Welcome to the Summer 2014/15 edition of Bereavement Practice in Palliative Care.

In this issue, Palliative Care Bereavement Coordinator, Jane Groom, has contributed our feature article: The Challenges of Providing Bereavement Support to Families Prior to the Death of a Loved One. This article highlights a range of challenges for carers that may be overlooked, particularly those relating to anticipatory grief.

Palliative care recognises and respects the uniqueness of each patient, their caregiver(s) and family members. The bereavement practitioner, in negotiating these sometimes complex relationships, has the challenging task of identifying and identifying the needs of this family and responding with skill and sensitivity. As Jane suggests, we can become the temporary safe container, which assists the family with the fear and confusion that can accompany care.

In addition to this feature article, we have included information on a range of upcoming professional development events; an interview with a palliative care bereavement practitioner; and a client information handout on Grief and Guilt. We are also pleased to announce that Specialist Educator Benjamin Wolfe, MEd (USA) will be delivering a series of workshops for us in early 2015 in Melbourne, Sydney and Brisbane. Information relating to this event is listed on page 3.

Wishing you all a safe and relaxing holiday season.

Christopher Hall
Chief Executive Officer
Australian Centre for Grief and Bereavement
The Challenges of Providing Bereavement Support to Families Prior to the Death of a Loved One

By Jane Groom, Bereavement Program Coordinator, Melbourne City Mission Palliative Care

Introduction
Discussing death and dying in contemporary, multicultural Australia is largely taboo and when it becomes a personal reality, people are often uncomfortable raising this delicate subject. Pre-death bereavement support however, is enshrined in the Australian Standards for Palliative Care (Palliative Care Australia, 2005) and can assist families prepare for the death – emotionally, spiritually and practically. Providing effective support however, can be fraught with challenges, requiring a delicate dance with clients and families at this very difficult time. This paper raises common challenges encountered and offers suggestions regarding managing them.

Communication
Open, empathic communication is the foundation of all effective care. Sensitivity when meeting with family members individually and separately from the patient may create more willingness to be open and to share real concerns. Supporting people who are experiencing anticipatory grief will assist them in being present to the dying person and later after the death. However every individual and every family will respond uniquely to the shock of diagnosis and the dying of a loved one, and not all will require or be receptive to counselling or spiritual support. Hudson and Aranda (2013) emphasise that ‘there is no one size fits all approach for family caregiving in the context of end-of-life.’

Therapeutic Relationship
Grief work is sensitive and exposing, demanding vulnerability by the bereaved. Establishing an effective and dynamic therapeutic alliance profoundly assists this work (Rubin et al, 2012). A relational framework can provide a ‘safe container’ or ‘holding environment’. Neimeyer (2012) advocates ‘following the affect trail’ of significant emotions, by staying with the client, and offering ‘empathic validation’. In pre-death work, the alliance is a powerfully supportive intervention, along with cultivating a ‘sense of timing’, which can facilitate ongoing grief work after the death. Being in the present moment, discerning when only to listen, when to inform, and when to refrain from sharing information, will communicate to a patient or family member that their perspective matters and build trust, which may later facilitate further enquiry and resolution of difficult conversations.

Ethnicity
Clear empathic communication is always required, especially in diverse societies, where cross-cultural issues abound. Any assumptions about cultural or religious norms regarding views about end-of-life care and decision-making should be avoided (Koffman, 2014). A clinician’s experience and knowledge of best practice may not be appropriate for a traditional family unit from a different culture and cultural imperialism can easily intrude. Hence the inevitable conversations about ‘whether the patient should be told he or she is dying’ require deep listening, respect and understanding of the family’s perspective, which may progress the conversation more openly than taking a direct stance. Hudson & Hudson (2012) note that ‘there is no right or wrong way of dealing with death and dying, as circumstances differ from person to person.’ Respectful enquiry best elicits information about specific values and practices and only an individual approach to each patient/client and family member, can establish the fundamental trust required to support a person with their grief and loss (Koffman, 2014).
The Australian Centre for Grief and Bereavement is pleased to present:

Iceberg Theory: Counselling Below the Surface

For presenter profile, venue, pricing and registration information, please go to www.grief.org.au/education

Benjamin Wolfe, MEd – USA
Melbourne | Sydney | Brisbane
February/March 2015

Working with patients/clients/residents or their families prior to, or after, the expected, sudden, or traumatic death of a loved one is challenging. As physicians, nurses, therapists, counsellors, chaplains or social workers — whatever our professional role — we need to remind ourselves: ‘What we see is not always obvious!’

