The Bereavement Collaboration ECHO Knowledge Network

Week 3: ‘Complexity’

23 November 2021
Network Recording Declaration

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the Data Protection Act 2018 General Data Protection Regulations (GDPR), under that law we need you to be aware that:

- This Data will be stored with password protection on the internet.
- This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
Welcome and Introductions
<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenter(s)</th>
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<tbody>
<tr>
<td>10:30</td>
<td>Welcome &amp; Introductions</td>
<td>Cat Sullivan, Senior Clinical &amp; QI Lead, Hospice UK</td>
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<tr>
<td>10:35</td>
<td>Bereavement &amp; Complexity</td>
<td>Gail Precious, Senior Development Officer, National Bereavement Alliance (NBA)</td>
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<td></td>
<td>Case presentation: Children and Young People bereaved of Suicide</td>
<td>Phil Lindsay, Children's Service Manager, Northern Ireland, Barnardo's Child Bereavement Service</td>
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<td>11:00</td>
<td>Discussion</td>
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<td>11:25</td>
<td>Bereavement in Prisons</td>
<td>Katie Reade, Senior Policy Officer, Hospice UK</td>
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<td>11:40</td>
<td>Questions &amp; Discussion</td>
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<tr>
<td>11:55-12:00</td>
<td>2022 ECHO Session Planning Zoom Poll</td>
<td>Cat Sullivan, Senior Clinical &amp; QI Lead, Hospice UK</td>
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<td>Call for future case presenters</td>
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Which parts of our ECHO would you like us to record?

Zoom Poll
Complexity & Bereavement

Gail Precious, Senior Development Officer, National Bereavement Alliance (NBA)
Complexity in bereavement

Gail Precious
National Bereavement Alliance & Childhood Bereavement Network
Quick poll

What do you want to gain from this session?

• Understanding more about complexity in grief
• Understanding what my colleagues do in relation to complexity in grief
• I want to share our situation or issues with this group
• I want to find out where to go for further information and resources
Overview

• Swift exploration different types of grief, focusing on complicated grief
• Highlight different situations where grief may be impacted by other factors
• Knowledge is key – partnership working
• What does this mean for your service?
• What can you do to help yourself?
Symptoms of grief

- sadness
- shock
- disbelief
- pangs or waves of grief
- yearning
- obsessive thoughts
- rumination
- changed sleep patterns
- confusion
- difficulty in concentrating
- anger

- anxiety
- guilt
- changes in appetite
- social withdrawal
- vivid dreams
- sensing the presence of the deceased
- hallucinatory experiences
Grief does not happen in a vacuum

Drive-by burials and FaceTime farewells: Grief in the Covid era will weigh on the American psyche for years to come

By Todd S. Purdum Dec. 9, 2020
Complicated grief

- Naming is everything!
  - Complicated grief
  - Persistent complex bereavement disorder
  - Prolonged Grief Disorder

- Key proponents of disordered/problematic grief:
  - Dr Katherine Shear
  - Professor Holly Prigerson

- Highlighted key approaches for those who are ‘stuck’:
  - Loss focused attention – painful, deep longing
  - Restoration focused attention – disbelief, resignation
Complicated grief - presentation

Symptoms of grief

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## What’s the difference?

<table>
<thead>
<tr>
<th>Grief</th>
<th>Depression</th>
<th>Post traumatic stress disorder</th>
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<tbody>
<tr>
<td>• Loss of interest or pleasure related to missing loved one</td>
<td>• Pervasive loss of interests or pleasure</td>
<td>• Heighted response</td>
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<tr>
<td>• Pangs of emotion triggered by reminders of loss</td>
<td>• Pervasive dysphoric mood across situations</td>
<td>• Fear and anxiety dominant feelings</td>
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<tr>
<td>• Preoccupation with the deceased; guilt and self blame</td>
<td>• Preoccupation with low self esteem; general sense of guilt or shame</td>
<td>• Hypervigilance</td>
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<td>• Avoidance of activities, situations and people because of the death</td>
<td>• General withdrawal from activities and people</td>
<td>• Relating to a specific event in time and space</td>
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<td>• Intrusive images of the deceased are common</td>
<td>• Intrusive images are not prominent</td>
<td>• Specific triggers</td>
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<tr>
<td>• Yearning and longing are frequent</td>
<td>• Yearning and longing not usually seen</td>
<td>• Responses can diminish over time and with help</td>
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</table>
Complicated Grief Treatment

