Childhood bereavement: what we do know in 2019?

Northern Ireland edition

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Childhood Bereavement Network

The Childhood Bereavement Network

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK. We underpin our members' work with essential support and representation: bringing them together across localities, disciplines and sectors to improve bereavement care for children.

Collectively, we share a vision that all children and young people in the UK, together with their caregivers, can easily access a choice of high quality local and national information, guidance and support to enable them to manage the impact of death on their lives.

www.childhoodbereavementnetwork.org.uk @CBNtweets

Part of the NCB family

We are proud to be part of the National Children's Bureau (NCB), a leading national children's charity working to build a better childhood for every child, by championing their right to be safe, secure and supported.

Along with other specialist interest groups and networks such as the Anti-Bullying Alliance and the Council for Disabled children, we operate under NCB's charitable status and are based at their London headquarters.

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Introduction

This compendium of statistics, information and the policy context around bereavement in childhood is intended to be a 'ready reckoner' for CBN members, helping you to

- keep abreast of research developments
- reflect on your practice
- prepare funding proposals
- make the case for your service.

We have tried to cast the net as wide as possible to include relevant research from around the world. As findings from one country don't always translate to the context of another country (Ribbens McCarthy with Jessop, 2005; Rolls, 2010), we have said where a particular study was done. We hope this will help you to judge the most useful findings for your work.

The compendium is not comprehensive, but it does include the research and policy we cite most frequently, and the ones which members most often ask us about. We hope to keep this publication updated, to include additional research and to address additional questions if we can. Please let us know how you use the resource and if there are other topics you think should be included in further editions.

This edition for Northern Ireland identifies how bereavement can compromise children's wellbeing, looks at factors affecting children's resilience and vulnerability, and explores models of intervention for children and young people. It ends with a summary of the current policy context for supporting children and young people across mental health and well-being, suicide postvention, end-of-life care and bereavement care.

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Numbers

There are many challenges in establishing accurate figures for childhood bereavement. As there is no central, official collection of the data on the number of children who are bereaved each year, we have to apply the proportions found in research studies to population and mortality data. This means we can only estimate the incidence.

All data in the table below should be used with caution. They will next be updated in November 2019. For details of the estimates of children in each local authority area, visit http://www.childhoodbereavementnetwork.org.uk/research/local-statistics.aspx

Table 1: estimated incidence of bereavement in childhood

	Northern Ireland	Great Britain	UK
How many parents died in 2015 leaving dependent children?[1]	800*	22,800*	23,600*
How often did a parent die that year, leaving dependent children?	Every 11 hours	Every 23 minutes	Every 22 minutes
How many children under 18 were bereaved of a parent that year?[2]	1,500*	39,000**	41,000**
How many children were bereaved of a parent each day?	4	107	112
What proportion of children aged 5-16 have been bereaved of a parent or sibling?		1 in 29	
What proportion of 16 year olds have been bereaved of a parent?[3]		1 in 20	

* rounded to the nearest 100 **rounded to the nearest 1,000

How many children and young people say they have been bereaved?

In a sample of 11-16 year olds (secondary school pupils) in the north-west of England (Harrison and Harrington 2001), 78 per cent said they had been bereaved of a close relative or a close friend. 92 per cent said they had been bereaved of a close relative, friend or pet.

What proportion of deaths are sudden or unexpected?

In England and Wales, at least 25 per cent of deaths are unexpected from sudden causes. However, many patients with chronic/long term conditions also die unexpectedly, which would push up the figure for unexpected deaths. It could be as high as 42 per cent (Blackmore and others 2011, UK).

Are some children more likely to be bereaved?

Ribbens McCarthy and Jessop (2005) point out that life expectancy varies by social class and geography. This means that some adults and children are more likely to die early, and therefore some children are more likely to be bereaved.

[1] Adapted from data from the Office for National Statistics, licensed under the Open Government Licence v3.0. Combines age banded mortality statistics with the proportion of adults living with dependent children (census data).
[2] Adapted from data from the Office for National Statistics, licensed under the Open Government Licence v3.0. Combines age banded mortality statistics with census data on the proportion of adults living with dependent children, and average number of children by family type.
[3] Percentage of young people included in the BCS1970 cohort study who had been bereaved of at least one parent by the age of 16 (Parsons, 2011).

The impact of bereavement

Dyregrov (2008) outlines common reactions to bereavement, which include anxiety, vivid memories, sleep difficulties, sadness and longing, anger and acting out behaviour, guilt, self-reproach and shame, school problems, and physical complaints.

Reactions he describes as 'a bit less common' are regressive behaviour, social isolation, fantasies, personality changes, pessimism about the future, preoccupation with cause and meaning, and a sense of maturation and growth as a result of being bereaved.

The course of bereavement

Melhem et al (2011, US) followed 182 children and adolescents for up to three years following the sudden death of a parent, using a range of tests including the Inventory of Complicated Grief (ICG) which looks at levels of problematic grief. They looked at how the children and young people were doing 9 months, 21 months and 33 months after the death. They found three distinct patterns:

- 58.8% of the respondents were doing better than the median score 9 months after the death. They improved towards 21 months, and continued to do relatively well.
- 30.8% of respondents were having more difficulty at 9 months after the death, but they also improved between 9 and 33 months
- 10.4% were also having more difficulty at 9 months, but showed almost no improvement 21 months and 33 months later. Of the 19 young people in this group, 6 (31.6%) met the criteria for depression, anxiety or PTSD throughout the three years they were followed up for. Seven (36.8%) had one of these diagnoses at the time of the death that was prolonged or had recurred, and 6 (31.6%) did not meet the criteria for any of these disorders.

Factors affecting children's reactions

The evidence on how bereavement impacts children, and the degree to which it constitutes a risk for poor outcomes, is often complex and contradictory. Ribbens McCarthy with Jessop (2005) provides an excellent summary of reasons why. The findings from studies conducted in one country may not be directly generalisable to another country. For example, the US has a very different model of healthcare to the UK, as well as differing mortality patterns (Ribbens McCarthy with Jessop 2005; Rolls 2010).

Ribbens McCarthy also highlights the importance of mediating and moderating factors influencing outcomes. Worden (1996, US) outlines six such categories of mediating factors.

- The death and the rituals surrounding it
- The relationship of the child with the deceased parent both before the death and afterwards
- The functioning of the surviving parent and his or her ability to parent the child
- Family influences such as size, solvency, structure, style of coping, support, and communication, as well as family stressors and changes and disruptions in the child's daily life
- Support from peers and others outside the family
- Characteristics of the child including age, gender, self-perception, and understanding of death.

Several of these have received particular attention in the literature,

- Age/developmental level
- Gender
- Individual factors in the child or young person such as self-esteem, external locus of control, coping style, mental health and area of competence
- Cause and type of death
- What the death means
- Relationship to the person who died
- The surviving parent and their capacity to support their child
- Socio-economic status
- Cultural background
- Other stressful life events

wider context of their lives when they experience this painful and difficult event.

> For some young people…bereavement may be compounded by other disadvantages or multiple difficult life events, and this may clearly indicate an increased risk of negative outcomes. Furthermore, bereavement and multiple losses are much more likely to be experienced by young people who are already disadvantaged, but these young people are less likely to have organised support available to them.
>
> Ribbens McCarthy with Jessop, 2005, p64

Adverse childhood experiences (ACEs)

The significance of other stressful life events for children's outcomes in bereavement tallies with the ACEs approach.

Increasing attention is being paid to adverse childhood experiences as a way of understanding poor outcomes in childhood and adulthood. While the approach can he a helpful way of considering adversity, it does have limitations, particularly when too narrow a focus is taken. For example, the original ACEs questionnaire asks about ten stressful experiences in childhood, but doesn't take into account any factors that might make a difference to how these played out, such as how long these lasted, or the availability of a supportive family member or wider context.

For the purposes of bereavement, it is important to note that the original questionnaire does not include bereavement as a stressful life event (Vaswani 2017).

However, it may be that an ACEs approach can shed some light onto why some children do better than others following bereavement: looking at the

Resilience and bereavement

Stokes (2009, UK) reports resilience among a group of children referred for direct services from a community-based child bereavement service in the UK (approximately 500 children a year for 15 years).

- 10% were highly resilient, easy to engage, likely to have a supportive parent and needing only the core aspects of the service
- 75% were moderately resilient, probably prompted to access the service by a professional, in some cases needing 1:1 sessions before participating in a group programme, needing to re-engage with the service at times of future transition
- 15% were highly vulnerable, affected by a range of social and psychological factors, lacking adequate parental support or in public care.

