



Palliative Care Patients with children: Supporting the family

November 2021

Fife Specialist Palliative Care
St Columba's Hospice care

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Hospice Care**



The focus should not just be about individuals, but nor should it just be about families; instead, it is both the individual and those who comprise the family that are of interest because of their often overlapping, but not completely concordant, realities.

(Breen et al 2018)

ACP: Patients *and* families as *unit of care*

1. Priorities and values of a person's lived experience
2. Patient's social networks
3. Individual's experience of well-being as the best guide- what matters to them
4. Valuing shared decision-making

(from Abel, Kellehear, Millington Saunders, Taubert and Kingston 2020).

Challenge for NHS staff



UNCRC article 12 (respect for the views of the child)

Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously...during...the child's day-to-day home life.

HOWEVER

Specialist palliative care work with families of patients occurs on a non-statutory basis, and except in very specific situations, such as impaired capacity, confidential information regarding prognosis can only be shared with the express permission of the patient (GMC 2009)

Reasons parents avoid talking to their children



- Fear of the impact of their illness and death frightening them and seeming to take away any sense of hope or not doing it ‘right’ (Elmberger et al 2005; Barnes et al 2000; Buxbaum and Brant 2001, Park et al 2016).
- Lack of knowledge about reactions or how to respond to them (Helseth and Ulfsaet 2005)
- Parents with dependents more likely to choose life-prolonging treatment over symptom relief in last 6 months of life and Report significantly more anxiety and worse quality of life at EoL (Park et al 2016; Yopp et al 2015; Lovell and Yates 2014)
- Worry about themselves “missing out” and losses of parental role and responsibilities
- Worry about the quality of the parenting their children would receive in their absence. Mothers described their emotional closeness with their children as irreplaceable (Park et al 2016)

Facilitating Parents to prepare themselves and their children for parental death



- Coping of surviving parents most important determinant of child's psychosocial functioning and adjustment to death.
- What understanding do parents have? They cannot talk about dying and death with their children until ready themselves
(Macpherson 2005)
- A parent stays a parent until they die: maintain the dying parent's role wherever possible
- Adjustment to loss is a lifelong process- children require repeated confirmation and explanation as they progress developmentally
- Parents can ensure other significant people in the child's life are using the same language and giving support

What we know matters to children..

The NHS Fife logo is located in the top right corner. It features the letters 'NHS' in a large, bold, white sans-serif font. Below 'NHS' is a white graphic element consisting of two curved lines that meet at a point, resembling a stylized 'S' or a bracket. Underneath this graphic, the word 'Fife' is written in a smaller, white sans-serif font.

- The best person to help the child is the one who will be their carer.
- Emotional developmental stage and understanding
- Experience of previous bereavements, cultural influences and family beliefs
- Circumstances of death
- Social relationships and supports-school/clubs
- Grief is a life-long process which children need help to experience and express in new ways at times of further change/loss
- Behavioural change is their way of expressing anxiety and result of the inevitable lapsing of boundaries as parents adjust

What do children need?

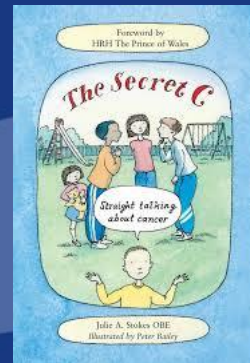
- Information at a level they can understand
- The chance to ask questions
- Remove sole responsibility to talk about their grief from them
- The message its ok to share feelings
- Most children don't need experts – like all humans they need to be heard and understood



All children



- Disease (not illness or infection)
- The name of the disease is cancer/name of life threatening illness
- COVID is a Virus
- Children can't make adults get cancer





How to use this keepsake box

It can sometimes be difficult to know where to start. Remember, what you choose to put into your box is a personal choice. Anything that's important to you that will be a keepsake for your child /family can go into your box.

A keepsake box is a precious gift that your child/family can treasure forever.

When making your box consider the important events of your life, your hobbies and skills, things that you are proud to have achieved, and most importantly **what makes you, you**!

We have included a few things to help you get started.

Postcards to school;

Postcards (how my teacher can help me). It can be helpful for children to be aware that staff at school are also affected by the situation. These postcards can help a child explain to their teacher some things they think might be helpful to them and give them additional support at school. For very young children a conversation with nursery staff about what is going on can be helpful as this way staff are more aware of a change in a child's behaviours (more than just playing alone, playing out what is happening as they try to make sense of it).

