



**University of Dundee**

## **Conceptualising bereavement in profound and multiple learning disabilities**

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*Table 1. Theoretical contributions to the understanding of bereavement and loss in people with learning disabilities*

<i>Author(s)</i>	<i>Aim/purpose</i>	<i>Driven or explained by</i>	<i>Applications/conclusions</i>
McLoughlin (1987)	To describe the grief reactions of a woman with LD.	Lindemann (1944) and Parkes (1964), in which typical mourning is described.	No applications offered. Further research is needed.
Oswin (1991)	Describe difficulties faced by bereaved people with LD.	Parkes' (1972) bereavement studies; normalisation (Wolfensberger, 1972).	Training for staff on grieving process, appropriate organisation of services for supporting emotional wellbeing, minimising disruption, support participation in funerals.
Harper <i>et al</i> (1993)	Describe grief reactions.	Bowlby's attachment theory (1980); Piaget's (1954) cognitive theory of development.	Identify concerns of the bereaved individual, anticipatory training programmes on death education and coping strategies, support for family and staff.

Elliot (1996)	Describe a practical approach to helping people grieve.	Social model of disability (Makin, 1995); Heron's (1989) facilitation model of grief	Overcome barriers in social model of disability. For those experiencing uncomplicated grief, the facilitator should set goals and a plan of action for bereavement work; support the person to make meaning from the loss, focus on the reality of loss and explore emotion (may be supported by resource materials).
Luchterhand <i>et al</i> (1998)	Provide guidance on supporting people with LD to grieve and recover from loss.	Worden's (1982) four tasks of grieving.	Over 100 suggestions for supporting engagement with Worden's tasks of grief.
Stoddart <i>et al</i> (1999)	Present a model for individual assessment, intervention and group work.	Offer a systems-based model described in applications/conclusions.	Education, encouraging independence, participation in rituals and increasing support and interaction.
Blackman (2002)	Describe a therapeutic approach.	Offers the 'Resource for Opportunities' approach, described in applications/conclusions.	Bereavement therapy for the individual. Training and support for staff and their own issues around loss.

<p>Conboy-Hill (2002)</p>	<p>Discuss experience of grief and loss.</p>	<p>Cognitive psychology essays in bereavement (Kübler-Ross, 1981; Hinton, 1967; Parkes, 1972), counselling techniques (Murgatoyd, 1985) and grief therapy (Worden, 1983).</p>	<p>Level of understanding is critical for identifying type of support. Workshops for carers on impact of loss, reflection on practice and active listening.</p>
<p>Stoddart <i>et al</i> (2002)</p>	<p>Evaluate bereavement groups.</p>	<p>Worden's (1982) four tasks of grief; complicated grieving; systems based model (Stoddart <i>et al.</i>, 1999).</p>	<p>Bereavement group work.</p>
<p>Blackman (2003)</p>	<p>Describe the effects of bereavement and loss.</p>	<p>Provides an extensive review of models and approaches.</p>	<p>Support the person to develop relationships out-with family. Provide group education to people with LD, and training and support to professionals and family carers. Policies should reflect bereavement issues.</p>

<p>Clegg <i>et al</i> (2003)</p>	<p>Focus on conceptual approaches underpinning clinical intervention.</p>	<p>Although not a central focus, social constructionism (Danziger, 1997) makes sense of how bereavement and LD discourse has become ‘stuck’ on dated dogmatic assertions regarding intervention (e.g. attending funerals).</p>	<p>Explore individual understanding, how the family grieves and what aspects of this the individual wants to adopt. Support an evolving representation of the deceased. Avoid dependence on simplistic off-the-shelf interventions. Enable staff to support themselves, their clients and families in all emotional work.</p>
<p>Dowling <i>et al</i> (2003)</p>	<p>Pilot two interventions.</p>	<p>Worden’s (1991) four tasks of grieving; Stroebe &amp; Schut’s (1999) dual process model.</p>	<p>External support: training to cover bereavement in LD, practicalities and skills working with bereaved. Integrated support: training to encourage staff to consider and support loss-orientated and restoration-orientated tasks of grief.</p>
<p>Read <i>et al</i> (2003)</p>	<p>Explore issues from the perspective of people with LD, and consider proactive ways of supporting.</p>	<p>Offers the vulnerability perspective.</p>	<p>Advocate for ‘minimising effects’ of bereavement through assessment and planning.</p>

