

# **NHS Education for Scotland Bereavement Webinar Series**

## **Supporting children who are bereaved during and after the COVID-19 pandemic (06.10.2020)**

Donna Hastings, Family Support Worker, St Columba's Hospice  
Dr Catriona MacPherson, Children and Families Practitioner, Fife Specialist  
Palliative Care, NHS Fife

# Will bereavement support be needed more than ever following the Coronavirus pandemic?

Sprang and Silman (2013) reported that children who were isolated or quarantined during pandemic diseases were more likely to develop acute stress disorder, adjustment disorder, and grief. 30% of the children who were isolated or quarantined met the clinical criteria for post-traumatic stress disorder.

Acute grief after deaths due to COVID-19, natural causes and unnatural causes:

An empirical comparison

Higher grief levels occur among people bereaved due to COVID-19 compared to people bereaved due to natural loss. We predict that pandemic-related increases in pathological grief will become a worldwide public health concern.

<https://www.sciencedirect.com/science/article/pii/S0165032720327440>

[Maarten C.Eisma, Aerjen Tamminga, Geert E. Smid, Paul A. Boelen](#)

## Statistics

What do we know in Scotland 2019 –

**Table 1: estimated incidence of bereavement in childhood**

	Scotland	Great Britain	UK
How many parents died in 2015 leaving dependent children? <sup>1</sup>	2,500*	22,800*	23,600*
How often did a parent die that year, leaving dependent children?	Every 4 hours	Every 23 minutes	Every 22 minutes
How many children under 18 were bereaved of a parent that year? <sup>2</sup>	4,100*	39,000**	41,000**
How many children were bereaved of a parent each day?	4	107	112
What proportion of children aged 5-16 have been bereaved of a parent or sibling?		1 in 29	
What proportion of 16 year olds have been bereaved of a parent? <sup>3</sup>		1 in 20	

\* rounded to the nearest 100

\*\*rounded to the nearest 1,000

By the age of 16, 4.7 per cent or around 1 in 20 young people will have experienced the death of one or both of their parents (Parsons, 2011).

A Parent dies every 22 minutes across the UK. What about the other significant bereavements. Siblings, Grandparents, close family members or friends.

## Factors to consider

A wide range of interrelating factors can impact a child or young persons response to bereavement

- Previous bereavements
  - Circumstances of death
  - Beliefs and culture
  - Social relationships and supports available to them
  - Age/development will play a part in how they understand
- 
- Children and young people can revisit their grief – experiencing it and expressing it in new ways – particularly at times of change/loss
  - We know that a lot of children's needs are met in a stable supportive family with structure and routines such as school or clubs/groups – what happens when the majority of these were removed due to lockdown
  - Children's outcomes can be closely related to how their surviving parents or bereaved parent is coping, but what happens when parents are grieving themselves for the death and find it difficult to continue routines and remain available to their children.

## HOW CHILDREN & YOUNG PEOPLE WHO ARE BEREAVED HAVE BEEN IMPACTED BY COVID-19

- Already Bereaved –
- Person who died may have been the one who would have supported them
- Grief put on hold
- Couldn't visit memorials – cemeteries, places of remembrance
- Additional losses, school, friendships, community groups, social interactions,
- Bereavement support postponed /changed
- Limited outlets for grief reactions during lockdown – one hour a day exercise
- Family all grieving at different stages – 24/7 together
- Anxieties heightened already – more so about “who might get COVID and die next”
- Over exposure to information – TV /news/adverts all consuming about virus
- Isolation
- Ways of looking after yourself is suggested, like getting enough sleep, eating healthily and get some exercise. how many people were up at all times of night as their routine went out the window, young people have said their day's turned into night and vice versa
- As lockdown lifts – going back to school, with a changed grief, how others view grief after this time
- Risk taking behaviours for young bereaved people as lockdown eases
- Transition from nursery to primary, primary to high school, exams, prom, graduations – milestones missed
- University –isolation
- Some feedback though, reflecting on if the person had been poorly this year, experience would be changed

# Newly Bereaved

- Opportunity of choice to say goodbye removed in many cases
- Visiting restrictions prior to death might mean the child hadn't see the person for weeks/months in person
- Additional losses, school, routine, stability, friends, important transitions and events cancelled
- Lack of support/social interaction
- Separation – teachers, friends, other family members
- Intensity of grief in the house
- No opportunity of choice to see the person after death
- Funeral restrictions may mean that even with the closest death children cannot attend a funeral, there are webcasts which children can be encouraged to watch along with another adult, but feedback for some has been buffering and parts missed but also feeling like it wasn't real, or that it was intrusive and children have felt like they were bystanders watching others grief and felt various emotions with how this has made them feel, like they were left out
  
- It will be particularly difficult for children and young people whose culture or faith requires certain practices to be performed in particular ways for the person who has died. Churches, mosques, synagogues and other places of worship are closed to the public although faith leaders can still conduct services in places such as a crematorium or graveside. Children and young people may believe that their loved one has not been treated appropriately and may need reassurance, using the language of faith, that everything that is being done is respectful and necessary.

