

**“Leading the way in Bereavement Care”
Opening introduction to delegates attending Annual Conference, Warwick
University, 20 July 2010
Debbie Kerslake, Chief Executive, Cruse Bereavement Care**

Can you get 350 people together in a room who all believe in the same thing? This is our largest Cruse annual conference to date and we have our broadest spectrum of delegates, including those working in the Voluntary, Statutory and Private Sector; the Health Service, the Military, the Funeral Industry and Academia. Each contributes in their own way to the welfare of bereaved people.

But I think I can confidently say that **all** of us here today believe:

- Bereavement is one of the worst experiences anyone will face in their whole lives
- Bereaved people **should** be given appropriate, high quality support

We may **not** agree, however, on **what works** in terms of helping bereaved people. I'll come back to this.

Last week there was a headline in the Times:

It's official: Britain is best place in the world to die.

It referred to the UK being without equal when it comes to dying.

The UK has been ranked top of 40 countries in the 'Quality of Death' Index in attitudes to death and the treatment of the dying with its provision of end of life care. The index drawn up by the Economist Intelligence Unit placed the UK top based on its network of hospices, palliative care and measures such as access to painkilling drugs.

But as we all know end of life care does not stop with the death. It must include care of those bereaved. But are we '**Taking Care of the life that's left**'?

Where would we rank in looking after those who are bereaved – in a Quality of Bereavement Index?

There are around 500,000 deaths each year in the UK and for every death there will be those whose lives are never the same again. Evidence from research suggests that around 10% of the general bereaved population will experience complicated grief.

Our experience in Cruse is that increasing numbers of bereaved people are seeking our help. Early analysis of stats from last year show:

- More requests for help – nearly 100,000 (up by 5%)
- Face-to-face support provided to nearly 33,000
- More men are asking for help – a 4.5% increase
- Large increases in numbers supported from black and minority ethnic groups (55%) and children and young people (17%)

We provided face-to-face support to 2,500 children and young people under the age of 18.

The vast majority of people coming to Cruse have been advised to do so by their GP (55%), and a significant proportion of those seeking help do so following a death from suicide, accidents, homicide, road crashes and major disasters (15%).

Cruse worked with more than 1,700 people bereaved through suicide. Volunteers gave 570,000 hours - an all time high

These figures highlight the very large number of people Cruse works with. But despite the increases we know there are people not getting the support they need. There are

gaps in coverage; there is failure to reach particular under-represented groups and there are skills and areas of work that need to be developed.

So I'd like to briefly tell you about some of the key initiatives in Cruse to address these gaps and in particular about three national projects that have made significant progress this year.

We are addressing gaps in coverage through our Area development programme across Cruse. This includes mapping local services; identifying gaps in service provision, geographical coverage and service-uptake and developing action plans to meet identified needs. Our latest statistics seem to show that this work is starting to take effect.

We are developing the skills of our volunteers and staff through an extensive programme of training development –resulting in a library of cpd modules. There are now 9 additional modules available to our volunteers including Supporting those bereaved by death of a child at any age, Death by suicide and pre-bereavement.

This year we are developing a further 9 additional modules including diversity, bereavement in later life and personal safety. These are all optional modules that don't need to be delivered by a registered trainer and available for Cruse Areas and Branches to use as part of their ongoing training programme.

We are addressing skills gaps by enhancing our programme of external courses available to those who work with bereaved people. Building on our very successful 1 day programme on Bereavement Awareness for anyone working with bereaved people we are developing modules for specific groups. We are just about to launch a new 1 day external course for those supporting bereaved children and young people and hope to develop one for those in the funeral industry.

Within Cruse we are looking at the effectiveness of what we do. In 2009 patient reported outcome measures (PROMs) were introduced into the NHS, based on the concept it is the patients themselves who are best placed to say how they feel. If a patient says it works it does! In Cruse we have always been aware of the vital importance of client evaluation and if we were to rely on this alone we would be able to say very definitely that what we do works. But we are keen to look at the impact of our intervention.

