

Supporting children and families facing the death of a parent: part 1

Catriona Kennedy, Rosemary McIntyre, Allison Worth, Rhona Hogg

Abstract

Aim: To present findings from a review of key literature and from a scoping of current provision of support for children facing the death of a parent. A summary of the findings from these is reported here.

Methods: To set out the background and context to the evaluation of a new service aimed at supporting children and families facing the loss of a parent from cancer, key literature was reviewed and a scoping of current bereavement support for children and families was conducted using online searching, telephone and face-to-face communications.

Findings: The review processes uncovered a range of national and local bereavement services. Bereavement was reported as a normal life event and part of human experience. Health, education and social services personnel need to respond to individual needs, accepting that not all bereaved children require complex, long-term interventions.

Conclusions: At national and global levels there was recognition that the needs of bereaved children require careful assessment. A complex range of initiatives have been developed across the UK aimed at supporting children facing the death of a family member. The fragmented nature of provision makes it difficult to be comprehensive or all-inclusive when describing service provision in this area.

Due to the innovative nature of the service, and the short-term funding arrangements, MCS funded an external independent evaluation of the service. A research advisory group supported this. The evaluation was funded from October 2005 until January 2007, so the evaluation findings can only report on a finite phase in the development and delivery of the new service.

The research was conducted using a qualitative pre- and post-intervention evaluation design and case study methods. These are fully reported together with the evaluation findings and recommendations in the second part of the article, due to be published in a future issue of *IJPN*. This evaluation approach allowed the unique perspectives of users and stakeholders to be accessed before and after exposure to the service. To capture the context, an important part of the research design was to establish current knowledge and provision. To this end, key literature was reviewed and a scoping of current availability of bereavement support was conducted using online searching, telephone contact and face-to-face communications. This process uncovered a range of national and local services for bereavement and a summary of the findings from this is reported here.

Background

The death of a parent during childhood can represent one of the most profound losses to be experienced in life. Ribbens McCarthy and Jessop (2005) confirm that the death of a parent before the age of 16 is not as uncommon as might be supposed. Estimates suggest that every day in the UK, 15 children are bereaved of a parent before the age of 16, and around 4–7% of children will lose a father or mother. These authors also assert that bereavement can place children at increased

This is the first of two papers reporting a qualitative evaluation of a new service established in Scotland to support children and families facing the loss of a parent from cancer. The Children and Family Support Service (CFSS) was introduced in 2005 in a relatively small region in Scotland with a population of around 350 000. It developed from the existing bereavement service in recognition of the particular needs of children and young people facing the death of a parent from cancer. The service provides support, advice and counselling to parents, children, young people and other family members affected by a parent's terminal illness and death from cancer. Initially, the service was funded for two years by Macmillan Cancer Support (MCS), a major UK cancer charity.

Catriona Kennedy is Reader, School of Nursing, Midwifery and Social Care, Napier University, Edinburgh; Rosemary McIntyre is Research/Education Consultant; Allison Worth is Research Fellow, Division of Community Health Sciences, General Practice Section, The University of Edinburgh; Rhona Hogg is Research Lead/Facilitator for Community Nursing, NHS Lothian, Royal Infirmary of Edinburgh, UK