Lin et al (2004, US) reviewed what differentiated 'resilient' children from those with mental health problems following the death of a primary caregiver. They looked at 179 bereaved children aged 8 to 16 and their surviving caregivers. 44% were classified as resilient and 56% as 'affected' by mental health problems, based on the child, their surviving parent or carer, or teacher reporting that they had difficulties in the clinical range.

- Children were more likely to be resilient in families with higher levels of caregiver warmth and discipline and

lower levels of caregiver mental health difficulties

- Children who felt less threat in response to negative events, and who had greater personal efficacy in coping with stress were more likely to be resilient.

The team did not find a relationship between mental health problems, income, child self-esteem, control beliefs and active inhibition of emotional expression were not significantly related to children's mental health problems.

Outcomes of bereavement – the eight areas of wellbeing

The Children's Services Co-operation Act (Northern Ireland) 2015 sets out eight areas of wellbeing

- physical and mental health*
- living in safety and with stability*
- learning and achievement*
- economic and environmental well-being*
- the enjoyment of play and leisure
- living in a society in which equality of opportunity and good relations are promoted
- the making by children and young people of a positive contribution to society*
- and living in a society which respects their rights.

This section summarises some of the quantitative evidence about how bereavement challenges children's lives across some of these eight areas (those marked with a *)

As explained in the introduction, this section is neither comprehensive nor synthesized, but it summarises the key quantitative studies most often cited by CBN staff, and those that people most often ask us about.

Physical and mental health

Physical health

- Worden (1996, US) found that around 13% of bereaved children had **somatic symptoms in the clinical range** during the first year after the death, compared to around 4% of the non-bereaved children. Girls experienced these problems more than boys, and pre-teen more than older young people. By the second year after the death, the somatic scores dropped to nearer the non-bereaved group.
- Bereaved children were more likely than the non-bereaved to experience a **serious illness** by the end of the first year since the bereavement, with 10% of bereaved children experiencing such an illness. 70% of bereaved children reported mild illness. By the end of the second year, the percentage reporting serious illness had dropped to a similar rate found in non-bereaved children (Worden, 1996, US).
- 34% of children experienced **accidents** as they moved through the first year of their bereavement, compared to 26% among non-bereaved children. Adolescent boys had the majority of accidents (Worden, 1996, US)
- Fauth et al (2009, UK) found that children who had been bereaved were more likely also to have had a **serious illness requiring hospitalisation** at some point in their childhood (this might have been before the bereavement)
- Momen et al (2013, Denmark and Sweden) looked at all children born in Denmark and Sweden between around 1970 and 2007. They found that the death of a close family member (parent, sibling, maternal grandparents/aunts/uncles) slightly increased the risk of **childhood cancer** 3 or 12 months after the bereavement: with these children 1.1 times as likely as those who hadn't been bereaved to develop cancer.

- There is a suggestion that one route by which young people have an increased risk for poor outcomes is through dysregulated hypothalamic-pituitary-adrenal (HPA) functioning (Luecken, 2008) or **cortisol response**. Dietz et al (2013, US) found that parentally bereaved young people showed significantly different cortisol responses compared with non-bereaved offspring, over 5 years, characterised by higher total cortisol output and an absence of cortisol reactivity to acute social stress. Luecken and Roubinov (2012) have set out theories about how social and environmental factors in bereaved children's lives could influence their cortisol response and long-term health.

Mortality

- Li and others (2014, Denmark, Sweden and Finland) studied a cohort of over 7 million people. They found that those bereaved of a parent were **50 per cent more likely to die before they reached middle age** than those who had not been bereaved. The death of a parent due to non-natural causes was associated with an 84 per cent increase in the risk of dying young. The authors suggest this could be to do with both genetic susceptibility and the long-term impacts of parental death on health and social well-being.
- A **higher mortality risk** has also been found in people over the age of 65 who were bereaved of a parent during their childhood or adolescence, compared with those who were not bereaved (Smith and others 2014, US). Features of their later life, such as their marital status, later health and socio-economic status, did little to alter this association.
- A study based on the cohort of children born in 1958 did not find an independent association between the death of a sibling in childhood and increased mortality in later life (Smith et al 2014, UK).
- A more recent national cohort study followed over 700,000 young people from the age of 18 to age 31-40. This found that the death of a sibling in childhood was associated with an overall **higher risk of mortality** in surviving siblings. Risks were greater for those bereaved of a non-infant sibling, and those bereaved in adolescence, Excess mortality risk was found when siblings had both died from either natural or external causes, but not when one had died from natural and the other had died from external causes.

Health behaviours

- Sweeting et al (1998, UK) with a small sample, found that girls who had been bereaved of a parent were more likely than those living with both birth parents or whose parents had separated to **smoke by the age of 15 or 18, to drink by the age of 18, to have sex by the age of 15**.
- Over the three years following the death of a parent, a sample of 240 young people were more likely to do things that risked their health than their non-bereaved peers. These included **not wearing a seat belt, being in a car driven by someone who had been drinking, carrying a weapon, and being in a physical fight in the last year**. These findings held even after taking into account correlates of bereavement and risky health behaviours, such as aggression, and antisocial or anxiety disorders of the deceased parent (Muniz-Cohen et al, 2010, US).
- Among 176 young people bereaved of a parent by suicide, accident or sudden natural death, rates of **substance and alcohol abuse disorders** were higher 21 months after the death than among non-bereaved peers. Bereavement by suicide was particularly associated with these difficulties (Brent et al, 2009, US).
- Wilcox et al (2010, Sweden) found that those whose parent died during their childhood (between 1969 and 2004 in Sweden) were more likely to be **hospitalised for drug or alcohol use** than their non-bereaved peers. Generally the risk of later hospitalisation for drug use was greater among those who were under 12 when their parent died.
- A greater proportion of bereaved youth than non-bereaved youth exhibited substance abuse problems one wave following the loss, controlling for socio-demographics and previous symptoms of substance abuse.

- In a longitudinal, epidemiological sample of young people aged 11 to 21, Kaplow and others (2010, US) found a greater proportion of bereaved youth than non-bereaved youth exhibited **substance abuse problems** one wave following the loss, controlling for socio-demographics and previous symptoms of substance abuse.
- The 1970 British Cohort Study shows that being bereaved of a parent by the age of 16 is associated with **women smoking at age 30**, after controlling for other factors (Parsons, 2011, UK).

Sexual activity, sexual health and pregnancy

- Sweeting et al (1998, UK) found that girls bereaved of a parent were six times more likely to be **pregnant by the age of 18** than those living with both birth parents or whose parents had separated. However, this was based on small numbers.

Bullying

- Some children report being **bullied** as a direct result of being bereaved (Worden, 1996, US; Cross, 2002, UK)

Emotional and mental health

- Worden found that at each of the interview points in his study (1996, US) (4 months, 1 year and 2 years after the death), around 20% of bereaved children fell into the **'at risk' category for emotional/behavioural difficulties** at each of the time points they were interviewed. This meant they had scores on Achenbach's Child Behaviour Checklist in the clinical range. One third of all the children fell into the 'at risk' category at one or more of those points (i.e. at some point in the two years after the death).
- The difference in scores between bereaved and non-bereaved children was greater two years after the death than earlier, suggesting a **'late effect' of bereavement**.
- Higher rates of clinical levels of difficulty may be found among those children who get referred or whose families find their way to a child bereavement service: Lin et al (2004, US) reported levels of 40%.
- Fauth et al (2009, UK) found that bereaved children were around one and a half times as likely as non-bereaved children to **have a mental disorder**. (It is not known whether these difficulties preceded the death or whether the death caused the difficulty).
- Analysis of ALSPAC data looked at the impact of different stressful life events on over 14,000 children born in Avon in 1991-2. Parents were asked about their children's emotional, behavioural and social well-being at the age of 13 (Jones et al, 2013, UK). Teenagers who experienced bereavement at any age had **lower emotional well-being aged 13** than those who hadn't been bereaved of a family member. This remained significant even taking into account emotional well-being at age 10.

> This indicates that experiencing the death of a parent or family member in childhood may have continuous, worsening effects on a teenager's emotional well-being, long after the event has occurred... family bereavement had continuous, cumulative effects on children's emotional and social well-being, long after the event happened.
>
> Jones et al, 2013, UK

- In a population-based study of adults aged 18 to 64, Stikkelbroek et al (2014) did not find an increased risk of mental disorder in adulthood of those bereaved of a parent before the age of 16.