I am delighted that at this conference we are launching our evaluation toolkit which is aimed at improving our client evaluation and providing baseline evidence to underpin our service provision. We are also beginning work on identifying our social return on investment.

I referred to three national projects that have made significant progress in the past year.

Bereavement Pathways, a three- year Department of Health funded project brought together Cruse and the Bereavement Services Association, to explore bridging the gap between the NHS acute sector and voluntary and community services, between a death in hospital and support in the community.

The extensive range of work undertaken by the project has included:

- Holding discussion groups of bereaved people to ask them the question – what would have made a difference in your bereavement journey?
- Holding national and local stakeholder events

- Exploring assessment tools – can we predict who is likely to need specialist help?
- Surveying current bereavement provision within the NHS
- Consulting with Community Bereavement Services
- Developing a visual pathway of the bereavement journey shown here highlighting just how long and complex the journey is and how many people are involved
- Developing and piloting a menu of solutions to bridge the gap including the provision of core literature/information; the development of GP Protocols when a patient dies; improved assessment of bereaved people; improved follow-up from NHS Services and cross- sector networking and development of bereavement services.
- Developing guidance for commissioners on what a good bereavement care service should look like. Some PCTs have commissioned services from organisations with no experience or skills in working with bereaved people.

We found improvements. 80% of hospitals now have a bereavement service; more than 90% give information about services in the community and the gap between the acute sector and community services is narrowing.

However, things are still going wrong especially at the beginning of the bereavement journey. More than 50% of complaints to the Health Care Commission are bereavement related.

The project clearly highlighted the need for universal standards, guidelines and quality markers for the provision of bereavement care and the enhancement of training at every level to ensure the provision of appropriate high quality and culturally sensitive bereavement care.

We are reviewing the activities, collating the data and documenting the observations and findings and putting together a printed summary of conclusions. The supporting evidence will be available electronically on the Cruse website. Cruse and the BSA are drawing on the learning as we contribute to the Department of Health working group on bereavement; the End of Life Care Strategy policy proposals on bereavement and the development of the quality markers for bereavement care

We are delighted that the Department of Health has awarded us funding for a Gold Standards Bereavement Care Project to continue to work with the BSA:

- To build on and disseminate the work of the Bereavement Pathways Project
- Develop direct support for NHS services and community providers to implement the learning from this project
- Develop and deliver joint training for health professionals
- Develop an online portal for the bereavement care pathway and online interactive benchmarking tools
- To contribute to the development of standards in bereavement care.

We are all aware of the terrible loss of life in the Armed Forces with the UK involvement in the conflict in Afghanistan. There are also many in-service deaths that are not caused by military engagement.

The Services are good at providing support in the immediate aftermath of a death to the next-of-kin, but what about the mum, dad, sister and friends of the young soldier killed in Afghanistan; who provides support two years after a death to the girlfriend who is still struggling to face each day? What support is available for those in the reserves who are increasingly called up for active service and experiencing fatalities?

Our Armed Forces Project, led by Jenny Green, the Project Manager, funded by the Department of Health, has explored gaps in bereavement support; developed our

relationships with other organisations including the Ministry of Defence, the Royal British Legion, SSAFA and other service organisations so that we can complement the support provided and developed our training to enhance the skills of our volunteers in supporting those affected by a death in the Services. Our user group, made up of those who have lost loved ones whilst serving in the Forces have played a key role in identifying some of the issues that are different about a death in Service. These are highlighted in the project's DVD *Behind Every Headline is Heartache* and in the section of the Cruse website dedicated to supporting the military family.

A new leaflet has just been printed specifically aimed at the Armed Forces. This is being distributed across all the Services.

One in 29 of five to 16 year olds has been bereaved of a parent or sibling. One in 16 has been bereaved of a close friend. And yet the needs of many bereaved children and young people are often overlooked.

Building on our work in Northern Ireland and Wales, our **Every Bereaved Child Matters** project, funded by the Department of Children, Schools and Families, which aims to develop support for children and young people aged four to 18, is already having a significant impact.