Children may want to see the body of the person who died: to say a final goodbye, to begin to understand the reality of death, to express their loved one last time.

The national response to the coronavirus (COVID-19) outbreak means that children and young people who have a loved one die in this period probably won't have the chance to make the choices they normally could and may have to say goodbye in a different way.

# Bereaved from COVID -19

## Explaining that someone has died from Coronavirus

I have something very sad and difficult to tell you. [Name] died. You remember I told you that s/he had this illness called 'coronavirus' and that everyone was doing all they could to make them better? Sadly, despite all that [name] and the doctors and nurses did, the illness became too strong and their body could not get better. Their lungs stopped working and their heart stopped beating and they died."

**Unpredictability:** It's not only very old, very frail people who are dying. The person they know may have been a little frail before they contracted the virus or they may have appeared perfectly well

**Suddenness:** People may sicken and die quite quickly, giving children little time to adjust to a rapidly changing future.

Narrative of explaining death. Children may be angry that if there wasn't coronavirus then their person may not have died, however it's helpful to also remember that children bereaved through all causes of death can feel anger towards – suicide, cancer, other diseases/illnesses and question why their person died from it and why others didn't. It's giving an explanation of covid and helping children to build a narrative around this.

Constant reminders might mean It will be hard for children to avoid hearing other stories of people affected by coronavirus

Not being able to spend time with the person

Funerals and gatherings restricted

General time of anxiety and fear

Economic pressures (what are children hearing/experiencing at home)

Increase in cases – news about 2<sup>nd</sup> wave during winter – anxiety /worries for children who are bereaved are already heightened

Living in fear of who might get the virus next or who might die?

# Supporting bereaved children with current situation

## Balancing truth and reassurance

One continual challenge for parents and carers supporting children facing bereavement or those who have been bereaved is finding the right mixture of truth and reassurance. Children are expert at knowing if they are not being told the truth; if there are things that seem too difficult to share, explain that.

Equally, they will know the difference between genuine and false reassurance. Rather than saying “*nobody we know is going to die*”, maybe consider saying: “*from all I’ve heard, it is extremely unlikely that anyone we know will die and we will do everything we can do to keep safe.*”

## Sort out the facts and make sure parents realise children will nearly always wonder what they have done wrong

*Its not fair that my dad’s died. I did wash my hands all the time when he had chemo **and** the virus and he didn’t get better from his illness.*

Cancer is a disease, viral infections cause us to be ill but are usually not so serious. Children cannot make parents die and you are right its definitely not fair.

Structure

Routine

Boundaries

Age appropriate information

Access to supports

(information/resources/someone to talk too)

Factors to consider when

support for under 12’s if online



# WHAT GOOD PROVISION FOR BEREAVED CHILDREN AND YOUNG PEOPLE AND THEIR PARENTS AND CARERS LOOKS LIKE

3

Few

Outreach and specialist psychological 1:1/family support for those who are vulnerable or traumatised

2

Some

1:1/family and peer support

An easy to access consultative process to agree who and what could help a particular family

1

All

A supportive response from existing networks

Information about how children grieve, what can help, when to seek more support and what services there are

# 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).

# Changes and Lessons learned

- Constantly shifting situation and decision making process
- Initial local interpretation of advice- issues of equality
- Managing expectations- professional and public
- Initially no specific guidance for our sector
- Immediate loss of face to face and support groups
- Rapid learning for online practice
- Practitioner exhaustion and anxiety

# Guidance...

- Equality of access to services for children in Scotland
- Bereavement Charter *Everybody's responsibility*-  
bereavement training education and healthcare staff
- UNCRC will be implemented and incorporated into Scots law

# UNCRC

- **article 5 (parental guidance and a child's evolving capacities)** Governments must respect the rights and responsibilities of parents and carers to provide guidance and direction to their child as they grow up, so that they fully enjoy their rights. This must be done in a way that recognises the child's increasing capacity to make their own choices.
- **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. This right applies at all times, for example during immigration proceedings, housing decisions or the child's day-to-day home life.
- **Article 13 (freedom of expression)** Every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is within the law

# To think about...

- What kind of ethos do we want in Scotland?

Do we simply want our children 'sent' for counselling?

OR

Could we also help parents to learn how to teach and support their children themselves- long lasting relationship building and emotional well-being

- National bereavement Co-ordinator- lead role in every health Board to ensure policies and practice reflect a family and child centred perspective