Correspondence to:
Catriona Kennedy
Email: c.kennedy@napier.ac.uk

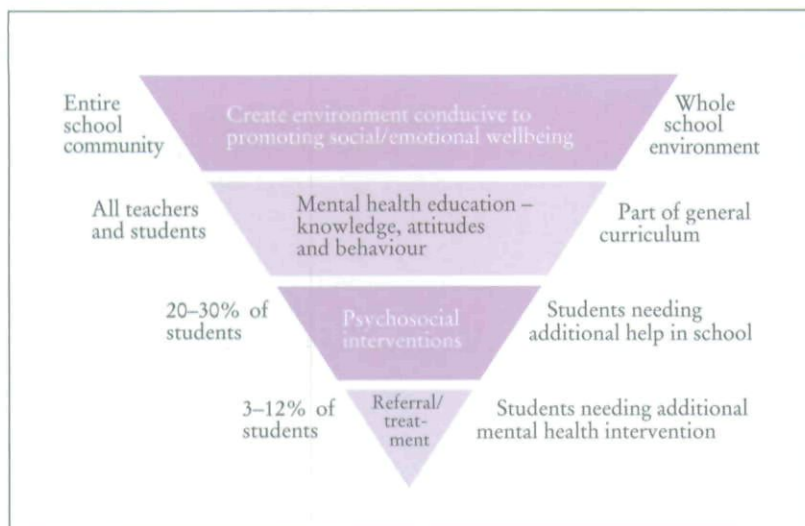


Figure 1. WHO framework for mental health promotion

risk of negative outcomes in later life and that these harmful effects are magnified in children who are already vulnerable or disadvantaged (Ribbens McCarthy and Jessop, 2005). Despite the magnitude of need that these figures might suggest, it has been found that within the UK, provision of support for bereaved children remains patchy and unco-ordinated (Rolls, 2005).

In 2005, the Scottish Executive commissioned a comprehensive literature review on bereavement care and support (Wimpenny et al, 2006). Informed by the findings from this review, and outputs from a bereavement seminar involving key stakeholders, a steering group is taking this work forward. Recommendations that will shape future policy for care and support for those bereaved from any cause and inclusive of age, gender, culture, language and disability are awaited. *Delivering for Health* (Scottish Executive, 2005) focuses on providing locally accessible integrated services characterised by cross-agency and multidisciplinary working. This reflects the context within which bereavement support might best be offered.

UK government policy has declared five key areas of commitment which are to help all children and young people to 'be healthy', 'stay safe', 'enjoy and achieve', 'make a positive contribution' and 'achieve economic wellbeing' (Department for Children, Schools and Families (DCSF), 2006). In response to this policy, schools must now identify and support any child or young person whose learning may be com-

promised for whatever reason, including bereavement (DCSF, 2004a; 2004b). The Childhood Bereavement Network (CBN) used the five key areas of government commitment set out above to contextualise and highlight the needs of bereaved children (Childhood Bereavement Network, 2004). The CBN is a national co-ordinating body that works with over 70 organisations and individuals who support bereaved children.

The impact of bereavement in childhood, and the potential negative mental health consequences for children and young people, are embedded within the World Health Organization (WHO) Framework for Mental Health Promotion in Schools. The WHO Framework advocates a preventive, community-based approach to child support, firmly based within the school community and beginning with 'least intrusive practice'. The WHO also advocates providing access to specialist support for a smaller number of children identified as having complex problems and/or enduring needs (WHO, 2005).

Bereavement risk in childhood

There is no clear agreement in the literature about the proportion of children who may go on to develop long-term difficulties as a result of their loss (Ribbens McCarthy and Jessop, 2005). Citing evidence from the Harvard Child Bereavement Study, Worden (1997) suggested that two years after the death of a parent around 33% of children may have enduring emotional and behavioural problems sufficient to merit counselling intervention. To identify and do preventative work with those young people most at risk, bereavement risk assessment is advocated (Aranda and Milne, 2000).

Complicated bereavement has been defined as a response to loss that may feature intense and prolonged mourning, depressive disorders, anxiety disorders and poor physical health (Aranda and Milne, 2000). A number of red flags that might suggest that a child is struggling to cope with bereavement were identified by Stokes (2004). Overall, there seems to be agreement that those children and young people most at risk following the death of a parent include:

- Children under the age of ten years
- Learning disability
- History of previous losses
- Personal or family history of

Table 1. Guidelines for assessment of bereavement risk

Guideline 1	Family members should be involved in assessment of risk of complicated bereavement outcomes
Guideline 2	Complicated bereavement risk assessment forms part of the palliative care team's duty of care and is a process requiring input from a range of professionals involved in the care of the patient and family
Guideline 3	Complicated bereavement risk assessment should commence at the point of referral to palliative care, and continue through care provision, patient death and early bereavement
Guideline 4	Complicated bereavement risk assessment requires structured documentation, review in team meetings and use of family assessment.
Guideline 5	Complicated bereavement risk assessment involves four categories of information: 1) the illness, care and nature of the death; 2) characteristics of the bereaved; 3) relationships including family functioning; and 4) characteristics of the deceased

Adapted from Aranda and Milne (2000)

psychological disorder

- Sudden, traumatic or violent death
- Threat to child's own life
- Multiple adversities
- Surviving parent failing to care for child (Stokes, 2004).

