



# Bereavement care for carers – online resources

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Bereavement can be particularly difficult for carers, who may have been caring for many years for the person who has died. They are losing not only their loved one – whether adult or child – but also the primary and all-consuming focus of their life. Inevitably they will be facing not just the grief of bereavement, but also the emptiness of a day previously fully occupied with caring responsibilities.

There is a general recognition in the caring professions that carers can be particularly vulnerable to complex grief reactions, and this is supported in the research literature. The European Association for Palliative Care has published a two-part policy paper on improving support in palliative care for family carers (<http://www.eapcnet.eu/LinkClick.aspx?fileticket=z4a-8JkAnFo%3D&tabid=732>). This emphasises the importance of pre-bereavement support and educational programmes for carers, with a particular emphasis on psychological interventions to address emotional, social, bereavement and spiritual issues.

The death of the person being cared for inevitably means that medical and social care support is immediately withdrawn. This can prove a 'double whammy' as the health and social support system may also have served to support the carer, especially if the person being cared for was housebound and required care around the clock. This will also occur when the person being cared for has to be placed in a residential or nursing home, which itself may be experienced as a form of bereavement.

Carers and those supporting them can readily find help, guidance and advice online. Treading your own path through the worldwide web can be empowering and, for those who are able to do so, searching the internet can bring unexpected results and rewards as new and different routes to the future are uncovered.

This article (written from the UK) concentrates on UK sources and resources. Different results will be found in different countries, depending on national and state policies and local

provision. However these search paths are likely to produce relevant results.

## Online forums

Search strings such as *carers + bereaved or bereaved carers + support* will yield plentiful links, and it's worth continuing past the first page of results. This is how I came across the lively online forum run by the UK-based Princess Royal Trust for Carers (<http://www.carers.org/carers-chat>). The Princess Royal Trust for Carers website is very useful generally, and gives contacts for its national network of carer centres.

Not surprisingly, death and bereavement feature frequently in the online forum discussions between carers and their comments suggest that the forum benefits users both before and after the death of the person they are caring for. Search for *bereavement* in the forum and it will bring up all the discussions relating to this theme within the past year. Topics include being prepared for death and how to cope with its aftermath, as well as thinking ahead to a good death for oneself, based on carers' experiences of the death of the cared-for person. The contributions are humane, reassuring and sometimes refreshingly robust, but always compassionate and supportive. This is a useful repository of information about a wide range of difficult subjects that will resonate with many carers, as well as information about carer support and other projects.

In addition to carers' stories – including those of young carers – there are carers' blogs recording their day-to-day lives, and much more. There is clearly a lively online community of carers ready and willing to share their own hard-learned wisdom. These kinds of forums may be particularly valuable to the isolated carer who is all-but housebound by their caring responsibilities and finds it hard to get out to meet other carers.

The Macmillan Cancer Support website (<http://www.macmillan.org.uk>) – another UK-based organisation – also includes a wealth of information for the bereaved carer. Searching for *carers + bereavement* produces a list of relevant publications on coping with a death – both the emotional impact of bereavement and the practicalities such as laying out the body, arranging the funeral, registering the death and so forth. ‘Life after caring’ also covers both emotional and practical issues, and offers suggestions of where else to find help. Macmillan runs workshops for carers on loss and bereavement, and the site includes information on these. It also offers online discussion forums, blogs and chatrooms where bereaved carers and those facing bereavement can find kindred souls offering information and peer support.

The Carers Direct website, provided by the UK’s National Health Service (NHS), claims that bereavement care and support ‘are now being routinely offered to all carers, family and close friends’ – it would be interesting to know if this really is the case (go to <http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx> and follow the links via *Practical guide to caring to End of life issues*, which includes bereavement support). The site has a wealth of useful links on topics such as living well with loss, and how to access bereavement support services, as well as a heartening video in which former carers discuss how they coped with bereavement and found new purpose in life.

