

Cystic Fibrosis here for you

Supporting a child bereaved
through cystic fibrosis



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Introduction

It's likely that someone with cystic fibrosis (CF) will have experienced periods of ill health throughout their life and in particular through their final weeks and days. Children close to that person will have an awareness of this.

Depending on the child's age, ensuring they understand what's happening before their loved one dies can help them to understand and cope with the death when it happens. It's a difficult conversation to have and the way you approach it will depend on the child's age and personality.

Several useful guides are available to help you with these conversations:

- www.hospicenet.org/html/talking.html
- www.dyingmatters.org
(Leaflet 8 'Talking to children about dying')

Telling a child about a death

Children, even from a young age, are very good at picking up on the emotions of those around them and will be aware that something is happening. You can't protect them from this loss but you can support them by ensuring they understand what's happened, involving them where appropriate and ensuring that they know they can talk to you or other people who love them at any time.

It's important that clear, honest and age-appropriate language is used when talking to children about death. Terminology such as 'passed away', 'gone to sleep' or 'gone to heaven' can be misunderstood by a child, leaving them unsure of where their parent, or other family member, actually is. Be honest, make sure they do understand that the person who has died won't come back. Children will cope with this conversation differently depending on their age and personality. You may be surprised at how quickly very young children accept this.

It's ok to be sad in front of the child - it's a natural reaction to loss and in fact may help them to feel comfortable about being upset and tearful themselves. Hiding your sadness might send a message that it's not ok to cry or be upset and therefore inadvertently encourage them to keep their feelings bottled up, which isn't helpful or healthy. However, if you are feeling overwhelmed with your

feelings and emotions, it may be helpful to ask family or friends for help with some childcare to give you the time you need. It's important that you look after yourself. Young children can become upset seeing a parent distressed for long periods of time.

The funeral

Deciding if a child should attend a funeral or not is a personal decision, but it is generally felt that children of any age can benefit from being part of this family ritual even if they are young and don't fully understand its significance. Children who are attending a funeral need to understand what to expect including that lots of people will feel sad and may cry.

There may be opportunity for them to be involved in the funeral in some way for example, writing a note or poem for the coffin, lighting a candle or choosing music. Their involvement in the funeral doesn't have to be conventional; do whatever works for you and your family but try to make it accessible and comfortable. Older children should be given the choice of attending or not; according to the organisation Child Bereavement UK, children generally do not regret attending a funeral, but do suffer from being excluded.

Coping with grief

Helping a child or young person when someone special dies is made easier if we have some understanding of how children cope with bereavement at different ages and stages of development. Children vary greatly in maturity and development but the following are general guidelines for different ages.

Pre-school children tend not to understand the permanence of death and may think it is temporary or reversible. Children of this age may need to be told repeatedly that their loved one has died and is not coming back. Tell them simple, brief, clear, honest facts when they ask questions. They may revert back to behaviour they showed when they were younger, such as bed-wetting, tantrums, clinginess, separation anxiety or nightmares. Try not to worry, as this should pass with time. Give lots of cuddles, love and sympathy and keep to normal routines as much as possible (eg nursery, school) as this will give them a sense of security.

School-age children tend to have a more realistic understanding of the permanence of death. They may also revert back to behaviour they showed when they were younger. They may ask questions about the physical process of death and its causes. Sometimes children may

seem to flip from very sad to quite happy, and although this can seem strange or upsetting to some adults, this is quite a normal grief reaction.

Teenagers may show changed behaviour, perhaps by increasing in rebellious behaviour, immersing themselves in their own lives or withdrawing altogether – whatever their coping strategy, it's important that they know you are there to support them and talk whenever they need. Even at this age you may need to reassure them that they are in no way to blame for the death. Give lots of love and support but also space, and set safe limits with regards to acceptable behaviour.

