

Unseen support for bereaved families



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The results of a survey of users of a childhood bereavement helpline found that only 7% of telephone calls resulted in formal referrals to the back-up service, with all other callers having their needs met sufficiently

through telephone conversations with a support worker.

Although no official statistics have been collected about bereavement in children and young people in the developed world, estimates have been made that suggest a range of between 2% in the UK¹ and 6% in the USA² are bereaved of a parent before the age of 18 years. That bereavement in childhood is likely to affect psychological development has been highlighted in various studies. One in five may be likely to develop a psychological disorder³, others may be at more risk of having difficulties with relationships in adulthood⁴, or they may be more likely to be troubled during adolescence⁵. The Harvard Child Bereavement Study found that many bereaved children are able to adjust to their loss without professional interventions. Certain actions by those in close contact with the child may help to minimise the risk of problems arising, including providing information, addressing fears and anxieties, and offering reassurance and understanding of strong feelings⁶. Some children benefit from further help to come to terms with their situation, and interventions may be needed to prevent future problems for those individuals⁷. Identifying those who need further help from a trained professional remains a challenge.

Numerous services have been established in recent years to offer support to children and young people who are bereaved and possibly help them to avoid future problems. These include national helplines which may be aimed at professionals, carers and/or the children themselves: some examples in the UK are the Childhood Bereavement Network (CBN), Winston's Wish and ChildLine. In addition, local organisations have also been set up to offer support. The CBN, commissioned by the UK Children and young People's Unit,

has recently carried out a mapping exercise to identify all open-access specialist bereavement support services for children and young people in England⁸. This open access directory identified four services in the greater London area: the Brent Bereavement Service; St Joseph's Hospice Children and Young People's Bereavement Service; Zig Zag Children's and Young People's Bereavement Service; and St Christopher's Hospice Candle Project.

THE CANDLE PROJECT

This article deals with a survey, carried out at the end of 2001 to gather information about the Candle project. The survey examined who was ringing Candle, for what purpose, what action was taken and, in some cases, the clients' views of the service they received.

St Christopher's Hospice offers bereavement support to the families of patients of the hospice and its Home Care service. However, the Candle Project was established in 1998 as a wider resource to provide bereavement support to all children, young people and their families

EDITOR'S NOTE

Sometimes those who are working with bereaved young people search for help and support. They may not require a formal referral to a particular service, or they may consider that to be too daunting when really all they want is some practical advice and support. The Candle Project Helpline provides just such a low-key, easy-access service, and this article describes how it has been used by some of its callers. It demonstrates that there is a need for more such services, and would be relevant to anyone considering setting up a similar project. DT

in the south east London area. This can include those who are suddenly bereaved, and in fact, 70% of the children seen by Candle have been bereaved by an unexpected death. Candle also offers a specialist training, advice and consultancy service to schools and other agencies working with children facing bereavement, accessed through its helpline. The service is designed to take referrals mainly from adults, either professionals or relatives/carers on behalf of children, and for that reason the telephone line is not advertised to children directly. At the time of the survey, the service was run by two part-time (1.6 full-time equivalent) workers with occasional assistance from a part-time sessional worker.

SURVEY METHOD

All calls to the service between 10 September and 14 December 2001 were logged. Details such as what callers were requesting, how they had heard of the service, what type of caller they were, and what actions were taken were recorded. At the end of their call, most were asked whether they could be contacted as part of the survey.

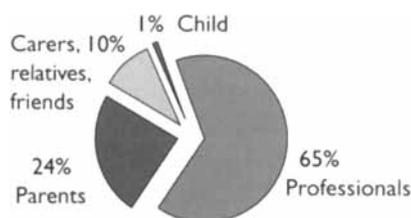
All callers were assigned an ID number and every third person was selected for the survey. Where callers had not agreed to take part, the next person on the list was contacted. Between one and four weeks after the initial contact, an independent worker from St Christopher's Hospice made a follow-up telephone call to the selected callers using a short, structured telephone interview to find out:

- the information/advice given
- whether the Candle workers had understood exactly what was needed
- the Candle workers' manner (eg did they seem to be encouraging, facilitative, warm or cold, distant, unhelpful)
- availability of the telephone service and answerphone
- how long information took to arrive (where applicable)
- what else could have been done
- whether the caller would be willing to ring again for further information if required.

