

GriefMatters

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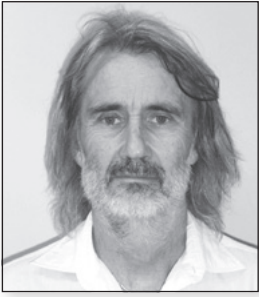
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Editorial

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The week before writing this editorial I was in a remote Indigenous community in which two young adults had taken their lives in the recent months, the first by very violent and visible means that triggered a prompt, coordinated and broadly based response. Between patients, I was approached by researchers who were following up with respondents to a survey of marijuana use in 2011. One young man who had given up for more than a year when interviewed reported that he was smoking again – very heavily. He explained that he was the first on the scene following the first suicide (a close cousin), that he had persistent experiences since then – that I judged were consistent with posttraumatic stress disorder – and that nobody had approached him to provide support.

So much for our prompt, coordinated and broadly based response. But, while I don't take comfort from it, I realise that at such tragic times not everyone in need can be identified and, indeed, not everyone is willing to accept help. That is particularly the case where there are cultural differences and where historical factors continue to colour perceptions of mainstream service providers. Of course, as with the young man above it may also be a matter of timing – but that then means that comprehensive response is not simply an immediate intervention.

These are points made by Martin Ryan in describing the newest of the five organisations profiled in this issue of *Grief Matters*. Based in Melbourne and operating since 2004, Support After Suicide (run by Jesuit Social Services) seeks to provide timely and appropriate support to individuals and families bereaved by suicide. Ryan makes the important additional points relevant to our own experience that interventions need to be tailored to the individual's needs and that supports need to be there “for the long haul”.

Judi's House, which began in Denver, Colorado in 2002, seeks to “contribute to a world in which no child is left alone with his or her grief”. Brook Griese and her colleagues describe the in-house and outreach activities that have evolved over the last decade, including the establishment of a Comprehensive Grief Care Network across organisations, agencies and institutions in the Denver region and further afield. The importance of research and advocacy are emphasised not only to support existing activities but also to ensure wider “appreciation for the costs of inaction to society as a whole if effective grief-informed services are not fully identified and offered”.

The Australian Centre for Grief and Bereavement (ACGB; publishers of *Grief Matters*) has been operating since 1996 and Christopher Hall (Director of the Centre and Editor of *Grief Matters*) describes the Centre's unique service model, which includes a statewide specialist bereavement counselling service, a wide range of educational and clinical training, and research. ACGB aims to respond to the diversity of needs of bereaved

people and to “enhance community wellbeing by building the capacity and resilience of individuals, organisations and communities to cope with adverse life events”.

Founded at almost the same time (1995), Merimna is an Athens-based nongovernment organisation responding to the needs of children and families contending with life-threatening illness and/or grief. Danai Papadatou describes its evolution and activities: advocacy and raising awareness, training, research and service delivery. In relation to the last (and resonating with the mission of Judy's House) and informed by a resilience-enhancing model, Merimna's Bereavement Counseling Center aspires to provide support to *all* bereaved children and families. As an organisation that benefits from the work of volunteers and is entirely funded through private and corporate donations, the crisis in the Greek (and wider European) economy presents major challenges.

Voluntarism is the engine of the final profiled organisation, Cruse Bereavement Care, which is a nationwide network in the United Kingdom that seeks to provide “somewhere to turn to when someone dies”. It is also the oldest of the five profiled organisations, founded in 1959 to address the unmet needs of widows and their families. Debbie Kerslake, the Chief Executive, emphasises the “heavy lifting” of the volunteer sector in the UK and the professionalism of the 6,000 volunteers (supported by 128 largely part-time staff) responsible for a wide range of individual, group, institutional, population and IT/telecommunication-based activities.

As different as their locations and circumstances are, these five organisations, which have developed in response to perceived local needs over some fifty years, have much in common. All have simple and clearly articulated goals that recognise the universality of needs in relation to bereavement and a commitment to addressing “hidden grief”. To that end, different approaches based on theory and experience have developed with a common understanding that one size does *not* fit all. Finally, all identify the importance of evaluation and research. Together, these contributions provide the reader with a palette of approaches to a common purpose. They remind us of how much there is yet to be done and, in the face of predictable challenge, of the need for innovation and ingenuity.



Cruse Bereavement Care – Somewhere to Turn When Someone Dies

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Abstract

Cruse is the United Kingdom's leading bereavement care charity, providing a range of national and local services across a branch network. This article describes the development of Cruse from a small local service, supporting widows and their children, to a national charity that supports an increasing number of adults and children. The article shows how volunteering is at the heart of Cruse's service model, utilising services provided by a trained and fully supported network of 6,000 volunteers. It also outlines the charity's role in campaigning and influencing policy, its partnerships with other organisations, and the ongoing use of research and evaluation into the most effective ways of supporting bereaved people.

Developing a Nationwide Bereavement Support Service

Cruse Bereavement Care has developed from a small local service supporting widows and their children to become the United Kingdom's (UK) leading bereavement care charity, providing a range of national and local services across a branch network. The 6,000 volunteers across England, Wales and Northern Ireland deliver high-quality support to anyone who has been bereaved, providing them, as the organisation's strapline says, "somewhere to turn when someone dies". Services are provided free of charge by volunteers who have completed comprehensive externally accredited foundation training, with ongoing continuous professional development and a robust system of support and supervision. Cruse recognises that everyone's experience of bereavement is unique and support needs to be tailored to individual needs. Bereavement is not an illness but it can have an impact on mental and physical health.

Volunteering

The essence of volunteering is something so fundamental to Cruse that this author was surprised when attending the 8th International Conference on Grief and Bereavement in Contemporary Society in Melbourne in 2008 to be challenged by a fellow delegate after describing that Cruse Bereavement Care services are delivered by volunteers. "But you wouldn't have a volunteer heart surgeon," she pointed out, questioning the skills and experience of volunteers to effectively provide services to those experiencing complicated grief. In the UK, services ranging from manning lifeboats and mountain rescue to the provision of helplines for suicide prevention and child protection, are all delivered by volunteers. Out of an adult UK population of 48,347,500¹ (Personal communication, Office for National Statistics, 3 December 2010), 17.1 million adults in England volunteered during the 12 months 2009–2010 (Volunteering England, 2010) and it is widely believed that the success of the 2012 London Olympics and Paralympics, which relied

heavily on the contribution of 70,000 volunteers (and for which Cruse was commissioned to provide bereavement support services), will act as a trigger, dramatically increasing the number of people who volunteer.

Volunteering and all that this implies is at the heart of the Cruse service model. People voluntarily give of their time, energy and skills. Cruse has nearly 6,000 volunteers from the youngest, aged 12, who volunteers for our Youth Advisory Group (YAG), to an 87 year old who was recently honoured with an MBE for his contribution to his local community. Volunteers are supported by 128 staff, who predominantly work part time. For Cruse, volunteering is an act of generosity, a sign of a healthy community and a source of energy and innovation as well as a way in which people who have experienced bereavement may be able to help others.

Cruse was founded in 1959 by former social worker Margaret Torrie to support widows. Fifty years later, Cruse is the leading bereavement care organisation in the UK and the only one of its kind in the world. The organisation has developed from "Cruse Clubs Counselling Service for Widows and their Families", run from Torrie's dining room table in Richmond, Surrey, to the organisation we are today: delivering a range of services through a network of 123 areas and branches across England, Wales and Northern Ireland with a sister organisation in Scotland.

Cruse grew out of Torrie's concern for women following the death of a husband and the often-major emotional, social and economic crisis that followed. At that time there were 2,500,000 widows in England and Wales, of which 500,000 were under the age of 54, with the majority raising families. These women often had had no training or job outside the home, had not had their own money, had never paid a bill and had no social life without their partner. Many of them felt helpless, fearful and alone. They were often left completely isolated and in desperate financial straits.

Although the organisation is not a religious one and is there for those of faith and none, the name Cruse was chosen from a story in the Bible of a widow who, during a famine, shared her last meal with a stranger. The man told the widow he was the prophet Elijah and, because of her generosity, her cruse (jar) of oil would go on being replenished until the famine ended.

Developing the Cruse Service

From the beginning, services were developed drawing on best practice and research. Torrie's husband, psychiatrist Dr Alfred Torrie, was the first Chair and he was succeeded by the world renowned Dr Colin Murray Parkes. Parkes was working with Dr Cicely Saunders at St Christopher's Hospice, where his research resulted in a model of bereavement support based on the contribution of trained volunteers. Parkes's longstanding involvement with Cruse, and that of other psychiatrists

(including Dr Dora Black, whose pioneering work on traumatic bereavement is internationally recognised), has ensured that developments in the understanding of grief have continuously been incorporated into the organisation's work.

Fifty years ago, Cruse's services included parents' circles for widows with children under 16 to help with the difficulties of being a one-parent family, counselling to address emotional needs and practical support, with a secondhand clothing distribution point and support applying to trusts for financial assistance. From research and experience, it became increasingly clear that the need for the kind of support provided by Cruse following bereavement was not confined to widows, and the service was expanded in the 1970s to include the needs of widowers and again in the 1980s to all those bereaved by death.

Cruse recognises that:

the death of someone close is likely to be the most distressing experience we will ever face. No two bereavements are the same and everyone's experience is unique. Grieving is a natural process, usually painful and of uncertain duration, being influenced by,

for example, the nature of the death, the circumstances of the bereaved person and his or her relationship with the person who died.

Most people negotiate the process safely with support from family or friends. Some people, however, experience difficulties and may need particular help and support. Grieving is not an illness but it may bring risks to physical and mental health. (Cruse Bereavement Care [CBC], 2004, pp. 9, 20)

Today, with a mission to offer support, advice and information to adults, children and young people when someone dies, to enhance society's care of bereaved people, and driven by the needs of bereaved people, Cruse has developed a broad range of free services to respond to varying needs.

Cruse is also the largest provider of bereavement care for children and young people in the UK. These services include: a free phone helpline (0808 808 1677); a specialist website, email support and message board service (www.rd4u.org.uk); leaflets specially written for children and young people; and one-to-one, face-to-face bereavement support and counselling.



Cruse Services



Figure 1
Bereavement support services offered by Cruse Bereavement Care.

The Cruse Service Model

The service model provides a flexible and comprehensive range of support tailored to meet the needs of individuals. It recognises that different types of support are needed along the bereavement pathway from reassurance, for example, in the immediate aftermath of a death when people will call our national helpline with the question “*Am I going mad?*” to the need to share experiences and coping strategies with others who have experienced a death through suicide in a facilitated peer support group. Others facing isolation and loneliness meet for social support in friendship groups. The majority of services provided are either bereavement support or bereavement counselling delivered on a face-to-face, one-to-one basis. The service model means that Cruse can provide the three tiers of support set out in the National Institute of Clinical Excellence (NICE) Guidelines (NICE, 2004). While many initially hear of Cruse from their medical practitioner, clients self-refer.

Following referral to Cruse, a needs assessment is undertaken using an assessment framework to identify those who “need help or reassurance to negotiate the grieving process; those whose grieving may be stuck, delayed, protracted or intense; those who may be at serious risk of complicated grief reactions”; to agree “what kind of support is appropriate and whether Cruse can provide it” and to explore “what other services are available and appropriate” (CBC, 2004, p. 34). Assessment continues throughout the working relationship.

Volunteer Recruitment and Training

All those delivering client services undergo a robust system of recruitment and selection. Those who volunteer do so for a range of motivations. Some have experienced bereavement themselves and particularly understand the need for support; some have themselves been helped by Cruse; a significant number are qualified counsellors who use their volunteering hours for British Association of Counselling and Psychotherapy (BACP) accreditation; and others are training to be counsellors.

Recent initiatives have included seeking to recruit younger volunteers. Our Youth Advisory Group (YAG) in Northern Ireland has recruited young people aged 12 upwards to advise on the development of services, work with local schools and develop resources, for example, producing a film called *Ask the Experts* (2008) in which they advise all those who come into contact with bereaved young people, particularly teachers, how to respond when a child or young person has been bereaved (CBC, 2008).

From its earliest days Cruse has placed great emphasis on the provision of high quality training and development. All volunteers with direct contact with clients are required to complete mandatory externally accredited training. The course (Awareness in Bereavement Care – The Cruse Foundation Course [CBC, 2007]) comprises 48 hours teaching time and 12 hours of self-directed study and is divided into 16 modules, usually delivered over several months to allow trainees sufficient space for reflection, practise and linkwork in between. All complete a portfolio, which provides evidence of an individual’s learning, experience and personal development and is used in the moderation process.

The course introduces trainees to the earlier models and theories of grief that have significantly influenced

our understanding. From the Attachment theory of Bowlby (1969–1980); Parkes’s Phases of Grief (1975); Worden’s Tasks of Meaning (1991) through to Klass, Silverman and Nickman’s Continuing Bonds (1996); and Neimeyer’s Reconstruction of Meaning after Loss (2001). The course draws heavily on the Dual Process Model of grief (Stroebe & Schut, 1999, 2010) with its emphasis on oscillation between a restoration and loss orientation. The course is currently being revised to bring it up-to-date with latest thinking.

