Welcome to the second edition of our new publication, *Bereavement Practice in Palliative Care*. We received a range of very positive feedback from the first edition, and are pleased that you found the publication of interest and practical.

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We are also pleased to introduce to you our new Bereavement Practice in Palliative Care Newsletter Editorial Group (below), which is comprised of a number of grief and palliative care practitioners who will meet regularly to guide this publication into the future.

Best wishes for the upcoming holiday season.

Christopher Hall,
Director, Australian Centre for Grief and Bereavement

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**A Message from Chris Hall**

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**Bereavement Practice in Palliative Care Newsletter Editorial Group**

The Australian Centre for Grief and Bereavement has formed an Editorial Group made up of bereavement and palliative care practitioners to ensure that this publication remains relevant and up-to-date.

**Current Members**

- **Jill Davidson** has a background in community nursing, and seven years in Regional Palliative Care Loss and Grief Consultancy. She now has a part-time loss and grief consultancy private practice consulting from a home office at Terip Terip in northeast Victoria and in Benalla. Jill specialises in grief counselling, professional supervision and occasional education sessions.

- **Linda Espie** is a counsellor, educator, supervisor, consultant and author who has specialised in loss and grief for over 26 years. Linda works part time in private practice and is the Manager of Client Support Services and the Psycho-social Team at Banksia Palliative Care Services. Linda has provided annual workshops and lectures to palliative care staff in Japan over the past 11 years.

- **Christine Pedley** is the Manager of Allied Health at Eastern Palliative Care, and commenced working in Palliative Care in 1999. She has a Social Work background, is passionate about providing the ‘right palliative care’ within the community, and has a particular interest in bereavement.

- **Jenny Field** is a Senior Bereavement Counsellor and Volunteer Coordinator at the Australian Centre for Grief and Bereavement. She has previously worked in case management and counselling positions within family support, domestic violence, addiction and dual diagnosis settings. Jenny has an interest in theories and thoughts related to attachment, meaning making and continuing bonds around grief and loss, and in narrative frameworks that assist in building and reframing people’s life stories.

- **Wayne Lynch** is Manager of the Bereavement Counselling and Support Service, at the Australian Centre for Grief and Bereavement. He has previously managed a variety of organisations and provided education, counselling, and support across a range of services including detention and correctional services, health and education settings. He has a particular interest in disenfranchised grief and the bereavement experience of culturally and linguistically diverse populations.

The Editorial Group met for the first time in September, and will continue to meet twice a year, to discuss content ideas and direction for this publication.

If you are interested in joining this group, please contact Jenny Field on (03) 9265 2100 or email j.field@grief.org.au
The Traumatic Death and Bereavement in Palliative Care

By Marian Allison, Clinical Nurse Consultant, Melbourne Health

Death, like birth, is as individual as a fingerprint. Nature has a job and we have limited control over the circumstances by which each generation is to be succeeded by the next (Nuland, 1995). ‘Death with dignity’ or a ‘good death’ is society’s expression of the universal yearning to achieve some control over the process of death, but the reality is that despite compassionate and informed professional support, many experience palliative death as traumatic. For the purposes of this article traumatic bereavement is defined as adverse experiences resulting from traumatic death experiences that cause a traumatic bereavement that is outside typical trajectories observed with bereaved populations e.g. flashbacks of palliative death events, or constant rumination six months after a loved one’s death (Rando, 1993). Palliative care professionals need to be aware of circumstances that can lead to traumatic death in order to reduce the impact on families and healthcare professionals.

A ‘Good Death’

Experience, including the experience of loss, is never simple and tidy (Kleinman, 2012). To understand what may constitute a ‘traumatic death’ in palliative care, we need to understand what constitutes a ‘good death’. The nature of a ‘good death’ can be described as relief from pain and suffering, accepting the timing of one’s death, acceptance and autonomy, keeping hope alive, preparing for the departure and making the decision about where to die. These are experiences that are presumed to enhance a patient’s dignity, which in turn helps to leave family and friends with memories of the death that do not taunt them or cause traumatic memories and subsequent rumination as they begin to grieve. Supporting a good death includes family presence, family support, good pain and symptom management, and good communication between patient, family and the healthcare team. (Granda-Cameron & Houldin, 2012).