The project aims to set up 20 new Cruse services and recruit and train 110 new volunteers to work with bereaved children and young people. In the first year alone 105 were recruited and trained. As Alison Thompson, our Service and Development Manager said to me, "We're not going to reach our targets; we're going to smash them." This level of expansion will enable us to reach thousands more children and young people over the next five years.

Our new *Awareness in Children's Bereavement Care* training course has led to the recruitment of trainees from a range of backgrounds including nursing, social care and teaching.

We have two Cruse websites – the main site cruse.org.uk, where a considerable amount of material has been developed on supporting children and young people and rd4u for children and young people. Ten years ago when rd4u was set up; we didn't pay lots of money to get in expensive website designers (sorry if there are any expensive website consultants here!!). We got together groups of young people who had been bereaved to ask them what the site should look like. Ten years on we have had a major consultation exercise with children and young people as well as professionals working with them to explore what changes we need to make to the site, prior to a major overhaul. Even, without this, the site is the one most used throughout the world by bereaved children and young people with some 300,000 visits last year.

A schools resource pack has been developed to help those working in schools to effectively support children and young people. It also aims to raise our profile so that more people know of the support available.

In Cruse we are extremely proud of our children's services. I hope you'll forgive me using this opportunity to ask for your support. Our service for children and young people in Northern Ireland has reached the finals of the National Lottery Good Causes Awards, the annual search to find the UK's favourite lottery funded project. I know I am biased but it really is an outstanding project. From the beginning bereaved children and young people have designed the service. They have advised on our website; developed a DVD called *Ask the Experts* and gone into schools to raise awareness of the impact of bereavement. Many more volunteers been recruited to work with bereaved children and young people throughout the Northern Ireland.

The project is featured in a live BBC programme on 4 September 2010 but before then there is a public vote. This is a fantastic opportunity for us to raise millions of people's awareness of the life-changing work we do with bereaved children and young people. So please can I ask you to take down this number **0844 686 1434** or switch on your mobiles and put it in your contacts. Or go onto our website where there will be a link when voting opens on Monday 26 July 2010 and please vote - and get your family, friends and colleagues to support us.

What all these projects have in common is listening to bereaved people and addressing unmet needs. They also seek to be guided by and at the forefront of best practice.

Bereavement Care is an international journal for all who work with those who are bereaved, published by Routledge in association with Cruse. Published three times a year, it aims to provide reliable, accessible evidence based information on all aspects of bereavement care.

Julie Stokes described it as "The UK's leading bereavement journal".

Earlier, I said that we won't all agree about what works for bereaved people. We don't normally think of the bereavement world as being highly contentious but anyone who reads Bereavement Care will know that there have been some extremely heated debates going in recent editions about the efficacy of bereavement interventions. Colin Murray Parkes in the most recent edition describes this as an exciting time for bereavement researchers and practitioners with a new cohort of promising interventions and therapies.

Robert Neimeyer also in this edition described *"grief counselling and therapy as being in a period of ferment as long-held assumptions are being questioned and emerging claims and models are developed that challenge our assumptions about how people accommodate loss and therapists can best help them to do so"*.

I urge you to take a look at the journal and consider subscribing.

Last year I received a letter from a Cruse volunteer - Jane. She had attended Cruse conference a year earlier and described to me how she had gone on to develop Cruse services in the local prison having been inspired by a workshop she had attended.

We have internationally renowned speakers at our conference: Margaret Stroebe, Jim Kuydendall and Bill Webster. We have workshop leaders who I know will challenge, motivate and inspire us. I hope that there will be many more developments arising from these two days.

These are difficult times with the impact of the recession and severe cuts ahead. But we have to do all we can to ensure that bereaved people do not lose out in the fight for resources and we remain committed to continually developing and extending to provide the highest quality of care to any bereaved child, young person or adult who needs it. The risks to mental and physical health of not doing so could be catastrophic.

The UK may be the best place in the world to die. Together we can make it the best place in the world to be bereaved.

Debbie Kerslake, Chief Executive, Cruse Bereavement Care
July 2010