It has also been suggested that the strongest predictor of risk to children from parental loss is the level of adjustment and psychological wellbeing of the surviving parent (Silverman and Worden, 1993).

Childhood bereavement literature is growing exponentially, but coverage of pre-bereavement is less evident. Christ (2000) researched families both pre- and post-bereavement, and offers a comprehensive and structured approach to working with children facing the anticipated death of a parent. This identifies the development stages that are key to understanding children's needs, responses and coping strategies (Christ, 2000). Supporting children during pre-bereavement is, however, racked with uncertainty, and has been described as being like wading through swampy ground sown with landmines. Nevertheless, it is argued that effective intervention need not be long term (Chowns, 2004).

Whichever tool or strategy is used to identify children at risk, it is essential that the assessment process follows clear, unambiguous guidelines. *Table 1* shows an example of guidelines that may be used for assessing bereavement risk in families.

In summary, national policy is still emerging. There is recognition, nation-

ally and globally, that bereaved children's needs require to be assessed. Bereavement is a normal life event and part of human experience. Therefore, health, education and social services need to respond to individual needs in recognition that not all bereaved children will require complex or long-term interventions. The next part of this review will offer an overview of current service provision for bereaved children in the UK.

Summary of existing service provision for bereaved children

In a study conducted by Rolls and Payne (2003), the range and scope of bereavement support across the UK was reviewed. The authors described bereavement service provision as a 'complex tapestry' in terms of type of service provided, funding arrangement, interventions and service organisation. They reported a lack of consistency or standardization of service and they found that access to bereavement support varied enormously across the UK with service provision being in general fragmented and unco-ordinated (Rolls and Payne, 2003).

This was corroborated by Wimpenny et al (2006), who undertook a critical review of literature on bereavement support. Their findings confirmed that much of the current provision comes from the hospice movement, the focus is mainly on cancer-related bereavement and there is a need for wider co-ordination and better integration of bereavement services. This echoes findings from the scoping of bereavement services undertaken for the current study.

The literature and the findings from scoping of services confirmed that a number of key initiatives have been developed across the UK aimed at supporting children dealing with the loss of a family member (Rolls and Payne, 2003; Stokes, 2004). However, the fragmented nature of bereavement support provision makes it impossible to report this in full, thus rendering it difficult to be comprehensive or all-inclusive when describing existing services. By way of a summary, some key providers of bereavement support are outlined briefly below.

Winston's Wish

Winston's Wish is a highly respected children and family bereavement support

'The Candle Project offers an exemplar of service development in bereavement support for children'

service which was established more than ten years ago in Gloucestershire. The service is designed to promote the psychological wellbeing of all children and young people who experience the death of a close family member. Around 250 referrals are taken each year (based on a health population of 500 000) for children and young people between the age of five and 16 who are coping with either the sudden or expected death of a mother, father or sibling. The service is now a recognised standard bearer for high-quality services for bereaved children. In areas local to Gloucestershire face-to-face support and weekend camps are provided. For those not living in these areas a helpline and interactive website are available (www.winstonswish.org.uk). Winston's Wish also provides a range of high-quality publications, videos and DVDs and other educational materials.

St Christopher's Candle Project

St Christopher's Hospice (www.stchristophers.org.uk) has provided bereavement counselling to patients' families for over 30 years and is another major flagship provider of child bereavement support that has led many service developments in this key area of practice. The Candle Project offers an exemplar of service development in bereavement support for children. This service extends support to all bereaved children, young people and their families living in the south-east area of London. St Christopher's also offer professional training, advice and consultancy services to schools, health care professionals and other agencies working with children facing bereavement.

