

'Death sucks'

An internet-based peer support service for young people



Ann Salter

Project Manager, Youth Involvement Project, Cruse Bereavement Care, Manchester, UK

An internet-based service for bereaved young people has shed new light on how teenagers cope following bereavement and on the kind of help they have found useful. Here we describe some of what we

have learned from providing this service, and examine the value of the support that young people can gain from a virtual community and to what extent this support translates into a difference in their everyday lives.

The service, rd4u, was developed by the Youth Involvement Project of the UK national charity Cruse Bereavement Care, and funded by the Diana, Princess of Wales Memorial Fund, to find ways to reach and support bereaved young people. Following initial consultation with groups of teenagers across the north west of England, we came away with two clear messages: many teenagers feel a high degree of isolation after someone close to them has died, and many of them tend to turn to the internet for support.

This led us to develop a website (www.rd4u.org.uk) designed by young people and built by Toucan-Europe, a not-for-profit organisation based locally. Since the launch of the site in June 2001, its use has continued to grow from just under 50 visitors in the first month to over 4,000 in December 2003 (see graph on p4). The majority are from the UK but, increasingly, our visitors are from all over the world.

We also offer a freephone helpline for young people, who have told us that they are more likely to ring if there is no charge and if their call will leave no trace on a phone bill. The number is advertised on the website and young people are often encouraged by our email supporters to ring as a way of getting more support. Calls connect to Cruse's national helpline.

While the internet and helpline services are aimed primarily at young people, adults tell us they also benefit in various ways. One youth worker wrote, 'the site is informative, comforting, and has provided me with tools...to support young people.' A

woman whose mother died when she was a teenager told us, 'I think this site is wonderful...it is something that would have helped me so much...I may send people I know who find it strange that I still mourn...to look at your site.'

THE SET-UP

Young people can use the site in a number of ways:

- to read the experiences of others who are bereaved and send in their own stories to share with others
- to enter into a dialogue or 'conversation', offering and receiving support, advice and encouragement

EDITOR'S NOTE

Adolescents are a notoriously difficult group to engage. However much you fight it, it's just not cool to be an adult (and it's certainly not cool to use the word 'cool' if you are an adult!). This paper describes an innovative attempt to reach this group who often give the impression that they do not want to be reached. The effectiveness of horizontal support has been well documented*, and this project has enhanced this phenomenon by training and supporting the volunteers enough to make them useful, but not so much that they are unreachable. We use play to connect with younger children, so it is common sense to use the internet to reach adolescents. Surely this would be a worthwhile project for any funder? DT

*Worden W. Children and Grief. New York: Guilford Press, 1996.

- to access general advice, or to send a confidential email to be answered by one of the Youth Involvement Project volunteers.

The design of the site is colourful and lively and includes some more light-hearted games and animations. Users can add their story to a time line, their photos and pictures to a gallery, and young men have a dedicated Lads' Only section to encourage them to interact. We remove any contact details before we put a message on to the site and all material is checked and, if necessary, edited before it goes up.

After the initial design, we have ensured that young people remain at the heart of the service by having them direct the development of the website and work as trained and supported volunteers answering emails from young people who contact the site. This peer support aspect lies at the heart of the service and, from the feedback we get from users, it seems that it is key to its success.

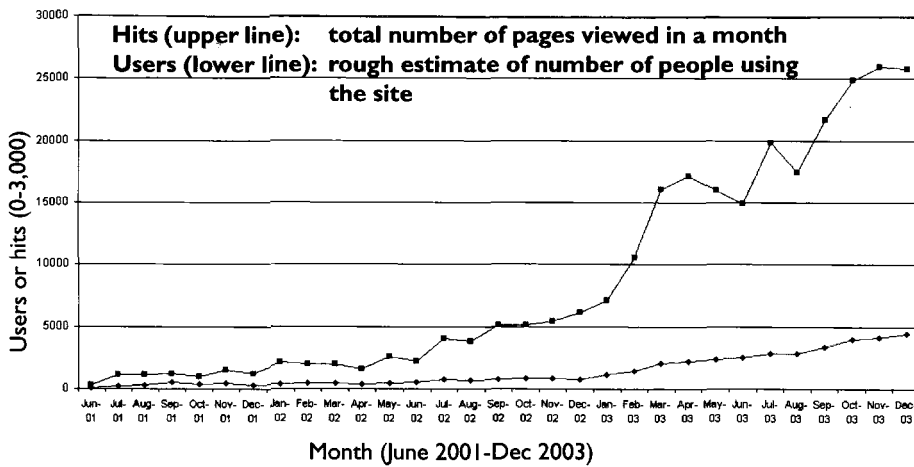
The volunteers who answer emails are mainly students aged between 16 and 25, and receive a preliminary two days' training in bereavement awareness and email support skills. They then have a programme of ongoing training, including issues such as self-harm and suicide. All emails are answered at the project base with the support and supervision of a small team of paid and experienced staff. No email is sent without first being checked.

WHY DO BEREAVED YOUNG PEOPLE USE THE SITE?