Traumatic Death

A patient’s perception (and indeed the perception of their loved ones) of a good or bad death is particular to individual values and wishes. (Vig, Davenport & Pearlman, 2002) There are, therefore, a number of potential scenarios that can cause a death, and subsequent bereavement, to be experienced as traumatic.

The process of death we witness in a palliative care setting often involves the ebbing away of strength, loss of appetite, loss of bowel and bladder control, spiritual distress and loss of cognitive abilities. Unresolved physical and psychological problems that are unresponsive to treatment or care, may all be associated with traumatic death. It is important that a patient’s experience leading up to death, is closely monitored and effective communication is developed and maintained between healthcare professionals and family members. A successful team will be comprised of sufficient staff with an appropriate mix of skills to allow for expert assessment and intervention (Costello, 2006).

A prolonged dying experience can also be perceived by families as traumatic. Commonly the patient is unconscious and not taking food and fluids, and whilst death is predicted, it may take days or weeks. Families may have been told that death is imminent, lives are put on hold, and families worry that the patient ‘must be suffering’. Undeniably health professionals, too, find this prolonged dying difficult to witness. However, it should be seen as a palliative role to be confident, knowledgeable, empathetic, and responsive, when supporting families and other health professionals. Achieving tranquil patience in our rushed, instant society takes calm confidence and this tranquility can, invariably impact favourably on the nature of the bereavement in ways that are immeasurable.

Some deaths are perceived as traumatic because of their circumstances. A patient, who is terminally restless – unsettled, agitated, trying to get out of bed and delirious is a difficult and upsetting situation. Scenarios such as a patient haemorrhaging to death or dying suddenly and unexpectedly, even in a palliative care setting, can all, potentially, culminate in a traumatic bereavement. Many adverse events can be predicted and sensitively communicated to families and carers, and this should include documented pre-emptive medical plans. It is important to remember that the perception of the events by the family will be influenced by the response of health professionals. A dedicated and calm healthcare professional, remaining with families whilst others control the situation medically, allows for the situation to appear as calm and as controlled as possible. Simple explanations and constant reassurance allows for understanding and reduction in fear, anger, shock and trauma. An institutional philosophy of staff support and discussion of these events to allow professional development and improved management of these situations will assist loved ones and staff to cope with traumatic death.

Conclusion

The concept of a good death is fluid and highly individual; therefore what constitutes a traumatic death is also highly individual. Traumatic death can confound the pain, grief and bereavement experienced by all involved. Whilst every effort may be made to ensure dignity at the end of life (e.g. good symptom management, appropriate explanation and a calm, controlled environment), carers and family members may still experience the death as traumatic. Health care professionals’, irrespective of the way in which the patient dies, should use all the intuition, observations and family conversations available...
to them, to identify families and carers who may be at risk of a traumatic bereavement experience and use whatever resources available to them to follow up those for whom they hold concern (ETAP, n.d.).

Marian Allison is a Clinical Nurse Consultant at Melbourne Health. This article has been edited by Wayne Lynch, Manager — Bereavement Counselling and Support Service, Australian Centre for Grief and Bereavement.

References


Grief Matters: Palliative Care Edition

Grief Matters: The Australian Journal of Grief and Bereavement has been published by the Australian Centre for Grief and Bereavement (ACGB) since 1998, and encompasses both academic and applied aspects of grief and bereavement.