WHAT THE SURVEY FOUND

A total of 126 calls was logged during the three months of the survey. Professionals accounted for two-thirds (65%) of all calls, parents for a quarter (24%) and the

remainder were carers, relatives or friends (5%), with one call from a child. The professionals who called were mainly from social services, schools or other voluntary groups or organisations, but also from police, hospital social work departments, doctors' surgeries, health visitors, district and school nurses. The majority had heard of Candle through one of the project leaflets, which had been distributed widely within the local area to schools, local doctors' surgeries and health clinics.



Total callers to Candle during the three-month survey period

Of the 126 callers, 84 (67%) agreed to take part in the survey. Of those who did not agree, 23 (54%) were professionals and 19 (45%) were non-professionals. They did not all necessarily refuse permission; some were not asked because the Candle workers felt it was inappropriate. This may have been because there had been a very recent bereavement and the client was upset, or because there had been a long and involved call, and to introduce the subject of a survey would have felt too intrusive.

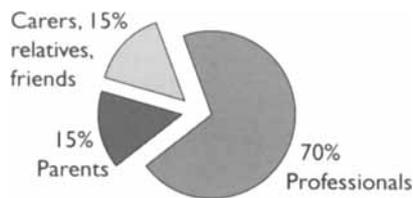
The main reasons for contacting the helpline were to talk over and seek advice on how to handle a particular situation, or to discuss possible referrals. In some cases people called from outside London to ask about availability of services elsewhere, while others were looking for information about setting up a childhood bereavement service, or childhood bereavement issues generally.

Around three-quarters of the callers received information over the telephone (96 or 76%), about half also had literature sent on to them, while 11 (13%) received advice or counselling during the call. Referrals resulted from just 14 (17%) of the calls – nine to Candle, three to another agency, and two to another child bereavement service. Five (6%) calls resulted in training or media contacts.

VIEWES OF THE SERVICE

Of the 84 people who had agreed to take part, 40 in all were selected and contacted. They comprised 28 professionals (70%), six parents (15%), two carers (5%), one relative (2.5%) and three friends (7.5%). In comparison with the total number of callers, the sample contained more

professionals (70% vs 65%) and carers, relatives and friends (15% vs 10%) but fewer parents (15% vs 24%).



Callers who agreed and were selected to take part in the Candle survey

This statistically significant difference probably arose because bereaved parents were less likely to have been approached for permission to take part in the survey, for the reasons given above.

Quality of the information and advice

The great majority of callers (35 or 87%) said they had received the information or advice they needed. Four (10%) of the callers felt that, though informative, the service was not really able to help them and one (2%) had only wanted booklets. Most people commented that the person they had spoken to had been very helpful and explained things very clearly and 38 (95%) felt the Candle workers had understood exactly what they wanted or needed to know.

Convenience

The service was available at convenient times for 22 (55%) of the callers in the survey and a further six (15%) felt this was not relevant (mainly because they were only making a telephone enquiry and not trying to make a referral). Only 13 (32%) of the callers had got through to the Candle service directly, but the answerphone was a satisfactory alternative for many (16 or 40%), who were happy with the time lapse between leaving their messages and being called back, usually within a couple of hours on the same day. Five people (12%) mentioned having to use the answerphone and six (15%) had not been willing to leave a message and had called back again later instead.

Posted information

Information arrived between two days and a week after the original call for 23 (57%) of the callers. Two people (5%) did not know how long the information had taken to reach them. The majority were very happy with the quick delivery of literature:

'It came within a couple of days. I was very satisfied, indeed I was very grateful.'

Further help

The great majority, 34 (85%) of the callers, felt there was no more that the service could have done for them. Some com-

mented on the absence of help for adolescents with ill parents, though a service is available after a death. Another wanted recommendations for research that they could tap into. All said that they would definitely feel able to ring again if they required further advice or information.

WHAT CAN BE LEARNED?

The majority of callers surveyed were extremely happy with the information and/or advice given, often describing the service as excellent. The reason for 94 calls (75%) was to discuss how to deal with a particular situation, possible referral and availability of bereavement services. The most significant finding was that of the 126 calls, only nine (7%) resulted in a formal referral to the Candle service. The low number of referral highlights the 'unseen' nature of a service such as this. It suggests that many people's needs were met sufficiently by a telephone conversation with a Candle worker without being officially recorded as clients.

Many of the calls resulted in written information about the Candle project being sent out, ie literature, leaflets offering advice for dealing with bereaved children and young people, suggested reading lists. Several people found the leaflets so useful that they had requested more, or made their own copies to pass on to others. It is therefore difficult to be precise about the exact numbers of people who are being helped, since the information is being disseminated outside Candle.

