Volume 30 No 2 **WEBWATCH** 33



Bereavement websites for children and young people

Jill Sanders

Information officer
Cruse Bereavement Care

Bereaved children and young people need no longer suffer in isolated silence, thanks to the worldwide web. There are several specialist websites designed for bereaved children and young people. Some provide information; some go the extra mile and enable children and young people from across the globe to talk among themselves; some are highly imaginative and interactive; some have been designed, inspired or created by young people themselves. There are also some delightful websites for children and young people that, while not specifically concerned with bereavement, would be of help to them, and their families and friends.

The oldest of the interactive child bereavement websites – developed in 2001– is rd4u (www.rd4u.co.uk), established by Cruse Bereavement Care for bereaved children and young people aged up to about 25. [Here I have to declare an interest, as I manage this website and so have access to detailed data on its usage.]

A longstanding site like rd4u can tell us much about how children and young people use these kinds of websites where they can communicate directly with each other, and about what they find helpful and why.

The website offers young visitors several ways to share their stories, experiences and feelings: a general message board where they can post messages and reply to others; a gallery where they can upload images and memorials; poetry pages; a special page for boys, and a timeline. The timeline allows them to record their feelings from the start of their bereavement to where they are now.

The site also carries information and advice about grief and the feelings bereavement may stir up, which young visitors to the website can print or save.

The children and young people's own messages are the heart of the site, however. These are moderated as they come in, to keep visitors safe and their identities protected and to ensure the content is appropriate. The website also features a direct link to trained volunteers via email or telephone helpline.

Because it is so long-established, rd4u has become an extensive and invaluable repository for children and young people's experiences and views about bereavement and grief. To have so many messages and personal experiences stored on one site is very helpful for other bereaved children and young people, as they say in their feedback (below – spelled here as posted). It is also a goldmine for researchers interested in young people's firsthand accounts of bereavement and how they have coped. New visitors often search back over many years and gain much from reading other messages, however long ago they were posted.

'i like it because you can see how many other peoples brothers and sister have gone from there life it is the best you can do for us so thank you for your help, there is nothing that i don't like of this website. i have never seen a website like this.'

The stats show that many of the young users visit the site many times, and on most visits they look at many different pages. This is the advantage of having access to so many messages dating back over so many years: the young visitors have so much more material to explore in search of messages that resonate for them.

rd4u is UK-based but receives visitors and messages from about 70 countries around the world, and from young people whose first language is not necessarily English. It has remained pretty much unchanged in its design, but its young visitors do not appear to be bothered by its old-fashioned look; they say they like it and find it very easy to use.

Winston's Wish (www.Winstonswish.org.uk) is the other main charity providing child bereavement support in the UK. It also hosts an imaginative site offering several different ways for children and young people to interact and describe and express their feelings. These include a graffiti wall where visitors can scrawl messages using spray paint icons, and a 'sky-scape' – a night sky where the young person can attach significant messages or memories to 'stars' orbiting across the screen.

© 2011 Cruse Bereavement Care DOI: 10.1080/02682621.2011.555245

rBER Issue 30_2 TEXT.indd 33 21/06/2011 14:53:12

34 WEBWATCH BereavementCare

Like rd4u, Winston's Wish has amassed a repository of several thousand messages for the young visitor to browse through, and bereaved children are able to support and advise one another through its forums, which cover the range of possible bereavements – mother or father dying, both parents dying, sibling, grandparent, friend, or simply 'someone important'.

A quite different website is The Seeds of Hope Children's Garden (www.seedsofhopechildrensgarden.co.uk). This is another UK site — a virtual garden that grew from a real, commemorative garden created in the grounds of Guildford Cathedral. It is a calm and delightful website with an emphasis on the natural world and the cycle of life. There are 'memory meadows' where bereaved children can 'plant' flowers with messages. The garden is divided into areas representing the four seasons and the idea is to help children think about nature's cycle of regeneration and death. This process is assisted by an attractive and intelligent activity pack, available as a free download, which can be used in any park, garden or woodland.

KidsAid (http://kidsaid.com) is part of GriefNet, a US-based site for bereaved people. It was set up by the daughter (then aged just nine) of the woman who founded GriefNet, working with a young boy in the UK, who together provided the ideas and wrote quite a lot of the content. Several years and several rebirths later (with its founder now starting at college), KidsAid declares itself to be: '2 Kids, 4 Kids, By Kids'. Its stated aim (shared by most such sites) is 'to give kids their own place to deal with their feelings with other kids who have suffered major losses. Kids can often help kids better than adults can, because they understand a lot of things that adults might not.'

Its goal is 'to reach kids all over the world and let them know we're here, to find out what helps kids deal with grief, and to help kids get those things that help them.'

There are support groups for children aged 12 and under, and young people aged 13–18. Adults as well as children and young people can register for these groups, but only kids can send messages. GriefNet contacts the parents of anyone who registers aged under 18.

The site also includes a gallery of stories and artwork sent in by children and young people, and a 'kids and aminals' (sic) section where they can place memorials to dead pets. There is a Q&A section where visitors (children and adults) post problems and concerns and are given answers and advice. It is impossible to tell if the site is 'live' as there are no dates attached to postings.

Generalist websites

There are some excellent sites for children and young people that aren't grief/bereavement specific, or include it among a range of topics to do with mental health and well-being.

One is Reach Out (http://us.reachout.com) – a lively, boldly designed website for teens and young adults founded in 1998 in Australia, originally to try to stop teenage suicides. The site covers all aspects of young people's emotional lives – mental health problems, family relationships, peer relationships, drugs and alcohol, sexual relationships, suicide, and also loss and grief.