The Invisible String. A lovely book about separation and connectedness. This tells the story of a parent explaining to children about how we are all connected by an invisible string and how when we love someone, no matter the distance, we can keep connected by the love we have for them.

The Invisible String illness leaflet. Finding the words to explain to children when someone has a terminal illness can be difficult. This leaflet provides information to be able to share the story of what is happening in an age appropriate way. Often it can be helpful reading this a few times yourself before having the conversation with children. If you would like to talk this over with our child and families worker, please call 0131 551 7760

The Big Bear and the Little Bear. The idea with these bears is that the big bear represents the parent and the small bear represents the child. The adult keeps the small bear and the child keeps the large bear. This can be a comforting resource for

Website info:
riprap - when a
parent has cancer –

[Support for children
whose parent has
cancer | Coping
with cancer |
Cancer Research
UK](#)



<http://recordmenow.org>

Pre-bereavement resource
packs
Adapted to suit needs

Might add – The Secret C,
or When mummy or daddy
has cancer

Reactions to loss and understanding of death: pre- school age

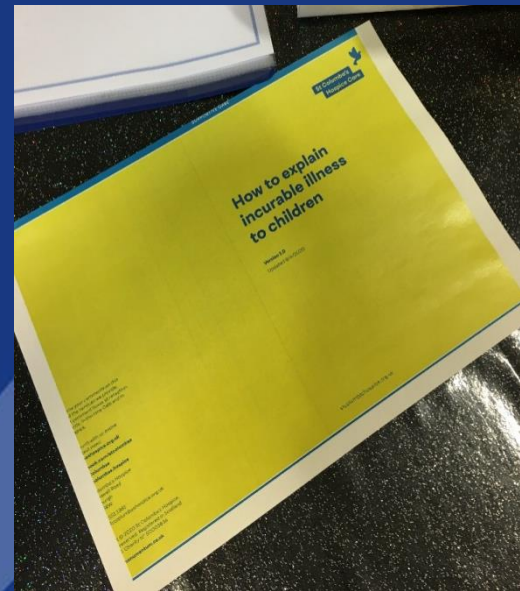
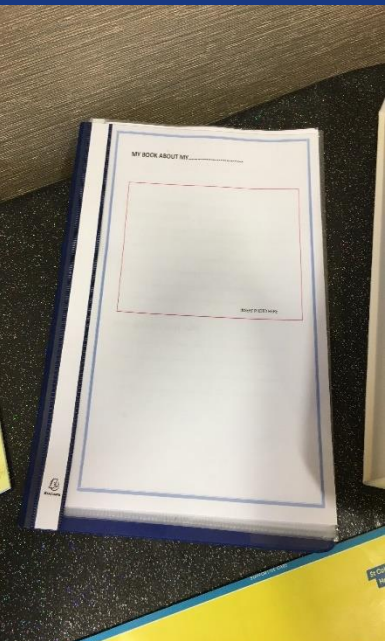
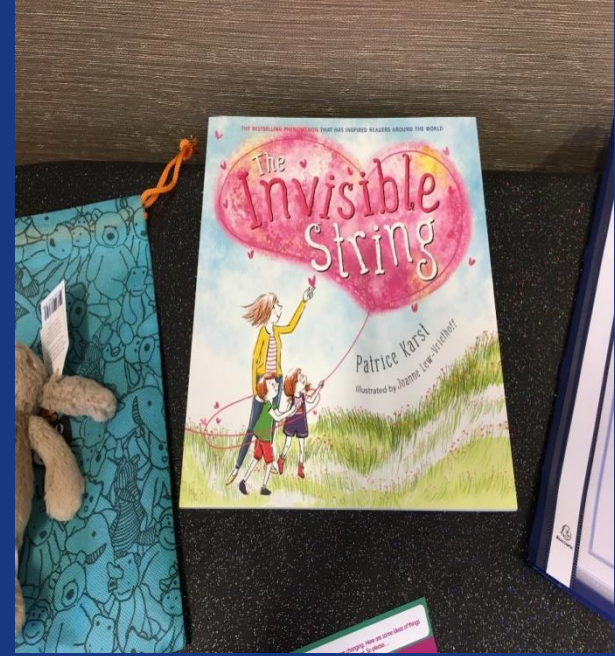
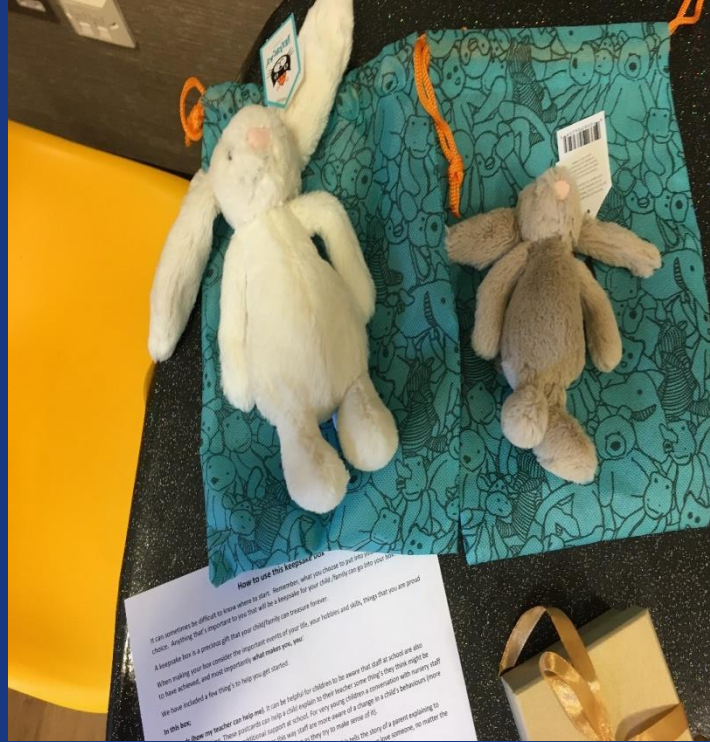
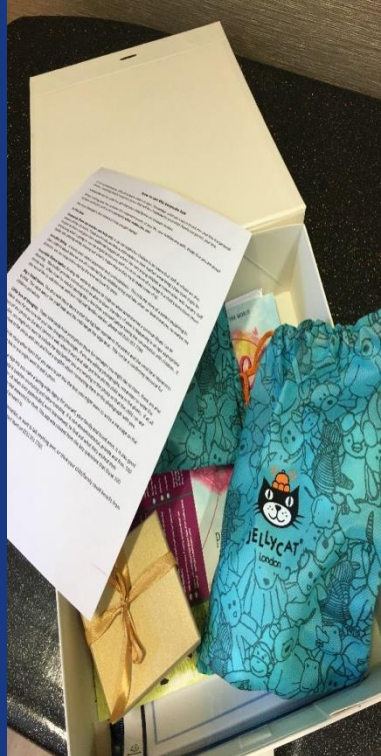