This workshop will provide strategies and interventions to help individuals and families trying to cope with the opportunities and struggles on the ‘loss’ journey. This interactive workshop will explore clinical interventions dealing with loss in its broadest sense, factors that influence grief, and family make-up and communication styles. Additionally, the day will remind us that we too are changed by the work we do.

Dates
Melbourne: Friday, 20th February 2015
Sydney: Tuesday, 24th February 2015
Brisbane: Thursday, 5th March 2015

References
Hudson, P. & Aranda, S. BMJ Supportive & Palliative Care Published Online First: December 17, 2013. ‘The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients.’


Learning Outcomes
At the conclusion of this workshop, participants will be able to:

• list four different types of losses and their impact on the bereaved
• describe concepts such as ‘stories’ we hear, ‘dark emotions’, ‘iceberg theory’ and the ‘family mobile’ and how they affect an individual’s grief
• describe what is meant by ‘living in the second circle’
• list various factors that need to be considered when working with individuals and families
• explain how family make-up and communication styles affect loss, regardless of the loss issue
• describe the ramifications of a traumatic death
• identify coping strategies that can be utilised as a result of compassion fatigue or secondary trauma.

Conclusion
Most family support workers can probably recall the sting of being misunderstood or misquoted: the work is risky – and sometimes it backfires! Not all patients and families can acknowledge that death is close at hand and clinicians can be caught in the crossfire. Learning to stay in the pain of difficult situations, to be authentic and express regret is essential. Families can be labeled as ‘resistant’ or ‘in denial’, but most people do the best they can in facing the imminent death of a loved one. The respect and acceptance of all clinicians will serve them best in the long term, alongside keeping the door open for bereavement support after the death has occurred.

The Carer’s Experience
Personal death anxiety is often triggered when facing the death of a loved one. Emerging existential questions and issues can overwhelm family members, who can literally be ‘lost for words’ at this time.

Providing support for the mental health of family caregivers during the illness trajectory can be challenging. Recent research has identified a high incidence of depression (12%–59%) and anxiety (30%–50%) in caregivers (Hudson et al., 2011). Time constraints and the stresses of caring, result in carers not attending to their own health and wellbeing prior to the death of a loved one, which can exacerbate complications later. Counsellors’ encouragement of self-care can help avoid further health crises after the death.

Clinicians may be unconscious of ethical and moral dilemmas facing families: fears of hastening death by speaking about it to the patient, or anxiety about the use of opioids, may contribute to guilt and regret in carers.

Time constraints frequently challenge clinicians when engaging with the client and carers about death and dying; these conversations require spaciousness and cannot be rushed. Families need to feel safe, to be given time to allow their thoughts to form, for their emotions to be felt, and their voices to be heard.

As physicians, nurses, therapists, counsellors, chaplains or social workers — whatever our professional role — we need to remind ourselves: ‘What we see is not always obvious!’
Experiencing feelings of guilt is very common when grieving. We beat ourselves up over the ‘should haves’, drown in the ‘what ifs’ and ‘if onlys’, and grapple desperately with the unanswerable ‘why?’

Some people feel guilty that they weren’t able to prevent the death of their loved one, or that they survived when their loved one did not. Others feel guilty that they didn’t say the things they needed to say, that they weren’t as close as they should have been, or that they failed their loved one in some way.

It’s important to understand that whilst difficult, guilt is a very normal grief response, and will be experienced by most grieving people in some shape or form.

What guilt can look like
Guilt can manifest in many ways. It can bring sadness, regret, shame, doubt, heaviness and anxiety, as well as feelings of failure, inadequacy and unworthiness. Guilt isn’t always logical, or satisfied with reasonable explanations. Often grieving people say they know their guilt isn’t rational and their expectations of themselves are unrealistic, however this doesn’t stop them from feeling this way.