Dr Shear’s approach

- understanding and accepting grief,
- managing painful emotions,
- planning for a meaningful future,
- strengthening ongoing relationships,
- telling the story of the death,
- learning to live with reminders, and
- establishing an enduring connection with memories of the person who died.
Complicated grief – responses

• its emergence from a white, Western approach with research in other contexts less well developed
• being based firmly in the US health system - ie a diagnosis is needed to get treatment funded by medical insurance
• put too much emphasis on individual responses and not enough on the complex circumstances of bereavement
Traumatic grief

• Where the manner of death is as loud to the bereaved than the grief around it

• Not unique to incidents considered traumatic (homicide and suicide) – other sudden or unexpected deaths could be considered traumatic to the person bereaved

• Restrictions around pandemic may have heightened bereaved people’s feelings of regret

• UK Trauma Council has a wealth of information about trauma, and traumatic bereavement, particularly for children and young people
Disenfranchised grief

- A loss that is not acknowledged by the community or society of the bereaved person
- Range of losses – including significant relationships (e.g., pets, a co-worker) and deaths which are ‘socially difficult’ to support: suicide, capital punishment
- Grandparents’ loss of a grandchild is often disenfranchised
  - not in the immediate family so often not included in support
  - grieving for the grandchild
  - grieving with the adult child who has lost (Davidson, 2010)
Additional complicating factors

- Conflict within family relationships
- Poverty
- Family living geographically away from the person who died
- Anxiety
- Gatekeeping & accessing services – for example, learning disabilities, children and young people
Working together

- Partnership building
- Knowing your referral routes
- What happens when referrals get stuck
It’s not just down to you

Burnout
Comes from working too hard for too long.
Can lead to feelings of dissatisfaction, exhaustion or inefficacy

Both can result in ill health, depression and finding work harder

VT
Develops from a helper’s empathic connection with someone’s suffering or trauma.
Can result in self-protective ‘shutting down’
What does this mean for you?

- What resonated with you during this session?
- What are you seeing locally?
- How does this make you feel?
- What interventions work well for you or your service?
- What hasn’t worked? How did you adapt?
- Who else have you included in your support for that person?
- Why did you make those decisions?
Further resources

Complexity in grief
• Sign up to updates from the Therese Brady Library at the Irish Hospice Foundation for articles on all aspects of complexity in grief
• [https://prolongedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/](https://prolongedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/)
• 'Why grief gets stuck and how we can help’ [http://www.sad.scot.nhs.uk/events/previous-webinars/](http://www.sad.scot.nhs.uk/events/previous-webinars/)

Traumatic grief
• UK Trauma Council’s resources around
  • traumatic bereavement
  • Coronavirus and trauma
Bereavement and Complexity:

Children & Young people bereaved by Suicide

Phil Lindsay
(MBACP Accred)
Please look after yourselves.
If you need a break, take one but please come back and let me know you are okay.
Everyone thinks differently about life so please respect each other’s opinion.

Reminders of Gail’s prompts earlier.
• What resonated with you during this session?
• What are you seeing locally?
• How does this make you feel?
• What interventions work well for you or your service?
• What hasn’t worked? How did you adapt?
• Who else have you included in your support for that person?
• Why did you make those decisions?
Introduction and Aims:

- Definition
- Who we interface with professionally: examples
- Approach adopted by the local EA around deaths by suicide
- The reasons for this and challenges
- Approach some parents take around deaths by suicide
- The reasons for this and challenges
- What this means realistically for children and young people (the emotional effect, the case study example learning disabilities whose grief was disenfranchised by her parent perhaps)
- What this means practically for bereavement work and service offers
“In a traumatic bereavement, how the child or the young person experiences or understands the death – the meaning they make of it – results in it being experienced as traumatic.”