The current edition, (Volume 15, Issue 2, Winter 2012), looks at bereavement and palliative care with a focus on non-malignant disease, and includes the following articles:

Paediatric palliative care: The challenging dimensions
Melissa Heywood and Jenny Hynson

Motor neurone disease and palliative care
Robyn Reid

Addressing grief following patient death in aged-care facilities: The views of patients with mild dementia and staff
Margaret O’Connor and Heather Tan

The current volume of Grief Matters is available exclusively to ACGB members and subscribers; however, as a special one-off offer, this issue can be purchased by Bereavement Practice in Palliative Care readers for $30 (inclusive of GST and postage). Simply quote the following promotional code to claim this offer: GM152PC

If you would like to purchase a copy of this edition, or would like to subscribe to the journal, please contact the Centre on (03) 9265 2100, or email info@grief.com.au

COMING EVENTS

National
Palliative Care Nurses Australia
4th Biennial Conference: Enabling, Enriching, Transforming
10-11 December 2012
Melbourne, Victoria
www.pcna.org.au/conference

Australian Pain Society 33rd Annual Scientific Meeting
17-20 March, 2013
Canberra, ACT

International
IAPCCON 20: International Conference of IAPC: Challenges in Palliative Care
8-10 February 2013
Bangalore, India
www.iapcccon2013.in

4th International Society of Advance Care Planning and End of Live Care Conference
9-11 May, 2013
Melbourne, Australia
www.acpelsociety.com/conference
Grief & Significant Occasions

Information for families and friends of those in palliative care.

Dealing with anniversaries, special occasions and other significant events

Anniversaries, holidays, birthdays, special occasions and other milestones can often be difficult for those who are grieving — particularly in the first few years. In fact the lead up to such events can often feel worse than the actual day itself. This information sheet is designed to provide ideas and strategies to assist you to support yourself, or someone who is grieving, during these times.

Self care tips and strategies

**Beforehand**
- Look at your diary and make a note of events and milestones that may be difficult for you. Start to think about what you can do during these times to look after yourself.
- Decide how you want to spend the day, and let friends and family know so they can better support you.
- Consider arranging to be with someone who understands during these times.
- Think about how to answer certain greetings in advance. For example, when someone wishes you a ‘happy holidays’, you may respond with ‘thank you’, ‘I’ll do my best’, or ‘best wishes to you too’.

- Keep a journal in the lead up to, and after the significant occasion – make note of things that were particularly difficult so that you can better navigate them next time.

**On the day**
- Free yourself from the expectations of yourself and others, and give yourself permission to not be ok.
- You might like to come up with some small rituals to honor and acknowledge your loss – perhaps writing a letter to your loved one, visiting a landmark, or arranging to meet up with friends and family.
- Express your feelings through a creative outlet — e.g. painting, art and craft, writing, dancing etc.
- Talk to other people about the memories of your loved one, and ask them about theirs.
- Do something you wouldn’t normally do in memory of your loved one e.g. make a donation in their name, plant a memorial tree, sign up for a class in something you’ve always wanted to do or volunteer to help a charity.
- Do something that makes you feel good. It may be as simple as reading your favourite magazine, going for a walk, listening to music, getting a massage or enjoying a good cup of coffee.

Seeking further help

When grieving, or caring for someone who is grieving, it is important if you are concerned in any way, to find out more. You may like to do some further reading about grief, confide in friends and family, or if you are truly concerned, seek help from a health professional. It’s ok to admit that you are struggling in your grief, and no one will think any less of you if you ask for help along the way.

For further information on grief and bereavement visit www.grief.org.au
I love listening to people’s stories and know how powerful being listened to while reflecting on one’s life can be, especially towards the end of one’s life."

Interview with a Palliative Care Volunteer

The interviewed volunteer works with Eastern Palliative Care (EPC)

How would you describe your role?

I work with the Biography Service at EPC. I meet with clients over approximately eight sessions and record their life stories, which I then type up and put into booklet form. This is the practical part, but the most important aspect is the process of listening and enabling people to reflect back on their lives, hopefully assisting them to reach a sense of calm and accomplishment and to leave a wonderful gift for their families.

What was it that attracted you initially?

Having experienced the support of EPC in the past with my husband and parents, and knowing what a great function biography can perform, I wanted to be involved. I love listening to people’s stories and know how powerful being listened to while reflecting on one’s life can be, especially towards the end of one’s life.

