carers

Talking to children about death and dying

because you matter



For an alternative format or language, please contact; enquiries@stnh.org.uk

NMY

It may be the panic of being on your own in the future, or the grief of leaving your family behind; it's okay not to be okay and to have all those feelings inside. There is no right way to grieve, and there is no easy way through this. Grief is messy, it could be the rain cloud above your head, the deep dark hole you are stuck in or the thick custard you have to wade through. The complexities of grief, either, knowing a person is dying or the death of a person is experienced and understood differently depending on the child's age and developmental stage.

Young children may revert back to earlier behaviours such as being more dependant and clingy, have separation anxiety, more tantrums, wet their bed, have difficulties sleeping or have no appetite. This is their way of telling you that something feels very wrong in their world.

If you are reading this, you may be going through one of the most difficult events of your life. Or, it could be one of many losses you and your family are facing.

Whatever the reason, thank you for taking the time to read this; know that you are not alone and that grief is a normal process children need to go through. We have put together some information in the hope that some of your questions may be answered.

Every child is unique, and although there are many similarities in the stories we hear, any change of behaviour that is different in **your** child could be a result of what is happening for them at this time.

Grief can start the moment you hear of the diagnosis, seeing the deterioration of health on a daily basis, or noticing the small or the big changes.

visit www.stnicholashospice.org.uk

Older children may be able to find the words to mirror their feelings, but the enormity of the situation may be overwhelming and behaviours may also change. You may see signs of rebelling, anger outbursts, fighting, self-harming, withdrawal, or crying. You may be shocked at what they might be thinking, their confidence and self-esteem may plummet to rock bottom. Remember, there is no one way to grieve. Right now your children are expressing their feelings in the only way they know how to.

Often adults feel the need to protect children from the truth and are desperate to find ways of making everything okay again.

Questions we are often asked are:

"How do I tell my child_____is dying?" "What do I say when they ask where_____is?" "How can I get my child to talk to me?"

The truth can often be the elephant in the room. The floor might feel like it is disappearing under you when you hear the little voice ask "when is......coming home?" Or, the teenager shouting "I hate you, you don't understand!" Take a deep breath! If you feel you can respond then answer truthfully. What is the truth? The truth is 100% what is happening, what happened or how you are feeling, but the amount of information given to the child or young person will depend on their age. Imagine a puzzle. It has the same picture for all children but the size and number of pieces will depend on the child's ability. The truth can be elaborated on in the future if the child has a good foundation.

If you do not feel you can answer their questions, tell them, and say, "That's a really good question. I'm not sure how I can answer that right now, but when I have thought about how to answer, let's talk."

Do not give them false information or say nothing at all. Use appropriate language and don't be scared of using words such as dying, died and dead. Explain to your child what may happen and what is going on. Explain the difference between being alive and being dead to younger children. The body stops working, but they have not gone to sleep. The truth can help make sense of the unimaginable and could prevent them from making up their own fantasies in their head, which could in turn lead to nightmares. Think about where you might have these conversations, and allow the time for the child to process what they have been told. Children and young people often find it easier to listen when they are doing something with you. Could you go for a walk together, cook or bake, get busy in the garden or get the art materials out?

Be prepared for children to ask many

questions. If it is the same question every day, that's fine, it is their way of processing what is happening or it may be that they need more information. Find books that are individual to your story so the child can relate to it. If you cannot find one that is right, then make a scrapbook, or write your own story.



The conversation might start like this:

".....illness has a nameit's called cancer....is it okay to tell you more about it now? You can ask me any questions you want."



"The doctors have tried to make.....better- they have tried every treatment but, unfortunately, none of them seem to be working. Sometimes this can happen with particular illnesses"

"The doctors have said cancer has got much worse and we now know that he/ she will die. He/she may seem okay to begin with and the doctors will do their best to make sure he/she is not in pain"

Above all, listen, just listen, be a heart with ears and be guided by your children, and find someone to listen to **you**.

Hospice Advice line

Call our 24/7 advice line for health care professionals and families if you need support with symptom management and end of life care.

enquiries@stnh.org.uk www.stnicholashospice.org.uk

01284 766133

Your Experience Survey

We want to develop our services in response to feedback; please consider filling out our survey which is available online or can be requested in paper form.

www.stnicholashospice.org.uk /your-experience-survey

because you matter



Date produced: June 2022

St Nicholas Hospice Care Hardwick Lane, Bury St Edmunds IP33 2QY