<p>Summers <i>et al</i> (2003)</p>	<p>To make sense of the grief reactions of a woman with LD.</p>	<p>Klein (1940); Bowlby (1981); Freud, (1957); Parkes (1996).</p>	<p>Psycho-educational and psychodynamic approaches.</p>
<p>Clements <i>et al</i> (2004)</p>	<p>Explore factors underlying bereavement, loss and grief.</p>	<p>Moddia and Chung's (1995) six factors; ego strength, age, degree of dependency, emotional closeness, circumstances of the death and capacity to cope with anxiety and stress.</p>	<p>Staff to support development of: therapeutic relationships, concrete goal-setting and methods of reducing stress. Desired outcome is adaptation and "functioning grieving".</p>
<p>Crane (2005)</p>	<p>Consider bereavement and loss for pupils with severe and complex LD, and develop school guidance.</p>	<p>Brown's (1999) phases of grief. A developmental approach to understanding death was also offered, described in applications/conclusions.</p>	<p>School guidance reflects that post-bereavement behavioural changes are normal. Pupils should be provided with opportunities to express emotion. Schools should develop bereavement policies that support death education and working through grief.</p>

<p>Meeusen-van de Kerkof <i>et al</i> (2006)</p>	<p>Provide a framework for understanding perceptions of death in varying levels of LD.</p>	<p>Piaget's (1954) cognitive development theory; Dosen's (2005) socio-emotional development; Timmers-Huigen's (1998) order of experience; Fowler's (1981) stages of faith.</p>	<p>Applications dependant on intellectual level. For example, people with PMLD require closeness, fixed patterns, concrete experiences. People with mild LD require closeness, conversations around the death, remembering, rituals and participation in mourning rituals.</p>
<p>Read <i>et al</i> (2007)</p>	<p>Describe life story work with a woman with LD.</p>	<p>Doka's (2002) disenfranchised grief.</p>	<p>Using life story work and narratives to provide constructive help in guiding the individual through emotions.</p>
<p>Read <i>et al</i> (2007)</p>	<p>Focus on bereavement needs and explore support in practical terms.</p>	<p>Offered a continuum of bereavement support model, integrated with a systems approach.</p>	<p>Education, participation, facilitation and intervention, at micro, seco, exo and macro levels.</p>
<p>Blackman (2008)</p>	<p>Describe a developing tool for assessing bereavement needs.</p>	<p>Le Poidevin's (Payne <i>et al.</i>, 1999) seven dimensions of loss; Shuchter <i>et al</i>'s (1993) six dimensions of loss; Klass <i>et al</i>'s (1996) continuing bonds.</p>	<p>Use the tool for assessing grief responses, support around the individual and to explore the meaning that the individual attributes to the loss. This tool can be used to facilitate discussion and understanding among carers.</p>

Dodd <i>et al</i> (2009)	Present and synthesise research on grief, with relevance to general population.	Complicated grieving (e.g. Prigerson <i>et al</i> , 1999).	Further research on nature of grief is required to devise resources.
Grey (2010)	Examine difficulties faced, stages of loss and factors when assessing risk of complicated grieving.	Stages of loss (Kübler-Ross, 1970).	Assessing risk, support understanding of bereavement and loss, therapeutic tasks, work with families, supervision for bereavement supporter.
Blackman (2011)	Establish a review of internal and external factors affecting the bereavement process.	Bowlby (1973) theory of attachment; a model of psychodynamic psychotherapy	Reduce external factors complicating grieving, develop staff confidence to facilitate expression of grief in people with LD, training on grief reactions and national policy developments to reflect these needs.
Sormanti <i>et al</i> (2011)	Describe losses that are particularly difficult, expected grief responses, issues with coping and intervention guidelines to establish healthy grieving.	Worden's (1982) four tasks of grieving; challenges versus suggested strategies framework.	Facilitate understanding of death and dying, support management of external and internal emotional impact, help maintain relationships.



