Welcome to the third edition of our new publication, *Bereavement Practice in Palliative Care*, and our first for 2013.

This edition, we welcome Cathie Paul to the Bereavement Practice in Palliative Care Newsletter Editorial Group. Cathie is a Family Support Consultant at Eastern Palliative Care, and will be filling in for Christine Pedley while she is on leave.

In this issue, we have included an article on the Victorian Government Department of Health publication *Bereavement Support Standards for Palliative Care Services*. Developed by the Australian Centre for Grief and Bereavement in partnership with the Centre for Palliative Care, these standards provide guidance for the provision of bereavement support by palliative care services. This publication is targeted at all carers and bereaved individuals with elevated risk of developing prolonged or complicated grief or with current psychosocial and/or spiritual distress.

Alongside the feature article, we have also included an interview with a Palliative Care Music Therapist; a client handout looking at common misconceptions around grief; and information on an upcoming professional development opportunity with Dr Robert Neimeyer, a US clinician world-renowned in the bereavement field.

Christopher Hall
Director
Australian Centre for Grief and Bereavement

### COMING EVENTS

**12th Australian Palliative Care Conference**

**Palliative Care: Everyone’s Business**

Palliative Care: Everyone’s Business will bring together over 700 delegates from across Australia and the world to explore the importance of palliative care in all its dimensions.

Clinicians, researchers, volunteers, allied health practitioners, educators, carers, and all those who have a passion for palliative care will share best practice, hear the latest research, be challenged by keynote speakers and build valuable networks.

This conference is organised by Palliative Care Australia and Palliative Care ACT.

**When:** 3–6 September, 2013

**Where:** National Convention Centre, Canberra

**Website:** www.dcconferences.com.au/apcc2013

**Inaugural National Palliative Care Research Colloquium**

This colloquium aims to foster collaboration and conversation with those actively involved in palliative care research, with invited speaker presentations from national leaders.

The target audience is Australian and New Zealand researchers actively engaged in publishing, grant writing and higher degree supervision in palliative care and related fields.

The colloquium is organised by the Centre for Palliative Care (c/o St Vincent’s Hospital and Collaborative Centre of The University of Melbourne).

**When:** 18–19 July, 2013

**Where:** The University of Melbourne, Melbourne

**Website:** www.centreforpallcare.org/index.php/events/
A range of Australian and Victorian Government policy initiatives have led to identifying a need to develop bereavement support standards for specialist palliative care services.

While there has been a significant growth in bereavement research in a range of disciplines, there is limited empirical evidence to support decision-making regarding assessing risk for adverse bereavement-related outcomes or providing appropriate bereavement interventions. Consequently, Victorian and Australian palliative care service providers have not had access to systematic guidance on assessing bereavement risk or on intervention responses.

Following funding to the Australian Centre for Grief and Bereavement from the Victorian Government Department of Health, and a collaboration with the Centre for Palliative Care, bereavement support standards have been developed for use in all Victorian government-funded, adult, specialist palliative care services including community, inpatient, acute and consultancy services. The standards can be downloaded at http://docs.health.vic.gov.au/docs/doc/Bereavement-support-standards-for-palliative-care-services.

Since their release the standards have generated extensive interest within other Australian jurisdictions and international palliative care service providers. The standards provide a broad tool for all palliative care services staff to use. The key principles underpinning the standards are that bereavement support is delivered:

- in a targeted way with those who would benefit most from specialist interventions being identified through structured screening and assessment
- with a focus on identifying the bereaved person’s own resources and capacity that will enhance their resilience
- over a period from pre-death to several months post-death and beyond where required
- within the policy context that there is no limitation on the time period for providing bereavement support by Victorian palliative care services
- with a focus on the palliative care client’s primary carer and extending to other carers/family members where resources allow.

The document stresses the importance of maintaining a holistic perspective when considering the context and factors that impact upon grief reactions. Given the distinctive nature of complicated bereavement, anxiety and depression, it is important that any assessment be both comprehensive and broad in its character. Modern developments in grief theory recognise human diversity and suggest the need for an integrative approach to assessment that examines both risk factors and coping styles (Agniew et al., 2010). In the palliative care setting, the bereaved have frequently undertaken caregiving roles that can have both positive and negative features, with carers often prone to physical and psychological morbidity, financial disadvantage and social isolation (Hudson et al., 2011). Depression rates of between 12 and 59 per cent (Hudson et al., 2011) and anxiety rates of between 30 and 50 per cent (Grunfeld et al., 2004; Hudson et al., 2011) in carers have been reported.

The core of the document is the statement of 11 standards, which recommend a minimum level of bereavement support that should be provided to primary carers and bereaved people by palliative care services. These standards are further integrated into the second key component of the document — the bereavement care trajectory. The standards are:

1. **Access**
   All primary carers of clients cared for by a specialist palliative care service are eligible to access palliative care bereavement services regardless of age, gender, culture, sexual orientation, socioeconomic status, religious beliefs, physical or other disability or ability to pay.