Depression

- In a survey of 1746 11-16 year olds, Harrison and Harrington (2001, UK) found the death of a close relative or friend was associated with **depressive symptoms**. Those bereaved of a parent had a mean self-report of depressive symptoms of 19.7 compared to 14.9 among those not bereaved of a parent. Those bereaved of a sibling had a mean self-report of 21.9 compared to 14.8 among those not bereaved of a sibling.

- Melhem et al (2008, US) found that young people who had been bereaved of a parent suddenly (through suicide, accident or sudden natural death) around 9 months earlier, were three times more likely than their non-bereaved peers to have developed **diagnosable new-onset depression**. (The research team used the Schedule for Affective Disorders and Schizophrenia for School-Age children present and the Mood and Feelings questionnaire). This held true even when controlling for other risk factors that preceded or accompanied the death.
- Brent et al (2009, US) found that **major depression** 21 months after a parent's death was more common than among comparison subjects. In particular, those whose parents died through suicide or accidental death had higher rates of depression. Those bereaved by suicide had a higher incidence of depression than those bereaved by sudden natural death. Bereavement and a past history of depression increased depression risk in the 9 months following the death, which increased depression risk between 9 and 21 months. Losing a mother, blaming others, low self-esteem, negative coping, and complicated grief were associated with the depression in the second year.
- A national cohort study in Sweden found that the death of a parent in childhood was associated with a small increased risk of outpatient care for **depression as a young adult**, and the risk was greater for those whose parent died from suicide, accident or homicide. Those bereaved at a younger age were at increased risk (Berg et al 2016, Sweden).
- After controlling for other factors, being bereaved by the age of 16 is associated with **women reporting depressive symptoms at the age of 30** (Parsons, 2011, UK).
- Appel and others (2016, Denmark), in a nationwide population-based cohort of children and young adults born in 1970-1990 and followed up in 1997-2009, found **increased use of anti-depressants** among those who had experienced early parental death. The increased risk remained more than two years after the death. Subgroups with particularly increased risk included women who were bereaved by suicides, women who experienced loss of a mother, and women who were bereaved when young.

Anxiety

- Worden (1996, US) found that 4 months after their parent's death, 44% of children expressed **fear for their surviving parent's safety**, especially when it was their mother who had died. By one year after the death, this had risen to 62%, and half were still fearful two years afterwards
- Children's **fear for their own safety** rose over the first year from 11% to 16% and was associated with the death of a father.
- Fauth et al (2009, UK) found that children bereaved of a parent or sibling were more likely than non-bereaved children to have **clinical levels of anxiety**.
- A four-wave prospective cohort study found that children bereaved of a parent or sibling reported **more internalizing problems within two years of the death**, compared to their non-bereaved peers, taking into account the level of difficulties they had before the bereavement. Within two years of the death, 22% of bereaved children newly reached clinical levels of difficulty, compared to 5.5% new cases among non-bereaved controls. Low socio-economic status predicted more internalizing problems among bereaved children, but not among the non-bereaved (Stikkelbroek et al 2016, Netherlands).
- In a representative sample of young people aged 11 to 21 in a longitudinal study Kaplow and others (2010, US) found higher levels of **separation anxiety** among those who had been bereaved of a parent or someone else close, in the wave where the death happened, even after controlling for socio-demographics and prior symptoms.

Conduct disorder

- Fauth et al (2009, UK) found that children bereaved of a friend were more likely to have **difficulties with conduct** than their non-bereaved peers.

- In Kaplow and others' study (2010, US), parentally-bereaved young people aged 11 to 21 were more likely to exhibit **symptoms of conduct disorder** one wave following the loss, again after controlling for socio-demographics and previous symptoms of conduct disorder.

Post-traumatic stress

- Melhem et al (2008, US) found that young people who had been bereaved of a parent suddenly (through suicide, accident or sudden natural death) around 9 months earlier, were more likely to have developed **new-onset Post-Traumatic Stress Disorder (PTSD**) than their non-bereaved peers, especially those bereaved by suicide or natural death. The research team used the Child PTSD Symptom Scale Interview.
- **Elevated rates of PTSD** have been found in friends of young people who died by suicide (Brent et al 1993), children and young people bereaved of a parent through disease or accident (Stoppebein and Greening, 2000, US).
- McClatchey and Vonk (2005) did not find a difference in rates of PTSD between children bereaved through expected vs sudden unexpected death.

Problematic forms of grief

The definition of 'complicated grief', 'prolonged grief' or 'persistent complex grief-related disorder' is not without controversy (e.g. Stroebe et al, 2008). Dyregrov and Dyregrov's (2013) survey of 39 very experienced clinicians and researchers found that professionals struggled with defining complicated grief in children, although they were in agreement that the main defining aspects were intensity, duration and longevity of reactions. They identified traumatic and delayed or inhibited grief as major types, and also agreed that adult criteria were inappropriate for children.

Two of the most widely discussed current constructs are **Persistent complex bereavement-related disorder (PCBD)** and **Prolonged Grief Disorder (PGD).** These constructs are overlapping but distinct (Boelen et al 2019).

- **Persistent complex bereavement-related disorder (PCBD)** has been included as a candidate disorder for further research in the fifth edition of the Diagnostic and Statistical Manual for Psychiatric Disorders (DSM-V) (American Psychiatric Association, 2013). PCBD can be seen as a 'hybrid' disorder influenced by several schools of thought, primarily on adult forms of maladaptive grief including 'pathological grief', 'prolonged grief disorder' and 'complicated grief' (Kaplow et al 2014).

  The proposed criteria involve four dimensions following the death of a significant other: separation distress (e.g. yearning, longing, preoccupation with the person who died); reactive distress (e.g. anger, difficulty accepting the death); social/identity disruption (e.g. difficulty trusting others, feeling that part of oneself has died with the person); and preoccupation with the circumstances of the death. It can be diagnosed when symptoms have been experienced to a level that impairs functioning, for at least 6 months after the death (12 months in adults), to a degree that is inconsistent with cultural, religious or age-appropriate norms. It includes a traumatic bereavement specifier if the death was by homicide or suicide and is an ongoing source of distressing thoughts or feelings related to the traumatic features of the death (American Psychiatric Association, 2013).

  - Boelen et al (2019, Netherlands) found that 3.4% of the 291 help-seeking bereaved 8-18 year-olds in their study reached the threshold for a probable diagnosis of PCBD (as measured by items from the Inventory of Prolonged Grief for Children and Adolescents, the Children's Depression Inventory of the Child Posttraumatic Stress Disorder Symptom Scale). PCBD was significantly associated with depression, post-traumatic stress and disturbed grief.
  - Using a new PCBD checklist, Kaplow et al (2018) found that among their sample of 367 8-18 year-olds, 18% met criteria for PCBD. Meeting the PCBD criteria was

associated with higher depressive and post-traumatic stress symptoms and functional impairment.

- **Prolonged Grief Disorder (PGD)** has been included in the 11th edition of the International Classification of Diseases (ICD-11). It can be diagnosed when a child or young person experiences one of two symptoms of separation distress and at least one of ten other symptoms such as difficulty accepting the death, difficulty engaging with social or other activities, to a 'distressing and disabling degree' (Boelen et al 2019) for at least six months in a way that clearly exceeds social, cultural or religious norms.
    - Boelen et al (2019, Netherlands) in the study mentioned above, found that 12.4% of the 291children and young people met criteria for PGD, meaning that PGD criteria lead to a significantly higher prevalence rate than PCBD criteria. PGD was significantly associated with depression, post-traumatic stress and disturbed grief.
    - Using new measures of Prolonged Grief in Children and Adolescents, Spuij et al (2012, Netherlands) found that scores were correlated with depression, PTSD and functional impairment, and more strongly correlated with a measure of traumatic grief than with measures of positive memories.
    - Using the Traumatic Grief Inventory for Children (an adapted version of the adult Inventory of Complicated Grief-Revised, a precursor of measures of Prolonged Grief) in a sample of 12-19 year olds, Dillen et al (2009) found that the grief symptoms formed a unidimensional cluster of symptoms that were moderately correlated with but distinct from symptoms of anxiety and depression.
    - Melhem et al (2007, US) also used a modified version of the adult Inventory of Complicated Grief-Revised. Their construct of Complicated Grief was partially independent of depression, anxiety and PTSD among children and young people aged 7 to 18 bereaved suddenly by suicide, accident or sudden natural death. It was also associated with clinically rated impairment, even after controlling for each of depression, anxiety and PTSD; and with suicidal ideation.
    - Boelen et al (2017) explored patterns in symptoms of PGD and PTSD among 331 help-seeking bereaved 8 to 18 year olds. They found three groups of participants: a resilient class (38.6%), a class who met criteria for PGD (35.2%) and class who met criteria for both PGD and PTSD (26.2%), which provides some evidence for the validity of the construct of PGD.
- **Childhood Traumatic Grief** Cohen et al (2002, US) is a concept in which trauma-related symptoms encroach on a child's ability to negotiate the normal bereavement process, following a bereavement that is objectively or subjectively traumatic. The concept overlaps with but is distinct from uncomplicated bereavement, adult complicated grief, and posttraumatic stress disorder.

