

Supporting bereaved children and young people with special educational needs: selected references

BARNES, J. and others (1998)

Communication about parental illness with children who have learning disabilities and behavioural problems: three case studies. **Child: Care, Health and Development**, vol.24, no.6 (Nov), pp441-456. (Reports on three cases where the mother had breast cancer and one child in the family had a disability. The extent and specific characteristics of their communication about the maternal illness with their children, behavioural changes in the children, explanations of communication strategies and attributions of behavioural changes are described. Implications for possible clinical interventions are proposed based on what children might understand; ways in which to communicate effectively; strategies for coping with long-term implications of serious parental illness)

BELTRAN-DEL OLMO, M. (2005)

Frankie finds tears for his father. **The Autism Perspective**, vol.2, no.1, pp50-51. (A mother's account of her son's bereavement following the death of his father).

BRICKELL, C. and MUNIR, K. (2008)

Grief and its complications in individuals with intellectual disability. **Harvard Review of Psychiatry**, vol.16, no.1, pp1-12. (Bereavement and loss have significant impact on the lives of individuals with intellectual disability (ID). Although there is a growing impetus to define the symptoms of grief that predict long-term functional impairment, little is known about maladaptive grieving among individuals with ID. We examine the literature concerning the phenomenology of traumatic grief (TG) in the general population, along with what is known about the manifestations of grief in individuals with ID. We then apply modern theories of grief and grief resolution to individuals with ID in order to highlight potential areas of vulnerability in this population and to lay the groundwork for interventions that will facilitate their adaptation to loss. We provide a theoretical framework for the proposition that individuals (including children and adults) with ID are more susceptible to TG, based on an increased risk of secondary loss, barriers to communicating about the loss, and difficulty finding meaning in the loss. We conclude that individuals with ID should be considered as potential candidates for targeted bereavement interventions. Further research is required, however, in order to develop population-appropriate measurement scales for testing these hypotheses).

DENES S. and LAVIN C. (2008)

When a loved one dies: communicating loss to people with autism. **Autism Advocate**, vol.51, no.2, pp26-28, 30. (A parent describes how she told her son with autism about the deaths of close family members over the years. In the rest of the article a psychologist gives strategies to help people with developmental disabilities cope with the grieving process following a bereavement).

ELLIOT, D. (2009)

Autism and bereavement: support for all ages: a carers guide. Sheffield Hallam University. (Outlines the impact of bereavement on a person with autism. The booklet focuses on concepts such as attachment, loss and grief and their meaning for a person with autism. Assessing the bereavement needs of a person with autism is emphasised, and a bereavement assessment tool is included, to facilitate this process. The author draws on his own experience to offer support to a bereaved person with autism. Ways to offer support to carers are also suggested. The booklet includes: how people with autism make sense of and cope with their bereavement; details an assessment tool which can be used to assess their bereavement needs; gives advice on how to support bereaved people with autism; and identifies resources which can be used with bereaved people with autism). ISBN: 1905282192

EVERETT, A. and GALE, I. (2004)

Children with learning disabilities and bereavement: a review of the literature and its implications. **Educational and Child Psychology**, vol.21, no.3, pp30-40.

(Bereavement and loss are common experiences. Two groups frequently neglected at such times are children and people with learning disabilities. This paper considers those falling in both these groups – children with learning disabilities. There is little direct evidence on how to help children with learning disabilities with grief. A brief review of the literature on bereavement in children is followed by a consideration of what this means for people with learning disabilities. Emphasis is placed on the behavioural indicators that a child is not coping; preparing a child for loss; and supporting a child with learning difficulties to cope with grief).

FORRESTER-JONES, R. and BROADHURST, S. (2007)

Autism and loss. London: Jessica Kingsley. 207pp. (Aims to provide carers with knowledge, skills and appropriate resources to enable them to offer effective support to people with autism experiencing bereavement. Includes photocopiable factsheets and practical tools). ISBN 9781843104339

GRAY, C. (2003)

Gray's guide to loss, learning, and children with ASD. **Jenison Autism Journal**, vol.15, no.1, pp2-42. (This article explores the support a parent or professional can give a child with Autistic Spectrum Disorder in coming to terms with and learning from loss of every kind, from day to day losses, to "larger" unplanned losses such as critical illness or death).