**The trauma gets in the way of the typical process of grief and blocks the child or young person’s ability to process the loss.**

A child can experience traumatic bereavement at any age. Any type of death can result in a traumatic bereavement. Traumatically bereaved children and young people experience significant distress and difficulties, over and above a more typical grief. It is vital that these children are identified and given the appropriate help and support.
Who we interface with:

CAMHS
EA: Critical Incident Teams
PHA commissioned Services
Trusts services
Bereaved by Suicide Adult Team
Schools
Colleges etc
Children, young people and their families
EA Critical Incident team:
critical incident may be defined as any sudden and unexpected incident or sequence of events which causes trauma within a school community and which overwhelms the normal coping mechanisms of that school.
Believe in children
Barnardo’s Northern Ireland

Trauma

Adapted by Ruby Jo Walker from Cheryl Sanders, Steve Hoskinson, Steven Forges and Peter Levine

Barnardo’s Registered Charity
Nos. 216250 and SC037605
APPENDIX 9

DEATH BY SUSPECTED SUICIDE

INFORMATION FOR STAFF

1. The term suicide should not be used by a school until it is determined by the Coroner’s Office. Where an inquest is required it may be a considerable period of time after the death.

2. When providing support for vulnerable pupils, it would be prudent to make a working assumption of suicide, if all reasonable indicators suggest that this might be the case. Pupils and members of the community may be inclined to describe a death as a suicide before this has been established. Phrases such as ‘tragic event’ or ‘sudden death’ should be used by the school when talking to pupils.

3. In the aftermath of a sudden death within the school community pupils' vulnerability may increase. Teachers should realise that some pupils may develop suicide ideation and/or self harm. Staff need to be proactive in identifying and monitoring these pupils. Pupils considered to be ‘at risk’ should be immediately referred to the Designated Teacher for Child Protection who will then notify parents and advise them of the referral pathway to obtain support for their child. This will
Challenges to Therapeutic Support for CYP

Example: A member of staff in a school
Children’s understanding
How this played out for children and families: eg bed wetting, poor sleep, poor eating, filing in gaps in information or making more up
Attendance at funeral
Respecting bereaved family wishes
Respecting parents wishes
Available for staff discussions re individual cyp
Explained how to give age appropriate info to adults should they wish to share with own children
Containing cyp and their concerns
Little exercise to support conversations
Training/awareness sessions with parents/carers
Assessments/consultation for those who still need
Families impacted by a close suicidal death

Story of Anne, 10/11 years; dad died by suicide, Anne isolated at school due to SEN and in mainstream, geographically rural
Adamant she hadn’t seen – mum refused to share info
Respect for parental decision
Ended with service
Contacted by CAMHS – collusion by Anne
Work resumed – yp knew
Parents Worries

- I will really upset my child
- What if they consider suicide also.
- My child won’t cope with the truth
- They are too young/sensitive to understand.
- They won’t understand and will forget about it.
How long does a child’s grief last for?

- A significant bereavement will be part of a child’s experience for the rest of their life.
- Certain events, reminders or anniversaries are likely to trigger feelings and thoughts about the dead person.
- Children go in and out of grief. This is true both over the short and longer term. Directly following a bereavement, they may move in and out of grief feelings from moment to moment - circle and square.
If it was a suicide- should we talk about that?

Parents/carers have the right to decide about what they feel is best for their own child.

We advise that children should be told in a child friendly/age appropriate way about a suicide death. It stops the mystery, the wondering and helps children feel important to hear information.