Marie Curie Cancer Care

Marie Curie Cancer Care (MCCC) (www.mariecurie.org.uk) is the UK's largest provider of end-of-life care. Bereavement support is offered within each of the ten Marie Curie Hospices across the UK. Until recently, the focus was on supporting bereaved people (mainly adults), either by access to a dedicated bereavement support worker or by the pastoral support team made up of social workers and chaplains. A nationally co-ordinated child bereavement service was piloted by MCCC during 2004–2005 and findings have yet to be reported. Currently, all children who are affected by the death of a

family member under the care of this charity are offered short-term bereavement support in the period before, around and immediately after the death. If ongoing support is judged to be needed, the child is referred on to local support services in the community.

Notre Dame Centre (Glasgow)

The Notre Dame Centre (www.notredamecentre.org.uk) is a non-denominational organisation founded in 1931. It is a registered charity and operates on a not-for-profit basis. The principal areas of activity are: the assessment and treatment of emotionally disturbed children, young people and their families; and training and consultancy to parents and professionals. The Centre employs around 40 staff and volunteers drawn from a variety of disciplines, including psychology, social work, play therapy, art therapy and group therapy. The Centre has a significant and well developed training and education function, providing postgraduate courses in play therapy. It is also an approved provider of continuing professional development courses for teachers.

Seasons for Growth

Notre Dame also delivers 'Seasons for Growth' (www.seasonsforgrowth.co.uk), a change and loss peer support programme licensed to Notre Dame Centre from Australia where it originated (Seasons for Growth, 2005). A cascade training model is used to equip those who regularly work with children (such as teachers) to act as 'companions' to bereaved young people. Companions facilitate small groups of young people experiencing change and loss, including bereavement, enabling them to work through their own grief and support each other. The Seasons for Growth programme is supported by high-quality learning and teaching materials. Notre Dame Centre also provides 'Train the Trainers' courses to ensure that enough trainers are available to prepare sufficient 'companions' across the country to keep the service working. Around 1 400 volunteer companions have successfully undergone training. The Seasons for Growth programme is normally delivered over eight weeks, but specialist help is available within Notre Dame Centre for children who have experienced traumatic bereavements.

'Creative use of technology can make a timely, significant and lasting difference to bereaved children and families'

Local bereavement services

In addition to the above, a significant number of local, mainly single practitioner bereavement services were found to be operating across Scotland. Most serve the needs of the bereaved across the age span to include both adults and children. Services were mainly allied to hospices or NHS palliative care providers, but some were part of social service or mental health provision. While acknowledging the significant contribution that these services make to bereavement support, in this brief paper it has not been possible to include the full range of services that currently operate.

Telephone and online bereavement support

The cornerstone of bereavement support for young people is likely to remain in face-to-face contact. However, this may not be available to everyone who needs it, and not all will wish it. Creative use of technology can make a timely, significant and lasting difference to bereaved children and families. Crucially, telephone helplines and dedicated websites can have a much wider reach and can offer information and support to bereaved children and young people right across the UK. These methods of support can be attractive to young people, especially teenagers. Young people accessing support in this way can maintain anonymity and can exercise personal control over the course of the interaction (Stubbs, 2005). The internet offers a myriad of examples of web-based and telephone support services for bereaved children and young people as a Google search will confirm. A few examples are identified here by way of illustration.

Online providers include Childline (www.childline.org.uk), a national provider of telephone support to children experiencing distress including that from loss and bereavement.

NHS 24 Breathing Space (www.breathingspacescotland.co.uk) is a telephone advice service for young people experiencing low mood or depression from any cause with the main target group being young men aged 16–24 years. Specific to bereavement support for young people, 'RD4U' (www.rd4u.org.uk), part of the 'CRUSE Youth Involvement Project', is tailored to bereaved young people. 'Winston's Wish' also offers telephone

support and a specialist online bereavement support through its excellent interactive website.

Service delivery models for child bereavement support

The concept of routinely providing services for all bereaved children and young people has elicited differing opinions about the validity and efficacy of such an approach. In the Harvard Child Bereavement Study, Silverman and Worden (1993) studied a non-clinical sample of 125 children bereaved of a parent and a control group of non-bereaved children over a two-year period. Findings from this study have implications for service development. Later, Worden (1997) used these findings to identify three different models that might be used for the provision of children's bereavement services. These are set out in *Table 2*, together with brief critique of each.