The course challenges trainees at an emotional level, for example, looking at their personal values, assumptions and beliefs. It is critical therefore, that trainers create and maintain a safe learning environment. The course includes two learning models – “Awareness, Skills and Knowledge” and “Feelings, Thoughts and Actions”. The course is experiential; trainees have extensive opportunity to undertake skills practise in triads, taking on the role of client, Bereavement Volunteer and observer. Trainers continually assess trainees and their potential to go on to volunteer, offering feedback and support.

Development of the course was driven by the changing needs of bereaved people, including the fact that bereaved people were approaching Cruse earlier in their bereavements; the significant percentage of those who had been bereaved through sudden and traumatic death; and the need to embrace diversity in all its respects throughout the training.

During the first 12 months of volunteering, all volunteers are required to complete additional modules in sudden and traumatic death and children’s grief and, after that, undertake 15 hours of continuing professional development annually. A library of training modules has been developed. Needs are identified in supervision and an annual development review. Volunteers applying to work with children and young people, to provide group facilitation or to undertake supervision, undertake externally accredited Cruse training in these areas.

Recent training has focused on developing Cruse’s preparedness for a major incident. Cruse has a history of responding after major incidents. The organisation was mobilised by the Foreign Office after 9/11, sending volunteers to New York to support British families, and by the Metropolitan Police after the London bombings.

Supervision and Support of Volunteers

The quality of Cruse’s services is underpinned by standards and supervision. Internal standards have been developed across practice, management and training. All of them are compatible with the UK Standards for Bereavement Care, which Cruse developed in conjunction with other leading bereavement care organisations and which Cruse is currently in the process of revising with the Bereavement Services Association (the national network for all those who work in bereavement support services, but primarily those in the National Health Service).

All volunteers who work directly with clients are supervised every four to six weeks either one-to-one or in a group. Supervision safeguards the wellbeing of the client and ensures that their needs are being addressed. It ensures the quality of the work, provides volunteers with the opportunity to reflect on their practice, and gives opportunities for support, personal growth and development.

Evaluation of Services

In order to provide high quality services that help bereaved people, ensure that resources are used effectively and convince funders of the value of investment, it is vital to continually monitor the effectiveness of our work with bereaved people. The challenge of evaluating the effectiveness of bereavement interventions was highlighted in an edition of our journal *Bereavement Care* that focused on evaluation (Jackson, 2011).

For many years Cruse relied on clients completing evaluation forms. These continually highlight considerable satisfaction with the service, something that was emphasised in research undertaken by Gallagher, Tracey and Miller (2005), which surveyed the views of ex-clients of a Cruse branch in Northern Ireland six weeks after their counselling ended and found that former clients were very satisfied with the counselling service on a number of important dimensions. They felt their loss less intensely, had fewer physical symptoms and generally felt better. The only negative comments were about the time from referral to being seen by a volunteer. But satisfaction is not the same thing as effectiveness.

More recently it has been essential to become more sophisticated in terms of how we measure our outcomes and the difference we make to the lives of our clients. A range of methods is used throughout the organisation, as funders require different ways of evaluating services. Cruse has been working on an evaluation toolkit that draws together a range of different tools, including the Warwick Edinburgh Mental Wellbeing Scale, Core 10 (clinical outcomes in routine evaluation), GAD-7 (Generalised Anxiety Disorder Scale) and PHQ-9 (Patient Health Questionnaire). An Outcomes Star has been amended to make it relevant to bereavement.

Research

Cruse contributes to research that benefits bereaved people, extends our and society's knowledge of the impact of bereavement, considers the ways in which bereaved people are, or could be, supported, and the means by which existing services could be improved.

Some research proposals originate from within Cruse; for example, Wilson (2011) undertook research into the efficacy of a Cruse support group for male prisoners within a custodial setting. Cruse may also be approached to support research.

For example, Cruse participated in a random allocation study of bereavement support for bereaved people with learning disabilities. Those receiving volunteer support had "unequivocally better outcomes" than those offered integrated support from professional staff known to the subjects (Dowling, Hubert, & Hollins, 2003).

Our sister organisation, Cruse in Scotland, is currently engaged in an evaluation of the efficacy of the bereavement support service they offer, working with researchers from Utrecht University's Centre for Bereavement Research and Intervention to design and deliver a controlled trial that would compare outcomes for recipients of each of its three modes of "stepped care" with a group of bereaved people receiving no care.

Cruse also hosts an annual conference that brings together leading international speakers and showcases best practice in bereavement care.

Campaigning and Influencing

In addition to direct service delivery, Cruse recognises that as an organisation we can impact on the experience of bereaved people through influencing government policy. This dates back to Margaret Torrie who campaigned for improvements in widows' benefits. At the time of the Falklands War, Cruse was involved in urgent discussions with representatives from the admiralty, naval chaplains and the Ministry of Defence on the practice of burial at sea, highlighting the extra dimension of loss if no body was returned home. Most recently Cruse has campaigned for improvements to the coronial service and been instrumental in the reform of the death certification process following the Harold Shipman scandal, when a doctor was found guilty of murdering 15 people and over 250 murders were positively ascribed to him (The Shipman Inquiry, 2005).

Expansion of Cruse Services

The numbers approaching Cruse for support continue to grow year on year. Each year over 100,000 people contact Cruse.

But despite the large numbers, we know that there are groups who are under-represented and those whose needs we are not meeting adequately. Cruse has undertaken specific projects to target such groups. The Cruse Armed Services Project, for example, funded by the Department of Health, highlighted gaps in bereavement support for serving and ex-services personnel. The work included developing training for

Clients of Cruse Bereavement Care

39,162
received information
and advice

38,922
received
one-to-one
support

7,918
received support
in groups

5,343
children and young
people received
face-to-face support

Figure 2

Cruse Bereavement Care client contact statistics 2011–2012. (CBC, 2012)

Cruse volunteers and external agencies (face-to-face and e-learning) on the specific features of a military bereavement; developing a dedicated section of the Cruse website; raising the profile of our work among those in the military family and developing our links with other organisations working with this client group. DVDs were made about bereavement through death in the military from an adult and child perspective. Relevant literature was developed for distribution throughout the armed services and new leaflets were developed to explain the inquest process to young people in their teens and very young children.

Our latest project is our Early Intervention Project, again funded by the Department of Health, which will create a new and innovative early intervention service for bereaved people who are identified as being at risk of developing Prolonged Grief Disorder. Cruse will offer rapid specialist assessment by telephone and, where appropriate, ongoing telephone support sessions or fast track access into face-to-face bereavement support services.

Working in Partnership

Increasingly Cruse is working in collaboration with other organisations. “Bereavement Pathways” was a major three-year national project between Cruse and the Bereavement Services Association, looking at how we can better bridge the gap for bereaved people between the National Health Service’s acute sector and community services. The range of work included developing a visual pathway of the bereavement journey and creating and piloting a menu of solutions to bridge the gap. Building on this work, our “Gold Standard” Project is working proactively with bereavement services to develop these bridges and improve the delivery of joined up, cross-sector provision, as well as developing cross-sector training in bereavement care.

Conclusion

So to answer the challenge posed in Melbourne, volunteers can and do deliver high-quality services of a calibre that leads to more than 50% of our clients being referred to us by their medical general practitioner and our services being contracted by government departments, local authorities and health primary care trusts. We are recognised as delivering a high-quality service that provides good value for money. Our volunteers work with those across the spectrum of need, including those with Prolonged Grief Disorder, while also recognising when it is necessary to refer someone for different or more specialist services. Our face-to-face services are rooted in local communities, our helpline offers a nationwide service, while our website has a worldwide reach. It is a model that, with cultural adaptations, could be replicated around the world.

Many things have changed over the 53 years of Cruse’s history, including the extent of our coverage, the ways in which we deliver our services, and the models and theories that underpin our work. Some things have not changed: the need of bereaved people to have somewhere to turn, the necessity to deliver a range of services that meet individual needs, and the passion and commitment of our volunteers to be alongside people at the worst time of their lives. With a structure that delivers national and local services, firmly rooted in local communities, and based on an ethos of volunteering, which draws on the contribution of thousands who give their time, skills and passion, Cruse continues to provide somewhere to turn.

Note

¹ Mid-2010 population estimates, United Kingdom – adults. UK population over age 18. Population data from the Office of National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency.

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Abstract

The Australian Centre for Grief and Bereavement (ACGB) is an independent, not-for-profit company that is the largest provider of bereavement education in Australia and the largest provider of specialist bereavement support in Victoria, with a mission to enhance community wellbeing by building the capacity and resilience of individuals, organisations and communities to cope with adverse life events. The Centre has three primary spheres of activity: education and health promotion, counselling and support services, and research, with the view that each of these elements informs the others, that is, ACGB's education and clinical programs should be informed by the best available evidence and that research and teaching activities should be informed by clinical activity. ACGB's clinical services are responsive to the diversity of needs of bereaved people by offering a range of services and programs in recognition that people grieve differently and that different things help different people.

Origins of the Australian Centre for Grief and Bereavement

The origins of the Australian Centre for Grief and Bereavement (ACGB) can be traced back to a unique attempt to respond to a community need at a local level. A groundswell of community concern about the health issues associated with bereavement led to a public meeting in 1989 and the establishment of the Peninsula Bereavement Support Project. The common experience of those who attended was that recovery from grief was often complicated by inappropriate responses from family, friends and service providers. It was thought that this often stemmed from lack of information and knowledge about the grief process and a general discomfort in talking about death and bereavement. A number of health and support workers expressed a sense of helplessness when confronted with death. When assisting a bereaved client they reported feeling "out of their depth".

The people seen by this project were alone in their grief for a variety of reasons – because they were geographically or socially isolated; because the type of loss was unusual or unrecognised (e.g. suicide and miscarriage); because the relationship between the bereaved and the deceased person was unrecognised (e.g. the grief of grandparents after a child has died); because others were too anxious to reach out or simply fearing death and grief and would rather not be confronted by it. Regardless of the reason, the widespread isolation of the bereaved had resulted in a range of adverse health outcomes. The project report recommended that a broad range of interventions with the bereaved and the general community were needed to effectively address this central problem.

The creation of the Centre was also rooted in the new public health movement around the world, in particular the publication of the Ottawa Charter for Health Promotion (World Health Organization, 1986), released in 1986. This movement was focused on a process of enabling people to increase control over, and to improve, their health. Central to this charter were the goals of: (a) building healthy public policy, (b) creating supportive environments, (c) strengthening community action, (d) developing personal skills, and (e) a reorientation of health care services toward prevention of illness and promotion of health. This broader health promotion framework is important to consider given the vital role played by the social network in either supporting or complicating the adjustment of the bereaved (Burke, Neimeyer, & McDevitt-Murphy, 2010). Strengthening the capacity of communities of care to be able to provide effective support and to enhance the resiliency of the bereaved remains a core goal of ACGB.

One finding of this initial project was that education activities needed to be designed so that both the general and professional community are encouraged to reach out to bereaved people, in addition to creating opportunities for specific groups of bereaved to meet together. It became clear that several levels of change were required to improve the health and welfare of the bereaved within the community as a whole. The project proposed the creation of a grief education and training facility, which would serve the dual purpose of offering support services to the bereaved and developing the skills of health and support staff.

Following an initial grant from the Victorian Health Promotion Foundation to develop community skills in facilitating healthy grief, the then Victorian Department of Human Services (now the Department of Health [DH]), through the Palliative Care Program, funded the establishment of a grief education centre that provided a range of education, training, research and related services to those working in the area of grief and bereavement. The recognition by the Department of Health some 17 years ago of the significant adverse health affects of bereavement saw the Centre initially receive funding for its work. The achievements of the Centre have relied heavily on a collaborative and supportive relationship with the Victorian Government.

In 2004, the Victorian Government undertook a statewide review of funded bereavement services, recommending that the then four existing specialist grief and bereavement agencies be consolidated into a single entity. A comprehensive service system framework was also developed for the provision of bereavement support in Victoria. The Australian Centre for Grief and Bereavement (ACGB) was successful in securing the tender and in later years the Statewide Specialist Bereavement Service saw an expansion of services in metropolitan Melbourne and regional Victoria.

The mission of ACGB is to enhance community wellbeing by building the capacity and resilience of individuals, organisations and communities to cope with adverse life events. A fundamental principle of our clinical services is to be responsive to the diversity of needs of bereaved people by offering a range of services and programs, in recognition that people grieve differently and that different things help different people. An awareness of cultural factors and a systemic orientation to bereavement support and interventions is integral to the work of the organisation.

