WW Integrated Hospice Palliative Care
Grief/Loss and Bereavement Care Standards and Recommendations

It is understood that grief is a normal process in living and dying. Family members transition to the bereavement stage of the HPC journey and may continue to require support from health care providers to enable the family members rebuild their lives and reintegrate into their communities.

CHPCA states “For society, a family’s suffering and the quality of their lives is a public health issue, by focusing on relieving suffering and improving quality of life, hospice palliative care aims to promote health for everyone who is affected by illness and bereavement, including those who provide care.” (Canadian Hospice Palliative Care Association, 2002 p. 13-14)

The WWHPC Network, System Plan Committee established a Bereavement Working Group in fall 2010 to complete task of creating a WW Bereavement Service Delivery Inventory list. In the progress of developing the inventory list, the group also reviewed bereavement best practices and literature on bereavement standards of care. The group established this document as a discussion paper for consideration as the Waterloo Wellington Integrated Hospice Palliative Care Program is developed and implemented.

The Bereavement Working Group held a Town Hall Meeting of thirty local bereavement stakeholders to discuss best practices in bereavement care. The participants provided input into this document, the development of eleven standards and prioritize the activities to improve bereavement care for the residents of Waterloo Wellington.

Definitions

What is “bereavement?”
- “Bereavement is not only the loss of a significant person but also the period of transition for the bereaved individual following that person’s death (Stroebe & Schut, 1999). Bereavement is also used as a broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one (Christ, Bonanno, Malkinson & Rubin, 2003).” (Canadian Hospice Palliative Care Association, 2009)

What is Grief?
- “Sorrow experienced in anticipation of, during and after a loss (CHPCA, 2002); The diverse natural reactions, such as psychological, physical and social reactions, to the loss of a significant person are characterized by both suffering and growth (Stroebe, Hansson, Stroebe, & Schut, 2001), Grieving is a process that takes time. It is normal to experience grief responses many months and years after the death (Pereira, 2008).” (Canadian Hospice Palliative Care Association, 2009)

What is “complicated grief”?
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(1) A chronic grief which continues on without stopping and never comes to a satisfactory conclusion.
(2) Delayed grief in which the normal grieving process is suppressed or limited at the time of loss and then resurfaces later with far greater emotional intensity.
(3) Exaggerated grief in which the person feels completely overwhelmed with grief and resorts to behavior which makes his or her situation worse.
(4) Masked grief, similar to exaggerated grief, but here the person is not aware of the loss (or losses) lying behind the symptoms.

What is “anticipatory grief”?
- “Grief can occur before a death as well as after. People living with terminal illness often experience what’s called anticipatory grief. This grief is generally related to loss of independence or changing roles within the family and the workplace. For families, anticipatory grief involves witnessing these changes and reacting to them. Family members may feel the loss of future plans as well as recognition that the family will never be the same.” (Canadian Virtual Hospice) Retrieved November 4, 2011, from www.virtualhospice.ca

Bereavement Care Provider (BCP) is a professional or volunteer trained to assist, support and/or be a companion to individuals in the state of having suffered a loss of a significant person in their life.
Guiding Principles

A compassionate approach that is client centred to all procedures and processes surrounding death can impact positively on bereavement. The involvement of relatives, friends, families and pets is essential.

Cultural and spiritual factors need to be incorporated into all areas of bereavement care.

Socioeconomic factors need to be considered in planning bereavement care.

Standards, policies and guidelines for bereavement care should be considered in all care settings.

Integration within the health and support system – part of the general health and support system working to promote the health and well being of the bereaved individuals and the wider community.

Resource Allocation – resources are allocated in a systematic manner that allows the bereavement support program to respond to the changing needs of the individuals, families, friends, and the wider community.

Privacy and confidentiality – ensures the privacy and confidentiality of the individuals, families, and friends.

Staff /Volunteer Support – recognizes and responds to the impact on the staff and volunteers of providing care to the bereaved.

Access – bereavement support program designed to ensure bereaved individuals has access to services regardless of age, gender, sexual orientation, socio-economic status, religious or spiritual beliefs, physical or other disabilities or ability to pay and is inclusive of sudden or anticipated deaths.

