Welcome to the Winter 2015 edition of Bereavement Practice in Palliative Care.

In 2014, the Australian Centre for Grief and Bereavement (ACGB), in partnership with the Victorian Government Department of Health and in consultation with a range of paediatric palliative care providers, conducted research into enhancing bereavement support for parents following the death of a child in a paediatric palliative care service.

ACGB appointed Alison Boughey Consultancy to undertake the research element of this project, which aimed to map the current needs of bereaved parents and siblings and to identify gaps in support information that needed to be filled.

Our feature article, prepared by Alison and myself, looks at the findings of this research and the recommendations made regarding the development of a new resource designed to fill some of the current gaps and better meet the needs of parents of children with a life-threatening illness. We’ve also included information on this new, downloadable resource, along with information on a range of upcoming professional development events and a client information handout on grief and relationships.

Christopher Hall  
Chief Executive Officer  
Australian Centre for Grief and Bereavement

**COMING EVENTS**

<table>
<thead>
<tr>
<th>Event</th>
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<tr>
<td>13th Australian Palliative Care Conference</td>
<td>1–4 September 2015</td>
<td>Melbourne, Australia</td>
<td><a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a></td>
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<td>International Conference on Hospice and Palliative Care</td>
<td>31 August – 2 September 2015</td>
<td>Orlando, Florida, USA</td>
<td><a href="http://www.palliativecare.conferenceseries.com">www.palliativecare.conferenceseries.com</a></td>
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Provision of bereavement care to families of children with a life-threatening condition is a fundamental element of best practice palliative care. This care should be delivered within the context of each family’s spiritual and cultural needs. It should also take into account the unique ways in which individuals experience bereavement that can be influenced by their gender, age, developmental stage, life experiences and their unique character and personality.

Whilst there is embedded practice of delivering bereavement care to adults in palliative care, there is no best practice framework for delivery of bereavement care within the context of paediatric palliative care. The practice of bereavement care for adults cannot simply be transferred to delivery of bereavement care in a paediatric setting, as there are a number of key differences in the services provided. Notable features of paediatric palliative care as compared with adult palliative care include:

- As a result of low child mortality rates, fewer Australian children require palliative care than adults.
- The conditions for which children require palliative care can be more diverse and rare than for adults, with a higher percentage of non-malignant conditions in children requiring palliative care.
- The stress experienced by families, parents, siblings and carers of children requiring palliative care (as well as on the children themselves) can be very traumatic and lead to lifelong consequences for the surviving family members (RCH, n.d.).

There is a greater necessity for a family-centred approach when dealing with children with a life-threatening condition.

**Paediatric Palliative Care Resource and Services Mapping Project**

In 2014, the Australian Centre for Grief and Bereavement (ACGB) was funded to undertake a grief and bereavement initiative for the paediatric palliative care sector. The purpose of the consultation was to map services and resources available for Victorian families of children with a life-threatening condition so that these families can be directed to them as a source of support. Where gaps were identified in available resources and services for children with a life-threatening condition and their families, recommendations were made for further resource and service development.

The consultation phase of the project involved working with ACGB and the project steering committee to:

- Consult with paediatric bereavement service providers and bereaved parents and family members;
- Map current paediatric bereavement services in Victoria;
- Identify and assess resources currently available to support bereaved parents and family-members of children with a life-threatening condition; and
- Make recommendations for the development of new resources where necessary.

Alison Boughey Consulting was commissioned to undertake the consultation and mapping phase of the project. A multi-method approach was taken, inclusive of stakeholder interviews, high level literature review, electronic survey and an evaluation of existing resources.
Findings of the Consultation Phase
32 representatives from 29 Victorian palliative care services participated in the survey component of the project, and representatives from 22 services participated in an interview component, along with two bereaved parents.

It was found that paediatric palliative care in Victoria is predominantly provided by Very Special Kids (Victoria’s children’s hospice), the Royal Children’s Hospital (RCH) and by inpatient, community and consultancy palliative care services. Most funded palliative care services were not providing a significant amount of palliative care to children and the numbers of children seen overall were found to be relatively small. For example, in 2012, 20 palliative care services provided care to a total of 37 children. This low exposure to children and families results in palliative care staff in the mainstream services not feeling they have sufficient confidence and experience to deliver services to these children and their families.

Indeed, the most common theme to emerge regarding the challenges services face when providing bereavement care to families of children with a life-threatening condition was that these small numbers resulted in palliative care staff not having enough opportunity to develop the specialised skills needed for the task. Resources available to palliative care services for training are necessarily finite and it may be difficult for them to justify training staff in this highly specialised area.

Where palliative care services did provide bereavement support to families of children who have died, these services commonly included:

- Provision of information or resources;
- Grief and bereavement counselling for parents;
- Practical support for families; and
- Grief and bereavement counselling for siblings.

Knowledge of what resources are available for bereaved families following the death of a child is variable. Some participants felt there was not enough resources for families (including specific groups within families such as adolescents and young children) whilst others commented that there are a lot of resources but it is hard to know which ones have been peer reviewed and are suitable for them to provide to families. It is notable also, that the bereaved parents interviewed were unaware of the extent of resources.

“As most of our clients are elderly, we tend to forget some families bereaved by the loss of a child. We have ample materials for the older population but this survey awakes my awareness to be inclusive of other people from other backgrounds and for all ages.”

– Survey Participant

A number of participants noted that distance and geography pose a challenge to assisting children and families in rural areas with appropriate grief and bereavement resources. It was also noted that it was difficult to find culturally appropriate resources for CALD and Aboriginal and Torres Strait Islander families.