More specifically, the Centre:

- develops and provides a range of specialist interventions and innovative education services, informed by evidence-based practice, for grieving people who are at risk of adverse outcomes
- provides grief education and a range of consultancy services to develop and enhance the capacity of individuals, organisations and communities to deal effectively with loss
- provides grief and bereavement counselling training and supervision through the placement of practitioners at ACGB's Bereavement Counselling and Support Service (BCSS) and other settings as deemed appropriate
- builds the capacity of universal health services to provide bereavement supports and responses
- provides advocacy and representation on grief and bereavement issues in order to inform policy development, raise community awareness and support universal access to mainstream grief and bereavement services
- undertakes research, program evaluation, public policy development and the production of evidence-based publications and resources to enhance grief and bereavement knowledge and practice
- maintains cooperative links with relevant state, national and international groups and organisations in relation to grief and bereavement
- provides a national clearing house of grief and bereavement resources and literature to inform policy, practice and research into grief and bereavement and to enhance the activities of the organisation, other practitioners, support agencies and self-help groups.

The Centre, in keeping with a broad health promotion focus, utilises a range of generalist and specialist approaches in order to support the bereaved.

This ranges from building the capacity of communities to support themselves following loss, through to providing a range of direct clinical services where social and community support is either inadequate or insufficient. This service model is depicted in Figure 1.

ACGB is the largest provider of bereavement education in Australia and the largest provider of specialist bereavement support in Victoria. Today, ACGB is an independent, not-for-profit company and employs 31 staff in 12 locations throughout Victoria, has 29 interns and practitioner associates, and 95 volunteers. Each year the Centre provides support to approximately 1,400 clients and 825 hours of education and training to 3,300 participants nationally. The Centre has an operational budget of approximately 2.4 million dollars.

The Centre has three primary spheres of activity: (a) education and health promotion, (b) counselling and support services, and (c) research. A strongly held view of the organisation is that each of these elements should inform the others. That is, our education and clinical programs should be informed by the best available evidence and that our research and teaching activities should be informed by clinical activity. This interconnection and intercommunication is critical to the development of each of these three areas of endeavour.

The Centre is committed to move beyond the simple dissemination of knowledge into the translation of this knowledge into practise. Knowledge translation, as defined by the Canadian Institutes of Health Research, is a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system (Canadian Institutes of Health Research, n.d.). Knowledge translation is fundamentally about: (a) making users aware of knowledge and facilitating their use of it to improve health and health care systems; (b) closing the gap between what we know and what we do (the "know-do" gap); and (c) moving knowledge into action.

Boren and Balas (1999) estimate that new evidence-based interventions languish for 15–20 years before they are incorporated into core practice, and then only a small proportion of innovations find their way into service delivery. Audits in a variety of health settings have revealed that high-quality evidence is not being used consistently in practice, with one US study finding that patients, on average, receive about half of the recommended medical care (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005).

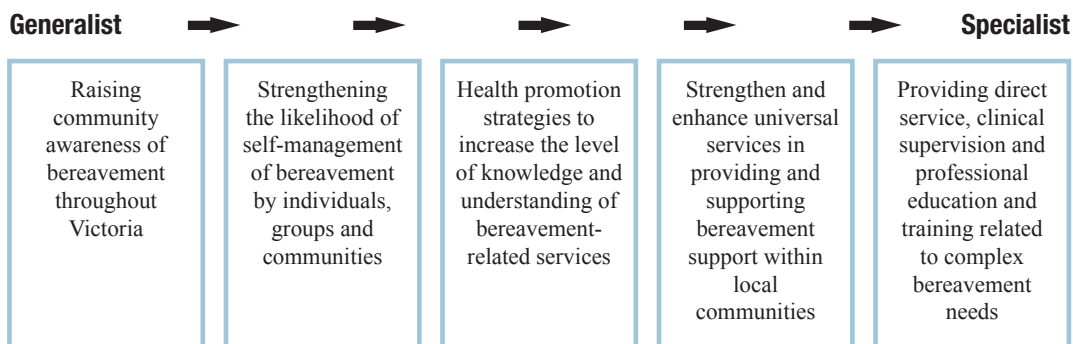


Figure 1
Continuum of generalist and specialist services.

Although this finding is from a medical setting, it does raise the question of what gaps exist between what we know works in the bereavement setting and what is actually done.

Research

The peer-reviewed journal *Grief Matters: The Australian Journal of Grief and Bereavement*, published by the Centre in-house since 1998, encompasses both academic and applied aspects of grief and bereavement and is a ranked journal with the Australian Research Council as part of the Excellence in Research for Australia (ERA) initiative. The journal was also recently ranked 30th of 700 journals on a leading academic database, with readers downloading more than 7,600 articles from over 320 unique documents this year (at time of writing).

ACGB also has within its charter the conduct of research into aspects of bereavement and participation in collaborative national and international research projects. Most recently the Centre has published the *Bereavement Support Standards for Specialist Palliative Care Services*, which provide guidance to palliative care services on bereavement support (Hall, Hudson, & Boughey, 2012).

Counselling and Support

ACGB operates a Statewide Specialist Bereavement Service for Victoria. Counselling services in Melbourne are provided by employed counselling staff and either experienced counsellors undertaking advanced training in bereavement counselling (Intern Bereavement Counsellors) or already qualified bereavement counsellors (Practitioner Associates). Approximately 50 practitioners provide counselling through these programs.

In regional Victoria, five Regional Specialist Bereavement Counsellors are employed full-time, located in the five Department of Health regions. Sixty-five per cent of their time is allocated for direct service delivery (such as counselling and support groups), 25% for capacity building (such as providing advice and consultation to workers in regional specialist and mainstream services), with the remaining 10% for administration. Each Regional Specialist Bereavement Counsellor has a local Advisory Group comprising key professionals who provide support and guidance in the development and provision of regional services.

Nearly one quarter of clients attending counselling services were bereaved as a result of a sudden illness, 29% were deaths resulting from cancer, 17% from chronic illness, 15% from accidents, 9% from suicides and 2% from homicides. Twenty-two bereavement support groups are also run by ACGB staff and volunteers throughout Victoria, often in partnership with other agencies.

Two toll-free telephone services – the Bereavement Information and Referral Service and the Practitioner Consultancy Service – operate on weekdays during office hours. The former is available to the general public and health professionals seeking information about bereavement services in Victoria, with the latter available to health practitioners seeking advice and consultation in complex bereavement situations.

In addition to counselling, a range of related support services are provided.

These include:

- an e-newsletter, which complements the Practitioner Consultancy Service, and brings up-to-date information and resource material (*Bereavement Practice Notes*) to around 700 health professionals working with bereaved people, particularly those in agencies where loss, grief and bereavement is only one of a range of areas of work
- a more general quarterly newsletter, *The Rosemary Branch*, is produced for clients and has a circulation of approximately 1,500; content is developed by a working group of staff, volunteers and past clients (that many contributions are received, along with positive feedback, indicates it is a valuable service)
- an annual Ceremony of Remembrance
- a collection of relevant literature is also available (which can be emailed).

Some of ACGB's key achievements include providing clinical services to those bereaved following a range of disasters. Currently, through the Victorian Bushfire Appeal Fund and the DH, to those bereaved as a result of the Black Saturday bushfires in February 2009 (Hall, 2011). This support is provided through four half-time Bushfire Specialist Bereavement Counsellors (located in selected areas around Victoria). Funding was provided to establish twelve adult bereavement support groups, which was subsequently extended to also establish groups for children bereaved through the bushfires.

The last few years has seen the development of a new dataset that is collected at intake. In addition to the collection of a range of demographic-, individual- and deceased-related information, clients also complete the Integration of Stressful Life Experiences Scale (ISLES; Holland, Currier, Coleman, & Neimeyer, 2011), the Inventory of Complicated Grief (PG-13; Prigerson & Maciejewski, 2012), and the Inventory of Social Support (Hogan & Schmidt, 2002). Future work will look at how this data can be used to influence clinical decision making, intervention selection and measurements of bereavement intervention efficacy. For example, the recent findings by Johnsen, Dyregrov and Dyregrov (2012) that in regard to bereavement support groups, participants who fulfil the criteria of prolonged grief, are in general less satisfied with groups and report less-positive effects on life quality, merits further examination and may in the future influence intervention selection.

Theoretical Orientation

The Centre takes an eclectic and theoretically diverse perspective on bereavement counselling and draws from the findings of common factors research (Morawetz, 2002), which suggests that treatment is most likely to be effective when it is responsive to the client's specific problems, strengths, values, beliefs, world views, goals, personality, sociocultural context and preferences. Research suggests that ensuring a fit between the model and the client's world view can influence both retention and outcomes in therapy (Johnson & Talitman, 1997). We encourage counsellors to have a thorough familiarity with several diverse models so that they can adapt these to the needs of their client rather than vice versa. We focus in particular on achieving positive outcomes in the areas of alliance building, client engagement, the generation of hope and expectancy, understanding their bereavement experience in relational terms and through the reconstruction of meaning in regard to the unique

world of the client. It is strongly felt that bereavement practitioners should have a thorough grasp of theory and research related to topics of human development, trauma, culture, gender, ageing, relationships, family relationships and spirituality. There is a danger that bereavement practice, in becoming a sub-specialty, fails to recognise the broader context of the bereaved individual and comorbid issues such as depression, anxiety and posttraumatic stress disorder.

The Centre is also influenced by recent studies on the efficacy of bereavement interventions (see Hoyt & Larson, 2010; Neimeyer, 2010; Schut, 2010), in particular the findings that we are most helpful in our intervention efforts when these are directed to those who are suffering substantially and that services provided to bereaved people who may already be coping adaptively and resiliently with their loss shows less benefit. Currently the Centre focuses on bereavement counselling and psychotherapy using evidence-informed specialist interventions for complicated grief, such as:

- Cognitive Behavioural Therapy for complicated grief (Boelen, van den Hout, & van den Bout, 2006)
- Focused Family Grief Therapy (Kissane & Bloch, 2002)
- Complicated Grief Treatment (Shear, Frank, Houck, & Reynolds, 2005)
- Meaning Reconstruction approaches to grief therapy (Neimeyer, 2000).

Education and Health Promotion

ACGB provides a wide range of education and training programs, targeted to health professionals, students, volunteers and other individuals or agencies wishing to enhance grief and bereavement knowledge and practice. Education and training is offered through seminars, workshops, short and long courses and customised training to meet specific needs.

Our suite of training now includes the nationally recognised, postgraduate qualification – the Vocational Graduate Certificate in Bereavement Counselling and Intervention (VGCBCI). This qualification is the only face-to-face vocational bereavement counselling training program in Australia and is a ten-month, part-time course designed to provide training in applied competencies and theoretical frameworks deemed essential for the provision of effective bereavement counselling and intervention. Accredited under the Australian Quality Training Framework, the VGCBCI is the only postgraduate program in Australia solely dedicated to the vocational training of bereavement counsellors. The course is designed for counsellors, social workers, health workers and psychologists with appropriate counselling training and substantial work experience in the human services field. The course aims to equip students with applied competence in effective bereavement counselling and intervention; theoretical frameworks associated with the field of loss, grief and bereavement; ethical supervised practise and worker self-care.

There are likely several qualities that make bereavement practitioners proficient and finding ways to identify and recruit those with inherent talent is a compelling research question. The fact that treatment outcomes are systematically related to the provider of the treatment (above and beyond the type of treatment provided) gives

strong evidence for the importance of understanding expertise in clinical practice as a way of enhancing client outcomes (Timm & Blow, 1999).

The organisation's general orientation to bereavement is perhaps best summarised by the content and framework that is provided by the five core units provided within our VGCBCI course:

1. Concepts of bereavement responses and care

This module provides a background and the concepts and processes of grief and bereavement. It considers the roles of grief education, psycho-education and psychological first-aid, in addition to ways of strengthening natural support networks; the legal and ethical context of bereavement counselling with an examination of the death system in Australia and the legal and social context of sudden death in Victoria; a systemic understanding of bereavement interventions; and the risks for the bereavement counsellor.

2. Work within a clinical supervision framework

This module explores the skills and knowledge required to participate in effective clinical supervision for the continued improvement of counselling skills and clinical practice. It examines risk management strategies, self-awareness, professional supervision, ongoing professional development and research practice; develops specific skills in supporting children, adolescents and families are developed alongside special populations (such as cultural diversity, bereavement in Indigenous communities, bereavement and addictions, disability, mental illness and those bereaved through suicide); considers complicated and prolonged grief determinants, assessment and treatments; and appropriate therapeutic interventions for grief associated with trauma.

3. Provide bereavement counselling and support

This module describes the skills and knowledge required to determine and apply appropriate approaches for bereavement counselling and support interventions. It considers skills development in the areas of Gestalt, Attachment, Psychodynamic and Constructivist theory and practice, as well as group work, working with communities and single session work.

