Supporting bereaved children who have additional needs

BRAKE
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REBUILDING LIVES TOGETHER
What increases the vulnerability of children and young people with learning disabilities to a bereavement, compared with other children?
Children with learning disabilities

- Are often assumed to need protection from death and dying
- We can underestimate their abilities to cope with the tough things in life
- The challenge is to find creative ways to communicate, especially when words are not appropriate
Children with Learning Disabilities may need additional help with:

- Communicating the truth
- Understanding the concept of death
- Expressing their grief
- Remembering the dead person
Recent research

☀ PAMIS – Bereavement and Loss Project 2014
• Focused on support for bereaved people with PMLD
• Focus groups of professionals, parents, carers
• Interviewed 24 carers across Scotland
• Developed a learning resource pack
  – Supporting bereaved people with PMLD
  – Supporting bereaved parents and carers

http://www.pamis.org.uk/
Things that may make grieving difficult

- Not being prepared for the death
- Other types of losses
- Secondary losses
- How family and friends are coping
- Child’s ability to manage stress
- Lack of support/information available
- Those around the child being unaware of the grief, being unsure how to provide support or being reluctant to confront it

(PAMIS study 2014)
ASD and Learning Disabilities

- Between 44% - 52% of autistic people may have a learning disability.

- Between 48% - 56% of autistic people do not have a learning disability.
ASD and Learning Disabilities

Around a third of people who have learning disabilities (IQ less than 70) are also autistic, according to research published by Emerson and Baines in 2010.
Fact or Myth?

🌞 Autism affects more than 1 in 100 people?

🌞 Fact
Fact or Myth?

- People tend to 'grow out' of autism in adulthood
- **myth.** It's a lifelong condition – autistic children become autistic adults.
Fact or Myth?

BMI Some autistic people don't speak

fact. Some autistic people are non-verbal and communicate through other means.
Fact or Myth?

🌟 Autism is a mental health problem

🌟 Myth. Autism is a developmental disability. It’s a difference in how your brain works. Autistic people can have good mental health, or experience mental health problems, just like anyone else.
What is autism?

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.
What is autism

- “Triad of impairment”
  - Communication
  - Social Interaction
  - Imagination

- DSM5 - Now – 2 areas of persistent deficits in social communication/interaction across contexts, not accounted for by general developmental delay
Theory of Mind
(Baron-Cohen et al. 1993)

- Our ability to make very accurate guesses about what the people around us know, feel and believe.

- Empathy
Social communication

- Autistic people have difficulties with interpreting both verbal and non-verbal language like gestures or tone of voice. Many have a very literal understanding of language, and think people always mean exactly what they say.

- Bereavement?
Social Interaction

Autistic people often have difficulty 'reading' other people - recognising or understanding others' feelings and intentions - and expressing their own emotions. This can make it very hard for them to navigate the social world.

Bereavement?
Repetition and routine

The world can seem a very unpredictable and confusing place to autistic people, who often prefer to have a daily routine so that they know what is going to happen every day.

People on the autism spectrum may not be comfortable with the idea of change, but may be able to cope better if they can prepare for changes in advance.

Bereavement?
Explaining death

A biological approach is practical, clear, and could be presented visually. You could even use real insects or flowers to demonstrate the difference between living and dead.
Avoid euphemisms

Something simple such as "sometimes people's bodies become worn out and stop working" may be appropriate.

A sudden death leaves everyone shocked.... simple, factual explanations are best
What might help?

- Visual aids – timetables, cues, photos etc
- Identifying symbols/signs/words that might be required e.g. PECS
- Multisensory stories
- Comic strip conversations
- Clear, simple explanations
- Honesty
- Repetition
Things to consider

- Importance of acknowledging the death regardless of child’s capacity to understand it
- Allow the child the opportunity to express emotion
- Plan for change and offer choice
- Recognise and respond to distress and upset
- Complementary therapies and activities
- Importance of rituals and practices
- Preparation
Tasks of Mourning

- To accept the reality of the loss
- To process the pain of grief
- To adjust to a world without the deceased
- To find an enduring connection with the deceased in the midst of embarking on a new life

Our website

Child Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Call our helpline
0800 02 888 40

www.childbereavementuk.org
North Development Project

- Four areas of multiple deprivation
- Network, collaborate, signpost, train….
- Advisory Groups
Manchester

🌞 Clare.....

🌞 Study day

🌞 Collaboration

🌞 Wythenshawe
Recently…..

- Manchester
- York
- Chorley
- Newcastle
Memory not processed

Memory or thought suppressed or avoided

Intrusions eg. memories, images, dreams, thoughts

Original fear, horror, helplessness

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