Decisions about which service model or which type of intervention to use have long been debated. Ethical considerations abound, with some suggesting that effective bereavement intervention requires sustained and intensive work. Others argue for a community-based, non-pathologising approach. Winston's Wish has been offering a community-based support service (see Model 'C', *Table 2*) since 1992. This is designed to promote the psychological wellbeing of all children and young people who experience the death of a close family member (Stokes et al, 1994). The authors also state that by working in partnership such community-based interventions could offer an effective filter on to specialist support for those children who need this.

Christ (2000) suggests that skilled, short-term work before the parent's death can do much to benefit both child and family, and that by offering short-term interventions independence and resilience are encouraged. However, such interventions must be delivered within a robust framework, which requires:

- A clear working alliance with a productive therapeutic relationship
- Clarity regarding aims, scope and boundaries of the service (for example, up to six sessions)
- Counsellors to bring to supervision decisions about input beyond brief

Table 2. Bereavement support delivery models

Model	Focus of the model	Critique of the model
Model 'A'	Offer intervention only where children display observable emotional and behavioural problems and psychological distress	Maximises scarce resources Depends on skills of referrers Assumes children not showing distress do not need help Priority given to those children 'seen' to be having problems
Model 'B'	Offer intervention only to those children identified by a screening measure. This preventative mental health model aims to target 'at risk' groups	Using behavioural criteria alone means some children might not be getting the help they need. The validity of screening tools needs to be tested across time and populations
Model 'C'	Offer support to all bereaved children, recognizing that 'the death of a parent is one of the most fundamental losses a child can face' (Worden, 1997: 9)	Often considered too costly Only a minority seemingly at risk Most seem to adjust well More evidence of outcomes needed to support this approach

Adapted from Worden (1997) and cited in Stokes (2004)

intervention

- Regular reminding of children/adults of the time passing and left remaining on their programme
- A clear, positive and affirming ending
- Access (by telephone) if problems re-emerge (at key points in the future).

Concerns about services that might engender dependence and inhibit coping and resilience from extended intervention are summed up as follows:

'Children with a parent dying face particular challenges...Effective work rests on a few well-known precepts. Our role is not to become part of the problem by increasing their dependence on us. They should be strengthened and empowered to find their own way. If we can hold to the guiding principles of honesty, respect, choice and control we stand a fair chance of negotiating that minefield' (Monroe, 2005).

Most people who attend a short-term intervention programme, such as the one offered by St Christopher's Candle Project, progress through bereavement without further intervention. However, 12-15% of families refer themselves back for further support under the terms of an 'extended warranty.' This is an agreement which ensures telephone access to the centre if problems re-emerge (Kraus, 2005). The principles underpinning the 'extended warranty' agreement are as follows:

- Relevance is key – families may call up

with seemingly unrelated issues. Their concerns are listened to on the phone and these are then taken to supervision to explore whether they fall within the remit of the service

- The warranty is for the service not for any particular staff member. This is explained in the agreement
- The aim is to promote resilience and emphasise strengths.

The safety net of an extended warranty comes with the following cautionary note:

'Bereavement is a normal process of adjustment to a major life event, and attending counselling sessions long term can reduce the family's coping skills by creating a dependency on the bereavement counsellor or agency. Children form close relationships very quickly and the ending of a long term counselling relationship can give them another loss to cope with' (Kraus, 2005).

Providing services that will support bereaved children is challenging. Ensuring the quality of service provision and the safety and wellbeing of children who access services, and practitioners who deliver them, requires compliance with ethical and quality assurance frameworks. The Childhood Bereavement Network (CBN, 2004) has produced *Guidelines for Best Practice* in relation to childhood bereavement support. These clearly define a criteria against which new and existing child bereavement services can be benchmarked.


Children and family support service

The new children and family support service operates alongside, but separate from, the existing bereavement service that operates in the area. The service and the post-holder sit within the palliative care services. This enables regular liaison with other palliative care professionals at multidisciplinary meetings and events. Wider links also operate at national and local level, providing professional networking opportunities and access to professional dialogue and supervision.

