

The **CHILDHOOD BEREAVEMENT NETWORK** (CBN) is a multi-professional forum and the national co-ordinating body in the sphere of bereavement care for children and young people.

The CBN is supported by all the major bereavement care providers including Cruse Bereavement Care, Marie Curie Cancer Care, the Child Bereavement Trust, Winston's Wish, ChildLine, Barnardo's and St. Christopher's Hospice [Hospice Information], and has approximately 250 members across England and the UK; c. 70% are organisations. Most of these organisations operate in the voluntary sector, and have charitable status. All members subscribe to a *CBN Belief Statement* that states,

"all bereaved children and young people have the right to information, guidance and support to enable them to manage the impact of death on their lives."

Approximately 53 children a day are bereaved of a parent in the UK, equating to around 20,000 bereaved children and young people each year.¹

Since the establishment of the CBN in 1998, significant achievements have been:

- the establishment of a 'virtual' national network to link disparate organisations and individuals working with bereaved children/families in both voluntary and statutory sector settings.
- The achievement of consensus within the sphere of a set of *CBN Guidelines for Best Practice*. Previously, there was no common agreement on key principles for quality care.
- Delivery of an annual programme of regional seminars and focus groups, plus a national conference. To date, 100+ training and networking events have been hosted by the CBN.
- A mapping exercise in 2002 of accessible specialised bereavement support services in England [funded by the Children & Young People's Unit] and the subsequent launch of an online *CBN Directory* [www.ncb.org.uk/directory].

The CBN is currently funded by the Community Fund [Strategic Grants, England] to:

- run a campaign to develop bereavement support services for children and families;
- further develop into detail the *CBN Guidelines for Best Practice*, alongside the design and implementation of a self-assessment quality assurance system [subject to funding];
- increase the capacity of the CBN and its members to share/disseminate information, promote good practice and increase awareness, to include the compilation of a resource pack on developing a support service for bereaved children and families;
- ensure common policy development so that childhood bereavement is included in all key government initiatives.

¹ Statistics supplied and verified by Winston's Wish, a bereavement support service for children and young people.

THE ISSUE

In a study published in the *Journal of Adolescence* 2001, 24, 159-169, from a study group of 1746 adolescents surveyed in a secondary school, 1355 (or 77.6%) reported that at least one of their first or second degree² relatives or close friends had died.

The death of a parent, sibling or other close relative or friend can have a devastating impact on the life of a child or young person, and their family. Bereavement and loss can significantly diminish a child's resilience and affect their emotional and physical health in both the short and long term.

At key transition points in their life, bereaved children will revisit and reassess the impact of the death. These periods of readjustment - which may occur years after the death or loss - may also affect their physical and mental health, and/or behaviour. Bereaved children are particularly vulnerable to being bullied and to school exclusion.

The death of a significant member may also have an adverse, traumatically disruptive effect on family dynamics, relationships and functioning.

- "We're worried about Dad – he doesn't wash, he's always in the pub. I try to wash and iron like Mum. I do a paper round so I've got some money for food."
- "Dad's only like this because Mum died. He cries a lot and then goes to the pub. He only beats me after that."³

There is increasing evidence that the experience of bereavement – if not properly acknowledged and supported - can lead to negative outcomes for children, young people and their families, and may have an adverse and enduring impact on emotional and physical health. Unfortunately, lack of research and comprehensive statistical data has inhibited informed debate on the issue and the development of effective policy and practice in the field of bereavement care for children.

Every child will have an experience of death and bereavement in their life and will need support at some level to manage their response to the loss. As a preventative measure, to actively promote long term physical and emotional well being, the CBN advocates that ALL children and young people should have easy access to a range and choice of information, guidance and support to enable them to manage the impact of death on their lives.

Therefore the Childhood Bereavement Network welcomes this consultation by the Department of Health as an opportunity to highlight priorities and actions which can promote good outcomes for bereaved children and young people.

² In this research, a first degree relative denoted a parent or sibling; other relatives were classed as second degree.

³ Cross, S. (2002) 'I can't stop feeling sad: calls to ChildLine about bereavement', Harrison, H. (ed.) ChildLine

PRIORITY: DEVELOPMENT OF THE EVIDENCE BASE

Bereavement is a cross cutting issue which affects the mental and physical health of children and families in all settings and circumstances. All organisations - across every sector - need to work collectively and internally:

- to collect data on the number of bereaved children in England. This should include the number of bereaved children who are being cared for by grandparents, other relatives or friends, and the number of bereaved children and young people in public care.

A forthcoming literature review, funded by the Joseph Rowntree Foundation, highlights the lack on explicit data on bereaved children. In contrast, the Office of National Statistics calculates and reports annually on children affected by divorce.

