

General Guidance on supporting children/ young people a with moderate/ severe Learning Disability who have experienced bereavement

The aim of this sheet is to provide some principles and considerations to take into account when working with or supporting a child/ YP with a learning disability who has experienced a bereavement. Every child and circumstance is different and so this guide is not aimed to tell you exactly what to do or provide a model for all. It is aimed to be used alongside your knowledge of the child to inform your approach. Family will also be a crucial central source of knowledge on circumstance and approach.

It is suggested you also speak to those within the child's network e.g. CAMHS, Speech and language therapist (SALT), Occupational therapist (OT), sensory specialist team, respite or school to inform your approach and develop a plan you can all follow. At the end there is a list of further reading and links, in case of use.

Core principles

- There is sometimes a belief that a child with a learning disability does not understand death and so does not need to be part of any rituals or processing. The child may not have a full understanding of what the concept death means but they do experience loss (for example loss of an enjoyable interaction or attention) and should be included where possible within family rituals. Where it has not been possible for the child to be at the actual event an appropriate alternative ritual should be carried out. If appropriate photos can be taken or a relevant object chosen to go into a resource (e.g. social story or memory box) that can be looked at with the person.
- Having a learning disability means that there is a delay in processing information, the degree varies and you will know best what this is from your work with the child. This means that you may not see any change in the child and then a few months or weeks later there is a change in behaviour or engagement. You do not need to wait for a change to begin any work but it is helpful to be mindful of the difference in processing time and the impact of this on presentation.
- It is also important to remember grief is not a one off experience, you grieve over time and adjust and some times it may be more difficult than others. Children with a learning disability are no different in this respect.
- Use the language and format that the child knows, this is most accessible to them. If you are unsure check the child's last SALT report or school review which is likely to say what communication system they use and at what level. If there is a SALT who knows this child they are often best suited to advise on the format of information.
- For some children it can be helpful to think about what they will miss and what that person represented to them in consideration of appropriate explanation.
- Consider the use of symbolic acts to help the person understand. For example, waving goodbye to picture, blowing out candle or remembrance activities.
- Be honest about what has happened and when.
- Be prepared to answer questions.
- Death is a really hard word to say which is why we tend to use phrases like passing away, gone to heaven etc. But these phrases are extremely confusing for children with a

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learning disability (and Autism). Please only use concrete terms or you may find a child trying to find a way to heaven so they can see X again.

- Explain what death means and that they are not coming back even though they want to e.g. death is when the body stops working, you cannot eat or drink and be clear this does not mean they are dying.
- Be aware of how you are feeling and what support you need. Death is a sensitive topic and if you feel you are not able at this time to support the child with direct work please speak to your supervisor or employer as your self-care is important. But also be reassured by the point below that just by being with that person, being consistent and routine you are helping.
- Know the child's cultural/ religious background and what death means in their home and what traditions they follow.
- All children will respond differently but for those with a learning disability which heavily impacts their communication this is more likely to be expressed through their body language, behaviour and engagement. It is important now more than ever to see behaviour as a communication.
- For those with more severe/ profound learning disability evidence strongly suggests the importance of support for the primary care giver in processing their loss. The child may actually be responding to the change they are noticing in their parent/ carer, perhaps acting in a different way or being less available. Try to find out how the care givers are and if they need support, if they do you could direct to national services such as Cruse or local services which can be found through their GP or the harrowlocaloffer.co.uk.
- Consistency across environments is really important. It is important that the wording and approach used is the same for the child across their environments. You will need to work together over time to give this same message.
- Consider the need to work with the child to build their understanding of their emotions, helping them with a vocabulary (picture/ object, etc.) and what helps them when they feel each. Whilst being aware the more impacted they are by their disability the less likely they will be able to recognize by themselves and it may only be through external aids, consistent support and direction they will develop an ability to regulate. If the child is known to Occupational Therapy they may be able to advise on strategies to aid regulation of arousal levels.
- For overall wellbeing we know regular exercise helps expel energy and promote positive emotional wellbeing. In addition to a good sleep routine and diet.
- **Routine, consistency and being understood are some of the most valuable elements of support.** Don't feel you have to have made an elaborate resource or you have not helped. By being there consistently, providing routine and understanding that person helps them to process and manage emotions.
- **Not everyone will need additional support, for some with the above they will process and grieve over time. For those where there is continued and prolonged emotional anguish seek specialist support.**

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Ways to help the child process and make sense of the loss

There are many different ways to help a child process and below are some suggestions for you to consider. Whatever tool you choose, repetition is key, at a time and space that is most appropriate for the child and that this same message is given across environments. Adapt the resource format to what is best to meets the needs of the child.