4. Provide appropriate support interventions to support people experiencing complex bereavement

This module provides the knowledge and skills to assist people who are experiencing complicated or prolonged reactions to grief. This considers the factors that can complicate the bereavement experience and implement strategies for supporting those experiencing complicated or prolonged bereavements. It considers the facilitation of posttraumatic growth and the development of protective factors that may assist in adaptation to loss.

5. Access services to support clients experiencing bereavement

This module provides the knowledge and skills to enable counsellors to identify the need for outside support and services for clients, and to access those supports and services. This includes aligning client needs to specific intervention options, identifying and providing the delivery of services to meet client needs and methods of supporting those from special populations.

Future Directions

The Centre is keen to develop a range of online-based interventions building upon the work of Wagner and others (Wagner & Maercker, 2007). This would include mobile applications (i.e. iPhone or Android “apps”) that could assist the individual in self-managing their bereavement experience or as an adjunct to their bereavement counselling. This could include, for example, a grief diary that could be shared with a counsellor in addition to a range of self-directed bereavement support strategies.

Although it is important not to assume that bereavement interventions that have not been studied are ineffective, good practice and good science calls for the testing of clinical practices. We need to further develop compelling effectiveness data. This would include the exploration of dose-effect relationships between the number of sessions (dosage) and the therapeutic outcome (Howard, Kopta, Krause, & Orlinsky, 1986). We are also interested in further exploring the role that brief/single session therapy might play in bereavement support. Single session work is based on two key findings: first, that across a range of counselling and therapy services, the majority of clients attend one or two sessions and, second, that studies following up these clients, although traditionally seen as dropouts, have found them to be generally satisfied with the service they have received (Boyhan, 1996). This would follow the work undertaken by the Bouverie Centre, a centre for training, research, and clinical family therapy in Melbourne, Australia (O’Neill & Rottem, 2012). As a government-funded agency, our research agenda needs to consider issues of accessibility and utilisation of bereavement services; the cost-effectiveness and cost-benefits of bereavement services; and how we can further support the building of a community’s capacity for resilience and self-care following bereavement.

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Merimna: The Society for the Care of Children and Families Facing Illness and Death

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Abstract

Merimna (meaning “care” in Greek) is a nonprofit organisation, whose mission is twofold: (a) to provide timely and quality care, relevant to the needs of children and parents who live with a life-threatening illness or grieve the loss of a loved person; and (b) to develop supportive communities through appropriate training and education. Merimna is the only organisation in Greece that provides community-based childhood bereavement support, as well as paediatric palliative home care services. Moreover, it seeks to educate professionals, train volunteers and raise public awareness on issues related to childhood grief, community support after a traumatic or disaster event, and holistic care for children and adolescents with a life-threatening illness and their families. Faced with new challenges evoked by the socioeconomic crisis in Greece, Merimna seeks to address emerging needs for bereaved children and families, secure funding for its projects and activities and, concurrently, mobilise local communities to support expanding services across the country.

Merimna

Merimna (which means “care” in Greek) is a not-for-profit organisation for the care of children and families facing illness and death. It was founded in 1995 by an interdisciplinary team of nine experienced health care providers and university professors. After their repeated appeals to governmental officials for the development of paediatric palliative and bereavement services had failed, they decided to collaborate closely and founded Merimna with the mission:

to provide timely and quality care, relevant to the needs of children and parents who live with a life-threatening illness or grieve the loss of a loved person, and to develop supportive communities through appropriate training and education.

Goals, Activities and Services

Merimna has four main goals:

1. To *raise public awareness* on issues related to death, dying, grief, and bereavement support.
2. To *train and educate* professionals and volunteers.
3. To *develop and offer bereavement and palliative care services* to children, families, schools, and communities that are affected by serious illness and death.
4. To *conduct research* in childhood bereavement and paediatric palliative care.

To achieve these goals, Merimna has developed over the years many clinical and educational projects and activities thanks to the volunteer contribution of its board members, and the invaluable work of its administrator and employees. These are briefly described, in relation to each of the identified goals of Merimna.

Goal 1: Awareness-raising and Dissemination of Knowledge

In Greece, death is perceived as a taboo topic and a reality from which children are to be “protected”. This applies especially to those children who live in urban areas, who are never involved in the care of a seriously ill relative and rarely attend a funeral. In an attempt to change these attitudes, which deprive bereaved and seriously ill children of adequate support, Merimna seeks to create an “open space” for discussions about death, dying and bereavement by raising public awareness about the needs of children and adolescents who encounter losses that affect their life and development. To this day, several hundreds of lectures and seminars have been offered all over the country, while national conferences, available to both professionals and the public, have been organised on the following topics: “Mourning in our life” (1996), “When illness and death affect school life” (1998), “Losses in children’s lives” (2003), “Paediatric palliative care: Challenges and opportunities” (2009), “Paediatric palliative care: Service development” (2011). Dissemination of knowledge is also promoted through the publication of booklets, leaflets, informational kits for educators, conference proceedings, translation of children’s stories, and educational DVDs on issues related to childhood grief, paediatric palliative care, and crisis intervention following traumatic losses (Merimna, 2009).

It is our firm belief that in order to develop community services for children and families, we must first cultivate a fertile ground where bereavement and palliative care can flourish. Supporting seriously ill and bereaved children is a collective responsibility, assumed by caring communities, and Merimna’s broad sensitisation seeks to de-professionalise grieving and inform the public how to recognise and address in appropriate ways the needs of children and families who are affected by illness and loss.

Goal 2: Training and Education of Professionals

Since its foundation, Merimna has offered comprehensive training programs for professionals who wish to acquire knowledge or specialise in the fields of childhood bereavement support or paediatric palliative care. Each training program is carefully designed and evaluated according to its goals, objectives, and level of training. At level 1, training is basic and addressed to volunteers, undergraduate and graduate

students, educators and all health care providers. At level 2, it is addressed to professionals who already work with children in different settings. Finally, at the advanced level 3, training is offered to those who wish to specialise in childhood bereavement support or paediatric palliative care.

Adapted to each level of training, Merimna's educational programs define goals and learning objectives which aim at: (a) the acquisition of knowledge and skills in assisting and supporting children and families; (b) the capacity for interpersonal thinking and interprofessional collaboration, which has multiple benefits (e.g. cope with prejudices, bias, communication obstacles among different disciplines); and (c) the increase of awareness and insight into individual and team functioning in death situations.

Trainees learn to adopt a "relationship-centred approach to care", which focuses on the reciprocal influence and in depth understanding of how they affect and are being affected by their encounters with children, families, co-workers and colleagues, as a means for developing enriching relationships to those who seek and those who provide care (Papadatou, 2009). A "relational approach to learning" seeks to transform the educational context into a "safe space" for trainees, clinicians, instructors, and families that are involved in a learning process. It allows them to reflect upon their interactions, partnerships and collaborations (Browning & Solomon, 2006; Papadatou, 1997, 2009). Methods of teaching are both didactic and experiential, with supervised clinical practice being central to the learning process.

Three educational programs have been repeatedly offered, so far: "Childhood, family, and community bereavement support", "Paediatric palliative care", and "Psychosocial interventions in disaster situations" (the duration varies from 100–250 hours). To this day, 260 psychologists, child psychiatrists, social workers, educators, paediatricians and nurses from all over the country, have received training at levels 2 and 3, and serve as "reference professionals" in their work setting and local community. They belong to a national network of trained professionals and collaborate with Merimna on various occasions. Finally, Merimna offers opportunities for supervised clinical practice to a selected number of postgraduate students in nursing and psychology from the University of Athens.

Goal 3: Provision of Community-based Services

Merimna runs three distinct services, which are addressed to different populations of children who are affected by a serious illness, death(s), or disaster event. These services are provided free of charge by teams of trained professionals.

1. *Bereavement Counseling Center*: for grieving children as well as their family and school community
2. *Disaster Intervention Team*: assisting communities to develop supportive systems for affected children and adolescents
3. *Paediatric Palliative Home Care Service*: for seriously ill children, their siblings and parents.

Bereavement Counseling Center

When developing the Bereavement Counseling Center, we had to decide which among the three models of community bereavement services we should adopt (Worden, 1996; Stokes et al., 1999). According to

Model A, bereavement services are offered only to children who exhibit observable psychological problems and high levels of distress. This model tends to pathologise manifestations of grief, and disregards children who deliberately hide their distress and appear unconcerned when they actually suffer internally. Model B proposes that services be offered only to children who are assessed being "at risk" for developing long-term difficulties. Finally, Model C supports that services are available to *all* bereaved children and families. Even though Model C is the least cost effective, it nevertheless has several benefits because it normalises the grieving process, offers early intervention that prevents complications, and promotes childhood and family resilience.

Merimna developed its Bereavement Counseling Center according to Model C, which promotes resilience, by maximising resources and minimising conditions that render children, parents and school communities vulnerable to grief complications and adjustment difficulties. Based on a resilience model, the following types of services are provided:

- *grief counselling and occasionally grief or trauma therapy* to children and families
- *consultation and support to school communities* that are faced with loss situations
- *consultation and supervision* to clinicians who support bereaved children and families
- a *telephone helpline* that provides parents, educators and health care professionals from all over Greece, counselling and guidance in death situations.

The Bereavement Counseling Center's staff comprises eight psychologists, trained through Merimna's educational programs and selected for their clinical skills and ability to work with a team spirit. When families come to the Center, psychologists address their immediate needs, and conduct a thorough standardised assessment of the child's, the parent's and the family's functioning and wellbeing. This clinical assessment (which has been developed after years of clinical experience coupled with the study of existing research on childhood grief and trauma) helps clinicians to identify adaptive coping patterns and resources, or potential complications displayed through post traumatic stress disorder, depression, or traumatic grief responses. Each family is then presented with a plan of support for its members, which includes one of the following three options:

- *individual grief counselling or therapy* is proposed to children and parents who are at risk for complications or display major adjustment problems.
- *family or spousal counselling* is proposed to families or couples that experience unresolved losses, maintain secrets, or place a large burden upon children to either support their parents or replace a deceased family member
- *bereavement support groups* are offered to children, adolescents, and parents who experience a healthy grieving process.

The plan of support is not imposed but proposed and *owned* by children and adult caretakers who are informed about the outcomes of assessment and actively participate in decisions about types of support that can best serve their needs. Our main goals are to (a) help



children and parents cope with any traumatic responses that complicate their grief, (b) facilitate a healthy grieving process and effective adaptation through the development of new skills and resources, and (c) encourage the reconstruction of a personal and family story that is meaningful and comforting to them. The psychological wellbeing of children and parents are re-assessed at the end of individual, family or group interventions, and the effectiveness of the delivered services is evaluated.

Disaster Intervention Team

In response to requests from the Ministry of Education and the Ministry of Health and Social Solidarity, Merimna has provided psychosocial support to schools and local communities after major disasters or traumatic events (i.e. the earthquake in Attica in 1999, a road traffic accident that caused the deaths of seven teenagers in 2004, and the Peloponnese wildfires in 2007). Members of the Disaster Intervention Team are different with each intervention and comprise members of the Board of Directors, psychologists from the Bereavement Counseling Center and a selected number of professionals trained by Merimna.

Transferring and implementing effective interventions to schools and communities that experience multiple deaths due to a traumatic event or disaster is an ongoing challenge. Using a systemic framework, we seek to co-create interventions with key members of the local community, in order to address both individual and collective grief and trauma. Interventions extend beyond the cultivation of individual resilience and address the needs of various systems in order to promote community resilience. The ultimate goals are to empower students, teachers, parents and local practitioners, whom we train, to convert inaction into constructive action, to develop supportive systems and resources, to ritualise their grief, and to progressively reconstruct a collective story that is meaningful and comforting to them. This approach differs from the classical psychiatric model of intervention that focuses on prevention and treatment of psychopathology and which victimises children and adolescents by viewing them as highly vulnerable and damaged by traumatic events. We perceive communities as able to cope with challenges when they mobilise existing resources, develop new ones, and benefit from the information, guidance, and support that we provide along with local mental health professionals, in order to address the needs of those requiring long-term help.

What is unique to Merimna's interventions is a collaborative alliance with schools and community leaders, in a shared effort to address both the immediate, short- and long-term needs after a traumatic or disaster event. No intervention is alike, since each community is unique. Some of the lessons learned through these collaborations have been documented through published articles (Papadatou et al., 2012a, 2012b), educational DVDs (2009), and an information kit, *Life Losses – Bridges of Care*, has been developed to assist educators in supporting grieving students and taking appropriate actions when a school community is affected by loss(es). In 2013, more than 2,000 educators will be trained across the country and the kit's material will be made widely available.

Paediatric Palliative Home Care Service

To understand the development of paediatric palliative care in Greece, it is important to consider the social context in which health care services are provided to people who suffer and die from life-threatening conditions. Life preservation remains a high priority for most health care professionals who assume a disease-centred approach in the care of the dying children, adolescents and adults. Hospices do not exist and home care services are available only for adults who are seriously ill. Palliative care is made available mostly through pain clinics, which remain focused on the treatment of physical symptoms and lack an interdisciplinary approach to care. The existing law about palliative care is adult-oriented, limited in its efficacy to encourage the development of appropriate services, and totally oblivious of the needs of seriously ill children, adolescents and their families.