This brief article has set out the background and the context for the development of the new service. The second part of this article will go on to describe the methods used to evaluate the new service, together with the findings and the recommendations to emerge. These will be

Key words

- Bereavement
- Children
- Family
- Palliative care
- Bereavement services

reported drawing on rich qualitative data from the interviews with the children, parents and other stakeholders involved in the service. 

The authors of this paper would like to acknowledge the contributions of all participants and in particular the children and families who contributed to this study at a time of considerable difficulty.

The views expressed here are not necessarily those of the funding body or the providers of the children and family support service.

Aranda S, Milne D (2000) *Guidelines for the assessment of complicated bereavement risk in family members of people receiving palliative care*. Centre for Palliative Care, Melbourne

Childhood Bereavement Network (2004) CBN Policy Briefing: Response to 'Every Child Matters'. www.childhoodbereavementnetwork.org.uk/documents/Guidelinesforsupportingparents_000.pdf (accessed 3 March 2008)

Christ G (2000) *Healing children's grief; surviving a parent's death of cancer*. Oxford University Press

Chowns G (2005) 'Swampy ground': brief interventions with families before bereavement. In: Monroe B, Krauss F. *Brief Interventions with Bereaved Children*. Oxford University Press, New York: 124-39

Department for Children, Schools and Families (DCSF) (2004a) *Every Child Matters: Change for Children*. www.everychildmatters.gov.uk/_files/F9E3F941DC8D4580539EE4C743E9371D.pdf (accessed 3 March 2008)

DCSF (2004b) *Additional Support for Learning (Scotland) Act*. www.opsi.gov.uk/legislation/scotland/

acts2004/20040004.htm (accessed 3 March 2008)

DCSF (2006) *The Children Act (Scotland) Report 2004-2005*. www.dfes.gov.uk/publications/childrenactreport (accessed 3 March 2008)

Krauss F (2005) The Extended Warranty. In: Monroe B, Krauss F. *Brief Interventions with Bereaved Children*. Oxford University Press: 113-24

Monroe B, Krauss F (eds) (2005). *Brief Interventions with Bereaved Children*. Oxford University Press: 138

Ribbens McCarthy J, Jessop J (2005) *Young people, bereavement and loss: disruptive transitions?* NCB Books, London

Rolls L (2005) UK Bereavement services for children and young people. *European Journal of Palliative Care* 12(5): 218-20

Rolls L, Payne S (2003) Childhood Bereavement Services: a survey of UK provision. *Palliat Med* 423: 32

Scottish Executive (2005) Delivering for Health. www.scotland.gov.uk/Resource/Doc/76169/0018996.pdf (accessed 3 March 2008)

Silverman P, Worden JW (1993) Children's reactions to the death of a parent. In: Stroebe MS, Stroebe W, Hansson RO. *Handbook of Bereavement Theory, Research and Intervention*. Cambridge University Press: 300-16

Stokes J (2004) *Then, now and always: supporting children as they journey through grief: a guide for practitioners*. Published for 'Winston's Wish' by Portfolio Publishing, Cheltenham

Wimpenny P, Unwin R, Dempster P et al (2006) *Literature Review on Bereavement and Bereavement Care*. www.rgu.ac.uk/nursing/research/page.cfm?page=32496 (accessed 3 March 2008)

Worden JW (1997) *Children and Grief: When a Parent Dies*. Guilford Press, New York

World Health Organization (WHO) (2005) Model of school-based mental health promotion. In: *Brief Interventions with Bereaved Children*. Monroe B, Krauss F. Oxford University Press, New York: 161-3

internurse.com

The UK's largest online archive of nursing articles



internurse.com provides access to an extensive library of thousands of peer-reviewed clinical articles in all areas of nursing

For subscription details, visit internurse.com or call free on 0800 137201

search **internurse**

Over 11,000 nursing articles online

NOW with a clean new look and improved search engine



MA Healthcare Ltd, Jesses Farm, Snow Hill, Dinton, Nr Salisbury, Wiltshire SP3 5HN tel 01722 716997 fax 01722 716926

Copyright of International Journal of Palliative Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.