- Social story using meaningful pictures, objects or sensory items; a social story aims to help a person understand a situation. They were developed by Carol Gray and her website has examples of stories <https://carolgraysocialstories.com/social-stories/what-is-it/> or a basic introduction can be found on <https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>. Please note they do not need to be complex, they just need to be make sense and be meaningful for the child.
- Multi-sensory story. This involves using objects to touch, look at and listen to; things to smell and even to taste to explain the experience/ story. Further information <http://bagbooks.org/>.
- Life story book using materials as suited to that child, photos of person, objects, and picture communication systems. These aim to help a child/ young person make sense and develop a coherent narrative of the experience, it is often when something does not follow what we expected or make sense it can cause confusion and emotional distress. A life story book aims to help a person process the event through placing it in context within a timeframe. They should be made suited to the child and the child be an active part in making the book. It is helpful if there is a brief guide on key events and wording to be used so that all offer a consistent message and approach.
- Memory box. Make a box with the child/ young person with meaningful objects that you can explore together and give the same consistent message each time. It is often helpful to have a prompt sheet in the box so all give the same message and use the same language.
- Hold a celebration of the person's life. Take photos and make into a story/ resource that can be read through or looked at/ touched/ heard by the child.
- Some more creative ideas
 - Making a playlist of songs
 - Making a song together
 - Memory garden
 - Making items out of a few pieces of the persons clothes
 - Looking through photo albums together

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Resources and links

Multisensory stories:

- PAMIS (2014) *Bereavement and loss: supporting bereaved people with profound and multiple learning disabilities and their parents. Learning resource pack.* www.pamis.org.uk
- Young, H. & Lambe, L. (2011) Multi-sensory storytelling: for people with profound and multiple learning disabilities. *PMLD Link sharing ideas and information. Speaking up - being heard* Vol 23 (1), pp29-31.
- Young, H., Fenwick, M., Lambe, L. & Hogg, J. (2011) Multi-sensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues: a multiple research methods analysis of engagement and outcomes. *European Journal of Special Needs Education* 26(2), pp127-142.

Memory boxes:

- Young, H. & Garrard, B. (2015) Bereavement and loss: developing a memory box to support a young woman with profound learning disabilities. *British Journal of Learning disabilities* 44, pp78-84.

Bereavement charities/ voluntary agencies

- Child Bereavement UK- www.childbereavementuk.org 0800 028 8840
- Winston's Wish www.winstonswish.org/coronavirus 0808 802 0021
- National Autistic Society- <https://www.autism.org.uk/about/family-life/bereavement.aspx>
- MENCAP, 0808 808 1111 <https://www.mencap.org.uk/advice-and-support/dealing-bereavement>
- Care www.bereavementcareandsupport.co.uk 0208 427 5720

Books and Brief Resources

- Books Beyond words <https://booksbeyondwords.co.uk/search?q=bereavement>
- Guides for carers
 - <https://www.leedsth.nhs.uk/assets/1d6a79f573/Easy-health-SUPPORTING-PEOPLE-WITH-DISABILITIES-COPING-WITH-GRIEF-AND-LOSS.pdf>
 - <https://www.essexice.co.uk/media/46502/beareavement.pdf>
 - <http://www.cwp.nhs.uk/media/3508/bereavement-and-learning-disabilities-a-guide-for-carers-master.pdf>
- 'When someone dies' Easy read by Northern Health and Social Care Trust – clear with pictures, explaining death, what it means and possible feelings and who to speak to. <http://www.hscbereavementnetwork.hscni.net/wp-content/uploads/2015/05/96885-NHSC-Client-Booklet-2016.pdf>
- SCOPE supporting people with a learning disability who have faced bereavement or loss: <https://www.easyhealth.org.uk/wp-content/uploads/2020/02/SUPPORTING-PEOPLE-WITH-DISABILITIES-COPING-WITH-GRIEF-AND-LOSS.pdf>

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