In spite of these difficulties, in 2010 Merimna developed the Paediatric Palliative Home Care Service, the first and only service of its kind available in Greece. The services provided to children and their families comprise:

- symptom relief for the seriously ill child or adolescent
- psychosocial and spiritual support for seriously ill or dying children and their family members
- collaborations with schools to facilitate the integration of the seriously ill child, and support peers and educators through their grief
- bereavement support for families, peers, and significant others.

To ensure continuity of care between hospital and home, Merimna has established Collaboration Agreement Protocols with public paediatric hospitals. These enable members of the paediatric palliative care team to meet families of hospitalised children and discuss – along with the treating physicians – the option of home care. Through this collaboration hospital personnel are introduced to the principles of paediatric palliative care and facilitate referrals of children and families who can benefit from palliative home care services.

Members of the palliative care service include paediatricians, nurses, a social worker and a psychologist, all with extensive and specialised training in paediatric palliative care. It is only recently that volunteers trained by Merimna have been actively involved in assisting families, supporting the work of professionals, and helping with administrative and practical tasks.

The need for coordinated actions among clinicians, parents, academics, and various national paediatric organisations and associations, to set paediatric palliative care as a high priority in the government's health care policies and pursuits, is imperative. It is the least a society can do to ensure a dignified life for children who will never grow into adulthood and for their families who will have to learn to live with such a loss.

Goal 4: Research in Childhood Grief and Paediatric Palliative Care

Despite the wealth of Merimna's clinical experience in the fields of childhood grief and paediatric palliative care, research has been limited, and mostly achieved through collaborations with the University of Athens. To this day, studies have been focused on needs

assessment and service evaluation. An early national study assessed educators' attitudes and behaviours towards seriously ill and bereaved children (Papadatou et al., 2002a, 2002b), while more recent studies explored the factors affecting long-term adjustment among traumatised adolescents (Papadatou et al., 2012a, 2012b). Currently, a study aims to evaluate both the *process* and the *outcomes* of the palliative home care services that are being offered by Merimna. The outcome of Merimna's research objective is to develop appropriate measures to evaluate the effectiveness of the bereavement and palliative care services, and ascertain that the needs of children, adolescents, families, and professionals are being met in appropriate ways.

Organisational Structure and Culture

Merimna is a relatively small organisation with 16 employees (both full- and part-time) and seven external collaborators. Since its inception, members of the board of directors who have extensive clinical experience in health care and educational settings, have been actively involved in the development of clinical services, the selection and ongoing formation of staff, the development of educational programs and the organisation of conferences and public events, which are addressed both to professionals and lay people.

To address issues with regard to Merimna's daily functioning, a monthly "open space group" (or "sensitivity group"), facilitated by an external consultant, provides members of the organisation (administrator, staff, secretaries, and Chair of the Board) with opportunities to discuss issues they feel strongly about, and to share concerns, frustrations, disappointments, gratifications, and achievements that are integral to the pains and joys of growing and maturing as an organisation.

The close relationships among employees and administration have contributed to the development of a cohesive, friendly atmosphere with a clear hierarchical structure that promotes open communication and collaboration. Merimna's organisational culture offers a framework for understanding and making sense of its work and development. Given that there is not one singular culture per organisation, but several subcultures, these are reflected in the daily interactions with children, families and schools, as well as among members of the organisation and their collaborations with local community services. Following are described the espoused core values that are reflective of Merimna's subcultures:

A culture of care

Merimna's choice of logo depicts the significance placed on the quality of care for children, families and communities but also the care of its employees, by attending to professional, educational and, occasionally, personal needs. The Board of Directors operates under the assumption that the extent to which professionals are emotionally held and supported by their organisation, affects their ability to hold and support dying and bereaved children and adults in similar ways. Defining "care" and acknowledging and valuing the multiple ways by which it is offered and received, is an ongoing process and a shared responsibility between administration and employees that requires participation of all members.

A culture of collaboration

Merimna's founders are experienced professionals with expertise in different fields who collaborate as a team for the development and growth of this organisation. Their commitment to interdisciplinary collaboration is reflected in every aspect of the organisation's life and relationships among staff members. Time is devoted to reflect and process collaborations within and between teams and to facilitate the coordination of services, which have progressively become standardised, transparent and accountable. While Merimna's initial focus was to enhance fruitful collaborations within the organisation, over the past few years, there has been a cultural shift affected by what Payne (2000) refers to as "open teamwork". Open teamwork involves the development of external relations and collaborations with other professionals, teams, agencies, or services within the community in order to respond to the needs of families who are being served by Merimna. It requires permeable team boundaries to allow the circulation of information and an openness to integrate different approaches, value systems and organisational cultures in a network of different organisations.

A culture of learning

A culture of learning goes beyond the provision of staff training, which is provided on a regular basis according to the identified needs of each team. Staff members – and volunteers alike – are offered "protected time" for learning *together* from complex issues, achievements and mistakes, and regular reviews of their goals, values and modes of operation. Shortcomings and mistakes are viewed as opportunities to expand the team's and the organisation's knowledge and capacity to change, rather than as occasions to criticise or blame others. Following are described some of the routines and procedures through which learning, innovation, and change are promoted:

- *Supervision sessions* enable professionals to explore personal and team issues triggered by their encounters with bereaved and/or dying children and families. "Super-vision" helps them to develop an alternative view on their lived experiences, challenge their "comfort zones" and engage in reflective practice and new learning about self, relationships and collaborations.
- *Team meetings* address theoretical and clinical issues associated with the delivery of services and goals of care. They also offer opportunities to discuss new ideas and projects. These meetings are distinct from the weekly in-service staff meetings, which aim to plan and coordinate the provided services.
- *Annual review meeting* enables members of each team to revisit their individual and collective goals, procedures, modes of operation and to decide upon changes deemed necessary or innovative interventions that can best serve the needs of children, families and school communities.

Over the years, Merimna's organisational culture has experienced various shifts. With the expansion of its services, staff, and collaborations, some of the "ways of doing things" have changed; however, the underlying values, beliefs and assumptions have remained stable. The strong and homogeneous nature of Merimna's subcultures have both benefits and limitations when it comes to organisational change.

Strengths, Weaknesses, and Threats

Merimna attends to the needs of all children and adolescents who are affected by death. In that respect, its services are situated at the crossroads of adult palliative care (children with a dying parent), paediatric palliative care (children suffering from a life-threatening illness), grief counselling and therapy (children and family members who are affected by the loss of an adult or child), and community intervention in disaster situations (children who are affected by multiple personal and community losses).

The organisation's strengths lie in its reputation for the delivery of high quality services by trained professionals who are committed to a job they like and derive satisfaction from. Merimna's mission and goals are clear, procedures are reviewed regularly, and working conditions are excellent. The organisation benefits from the invaluable support of volunteers who belong to an association, named "The Friends of Merimna", whose aim is to support Merimna's goals through fundraising activities and the promotion of its philosophy and work. It is worth noting here that Merimna's funding resources rely exclusively on private individual and corporate donations (no governmental support).

Merimna's weaknesses are associated with its highly controlled and limited exposure to the media, and its limited publications on aspects of a long, and extremely rich clinical experience. A major threat to the organisation is the drastic reduction of its funding sources, due to the economic crisis, and a recent law that discourages Greek donations, which are no longer exempted from taxes but, instead, are taxed when they are larger than a predetermined amount.

Conclusion: What About Opportunities?

Faced with new challenges, Merimna strives to cope with significant financial restraints, while seeking to develop new approaches, novel interventions, and expand services to an increasing number of bereaved children who experience traumatic deaths, grief complications and/or family mental health problems associated to the Greek socioeconomic crisis. Rather than "doing more with less", Merimna seeks to "do things differently" by expanding partnerships with other European and international organisations that face more or less similar challenges.

We believe that a hopeful response to a fast changing world, in which loss and grief are inevitable experiences, is the creation of bridges of communication, collaboration and mutual support that may enable those who accompany children who live with the threat or reality of death, to coordinate national and international actions for their support. The benefits for all parties involved will undoubtedly be many. Together, we can discover how far we can go to create a better world for children, families, schools, and communities that strive to adjust, develop and grow in the midst of loss, change and adversity.

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Upcoming Conferences

Association for Death Education and Counseling (ADEC) 35th Annual Conference Reframing Images of Grief: Identity Transformation Through Loss

April 23–24, 2013

Pre-Conference Institute

April 24–27, 2013

Loews Hollywood Hotel (formerly Renaissance Hollywood Hotel and Spa) Hollywood, California, USA

No one seriously debates the notion that loss changes life. The often-repeated phrase that “life will never be the same” is certainly true, but some of those “not the same” characteristics of loss can be revolutionary. People gain new passion. Purpose is reignited. Great movements are begun. In short, the identity of the grieving person is utterly transformed. That’s what this conference is all about – finding the ways we as death educators, bereavement professionals and counsellors come alongside the dying and bereaved to help them learn how to live in a radically changed world.

Contact

Check the ADEC website’s conference page for updates <http://conf2013.adec.org/>



Centre for Death and Society (CDAS) Conference 2013

New Economies of Death: The Commodification of Dying, the Dead Body, and Bereavement

June 29–30, 2013

Bath Royal Literary and Scientific Institute Bath, UK



The 2013 CDAS Conference will explore the constantly evolving relationship between commodification and human death. We are interested in papers and presentations that examine the commodity values (both real and speculative) attached to the following themes:

- physical and conceptual understandings of death
- the dying process and care of the dying
- the buying and selling of human body parts
- tissue economies and the selling of dead bodies
- cultural resistance to commodification in the market for human goods
- dead body donation for medical schools and anatomical research
- the gift relationship and the exchange of human biological materials
- organ markets, both government operated and blackmarket
- the political economy of organ markets
- consumer costs for funerals, dying, and memorialisation
- new critiques of capitalism and its relationship to death and dying as forms of labour
- the dead human body as a labouring body
- future postmortem economies built around life extension
- the capitalisation of digital spaces for memorialisation
- the commodification of social networks, both real world and digital, that deal with death
- postmortem digital property rights and the next-of-kin relation
- the multitude as composed of both living and dead bodies
- the aesthetic commodification of death, dying, and the dead body in film, literature, architecture, etc.
- political economies built around end-of-life care and the politics of death
- grief and bereavement as commodifiable human activities
- media commodification of death and dying in television, print, and online.
- All call for papers will be issued shortly.

More information and updates online:

Website: <http://www.bath.ac.uk/cdas>

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Working Well With Those Bereaved by Suicide: The Practice Experience of Support After Suicide in Melbourne

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Abstract

Support After Suicide has a number of complex features with loss, trauma, stigma and the fact that death was self-inflicted all involved. Support After Suicide, Melbourne, Victoria's sole specialist suicide bereavement counselling service, has been operating since 2004 and in that time has built up considerable clinical experience. This article describes this program and its operations, reviews the theoretical approaches utilised, and discusses the key lessons that the program has learned in working with those bereaved by suicide.

Background on Need for This Service

Support After Suicide has been operating since 2004 as the sole specialist suicide bereavement counselling service in the state of Victoria. This article presents some of the key lessons learned in those eight years of working with people bereaved by suicide. The article presents: the statistics on suicide in Australia and Victoria; the key features of the Support After Suicide program; theoretical approaches utilised in the program, illustrated via a case scenario; key lessons from Support After Suicide's work; and some concluding comments.

In 2010 there were 2,361 deaths registered as suicide in Australia (1.6% of all deaths). Of these, 1,816 were men (77%) and 545 women (23%). In common with the worldwide trend, Australian males take their lives nearly four times more than females. The highest rate was males aged 40–44 (27.7 per 100,000), followed closely by males aged 35–39 (27.5 per 100,000). The method most frequently used (at 56%) was hanging. The number of suicides in Victoria in 2009 was 531, of which 405 were men (76%) and 126 were women (24%). These figures represent just fewer than 10 per week, or one to two per day, in the state (Australian Bureau of Statistics, 2012).

Support After Suicide Program

Support After Suicide is a program of Jesuit Social Services, which is a nongovernment welfare agency adhering to the traditions of St Ignatius Loyola, the founder of the Catholic religious order the Jesuits. The main work of Jesuit Social Services is with disadvantaged people, particularly young people involved in the criminal justice system. Jesuit Social Services began in 1977 and has become known in Victoria for working at the cutting edge with those who are particularly disadvantaged and stigmatised.