Suicide

- A study looked at rates of suicide attempts among all young people born in Denmark between 1983 and 1989 – these young people were aged between 10 and 22 when the study took place. Those who had been bereaved of a parent were more likely than their peers to have **attempted suicide** (1.71 times as likely). The increased risk associated with a mother's death disappeared when fathers had a medium or high income. Both parents dying increased the relative risk to 2.7 (Jakobsen and Christiansen, 2011, Denmark).
- Wilcox et al (2010, Sweden) looked at the outcomes for all those children in Sweden whose parent died from suicide, accident and other causes between 1969 and 2004. Those whose parent died by suicide by the time they were 17 were three times more likely than their non-bereaved peers to themselves **die by suicide**. Those who were aged 0-12 when their parent died accidentally were twice as likely. Those whose parent died by suicide were also more likely to be **hospitalised for a suicide attempt**.
- Also using a Swedish sample, Niederkrotenthaler and others (2012, Sweden) found that childhood exposure to parental suicide or suicide attempt, or death by another cause,

was associated with increased risk of **death by suicide and hospitalisation for a suicide attempt,** after controlling for socioeconomic status. The risk of death by suicide was greater among those who were youngest when their parent died by or attempted suicide, while those bereaved by causes other than suicide were more at risk the older they were when their parent died. The **risk of attempting suicide** after parental suicide increased with increasing age of exposure.

- Guldin and others carried out a population-based matched cohort study in 3 Scandinavian countries (a total of over 8 million people) and found that the risk of **death by suicide** was twice as high among those bereaved of a parent before the age of 18, and more than three times as high among those whose parent had died by suicide. The increased risk lasted for at least 25 years after the parent's death (2015, Denmark, Finland and Sweden).

Hospitalisation for psychiatric disorder

- Wilcox et al (2010, Sweden) found that children and young people in Sweden whose parent died by suicide, accident or other causes were more likely later to be **hospitalised for a psychiatric disorder** – generally the risk was greater for those whose parent had died by suicide, and for those who were under 12 when their parent died.

Psychosis

- Adults who had a **first episode of psychosis** were three times more likely to have been bereaved of a parent by the age of 16 than those who had no such episode. These findings held when controlled for age, sex, ethnicity and parental mental illness (Morgan et al, 2006, UK).
- A cohort study found an **increased risk of psychosis by early middle age** among those who had been bereaved before the age of 13 (Abel et al 2014, Sweden). The risk was higher the younger the child was when they were bereaved, and also for those bereaved by suicide, especially the risk for affective psychosis.

Functioning

- Melhem et al (2008, US) found that young people who had been bereaved of a parent suddenly through suicide or sudden natural death around 9 months earlier had greater **functional impairment** than their non-bereaved peers, based on the (Children's) Global Assessment Scale.
- Kaplow and others (2010, US) also found **decreased global functioning** among young people aged 11-21 bereaved of a parent, and those bereaved of a grandparent or aunt/uncle compared to non-bereaved young people. Those bereaved of a parent showed decreased global functioning compared to non-bereaved peers, even before the death, suggesting that they were already having difficulties in one or more areas of life (home, community, school, social networks).

Living in safety and with stability

Living arrangements

- Franzen and Vinnerlung (2006, Sweden) found that many more 18-year-olds who had been fostered during childhood had experienced the death of a parent (26 per cent) than those who grew up in their birth families (4 per cent).
- A study of the care histories of younger looked after children (under five years old) in Northern Ireland found that 30 per cent of the sample had experienced significant bereavements (Cousins and others 2003, p. 56).
- Professionals consulted as part of a CBN study (Penny, 2006) believed that looked after children and young people were more likely to have experienced the death of someone close to them. This was both because the death of a primary carer was a contributory factor for entry into care, and because of higher mortality rates among family and friends. They cited drug and alcohol misuse and other risk-taking behaviour, poor general health, severe mental health problems, domestic violence and

involvement in crime as contributing factors to higher mortality rates – and greater proportions of sudden and traumatic deaths - among the birth families and friends of looked after children and young people. Some of these factors are similar to those that could have led to a child or young person becoming looked after in the first place.

Relationships

- Ribbens McCarthy's review of the literature found **contradictory evidence on partner relationships** among bereaved young people, and suggests this could be explained by individuals showing polarised tendencies – some moving quickly into committed relationships and others avoiding them (2005).
- Using data from national registries, Høeg and others (2018, Denmark) followed all children born in Denmark between 1970 and 1995 (over 1 million), finding that parental loss was associated with a **higher rate of relationship formation for young women**, but not young men, and **higher rates of separation** for both men and women. The associations with separation were stronger for persons who lost a parent to suicide than to other causes. The effects were relatively small.

Learning and achievement

Attainment and achievement

- The evidence around the impact on schooling is complex and may mask 'opposite effects' (Ribbens McCarthy, 2005).
- Around a fifth of children in Worden's study (1996, US) reported **concentration difficulties** in the first months following a death. While concentration did improve significantly for the group overall during the first year, at one year after the death, bereaved children's concentration was significantly lower than that of non-bereaved children.
- Around a fifth of children also reported **difficulties with learning** in the early months – boys were more likely than girls to report this than girls. Adolescent boys were the most vulnerable to learning problems. As the first year progressed, boys' difficulties improved but teenage girls began to have more problems. Overall though, these levels were not different to non-bereaved children.
- Abdelnoor and Hollins (2004, UK) found that parentally bereaved young people's **GCSE scores** were an average of half a grade lower than their non-bereaved peers. Girls bereaved of a sibling scored almost a full grade below their controls.
- After controlling for other factors, the death of a parent by the age of 16 is associated with **women failing to gain any sort of qualification** (Parsons, 2011, UK).
- ALSPAC data did not find an association between bereavement and lower educational attainment and school well-being (Jones et al, 2013, UK).
- Analysis of a nationally representative sample in the US found that, after accounting for demographic characteristics and other traumatic events, experiencing sudden loss of someone very close was associated with **lower academic achievement, lower ability to concentrate and learn, less enjoyment of school, lower school belongingness, and lower beliefs that teachers treat youth fairly** (Oosterhoff et al, 2018, US).
- A register-based national cohort study found that the death of a parent before the age of 15 was associated with **lower grades and school failure**. Much of the effect, especially for deaths by external causes, was associated with socioeconomic disadvantage and psychosocial problems in the family (Berg et al, 2014, Sweden).
- Prix and Erola (2017, Finland) looked at the educational trajectories of children whose father had died before they were 16, in a representative sample of 10% of the Finnish population born between 1982 and 1987. On average, even after controlling for other family changes and family resources, they had a **higher risk of dropping out of secondary education** by age 18 and were **less likely to have entered higher education** (either a polytechnic or university) by age 23. However, if their surviving mother had high levels of socioeconomic resource, they were not more likely to drop out of secondary

school or less likely to enter polytechnic. However, even those with mothers with the highest levels of education, income or social class were somewhat less likely to go to university.

- Using total population data on children born between 1982 and 2000, Høeg and others (2019, Denmark) found that In comparison with non-bereaved people, those who had been bereaved were **less likely to finish compulsory school, high school or vocational training, bachelor degree or professional programme and university graduate degree,** regardless of the gender of the parent who died, the cause of death or the child's age at the time of death. (The only exception was women's completion of a bachelor's degree, where women bereaved between the ages of 6 and 12 fared better than those younger or older at the time of the death).

Exclusion

- In a sample of 70 young people aged 14 to 16 who had been **excluded from school** King (2016) reported a high number of bereavements, often multiple and in already difficult circumstances. It was not clear whether bereaved young people were over-represented in this sample, but young people often reported bereavements as critical moments in their lives.

