

Response to

When a patient dies - Advice on developing bereavement services in the NHS

Introduction

The Childhood Bereavement Network

The Childhood Bereavement Network 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 and has approximately 280 members across England and the UK; c. 70% are organisations. Around 15 of our members are based in hospitals. 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". The CBN is hosted by the National Children's Bureau.

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, over 120 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].

This issue of childhood bereavement

Between four and seven percent of children are bereaved of a parent before the age of sixteen. Winston's Wish has estimated that 20,000 children are bereaved of a parent each year, or one child every half an hour. It is not just parental death which affects children and young people but also the death of a sibling, friend, grandparent or someone else close to them. 78% of one survey of 11-16 year olds reported having been bereaved of a first or second degree relative or friend.

Many children are bereaved suddenly: of the children with whom Winston's Wish worked in 2001-2002, 38% had been bereaved through an anticipated death arising

from chronic conditions including cancer, motor neurone disease and multiple sclerosis, while 62% of the deaths were unexpected including RTAs, heart conditions, murder and suicide. As the organisation says, even those deaths which were medically expected may have come as a shock and surprise to children involved.

This document

This response makes some general comments and then answers the questions laid out in the consultation document, commenting on particular paragraphs. The response concludes with some ways in which the Childhood Bereavement Network can contribute to taking this work forwards.

Quotes in this response are taken from three videos made by the Childhood Bereavement Network with the help of staff and young people at member services: the St Christopher's Candle Project, Jigsaw4U, Penhaligon's Friends, Chums Child Bereavement Service and the Northampton General Hospital Trust Child Bereavement Service.

The Response

General comments

Overall, we welcome this guidance and the efforts to improve services provided by NHS Trusts to bereaved families, including children and young people.

We also welcome the statements throughout which refer specifically to provision for children and young people, and feel that these sections could be usefully expanded. Some of the children we have spoken to felt that their access to help and support from an NHS trust before and after the death of a relative was compromised by their age:

'I couldn't really see him a lot, not that much, because they said I was too young and that.'

'We were talking about hospital nurses, doctors, surgeons, whatever, they could have been more helpful. Maybe more kind, told you more information, not so blunt.'

'The nurses didn't talk to me, they didn't help, they just walked about with needles and things. They could have told me what was happening and said what was going to happen, instead of just walking past me.'

'Also in hospitals to help they should let children visit their parents or if someone's died in their family, because they can't like read minds and say 'oh, dad's going to die'. I think they should let you visit say a person in your family who's ill much more than usual.'

Providing bereavement information and support to children and young people is certainly a matter of equality of provision, as suggested in the Advice part 1

paragraph 44. However, it is also a way of contributing to the *Every Child Matters* agenda, helping children and young people to achieve the five outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being. In particular, it will help to achieve the government's aim of children 'developing self-confidence and dealing successfully with significant life changes and challenges.'

Does the advice clearly set out the essential elements of a good bereavement service?

Ongoing support

We felt that there was some confusion about the terminology used in the Advice. The term 'bereavement service' suggests ongoing, long-term support to bereaved people, whereas the majority of the Advice discusses support (largely practical) around the time of death.

Two possible ways of resolving this fundamental tension might be

1. expanding the sections of the Advice which refer to the provision of ongoing support by the Trust to bereaved families. As it stands the Advice does not provide sufficient information to establish an ongoing support service.
2. expanding the sections of the Advice which refer to working in partnership with other providers of bereavement services in the community, and being more explicit about limiting Trust based bereavement support to the immediate aftermath of a death.

The majority of the Advice seems to favour the second approach, but we feel that this needs to be made clearer.

Supporting communication within the family

Some families may be uncertain about how to talk about death and bereavement with the children and young people in their family. Anecdotal evidence refers to the widespread use of euphemisms designed to protect children but which may serve to confuse them: children searching for someone described as 'lost', or fearing that they may be lost themselves, children being scared when asked if they would like to see a relative's 'body', as they are confused about what has happened to the person's head.

We felt that the advice could be much fuller around supporting communication, for example supporting parents in answering their children's questions, talking about suitable language to use in talking with children, helping the family to make a decision about how children will be involved in the funeral. Young people are clear about their need to be given a choice about being kept involved and informed:

'Two days before he died I went to see him and before I went everyone was telling me he was OK and I went to see him and he was wired up to every machine possible and that just made me even more upset to feel that nobody could trust me to tell me. It felt to me as if they couldn't tell me and I wanted to know.'

while one young person was clear about the need for direct support from staff:

‘Even if you’re not allowed to see them [the patient] so often, there should be someone to support you. I know you have your family but like somebody else to support you. You could have somebody who would understand but you’d know they’re not that emotional.’