Reading the feedback we receive from teenagers, the overwhelming response is that they go to the site as a way of feeling less isolated: 'To know that I'm not the only person in the world who has lost a parent'; 'It gives me the opportunity to talk about how I feel without actually having to be face-to-face with someone'; 'It shows me that other people have coped so I can cope too'. This seems to be at the heart of what young people gain from our service and also indicative of what, for whatever reason, is missing from their everyday lives.

We are all aware that strong connections with peer groups are an important part of an adolescent's transition to adulthood at a time when young people may be relying less on their family. When something as devastating as bereavement happens, many teenagers find themselves

NUMBER OF HITS AND USERS PER MONTH



doubly bereft: of the person who has died and of their friends, who they no longer seem to be able to connect with. 'I just can't talk to anyone', and 'Nobody understands', are common refrains. So, to find a forum in which other young people not only understand, but may have had similar experiences, can be a powerful release.

The dialogues on the message board often show a high degree of caring and empathy and, crucially, can assure young people that they are not alone in their feelings. Here, one person posted a message about the death of her father which was then answered by two others:

Back in march my dad died of a heart attack. I've had to go to counselling because i saw him die...At times i feel like i'm the only 13yr old that knows wot i'm goin thru...None of my friendz understand n they dont know how i feel. I find it really hard 2 talk 2 people about it - even my best mate. Anyway thanx 4 readin dis

Hiya. last march my dad died after a massive heart attack as well. I was also there and i no how hard it is 2 talk to people....none of my mates understand what its like and if u need 2 tlk 2 anyone then u can tlk 2 me. I thought i was the only one this happened 2 and i was thinking of killing myself...if u wanna chat u can tlk 2 me!!

i no wat u r all going through if ur dads died. my dad died 7 month ago and i miss him so much...my mates...dont understand because there not going through it

The first person who had left a message then posted a further reply:

Thanx 4 replying 2 my message. I'm really sorry 2 hear about your dad, i suppose that even afta 18 months it still hurts...I bet moving schools made it even harder for u havin 2 leave all ure mates behind...thanx alot 4 readin my first message itz made me feel a bit betta. Again i'm very sorry about ure dad n i bet u miss im loads. Just remember however hard it gets you're never alone.

There is a sense of a connection here, of a kind that seems missing for these young people in their 'real' lives, despite the fact that they have no way of making contact outside of the message board arena. The language used on the message board is often 'text talk', as in text messaging on a mobile phone, which adds to the sense of immediacy and online community. It also underlines the importance of having young volunteers who are able to reflect back to emailers using the same kind of language.

DOES INTERNET SUPPORT HELP?

The aim of our service is to enable young people to access the support they need in their own lives. This can be through informal family and friendship networks, or it can be through a more professional route. For example, some send in emails saying they wish they were dead; some tell us how they plan to take an overdose. Many of the young people who contact us self-harm, some putting themselves at risk. In these cases, we act as a kind of intermediary: it can be just too big a step for young people to actually disclose their behaviour, or how they are feeling, face to face and so much easier to ask for help anonymously, via email. The encouragement they receive from the rd4u team may be enough to empower them to seek out support for themselves. One young man emailed a few times, trying to get the courage to phone a helpline. After a couple of weeks he felt able to make the call, and so came a step closer to getting what he needed to help him through this difficult time.

The message board 'conversation' above illustrates the fact that the website does not replace other forms of professional support, in that the first person leaving a message says that she has received counselling. Often young people who contact the site are either going to counselling, or have had counselling in the past. Where

appropriate, we use the private email service to encourage young people to seek professional support.

Internet psychologist Adam Joinson in his book, *The Psychology of Internet Use*¹, details research into online social support among adults. The benefits he identified could apply equally to young people who use rd4u: 'being in the same boat', 'social support and information bridges', 'the physical and mental benefits of disclosure', 'anonymity' and 'accessibility.' In terms of the impact of internet use on a person's functioning in life, the result of the study showed that 'well over half of internet users say that the internet has improved their connection to family and friends'. So it is possible that in the same way the connections made on the rd4u website act as a kind of bridge to family and friends.

We have found that the benefits of this type of peer support include the ability of young people to relate on a more 'horizontal' level with the emailers. The volunteers who reply to the emails may or may not have experienced bereavement, but they do know what it is like to be a young person, and so have a greater understanding of the issues that the emailers are facing.

The service is at present undergoing an evaluation by an external consultant, Helen Caton, from Forton Bank Consulting Ltd. The results, when published, will go some way towards assessing the efficacy of this type of support. In the meantime, Helen comments:

The rd4u website really captures the raw emotion felt by young people and communicates the bond of affection created through the growing, international, online community. There is clear evidence of bereaved young people reaching out beyond their shattering experiences and touching others, more recently affected, in positive and supportive ways.

THE FUTURE

The initial funding period for this project is due to an end in March 2004. What was originally conceived as a pilot project, to address some of the support needs of young bereaved people, has now become a key part of Cruse Bereavement Care's services to children and young people. Young people need to feel understood, and this is a place where they can find that vital understanding. In the words of one young person: 'This site rocks. Without it, I don't know if I'd be here today.' BC

Reference

Joinson A. *Understanding the Psychology of Internet Behaviour: Virtual Worlds, Real Lives*. Hampshire, UK: Palgrave Macmillan, 2003.