Children’s imaginations can be really creative.
Elephant in the room

Why can we not talk about them?
Difficult conversations....
We can’t make the pain less if we don’t talk about the person who has died.
Pain will sit with us- our body always remembers.
Impact of covid on our work over past 1.5 years
What do you do when you are worried?

Keep the relationship going

Refer to a specialist service

Hold the hope.
I am here

And

I hear you
C.S. Lewis described his grief on the death of his wife as feeling like fear: ‘No-one ever told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid – the same fluttering of stomach, the same restlessness, the yawning. I keep on swallowing. At other times it feels like being mildly drunk or concussed. There is a sort of invisible blanket between the world and me. I find it hard to take in what anyone says.’
"I would recommend the service to any young person for support after a suicide - from the beginning I said that I wasn’t talking and you have helped me find the words”, young person aged 14 years

A parent shared "I feel a massive weight has been lifted of my shoulders and feel such relief. I can see now my son was ready and needed this part of the story to help him move through his journey - I thank you for this”. Parent of a child bereaved by suicide.

Another young person shared "when mum told me how and what had happened it helped me understand and move on, I knew there had to be something else”. 11/12 year old child.

A mum shared "I have got my wee son back and he is much more settled and less anxious. I as a parent am much less worried about him and have stopped watching every move he makes. Thank you so much for your support”.

A primary 7 child shared “Thank you so much for helping create all the things to help me have memories of the good times I had with Daddy”.

“I feel you really respected me and let me be more open about my feelings” was shared with a worker on completion with a young female client.

Another young person who was supported in the work in the service said “I didn’t realise I would remember so much, you helped me think more about what I remember”
Thank you

www.barnardos.org.uk/childbereavementservice

Advice line Service 07867372711
(Monday, Tuesday 10am - 1pm and Friday 10am - 12pm)
Useful links:
https://www.winstonswish.org/
https://www.sands.org.uk/
https://www.cruse.org.uk/
Bereavement in Prisons

Katie Reade,
Senior Policy Officer,
Hospice UK

www.hospiceuk.org
Policy and Advocacy at Hospice UK:

• Conduct research and identify solutions
• Work with Government, the NHS and others to influence their policy
• Campaign for positive change for people with palliative and end of life care needs

All with the aim of improving access to, and the quality of, end of life care for all.
Dying Behind Bars:

• Ageing prison population and rising deaths in custody mean increased need for end of life care

• Analysis of Fatal Incident Reports by the Prisons and Probation Ombudsman revealed:
  – inequivalent care to what is received in the community
  – inappropriate use of restraints
  – delayed or no consideration of compassionate release
The report’s findings on bereavement:

- No explicit mentions of bereavement support within the fatal incident reports analysed, with less than one quarter mentioning general ‘support’

- Recommended that bereavement support within prisons be established at a national level and hospice services should explore the possibility of supporting or providing this care.
Questions:

• What experiences do you have, if any, of delivering bereavement support to people in prison, their families or prison staff?
• Have you come across any good or bad practice in this area?
• What should bereavement support in prisons look like? What needs to improve to enable this?
## Upcoming Sessions

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<td>24.08.2021</td>
<td>10:30 – 12:30</td>
<td>Curriculum Setting</td>
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<td>21.09.2021</td>
<td>10:30 – 12:00</td>
<td>Demand</td>
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<tr>
<td>12.10.2021</td>
<td>10:30 – 12:00</td>
<td>Supporting Staff</td>
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<tr>
<td>23.11.2021</td>
<td>10:30 – 12:00</td>
<td>Complexity</td>
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<tr>
<td>TBC</td>
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<td>Managing Space</td>
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<td>TBC</td>
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<td>Volunteers</td>
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When, how often and how long would you like these sessions to be?

Zoom Poll
Before you go…

Let us know your feedback via this survey monkey:

https://www.surveymonkey.co.uk/r/Nov2021_Bereavement_ECHO