Service provision – provides a range of support services that are sensitive and appropriate to the person’s needs, in particular life stage and style of grieving.
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### Standards and Recommendations

Status to be determined through community engagement process

- **Red = not met**
- **Yellow = in progress**
- **Green = met**

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### Assessment, referral, access and care

- **Assessment, referral, access and care**

- **1. Bereavement Assessment** – routinely undertaken as part of the initial and ongoing individual/family assessment
- **2. Referral to specialist services** – where individuals need exceeds the available capacity of the program, the individual/family are referred to external specialist services
- **3. A range of list of bereavement services** must be offered as interventions should be offered and tailored to individual need.
- **4. Coordination of the bereavement support program** – provides coordinated services to the individual/families/friends. A coordinated approach to bereavement care that encompasses professional and volunteer agencies is provided with regular inter agency linkages and follow up with bereaved people.
- **5. Ideally spiritual care extends to bereavement care.** Palliative care programs should establish processes to ensure that systematic bereavement support is provided.
- **6. Health care professionals** should establish consistent practices for contact with family or friends following the death of a patient. This could include as appropriate for example sending condolences, attending funerals, holding memorial services, or other rituals to offer support and connection with the family and friends.

### Research and quality improvement

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- **7. Research** which includes case studies and leads to establishing best practices on bereavement and bereavement care is needed. This can be established by improving linkages and relationships with universities.
- **8. Community awareness of bereavement issues, support for the bereaved as well as acceptance of the bereaved is recognized and acted upon.**
- **9. There are a range of information needs that need to be addressed at local and national levels**
- **10. Staff/ Volunteer Education** – is available on an on going basis to all staff and volunteers to develop, maintain and enhance their bereavement support skills
- **11. Care is available for staff and volunteers to promote self care.**
Components required for implementation of the Bereavement Care Recommendations

Infrastructure
Regional bereavement care policy
Regional bereavement definition accepted by all participating organizations
Leadership and organizational support
Human Resources - Bereavement care provider job description and core competences
Dedicated funding and allocated resources
Evaluation and research
Data collection, quality indicators, benchmarking
Maintenance of records – documentation system and formal communication strategies
Confidentiality policy

Before death
Skilled psychosocial assessment --- by who in the system and when before death
Bereavement risk assessment ------ by who in the system and when and frequency of re-assessment – storage and trending of the information, timing of interventions
Helpful information about the dying process

At time of death
Attendance by a professional (nurse, physician), allied health, para-professional (psw, volunteers)
Liaison with clergy and funeral home
Provide opportunity for family and friends to say their goodbyes

After death
Continue the Bereavement risk assessment – by who and when, frequency of re-assessment – storage and trending of the information, timing of interventions
Time and support for staff to attend funerals** cost implications and service delivery pressures
Multidisciplinary bereavement conference
Development of bereavement care plan
Monitoring of needs over time
Proactive and systematic outreach according to assessed risk

Menu of Services to be available
Befriending and support from trained volunteers
Periodic letters offering information and opportunities to stay in touch
Coffee mornings
Support groups according to needs, ages, and stages
Practical life skills groups
Information sessions
Counselling – individual and family
Therapy (for complicated bereavement)
Home visits – by who and what purpose
Anniversary cards
Referral to other services
Memorial services

**Staff development, education and training**
Attendance at courses – in-house and external
Supervision – individual and group
Debriefing sessions
Individual counselling
Quiet room (in patient setting)

**Community linkages**
Collaboration with community agencies and groups offering bereavement support
Public awareness sessions to other professionals and general public
Regional bereavement inventory
Resources
Resource list approved by WW IHPC Bereavement Working Group – December 2012

Resources on grieving for adults, children and teens
This list is a sampling of useful and helpful resources. These may be available from: bookstores, local libraries, churches, hospices, and funeral homes. Your local library can get any of these books on inter-library loan. Some titles are available in e-book form.

For adults:


For adults who are caring for children/teens:

Bluth, D. (Director & Producer). 2004. *The Land before time* [DVD]. Universal Pictures. (cartoon for children of all ages - the first one in series is the most useful)


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**For children:**


**For teens:**


**Web resources for adults, teens, children:**

Bereaved families of Ontario (has a video link to YouTube) [www.bereavedfamilies.net](http://www.bereavedfamilies.net)

Canadian Virtual Hospice [www.virtualhospice.ca](http://www.virtualhospice.ca)

Crisis, Grief and Healing -Tom Golden [www.webhealing.com](http://www.webhealing.com)
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The Coping Centre www.copingcentre.com

The Dougy Center: The National Center for Grieving Children and Families www.dougy.org

Hospice of Waterloo Region www.hospicewaterloo.ca

Hospice Wellington www.hospicewellington.org

Support for teens www.soul2soul.ca
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References


Foundations of Bereavement Support in Hospice and Palliative Care, A Discussion Paper compiled by Irene Renzenbrink, M. Soc. Admin.; April 2002

Mapping practice in bereavement care against research; Stephen, A.I., Wimpenny, P; April 2008


Minimum Standards for Bereavement Support Programmes in Palliative Care Services: Centre for Grief Education, Department of Health and Community Services, Victoria, Australia, January 2001