2. **Coordination of bereavement services**
   Bereavement programs in palliative care services provide coordinated services.

3. **Training and support**
   All staff in a palliative care service, including administrative staff, will come into contact with bereaved people and will therefore require training and support in dealing with those bereaved people.

4. **Screening and assessment**
   Screening and assessing for psychosocial and spiritual distress and risk of complicated grief is a continuous process undertaken from the time the client enters the palliative care service to many months after the client’s death (where appropriate). These assessments are a multidisciplinary and interdisciplinary undertaking because clients may disclose different information to different staff at different times.
5. Bereavement support strategies
The recommended bereavement supports include two types of strategies — (1) universal strategies that are targeted at all carers and bereaved people and (2) specialist bereavement support strategies targeted at those with an elevated risk of a developing prolonged or complicated grief or with current psychosocial and/or spiritual distress. In general, the more complicated the grief process, the greater the efficacy of specialist bereavement interventions.

6. Clinical handover and referral to specialist services
Where providing bereavement support falls outside the skills and competencies of palliative care staff, referral to external specialist agencies or practitioners is undertaken. These include the Australian Centre for Grief and Bereavement Practitioner Consultancy Service, the Bereavement Information and Referral Service, or local community health services.

7. Community education and health promotion
The importance of promoting community awareness of bereavement issues and acceptance of the bereaved is recognised and acted upon.

8. Privacy, confidentiality and consent
The palliative care bereavement program ensures the privacy and confidentiality of its bereaved clients.

9. Integration with the health and support system
The bereavement support program is part of a general health and support system working to promote the health and wellbeing of bereaved people and the wider community.

10. Resource allocation
Resources are allocated in a systematic manner that allows the palliative care service’s bereavement program to respond to the changing needs of clients and staff.

11. Program evaluation, quality improvement and research
Palliative care services are committed to improved outcomes for bereaved people through research, program evaluation and quality improvement.

In addition to these 11 standards, recommendations are made for implementing the standards along the grief trajectory. While all of the standards apply at each point on the grief trajectory, the document highlights where a specific standard applies to different actions along the bereavement support pathway.

In coming months, a one-day workshop will be made available to all palliative care providers in both metropolitan Melbourne and the five Department of Health regions. These workshops will consider the implementation of the support standards and will examine a range of clinical responses to meet the diverse needs of bereaved clients.

Further information about these workshops will be released via the Australian Centre for Grief and Bereavement website (www.grief.org.au) in due course.

References


The Australian Centre for Grief and Bereavement is pleased to present:

**Robert A. Neimeyer, PhD**
*University of Memphis - USA*

**Techniques of Grief Therapy:**
*Creative Practices for Counselling the Bereaved*

**Melbourne, Brisbane, Sydney, July 2013**

A rare, in depth training opportunity not to be missed!

- One of the world’s leading thinkers in the grief and bereavement field
- Author of nearly 400 articles and book chapters
- Editor of new book *Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved*
- Served as Chair of the International Work Group for Death, Dying, and Bereavement
- Editor of the journal *Death Studies*

As contemporary models of bereavement have become more nuanced and empirically informed, so too have the practices available to grief counsellors and therapists. Dr Neimeyer’s workshops offer in-depth training in several of these techniques, nesting them both within the therapy relationship and in the context of current theories and research that provide flexible frameworks for intervention. Making extensive use of actual clinical videos as well as how-to instruction in the use of numerous therapeutic tools, participants will discuss and practice several methods for helping clients integrate the reality of the loss into the ongoing story of their lives, while also reconstructing their continuing bond to their loved one.
Common Misconceptions Around Grief
An information sheet for families and friends of those in Palliative Care

Grief is a topic that doesn’t tend to be openly discussed in Western society. As a result, there are a great many misconceptions in relation to the way people grieve that can leave the bereaved feeling uncomfortable and confused.

Following the death of a loved one, it is important to keep in mind that there is no set formula, or ‘right’ or ‘wrong’ way to grieve. Most behaviours, so long as they are not harmful to you or others, are completely normal and are simply a part of your grief experience.

1. Misconception: Grief has an end or recovery point with ‘progress’ measured in linear time of months or years.
   Reality: Grief doesn’t have a timeline and is different for every person. We don’t ‘get over it’, but rather we gradually, over time, learn how to live with and around our loss.

2. Misconception: Members of a family should grieve in the same ways when they experience the death of the same loved one.
   Reality: Every individual varies in their responses and how they express the loss of a loved one. Siblings for example, may each have lost their father, but each of them has had a different relationship with him, and has different memories and experiences. Your grief is unique to you, and should not be compared to that of others.