Employment

- After controlling for other factors, bereavement by the age of 16 is associated with both men and women being **unemployed at the age of 30**. (Parsons, 2011, UK).

Economic and environmental well-being

Bereavement as a route into child poverty

- A study from the Social Policy Research Unit found '***one route to poverty and one cause of deepening of poverty*** *to be the death of a life partner*' (Corden et al 2008, UK). The household incomes of three out of four families with dependent children in this study declined after the death of a partner, including almost half whose equivalised incomes dropped by more than £100 a week.

- As well as this evidence of objective poverty, more families **felt worse off** after the death. 30 families with dependent children before and after the death of a partner provided an assessment of recent financial change on both occasions. Before the death, 17 per cent (n=4) felt their financial situation had worsened over the previous 12 months; after the death this proportion had increased to 49 per cent (n=12).

- Widowed parents surveyed by the Childhood Bereavement Network about their experiences of finances, work and childcare described the transitions they faced when their Bereavement Support Payment ended. (90.1% (n=71) said that the payments ending had made it **a bit (33.8%) or much (56.3%) harder to put their children's needs first**.

Poverty as a complicating factor

- Children and young people bereaved of a father suffered a drop in their educational chances if their mothers had only low levels of socioeconomic resources (Prix and Erola 2017, Finland)
- Berg et al (2015, Sweden) found that much of the association they found between parental death and lower grades and school failure was associated with family socioeconomic position and parents' psychosocial factors.
- A study exploring factors affecting children's mental health difficulties following the death of a parent (on average 10.4 months previously) did not find an association with family income over the last year. The authors suggest that this '*may indicate that the drop in income rather than the level of income per se is more predictive of bereaved children's mental health problems*' (Braver, Gonzales, Wolchik, & Sandler, 1989).

The making by children and young people of a positive contribution to society

Life satisfaction

- The death of a grandparent or other close family member was associated with children having **low life satisfaction** at the age of 7. This finding held, whether or not the children were showing emotional or behavioural difficulties (Parkes et al 2014, Scotland).

Self-esteem

- Two years after the death, Worden (1996, US) found a large and significant difference between bereaved and non-bereaved children's self-esteem, with bereaved children reporting significantly **lower self-worth**. This difference was not apparent one year earlier, and can be seen as a 'late effect' of bereavement.

Self-efficacy

- Worden (1996, US) found that bereaved children felt **less able to effect change** in what was happening to them (locus of control) than their non-bereaved counterparts. This was true one year after the death, and the difference was even more so two years afterwards.

Maturation and growth

- Worden (1996, US) found that boys and adolescents were most likely to report that they felt they had **matured** through the death of their parent
- Brewer and Sparkes (2011, UK) interviewed 13 young people who had been bereaved of a parent, exploring the positive changes and themes of **post-traumatic growth** in their accounts. These included
    - **positive outlook** – reframing events positively
    - **gratitude** – learning to be grateful for what they do have
    - **appreciation of life** – cherishing life
    - **living life to the full** – pushing themselves beyond their comfort zone
    - **altruism** – using their experiences to support others.
- Wolchik et al (2008, US) found that over the six years following a death, coping processes including active coping and beliefs that coping would work, along with seeking support from the surviving parent, accounted for improvements in several areas of growth including **developing new areas of interest, accepting help from others, and coming to a realisation of personal strength**.

Criminal and disruptive behaviour

- The death of a parent by the age of 26 increased the risk for **violent criminal convictions** among offspring of parents who died of suicide, accidents and other causes. The risk did not differ by the way the parent died, nor by the age of the child when their parent died (Wilcox et al, 2010, Sweden).
- Bereaved children and young people are **over-represented in the criminal justice system**. Studies suggest that around 4 per cent of the current general population of 11- to 16-year olds have been bereaved of a parent (Harrison and Harrington, 2001, UK) compared to
    - 10% of prisoners who were convicted of a grave crime when they were children (Boswell, 1996, UK)
    - 13% of young people under supervision by YOTs (Youth Justice Trust, 2003, UK)
    - At least 17% of persistent young offenders (Vaswani, 2008, UK).

A study of the bereavement experiences of young men in HMYOI Polmont found high rates of traumatic and multiple bereavements (Vaswani 2014, UK).

What do children need following a death?

Following his longitudinal study of bereaved children and young people, Worden (1996, US) concluded that most will need

- Adequate information
- Fears and anxieties addressed
- Reassurance they are not to blame
- Careful listening
- Validation of individuals' feelings
- Help with overwhelming feelings
- Involvement and inclusion
- Continued routine activities
- Modelled grief behaviours
- Opportunities to remember.

Ideally, children's needs are met in a stable and supportive family, with the help of their usual networks such as school and community groups. Children's outcomes are closely related to how their surviving or bereaved parent is coping. Yet while parents are grieving themselves it can be a huge strain to continue routines and remain available to their children. Following the death of a partner, they will be adjusting to new responsibilities of life as a single parent: the death of a child poses different challenges. When a child's main carer dies, they may have to move to be brought up by a more distant family member or friend, which brings additional pressures.

As shown in the previous chapter, when children and young people's support needs go unrecognised, bereavement and the changes that accompany it can make them more vulnerable to poor outcomes, particularly in disadvantaged circumstances.

What is needed?

As part of its *Grief Matters for Children* campaign, the Childhood Bereavement Network has set out the support that should be available in each local area (CBN, 2017). To underpin the support of families, friends and communities, local children's and health services should work with other services in each area to make sure

- they know how many children and young people have been bereaved of a parent or carer, brother or sister that year, and what support they need
- all children and young people and their families can access high quality support before and after the death of someone close (see figure 1)
- adults who work with children get training and support to understand how they might help someone who has been bereaved, and when and where to find extra support.

To play their part, each school should have

- Sensitive and flexible people and systems that provide support and information for pupils when someone dies
- Opportunities to learn about death and bereavement as part of life.

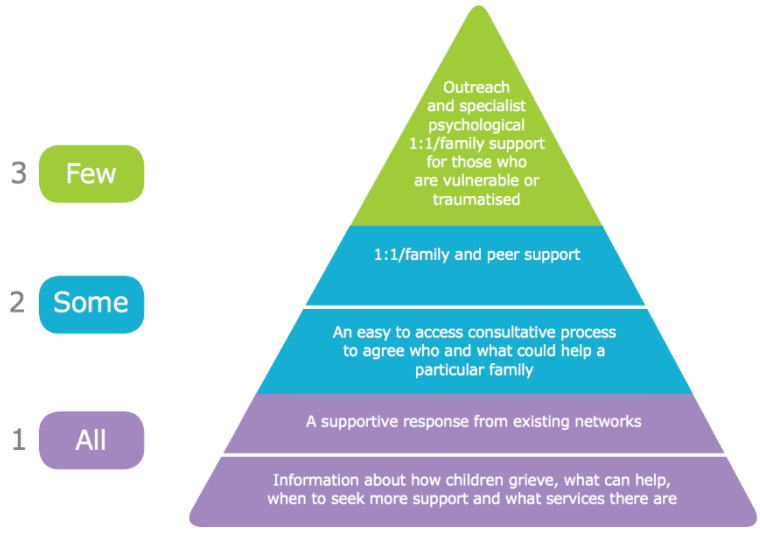

Figure 1: what good provision looks like for bereaved children, young people and their families

Support in school

Pastoral support

The value of support in school

- In a sample of 8 to 18 year-olds whose sibling had died 3-12 months previously, Sharp et al (2018, US) found that school-based social support may enhance the positive effect of parental support for bereaved siblings and, in the case of peer support, compensate for low parental support. Specifically, support from parents, close friends and teachers was associated with more grief-related growth, and support from parents and peers other than friends was associated with fewer grief symptoms. Support from close friends and teachers also seemed to accentuate the positive effect of support from parents on children and young people's grief. Peer support also seemed to buffer the effect of low parent support for older young people, but not for younger children.
- When asked who they would turn to if someone close to them died, a sample of 31 12-18 year olds in one large Scottish secondary school were most likely to say parents (87%) and friends (65%), followed by siblings (52%) and grandparents (48%). 19% anticipated turning to teachers. A much greater proportion of teachers than parents or young people identified school as a potential source of support (Scott et al 2019, UK).
- McLaughlin et al (2019) have summarised the evidence on schools' supportive response to bereaved pupils, finding it patchy. Although their policy findings relate to the English education system, the report has relevance for the other UK nations.