It's a good idea to keep the child's school informed about what's happened; ideally they'd be aware that a parent or close relative is very poorly before they die. The school can help support a child going through the stresses of bereavement and look out for warning signs that might indicate a child is struggling to cope. In this case, a school might be able to make small adjustments in recognition of these exceptional circumstances.

Child Bereavement UK has some excellent information resources explaining children's grief in more detail. Please see www.childbereavementuk.org

Remembering

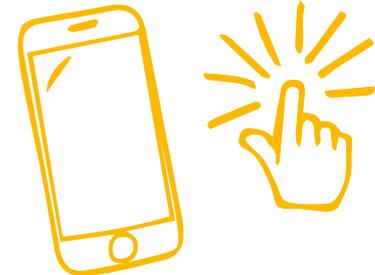
Loved ones will be remembered throughout the year but there are some dates and occasions that might feel especially important, for example their birthday, mother's/ father's day and other special anniversaries. Some children might like to mark these occasions with activities that remind them of their loved one – for example releasing a balloon, lighting a candle or going to their favourite restaurant – or whatever has a positive memory or focus for the child and their family.

Memory boxes can be created by a person before death; sometimes parents do this for their children. However, families can also create memory boxes after their loved one has died. The box could contain anything that is meaningful to you and your family; photos, children's drawings or personal belongings (perfume for example). The process of creating and adding to the box can feel positive. The memory box is a lasting keepsake for family and friends, giving a physical focus to their memories.



Getting help

- **Cruse** is a well-known and respected charity providing bereavement support through their network of volunteers. You can find out more about their services here: www.cruse.org.uk
- **Winston's Wish** is a charity dedicated to supporting children through the loss of a parent or sibling. They offer a range of support services including a helpline dedicated to supporting those caring for a bereaved child and specialist resources for schools who are supporting a bereaved child. Find out more here: www.winstonswish.org.uk or contact their helpline on 08088 020 021 (Monday–Friday, 9am–5pm).
- **Child Bereavement UK** supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement. They offer a range of services including information resources, a helpline and specialist resources for schools who are supporting a bereaved child. Find out more about them here: www.childbereavementuk.org or call their helpline on 0800 02 888 40.
- **The Childhood Bereavement Network** provides information about supporting a child or young person through a bereavement. Have a look at their website for more information: www.childhoodbereavementnetwork.org.uk
- **The Royal College of Psychiatrists** has a useful page on helping children or young people cope with bereavement. You can find it at www.rcpsych.ac.uk - click on the health advice tab and follow on to the parents and youth page.
- **The Cystic Fibrosis Trust helpline**, while not a dedicated bereavement support service, provides a listening ear service run by trained staff who understand cystic fibrosis. You can contact the helpline on 0300 373 1000 (Monday–Friday, 9am–5pm) or at helpline@cysticfibrosis.org.uk



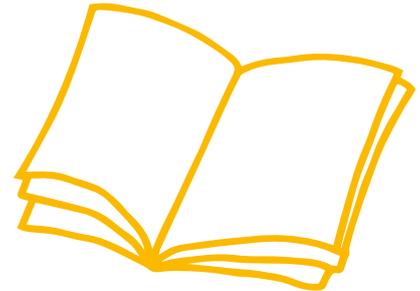
Useful literature

There is lots of children's literature developed to help children understand and cope with death and bereavement.

The following list may give you some ideas.

- Annette Aubrey (2007) **A Place in My Heart** published by QED Publishing
- Rebecca Cobb (2012) **Missing Mummy** published by Macmillan Children's Books
- Alan Durant (2013) **Always and Forever** published by Random House
- Marge Geegaard (1988) **When Someone Very Special Dies** by Woodland Press
- Debi Gliori (2005) **No Matter What** published by Bloomsbury Publishing
- Michaelene Mundy (2004) **Sad isn't bad** published by Abbey Press

- Michael Rosen (2011) **Michael Rosen's Sad Book** published by Walker Books
- Janis Silverman (1999) **Help Me Say Goodbye** published by Fairview Press



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