- to enable the development of good practice, to promote research into the impact of bereavement on children, young people and their families.

Bereaved children attend their GP more frequently than non-bereaved peers.

It is probable that there is a correlation between bereavement and 'destructive choices; such as drugs, alcohol, tobacco, sex... Early pregnancy [under 18] is 40% more likely in girls who are bereaved of a mother or father. 47% of children bereaved of a parent have tried drugs.

The Youth Justice Trust now identifies 'significant loss' as a factor in the assessment of young offenders. In one study, 41% young offenders were bereaved; others studies have calculated the figure at over 50%.

PRIORITY: DISSEMINATION OF INFORMATION TO INCREASE AWARENESS OF THE IMPACT OF BEREAVEMENT IN CHILDHOOD AND OF WHAT CAN MAKE A DIFFERENCE TO BEREAVED CHILDREN AND FAMILIES

Across all sectors there needs to be recognition that bereavement is a challenging issue for children, young people and their families to manage.

- Increasing awareness of the needs of bereaved children and young is a public health issue and should become the focus of a public health information campaign.
- As employers, across every sector, organisations can make a positive difference to the lives of bereaved children and their families. Organisations should implement action to identify and support any employee caring for a bereaved child or young person. This may imply a widowed parent but many bereaved children are now cared for by grandparents or other relatives.

Research has shown that positive health outcomes for bereaved children are linked to the capacity of the surviving parent or care to nurture and support the bereaved child/children.

Organisations should anticipate need and take steps to collect information about helplines, websites and local bereavement support services and community initiatives that can offer support to a bereaved family. Information and advice should also be compiled

and made available to bereaved employees on practical issues: benefits, financial planning, housing options etc.

Fathers are increasingly being offered paternity leave following the birth of a child. Such an arrangement needs to be in place for widowed parents to enable them to adapt to their loss and changed routines, and to offer support to their children. Overall, organisations should consider the support and care offered to families expecting the birth of a child compared to that which is customarily offered following a death.

- All organisations need to ensure that bereavement is integrated as an issue into all their working practices and policies, through training of managers, supervisors and other key personnel, to enable them to acknowledge, discuss and positively respond to the range of issues being experienced by bereaved employees. This should include training to increase awareness of different cultural responses to death and bereavement, in mourning rituals and religious beliefs, for example.

Winston's Wish, a national grief support service based in Gloucestershire, works with schools to develop a bereavement support plan for bereaved pupils. Such an approach could be adopted within organisations for bereaved employees to include a range of issues, such as different working patterns, help with childcare arrangements, leave of absence, contacts at times of distress etc.

- Organisations also need to ensure that support exists for the personnel who provide support: there should be easy access to guidance, resources and training.

In the Queen's Medical Centre in Nottingham, a Child Bereavement Facilitator - whose post was established via a partnership between the Child Bereavement Trust and the Primary Care Trust - works with staff to develop their skills and generally increase their capacity to support families whose relatives die in the hospital.

PRIORITY: WORKING TOGETHER

The majority of bereavement support services are voluntary organisations and charities. Voluntary sector organisations generally have the capacity to be flexible and responsive to the needs of individuals and communities, and to deliver non-stigmatising, innovative and accessible services. However, securing sustainable and reliable funding which allows consistent delivery of services and high quality of care is difficult for voluntary organisations.

- Bereavement should be included in all key policy initiatives at local, regional and national level, and resources should be made available to support sustainable community bereavement support services for children and young people.

Within the CBN, some bereavement support services are commissioned by PCTs; some receive funding from education or social services departments; other are trust funded. Models of funding and of successful partnership initiatives could be shared, promoted and disseminated across all sectors.

- Public sector organisations need to be aware of community initiatives which support bereaved children, via mapping exercises and established procedures and mechanisms which include community/voluntary sector bodies in planning and policy development.
- Organisations should take a lead and become involved in supporting community initiatives which can help bereaved children and families.

Many services in the Network have formed strong mutually beneficial links with local industry, businesses and community groups [For example, Noah's Ark Trust in Worcestershire, Winston's Wish in Gloucestershire, Jeremiah's Journey in South Devon]. Support is offered through sponsorship, fundraising, donations, secondment, gifts in kind, volunteering, trusteeship etc. Public support of this kind plays a positive role in increasing awareness not just of the service but also of the issues and the needs of bereaved children and their families. Bereavement support becomes acknowledged as a normal compassionate response from a community to families who are experiencing a crisis in their lives.

LEADERSHIP FROM ORGANISATIONS ACROSS EVERY SECTOR

- All organisations should take a lead in changing attitudes to death within society, and creating a culture in which bereavement is acknowledged as a public health issue.