

Supporting neurodivergent individuals who have been bereaved

Sarah Helton
BackPocketTeacher





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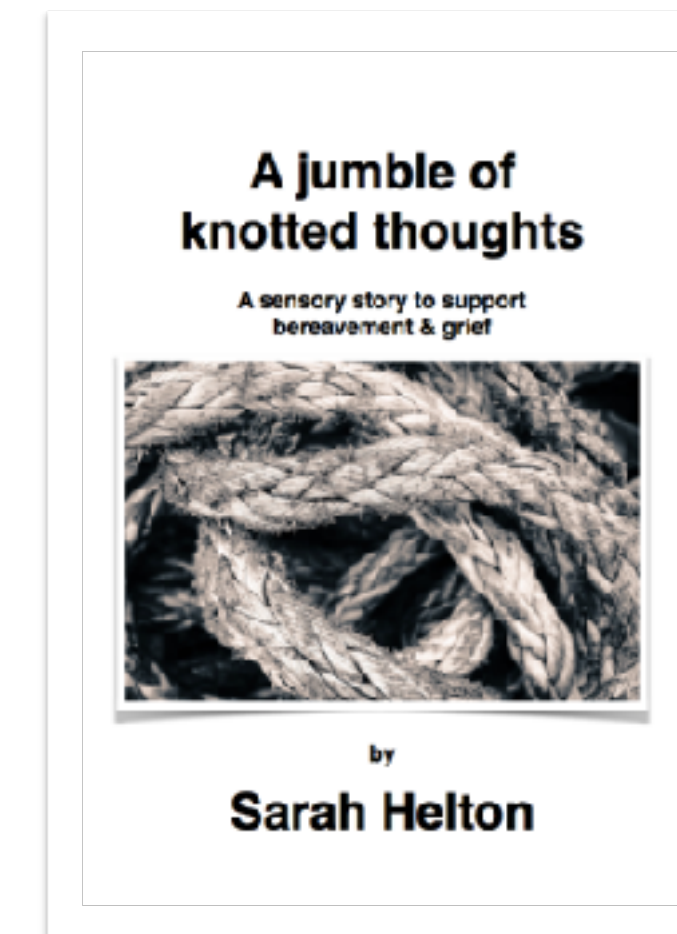