Is the advice sufficiently comprehensive to allow Trusts to build a service which will meet their own local needs?

In light of the comments outlined above, we felt that Trusts might need more guidance on working with the other services within their community, including contact details for Cruse Bereavement Care, the Childhood Bereavement Network and other organisations.

Are all the critical aspects of bereavement care covered by this advice? Please give details of gaps if appropriate.

Suggestions refer to particular paragraphs

Part 1

14. This training course needs to include training on supporting bereaved children and young people. It would be helpful to include details or reference to the recently published guidance from the DfES on the Common Core of Skills and Knowledge for the Children’s Workforce, www.everychildmatters.gov.uk/commoncore which sets out required knowledge and skills to practise at a basic level in six areas of expertise including effective communication, child and young person development and supporting transitions. This last area acknowledges that

‘Some children may have to face very particular and personal transitions which not necessarily shared or understood by all their peers. These include family illness or the death of a close relative’. p16

People working with children should be able to
‘listen to concerns,...empathise by communicating simple reassuring messages about key transitions,...reassure children, young people and those caring for them by explaining what is happening,...provide information about the facts surrounding the transition,...know about the likely impact of key transitions, such as bereavement.’ p17

20. It would be helpful if the principles of communication and information could have an age-appropriate element.
24. Bereaved children and young people have particular needs and a particular pathway for their care should be included in the written policy.
32. We have two suggestions for inclusion in the training and learning opportunities for relevant staff:

- an appropriate level of knowledge and understanding about death, bereavement and grief *to include bereavement and grief in children*
 - an awareness of resources and services in the community.
51. It may be helpful to develop a leaflet with written information about the kind of support which organisations in the community can provide - families may find it difficult to retain large amounts of information at the time of death.
52. As well as informing the GP and other social care professionals, there will be a role for Trust bereavement services in advising families about how to inform a bereaved child's school or preschool.
66. Information may need to be given to families to help them consider whether bereaved children and young people will attend the funeral. Some children report feeling excluded from the funeral, and many bereaved people later regret that they were not allowed to attend.

Part 2

8. An audit of local bereavement support needs to look at provision for children and young people as this may be a gap in services.
9. Some children may revisit their experience of bereavement as they enter new developmental stages: for example acquiring a greater knowledge of illness and death as they get older may prompt them to seek answers to questions which did not occur to them when they were younger. In such cases, the possibility of being able to contact specialist staff, sometimes years after the death, could be very helpful.
15. We welcome the recommendation that all staff know how to communicate with people who have been bereaved, and should know how to respond to different reactions and expectations. It would be helpful if children and young people could be mentioned here as a particular group.
24. We recommend that wherever possible areas and rooms for bereavement support are (or can easily be made) child friendly. One of the children we spoke to was clear about the need for an appropriate environment:

‘He was in a big ward. It felt really weird because everybody else was like next to him and everybody was there and people were all around and watching and everything. It felt really weird. They could have had a room where you could talk about it. It would be easier if they had a playroom in the hospital where you could sit and think and everything. In hospitals they’ve got playrooms but only in the children’s ward and that’s sometimes on the other side of the hospital, which takes a long way to get to.’

Is the advice clear and easy to read? Does it provide sufficient other references?

It would be helpful to provide references to sources of support in developing bereavement services, such as the training courses offered by many providers such as the Child Bereavement Trust, Sir Michael Sobell House and St Christopher's Hospice

As mentioned above, reference to the Common Core of Skills and Knowledge would be helpful in the sections on staff training.

Does the advice indicate sufficiently clearly the importance of taking cultural and religious differences into account?

The advice does indicate the importance of taking cultural and religious differences into account in terms of the practical arrangements after death. It might also be helpful to flag up the differing emotional needs which people may have according to their religious beliefs, including those of a humanist faith or no faith background. More account could also be taken of the linguistic needs of patients and families, and how this will affect the provision of both oral and written information. It might also be helpful to acknowledge that different members of the same family may have different religious beliefs and cultural needs: returning to the principles of respect for the individual, equality of provision and choice are key here.

How the Childhood Bereavement Network can help

The CBN can help take this work further in a number of ways:

- Many of our members provide direct services to bereaved children, young people and families and can be an appropriate place for Trusts to signpost and refer families for more support
- Many of our members provide training locally and would also be able to offer advice on resources and procedures for supporting bereaved children and young people to their local Trust
- Some of our members such as the Child Bereavement Trust provide nationwide training in developing bereavement services
- CBN staff can coordinate comments on national resources, policies and training packages from childhood bereavement practitioners.

For more details of our work or this response, please contact

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