The Support After Suicide program is funded by the Australian Commonwealth Department of Health and Ageing under the National Suicide Prevention Strategy. The program aims to directly enact Shneidman's (1972) dictum that "postvention is prevention for the next generation" (p. x). The program is funded by the federal government as a suicide prevention program, based on the understanding that those bereaved by suicide or

even exposed to suicide are at greater risk of taking their own life. This is supported by research evidence, such as Crosby and Sachs (2002) who reported that people who had died by suicide within the previous year were 1.6 times more likely to have suicidal ideation, 2.9 times more likely to have suicidal plans and 2.7 times more likely to have made a suicide attempt.

The goal of the Support After Suicide program is to increase the availability of timely and appropriate support to individuals and families (especially those with young children) who are bereaved by suicide. Timeliness means that we respond at any time following the suicide, from within days of the death occurring, through to a number of years afterwards. Appropriate support involves tailoring the forms of support for individual, family or couple counselling, or support groups based around what individuals need and want.

As a relatively new program, Support After Suicide has been able to introduce innovative and flexible programs, including: counselling/family work; group work; activities for young people and children; education; secondary consultation; and provision of information/resources that include a specialist website, Facebook page and, from 2011, new website developments in the form of an online community for chat, discussion and information-sharing purposes. More recent initiatives have included the development of a men's group to better meet the needs of male clients, and an extensive volunteer program that would include training volunteers to act as peer supporters.

The program employs six counsellors/community educators, as well as a half-time administrative person. The program is offered at a central location (in Richmond), as well as having access to four other sites around Melbourne including a CBD office. Volunteer bereavement counsellors also enable the bereaved to access the service at three other locations in the state, including two in regional Victoria. Staff have a variety of professional backgrounds including psychology, social work, counselling and psychotherapy, plus bereavement counselling experience (and preferably additional training in this area as well). All staff work part-time, with the exception of a full-time manager. This means that most work part-time from two days per week up to four days per week.

The program operates on the philosophy that people need access to highly skilled clinical support to be provided immediately postsuicide and that support should continue long term due to the enormous impact and disruption as a consequence of suicide. It does not matter how soon people come in contact with the program. If support is offered immediately after suicide, it is likely that the bereaved are in a shocked and numb state, but means that contact can be established with Support After Suicide and they may well return later when counselling or other activities may be more useful.

At this early stage, the principles of psychological first aid guide the response.

Support continues on average for 18 months postsuicide. The service is provided free of charge, with no maximum limit on the number of client sessions. The mean number of sessions is 24, which means being seen for an average of six months at the rate of one session per week, but most clients are seen less frequently than that after an initial period of weekly sessions. The program aims to keep the waiting period to a minimum after an initial intake phone call, with most people being seen within a week of initial intake.

The question of whether suicide bereavement is different from other forms of death is one that has featured in the literature for a number of years. Jordan and McIntosh (2010) have systematically addressed this, and found that some features (such as shame, stigma, blaming and increased suicidality), were supported by the existing research evidence. Other features (such as guilt, anger and searching for an explanation for the suicide) were not currently supported by research evidence but, rather, were supported by "... clinical experience and survivors' anecdotal accounts" (p. 31). Based on our clinical experience at Support After Suicide, we have found that suicide bereavement has both unique and complex features (Flynn, 2009). These features include: (a) trauma (sensory or informational); (b) an impact on identity and sense of self; (c) an experience of failure; (d) a significant impact of stigma; (e) the search for an explanation; (f) a particular impact on young people and their development; (g) disruption to social network and family relationships; and (h) an increased risk of suicide.

Applicable Theoretical Approaches

At Support After Suicide, the following theoretical frameworks have been found to be most useful in working with people bereaved by suicide: (a) Dual Process Model (Stroebe & Schut, 2008); (b) Disenfranchised Grief (Doka, 2002); (c) Grieving Styles (Doka & Martin, 2010); (d) Continuing Bonds (Klass, Silverman, & Nickman, 1996); (e) Narrative Approach (Neimeyer, 2001; White, 2007); and (f) a broadly Psychodynamic Approach (Chandler, 2005). Each of these frameworks is described below, particularly how they are linked to suicide bereavement.

Dual Process Model

The Dual Process Model diagram is made available to our clients and is given to them and actively used and discussed in counselling sessions. Like many bereaved people, they are often relieved to know that it is normal to oscillate between the two orientations of loss and restoration. We find that in the early period following the suicide that many people are almost exclusively in the loss orientation.

Disenfranchised Grief

Disenfranchised Grief occurs when survivors of loss are outside the "grieving rules" of society, i.e. the loss is not socially sanctioned. This means that the grief cannot be openly acknowledged, publically mourned or socially supported. Death by suicide often falls under this heading and as a consequence survivors can suffer even more.

Grieving Styles

Again, this is something we may provide psychoeducation about. People do grieve differently depending on where they are on the grieving style continuum from intuitive to instrumental. Normalisation can be provided if the client presents with different styles.

Continuing Bonds

By suggesting to people that they have a continuing relationship with the deceased can be reassuring, even liberating. Continuing Bonds may present particular difficulties to someone bereaved by suicide as there may be considerable anger, resentment or even hatred towards the deceased.

Narrative Approach

This approach broadly posits that bereaved people are forced to change their view of the world following the death and that process involves affirming or reconstructing identity and meaning. This can pose particular problems for those bereaved by suicide as they engage in a review of what happened in the person suiciding, why it happened and their own role in the suicide. The goal is to arrive at: "... a complex, realistic and compassionate narrative of the suicide" (Jordan, 2010, p. 198). Sands (2009) has provided the fullest application of this approach to suicide bereavement.

A broadly Psychodynamic Approach

This approach gives due regard to the intra-psychic, particularly emotions determined by the unconscious (as well as broader extra-psychic factors), both for the bereaved person and in the interaction and relationship between client and counsellor. A factor of particular importance in this approach is the influence of early childhood attachment experiences.

Case Scenario

Theory should be able to describe, explain and predict phenomena. It is only useful when it provides substantive help in clinical practice, i.e. in actually working with people. How these various theoretical approaches can be applied in practice are illustrated in the following hypothetical case scenario. The scenario is not real but, at the same time, it is both realistic and typical. It is based on an amalgam of clients we have seen at Support After Suicide.

Jean

Jean is a 53-year-old woman whose son Daniel (22) took his life eight months ago. He hanged himself in bushland close to the family home. His body was found by a jogger. Daniel was a heavy marijuana user and suicided following a violent argument with his girlfriend.

Jean has a husband (Maurie, aged 56) and three other children. Daniel was the youngest and lived at the family home. Since Daniel's suicide, Jean feels that people she previously knew now avoid the family because of the suicide. She feels very alone and not acknowledged in her grief, despite having lost a son (*Disenfranchised Grief*). Maurie, in contrast to Jean's tendency to be openly sad and distressed at times at Daniel's death, tends to be very silent and talks very little about Daniel (*Grieving Styles*).

Jean finds life very difficult at present, particularly at work. It feels better when she visits Daniel's

grave, which she does daily. She also welcomes the opportunity to talk about him when Daniel's friends visit her (*Dual Process Model*). She looks at Daniel's Facebook page regularly where his friends still post messages. It is a way that she feels that he lives on. She has also "seen" him and dreams of him frequently (*Continuing Bonds*).

She has tried to make sense of his suicide by blaming his girlfriend for the argument before his death. She was also aware that his heavy marijuana use changed his mood and made him quite depressed at times. Daniel was also worried about his increasing use of marijuana and thought he may have been addicted (*Narrative Approach*). Jean consulted a psychic who said that Daniel is now at peace, but did regret what he had done. The psychic also said that his life had not been the same after he had been sent to live with relatives in the country at the age of seven, when Jean had undergone intensive treatment for cancer. He had been separated from his mother for nine months at that time and only saw her once during that time (*disruption in Attachment – Psychodynamic Approach*).

What Support After Suicide has Learned About Working With Those Bereaved by Suicide

In working with people bereaved by suicide, Support After Suicide has learned a number of valuable lessons. They are: (a) the need to work with the grief, trauma, stigma and the fact that the death was self-inflicted; (b) persisting with people for the long haul (i.e. expert companionship; Jordan, 2009); (c) the need to be flexible and creative, particularly with young people; (d) the power of group work; (e) the need for factual information about suicide and processes surrounding it for clients; and (f) to be open to clients' extraordinary experiences and the use of psychics and mediums.

The need to work with the grief, trauma, stigma and that the death was self-inflicted

All four of the elements are significant (grief, trauma, stigma, and that it was suicide). In combination, they signify that suicide bereavement can be complex and difficult. At some point, the counsellor and the bereaved client may need to engage with each of them. A counsellor must be comfortable with, and have the skills, to work with all four elements. (This author did not have skills in trauma work when starting work at Support After Suicide, and therefore had to acquire them.)

When and how to engage with these four elements are crucial questions. A good rule is to be guided by the bereaved person, by asking them: *What is most troubling for you at present?* If it is traumatic images or flashbacks, work on the trauma may be a priority. If acute loss of the person is being felt most, work with the grief may be required first. Essentially, it is important to follow the client's lead on this; the counsellor needs to bear in mind that some control and guidance needs to be exercised by them in this process. The counsellor has a role here in providing expertise and also "containing" the pain and other emotions within a session.

Dosing is important for both traumatic images/memories and also in terms of grief. With the latter, the Dual Process Model (Stroebe & Schut, 2008) can be used (Jordan, 2010). Self-dosing is an important skill to acquire. This can be a trial and error process in not only going "toward" the pain and feeling it, but also learning what helps a person to distract them from the pain and move away from it.

Persisting with people for the long haul

As stated previously, the mean number of counselling sessions at Support After Suicide is 24, which even at the rate of one per week represents six months of contact with a person. Jordan (2009) has termed persisting with people for the long haul as "expert companionship". It involves wisdom, building a relationship and bearing witness. It entails "sticking with it" through ups and downs, with the latter certainly predominating at times. "Sticking with it" can be hard at times and requires determination to sit in the presence of acute pain and distress. This persistence may be as important, if not more important than the counsellor having fancy clinical techniques at their disposal. It can seem like the film *Groundhog Day* at times, in that the counsellor is hearing the same thing again and again. It may seem like the same thing, especially the story of the suicide and the explanation of it, but the counsellor needs to listen for subtle changes and then explore these with person. Such small changes can lead to further processing and integration of the experience.

The need to be flexible and creative, particularly with young people

Suicide bereavement counselling is not necessarily confined to traditional office-based counselling or therapy. As a social worker, this author is used to, and believes in, doing casework (assisting a person with practical difficulties and helping them find and connect with appropriate resources). It provides real practical help to them plus performs the important task of engaging with the person. This can take the form of emergency relief, food, housing, and obtaining social security benefits. Referrals may well need to be made to other organisations, for example, alcohol and drug services, mental health, financial counselling and housing services. It is also important to be creative and flexible by running with hunches and your clinical intuition within sessions. This means assessing whether something is not working with particular client, and being prepared to try something else.

In suicide bereavement counselling, one needs to be prepared to work outside the box of narrow, one-on-one, office-based counselling, particularly with young people and men. Activity-based modes, for example, camps, circus arts, surfing, playing football or cricket may be more suitable for young people. Chatting while kicking a football or bowling a cricket ball, and sitting around a campfire in the dark talking with others, can be very simple and powerful ways to encourage them to open up and share their thoughts and feelings.

A particular example of the need for a counsellor to be flexible is discussing tattoos with a client, as people, and not just young people, are increasingly having these done as a memorial for the person who died. There needs to be recognition that tattoos constitute a permanent memorial to the person, as it is on the skin and is therefore a close and personal reminder. Having a tattoo done also constitutes a ritual, as well as being a form of continuing bond with the deceased.

The power of group work

People who are bereaved by suicide often speak of wanting contact with others who have been through the same experience. Hence their initial request for help may be in the form of wanting to participate in a group. That sort of motivation often serves them well in taking advantage of what a group has to offer: real

connection and support from others which provide them with something often that no-one else can give them, i.e. understanding from the lived experience.

People bereaved by suicide often feel isolated and alone; they can consider themselves as an “outsider” and freakish. Participating in a group can have a significant impact for such people. Support and information from others who have been through the same experience can be often more important than what counsellor can do in individual work.

Louise Flynn (current Manager of Support After Suicide) is undertaking doctoral study on the effects of being in a group for those bereaved by suicide, particularly for its impact on stigma. She documented the impact of two early bereavement groups run in 2010 at Support After Suicide, including in-depth before and after interviews with participants and interviews with co-facilitators after each session. She found that group participants can be very helpful to each other as a group can assist in both restoring connection to society and a sense of belonging. As such, being in a group can have a powerful effect in aiding people’s healing.

The need for factual information about suicide and processes surrounding it for clients

Those bereaved by suicide inevitably encounter the official investigation system for deaths. In Australia, this is the coronial process; the task of which is to investigate and establish the cause of death. Coping with this process can be a difficult experience for people but these systems can provide important information for people in trying to understand a loved one’s suicide. We have found this to be very important and counsellors need to be prepared and able to do this kind of work. For us, this involves contact with the State Coroner’s Office, particularly its counsellors, to access such information. This may also involve assisting clients to understand the autopsy and/or toxicology and police reports emanating from the coronial processes, when it is within our knowledge; otherwise we seek expert assistance. By doing this, counsellors are assisting people to clarify what actually happened, rather than live with what they imagine that may have happened. This involves dealing with informational trauma (e.g. when they imagine what may have happened) as opposed to the reality of what happened.