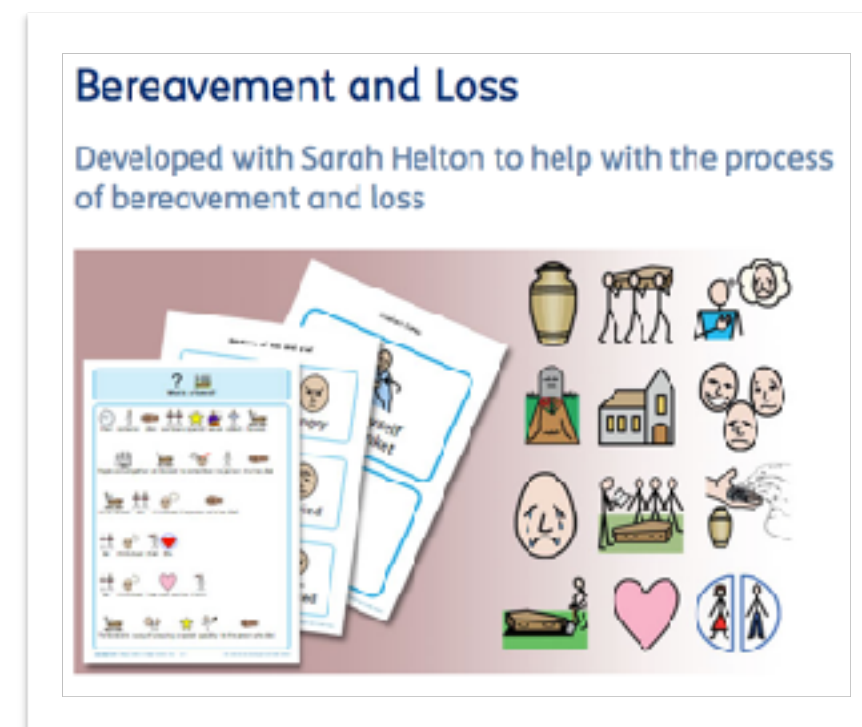
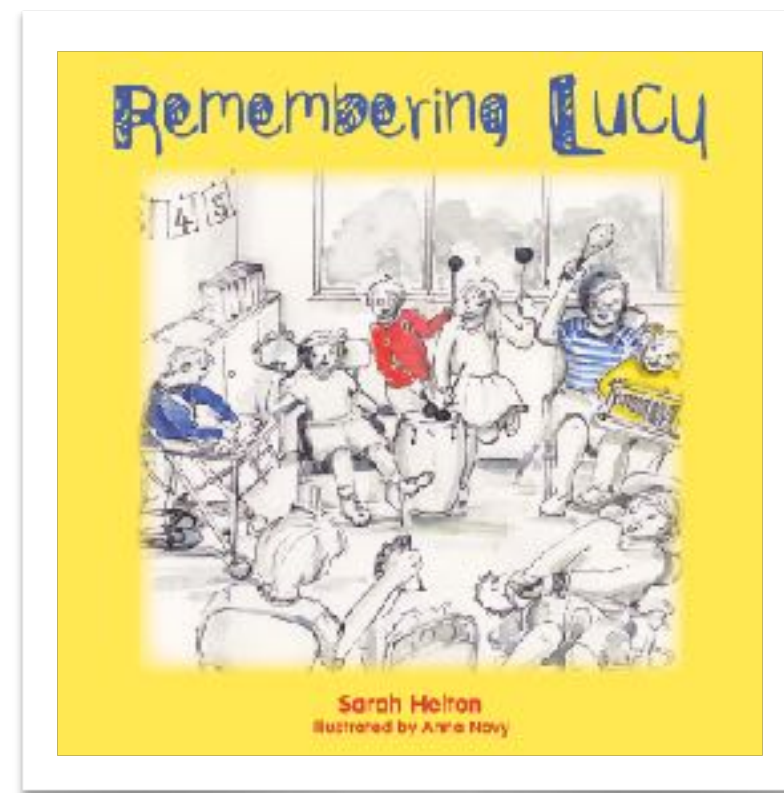
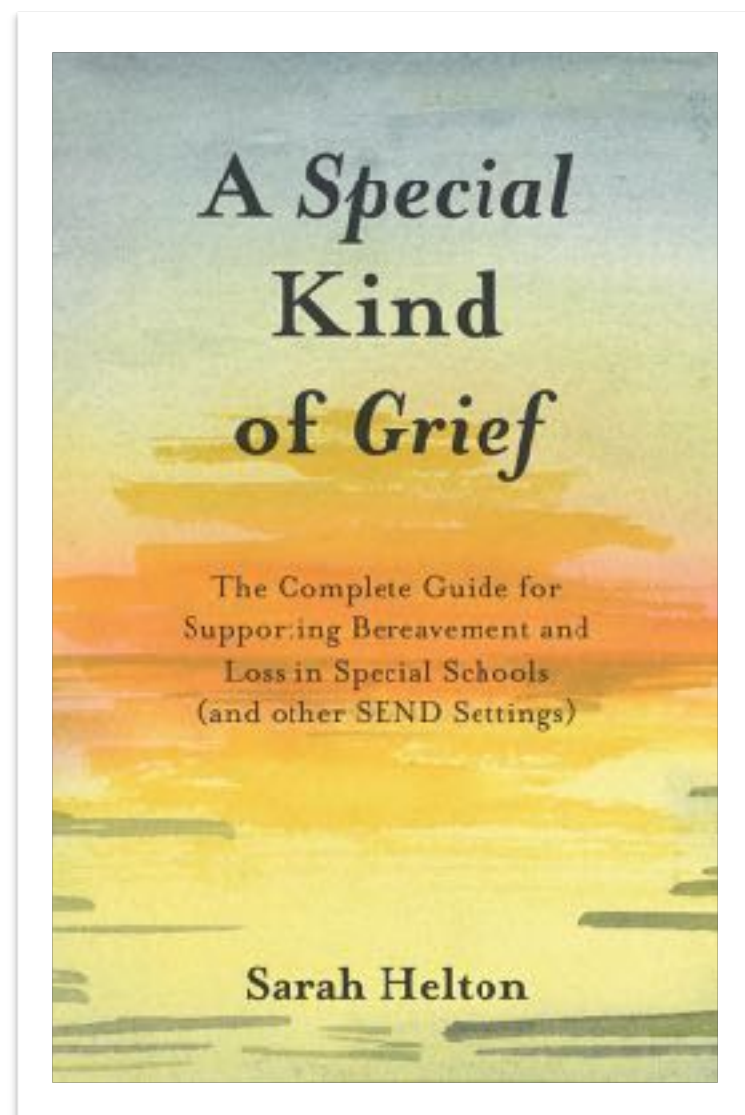
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Why is this such an important topic?