How schools respond to bereaved pupils – views of pupils

- Among 32 adolescents bereaved by the suicide of a close family member or friend, many were satisfied with the care and support they received in school, others found this inconsistent and 32% wanted more support. Those pupils who felt that teachers did not believe their experiences or felt they were taking advantage of the situation had particular difficulties. Some acknowledged that offers of support needed to be repeated (Dyregrov K, 2009, Norway).
- Looking back on their experiences of bereavement before the age of 16, 14 young adults reported inconsistent support in school (Abdelnoor and Hollins 2004b, UK).
- Focus groups with 39 parentally bereaved young people aged 9 to 17 revealed that The study found that they struggled to reconnect with classmates following the return to school and often feel alone, that schools fail to have guidelines in place for what students are allowed to do if becoming sad in class, and that schools seem to forget their loss as time passes (Lytje 2018, Denmark).

How schools respond to bereaved pupils – views of school staff

- Among a sample of schools in Hull and North Suffolk, 83-90% rated bereavement as an important or very important priority (Holland and Wilkinson, 2015, UK). 39% of the Hull schools and 23% of the North Suffolk schools had a formal policy, and 39% and 50% respectively reported having an ad-hoc response after a death. 41-45% of the schools had an individual responsible for the area of bereavement, and 57% and 35% respectively reported that staff had had training in the area.
- 8 primary and 5 secondary school teachers in south-east London were interviewed by Lowton and Higginson (2003, UK) who found that their capacity to respond to bereaved pupils was influenced by a general silence around bereavement in British society, the levels of deprivation and mobility among pupils and their families, and a lack of information from families about pupils' experiences. Teachers expressed anxiety about managing different faiths' responses to death, and those in secondary school also expressed some worry about upsetting students further. The most common ways in which teachers responded to bereaved pupils were to involve outside agencies and involve the family (generally more straightforward for primary than secondary schools), and to

use practical steps such as time out cards, contact books and memorial activities. Teachers felt they had to be strong, even when they were distressed themselves.

- Among 138 respondents to a survey of school personnel, around 70% agree to some extent that grieving students are overlooked in school, and more than 90% acknowledge that teachers should take the initiative in relation to bereaved students, and more than 90% acknowledge they know too little about how to support them. Those with experience of actually supporting bereaved pupils indicated more knowledge about how to support and were less afraid of showing their own feelings (Dyregrov et al 2013, Norway).
- 22 Norwegian teachers and headteachers (evenly split between primary and secondary schools) took part in focus groups and highlighted a new societal discourse allowing more discussion and attention on bereaved children's needs. They noted that parents were more likely to inform them about relevant bereavements than in the past. They highlighted school as a safe place for bereaved children, but were wary of being asked to take on too much of the psychosocial support of grieving pupils, because of a lack of expertise and an increase in rigidity in the school life (Dyregrov A et al 2013, Norway). They identified the importance of bereavement action plans, with most being aware that these existed but less sure what they contained. They also recommended resources and clarification of roles, and the importance of care, availability and communication. They made practical suggestions of adaptations to the school's requirements to take account of individual bereaved children's needs. They wanted a stronger focus on bereavement and greater knowledge of how to help (Dyregrov K et al 2015).
- 12 teachers in a qualitative study described how they needed to show flexibility in supporting individual bereaved pupils, across six continuums: maintaining or adapting normal practice; openness in talking about the bereavement, providing/not providing direct emotional support and/or encouraging the student to seek support elsewhere, the levels of emotion experienced in relation to working with the adolescent, choosing whether to share their own experiences, and communicating with the remaining family members. Prior experience helped teachers manage their uncertainty and accept their own emotions (Lane et al 2014, UK).
- An internet survey of 967 teachers explored the strengths and weaknesses of the Danish Bereavement response plans, in place in 96% of Danish school to help teachers support grieving pupils. While the plans helped teachers feel more confident in supporting pupils, this comes at a potential cost of generalising children's needs in grief so that they fit into the school support system. While they are helpful in securing initial support for children, their usefulness seems to diminish over time. The system could benefit from being updated, and future plans paying greater attention to the experiences of bereaved students who have experienced the system (Lytje 2017, Norway).

Staff training

- Teachers in a number of studies identified the value of or need for (more) training in child bereavement (Alisic 2012; Lane et al 2014, UK; Dyregrov et al 2015; Holland and Wilkinson 2015).
- An action research project involving a hospice and teachers, parents and pupils from two primary schools identified education and training as a key practice innovation that would be a useful output from a partnership. The Hospice could not support all bereaved children in its catchment area and so transmitting knowledge to staff and parents was a practical way of helping school communities to manage death, dying and loss experiences (Paul et al 2016, Scotland).
- 89 per cent of teachers (n=281) said after a short, targeted school training they had learned new strategies to support bereaved children. An increase in confidence around recognising, acknowledging and responding bereaved children was also shown. 6 to 18 months after participating in the training, focus group participants said their confidence and skills had increased as a result of the training, and a greater language to talk to children about what had happened (McManus and Paul, 2019, Scotland).

Partnerships with other services

- School staff in a number of studies describe how they draw on external agencies or would like to do so (Holland and Wilkinson 2015; Dyregrov et al 2013)
- Other practice innovations emerging from Paul et al's (2016, Scotland) action research project between a hospice and two primary schools included curriculum development, provision of information about the hospice for fundraising events, parent/carer bereavement workshop and a bereavement policy.

CBN's *Grief Matters for Children* campaign (2017) sets out:

> Up to 70 per cent of primary schools have at least one recently bereaved pupil on their roll (Holland 2001, UK). To promote the well-being of bereaved children and young people, a lead person should take responsibility for ensuring that pastoral support is proactive, flexible and involves:
>
> - checking with the child and their family how they would like support to be provided
> - a system for managing and communicating important information about a bereavement, including across transitions from one class or school to another
> - bereavement being included in relevant plans and policies
> - staff training and support to increase their awareness and confidence, helping them understand how to respond helpfully, and where to get extra support
> - swift and easy referral to a range of specialist provision
>
> Schools which have experienced a death in the school community often wish they had been better prepared. Setting out clearly how the school will respond to the death of a pupil, parent or staff member or a critical incident can be very helpful if and when it happens.

Death education - curriculum development

- 80% (n=119 parents) and 63% (n=142) teachers of Irish primary-school children supported the view that death should be discussed with children before they encounter it. 72% of parents and 70% of teachers agreed it was a suitable topic for a life skills programme. Only 11% of parents and 21% of teachers thought that the topic would scare children. Teachers (40%) were more likely than parents (23%) to believe that teaching about this topic this would interfere with the role of parents. Overall, 90% participants agreed that further training would be helpful to teachers in preparing to teach this topic.
- Among 108 parents and 37 staff in one large Scottish secondary school, families were identified as being the best people to engage in discussions with young people about loss and death. A large majority of teachers (85%) and a smaller percentage of parents (65%) also saw teachers as being appropriate to have these conversations. (Scott et al 2019, Scotland).
- Almost half (48%) of respondents to a representative Child Bereavement UK YouGov poll (2016, UK) agreed that topics on death and bereavement should be included in the compulsory primary school syllabus.

CBN's *Grief Matters for Children* campaign (2017) sets out

> Given the numbers of children who will experience bereavement during childhood, there is a strong case for them to learn about common feelings and reactions to loss, coping strategies, and where to seek help. This could improve peer support between children, reducing the isolation – and outright bullying – which some can experience following a bereavement, and helping children to find help for themselves or their friends.

Children and young people are naturally interested in death and bereavement and often raise questions about this issue. Many young people – including those who haven't been bereaved – are keen for death and bereavement to be incorporated into the curriculum although they are clear that this needs to be handled sensitively.

75% adult respondents to a CBN survey said they wished their school had taught them about coping with bereavement. These topics can be covered in health, wellbeing and relationships education: other opportunities exist in the RE, citizenship, English and biology curricula.

As with other sensitive topics, teachers are often anxious about addressing death and bereavement in the classroom. Lesson plans, guidance and training are available from local and national child bereavement services, which can help staff deliver lessons effectively and confidently.

Bereaved young people's suggestions about what could help to make school a good place to learn about death and bereavement included teachers checking with young people who've recently been bereaved whether they are happy to join in the lesson, no pressure to talk about personal experiences, somewhere quiet to go or someone to talk to after the lesson if they are feeing upset, telling them where they can get further help and support.