Barber (2012)	Explore meaning of death, dying and bereavement for people with LD.	Kübler-Ross' (1969) five stages of bereavement.	Guidance on supporting each stage of bereavement.
McEvoy <i>et al</i> (2012)	Investigate understanding of death and perceptions of bereavement.	Piaget's (1960) cognitive development framework.	Sensitivity to individual theories of death. Biological explanations are only one way in which to develop a concept of death.
Schuengel <i>et al</i> (2013)	Review attachment research in LD field and implications for clinical practice.	Attachment theory (Bowlby, 1984)	Integrative therapy for attachment and behaviour, supporting affect regulation through established therapeutic relationships
Dodd <i>et al</i> (2014)	Explore complicated grief in relation to people with LD.	Complicated grieving; Prigerson <i>et al</i> 's (1999) traumatic grief; Bowlby's (1960) attachment theory.	Staff training on bereavement. Research on interventions is required.
Young <i>et al</i> (2014b)	Describe grief reactions of people with PMLD and offer suggestions of support.	Worden's (2008) four tasks of grieving.	Support overcoming barriers to grief through the use of multi-sensory methods and alternative communication.

Young <i>et al</i> (2015)	Describe memory box work with a young woman with PMLD.	Worden's (2008) four tasks of grieving.	Multi-sensory methods can be used to help explore bereavement and loss.
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*Table 2. Reported grief reactions in people with profound and multiple learning disabilities*

<i>Author(s)</i>	<i>Experience(s)</i>	<i>Method and reported reaction(s)</i>
Meeusen-van de Kerkhof et al (2006)	Bereavement	Reference to research: show no reaction through crying or mourning, looking for deceased, putting up resistance and aggressive behaviour.
Oswin (1985)	Bereavement	Based on accounts from parents: losing some abilities, insecure attachment behaviours and challenging behaviour.
Oswin (1989)	Mother and father died	Case study: loss of appetite.
Phillip et al (2005)	Death of Father	Case 1: young man. Changed from positive affect to withdrawal. At funeral his head was bowed down, tears in his eyes, very quiet when home and bid for affection and reassurance.

	<p>Death of Grandfather</p> <p>Death of Father</p> <p>Death of Grandmother</p>	<p>Case 2: young man. Continued to look at the chair where his grandfather would sit.</p> <p>Case 3: young man. Withdrew with head down, decreased appetite, challenging behaviour during the night, increased sleeping during the day. Vomiting and increased seizures. Increased sleeping. Returned to 'normal' self after four years.</p> <p>Case 4: young woman. Unresponsive and physically unwell for several months.</p>
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<p>Sinason (1992)</p>	<p>Staff member left residential centre</p>	<p>Case 1: Male, head banding.</p> <p>Case 2: Female, abandoned by her mother at the age of one. Biting and feeding on herself.</p> <p>Case 3: Female, sexually abused by her parents. Smears food on herself.</p> <p>Case 4: Female, abandoned by parents at age five. Eye-poking, gouging her hands and arms, continuous weeping, worse around Christmas (when she was abandoned).</p>
<p>Tuffrey-Wijne (2013)</p>	<p>Death of Father and later her Mother</p>	<p>Case study: woman. Responded with excitement when staff explained about the death. When taken to see her father in his coffin, she became quiet and made it clear she wanted to leave. Surprise when visiting family home and her father's chair was</p>

		empty. She tried to search for him by moving her wheelchair. After weeks, she became withdrawn for one year before returning to her normal self. When her mother died, she exhibited the same responses.
Young et al (2014a)	Bereavement	Interviews with carers: crying, withdrawal, loss of appetite and challenging behaviour.
Young et al (2014b)	Bereavement	Interviews with carers and a review of literature: insecure attachment behaviour, increased crying, withdrawal, changes in appetite, self injury, challenging behaviour, changes in sleeping, searching for absent person.
Young et al (2015)	Death of Brother	Case study: young woman. Calling her brother's name during the night and crying.