- The needs of these individuals are at last being seen and understood
 - neurodivergent
 - learning disabilities



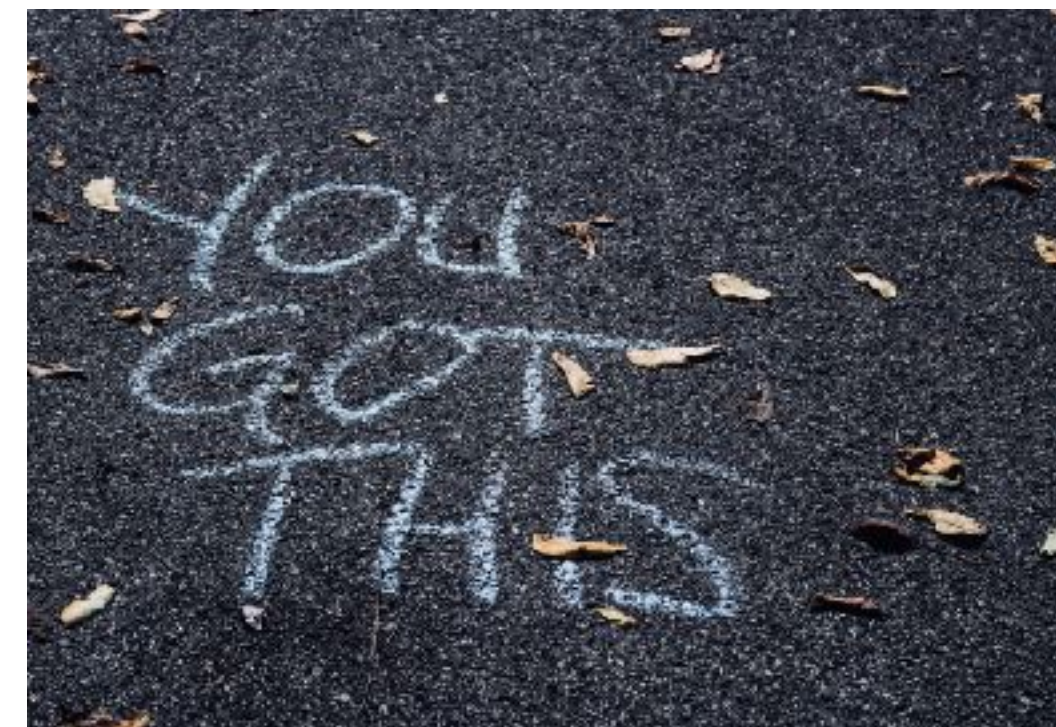
Family

- Have they considered the individual's involvement in the funeral/memorial?
- Have they considered the support that is available?
 - advice
 - resources
 - counselling
- Advocacy for the individual



Confidence

- Why do people try to avoid talking to neurodivergent individual's about bereavement, grief and loss?
- Who are we trying to protect?
- The confidence to say and do something
- It takes time and practice