The blame game
It’s amazing how readily we can find a way to blame ourselves or others for the death of loved one, e.g. ‘if I had been there, this never would have happened’, ‘it was the doctor’s fault’, ‘they should have noticed something was wrong’. Sometimes, we even start blaming our loved one, e.g. ‘they should have looked after themselves better’. Ultimately however, placing blame, whether justified or unjustified, on others, or yourself, is not going to ‘fix’ things. It won’t magically dissolve the guilt, it won’t make you instantly feel better and it won’t bring them back.

It’s okay to feel good
When we are consumed by our grief, it can often come as a shock when we feel happiness or laugh for the first time. It is very common to feel a wave of guilt when this happens, e.g. ‘how can I be feeling happy when they aren’t here?’ Try to keep in mind that feeling happy does not equate to forgetting. Happiness and sadness can co-exist — it doesn’t have to be an ‘either/or’.

How do I make these feelings stop?
Guilt isn't something we can necessarily just ‘get rid of’. What we can do however, is acknowledge that it’s okay for it to be there. Normalising these feelings, and accepting that it’s okay to have them, is the first step in starting to move towards a place where things can become bearable again.

Tips for managing grief
• Recognise that at the end of the day, we are all human. Nobody is perfect. We all make mistakes and we all have regrets.
• Normalise your guilt: The more you make your feelings of guilt ‘wrong’ the longer they will stay. Try to work with your guilt, rather than against it.
• Consider: If your loved one were still here — what would they say to you about how you are feeling?
• What would you say to a friend who was feeling this way? Can you say that to yourself?
• Try to remember both the good memories, alongside the hard ones.
• Ask your loved one for forgiveness, either out loud, in your mind or in writing. You won’t receive an answer, but the process of asking can be healing.
• Talk to a close friend, family member or a counsellor about how you are feeling. Saying things out loud and talking them through can go a long way to helping the process and work through our emotions.

Seeking help
If your guilt is disturbing your ability to function, then it is important that you seek further help. Talking to friends and family, or seeking help from a counsellor or health professional can ease the burden of guilt and help you to begin to accept and work with it.

For further information on grief and bereavement visit www.grief.org.au
Many people in palliative care seem to live every moment and appreciate life. This reminds me to do the same as I honour their sadness and mine.

Interview With a Palliative Care Professional

The interviewed palliative care professional wished to remain anonymous.

What has brought you to this field of work?

I am employed as a palliative care social worker. My role is diverse in the provision of social and emotional support to palliative care clients and their families. My past work in aged care and study in the area of grief and bereavement through the Australian Centre for Grief and Bereavement has offered me great skills for this work.

How do you bear the sadness you witness or people share with you?

Many people in palliative care seem to live every moment and appreciate life. This reminds me to do the same as I honour their sadness and mine.

How do you help people understand the complexities of their grief and bereavement experience?

It’s important to just be there, listen to their experience and validate what it’s like for them. I also make sure they have the best supports possible so they can make sense of their experiences.

What has been your most challenging situation when supporting or educating someone who experiences grief?

Sometimes it’s hard only working with people for short periods of time. Clients die and you don’t always get the opportunity to finish your work or to say goodbye. That can be hard. Sometimes it’s also because resources are so limited and you can’t give clients and carers what they ideally need, things like respite care.

What do you find most rewarding in your work?

Clients and family members are so appreciative of the small things we do in their lives. They value everything. It reminds me to do the same. I also enjoy the opportunity to empower people with information and resources that make their lives easier. This gives me pleasure.

What would be one piece of advice/insight for those working in the palliative care field?

I would encourage people to look after themselves and live life fully outside of their work. It’s also important to have good training that helps you understand grief and bereavement and the different ways it impacts people. Good training also helps you to have better conversations with clients and families about death and dying and the grief experience.

What are some ways you have engaged in self-care in this intense field of work?

I make sure I walk a lot. I also follow some good advice given to me by a person I work with — ‘at the end of your work day, leave work here and enjoy your life, remember you can only do your best.’

Want to share your experiences in the palliative care / bereavement sector with other professionals?

If you are interested in being interviewed for Bereavement Practice in Palliative Care, please contact Jenny at j.field@grief.org.au
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 and in regional areas (Grampians, Gippsland, Hume, Barwon South-West, and Loddon Mallee). 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

Bereavement Courses
The Australian Centre for Grief and Bereavement offers a number of research-informed, high-quality courses, including post-graduate training program, the 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 offers 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. 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. 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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