Services for bereaved children

High quality support

CBN's *Grief Matters for Children* campaign (2017) sets out:

> All services working with children and families and with death and dying have a role to play in supporting grieving children and those caring for them. This includes schools, children's centres, hospitals, hospices, GPs, CAMHS and specialist childhood bereavement services.
>
> The Childhood Bereavement Network believes that all bereaved children and their families should be able to access high quality support easily, wherever they live and however they have been bereaved.
>
> These local specialist child bereavement services offer direct support to children and families as well as ancillary services such as training and consultancy. Some work with particular groups (e.g. the children of patients at a particular hospice), while others work with all children, whatever the cause of death, be it anticipated, sudden, violent or traumatic.
>
> Services work with families to assess how the children are doing, whether extra help is needed, and what type of support would be best. This tailored support builds on families' strengths and prevents difficulties from escalating. For children or parents with mental health difficulties that pre-date or accompany their bereavement, onward referral to psychological therapy services may be most appropriate.
>
> Figure 1 (p19) outlines the support that should be available, who is likely to need it, and who should provide it. This maps on to the 3-component model of support recommended in the NICE guidelines.
>
> Local children's services and health services should
>
> - include bereaved children and young people among potentially vulnerable groups whose diverse needs should be assessed
> - plan and commission services in response to the needs identified
> - include bereavement support in plans for children who are already vulnerable (e.g. those in custody, those in public care).
>
> Inspection frameworks for children's services should examine how well bereavement support is provided locally.

Which children need organised bereavement support?

Around one third of bereaved children and young people will have emotional or behavioural difficulties that would warrant referral to mental health services at some point over the two years following the death (Worden, 1996, US). The proportions of children experiencing difficulties at this level may be as high as 40% among those attending childhood bereavement services (Lin et al, 2004, US).

Worden (1996, US) argues that there are three ways of deciding who should have access to childhood bereavement services:

- Offering services routinely to all children. He suggests this is costly and unnecessary.
- Waiting until children are showing high levels of distress, and then offering services. He rejects this on ethical grounds: Stokes et al (2009) also warn that some behaviours get children 'noticed' and referred (eg aggression at school), while other behaviours (such

as being withdrawn) are equally indicative of a child who is struggling with their grief but are less likely to get them referred.

- Screening children to identify those most at risk following their bereavement, and offering them services (his preferred model)

Stokes et al (1999) argue that there is currently no screening tool so sophisticated that it can discriminate accurately those children who might benefit from a service at some point by testing them at a particular point in time. **They favour offering a different model of support to any bereaved child in a particular community**. They describe this as community-based and non-stigmatising. They use ante-natal services as a simile for the time of support they envisage: support that is offered routinely to all people to help them prepare for a major life transition. This, they argue, can have benefits for any bereaved child or young person and their family.

Rolls (2010) suggests that the philosophy underpinning service provision in the UK is support for a journey, rather than a model of 'recovery' which is more typical of US provision.

What can help?

Haine et al (2008, US) outline the factors that evidence suggests affect children's bereavement, and which can be influenced by programmes of intervention. These are:

- **Increasing the child's self-esteem**
- **Increasing the child's healthy control beliefs**: ie helping them to give up the belief that they can control things that actually they have no control over, and strengthening their belief that they can influence things that they do have control over.
- **Improving the child's coping skills** – using active coping strategies and strengthening the belief that coping skills will work in difficult situations (coping efficacy)
- **Supporting adaptive expression of emotion that the child wishes to express**:

> The existing research suggests that although there is little evidence that cathartic expression of emotion is necessary for all children, that when children feel they must inhibit the expression of negative emotions they would like to express, they are more likely to experience greater mental health problems.
>
> Ayers et al, 2000, p5, US)

- **Facilitating a positive parent-child relationship** with open communication and a balance of warmth and effective discipline.
- **Reducing parental distress** through giving coping strategies and support, and through helping parents to protect their children from being overwhelmed by parental distress

> Parents were taught that while they did not need to hide their distress from their children, they should try to reassure their child...that although they are sad and upset now, that they or the family is strong and will get through this with time
>
> Haine et al 2008, p7, US

- **Increasing positive family interactions**: supporting families to have fun together.
- **Reducing child exposure to negative life events** and also supporting parents to prepare children for forthcoming changes.

Stokes (2009 p14, UK) outlines priorities for practitioners in promoting resilience among bereaved children.

- Enable a child to **construct a coherent narrative** that will grow and develop with them *'often resulting in a re-referral and the need for open-ended child bereavement services'*.
- Develop cognitive and behavioural strategies to help a child **rewrite negative scripts.**

- Help the child to develop **effective communication strategies** to use with their family and friends about their bereavement.
- Ensure the child has an **age-appropriate understanding** of the dual process model to help understand their grief journey.
- Provide opportunities for bereaved children to **develop empathy and have a positive connection with others who have been bereaved**, both directly and indirectly.
- Create **non-pathological services that are appealing to children.**
- Help children to feel **understood and confident with their peers and teachers at school.**
- Include **services for parents and carers.**
- Create services that **build family cohesion and adaptability** to this and secondary losses
- Provide activities that encourage children to **secure and maintain continuing attachments to a parent, brother or sister who has died**.

What do we mean by 'high quality' support?

All Childhood Bereavement Network members believe that all children and young people have the right to information, guidance and support to enable them to manage the impact of death on their lives. We believe that any information, guidance and support offered to children should:

- acknowledge the child's grief and experience of loss as a result of death
- be responsive to the child's needs, views and opinions
- respect the child's family and immediate social situation, and their culture, language, beliefs and religious background
- seek to promote self-esteem and self-confidence, and develop communication, decision-making and other life skills

If this information, guidance or support is offered as a service by an organisation or in a professional context, it should be:

- provided by people who have had appropriate training and are adequately supported
- provided in an appropriately supportive, safe and non- discriminatory context
- regularly monitored, evaluated and reviewed.

For more information, please see the CBN *Guide to developing good practice in child bereavement services.*

The impact of support

Stokes and others (1999) and Rolls (2011) outline some of the complexities involved in evaluating the effectiveness of child bereavement services. Rolls and Penny (2011) report on a mapping of evaluation work going on across the UK.

What do children and parents report about the benefits of organised support?

Braiden and others (2009, UK) interviewed six children and six parents who had taken part in an intervention for those bereaved by suicide. All the children reported being very glad to have attended, and that their aims had largely been met. They described knowing more about the causes of suicide and why people decide to take their own lives. Many had expressed a desire for the family to be able to spend more time talking about their loved one, and to feel more confident in telling people how the person had died. They reported feeling their families had benefited in that they had a chance to talk about the person and that this would continue in the family home. They reported feeling 'less alone', 'more confident' and 'happier'. They felt more able to cope with their worries and understood more about others' grief in the family.

Parents had largely attended to meet others, help their children understand, learn new coping strategies and enable their family to talk more openly and honestly about the death. Themes of the benefits of the residential group included the opportunity to talk to others with similar experiences, feeling better equipped with coping skills, developing new friends and social supports, understanding suicide better and feeling more equipped to manage their children's grief. They reported their families talking more.

Rolls and Payne (2007, UK) interviewed 24 children and 16 parents who had taken part in group and/or one-to-one interventions. Children and young people expressed relief about feeling less isolated and having the chance to talk about things they were worried about, without fear of upsetting someone. They understood more, and were less anxious about what had happened to them or the person who had died. Parents reported finding it helpful to be with others and consoled that they weren't alone with their experiences. They felt supported in their own grief, helped to cope and to release feelings, giving them space to think about what had happened and about the future. This gave them more confidence and made them better able to support their child, reassuring them. They felt the family was more able to communicate about what had happened and how they were feeling.

How effective are interventions with bereaved children?

Currier and others (2007, US) carried out a meta-analysis of the outcomes of interventions with bereaved children. This included 13 published controlled studies (i.e. those that compared children receiving a service with those not receiving a service). Overall the authors found that 'child grief interventions do not appear to generate the positive outcomes of other professional psychotherapeutic interventions' (p. 253). They suggest that interventions were more effective if they happened closer to the time of the death, and if children were selected for the intervention because they were showing more difficulties.

Rosner and others (2010, US) also carried out meta-analyses – one on controlled studies and one on uncontrolled studies – including 27 studies in total. They found small to moderate effect sizes, and that interventions for young people who were 'symptomatic or impaired' showed larger effect sizes than those for all young people. Particularly promising models included music therapy and 'trauma/grief focused school-based brief psychotherapy'.