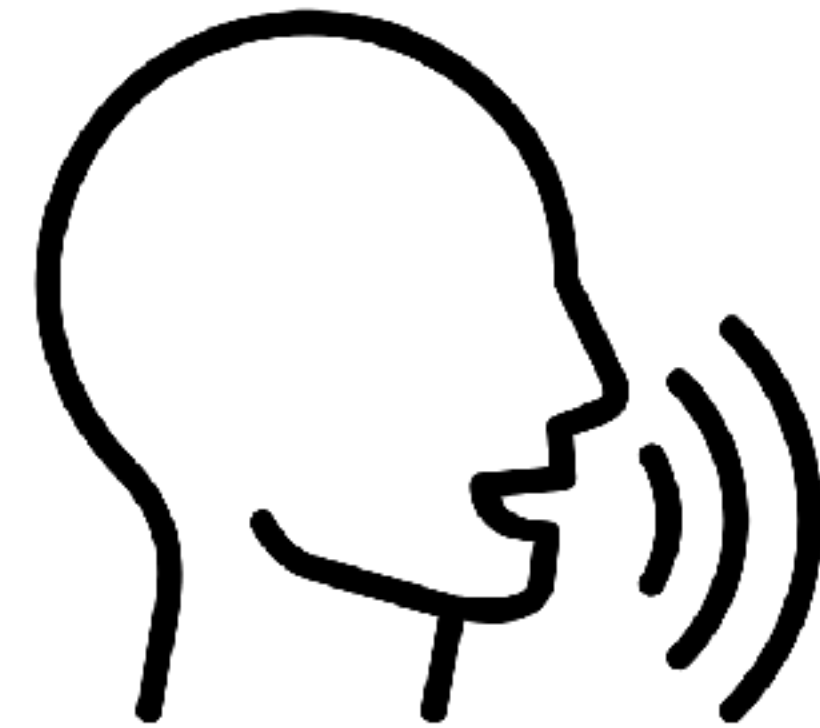
Barriers to support for bereavement



Communications of grief

EVERYONE has a VOICE

- Voiced communications of grief (verbal/audible)
 - Verbally
 - Vocalisations
 - AAC - electronic communication aids
- Voiceless communications of grief (non-verbal/inaudible)
 - Behaviour
 - Facial expressions
 - Body language
 - Physiology
 - AAC - sign language, symbols, objects of reference, paper-based communication books, photos, drawings/cartoons (pointing to these), creative expressions

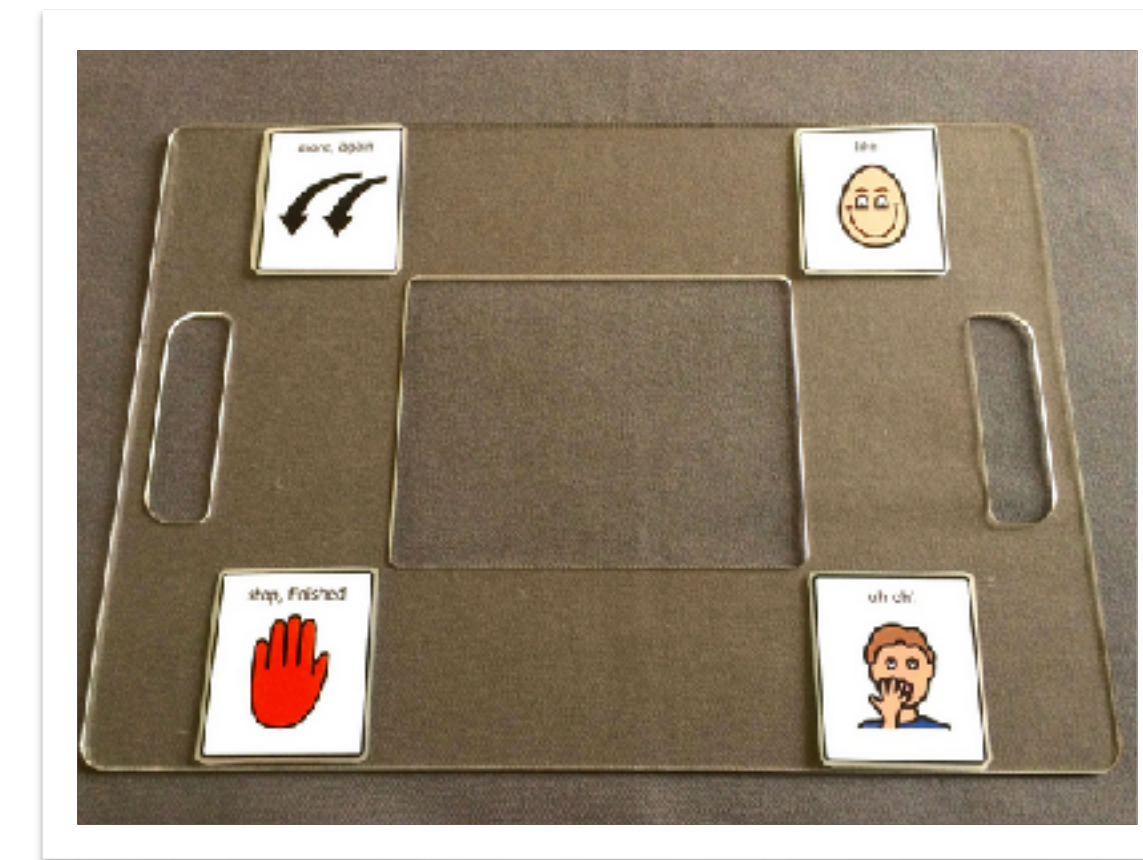


Communication



Bereavement and Loss

Developed with Sarah Helton to help with the process of bereavement and loss



Communication

- Meet the individual where they are at - in understanding, communication, physically
- Use the individual's modes of communication - to share the news with them and to answer their questions and worries
- Be honest and open
- Use the real words - no euphemisms
- How does the individual communicate sadness/concern/grief?
- Verbally, nonverbally (behaviour, body language, gesture, physiologically), AAC
- Use the individual's interests
- Widgit Communicate in Print
- Social Stories
- Easy Read Documents