People often also want information about the actual process of death involved in a suicide death, especially in relation to hanging, which is the predominant method of suicide in Australia. The work of Sauvagneau and her colleagues (2007, 2010), in analysing the sequence of events in filmed hangings, has provided useful information in this regard. Their finding that there is initially a rapid loss of consciousness (within 8 to 18 seconds) can be a source of comfort to many people.

The importance of being open to clients’ extraordinary experiences and the use of psychics and mediums

Many readers will be aware that bereaved people will tell you about “extraordinary experiences” as LaGrand (1999) has termed them. Sanger (2009) has defined these as “... feeling or sensing the actual presence of the deceased” (p. 71). These can range from seeing the person, hearing them, sensing their presence, dreams, messages from objects, etc. Bereaved clients will often tell their counsellor about these extraordinary experiences if they trust them. Such experiences can be comforting and helpful to them, but they also may

be disturbing (LaGrand, 1999, 2006). Key questions for counsellors to ask when clients relate these experiences are: (a) *How did you feel?* and (b) *What do you think it meant?*

In my experience, people bereaved by suicide seeking out readings from psychics and mediums are not uncommon, particularly as they seek an explanation for their loved one’s suicide and information on their current location and wellbeing. People often want to know: *Why did they die?* and *Are they at peace now?* The results of such readings can be comforting and/or provide answers, but that may not always be the case. In either instance, it may be something the person would discuss with their counsellor and counsellors need to be prepared to do so in an open-minded way.

Conclusion

In working with those bereaved by suicide, certainly no single method of support suits everyone. A variety of responses and supports are needed, including individual work, family work, group work, activity-based work and online responses that provide a range of supports (counselling, therapy, practical information and assistance) for the long haul.

Working well with those bereaved by suicide means: (a) having adequate clinical training (in a relevant profession), as well as bereavement and trauma counselling training and experience; (b) working effectively to meet clients’ needs; and (c) working compassionately. People who are suicide bereaved deserve and need counsellors with these three attributes as they contend with the enormous impact of someone close to them suiciding. Each person seeks help and finds comfort, answers, and relief in their own way. We, as counsellors, need to be open to that fact and respond accordingly with a full range of responses, which is our aim at Support After Suicide.

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GriefMatters

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- Death of an Adult Child
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Please email submissions, expressions of interest, and further suggestions for themes to the Journal Production Editor, Natalie Coish, at: n.coish@grief.org.au





Judi's House: Integrating Research and Practice in a Community-based Bereavement Centre for Children and Families

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Abstract

Judi's House (JH) is a nonprofit bereavement centre providing comprehensive, no-fee services for grieving children and families in Denver, Colorado. This paper describes an initiative that JH maintains to integrate clinical practice with longitudinal research, conducted collaboratively with research psychologists from the University of Colorado. One goal of the research is to continuously evaluate and improve the multifaceted services developed at JH, including bereavement groups, individual counselling, and community education, training and outreach. This paper presents illustrative findings that have increased understanding of grief reactions, while inviting discussions between clinicians and researchers working towards improving bereavement programs. Finally, this paper details the development of a collaborative network of practitioners, researchers and community partners intended to increase access to effective grief services, education and resources.

Judi's House and the Comprehensive Grief Care Model

Judi's House (JH) is a nonprofit agency founded in Denver, Colorado, in 2002 to meet the grief-related needs of bereaved children and families. The agency's mission expresses hope that JH will contribute to a world in which no child is left alone with his or her grief. This focus on protecting children from being isolated with their grief reflects the influence of theoretical concepts drawn from developmental models promoting resilience and decreasing vulnerability upon exposure to potentially traumatising or overwhelming events, such as the death of a primary caregiver or other loved one. Such concepts emphasise the importance of children growing up in reliable, empathic and supportive family and social contexts that predict successful social-emotional development (e.g. Cicchetti & Cohen, 1995, 2006; van der Kolk, 1984; Wind & Silvern, 1994). The community-based, "home-like" setting of JH is a tangible illustration of this commitment to creating a safe, comfortable environment for children and families to seek support from both caring professionals and understanding peers and volunteers.

Grief is a normal, adaptive reaction to loss that manifests in unique ways for each individual. Therefore, JH firmly believes that "one size does not fit all" when it comes to addressing diverse grief reactions to promote healing and help prevent complications the bereaved are at risk of developing (Worden & Silverman, 1996; Melhem, Porta, Shamsedden, Payne, & Brent, 2011; Sandler et al., 2010a, 2010b; Lutzke, Ayers, Sandler, & Barr, 1997; Brent, Melhem, Donohoe, & Walker, 2009; Kaplow, Saunders, Angold, & Costello, 2010; Harrison & Harrington, 2001). Services at JH are primarily provided through group modalities that offer normalisation, validation and decreased isolation

through the support and sharing of bereaved peers (e.g. Zambelli & Rosa, 1992; Schuurman & DeCristofaro, 2010). Skilled practitioners facilitate groups and also provide assessments and individual counselling services to ensure that the diverse and often complicated needs of the families are safely and effectively addressed.

JH fulfils its mission of helping bereaved children and families heal and feel less alone in grief through three primary domains: Research, Practice and Community. The Research domain is comprised of a longitudinal research initiative conducted through a collaborative partnership among researchers from the University of Colorado and practitioners at JH. The Practice domain – or direct service – includes mental health professionals, interns and volunteers who provide no-fee, comprehensive grief services to bereaved youth ages 3–25 and their caregivers through programs developed and tested at JH. Finally, the Community domain entails education, training and outreach in schools and other community-based organisations that serve children and families, including a long-term effort to foster integration of systems of care by developing collaborative partnerships among agencies and individuals who have contact with bereaved children.

The present paper provides an overview of the growth of JH and the work conducted within each of these three domains to form a Comprehensive Grief Care (CGC) model that is both research- and community-based. This model, as represented in Figure 1, applies the "Boulder" or "Scientist-Practitioner" model of clinical psychology (Raimy, 1950) within the community by bridging professional skills in research and practice to create an overlap of these domains necessary to inform and advance the bereavement field. The CGC model focuses on the importance of integrating research and practice to continually inform one another, while highlighting the importance of working collaboratively with individuals and organisations in the community to address the immediate and long-term needs of bereaved families. This collaboration allows JH to increase understanding of the needs of grieving children and families and improve access to effective services by pooling the "collective wisdom" from each domain.

The model of care utilised at JH exemplifies the convergence of this collective wisdom, including insights from the multidisciplinary professionals who have worked at JH over the past decade. The influence of varied models in the field is evident throughout the programs and research conducted at JH. These models include peer support programs (e.g. Dougy Center, 2012; National Alliance for Grieving Children, 2012), empirically supported prevention programs (e.g. Sandler et al., 1992, 2010) and interventions for traumatic grief reactions (e.g. Cohen, Mannarino, & Knudsen, 2004; Layne, et al., 2001; Goodman et al., 2007; Salloum et al., 2001), and the works of thought leaders who have

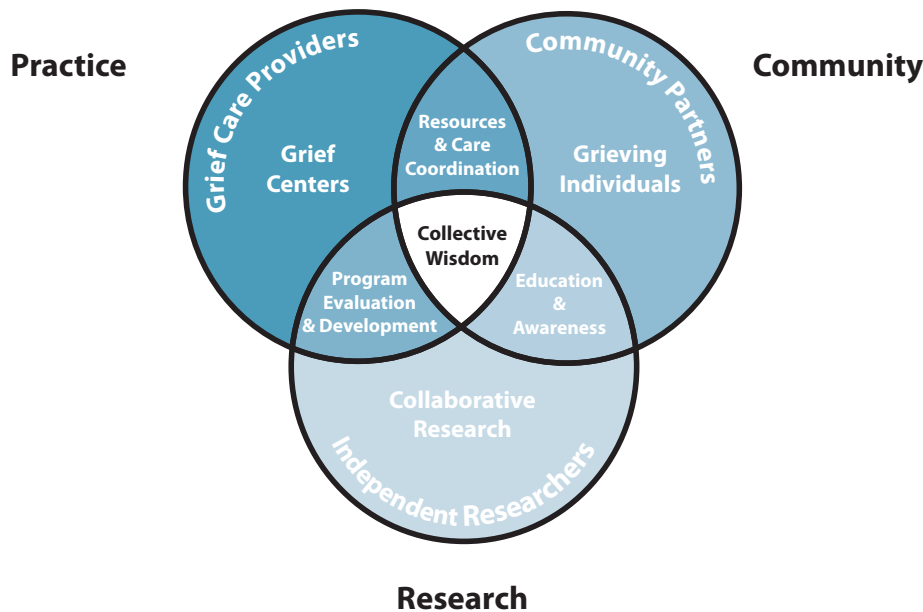


Figure 1
Comprehensive Grief Care (CGC) model that is both research- and community-based.

shaped our understanding of this issue for many years (e.g. Worden & Silverman, 1996; Webb, 2010; Wolfelt, 2009; Corr & Balk, 2010; Stroebe, Hannsson, Stroebe, & Schut, 2001). Most importantly, our programs have been shaped and influenced by grieving children and families themselves – the original source of all data, feedback, and wisdom gathered at our centre.

Integrating Research and Practice to Provide Effective Services

Collaborative, community-based research

A desire to more fully understand the population served at JH and the impact of its programs, coupled with a scarcity of empirical research on childhood bereavement and effectiveness of grief interventions (Currier, Holland, & Neimeyer, 2007), precipitated an ongoing research initiative established between JH and the University of Colorado in 2006. Through this partnership, JH conducts longitudinal program evaluation and developmental research on the nature and needs of grieving children and their families. Immediate and long-term impacts of childhood loss and the differential effectiveness of bereavement services are studied prospectively through a pre-, post-, and one-year follow-up research design, utilising a natural waitlist as a comparison group. The aims of the research initiative are to: (a) develop and refine a bereavement-specific assessment protocol useful for clinical and research purposes; (b) analyse relationships among individual differences to understand risk and protective factors for adjustment and answer numerous theory-based questions; (c) test the differential effectiveness of JH services; and (d) identify characteristics or conditions that systematically predict individual differences in improvement within JH programs. The participatory research model allows for a reciprocal feedback loop between program and research teams in which findings

about matters that concern staff members are shared with them throughout the research process, and staff members provide researchers with continuous feedback.

Comprehensive assessment

As an example of this collaboration, the university researchers and JH program staff developed and refined assessment protocols together, so all measures can be used simultaneously for clinical and research purposes. Assessments are key to the CGC model, in that they immediately inform clinical decisions around services. Given both informed consent from caregivers and assent from children and adolescents, anonymous assessment data is then made available for research purposes at the University of Colorado at Boulder, as approved by the university's Institutional Review Board. Every individual completes the same assessment process, regardless of consent to research.

The JH intake protocol includes a grief-and trauma-focused psychosocial assessment that contains open-ended and semi-structured interview questions as well as standardised measures of adjustment and measures developed at JH (contact authors for details). We use a multimeasure, multimethod approach, including both child and caregiver reports, and employ measures that elicit both grief-specific reactions, e.g. Inventory of Complicated Grief (ICG; Prigerson et al., 1995), and general aspects of adjustment, e.g. Beck Depression Inventory (BDI-II; Beck, Steer, & Brown, 1996), to gain a fuller picture of each child and adult in the family.

Intake assessments are administered by JH professionals, who are trained to do so in a sensitive, clinically appropriate manner. Clinicians report that the approximately one-hour assessment can be therapeutic for participants, who often spontaneously express appreciation for the opportunity to share their story during the interview. This supports previous

research indicating that, when done correctly, studying bereaved populations can be a positive experience for the participants and an opportunity for meaning making (Dyregrov, 2004; Walker, 2010). So far, the research has obtained intake data from over 2,000 participants, representing a successful bridging of research and practice.

Research Informing Practice

Among the most useful initial research findings have been empirical descriptions of the families served at JH and the range of adversities they face. JH families are ethnically diverse, with nearly half identifying as non-Caucasian. Over a third of families meet US federal guidelines for poverty and over half reported statistically significant decreases in income since the death. The children are grieving what are usually considered among the more disruptive deaths; approximately three quarters experienced parental death loss, 66% experienced a sudden death, 40% reported multiple deaths, and a quarter are grieving a suicide or homicide death. Additionally, many JH participants are facing multiple secondary stressors since the death. For example, over a third of the children changed residences, schools and friends since the death, and over 60% experienced a decline in school performance.