Can you also describe your involvement in the Bereavement Education Group?

I was asked to be present and then “share my story” at one of the education groups for recently bereaved people. I found this a deeply moving experience, feeling their palpable and raw pain that is experienced so soon after loss.

How does it feel telling your story to people who are recently bereaved?

It was challenging but extremely worthwhile. Of course it stirred up again the loss of my husband in particular and took quite an effort, but it was also a wonderful chance to reflect again on the love we shared and share this with others. It also highlighted for me the universality of the loss experience, and also the uniqueness of each of our journeys.

What are the most rewarding and challenging aspects of your role?

Being part of a terrific team where the values of the organisation are lived, not just stated is very rewarding. I have met some wonderful people and enjoy continuing to challenge myself. I do however, need to know when to say “no” and remember I am now retired – not a full-time worker! It is hard to fit in everything I want to do.

How do you self-care?

I take a break between clients and follow a range of other interests in my life, travelling, family, physical fitness, etc.

What advice would you have for others who are thinking of volunteering?

Do it! Whatever efforts you put in, you get rewarded far more in return.
Our Services

Bereavement Practice in Palliative Care
For all enquiries about this publication, please contact Jenny Field on (03) 9265 2100 or email j.field@grief.org.au. To download a PDF version, or to sign up to receive the publication as an e-newsletter, go to www.grief.org.au.

Bereavement Counselling and Support Service
The Australian Centre for Grief and Bereavement (ACGB) operates a statewide Specialist Bereavement Counselling and Support Service for Victoria. This program is supported by the Victorian Government Department of Health and has counsellors located across metropolitan Melbourne, in regional areas (Grampians, Gippsland, Hume, Barwon South-West, and Loddon Mallee) and in areas affected by the 2009 Victorian Bushfires. For further information, call (03) 9265 2100, or email counselling@grief.org.au.

Support groups
ACGB operates a range of support groups, including groups for adults, children, bereaved partners, loss of a parent and many more. For further information call (03) 9265 2100 or email support@grief.org.au.

Practitioner Consultancy Service
This service provides free information, consultation and support for practitioners who are working with bereaved clients experiencing complex and prolonged bereavements. To access this service call 1300 858 113 during business hours.

Education and training
ACGB offers quality education and training opportunities for health professionals, students, volunteers and any other individual or agency desiring to enhance grief and bereavement knowledge and practice. Education and training programs are offered as seminars, workshops, short and long courses, conferences and customised training. For full details of all programs and services offered go to www.grief.org.au/education.

Customised training and consultancy
ACGB offer a range of customised training and consultancy services that provide research-informed, high quality, professional development programs that meet the specialist training needs of organisations, groups and individuals. For further information contact the Centre on (03) 9265 2100 or email education@grief.org.au.

Grief Matters: The Australian Journal of Grief and Bereavement
Published by ACGB three times per year, this journal 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 (www.arc.gov.au). To find out how you can subscribe to this journal, call (03) 9265 2100 or email griefmatters@grief.org.au.

Internships
ACGB has a limited number of placement opportunities for experienced counsellors seeking to advance their knowledge and skills in bereavement counselling. For further information contact the Centre on (03) 9265 2100 or email info@grief.org.au.

Membership
Access a range of benefits through the ACGB membership program. An enhanced membership option, reciprocal membership with the Association for Death Education and Counseling (ADEC), is also available. For more information about membership options and benefits go to www.grief.org.au/get_involved or call (03) 9265 2100.

Donations
Donations over $2 are tax deductible and allow ACGB to continue to provide services including bereavement counselling, support groups, newsletters, events, education and training. To make a donation, visit www.grief.org.au or call (03) 9265 2100.

We value your feedback
If you have feedback about this publication, or any of the services delivered by the Australian Centre for Grief and Bereavement, we’d love to hear from you. Contact us on (03) 9265 2100 or email info@grief.org.au.

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