3. Misconception: The belongings of the person who has died should be packed and cleared away after the death, otherwise the person is being morbid and dwelling on their loss.
   Reality: People’s needs are individual and unique. For some bereaved people, belongings are a comfort, a symbol that links them to their loved person. In actual fact, some people clear away or throw out possessions too soon after the death, and come to regret it down the track. Take your time, and hang onto things for as long as you need.

4. Misconception: Bereaved people should visit the grave or ashes site.
   Reality: How an individual chooses to mourn, memorialise or create ritual after the death of their loved one is personal and entirely up to them. It’s ok to do what feels right for you, not what other people expect you to do.

5. Misconception: Rigid Beliefs or ‘Should and Shouldn’ts’ are helpful e.g. ‘You should/shouldn’t go back to work quickly … You shouldn’t start a new relationship “too soon” after the death of a partner … People should cry to express their grief … You need to talk about it.’
   Reality: There are no fixed ‘rules’ for grieving. Each person needs to be supported to do what they feel is important to them and this may change as time passes.

If you are concerned about your grief responses, or someone else’s, the following questions may be helpful in better understanding the situation:

- What is the context of the behaviour?
- What is the meaning of the behaviour to your/the bereaved person?
- Is it safe?
- Does it provide comfort?

If you are still concerned, don’t be afraid to seek further advice from a health professional.

For further information on grief and bereavement visit www.grief.org.au
Interview with a Palliative Care Music Therapist

Lisa-Marie Bartlett is a Senior Music Therapist with Eastern Palliative Care.

What brought you to this field of work?
I was drawn to the field of palliative care because of the extent that Music Therapy can assist people and their families as they navigate the challenges approaching end of life and during bereavement. As part of the interdisciplinary team, Music Therapy can help to improve quality of life by addressing the physical, emotional and spiritual challenges that may arise, and can also provide support and guidance to those affected by the loss of a loved one. Helping people who are approaching end-of-life to ‘live well’ is an incredibly rewarding and life affirming experience.

How do you help people understand their grief process?
At Eastern Palliative Care, Music Therapy is offered as one component of the bereavement services available. Music Therapy methods align with popular models of grief and can help individuals to navigate the process of grief. It can provide relief for acute symptoms, help individuals’ process and understand their grief, and help work through specific challenges. Music Therapy may focus on music relaxation, breathing and meditation techniques to help promote relaxation, reduce anxiety and target insomnia. Instrumental improvisation techniques and listening to music that represents different thoughts can provide catharsis for individuals who are unable to express in words how they are feeling. Guided song writing allows individuals to identify, express and explore their experiences and have these validated within the safety of the therapeutic relationship. Often these musical activities will facilitate conversations and the identification of more specific challenges that they face. As this process continues, Music Therapy may also focus on setting goals, identity exploration and reinforcement, reflection, and supportive counselling.

How do you support yourself when client stories or circumstances resonate with your own?
I’ve found the most important thing in navigating these situations is simply to acknowledge that there will occasionally be cases that personally affect me – and that that is OK! When this does occur, I take some time out when I’m back in the office or at home to reflect upon the situation and to express how I am feeling. This process of recognition and validation is generally enough to help me move forward.

What is it like supporting families of loved ones who have a terminal diagnosis?
Everyone experiences and reacts to events in life differently, so extending support to the family of someone with a terminal illness ensures that we are able to provide help where and how it is needed. My workplace acknowledges the importance of supporting the entire family unit, and as such our services extend to all family members both at the end-of-life stage and in bereavement. This ensures that our involvement continues to evolve as the needs and challenges faced by those involved do. It is really wonderful to work within such a model, and indeed so important to ensuring holistic care.

What would be the three pieces of advice for those working with the bereaved?
1. Remember that it is OK to be personally affected by occasional cases. It is not a reflection of poor professional boundaries; it’s just something that makes us human. Maintain good self-care strategies, and seek support if you need it.
2. Always be aware of a client’s cultural and spiritual backgrounds. This may greatly affect how an individual and their family will experience death and bereavement.
3. Like what you do. As long as you are enjoying the work, I believe you will continue to find it rewarding and surprising.

What sustains you in your work, how do you look after yourself?
On an individual level, I try to maintain a good work/life balance, exercise regularly, and continue to enjoy music in a way that is ‘just for me’. My organisation also acknowledges the importance of supporting its staff and has a number of services in place. These include providing regular professional supervision, an Employee Assistance Program, team days, and an annual Ceremony of Remembrance. Effective self-care strategies are extremely important to ensure that I can keep on doing my job, after all, we need to look after ourselves before we can effectively help others.
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

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, visit www.grief.org.au/education

Courses
The Australian Centre for Grief and Bereavement offers a number of research-informed, high-quality courses including post-graduate training program, the Vocational Graduate Certificate in Bereavement Counselling and Intervention (nationally accredited). For more information contact the Centre on (03) 9265 2100 or email courses@grief.org.au

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 info@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 visit 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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