Leaving messages on an answerphone was not a problem for most of those contacted, but for one or two it was a less than ideal situation. We have responded to this by installing a voice-mail system. A flashing light on the telephone now alerts Candle staff when a message has been left, even when they are on another call. Calls can therefore be returned very quickly. This is important when trying to reach professionals, especially those such as health visitors, school nurses and social workers who may change location frequently. The voicemail does not need to be switched on as it automatically takes calls after a set number of rings. In addition to this new system, we now have a part-time administrator who answers the telephone so that callers are more likely to reach a human voice than a recorded message.

Overall, the survey's main conclusion was that Candle is providing an excellent service to many satisfied callers. Every caller contacted would be very happy to use the service again, should the need arise.

They were very helpful from the first telephone call right up to now. (Parent)

It was brilliant; they made me feel a lot better about helping with the client. They helped me with a few things I hadn't thought about and I was able to pass them on to my client. (Social worker)

What the survey has highlighted is that the actual referrals to a bereavement service may be only the tip of the iceberg in comparison to the numbers of people in need of some form of support. Estimates of families helped by a service such as Candle should include these hidden clients, those who may have been given all the help they needed in a telephone conversation with a professional, as well as those seen face-to-face. Our results also provide evidence for the CBN's assertion that the needs of bereaved children, and of those who care for or work with them, are often simply for straightforward advice and support. We need to offer reassurance that what they are experiencing or how they are handling a situation is perfectly normal and that they are doing OK, to give practical information and to point out other options. 

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FORTHCOMING EVENT

2005 World Gathering on Bereavement. For professionals and bereaved people. Speakers include Earl Grollman, John Morgan, Alan Wolfelt. Also **The Compassionate Friends 4th Annual Gathering.** 17-21 August 2005. Vancouver, Canada. Apply to from Kay Johnson, Griefworks BC, Vancouver, Canada; ☎ +604 875 2741; website www.worldgathering.org

Counselling the bereaved in prison



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Bereavement is recognised by some prison authorities as a factor impeding the progress of certain prisoners towards acceptable behaviour. One such authority invited a local volunteer

bereavement service to be part of its prisoners' rehabilitation programme and here one member of the team describes what was involved, the difficulties and rewards of this challenging work.

The Rushmoor and Surrey Heath branch of the UK national charity, Cruse Bereavement Care, provided a bereavement support service for prisoners at Her Majesty's Prison Coldingley for four years, between 1998 and 2002. Prisons in this country are categorised A to D according to the level of security, A being the highest level.

Coldingley is a category C prison accommodating up to 372 prisoners. It is the only industrial prison in the UK, with three main industries – a commercial laundry, an engineering workshop, and a sign shop – that employ about 150 inmates working a 37.5-hour week. There is also a 'Trike' project making motor cycles for disabled riders and a bird project looking after and breeding birds of prey.

Coldingley shares the general aims assigned to all prisons. It holds prisoners in custody and tries to encourage and assist them to lead law-abiding lives on discharge. To that end, there are a number of agencies and counsellors operating in the prison working towards the rehabilitation of prisoners in various ways, such as assisting those addicted to drugs, exploring the offending behaviour, or helping with relationship problems. Our bereavement service formed a part of this rehabilitation programme.

THE SET-UP

A team of four volunteer bereavement counsellors provided the service, for which Coldingley paid an hourly rate. This payment helped in the running of the Cruse branch

and covered the volunteers' expenses. Each counsellor normally worked for a period of three months, in rotation. I was one of the counsellors, and also acted as co-ordinator, keeping in regular touch with the on-duty counsellor and the prison liaison officer. Our counsellors needed to be experienced and capable of dealing with the complex and sometimes harrowing work involved. Clients can be manipulative so boundaries had to be firm. Some members of our team worked in other counselling settings and

EDITOR'S NOTE

Members of bereavement services may be reluctant to reach out to bereaved people in prison for various reasons. These include fears for their own safety, antipathy towards prisoners, lack of financial support and lack of time. Yet there is good reason to regard many of those who suffer bereavement while in prison as being in special need of our help and, as Ruth Rodger points out, a little counselling and support may reduce the risk of further offending and of suicide.

This paper describes how a small team of counsellors were able to work with the authorities in a medium category prison to set up a self-funding service which seems to have achieved a great deal. For a further exploration of bereavement in a prison environment, see Margaret Potter's article, 'Inside grief' (*Bereavement Care* 1999; **18**(2): 22-25) and Ken Dolman and Rusus McGinty's 'Domestic killing: the perpetrator's need to grieve' (*Bereavement Care* 1997; **16**(3): 29-31). *CMP*