HAWTON, K. and SIMKIN, S. (2008)

Help is at hand: a resource for people bereaved by suicide and other sudden, traumatic death. London: Department of Health. 45pp. (Guide for people affected by suicide or other sudden, traumatic death. Describes the different procedures that could take place after a death and offers practical suggestions for dealing with them. Highlights the specific issues that arise for particular people, such as parents, children and people with a learning disability. Looks at how friends and colleagues can help, and how healthcare and other professionals can offer support). **Document Link:**

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_087031

HOLLINS, S., and SIRELING, L. (2004)

When mum died. London: Gaskell, 28pp. (Includes information on how people are likely to react when someone is very ill and to their death. It explores difficult emotions, possible physical feelings and behaviour changes. Guidance is given on how to relate to a bereaved person and how to answer the questions 'How do we feel when someone dies?', 'What happens after someone dies?' and 'How long does it take to get back to normal?'. There is advice for support staff and carers of those with learning disabilities (including how to formulate guidelines and a sample bereavement questionnaire), plus information on useful written resources and bereavement organisations that can offer further help). ISBN: 9781851830206

MALLON, B. (2010)

Understanding death: mental health issues in vulnerable children – AHHD, autism and children with special educational needs. *In: Mallon, B. Working with bereaved children and young people.* pp49-59. London: Sage. ISBN: 9781849203715

MARKELL, M.A. (2005)

Helping people with developmental disabilities mourn: practical rituals for caregivers. Independent Publishers Group. (Frequently, people with developmental disabilities are excluded from bereavement ceremonies when a loved one or friend dies, therefore not receiving the special care needed for comprehending their own feelings of loss. Focusing on creating mourning rituals for special needs people, this guide offers specific rituals and techniques for caregivers to use while helping explain death and dying. With more than 20 examples such as the use of pictures and storytelling or drawing and music, these practical tools can substantially lend to the understanding of grief and sadness for intellectually and developmentally disabled adults and adolescents).

ISBN: 978187965146

Buy here: <http://www.docstoc.com/docs/36426628/Helping-People-with-Developmental-Disabilities-Mourn>

MARKELL, M.A. and HOOVER, J.H. (2010)

Children with developmental disabilities, death, and grief. *In: Corr, C.A. and Balk, D.E. (Eds). Children's encounters with death, bereavement, and coping.* pp395-412. New York: Springer Publishing. (Although physical, emotional, and learning disabilities (e.g., in reading) certainly challenge individuals and families in their ability to deal with bereavement, it is cognitive impairment that most directly and severely affects the grief process. In this chapter, we explore the connections between issues surrounding death and dying on the one hand and developmental disabilities on the other. Our primary goal is to provide a resource that will support parents and caregivers as they help persons with developmental disabilities understand bereavement and mourn adaptively (Hunter & Smith, 2008). We begin by laying out the overall characteristics of developmental disabilities (DD) before turning to a description of how characteristics in DD likely intersect with end-of-life issues. An important consideration in dealing with the grieving process is the many transitions experienced by children and adolescents with cognitive disabilities. It does not always occur to caregivers that grieving may be invoked by movement from home to a group home or the loss of a favorite care worker through normal job attrition. A third section of this chapter deals specifically with Doka's (1989, 2002) concept of disenfranchised grief, certainly a significant issue for persons with developmental disabilities, their parents, and their care providers (Hoover, Markell, & Wagner, 2005). In this section, we address complex grief and factors producing difficulties in adjustment to the death of a loved one (or to disruptive change), including, most importantly, disenfranchised grief. Disenfranchised grief refers to situations where individuals' ability to grieve is curtailed by social factors (e.g., age, status as disabled), often with resultant wellness difficulties; in essence, the term disenfranchised grief is employed in reference to situations where directly or indirectly a person is not allowed to grieve effectively. Persons with developmental disabilities die at earlier ages than do age-matched individuals who do not manifest such disabilities (Doka, 2002). With this mortality issue in mind, a fourth section of the chapter deals with parental grief over the death of a child with disabilities, perhaps best conceptualized as a specific subset of disenfranchised grief. Finally, we examine programs and treatment modalities of two types. First, we attend to death education programs and practices in general that have a track record of effectiveness with children who are developmentally disabled. Steps to facilitate the grieving process are also addressed. ISBN: 9780826134226