A majority of child and adult participants also reported distress, symptoms, or behaviours that would be considered “high risk” or indicative of warranting intervention. Over 75% of children had scores above the suggested clinical criterion on at least one (and usually more) standardised measure of symptoms or adjustment problems. For example, 66% of children had scores above a commonly employed clinical criterion for Childhood Traumatic Grief (CTG subscale of Extended Grief Inventory; Layne, Savjak, Saltzman, & Pynoos, 2001), and 44% of adolescents had clinically elevated depressive symptoms on the Beck Depression Inventory for Youth (BDI-Y; Beck, S., Beck, & Jolly, 2001). Suicidal thoughts emerged for many youth; over 25% of teens reported wishing they were dead, and 13% of the children and teens reported that they have had thoughts of wanting to kill themselves. Concerning levels of adult caregiver distress have also been reported on standardised measures.

When such findings about JH participants began to emerge, they directly informed program development. Recognising the intensity of the needs of many individuals seen at JH produced a commitment to employ a greater number of mental health professionals to conduct assessments, facilitate groups and provide individual and family counselling and therapy. Hiring licensed clinicians also made it possible for supervision of interns and externs who in turn have increased our direct services.

Over time, the content of our programs has also changed. As examples, we have integrated more structure, psychoeducation and parenting and coping skills into our curricula, based on research and clinical observations about the needs of our families, as well as direct requests for these components from families who participated in early qualitative research and program evaluation. Our data supports previous findings that caregivers’ functioning is associated with children’s adjustment (e.g. Lutzke et al., 1997), and our adult participants often report that they appreciate the educational components and concrete parenting advice provided within their support groups. From a process evaluation perspective,

we have seen better attendance and stronger group cohesion in our current closed, 10-week groups than we did in the past with only ongoing, open-ended groups held bimonthly. Recognition of high levels of traumatic grief reactions has also led to the inclusion of more trauma-informed practices, such as cognitive-behavioural and narrative components common to interventions developed for traumatic and complicated grief reactions (Cohen et al., 2004; Layne et al., 2001).

Preliminary findings concerning comparisons between intake and postintervention assessments have indicated statistically significant improvements for youth and caregivers on measures of maladaptive grief reactions, emotional and behavioural problems, and depressive and posttraumatic symptoms. Nonetheless, we hope that with the research-informed improvements to the curriculum described above, later outcome data will reveal even greater effect sizes for the revised intervention. Importantly, improvements seen at 10 weeks cannot be attributed to only the passage of time; according to preliminary findings, caregivers’ reports about their children and themselves were significantly better at the postgroup assessment than parallel reports from others who were on a natural waitlist during the weeks in question.

Additionally, associations among individual differences continue to be relevant to interventions and assessment practices. To illustrate, we examined children’s reports of the subjective severity of the traumatic nature of the deaths experienced and found that these subjective appraisals significantly predicted elevated childhood traumatic grief; moreover, this was especially true for younger children (Nuttall, Gurtovenko, Silvern, & Griese, 2012). Such findings validated the importance of continuing to directly ask children about their subjective experiences of the death and their personal grief reactions, and to tailor services to their individualised needs.

Services Provided at Judi’s House

Pathfinders: 10-week grief support groups

A majority of individuals who seek services at JH are placed in groups that follow the Pathfinders curriculum (Judi’s House, 2012). Pathfinders is considered an introduction to the grief journey, focused on bringing individuals together to support one another in finding their own paths towards healing. Following a community dinner, four separate children’s age groups and groups for adult caregivers meet simultaneously and follow a parallel curriculum that allows facilitators to address core concepts using their own language and choosing from alternative psychosocial activities based on their understanding of their group members. Group participants share their stories, learn healthy coping skills, memorialise the deceased, and work towards integrating the loss into their life. Following group time, children have supervised free time in rooms designed to provide multiple modalities of expression and activity (e.g. sand tray, art, pretend play, and “big energy” rooms). By family members receiving parallel, age-appropriate content in their peer groups, they are encouraged to continue discussion of group topics and practise coping skills together at home, in addition to utilising activities and information in their individual Pathfinders journals.

The Pathfinders program is a conceptually integrative approach that draws on diverse practices associated with, e.g. family systems, cognitive behavioural, trauma,

attachment, and client-centred theories and approaches, as well as experiential and expressive therapies, such as art therapy. The curriculum incorporates components common to several evidence-based traumatic grief interventions (Goodman, Cohen et al., 2007; Salloum, 2001; Layne et al., 2001), as well as approaches used in traditional grief support settings (e.g. Schuurman et al., 2010), and is designed to be safe and appropriate for youth who have experienced varied types of death losses and a range of grief reactions. It is a bereavement-specific curriculum, but it is also trauma-informed because, as mentioned above, a majority of our families come in following an objectively traumatic death and with symptoms and distress that would be considered “high risk” for traumatic grief reactions.

The curriculum moves through three modules or phases. The first module is focused on providing grief and trauma education, including cognitive-behavioural techniques that promote affect regulation and adjustment. The second module focuses on forming and sharing a coherent narrative of the death and exploring the changes and challenges associated with the loss, as well as redefining the relationship with the deceased in order to maintain an enduring connection. The final module is focused on connecting with others, strengthening support networks and preparing for difficult waves of grief that are inevitable in the future. Pathfinders meets weekly and is a closed, 10-week group to promote consistent attendance and group cohesion. After a death loss, many children struggle with feeling that the world is unsafe and unpredictable. Through its structure and curriculum content, Pathfinders supports the reestablishment of security, and reinforces the development of positive relationships, consistent routines, effective parenting, and strengthened support networks for children and families.

Connections: Bimonthly continuous support groups

Following the 10-week Pathfinders groups, families are given the option of participating in Connections groups. These bimonthly groups run continuously through the year with clear points of entry for new and previous group members to connect or reconnect at the beginning of each quarter or season. Again, the commitment to each 10-week period of time is intended to promote consistent attendance and engagement in the group. Connections groups revisit the core concepts explored in Pathfinders but with more emphasis on the group members processing the relevance of the topics at this point in their journey and development.

Individual and family services

Individual and family counselling or therapy is also available free of charge for those in need of such services, as well as referrals to complimentary services and providers in the community. Individual sessions are often provided as a way to help prepare children or adults to participate in a group, or to complement the work that is being done in groups. This can be particularly useful for those experiencing traumatic or complicated grief reactions, or for those experiencing distress that cannot be appropriately addressed in a group setting.

Reaching Into the Community: Increasing Access to Research, Education, Resources and Effective Systems of Care

The broader community is the third domain in which JH is committed to expressing its fundamental mission of alleviating isolation and promoting resilience among bereaved children. Although JH provides grief services to approximately 1,000 individuals annually, this is only a small portion of the bereaved youth in the Denver community. Rather than pour resources into building additional centres, JH continues to explore multiple ways to extend its reach into the community by sharing research, programs and resources and encouraging the expansion of services available to bereaved families beyond JH.

One general approach that JH has adopted in expanding access to support includes sharing that role with community organisations and professionals that have pre-existing relationships with large numbers of youth but that have previously not developed capacities to provide grief support. JH is exploring varied types of connections with those potential partners to establish a “Comprehensive Grief Care Network” (CGCN) throughout Denver and beyond. For example, an adaptation of Pathfinders groups are currently offered in over 30 schools throughout metro-Denver, and a partnership with Boys and Girls Clubs to provide groups within their centres has been initiated. Additionally, JH offers training and consultation with agency staff to enrich their skills, with the ultimate goal of meeting youths’ grief-related needs within the context of these supportive, community settings. As JH grows its network, additional opportunities for partnerships with organisations of other types will continue to be explored, for example, military bases, juvenile justice programs, social service agencies, and mental and medical health providers.

Ultimately, the CGCN is envisioned to include multidisciplinary grief care providers, researchers and community organisations committed to partnering in an effort to establish best practices and increase access to evidence-based, grief- and trauma-informed care for bereaved individuals in all communities. The CGCN will foster collaboration among disciplines, provide training and resources, facilitate communication and care coordination, and grow a network of trained professionals who can increasingly meet the diverse needs of grieving children and their families. This network will also bridge research and practice to permit practitioners and researchers to collaboratively advance the child bereavement field through multisite research with diverse populations. To facilitate the dissemination of knowledge gained through collaborative research and program initiatives, JH has also partnered with leaders in the information technology field to begin development of a technological platform intended to improve efficiencies in the network aims stated above.

Ultimately, in order to substantially improve access to bereavement services for children and families, it is necessary to increase available resources devoted to this issue. For that social change to occur, it is imperative that stakeholders develop an appreciation for the cost of inaction to society as a whole if effective grief-informed services are not fully identified and offered.

Little research and fewer resources have been directed towards childhood bereavement, severely limiting understanding of grief and the most effective services

for particular subgroups of bereaved children and families. There are remarkably few well-designed studies that provide empirical evaluations and estimates of the prevalence of childhood bereavement, the availability of grief services, and long-term costs to society if effective interventions and support are not provided to bereaved youth. More research is needed to begin to answer the extent of the needs associated with childhood bereavement and the most effective and sustainable ways to meet those needs, and JH is committed to helping facilitate this contribution to the field.

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Programs and Services

The Australian Centre for Grief and Bereavement is located at 253 Wellington Road, Mulgrave, Victoria. The Centre provides a range of programs and services to both individuals and organisations. These include:

Consultation and Advice

Centre staff are available for consultation on grief and bereavement issues. These may include advice on program development, staff training, client issues and evaluation. A flexible fee structure has been developed for consultation, which takes the type of organisation into account.

Clinical Supervision

Clinical supervision for those who work in bereavement support is essential. Centre staff are available to take on a limited number of supervisees on a regular basis. Both individual and small group supervision is available for a moderate cost.

Bereavement Counselling and Support Service

The Australian Centre for Grief and Bereavement has a confidential bereavement counselling service which is available to people who have been bereaved through any cause. This service is provided by experienced counsellors participating in advanced training in bereavement counselling. These counsellors are closely supervised by experienced accredited grief and bereavement practitioners.

Counselling appointments can be made by telephone and should be made directly by the bereaved person.

Contact the Bereavement Counselling and Support Service on +61 3 9265 2111. The service is located at 253 Wellington Road, Mulgrave, Victoria.

Referral

The Australian Centre for Grief and Bereavement has a referral database and can put agencies and individuals in touch with private bereavement educators and counsellors. This referral database is comprised of professional educators and counsellors who specialise in grief and bereavement. For referrals to private grief counsellors phone the Centre's Bereavement Counselling and Support Service on +61 3 9265 2111.

Education and Training Programs

The Australian Centre for Grief and Bereavement offers quality education and training opportunities for health professionals, interns, students, volunteers and any other individual or agency wanting to incorporate counselling, therapy, support and education into their current work practice.

Membership

Membership of the Australian Centre for Grief and Bereavement offers a range of benefits including *Grief Matters: The Australian Journal of Grief and Bereavement* (issued three times per year), special discount member rate for ACGB seminars, workshops and ACGB products, access to ACGB library for research purposes, free member functions and voting rights at the Annual General Meeting. Membership rates and details are as follows:

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Individual Membership	\$110.00
Organisational Membership	\$275.00
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Reciprocal Membership of the Association for Death Education and Counseling (ADEC)

The Australian Centre for Grief and Bereavement now offers an enhanced level of membership, which includes reciprocal membership with the largest interdisciplinary organisation in the field of dying, death and bereavement, the Association for Death Education and Counseling (ADEC).

The US-based association is one of the oldest interdisciplinary organisations in the field of dying, death and bereavement. Its nearly 2,000 members include a wide array of bereavement practitioners, mental and medical health personnel, educators, clergy, funeral directors and volunteers. Further details on the organisation can be viewed at the ADEC website: www.adec.org.

In addition to the current benefits of ACGB membership, joint ACGB–ADEC membership will offer substantial benefits.

For full details, please refer to our website, www.grief.org.au or contact the Centre.

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Further information on the Australian Centre for Grief and Bereavement can be obtained by:

Telephone	+61 3 9265 2100
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Facsimile	+61 3 9265 2150
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Website	www.grief.org.au

ACGB Online



ACGB Website

The Australian Centre for Grief and Bereavement has developed a home page for access on the internet, and includes information about the Centre's activities, resources and a range of grief and bereavement information. Entries include information about education activities offered during the current semester, an order form for resource materials available for purchase, details about the Bereavement Counselling and Support Service and information from Bereavement Support Services in Victoria (a list of agencies and organisations which provide free or low cost bereavement counselling, support and services). Direct access is also available from the home page to other grief and loss sites.

The website is located at: www.grief.org.au

Support ACGB

The Australian Centre for Grief and Bereavement is an independent, not-for-profit organisation offering a range of education, counselling, research and clinical services in the field of grief and bereavement.

Donations over \$2 are tax deductible within Australia and allow ACGB to continue to provide services, including bereavement counselling, support groups, outreach, newsletters, events and education and training.

To make a donation, visit:
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