The Family Bereavement Program at Arizona State University has been extensively evaluated and some of the children and families who participated have been followed up for six years. The findings of this six-year follow-up were published too late to be included in either the Currier and others (2007) or the Rosner and others (2010) studies. The program is a group

intervention for parentally bereaved children and young people (aged 8–16) and their surviving caregiver, who met in separate groups for 12 two-hour sessions, some of which included joint activities for the whole family. Each family also had two individual family meetings. The program targeted multiple factors theorised to be risk and protective factors for the course of children's grief (Sandler and others 2003, US). The program was evaluated, comparing those who took part with those who did not.

- Immediately after the intervention effects were found on a range of outcomes including more positive parenting (caregiver warmth and discipline) and improvements in parental mental health; a reduction in secondary stressful events involving the children; more positive interactions between the parent and child; more positive coping among the children and less of a sense that they had to inhibit the expression of their feelings (Sandler and others 2003, US); and less problematic grief (including disturbing or intrusive thoughts, and impaired functioning) (Sandler and others 2010a, US).
- Eleven months later the effects of the program showed on children's mental health, lessening symptoms of anxiety and depression among those who had more difficulties when they joined the program, and reducing internalising and externalising problems among girls. Participants also showed reduced parental mental health difficulties and less inhibition of expression among children, along with improved children's beliefs about the control they had over life and circumstances. Positive parenting also improved for those who had lower scores when they entered the program (Sandler and others 2003, US).
- Six years later the program effects on reducing problematic grief were maintained (Sandler and others 2010a, US) and new program effects had emerged, meaning that children who participated had improved self-esteem and reduced externalising problems, compared with those who had not taken part. None of the earlier interaction effects of gender or initial level of problems were significant at the six-year follow-up (Sandler and others 2008, US). The program also reduced social detachment/insecurity among boys, older young people and those with fewer problems on entry (Sandler and others 2010a, US). The program improved educational expectations for children with fewer behaviour problems at program entry, and average grades for younger children (Schoenfelder and others 2014, US). The programme also appeared to prevent the development of problems with cortisol secretion associated with externalizing problems (Luecken and others 2010, US).

An uncontrolled study of a group intervention offered universally and preventatively by a UK child bereavement service found a small to medium-sized decrease in symptoms (Siddaway 2014, UK).

An uncontrolled study of another UK service offered specifically to children and young people bereaved by murder of manslaughter found statistically significant improvements in behaviour and emotions as reported by parents and carers (specifically: hyperactivity, emotional problems, conduct problems and total problems). Trends in improvements to peer problems and pro-social behaviour did not reach statistical significance (Trickey and Nugus, 2011, UK).

The policy context

Bereavement affects many areas of children and young people's lives, and so it is not surprising that the policy context is quite diverse, with no one government department having responsibility for meeting bereaved children's needs. This brings some challenges to coordinating support, but it also brings opportunities to make sure that bereavement is included across different policy areas.

This chapter summarises some of the national strategies and action plans that are particularly relevant to bereaved children and young people, in the areas of

- Overarching strategies
- Bereavement care
- Mental health
- End of Life Care
- Support after suicide

Overarching strategies

- **Health and Wellbeing 2026: delivering together** (2016) sets out a strategic vision to underpin a new model of person-centred care focussed on prevention, early intervention, supporting independence and wellbeing.
- The **Draft Northern Ireland Programme for Government** (2016-2021) sets out the former Executive's intended outcomes of societal wellbeing, and indicators for how these would be measured. Outcome 8 is 'we care for others and we help those in need' and Outcome 12 is 'we give our children and young people the best start in life'.
- The **Children's Services Co-Operation Act (NI) 2015** aims to improve co-operation amongst Departments and Agencies and places a duty on Children's Authorities to co-operate where appropriate as they deliver services aimed at improving the well-being of children and young people.

  The Act requires the Executive to develop and adopt a strategy which sets the strategic direction with a view to achieving improvements in the well-being of children and young people in NI. Wellbeing is defined as

  - physical and mental health
  - living in safety and with stability
  - learning and achievement
  - economic and environmental well-being
  - the enjoyment of play and leisure
  - living in a society in which equality of opportunity and good relations are promoted
  - the making by children and young people of a positive contribution to society
  - and living in a society which respects their rights.
- In line with the Act, the **Draft Northern Ireland Children and Young People's Strategy** (2019-2029) has been developed. On behalf of the Northern Ireland Executive, the Department of Education has lead responsibility for developing the Strategy. Its aim is '*To work together to improve the well-being of all children and young people in Northern Ireland - delivering positive long lasting outcomes*'. The draft Strategy sets out

  > The Strategy will place specific emphasis on prevention and early intervention (both intervening at an early age and/or at an early stage in a problem) and on children

> and young people who need our help most….We should do our best to prevent our children and young people from going through periods of suffering, difficulty and hardship as this diminishes their own childhood and affects their life chances for adulthood.
>
> Evidence clearly demonstrates that intervening early and focusing on preventative actions can improve outcomes for children and young people and result in savings for public expenditure. It is more difficult and more costly to intervene later when issues have become more entrenched or complex.
>
> Draft Northern Ireland Children and Young People's Strategy P26

- The draft Children and Young People's Strategic Partnership (CYPSP) **Northern Ireland Children and Young People's Plan 2019-2021** is out for consultation at the time of writing. CYPSP is a multiagency strategic partnership, consisting of senior leaders of all key agencies across statutory, voluntary and community sectors that have responsibility for improving outcomes for all children and young people in NI.
- Also anticipated are a cross-departmental Family and Parenting Support Strategy, and a **Looked After Children Strategy**, both of which have been out for consultation.
- **Making Life Better: A Whole System Strategic Framework for Public Health in Northern Ireland (2013-2023)** (Department of Health, June 2014). This Framework includes a theme of 'giving every child the best start in life' with key outcomes of good quality parenting and family support, healthy and confident children and young people and children and young people skilled for life.

Bereavement care

- **Northern Ireland Health and Social Care Services Strategy for Bereavement Care** (2009) is the strategy for bereavement in HSC services. The strategy acknowledges that professionals surveyed to help its development found talking to bereaved children to be one of their most difficult tasks, although supporting bereaved children is not an explicit part of the strategy. The strategy is organised around: (1) Raising awareness; (2) Promoting safe and effective care; (3) Communication, information and resources; (4) Creating a supportive experience; (5) Knowledge and skills; and (6) Working together.

Mental health

- **Mental Health in Northern Ireland: Overview, Strategies, Policies, Care Pathways, CAMHS and Barriers to Accessing Services** (Jan 2017) sets out the policy context for improving children's mental health, including a stepped care approach to CAMHS in response to the Bamford Review and the 2011 Review of CAMHS published by the Regulation and Quality Improvement Authority.
- **The Stepped Care Service Model for Child and Adolescent Mental Health Services (CAMHS)**(2012) is the preferred regional model for the organisation and delivery of mental health services and support for children and young people. The steps are targeted prevention, early intervention, specialised intervention services, integrated crisis intervention child and family services and inpatient and regional specialist services.
- **"Still Waiting". A Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland** (Sept 2018) This report from the Northern Ireland Commissioner for Children and Youth (NICCY) assesses the adequacy of mental health services and support for children and young people, using a children's rights framework. A number of young people who took part in the review identified bereavement as a risk factor and root cause of mental health difficulties. The review makes a number of recommendations about support and services.

End of Life Care

- **Providing high quality palliative care for our children: a strategy for children's palliative and end-of-life care 2016-26** (2016) objective 13 sets out that 'A range of bereavement support should be available in a timely manner to meet the specific needs of families who have experienced the death of a child. Every family should be offered practical advice about their availability by a professional who is already known to them.'

  'Bereavement support will need to take account of each individual family's journey and experience. It should be flexible enough to respond to a range of needs, and families should have the option of individual or group-based support. It should be recognised that families may need such support for years prior to and following their child's death.' (p23).

Support following suicide

- **Protect Life 2** is the draft suicide prevention strategy. The Department of Health developed and consulted on the strategy in 2017 and published a **response** to the consultation. The final strategy will require ministerial approval. Objective 6 in the draft strategy is 'Ensure the provision of effective and timely information and support for individuals and families bereaved by suicide', with the draft actions below:

  - continued support for bereaved families representative groups to enable them to influence policy and service design and delivery
  - provision of effective and timely services and information for those bereaved by suicide
  - awareness raising with health and education providers of increased risk of suicide and self-harm by those bereaved by suicide.

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