Listen

- Listen to what the individual's *is* and *is not* saying and doing
- Listen and watch for changes in bodily functions (sleep, eating, drinking, toileting) posture, behaviour etc.
- Make use of the power of silence
- Be honest - if you don't know the answer to a question find out for them as soon as possible
- Widgit Communicate in Print - Worry Cards



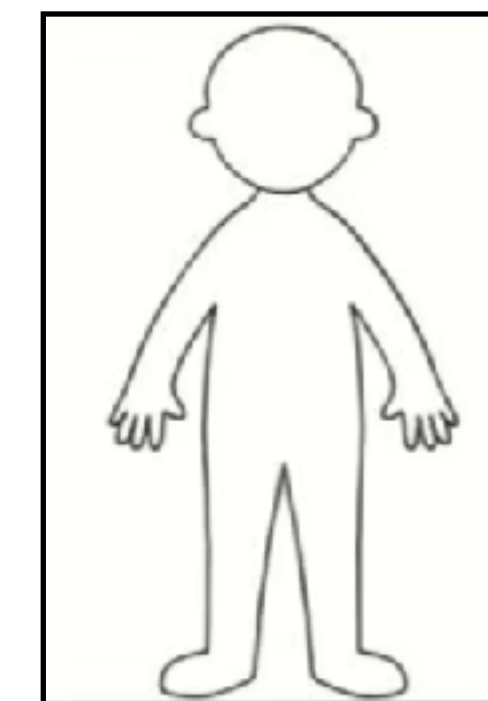
Layers

- Give layers of honest information
- Small conversations
- The need to reiterate the news and implications
- Their questions indicate what they want and need to know
- If you're unsure what they understand/know get them to tell you or show you, through play, art, AAC etc.
- I have a question about death by Gaines & Polsky
- Social stories/cartoon strips etc.
- Sensory stories



Emotional Detective

- How will I know how the individual is feeling about the loss?
- Look for signs in
 - what they say and do
 - what they don't say and do
 - body language, behaviours, stomach/headaches etc, facial expressions, creative play, artwork, use of AAC etc.
- Don't jump to conclusions and attribute changes to their diagnosis
- How I communicate grief and other feelings
- Feelings charts, body maps, comfort cards



Creativity



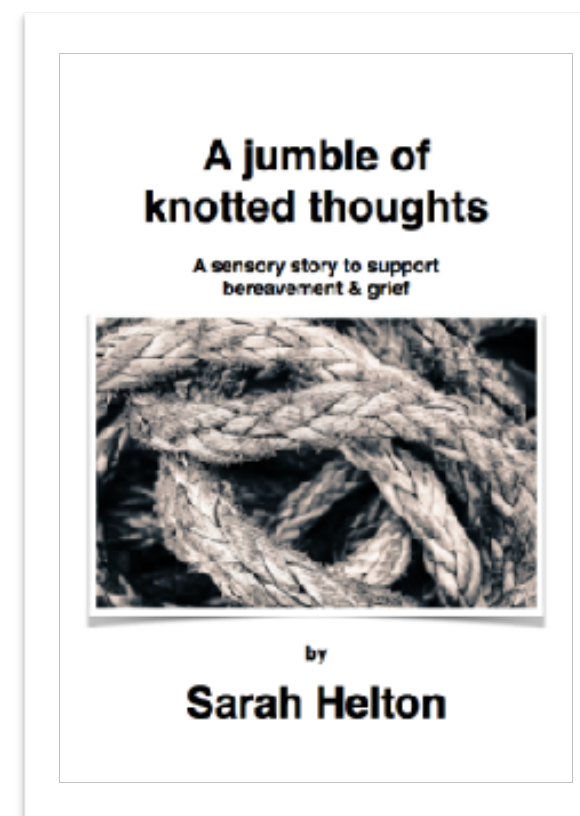
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Creativity