Participants were invited to make recommendations for further development of grief and bereavement resources for bereaved families following the death of a child. These included:

- Improving mechanisms for linking, connecting and supporting bereavement counsellors in this highly specialised area;
- Improving accessibility to available services (particularly for those who are geographically remote) through use of video-linking and telehealth;
- Provision of online resources for families and counsellors to access;
- More resources for parents and young siblings; and
- More training (mandatory) for bereavement workers in this area.

Resource Development
After review of the consultation findings, the Project Steering Committee, consisting of representatives from ACGB, VSK, RCH, the Victorian Government Department of Health and Alison Boughey Consultancy, agreed on two key courses of action.

1. Development of a new paediatric palliative care bereavement resource
It became clear during the consultative process that there was a range of information gaps in the bereavement literature available to parents and families of children with a life-threatening condition. As such, the steering committee decided it would be worthwhile developing a free resource, available in hard and soft copy that covered bereavement-related issues occurring both before and after the death of a child. It was recommended also, that the resource be designed in such a way that it could be picked up and put down as needed, as feedback showed that families often weren’t ready to take too much information at a time.

Based on this feedback, ACGB have developed the resource After the Loss of a Child: A Resource for Parents of Children in Palliative Care. This resource was written based on the data gathered from the research undertaken and has been reviewed by the Project Steering Committee, bereavement and palliative care clinicians, and by parents who have experienced the loss of a child in a paediatric palliative care setting. For further information on accessing this resource, please refer to page 4 of this newsletter.

2. Establish a platform for housing links to available online resources
From the consultation phase of the project, it also became clear that whilst there were paediatric palliative care bereavement resources out there, it was very difficult to a) find them, and b) determine their credibility.

As such, as the second phase of the resource development arm of the project, the Steering Committee recommended establishing an online platform for housing links to the online resources that were available. This information repository would be thematically structured so as to enable easy and timely access for both bereaved
No parent expects to outlive their child. It is the news that every parent dreads – news that feels horrible, unnatural, unfair and unbearable.

Having to contemplate caring for your sick child, yourself and your family, and to face a future without your child in it, can feel terrifying and completely overwhelming and there can be a lot of information to take in.

After the Loss of a Child: A Resource for Parents of Children in Palliative Care has been developed in order to help parents through this difficult time. It is designed for parents of children in palliative care, but is also a useful resource for any parent who experiences the loss of a child.

After the Loss of a Child looks at common issues and processes occurring both before and after the death, and provides information and helpful tips for navigating the grief experience of parents and families both immediately and in the long term.

The resource is divided into sections, so that it can be easily referenced as needed. It has been written as support guide, but is in no way intended to replace seeking advice from professionals.

Topics include:

• Before the death
• After the death
• About grief
• Grief and relationships
• Parenting after the loss of a child
• Grief over time
• Self-care
• Seeking help

Hard copies of After the Loss of a Child will be posted to Victorian Palliative Care agencies in coming weeks. The resource is also available online as a free, downloadable resource via the Australian Centre for Grief and Bereavement website: www.grief.org.au

The Australian Centre for Grief and Bereavement would like to thank everyone who has been involved in putting this resource together. In particular, Alison Boughey Consultancy; the Paediatric Palliative Care Project Steering Committee; the clinicians and bereaved individuals who reviewed the resource and provided their feedback; and the Victorian Government Department of Health who provided funding and support for this important project.
In many ways, the sustained love and support of family and friends can be very helpful following the loss of a loved one. Grief, however, can also cause great strain on relationships.

Relationships can include (but are not limited to):
- Partners
- Family (parents, siblings, children)
- Extended family (e.g. in-laws)
- Friends
- Work colleagues.

There are many issues that we can encounter in our relationships both prior to, and after, the loss of someone close. These can include hurt feelings, arguments, guilt, blaming/shaming, misunderstandings, lack of understanding, intimacy issues and conflicting grieving styles. Relationships can be hard work at the best of times, but when the additional pressure and stress that comes with the loss (or impending loss) of a loved one comes into play, it can cause extra strain on even the strongest of relationships.

Different Ways of Grieving

There are a range of factors that can influence the way we grieve, such as culture, gender, age, relationship to the deceased, personal experience, religion and belief systems. It is quite common for two people in a relationship or for members of the same family to grieve very differently, and this can sometimes cause resentment or misunderstandings.

Regardless of the way you, or those around you grieve, it is important to remember that grief is a highly personal and individual experience. Everyone is different and as long as you are not causing harm to yourself or those around you, there are no ‘right’ or ‘wrong’ ways to grieve. Try to respect each other’s way of grieving, even if you don’t necessarily relate to or understand it.

Communication

The key to any healthy relationship, regardless of whether it’s with a partner, family member, friend or colleague, is healthy communication.

We communicate not just by talking and listening, but also through our actions and body language, tone of voice, touch, and by being understanding. Not everyone is comfortable using words to express feelings, so you may need to try communicating in other ways, such as writing a letter, doing something thoughtful or helpful, or even simply giving them a hug.

Seeking Help

If your grief is affecting your relationships, know that this can be a very natural and normal part of the grieving process, due to the pain being experienced. If it is becoming problematic, however, talking to someone about it, whether it is the person involved, a supportive friend/family member or a health professional is a good idea. Grief can be a particularly testing time for relationships, but with love, understanding and good communication, your relationships can survive and with time, may even become stronger.

Useful Resources

Relationships Australia www.relationships.org.au

For further information on grief and bereavement visit www.grief.org.au
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 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 664 786 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 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 newsletters@grief.org.au

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Contact Us
Australian Centre for Grief and Bereavement
253 Wellington Road, Mulgrave, VIC 3170
Ph: (03) 9265 2100 | Freecall: 1800 642 066
Website: www.grief.org.au

Bereavement Counselling and Support Service
Ph: 1300 664 786 (toll free – Victoria)
Email: counselling@grief.org.au

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