MONROE, B. and KRAUS, F. (eds) (2009)

Brief interventions with bereaved children. 2nd ed. Oxford: Oxford University Press. 264pp. (This updated edition contains new chapters on support for very young children and for those with learning difficulties. It looks at different approaches to intervention including the use of new technologies, the importance of assessment, the value of

group work, work with children and families before a death, and appropriate responses to traumatic loss). ISBN: 9780199561643

PENTLAND, C. and DRUCE, C. (2007)

Hand-in-hand: supporting children and young people who have a learning difficulty through the experience of bereavement: a resource pack for professionals. Produced by SeeSaw, Grief Support for the Young in Oxfordshire. (SeeSaw, Bush House, Merewood Avenue, Headington, Oxford OX3 8EF). (Supporting bereaved children with learning difficulties presents particular challenges. Communication is often the main difficulty and relying on verbal communication alone when supporting bereaved children with learning disabilities is extremely limiting. So different ways to reach each individual child must be found. Prout & Strohmmer (1994), suggest that when working with people with learning disabilities there are two specific tasks to be considered: 1. Providing the client with a language or way to communicate thoughts, feelings and concerns. 2. Providing avenues and activities to encourage expression. This pack aims to try to address these challenges).

Document Link: http://www.seesaw.org.uk/files/SeeSaw_handinhand.pdf

ROBINSON, P. (2009)

When times are sad: helping a child with ASD manage grief. **Autism Asperger's Digest**, (Mar/Apr), pp15-17. (Outlines why children with autism may not show their grief in expected ways, and gives strategies and advice for supporting them).

SMITH, S.C. and PENNELLS, M. (1995)

Interventions with bereaved children. London: Jessica Kingsley, 352pp. (Looks at every aspect of working with bereaved children. Contains sections on: individual work; family work; groupwork; and specific client groups (including children with learning difficulties and children and families affected by AIDS/HIV). Includes chapters on: transcultural counselling; managing a tragedy in a secondary school; play therapy; direct work with siblings of children dying from cancer; drama therapy; and art therapy). ISBN: 9781853022852

SORMANTI, M., and BALLAN, M.S. (2011)

Strengthening grief support for children with developmental disabilities. **School Psychology International**, vol.32, no.2 (Apr), pp179-193. (Although a sizable literature investigates and describes children's grief, the majority of information focuses on typically developing children. Far less has been published about the loss and grief of children with developmental disabilities (DD), even though this population experiences significant and multiple losses, increasing their vulnerability to negative outcomes. Addressing this gap in scholarship, this article explicates common losses and important grief-related challenges experienced by children with DD. An overview of practice guidelines is provided to enhance the efforts of school-based mental health professionals in supporting this vulnerable population).

TRUEBLOOD, S. (2009)

The grief process in children with cognitive/intellectual disabilities: developing steps toward a better understanding. Wisconsin School Of Professional Psychology, Inc. 87pp., 3348804. (This paper addresses the needs of grieving children who have cognitive and intellectual disabilities. Due to limited empirical research and clinical information regarding this topic, it was necessary to utilize knowledge in the areas of children and grief, cognitive and intellectual disabilities, and grieving adults with cognitive and intellectual disabilities. As no written materials specifically designed for caregivers of grieving children with cognitive and intellectual disabilities could be located, this paper utilizes the knowledge obtained from an extensive literature review to develop a handbook for caregivers. The handbook consists of the following: a definition of cognitive/intellectual disability, reasons for learning about and telling the truth about death, how to tell the child about a death and relating the death to spirituality, informing

the child about and including the child in funeral/memorial services, typical grief reactions, activities for grieving children, and suggested literature and resources for caregivers).

Document Link: <http://gradworks.umi.com/33/48/3348804.html>

ULLIANA, L. (1998)

Bereavement and children with autistic spectrum disorder. **Keynotes (Newsletter of the Autistic Association of NSW, Australia)**, (Jun), pp4-6. (An article exploring how to help children with autistic spectrum disorder cope with bereavement).

WISOCKI P. A. (2006)

The experience of bereavement for those with developmental disabilities. *In: Baron M.G. et al (eds.) Stress and coping in autism.* pp371-387. New York: Oxford University Press. (Looks at the grief process for adults and children with developmental disabilities).

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