- May be more clingy to parent
- May ignore death or respond with puzzled detachment. Unable to grasp absence for several months. May ask same/similar questions about death repeatedly
- May show no apparent grief as long as have secure relationship with surviving parent and their life is otherwise little changed.
- Tend to associate death with what they know already- e.g. Going to sleep or being ill

5-8 years



- Intrigued by death- repeated questions
- May understand finality or may see as another category of being alive. Confusion with “magic”- cartoons –die and come alive again
- May associate it with aggressive feelings
- May see as punishment for wrong- doing
- Egocentric- may think it’s “my fault” and can experience guilt



To my teacher,
Someone close to me is seriously ill and so many things are changing. Here are some ideas of things you can do. I have ticked the ones I think will help me at the moment. So please...

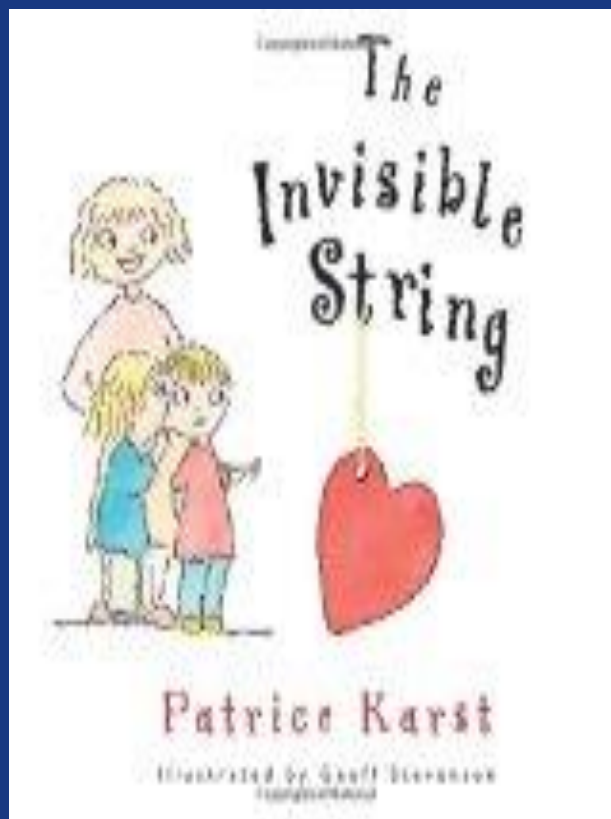
- talk to me about home and school and I'll let you know how I'm feeling
- if you want to know what's wrong with the person that's ill, just ask me
- treat me the same as everyone else
- let my other teachers know about what's going on at home
- at the end of the year, ask me how I want you to tell my next year's teacher what is happening
- please don't pressure me to speak aloud in class because sometimes it's hard. I will when I'm ready
- if I seem to be blaming myself, help me to remember it's not my fault
- understand that I may need more time for homework and deadlines
- talk to me on my own if you're worried about me.
- agree with me how I can leave class if I'm finding things difficult - perhaps a permission card
- give me space
- if I'm worried about what's happening at home, help my family know how to keep me informed during the school day
- please keep in touch with my their number is and they will keep you up to date on how the illness and treatment is going
- be aware of subjects and topics that might be difficult for me
- please try
- you could

Please understand that this is for now and my needs will change as the illness changes. Please check up on this with me. Thanks for reading and trying these. They do help although it may not always appear so.

8-12 years



- Able to give a logical definition
- Understand finality “cannot come alive again”
- Sorrow expressed in response to death
 - Prolonged crying
 - Withdrawn/apathy
 - hostility/aggression
 - Eating/sleeping disturbances
- Adults may find active expression of anger difficult
- Understand own mortality-questions about when will you die?



Resources

The invisible string

Paper

Coloured pencils/crayons

On hand for times of separation



Adolescents



- Social pressure to be “more adult”- fulfilling parental roles, looking after younger siblings
- Peer group may be unable to offer support- may lead to isolation
- May protect adults or delay meeting own needs
- Masking of emotional reactions in behaviour especially risk-taking and conflict
- Young people (13-21 years) took active role in shaping family communication. Attitudes towards openness ambivalent: some blocked information (Turner 2017)

What do we do for Children?



- Partnership with Parents: find a shared understanding
- Initiate/coach parents -facts for developmental stage
- Advise re day to day care/visiting
- Assessment-changes in behaviour
- Time as family/ 1:1 time
- Memorialising
- Liaison with school
- Direct support/counselling after discussion with parents
- Guidance about healthy ways to keep children emotionally connected to parent after death (Park et al 2016)

WHAT CHILDREN NEED

Measured information giving about dying and death



- Information- as soon as possible
- Truth ill
 - very ill/ may not get better
 - won't get better
 - dying
- Clear, simple language
- Individual judgement on child's reaction

e.g. fear of asking "will you die today?"
secrecy between siblings

How to help parents think through talking about it with their child



1. What does child already know/ suspect?

“You know Mum’s still in hospital – have you been wondering why?”

2. What child needs to know

What has happened

What is happening

What will happen

3. What likely to mean for them

“Who will make my tea”

Finish by....

- Any questions?....
- May need to repeat – certainly will at later date
- Stress usually impairs understanding and may cause regression in behaviour, beliefs and cognitive abilities

Process of Telling: Emotional Needs to Address

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- Fear of being abandoned – tell will not be left on own to cope
- Dying involuntary – nobody chose it
- Unwished – nobody wanted it
- Self-blame, guilt and shame. Nobody's fault for making it happen -especially not the child's, neither through actions nor thoughts (magical thinking).
- Not child's responsibility to make it better

The 'how many sleeps' rule...

This is not evidence based but it is what I use.

How to talk about 'dead'

- Clear and simple- avoid euphemisms

"like sleep" - night-time fears

"lost" - can come back?

"be a star" - what is that?