It aims to help young people 'get through tough times' and, although it was originally devised by adults, its emphasis is very much on mutual self-help. A big feature are the 'real stories' of young people's own experiences in the 'We Can Help Us' section, which include written, video and audio uploads. The grief and loss section also has helpful information on loss and grief, how to get through it, and why it's good to talk, and a hotline link.

For younger children, Cam's Den (www.camsden.co.uk) was set up by the Tavistock and Portman NHS Foundation Trust, which provides child and adolescent mental health services in the north London borough of Camden, in the UK. It is broadly a mental health promotion and awareness raising site for young children and their parents and teachers. It's an amazing site that manages to be both fun and child-friendly, and fulfil a serious purpose of explaining emotional difficulties and suggesting what can help. There are stories, information and films about feelings, including bereavement, all featuring Cam the sock puppet and Cam's sock puppet friends. It also includes a short film about Cam attending the child mental health clinic, presumably to reduce anxiety in young clients.

The stated aim is to encourage schools and other organisations to feel more comfortable about supporting children experiencing emotional difficulties, to support parents coping with troubled children and help them get help, and to provide a fun and interactive learning tool to accompany the national school curriculum's SEAL programme (social and emotional aspects of learning).

The site is fun and lively. It encourages children to explore their own feelings and actions through creating a daily diary, and there are activities children can do on the site, like reveal messages by rubbing a blank 'page' with a crayon. There isn't a facility for children and young people to post their thoughts and messages, but the content will get them talking and otherwise expressing their feelings, and there's lots of useful information for parents and teachers too.

Another wonderfully imaginative website especially for children is Signed Stories (www.signedstories.com). This is a delightful, lively website for deaf children, and indeed all children, where they can share stories with friends and family through 'books' that are signed, spoken and written for reading out loud. Children can choose from fairy stories, funny stories, slimy scary stories, folk stories, adventure stories, and more. Each of these sections has a choice of 20 or more books, and they include familiar favourites and much-loved authors. You will a need fast broadband connection, though.

There is a Signed Stories forum for chatting, sharing and asking questions. Young visitors can even learn to sing. The website has comprehensive sections for parents and carers and for teachers, but the animation and the fun is very much for the young users, and a great encouragement to explore the site. It will appeal to all children (and grown-ups) in every family. Again, this is not a website where the voices of the children and young people themselves are in much evidence, but its aim is clearly

rBER Issue 30_2 TEXT.indd 34 21/06/2011 14:53:12

Volume 30 No 2 **WEBWATCH** 35

to get them talking, sharing and laughing with each other, rather than online.

Fallen into disuse

It is quite common, and sad, to find that sites have fallen out of use, usually because they are no longer being maintained. This must be disappointing for children and young people looking for help and support. The Dougy Centre is a US national support centre for grieving children and families. Its website (http://www.dougy.org) includes the 'Inspire' support community for children and young people and their parents, where they can join discussion forums and share experiences and problems. However, few of its discussion forums have any posts – although it is noticeable that the recent arrival of a new communications director at the Dougy Centre appears to have revived activity, prompting over 40 responses where previously there had been just a few questions (from adults) dating back to early November 2010. This is perhaps a case in point – activity breeds interest and participation; it is vital that the host organisation maintains input and keeps the site 'alive'.

Another site that appears to have fallen into disuse is Grief Encounter. Grief Encounter is a London-based charity set up to support grieving children and their families. Its website (www. griefencounter.org.uk) says it offers help and support following a death, and opportunities for children to share thoughts with other bereaved children and families and read their experiences of grief and loss. There is also information for adults on child bereavement issues, and a 'Remember' section where visitors can create memorials, 'light a lantern', or create a memory board. Unfortunately, the lantern messages and memory boards are reproduced just as text, which misses the point of the interactivity.

But (perhaps for this reason) the site appears little used. The most recent messages on its Kids Zone and Teens Zone are dated some months back.

Holding On, Letting Go (http://www.holdingonlettinggo.org. uk/about.html) — a website set up for bereaved children and young people aged five to 16, and their families, in Kent, UK — seems similarly unused The links to the children's forums take you to error pages now, and the entire website is in limbo. Is this project now over — has the funding perhaps run out?



Cam's Den - fun, child-friendly but with a serious purpose



Signed Stories – sets a high standard for children's website design

The National Students of AMF ('Ailing Mothers and Fathers') (www.studentsofamf.org), based in the US, was set up by a college student at Georgetown University, following the death of his mother, to support other students grieving the illness or death of a loved one. David Fajgenbaum wanted to establish a support forum for others like him, who were suffering bereavement in isolation. The central website facilitates students who want to start similar 'chapters' in their own colleges. Each 'chapter' includes three programmes to support young grieving people: the Support Group for students to support each other; the Service Group where bereaved and non-bereaved students volunteer in projects concerned with terminal illnesses; and the Angels Program, which pairs mentors with students in the support group.

Reportedly over 100 colleges have created NSAMF chapters but the website seems to have no postings more recent than spring 2010. Its discussion forum is filled with spam, some of it inappropriate. This underlines the importance of having someone at the centre with time and expertise to keep a site alive and active. It is disappointing that those setting up such sites don't think to post an explanation, or refer visitors on elsewhere if they are unable to maintain them.

Websites like Cams Den and Signed Stories have set a new standard for children and young people's website design. In both cases the simple directions and lively animation make them a delight and pleasure to use. Contrast these with, say, the sibling support section for young people on the very serviceable and worthy Compassionate Friends website (http://tcfsiblingsupport.org.uk). It is all text and it is hardly surprising that it seems to be little used.

Young people today expect more than passive information. Well-designed websites — and that means clear signage, readable content, good graphics and regular maintenance, not just technical fireworks — can offer so much, and are so accessible. There is very little need for any young person to be experiencing grief in isolation, especially as other young people are clearly so very ready to help each other.