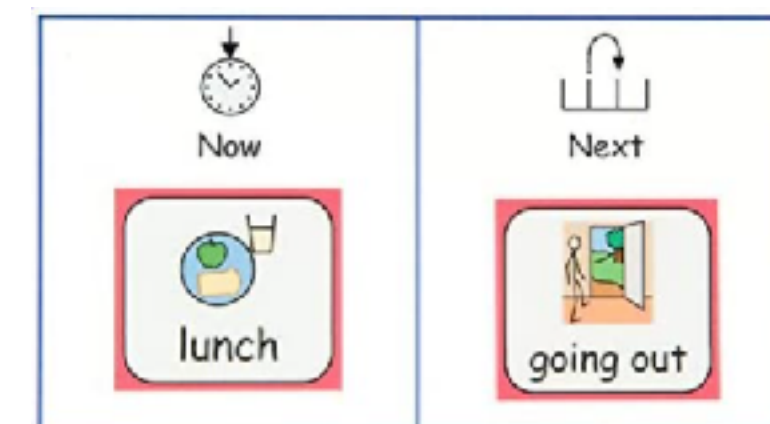
- The power of creativity, the arts, animations, videos, toys, being in nature, animals etc.
- Use creative approaches to
 - share the news
 - have conversations about what is happening
 - for the individual to process what has/is happening and rehearse/prepare for the next steps
 - express emotions
 - spend time together and create connections

- Good Grief Toys
- Arts (music, art, drama etc.) and crafts
- Creative writing (journalling, scrap books, cartoons etc.)
- Gross motor activities



Routines & Transitions

- Think about how the individual's routines will be affected?
- Minimise (as far as possible) changes to routines
- Plan and support these changes as you would other transitions
- Social stories, transition plans
- With resources and visual: symbols, pictures, photos, animations, videos etc.
- Good Grief Toys
- B-Plans/G-Plans



Autism and grief

- May struggle to see things from another person's perspective
- Could be hard for them to conceptualise death and its rituals
- Language and communication difficulties mean understanding the abstract concepts surrounding death can be complicated
- Information processing may be difficult - extrapolating things
- Difficulties with imagination and time perception
- More extreme or new preoccupations/interests due to their anxiety following the death
- Sensory difficulties - funeral etc.



What is the meaning / impact?

- ...of this particular death? (the cause)
- ...of this particular person? (relationship)
- ...at this particular time? (what else is happening?)
- ...living as part of this particular family?
- ...and as part of this particular community?
- ...on this particular person? (risk / resilience)



The Space Next To Me

by Jonathan Bryan

The Space Next to Me

Our classmate passed away last night,
We have no language for our loss,
Register's pause, curtains block light,
Our classmate passed away last night,
Adults say, "everything's alright".
Who is next? My friends look across,
Our classmate passed away last night,
We have no language for our loss.

www.eyecantalk.net



Research

- The creative use of limited language in psychotherapy by an adolescent with a severe learning disability - **Baike (2004)**
- Gray's guide to loss, learning and children with ASD - **Gray (2006)**
- Supporting students with autism spectrum disorder through grief and loss - **Hume et al., (2016)**
- Supporting children and young people with autism spectrum disorder through bereavement - **Koehler (2016)**
- The grief experiences of children with developmental disabilities. A narrative literature review - **Gaines (2022)**
- How do children/young people with severe, profound or profound and multiple learning disabilities communicate grief - **Helton (2023)**



Books/resources mentioned during the session

- Am I Allowed to Cry - Maureen Oswin
- We All Grieve - Winston's Wish
- A Special Kind of Grief - Sarah Helton *
- Remembering Lucy - Sarah Helton *
- A Jumble of Knotted Thoughts - Sarah Helton *
- Good Grief Toys[®] - Sarah Helton *
- When You Were Gone - Joanna Grace
- I Have a Question about Death - Arlen Grad Gaines and Meredith Englander Polsky
- Widgit Communicate in Bereavement - Bereavement & Loss Symbol Set - from www.widgit.com
- When Dad Died?, When Mum Died?, When Someone Died & Will I Die - all from Books Beyond Words www.booksbeyondwords.co.uk

* All available from www.backpocketteacher.co.uk



BackPocketTeacher bereavement & grief courses

- A Special Kind of Grief
- Grief & SLD/PMLD
- Using Good Grief Toys
- Policies & Procedures
- Bereavement & Grief Plans
- Developing the Curriculum
- The Losses of Life



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