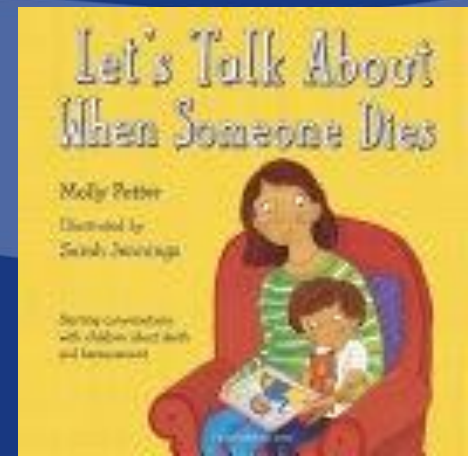
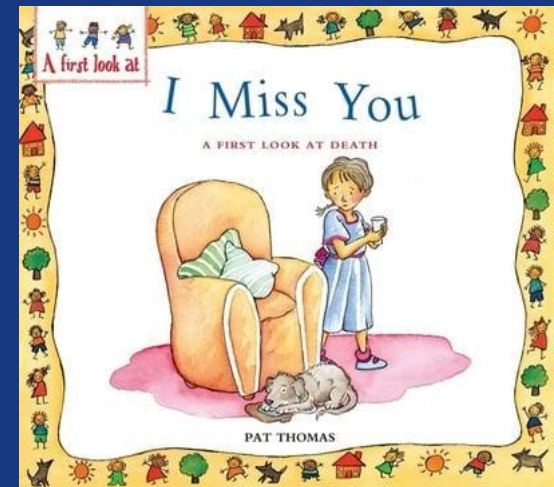
- What is "dead"?

Can't breathe

Can't move

Can't feel pain or sadness

Can't come alive again



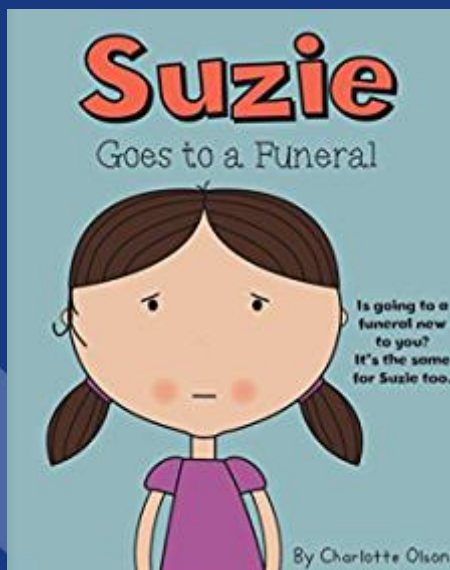
Immediately After Death: Families need help with



- Children viewing body- witness “dead”
- Saying “goodbye” to the body
- Model/Normalise/ translate immediate grief reactions and talking openly about dead parent
- Focus on helping to make immediate decisions regarding their children’s needs
- Reinforce importance of children attending funeral- or special children’s ceremony
- Journey to door

Funerals and children

- Studies show children almost always choose to attend
- Could be special children's' ceremony
- Tell them what will happen



HIGH COMPLEXITY



Emotional trauma

- Disclosure of extreme or sustained traumatic experience in childhood.
- Primitive emotions or wordless communication.
- Acute crippling anxiety / clinical depression
- Complex psychiatric history
- Drug and alcohol dependency

Family/ social complexity

- Pre-existing schisms between family members or parts of the family system.
- Entrenched positions and no apparent insight regarding compromise
- Legal/ structural uncertainty regarding domestic and/ or childcare arrangements
- Safety issues within the system (may be carefully concealed or disguised)
- High levels of projection across family members or parts of the system
- Child protection issues
- Staff asked to collude in secrecy or misinformation in “best interest” of another family member



HONESTY IS NOT THE SAME AS
OPENESS

Children can be helped to understand that:

- there are some “adult-only” family matters.
- not everything can be explained.

Being honest means acknowledging this.

What you can Do: Model

- Give words for what they can see
- Explain what you are doing and why
- Listen
- Encourage simple information giving to children
- Encourage parents to give children opportunities to ask questions
- Encourage pictures, photos, any form of communication possible



Further resources



Macmillan - Talking to teenagers and children when an adult has cancer

<https://www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/talking-to-children-and-teenagers-when-an-adult-has-cancer>

The Secret C: Straight Talking About Cancer by Julie Stokes

The Invisible String by Patrice Karst

I Miss You: A First Look at Death by Pat Thomas

Let's Talk About When Someone Dies: Starting conversations with children about death and bereavement by Molly Potter

Suzie Goes to a Funeral (Suzie and Sammy) by Charlotte Olson