The Dementia Centre (<http://www.dementiacentre.com/cpage-160-0-newdc-home.html>) based at Liverpool Hope University in the UK is a source of support for carers bereaved by dementia. Its website includes the charmingly named Dementia Café, which hosts discussion forums and a chat room for online peer support. You can also download a short and helpful fact sheet on bereavement for carers, and there are links to sources of counselling and other carer support organisations, advocacy and other help.

## Research findings

Another readily accessed source of international information by, about and for bereaved carers is the research literature published in academic journals. Having traced an article of interest, you may not be able to download it for free, as most academic journals require a subscription, or payment per download, but you will be able to read the abstract (summary) of the findings. A search for *research + bereaved carers* produces numerous links to research articles reporting studies of bereaved carers of people with cancer, bereaved carers during palliative and end-of-life care, their views of hospice at home care, bereaved carers’ narratives and much more. Such research can offer information, insight, validation, and understanding and enlightenment.

Some bereaved people will have been caring for someone who has died by suicide. This raises yet more complex issues for the bereaved person. Healthtalkonline (<http://www.healthtalkonline.org/>) and its sister website Youthhealthtalk ([http://www.healthtalkonline.org/Young\\_people/](http://www.healthtalkonline.org/Young_people/)) are operated by the charity DIPEX. The site contains over 2,000 personal accounts of people’s experiences of a vast range (60) of different

health-related issues and illnesses, including bereavement. The accounts are drawn from interviews conducted by researchers at the University of Oxford and are available as video and audio clips, and in written transcript.

The stated aim of publishing these personal stories online is to allow patients, families, carers and healthcare professionals to learn from the experiences of others. There are 40 interviews with families, individuals and carers bereaved by suicide, as well as another 40 with those bereaved by sudden traumatic death, and interviews with 41 people and one carer about living with a terminal illness. Again, suicide-bereaved carers are likely to find experiences to which they can relate and helpful information, validation and consolation in their grief.

## Looking to the future

Released from their caring responsibilities, bereaved carers may feel apprehensive about their own future – how to fill the void now they are no longer on 24-hour duty. Here the internet again can be very helpful to carers who are picking up the threads of life and work once more. Try searching for *life after caring* and *carers + back to work*. The weblinks include local as well as national resources. In the UK, again the excellent Princess Royal Trust for Carers (see weblink above) comes up trumps with a tremendously useful fact sheet for professional workers that lists the skills that a carer will have gained from their lengthy caring experience, pointing out that many of the skills could be usefully employed within the NHS. It also suggests that NHS managers could link up with their local Carer Support Centre to offer opportunities for work shadowing and guaranteed interview schemes, to help former carers back into the workplace.

Similarly, for those considering gaining new qualifications, Learn Direct ([www.learnirect.co.uk](http://www.learnirect.co.uk)) offers online courses in maths, English, IT and business and management. It also gives the contact details for its national network of learning centres, where more advice and information can be found. Some of its courses may be fully or partially funded.

The UK’s DirectGov website ([http://www.direct.gov.uk/en/EducationAndLearning/AdultLearning/GetLearning/DG\\_10033340](http://www.direct.gov.uk/en/EducationAndLearning/AdultLearning/GetLearning/DG_10033340)) has collected together onto one page several links that go straight to the most useful sources of information about adult learning, higher education for mature students and help with costs. This includes the Next Step site (<https://nextstep.direct.gov.uk/Pages/Home.aspx>) – another practical and accessible website for people returning to learning and work. Its subheading, ‘Helping you get on with work and life’, pretty much sums up what’s on offer, which includes help with creating a CV and, most importantly, how to fund your studies and training.

For those who lack computer skills and/or confidence in new communications technology, there are some 3,000 local Online Centres in the UK (<http://www.ukonlinecentres.com/get-online-free-courses-help-support.html>), in libraries and community centres, offering free or low cost classes. It may be that signing up for a computer course will be a first step towards re-engaging with the world. ■